

DISCOMFORT IN ADDRESSING SPIRITUAL NEEDS: A HOSPITAL-WIDE
EXPLORATION INTO THE HOLE IN HOLISTIC CARE

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DISCOMFORT IN ADDRESSING SPIRITUAL NEEDS: A HOSPITAL-WIDE
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ABSTRACT

Throughout its history, the nursing profession has claimed to provide holistic patient care, which is defined as bio-psycho-socio-spiritual care. However, many nurses do not feel comfortable with the “spiritual” element of care and are uncertain about their professional role in the assessment and delivery of spiritual care. Discomfort and avoidance of attending to the spiritual needs of human beings creates “a hole” in holistic patient care.

This case study examined a specific healthcare organization in its entirety to identify professional roles, processes, communication, and language of spiritual care when addressing spiritual distress in dying patients and their families. The study included examination of organizational procedures and the designated and perceived roles of key professionals in defining, identifying, and addressing spiritual distress of dying patients and their families within the single hospital. Strengths and gaps were determined by comparing the findings against a proposed conceptual framework developed from a synthesis of existing practice models for spiritual assessment and care of dying patients and families experiencing spiritual distress. The major gaps or problem areas that were identified included: (a) Lack of an organizational structure for spiritual assessment, planning, and implementation of spiritual care, or communication of the spiritual care plan among

healthcare professionals, (b) Screening questions that do not identify with spiritual distress, (c) No clear delineation of roles and responsibilities related to spiritual care, leading to tension between some disciplines, and (d) No healthcare provider education or training on understanding spirituality, assessing spiritual needs, and responding to spiritual distress.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Graduate Studies, have examined a dissertation titled “Discomfort in Addressing Spiritual Needs: A Hospital-Wide Exploration into the Hole in Holistic Care,” presented by Connie Francis Drury, candidate for the Doctor of Philosophy degree, and certify that in their opinion it is worthy of acceptance.

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CHAPTER 1

INTRODUCTION

Patients approaching the end of their life's journey often experience an arousal of their spirituality and want healthcare professionals to acknowledge and support their spiritual needs throughout the dying process (Blanchard, Dunlap, & Fitchett, 2012; Daaleman, Usher, Williams, Rawlings, & Hanson, 2008; Puchalski, 2007). Nursing as a profession has historically claimed to provide holistic care, which is an approach that emphasizes and integrates spiritual dimensions into all aspects of nursing care (bio-psycho-social-spiritual) (Dossey & Keegan, 2013). Tending to patients' spirituality, defined briefly as an individual's search for meaning and purpose in life and death, may be the most fundamental but least comprehended facet of holistic nursing (Vachon, Fillion, & Achille, 2009). Despite common knowledge that addressing spiritual uncertainties can be a source of comfort and healing, nurses report feeling apprehensive and unprepared in addressing this facet of holistic nursing, and patients often express dissatisfaction with the spiritual care provided within healthcare institutions (Astrow, Wexler, Texeira, He, & Sulmasy, 2007; Balboni et al., 2013; Carr, 2010; Dickenson, 2007; Dossey & Keegan, 2013; Puchalski, Lunsford, Harris, & Miller, 2006; Wallace et al., 2009).

One factor that contributes to nurses' discomfort in addressing spirituality is the frequent blurring and confusion between spirituality and religion. Attending to diverse religious needs is not an area that many nurses consider to be an aspect of nursing care. Another factor that contributes to nurses' discomfort with spiritual care is their lack of education and skill development for assessment, intervention, and appropriate referral of patients experiencing spiritual distress. Additionally, there are organizational barriers,

conflicts in the perceptions of spiritual caregiving roles among disciplines, and overall discomfort in caring for dying patients – perhaps because of perceived helplessness in attending to these essential, yet often subtle spiritual issues (Carr, 2010; Flannelly, Galek, Bucchino, Handzo, & Tannenbaum, 2005; Handzo & Koenig, 2004).

The North American Nursing Diagnosis Association (NANDA) defines spiritual distress as, “A state of suffering related to the impaired ability to experience meaning in life through connections with self, others, the world or a superior being” (Herdman & Kamitsuru, 2014, p. 372). Spiritual pain is defined as the intense anxiety associated with the realization of one’s mortality or impending death, which alludes to an anticipated loss of meaning and purpose, connectedness to others, or something beyond self, or loss of hope associated with life (Groves & Klauser, 2009; Saunders, 1988; Vilalta, Valls, Porta, & Vinas, 2014). Nurses spend more time with dying patients and loved ones than other healthcare professionals, which often in turn fosters a relationship of trust; thus, the nurse’s familiarity with the patient should aid in identifying patient signals of pain and suffering, including spiritual pain and distress (Dickenson, 2007; Dossey & Keegan, 2013; Gallison, Xu, Jurgens, & Boyle, 2013; Mitchell, Bennett, & Manfrin-Ledet, 2006; Wallace et al., 2009). If nurses are not able to identify and address spiritual pain and distress, the spiritual needs of dying patients may never be identified or addressed within the healthcare system (Daaleman, et al., 2008; Puchalski, 2007).

The study included examination of organizational procedures and the designated and perceived roles of key professionals in defining, identifying, and addressing spiritual distress of dying patients and their families within the single hospital. Strengths and gaps were determined by comparing the findings against a proposed conceptual framework

developed from a synthesis of existing practice models for spiritual assessment and care of dying patients and families experiencing spiritual distress.

Background

Spiritual Issues for the Dying Patient

Spiritual issues, needs, or questions exist for humans in any stage of health and wellness, but perhaps are brought most strongly to the forefront of consciousness when life is threatened or limited. Diagnosis of serious or chronic illness, cancer, or terminal illness can significantly impact an individual's spiritual health (Puchalski & Romer, 2000).

Terminal illness is arguably one situation in which holistic nursing is most important. End-of-life concerns that evoke apprehension for the dying patient may include: worry about being a burden to loved ones, fear of abandonment and dying alone, fear of suffering, the need to complete unfinished business, identification of personal meaning and purpose, and uncertainty of what lies ahead (Brunjes, 2010; Johnson, 2003; Sherman, Matzo, Pitorak, Ferrell, & Malloy, 2005).

The diagnosis of a terminal illness and the apprehension surrounding death and dying prompt a sense of urgency that creates spiritual questions regardless of one's religious affiliation (Johnson, 2003). During these times, patients often question the meaning and purpose of their lives. The search for meaning and purpose may entail a life review, contemplation of significant life experiences, and connectedness with others or a higher being (Ferrell, Otis-Green, & Garcia, 2013). Reflecting on one's life can reveal regrets of past behaviors toward self or others, squandered "opportunities," and the need to forgive or be forgiven. Realization of impending death causes an individual to become aware of the profound losses that occur when dying (Knight & Emanuel, 2007). End-of-

life losses can include loss of functional abilities, family and social roles, independence, control, dignity, future hopes and dreams, and ultimately the loss of life itself (Cheng, Lo, Chan, Kwan, & Woo, 2010; Knight & Emanuel, 2007; Mystakidou et al., 2005). These losses can contribute to physical, psychosocial, and spiritual suffering of a patient (Cheng et al., 2010). Patients may interpret their pain, suffering, and losses from the perspective of religious or cultural beliefs and may use their spiritual beliefs and practices as a source for coping (Milligan, 2011; Puchalski & Romer, 2000). “Spirituality plays a significant role in how patients perceive their health, face challenges, manage illness, and choose to die” (Wallace et al., 2008, p. 1). Addressing these spiritual uncertainties can be a source of comfort for the dying patient.

Nurses and Spiritual Care at End-of-life

The nurse’s role in the provision of spiritual care – most importantly spiritual assessment – should be considered a vital nursing function in holistic care (Dickenson, 2007; Gallison et al., 2013; Mitchell et al, 2006; Wallace et al., 2009). With three-quarters of all deaths occurring in healthcare facilities, every nurse should expect to provide physical, emotional, and spiritual care to dying patients (Dickenson, 2007). It is commonly in the stillness of a dark hospital room, when visitors have left and others have retired for the night, that patients express their spiritual pain, suffering, fears, and regrets to the nurse who comes to assess or offer a sedative. Avoiding exploration and intervention to the patient’s spiritual needs at that moment is a missed opportunity, possibly creating more distress and ongoing suffering (Dossey & Keegan, 2013; Gallison et al., 2013). Holistic care of the dying patient cannot exist without addressing the patient’s spirituality.

The primary objective for end-of-life care is to ease suffering through symptom management (Dunn, 2001). Suffering is not limited to the physical body or mental state of the dying patient, but also includes the patient's spirituality. To address spiritual distress, the nurse must possess knowledge and sensitivity for diverse cultures and religions (Ferrell et al., 2013; Gallison et al., 2013). Sources suggest that although nurses understand and recognize the importance of caring for their patients' spiritual dimension, they are apprehensive and lack the knowledge necessary to address the spiritual needs of those suffering from spiritual distress (Hermann, 2001; McSherry & Jamieson, 2013).

An Organizational View

Obstacles that hinder nurses in addressing the spiritual needs of patients at the end of life have been identified, yet looking at this issue from a "system" perspective is minimally reflected within the literature. The purpose of this case study is to examine policies and practices at the organizational and provider levels of care to determine potential strengths and gaps in end-of-life spiritual care. The "case" in this study is a single hospital, and the focus of study in the case is the process of addressing spiritual distress in dying patients and their families. The study includes examination of organizational procedures and the designated and perceived roles of key professionals in defining, identifying, and addressing spiritual distress of dying patients and their families within the single hospital. Strengths and gaps were determined by comparing the findings against a proposed conceptual framework, "Drury's Compilation of Existing Frameworks," developed from a synthesis of existing practice models for spiritual assessment and care of dying patients and families experiencing spiritual distress.

Drury's Compilation of Existing Frameworks

This section describes my proposed compilation of existing frameworks developed from a synthesis of existing practice models (described in more detail in Chapter 2) for spiritual assessment and care of dying patients and families experiencing spiritual distress. The framework also includes proposed ideas about what should exist at the organizational and provider care levels to adequately support spiritual care that are used in a matrix to guide data collection (Chapter 3) and to compare with the data obtained from the case study.

In this conceptual framework, it is assumed that body, mind, and spirit of each human being are intertwining inseparable domains. Any stressor, whether positive or negative, that influences or alters one domain, will affect the other domains and ultimately the person as a whole. Thus, patient assessment and care must be holistic for healing and generalized health to be attained. In order for patients to experience healing, healthcare providers must have the knowledge and skills necessary to address all the various domains of patient needs and how these needs intertwine – thus demanding that all disciplines work and join their various areas of expertise toward this common purpose.

Screening for spiritual distress should be completed upon admission by the admitting nurse. Since most admission data bases are quite lengthy, especially for a newly admitted patient experiencing acute symptoms of pain, nausea, shortness of breath, and so forth, the screening may be a question or two at most. Because today's patients are admitted sicker and inpatient hospital stays are shorter, opening an admission dialogue regarding spirituality and spiritual needs within the first few hours is imperative for

spiritual distress to be identified and spiritual care to be delivered before discharge. Based upon the spiritual screening, a more comprehensive spiritual assessment may be necessary.

The professional who conducts the comprehensive spiritual assessment is identified based upon the organization's resources for addressing spiritual care. Thus, the initial spiritual screening is done by the registered nurse performing the admission history and physical, but a more in-depth spiritual assessment may be performed by the same or another discipline. A comprehensive spiritual assessment does not necessarily need to be structured to be effective. Once dialogue about spirituality has begun, the healthcare provider can gain information by simply letting the patient lead the conversation in a direction that allows the patient to express their spirituality, spiritual needs, or spiritual distress in a manner that is meaningful for the patient. As part of the assessment, the healthcare professional should pay close attention to the verbal and nonverbal cues conveyed in their dialogue, witness patient's interaction with others, and request staff input. Spiritual distress and the patient's spiritual needs should be addressed as a section within the individualized holistic plan of care. As the spiritual plan is devised, it is imperative that the plan be explored, discussed, and approved by the patient as well as the rest of the healthcare team.

In this conceptual framework, no single discipline within the healthcare system is exclusively responsible for spiritual care. Simply based upon the ratios of nurses to patients as compared to that of chaplains or social workers to patients, nurses are much more likely to be present when a patient exhibits despair or spiritual distress. Chaplains and pastoral care providers may be few or even nonexistent within the organizational structure. Some hospitals provide spiritual care through volunteer ministers from the

community. Assuring a distressed patient who is experiencing fear, grief, or despair in the middle of the night that the chaplain can discuss these concerns or fears with them in the morning or after the weekend is not therapeutic or appropriate. These moments must be addressed in the moment. Restoring or improving a patient's spiritual health requires teamwork and collaboration, with the patient being a key member of the team.

Obviously, organizational structure is required for spiritual care to be effective. Based upon the organization's resources, spiritual care should be outlined in a formal process with identified roles for each professional discipline. The process for spiritual assessment and spiritual care delivery should involve a language of spirituality that is understood across the disciplines involved in patient care delivery. Furthermore, professionals should be aware of their role in the provision of spiritual care, the formal policies and procedures regarding spiritual assessment and spiritual care, the resources available to address the spiritual needs of patients, and they should possess the knowledge and skills necessary to fulfill their spiritual care roles and responsibilities. To ensure that each professional understands their roles and responsibilities in identifying and addressing spiritual distress in the dying patient, education and training are necessary.

Table 1 illustrates the important characteristics from selected frameworks that support Drury's Compilation of Existing Frameworks.

Table 1

Drury's Compilation of Existing Frameworks

Conceptual Framework	Key Characteristics
Fitchett's 7x7 Model for Spiritual Assessment (Fitchett, 2002)	<ul style="list-style-type: none"> • The body, mind, spirit are inseparable, conjoined domains of each human being. What happens to one domain affects the other domains, thus affecting the whole being. • Spiritual assessment should include: engaging the patient in conversation that is meaningful to the patient while being aware of the patient's verbal and nonverbal language; observing the interaction between the patient and others; review of the chart; and open communication with staff. • The plan of care should include spiritual needs within the broader holistic plan.
Four Domains Model of Spiritual Health and Wellbeing (Fisher, 2011)	<ul style="list-style-type: none"> • Spiritual wellbeing influences the general health of each individual. • Fortifying and enriching one domain will positively affect other domains and ultimately the whole being. • When illness or trauma creates suffering of one domain, the entire being is weakened. • The model offers a foundation for spiritual assessment.
Principal Components Model (McSherry, 2006)	<ul style="list-style-type: none"> • Policies support the idea that individuals are composed of many qualities that define and mold their spirituality. • The roles, language, misconceptions, and ambiguities of healthcare providers in relation to spirituality and spiritual care of patients must be identified, understood, and addressed so that at no time does the patient's spiritual needs go unnoticed, ignored, or leave the patient feeling estranged and hopeless. • Addressing the spiritual needs of patients is an inter-intra-disciplinary responsibility in that no one discipline is entirely responsible for the delivery of spiritual care within a healthcare facility. • Communication, collaboration, and cooperation among the disciplines is imperative. • Healthcare institutions and professionals should avoid fragmenting holistic patient care by appointing certain disciplines as sole providers for a specific domain (i.e., body, mind, or spirit). • All humans are assumed to be spiritual beings; general health and wellbeing can be achieved through spirituality. • Implementing the organizational model can assist in establishing a common language among organizations and care providers for addressing spirituality, developing spiritual assessment tools that aid in identifying spiritual distress and the spiritual needs of patients, developing spiritual care guidelines that meet the diverse spiritual needs of various populations, offering structure for healthcare organizations to address the spiritual needs of their patients, and advancing the knowledge of various

Conceptual Framework	Key Characteristics
Spiritual Care Implementation Model (Puchalski et al., 2009) (Puchalski, et al., 2009)	<p>healthcare disciplines in assessment and providing spiritual care to patients and their families.</p> <ul style="list-style-type: none"> • An organizational process is defined for how the interdisciplinary team communicates and collaborates to identify, manage, and evaluate the spiritual needs of patients. • The patient and interdisciplinary team work collaboratively to identify and address the patient’s spiritual needs. • Assessment and treatment of the spiritual domain are no less vital than those of physical suffering or mental illness. • An initial spiritual screening is needed to immediately identify spiritual distress. If spiritual distress is identified, a more comprehensive spiritual assessment is required. • Ongoing spiritual care may be necessary after discharge; thus spiritual care should be included in the discharge planning and follow-up.

Looking at the issue of spiritual care from a “system” perspective is minimally reflected within the literature. This framework outlines what I consider essential for organizational and individual practice levels of spiritual care. It was used as a guide for this case study research data generation and analysis, and it may also be applicable as a tool for assessing spiritual care structures and practices in other hospital systems. The purpose of this case study research is to examine policies and practices at the organizational and provider levels of care to determine potential strengths and gaps in end-of-life spiritual care.

Case Study Design

A case study design is fitting when the researcher aspires to closely investigate an experience or process in its entirety, within its real world context (Yin, 2003). The findings from case study research can then be used for both theory development and theory analysis (Munhall, 2012). A case study method was used for this study because it allowed the researcher to explore an experience or process about which little is known. The “case” in this study was a single hospital, and the focus of study within the case was that of spiritual distress in dying patients. A significant feature of case study design is the use of multiple sources of data that together allow the researcher to describe, characterize, and organize aspects of the focus of study (Lincoln & Guba, 1985; Munhall, 2001; Stake, 2005). Data sources proposed for this study included (a) review of hospital documents and (b) interviews with key professionals. Gathering and reviewing these data allowed the researcher to describe the organizational processes of a specific healthcare facility and compare them to a proposed conceptual framework developed from a synthesis of existing practice models for spiritual assessment and spiritual care.

Research Questions and Specific Aims

Data collection and analysis addressed the research question: How is spiritual care of dying patients and their families addressed at the organizational and provider levels of care within one Midwestern hospital? The specific aims identified to help answer this question included:

1. To describe how the organization addresses spirituality and spiritual care in major documents, including mission, vision and value statements, departmental policies, job descriptions, various admission and patient assessment forms, and patient education materials;
2. To describe how nursing, chaplaincy, and social workers address spirituality and spiritual care in assessment, diagnosis, communication and implementation of the care for the dying patient including:
 - a. the language used by the different disciplines in reference to spirituality, spiritual distress, and spiritual care,
 - b. perceived roles in assessment, diagnosis, and provision of spiritual care to dying patients and families experiencing spiritual distress, and
 - c. the communication patterns among the three disciplines when addressing spiritual distress and needed spiritual care;
3. To compare findings from aims #1 and #2 to the processes described in a proposed conceptual framework developed from a synthesis of existing models for spiritual assessment and care of dying patients and families experiencing spiritual distress.

Findings related to organizational issues, communication and language patterns, and role perceptions that affect the identification and treatment of spiritual distress in dying patients and their families can inform future policy changes, educational strategies, and clarification of interdisciplinary professional roles related to addressing spiritual distress of terminally ill patients and their families. Literature addresses spiritual care in the dying patient, but in a manner that is focused and limited, such as by discipline or education. There is nothing in the literature that contextualizes the overall system within which the processes and communications of spiritual care occur. This study aimed to do that which had not yet been done; that is, look at the system in its entirety to identify professional roles, processes, communication, and language of spiritual care when addressing spiritual distress in dying patients and their families.

Researcher's Voice

"The greatest obstacle to discovery is not ignorance but the illusion of knowledge."

(Boorstin, as quoted in Andersen, 2009, p. 68)

"True reality" is a mystery for me. Soul-searching for life's realities has caused me to develop the ontological assumption that pure reality is not tangible. One's reality is in the eye of the beholder. I do not believe that it is possible to truly understand another's reality. Each individual's reality is not stagnant, but constantly changing with exposure to others and life situations or crises. This aligns me with a constructivist, or interpretivist paradigm more than a "realist" and parallel to a post-positivist one. It is my belief that we each construct our own personal worldview based upon our perceptions and observations, but since perceptions are so unique to each person, our worldview can be flawed. There is much to be learned by studying the reality of others. While we may not be able to

understand the “absolute reality” of another, exploring the reality can give researchers insight as to why people feel passionate about certain issues and why individuals do what they do.

Axiology pertains to the role of values in understanding another’s perception. I believe that researchers must first identify their personal values, beliefs, and biases. This ability to identify values, beliefs, and biases is the initial approach to being self-aware during observation, interviews, and interpretation of participants’ responses. To a constructivist-minded researcher, it is an accepted axiological assumption that one always sees through one’s own lenses of past knowledge and experience and is never completely free of values, beliefs, and biases – that is, never totally “objective.” In order to be as open as possible to hearing the realities perceived by others, however, the researcher must be aware of their personal worldview – beliefs, values, and biases – and be able to listen to others’ narratives knowing that he is also listening for different values and is not unconsciously implying his own.

A term used in phenomenology to describe this identification and setting aside of personal values, beliefs, and biases is “bracketing” (Munhall 2001; Sandelowski, 1993). One technique for bracketing is journaling. Journaling is a helpful tool for analyzing one’s personal beliefs and the effects those beliefs may have on research findings and interpretations, thus keeping some conscious biases of the researcher in check. Being human, researchers may not always recognize their own biases, but the purpose and benefit of journaling one’s thoughts, beliefs, and attitudes can potentially uncover perceptions that might otherwise go unrecognized. Another technique is “decentering” (Munhall, 2001). In decentering, the researcher practices the “art of unknowing” by separating one’s self from

one's own principles, beliefs, attitudes, and values. Like bracketing, decentering requires that the researcher be cognizant of their own biases. One way to decenter is to practice listening to what others are saying without thinking of how to respond. The researcher must be solely present when another is conversing by maintaining awareness of what is being said rather than trying to process it to formulate it into something personally meaningful.

During this study, I practiced decentering while communicating with co-workers, students, family, and even strangers in the store. Biases were identified and reflected upon when I found myself struggling with decentering. Being cognitively aware of the biases allowed me to bracket them during interviews and exploring themes from these data. A significant bias that I identified was my belief that most individuals have some sort of fear, concern, or uncertainty regarding the afterlife while they are dying, regardless of their religious beliefs. Therefore, during a patient's final hours, their sole focus is on what is yet to come. In further reflection, I realized that my bias regarding a patient's sole focus on the afterlife and what is left to come, was exactly why spirituality in dying patients is a passion for me. When our bodies can no longer be cured and there is nothing more that we can accomplish for ourselves and others in this life, yet we are scared and uncertain of what, if anything, lies ahead in the spiritual world, who will relieve that fear and suffering, and who will console the soul?

Ontologically, my constructivist perspective allows me to look through my personal lens at the world and others without making quick and unrelenting judgments. As a researcher, I envision myself accepting the beliefs and responses of a single participant as their own personal reality that is separate from the realities of others, including my own.

Each reality plays its part in the whole, thus, like a director might say to an actor, “There are no small parts.”

Obviously, I value the concept of holistic nursing, particularly the spiritual aspect as it relates to suffering and death. I do not believe that anyone can truly be an expert in spirituality. The mystery surrounding the term spirituality reinforces the desire of this researcher to learn what others believe and how these beliefs reflect their journey through times of suffering. It is my perception that human suffering is unavoidable and regardless of whether we are rich or poor, ignorant or intelligent, social or reclusive, religious or agnostic, we will all at one time or another experience suffering. As a nurse, I have a desire to relieve suffering through providing direct patient care, conducting research that may enlighten nurses about how to identify and manage spiritual distress or suffering, and by educating future nurses about their role in caring for the spiritual dimension of suffering patients. The value I place on spirituality and the need to relieve spiritual suffering may not reflect the values of other nurses, since the role of nursing the spirit is not one that all nurses assume as their professional or moral obligation.

Epistemologically, my methodological approach is an inductive one in that I favor taking the pieces of research information and using them to describe the whole phenomenon rather than breaking down the whole phenomenon for the purpose of describing the pieces. In this case study, I cannot say that whether a deductive or inductive approach is superior. For me it is like a large puzzle where each piece affects the whole picture. A missing or broken piece alters the whole. Thus, examining the pieces of the process provides a better understanding of the whole. In this project, data were generated to represent these “pieces” through interviews with nurses, chaplains, and social workers.

These interviews allowed a glimpse of each participant's reality and how those realities collectively influence the overall system's process for recognizing and addressing spiritual distress in dying patients and families.

I believe that a researcher's awareness of their own beliefs, biases, and values should be shared in order to be transparent about how their worldview and perceptions may impact their research methods and interpretation of findings. As a human, researcher, healthcare provider, and patient, experiences have shaped my reality but as a researcher, I must be ever cognizant that each nurse, healthcare provider, and patient has lived experiences that have shaped their reality as well. I must be self-aware so that the lenses of my personal and professional reality do not cloud my vision in recognizing others' realities and how realities intersect within the healthcare facility of study in this research.

Definition of Terms

This section defines terms that are used frequently in this writing:

Dying: "A stage of life that fits into a broader philosophy, giving both death and life meaning" (Dossey & Keegan, 2013, p. 463). This term is used interchangeably with "end of life."

Healing: "A positive, subjective, unpredictable process involving transformation to a new sense of wholeness, spiritual transcendence, or reinterpretation of life" (Dossey & Keegan, 2013, p. 827).

Holistic Care: An approach that emphasizes and integrates spiritual dimensions into all aspects of nursing care (bio-psycho-social-spiritual) (Dossey & Keegan, 2013).

Spiritual Care: Addressing symptoms of spiritual distress through compassionate, patient care that provides a sense of peace, hope, and transcendence.

Spiritual Distress: “A state of suffering related to the impaired ability to experience meaning in life through connections with self, others, the world or a superior being” (Herdman & Kamitsuru, 2014, p. 372).

Spiritual Pain: The intense anxiety associated with the realization of one’s mortality or impending death, which alludes to an anticipated loss of meaning and purpose, connectedness to others or something beyond self, or loss of hope associated with life (Groves & Klauser, 2009; Saunders, 1988; Vilalta et al., 2014).

Spirituality: For the purpose of this study, spirituality is defined as the search for meaning and purpose in life based upon the individual’s beliefs and connectedness. These beliefs may be founded upon religious, cultural, or other personal values that provide meaning and motivation to transcend beyond stressors of existence and develop the inner strength necessary for the individual to find meaning and purpose in their existence and optimally, physical, psychosocial and spiritual wellness.

Terminally Ill: An illness that is reasonably expected to end in death.

Chapter Overview

In Chapter 2, the review of literature occurs in two parts. The first is a published article by the author of this dissertation that provides considerably more on the history, background, and significance of spiritual care provision in nursing than found within this introductory chapter. It identifies barriers to nursing consistently providing spiritual care and familiarizes readers with many existing (but seldom used) resources, including practice frameworks for spiritual care and spiritual assessment tools. A second part of Chapter 2 provides additional information on spiritual care needs and educational resources for patients at the end of life.

Chapter 3 is the Methodology. This chapter describes the methods used to complete all aims of the dissertation and contains the methods design. Chapter 4 presents the original data-based findings of the dissertation study. Chapter 5 presents a concluding discussion summarizing the key points of preceding chapters, making clear the importance of the overall study, and discussing the implications of the overall topic for future research, education, and practice.

CHAPTER 2

REVIEW OF THE LITERATURE

The literature review provides a groundwork and describes how the proposed study will build upon existing studies (Rudestam & Newton, 2007). Current research and knowledge related to organizational and provider level factors have been found to support spiritual care in institutions (Puchalski, Vitillo, Hull & Reller, 2014). Part I of this chapter is an article published in the Open Journal of Nursing (2016) entitled, “The Hole in Holistic Patient Care.” The topics addressed in the article include the history of holistic nursing as it pertains to the human dimension of spirituality, the language of spirituality, descriptions of spirituality and spiritual distress, barriers and misconceptions related to spiritual care, practice, and organizational models, and tools for spiritual assessment and care. Part 2 of Chapter 2 provides additional review of the research literature on spiritual care for patients at end-of-life, as the publication in Part 1 does not have that specific focus. This literature review provides evidence that the proposed research is unique, important, and meaningful.

Part 1: The Hole in Holistic Patient Care

Life threatening illness and related suffering are arguably situations in which holistic care is most important. Holism, a century-old concept, refers to healing the whole person – body, mind and spirit – rather than solely focusing on the physical suffering and treatment of a disease or condition (Dossey, Keegan, Guzzetta & Kolkmeier, 1988).

Holistic healing is the creation of a harmonious healing balance among the body, mind, and spirit of each patient to achieve health for the entire being (Cooper, Chang, Sheehan, & Johnson, 2013; Narayanasamy & Owens, 2001). *Holistic care* thus includes care for the whole person – including physical, psychosocial, emotional, and *spiritual care*. Avoiding the

provision of spiritual care – defined as attending to the spiritual needs of human beings by any healthcare professional – creates “a hole” in holistic patient care.

Provision of spiritual care is significant, as research has shown not only that spiritual health is related to better overall health outcomes but also that patients believe that spiritual needs should be addressed by healthcare professionals (Puchalski, 2007). Better health outcomes that can be promoted with spiritual care include disease prevention and recovery, sense of overall wellbeing, enhanced ability to cope with illness, and adjustment to stress-related life events (Ano & Vasconcelles, 2005; Balboni et al., 2013; Coyle, 2002; Gallison et al., 2013). Spiritual and religious interventions have been shown to decrease suicide rates, substance abuse, divorce, and depression in some populations (Chidarkikire, 2012; Gleason, 2004). Research findings indicate that patients expect nurses to help them explore the meaning of suffering and arrange for privacy for participation in spiritual and religious customs (Gallison et al., 2013; Ross, 2006). Nurses have the unique opportunity to enrich the hospital experience, to improve the quality of life for patients suffering from serious to terminal disease, and to improve patient satisfaction by attending to the spiritual needs of their patients.

Nursing, as a profession, has historically claimed to provide holistic care, yet research indicates that many nurses do not feel comfortable or adequately trained to address the “spiritual care” dimension of their patients (Carr, 2010; Dossey & Keegan, 2013; Puchalski et al., 2006; Wallace et al., 2009). Holistic nursing is defined by the American Holistic Nurses Association as “all nursing practice that has healing the whole person as its goal” (Dossey & Keegan, 2013, p. 5). The following sections will explore the history of holistic nursing as it pertains to the dimension of spirituality, barriers, and

misconceptions related to spiritual care, and end with a review of existing practice models for spiritual care and spiritual assessment tools that could promote the filling of the “hole” in holistic care.

Holistic Nursing: Historical Perspectives on Spirituality in Healthcare

Holistic origins. Dating back 20,000 years, Shamanism is the oldest approach to healing and still exists today (Dossey et al., 1988). Practically every native community used some type of Shamanism (Barnum, 2006). Shamanism assumes that the combination of body, mind, and spirit is a single inseparable entity rather than a consolidation of parts (Barnum, 2006). Shamans are individuals who the tribe believes possess special gifts for understanding and controlling the spiritual realm of others. Incantations, spells, drums, chanting, medicinal plants, and rituals are used in the treatment of pain, sickness, and suffering. The source of illness within Shamanism is attributed to the loss of “personal power” that makes an individual vulnerable to sickness (Dossey et al., 1988, p. 60).

In 500 B.C., an ancient Greek physician, Hippocrates, advised those who nursed the sick be attentive to the spiritual wellbeing of their patients and “to do no harm” (O’Brien, 2011, p. 25). From 700 B.C. to 300 A.D., ancient Greeks erected healing temples called Asclepians (named after the Asclepius, the Greek god of healing) which were sites of healing for the body, mind, and spirit (Dossey et al., 1988). Ancient Greek health practices offered in the temples included art, drama, music, prayers to the gods, rest, massage, herbs, and basic surgeries, with some interventions performed by priest healers (Dossey et al., 1988; Sawatzky & Pesut, 2005).

In the early years of Christianity, widows were the caretakers of the poor and afflicted. The term “widow” was a title that referred to pious older women who devoted their

time to caring for the less fortunate, elderly, and those stricken with illness (Dossey et al., 1988). Later these widows formed religious orders that performed acts of charity and works of mercy. Corporal works of mercy meant nurturing the spirit through tending to the physical ailments of the body. Treatment often involved exorcism, as illness was attributed to possession by evil spirits.

Christianity reigned throughout the Middle Age era, with religious orders establishing hospitals to facilitate care of the sick (Barnum, 2006). Patients in medieval hospitals had high mortality rates due to the lack of hygiene and curative treatments. Nursing care was limited to comfort measures such as providing shelter, nourishment, personal care, and prayer. Thus, the primary focus in caring for the sick was nursing the soul.

Holistic care wanes with scientific revolution. The era of holistic healing began to fade with the onset of the Scientific Revolution (Dossey et al., 1988; Sawatzky & Pesut, 2005). René Descartes, a 17th century philosopher, expressed the perception that the body and mind are each a separate entity that can best be understood through separation, rationalization, and reasoning (Dossey et al., 1988). This Cartesian dualism ushered in the scientific approach to viewing and treating illness from a purely physiological perspective. As specializations evolved in medical science, Western medicine distanced itself even further from the healing of the human spirit.

Florence Nightingale was the first nurse trained within a scientific curriculum who is recognized for practicing holistic care to patients by combining spirituality and science (Dossey et al., 1988; O'Brien, 2011; Sawatzky & Pesut, 2005). Nightingale believed that healing is a dynamic process of recovering from an affliction or disease, mending that which is damaged, and restoring and transforming the individual's body, mind, and spirit (O'Brien

& Gates, 2007). Nightingale personified her principle that spirituality is both “intrinsic to humans and compatible with science” (Maher, 2006, p. 419).

Most early to mid-20th century nursing schools in the United States maintained some aspect of spirituality through their affiliation with major religious denominations (O’Brien, 2011). Yet, as nursing curricula focused more on the scientific approach to nursing care, the characteristics of care, compassion, and empathy became less obvious (Dossey et al., 1988). In the later 20th century, university and college-affiliated programs established baccalaureate, masters, and doctoral programs in nursing. Great advances were being made in medical technology, and knowledge in the biological and behavioral sciences was flourishing. Along with these advancements, the focus of nursing curricula shifted from preparation for a spiritual vocation to preparation for a skilled, scientific profession. It can be said that the paradigm of nursing shifted from an art to a science (O’Brien, 2011).

Re-emergence of spirituality within healthcare. In the past few decades, the role of spirituality in healthcare has regained the attention of healthcare professionals, nursing organizations, regulating agencies, researchers, and consumers. During the 1970s and 1980s, the importance of holistic healthcare was reignited, as was spiritual health and spiritual care of the sick. In 1981, the American Holistic Nurses Association was established by Charlotte McGuire in response to a substantial nursing shortage, as nurses were leaving acute care settings to pursue opportunities that would allow them to refocus on healing the “whole” person rather than merely curing disease (American Holistic Nurses Association, 2007; Keegan, 1988). Holistic healthcare was defined by Cathie Guzzetta in 1988 as “a sensitive balance between art and science, analytic and intuitive skills, and the ability and knowledge to choose from a variety of treatment modalities to promote balance and

interconnectedness of body, mind, and spirit” (Dossey et al., 1988, p. 117). In this definition and others, spiritual needs are viewed as equally important to the physiologic and psychosocial needs in the provision of nursing care (O’Brien, 2011).

In 2001, the American Nurses Association developed a Code of Ethics for Nurses, declaring that nurses are to implement measures that promote the physical, psychological, and spiritual wellbeing of their patients. The Joint Commission on the Accreditation of Healthcare Organizations (TJC) has since mandated that accredited healthcare institutions “accommodate” both religious and spiritual care needs of their patients (Handzo & Koenig, 2004; Joint Commission of the Accreditation of Healthcare Organizations, 2004; Puchalski et al., 2009). Research has strengthened the push for spiritual care by revealing not only that spiritual health is related to better overall health outcomes but also that the majority of patients believe that spiritual needs should be addressed by healthcare professionals (Puchalski, 2007). Findings have reliably established a direct relationship between spiritual health and medical outcomes, including disease prevention and recovery, sense of overall wellbeing, and enhanced ability to cope with illness (Ano & Vasconcelles, 2005; Coyle, 2002; Gallison et al., 2013). A meta-analysis of 49 studies encompassing over 13,000 subjects linked positive religious coping to an individual’s ability to adjust to stress-related life events, while negative religious coping was associated with anxiety, depression, and distress (Ano & Vasconcelles, 2005). In another study, supportive spiritual care in terminally ill patients was associated with improved quality of life, patient satisfaction, increased hospice referrals, decline in the use of extensive medical treatments, and decreased medical expenses (Balboni et al., 2013). A study on the coping abilities of HIV patients revealed that intense spiritual events allowed them to better cope with pain,

anxiety, despair, and impending death (Coyle, 2002). Multiple studies have associated spiritual and religious interventions in the mentally ill with improved overall mental health and decreased readmission rates, suicides, substance abuse, divorce, depression, criminal behavior (Chidarkikire, 2012; Gleason, 2004).

In studies of patient perceptions, patients have consistently professed their desire for physicians and nurses to “consider” religious and spiritual needs and preferences in the delivery of patient care (Astrow et al., 2007; Balboni et al., 2013; Ramondetta et al., 2013; Williams, Meltzer, Arora, Chung, & Curlin, 2011). Research findings indicate that patients expect nurses to help them explore the meaning of suffering and arrange for privacy to allow for participation in prayer, spiritual customs, and rituals (Gallison et al., 2013; Ross, 2006). Nurses have the unique opportunity to enrich the hospital experience, improve the quality of life for patients suffering from serious or terminal disease, and improve patient satisfaction by tending to spiritual needs of their patients. Resolution of spiritual uncertainty ushers in the spiritual peace necessary to achieve a heightened quality of life (Astrow et al., 2007; Balboni et al., 2010; Gallison et al., 2013; Lichter, 2013; Puchalski & Romer, 2000; Williams et al., 2011). Each of these effects are well documented in a large body of research on spirituality in patients diagnosed with a serious, advanced, or terminal illness (Balboni et al., 2013; Dobratz, 2012; Gallison et al., 2013; Hermann, 2001; Miller & Thoresen, 2003; Ramondetta et al., 2013; Ross & Austin, 2013). Thus, evidence supports regulatory and organizational actions which have formally re-established the need for the role of the nurse to be a healer of the integral tapestry of the human, body, mind, and spirit. If one thread of this integral tapestry begins to unravel, the whole tapestry is at risk for disintegrating into a meaningless pile of thread.

Barriers to Spiritual Care

Regardless of research evidence and organizational and accreditation mandates, attention to spirituality often falls short in the current healthcare system (Cadge & Bandini, 2015). Reasons for this include: (a) a blurring of religion and spirituality boundaries; (b) insufficient attention to definitions of spirituality and spiritual distress; (c) role conflict with professional identity and role confusion among disciplines related to responsibility for spiritual care; and (d) insufficient education and skill development for nurses and other healthcare professionals related to assessment, intervention, and appropriate referral for patients experiencing spiritual distress (Cadge & Bandini, 2015; Carr, 2010; Flannelly et al., 2005; Handzo & Koenig, 2004). Although these barriers affect various healthcare professionals, this chapter predominantly addresses how they apply to the nursing profession. Nursing as a profession has historically claimed to provide holistic care, the definition of which includes spiritual care, yet research indicates that many nurses do not feel comfortable or adequately trained to address the “spiritual” dimension of their patients (Carr, 2010; Dossey & Keegan, 2013; Puchalski et al., 2006; Wallace et al., 2009).

Blurring of religion and spirituality. One challenge in defining spirituality is that the boundaries between spirituality and religion are often poorly defined or nonexistent. This erroneous blurring of the two is often seen in the language of both research and practice related to spiritual care, wherein it is implied that religion and spirituality are synonymous terms (Dossey & Keegan, 2013; Nardi & Rooda, 2011). Spirituality naturally exists within each human being, while one’s religion or religious affiliation is a personal choice (Dossey & Keegan, 2013). Religion can be defined as an organizational system created by an individual or group that accept the same beliefs, values, sacred text, rituals,

and divine being (Dossey & Keegan, 2013; Nardi & Rooda, 2011; Sinclair, Pereira, & Raffin, 2006).

Spirituality is a broader concept that may be expressed through an individual's religious beliefs, practices, and rituals, but religion is not necessary for spirituality to exist (Cadge & Bandini, 2015; Chochinov & Cann, 2005; Delgado, 2005; Dossey & Keegan, 2013; Johnson, 2003; Vachon et al., 2009). The word "spirituality" originates from the "Latin *spiritus*, meaning breath, and relates to the Greek *pneuma* or breath, which refers to the vital spirit or soul" (Dossey & Keegan, 2013, p. 722). Dossey and Keegan (2013) describe spirituality as:

The essence of our being. It permeates our living in relationships and infuses our unfolding awareness of who we are, our purpose in being, and our inner resources. Spirituality is active and expressive. It shapes – and is shaped by – our life journey. Spirituality informs the ways we live and experience life, the ways we encounter mystery, and the ways we relate to all aspects of life. Inherent in the human condition, spirituality is expressed and experienced through living our connectedness with the Sacred Source, the self, others, and nature. (p. 721)

According to Vachon et al. (2009), "spirituality could be defined as 'a search for meaning and purpose in life' or as, 'a feeling to have found a meaning and purpose in life and death'" (p. 55). Pesut (2008) and others have described spirituality as the core of our being and existence: "To be human is to be spiritual" (p. 98).

Insufficient attention to definitions of spirituality and spiritual distress. Most researchers agree that developing a simple standardized definition of spirituality to fit all individuals in all situations is an ambiguous, if not impossible task (Chochinov & Cann, 2005; Delgado, 2005; Dossey & Keegan, 2013; Kellehear, 2000; McSherry, Cash, & Ross, 2004; McSherry & Jamieson, 2013; Milligan, 2011; Puchalski, 2007; Puchalski et al., 2014; Reinert & Koenig, 2013; Tanyi, 2002). However, many human experiences are

subjective and difficult to standardize, yet our study of these subjective human experiences proceeds. Similarly, it is possible to identify a working definition of spirituality for research and practice by drawing on the essential aspects of various definitions. These include:

- a search for and/ or sense of meaning and purpose in life,
- connectedness to something beyond the self, which can include a higher power, loved ones, nature, art or music, and
- a source of inner strength to transcend the stressors of existence and suffering and optimally, to maintain physical, psychosocial, and spiritual wellness.

These essential aspects in definitions of spirituality form the logical basis for the nursing diagnosis of “Spiritual Distress” as described by the North American Nursing Diagnosis Association (NANDA) (Blanchard et al., 2012; Caldeira, Carvalho, & Vieira, 2013). Spiritual distress, as defined by NANDA, is, “A state of suffering related to the impaired ability to experience meaning in life through connections with self, others, the world or a superior being” (Herdman & Kamitsuru, 2014, p. 372). Symptoms that may indicate spiritual distress, per NANDA, include: anxiety, crying, fear, fatigue, insomnia, anger, guilt, isolation, hopelessness, and isolation. A stronger awareness and focus on these essentials – the search for life meaning, a need for connectedness, and inner strength to transcend suffering – as well as the related NANDA definition of spiritual distress would: (a) decrease the blur between religion and spirituality; (b) enable relevant spiritual assessment, patient education, interventions, and referrals related to spiritual health; and (c) help clarify role confusion among disciplines.

Conflict with nursing “professionalism.” Issues around spirituality for nursing are largely related to the strong, though erroneous, equating of spirituality with religion, and religion being something they most often do not see as a part of their professional scope of practice, given its now strong scientific basis. As society and healthcare have become increasingly secularized, nurses have grown more anxious and unsure about balancing their own beliefs and professional nursing roles when providing spiritual care (McSherry & Jamieson, 2013). Secularization and intolerance to religious beliefs has made nurses apprehensive in addressing patients’ spirituality for fear of being accused of proselytizing personal beliefs and values on their patients (Dossey & Keegan, 2013; McSherry & Jamieson, 2013). Those nurses who aspire to include spiritual care in their nursing practice, however, are aware that providing such care to their patients can be accomplished without imposing personal and religious beliefs or needing expertise in any particular religion (Dossey & Keegan, 2013; McSherry & Jamieson, 2013). As a profession, nurses must become knowledgeable, proficient, and secure in providing spiritual care, per accurate definition of spirituality, in order to truly be holistic caregivers.

Role confusion among disciplines. Much of the literature identifies that one of the key challenges in addressing the spiritual tasks of patients is the inability to clearly identify the provider of spiritual care (Chochinov & Cann, 2005; Gallison et al., 2013; Narayanasamy & Owens, 2001). According to Brunjes (2010), physical pain is treated by the patient’s physician, mental anguish by the psychiatrist, and social pain by a social worker or other social support system, but the referral agent for spiritual pain remains a mystery. The answer to this riddle is not such a mystery for those who attest that the chaplain is the spiritual expert in treating the soul, much like the physician is the expert for

the physical body (Emanuel, Scandrett & Emanuel, 2012; Handzo & Koenig, 2004; Puchalski et al., 2009). Healthcare professionals tend to agree that referral to the hospital or palliative care chaplain is logical for addressing the spiritual and religious needs of patients (Gallison et al., 2013; Narayanasamy & Owens, 2001; Tanyi, 2002).

Pastoral care professionals are trained to provide spiritual care and guidance to diverse religious denominations, those who do not have a particular religious affiliation, and those who claim to have no faith whatsoever (Emanuel et al., 2012; Handzo & Koenig, 2004). In reality, the ratio of chaplains to patients is quite small, and chaplaincy programs have not gained the momentum to train more chaplains, as jobs in healthcare are scarce and salaries are low (Blanchard et al., 2012; Emanuel et al., 2012). Thus, the more realistic question may not be “Who is the responsible healthcare professional to provide spiritual care to patients?” but rather “What is the role of each healthcare professional on the multi-disciplinary team in meeting the spiritual needs of patients?” Many feel that all healthcare professionals should claim at least a share of the responsibility for addressing the spiritual needs of patients since the establishment of trust between any healthcare professional and patient, at any given moment, can open the door for honest communication concerning spiritual feelings that could lead to the resolution of spiritual distress (Handzo & Koenig, 2004; McSherry, 2006). Who provides spiritual care is not nearly as important as ensuring that each healthcare professional has the resources, guidance, and interdisciplinary support to meet the spiritual needs of any patient or family who trusts them enough to share spiritual concerns (Brunjes, 2010).

Lack of education and skill development for spiritual care. The lack of education and direction within nursing curricula hinders the ability to incorporate spiritual

care into practice for patients experiencing spiritual distress (Balboni et al., 2013; Balboni et al., 2010; Ferrell et al., 2013; Gallison et al., 2013; Narayanasamy & Owens, 2001).

Improving the competence of nurses in defining spirituality beyond religion, and in identifying and addressing symptoms of spiritual distress would enhance patient outcomes of finding life meaning and purpose, connectedness, inner strength, and a state of spiritual peace – all of which can be severely disrupted by life-threatening illness and impending death (Dossey & Keegan, 2013). Through guidance and mentoring, nurses and other healthcare professionals can be empowered to provide spiritual care, to advance holistic practice, and to better meet the needs of patients and their families (Gallison et al., 2013). Nursing faculty, who may also feel inadequacies related to spiritual care, can be assured that creating such guidance for students does not rest solely on their shoulders, but that numerous models of spiritual care and tools for spiritual assessment already exist.

Spiritual Care Models, Assessment Tools, and Basics of Intervention

Awareness of existing resources for spiritual care and a level of proficiency in assessing spirituality is necessary. However, it is not meant to intrude or intervene in religious areas – but rather to explore the patient’s individual sources of meaning, purpose, and strength in life; their sense of hope, connectedness, beliefs, values; and, most importantly, how illness has impacted these essential life structures (Dunn, 2001; Johnson, 2003). The erroneous use of vocabulary associating spirituality solely with religion can be avoided by continually drawing on holistic definitions of spirituality and the nursing diagnosis of spiritual distress.

In Cadge and Bandini’s (2015) review of the evolution of spiritual assessment tools, these authors identify that over 40 such tools have been developed since the 1970s,

predominantly by chaplains, nurses, physicians, and social workers. Tool creation has occurred far more often in disciplinary silos than through interdisciplinary collaboration. Cadge and Bandini assert that the evolution of spiritual assessment tools and the involvement of the disciplines creating them reflect larger societal shifts in the U.S. across the years. The various societal shifts and healthcare responses are also reflected in newer models for spiritual care, some which are interdisciplinary. Such societal influences have included the development of clinical pastoral education (CPE) that integrated psychology and theology, Medicare reimbursement based on diagnosis related groups (DRGs), the history of holistic care reflected in nursing, the hospice and palliative care movement, TJC standards for healthcare organizations, and ongoing chaplaincy debates between approaches of unstructured spiritual presence versus a more structured approach to spiritual diagnosis and care planning. The latter is similar in many ways to nursing's path to professionalism, inclusive of the "nursing process" structure, theory, and research to support an evidence-based practice. Territoriality, often spawned by the disciplinary survival need to document their contribution to patient care, has also influenced claims of who is best qualified to diagnose spiritual problems and implement spiritual care. In response to both increased interdisciplinary collaboration as well as territoriality, spiritual assessment has also undergone a "triage" process of sorts, being divided into screening processes for immediate crises, followed by more in-depth spiritual histories. The result is a diversity of tools ranging from the two-question variety to full narrative, life history assessments.

As nurses review various spiritual care models to find an approach most relevant to their practice, they can compare the language, structure, and functioning of disciplines within the models to see what might fit best in their given healthcare structure and philosophy of

care. Likewise, when reviewing assessment tools to find resources most relevant to individual practice settings, perhaps the most important aspects to compare in the structure, language and questions posed in these tools are: (a) the focus, whether religion-limited or broader life meaning, purpose and connectedness; and (b) the length and time required to complete the tool; (c) where the tool should be integrated into practice; i.e., admission screening or a more in-depth spiritual assessment or spiritual history; and (d) how the tool can be used in practice; i.e., using it as a formal tool or adaptation to an informal, conversational approach to spiritual assessment. Although not all inclusive, several spiritual care models are briefly described here, followed by several existing spiritual assessment tools.

Practice Models for Spiritual Assessment and Spiritual Care

The Spiritual Care Implementation Model. According to the creator of the Spiritual Care Implementation Model (Pulchalski et al., 2009), spiritual care is necessary in any patient-centered healthcare system (see Appendix A for Spiritual Care Implementation Model). The model is described as a relational model; it illustrates a process of how the patient and interdisciplinary healthcare professionals should work together in discovering, communicating, collaborating, managing, evaluating, and following up to verify the effectiveness of the plan and modify the treatment plan as needed. The Spiritual Care Implementation Model has two “sub-models,” one being a specific model for inpatient, and a second, different model, for outpatient clinical settings. The Spiritual Care Implementation Model is also described as a “generalist-specialist model of care” in that board-certified chaplains are considered the spiritual care specialist of the team, but all members of the team should be generalists in their ability to be “first responders” to

spiritual needs – that is, to identify, assess, and respond initially – and potentially to make a referral to the chaplain specialist (Puchalski et al., 2009).

In the Inpatient Model, the implementation of spiritual care begins with a brief spiritual screening to promptly determine if the patient is experiencing spiritual distress. A more in-depth spiritual assessment is included within the psychosocial history portion of the clinical record to aid in identifying significant information regarding the patient's essential needs, hopes, and available resources that can help healthcare professionals determine whether the patient's spiritual status will enhance or complicate the overall medical care. If concerns arise regarding the patient's spiritual health, a referral brings a board-certified chaplain who will complete a comprehensive spiritual assessment which allows the patient to tell their story. The board-certified chaplain will develop a spiritual treatment plan which will be communicated to the entire treatment team, and will extend to discharge planning, bereavement care, and procedures that enable the interdisciplinary team follow-up contact with family and loved ones after the patient's death.

The Principal Components Model. The Principal Components Model is the result of grounded theory study by Wilfred McSherry (2006), based on interviews with members of multiple healthcare disciplines. The model emphasizes six components, which include: individuality, inclusivity, inter-intra-disciplinary, integrated, innate, and institution. Individuality refers to the numerous characteristics that shape the uniqueness of an individual's spirituality, such as culture, religious affiliation life events, social positioning, experiences, and traditions. Inclusivity refers to consideration of patient, healthcare professionals, and family caregivers in assessing understanding, uncertainties, and specific languages of spirituality that are meaningful, versus those that could alienate patients from

seeking spiritual guidance. Inter-intra-disciplinary indicates that no single discipline is exclusively responsible for the provision of spiritual care, but that collaboration is imperative. Lastly, integrated is the component that motivates the healthcare team to avoid fragmenting holistic care by separating the spiritual from the physical or psychosocial aspects of each patient in the delivery of healthcare. Implementation of the Principal Components Model could aid in finding a language of spirituality that is meaningful and applicable for the assessment and treatment of patients experiencing spiritual distress, developing practice guidelines for the delivery of spiritual care to diverse populations, structuring services involved in the provision of spiritual care, and advancing the knowledge and skills necessary for understanding, assessing, and providing for the spiritual needs of patients and their loved ones.

The Four Domains Model of Spiritual Health and Wellbeing. The Four Domains Model of Spiritual Health and Wellbeing, developed by John Fisher (2011), ascribes that the spiritual state of each individual determines the general wellbeing of all other human dimensions. In this model, the domains of spirituality are identified as “personal, communal, environmental and transcendental” (Fisher, 2011, p. 22). Every domain consists of two aspects: knowledge and inspiration. Spiritual health is attained by cultivating positive connections within each domain and is enhanced by integrating additional domains, a process termed “progressive synergism.” Personal growth within a domain not only strengthens the domain, but also overall spiritual health. The Four Domains model can be utilized as a foundation for development and refinement of theory and spiritual assessment tools.

The 7X7 Model. The 7X7 Model was designed and published in the late 1980s and early 1990s by an interdisciplinary team headed by chaplain researcher George Fitchett (2002), to provide a framework that views spirituality as an inseparable entity from the body and mind, yet does not presume what spirituality entails. The model identifies seven holistic dimensions including: medical, psychological, family systems, ethnic and culture, societal and spiritual, as they intersect with seven attributes of spirituality including beliefs and meaning, vocation and consequences, experience and emotion, courage and growth, ritual and practice, community, authority and guidance. The aspects of the 7x7 Model are described in detail without the inclusion of a formal set of questions, allowing the healthcare professional flexibility in the amount of time allotted for the assessment and consideration of the patient's clinical circumstances.

Spiritual Assessment Tools

According to Cadge and Bandini (2015), currently there are over 40 spiritual assessment tools identified in U.S. literature that have been created by various healthcare professionals including physicians, chaplains, nurses, and social workers. Few of these tools were created through multidisciplinary collaboration or were intended for interdisciplinary use; most were created within disciplinary silos. Lack of cooperation between disciplines in assessing spirituality has presented challenges in the communication among healthcare professionals about patients' spirituality and planning spiritual care, as well as widespread variation in the care provided. Language used in various tools ranges from traditional focus on faith and religion to a broader, more existential approach. It is important to examine the content of assessment questions, therefore, to ensure a match with nursing philosophy and diagnoses. Just a few of these tools are briefly described here.

The Spiritual Profile Assessment (SPA). An exception to the lack of cross-disciplinary work occurring in the 1980s, physician Elisabeth McSherry collaborated with chaplains to develop the first physician’s spiritual assessment tool, the Spiritual Profile Assessment (SPA). The SPA included three questionnaires: the Professional Health Inventory, the Religiosity Index, and the Ultimate Values Test (Cadge & Bandini, 2015; McSherry, Kratz & Nelson, 1986). The purpose of the comprehensive Spiritual Profile Assessment was to assist chaplains in planning and documenting spiritual care for individual patients.

The JAREL Spiritual Wellbeing Tool. The JAREL tool (Hungelmann, Kenkel-Rossi, Klassen, & Stollenwerk, 1996), is an example of spiritual assessment tools designed for a specific population. This tool was designed by nurses to evaluate faith, life and satisfaction of patients over the age of 65 years, meant to build on clients’ strengths and help foster personal growth.

The FICA tool. The FICA tool was published in 1996 by physician Christine Puchalski to help physicians and other healthcare professionals address spiritual issues (Cadge & Bandini, 2015; Puchalski & Romer, 2000). The FICA acronym prompts questions related to F: Faith and belief, I: Importance, C: Community, and A: Address. “Address” refers to questions about how their spirituality can be addressed within their healthcare.

The HOPE tool. In 2001, Gowri Anandarajah and Ellen Hight introduced the HOPE tool at least in part in response to TJC requirements (Anandarajah & Hight, 2001). The initial intent of the HOPE tool was to aid medical students and physicians in posing questions regarding patients’ sources of “H – hope, meaning, comfort, strength, peace, love

and connection; O – organized religion; P – personal spirituality and practices; E – effects on medical care and end-of-life issues.”

Screening for spiritual distress. Many nursing assessments done in hospitals upon admission of a patient have a “spiritual assessment tool” which consists of one or two questions. Questions such as “what is your religion (if any)?” and “would you like to see a chaplain?” seem intended to pass the buck versus actually learn anything about the patient. Keeping with the need to be efficient by limiting the assessment to a few questions, yet seeking to increase the effectiveness of those questions, Blanchard, Dunlap, and Fitchett (2012) developed and initiated a quality improvement project aimed at improving the collaboration between nurses and chaplains in assessing and referral of oncology patients who may experience spiritual distress during hospitalization. The primary goal was to train nurses to be more proficient at identifying patients who are at risk for experiencing spiritual distress. A simple algorithm commences with the nurse’s statement, “Our team is committed to the whole person. Do you have a belief, spiritual or otherwise, that is important to you?” Based upon the patient’s response, the nurse inquires, “Is that helping you now?” or “Was there a time that you did have a belief, spiritual or otherwise, that was important to you?” (Blanchard et al., 2012, p. 1078). Through this algorithm, two types of spiritual distress are distinguished. In the first type, the patient reports having specific established beliefs, but these beliefs are not a source of support at this time. The second type, the patient had specific established beliefs in the past but does not adhere to those beliefs currently. In both types of responses, the nurse initiates a chaplain referral. By placing these two questions on the nursing assessment, not only was the risk for spiritual

distress identified early in hospitalization, but it allowed for the initiation of spiritual dialogue between the patient and nurse.

Unstructured Assessment and Intervention

If a formal assessment tool is not available, spiritual assessment and the simple intervention of listening can be accomplished by asking open-ended questions. These types of questions along with active listening can ease the patient into a candid discussion about how illness has impacted their ability to enjoy the things that are meaningful to them and how it has impacted their sense of purpose in life. Though religion will often be involved in that meaning and purpose, the nurse need not worry about asking direct questions about religion.

Communication skills are vital for building patient relationships founded on trust, identifying spiritual distress, and implementing interventions that can ease the patient's suffering soul (McSherry, 2006). Especially important is the art of cultivating trust through active listening and presence so as to help the patient feel secure enough to be open about spiritual concerns and needs (McSherry, 2006; Milligan, 2011; Puchalski et al., 2006).

As an attentive listener, the healthcare professional must be able to involve the whole self in listening to the patient without intolerance or pondering on how to respond, while being attentive to the patient's posture, expressions, and other "nonverbal cues" that might indicate spiritual struggle or suffering. In the business of healthcare, it is easy to miss signals that a patient simply does not want to be alone, and presence may be the single, most vital spiritual intervention a healthcare professional can implement.

Much like active listening, presence requires the body and mind of the nurse to be exclusively present for the patient. Resonating the Zen Buddhist philosophy, an American

physician suffering from terminal illness wrote a leaflet entitled, “Don’t just do something, stand there” (Milligan, 2011, p. 53). There comes a time when patients simply want to feel the security and companionship of human presence (Hermann, 2001; Vachon et al., 2009). Through the gentle caring presence of the healthcare provider, empathy for the patient’s pain and suffering is personified, allowing the patient to feel valued and respected (Milligan, 2011; Puchalski et al., 2006; Zikorus, 2007). Each of these skills has a twofold purpose: spiritual assessment and spiritual intervention.

Other interventions may be more specific to religious aspects, such as supporting religious rituals, practices, and prayer. When asked about spiritual interventions, nurses and patients often allude to prayer (Dobratz, 2012; Gallison et al., 2013; Hanson et al., 2008; Hermann, 2001). The varieties of prayer differ from person to person and may be founded upon religious affiliation and culture (Dossey & Keegan, 2013). According to Dossey and Keegan (2013), “prayer flows from the yearnings of the soul that rise from a place too deep for words and moves to a space beyond words” (p. 729). A patient’s need for prayer may be satisfied through song, sacred text, meditation, speaking in tongues, silence, reciting traditional prayers, dance, or experiencing nature through simply being in the moment. Healthcare professionals can facilitate prayer or contemplation by simply providing privacy and a quiet, peaceful atmosphere for patients and family.

Sawatzky and Pesut (2005) defined spiritual care as “an intuitive, interpersonal, altruistic and integrative expression that is contingent on the nurse’s awareness of the transcendent dimension of life, but that reflects the patient’s reality” (p. 23). This definition of spiritual care is practical because it highlights that spiritual care should commence with the patient’s current reality rather than meet some standardized guidelines or nurse

expectations (Milligan, 2011). In the clinical setting, spiritual care is rarely based upon some pre-existing, written plan of care; rather, it is often the nurse acting in response to a sudden, unexpected patient dilemma (Milligan, 2011).

Summary

Although U.S. healthcare professionals claim to provide holistic care, nurses, as well as other professionals, do not feel comfortable or adequately trained to address the “spiritual” dimension of their patients. This dimension has been both separated and integrated into healthcare throughout history from ancient times through scientific eras. Spiritual care has most recently received increasing attention and is currently mandated by various healthcare organizations. Despite this, and despite the existence of numerous spiritual assessment tools and spiritual care models, barriers continue to exist, such as blurred boundaries between spirituality and religion, related role conflict over providing care deemed “religious,” role confusion over who bears responsibility for spiritual care, and inadequate training for healthcare professions related to spiritual assessment and care. In recent research, there are conflicts revealed between existing definitions of spirituality and understanding of the meaning of spirituality by healthcare professionals, as well as differences in understanding between healthcare professionals and patients. A return to basic spirituality definitions – focusing on life meaning and purpose, connectedness (to others, a higher power, nature), and inner strength to transcend stress and suffering – as well as interdisciplinary communication to promote common language and goals related to spiritual care, can do much to provide increased clarity of purpose, role, and processes of spiritual care giving.

Part 2: Spiritual Care at End-of-life

Spiritual Issues for the Dying Patient

Spiritual issues, needs, or questions exist for humans in any stage of health and wellness, but perhaps are brought most strongly to the forefront of consciousness when life is threatened or limited. Diagnosis of serious or chronic illness, cancer, or terminal illness can significantly impact an individual's spiritual health (Puchalski & Romer, 2000).

Terminal illness is arguably one situation in which holistic care is most important. End-of-life concerns that evoke apprehension for the dying patient may include worry about being a burden to loved ones, fear of abandonment and dying alone, fear of suffering, the need to complete unfinished business, identification of personal meaning and purpose, and uncertainty about what lies ahead (Brunjes, 2010; Johnson, 2003; Sherman et al., 2005).

The diagnosis of a terminal illness and the apprehension surrounding death and dying prompt a sense of urgency that creates spiritual questions regardless of one's religious affiliation (Johnson, 2003). During this time, patients often question the meaning and purpose of their life. The search for meaning and purpose entails a life review, contemplation of significant life experiences, and connectedness with others or a higher being (Ferrell et al., 2013). Reflecting on one's life can reveal regrets of past behaviors toward self or others, squandered "opportunities," and the need to forgive or be forgiven. Realization of impending death causes an individual to become aware of the profound losses that occur when dying (Knight & Emanuel, 2007). End-of-life losses can include loss of functional abilities, family and social roles, independence, control, dignity, future hopes and dreams, and ultimately, the loss of life itself (Cheng et al., 2010; Knight & Emanuel, 2007; Mystakidou et al., 2005). These numerous losses can contribute to

physical, psychosocial, and spiritual suffering of a patient (Cheng et al., 2010). Patients may interpret their pain, suffering, and losses from the perspective of religious or cultural beliefs and may use their spiritual beliefs and practices as a source for coping (Puchalski & Romer, 2000; Milligan, 2011). “Spirituality plays a significant role in how patients perceive their health, face challenges, manage illness, and choose to die” (Wallace et al., 2008, p. 1). Addressing spiritual uncertainties can comfort a dying patient.

Nurses and Spiritual Care at End-of-life

Nurses devote more time in direct contact with patients and families than any other healthcare profession; thus, their role in the provision of spiritual care – most importantly spiritual assessment – should be considered a vital nursing function in holistic care (Dickenson, 2007; Galliston et al., 2013; Mitchell et al., 2006; Wallace et al., 2009). With three-quarters of all deaths occurring in healthcare facilities, every nurse should expect to provide physical, emotional, and spiritual care to dying patients (Dickenson, 2007). It is commonly in the stillness of a dark hospital room, when visitors have left and others have retired for the night, that patients express their spiritual pain, suffering, fears, and regrets to the nurse who comes to assess or offer a sedative. Avoiding exploration and intervention to the patient’s spiritual needs at that moment is a missed opportunity, possibly creating more distress and ongoing suffering (Dossey & Keegan, 2013; Gallison et al., 2013). Holistic care of the dying patient cannot exist while ignoring the patient’s spirituality in the provision of healthcare.

The primary objective for end-of-life care in the terminally ill patient is to constrain suffering through symptom management (Dunn, 2001). Suffering is not limited to the physical body or mental state of the dying patient, but also includes the patient’s

spirituality. To address spiritual distress, the nurse must possess knowledge and sensitivity for diverse cultures and religions (Ferrell et al., 2013; Gallison et al., 2013). Sources suggest that although nurses understand and recognize the importance of caring for their patients' spiritual dimension, they are oblivious to the spiritual needs of those suffering from spiritual distress (Hermann, 2001; McSherry & Jamieson, 2013). Attending to patients' spirituality may be the most fundamental, but least comprehended, facet of holistic nursing (Dossey & Keegan, 2013). Despite common knowledge that addressing spiritual uncertainties can be a source of comfort and healing for the dying patient, nurses remain mentally and scholastically inept in the necessary skills for spiritual assessment and care of their patients, and patients often express dissatisfaction with the spiritual care, or lack of spiritual care experienced in healthcare (Astrow et al., 2007; Balboni et al., 2013; Carr, 2010; Dickenson, 2007; Wallace et al., 2009).

Nursing Education for End-of-life Care

End-of-life Nursing Education Consortium (ELNEC)

In 1997 the International Council of Nurses mandated that nurses have the primary role for assuring that dying patients experience a peaceful death. Noting the success of the hospice model, the precepts of hospice were examined and identified as a guide for the education of nurses in the provision of end-of-life care (American Association of Colleges of Nursing [AACN], 2014). Yet, establishment of a curriculum for end-of-life care has been inconsistent and even absent in the standard nursing curricula. As a result, in 2001, the ELNEC project was developed as a national initiative to establish a core curriculum for educating undergraduate and graduate nurses on the provision of holistic end-of-life care,

inclusive of spiritual care for those patients and families experiencing serious life-threatening or terminal illness (AACN, 2014; Ferrell et al., 2005).

The ELNEC is a train-the-trainer program that was developed by palliative care nurse experts for the purpose of educating the trainer on core content as well as the skills needed to teach the content (AACN, 2014; Ferrell et al., 2005). The curriculum content is divided into eight modules that address nursing competencies that are necessary for the delivery of quality care to the dying patient and family. The modules include: “Nursing Care at the End-of-life, Pain Management, Symptom Management, Ethical/Legal Issues, Cultural Considerations, Communication, Grief/Loss/Bereavement, Achieving Quality Care, and Care at the Time of Death” (Ferrell et al., 2005, p. 108). Since its implementation in 2001, the ELNEC curricula has grown to include: Pediatric Palliative Care, Graduate, Oncology, Critical Care, Geriatric, International, and Veterans.

The ELNEC work has been most significantly informed by three editions of the Textbook of Palliative Nursing (2001, 2005, 2010), edited by Betty Ferrell and Nessa Coyle, nurse experts in this arena and key players in ELNEC. Across the three editions, five full chapters address spiritual care, spiritual assessment, meaning in illness, the family caregiver’s journey, and reflections on the nurse chaplain. This content is deepened by Ferrell and Coyle’s text, *The Nature of Suffering and Goals of Nursing* (2008), in which ethical and theological perspectives on the nature of suffering and goals of nursing are explored, and in which the Chapter One opens with a scenario illustrating the very type of end-of-life spiritual issues that this research seeks to address. Obviously, this issue is not a lack of curricular material available; rather it is the lack of value and inclusion of such

materials into individual school programs or into continuing education programs for working nurses.

Despite the establishment of formal curriculum guidelines, many undergraduate nursing schools have yet to adopt the guidelines as part of their curriculum. Thus, graduate nurses who have not experienced the death of a patient or even a loved one may lack both the experience and the knowledge of the unique needs of dying patients and their families. Furthermore, most nurses without a well-developed curriculum such as ELNEC's express feelings of discomfort and incompetence in the provision of spiritual care to the dying patient (Carr, 2010; Ferrell et al., 2013; McSherry & Jamieson, 2013). One vital area of nursing education and training is teaching nurses to differentiate between the indistinct spiritual and psychological symptoms of the dying patient (Puchalski, 2013). Nurses who are able to distinguish between spiritual and psychological causes of distress are less likely to confuse the signals that indicate the patient is experiencing spiritual distress rather than depression or any other psychological disorder. The inability to differentiate between spiritual and psychological diagnoses and needs will likely result in care that is misguided and ineffective. Improving the competence of nurses in identifying and addressing spiritual distress should enhance dying patients' likelihood of finding meaning, purpose, and transcendence to achieve a state of spiritual peace (Dossey & Keegan, 2013). Through education such as that obtained through ELNEC, guidance, and mentoring, nurses can be empowered to provide spiritual care and therefore, advance nursing practice to better meet the holistic needs of dying patients and their families (Gallison et al., 2013).

CHAPTER 3

METHODS

Research Design

A case study design is particularly suited for this research because this methodology allowed the researcher to explore a particular entity with definable boundaries (such as an individual, organization, community or program) that exists and functions within a larger social context (Bromley & Hersen, 1985; Mason, 2002; Yin, 2003). The “case” in this study was a single hospital, and the focus of study within the case was the process of addressing spiritual distress in dying patients. Data sources used in this study included hospital documents and interviews with key professionals. Gathering and reviewing these data allowed the researcher to describe organizational procedures and the designated and perceived roles of key professionals in defining, identifying, and addressing spiritual distress of dying patients and their families within the single hospital. Strengths and gaps were analyzed by comparing the findings to the processes described to Drury’s Compilation of Existing Frameworks. This framework was derived from a synthesis of existing spiritual assessment and spiritual care models, including Fitchett’s 7X7 Model for Spiritual Assessment (Fitchett, 2002), Fisher’s Four Domains Model of Spiritual Health and Wellbeing (Fisher, 2011), McSherry’s Principal Component Model (McSherry, 2006), and Puchalski’s Spiritual Care Implementation Model (Puchalski et al., 2009).

Research Site

The site for this study was a regional medical center that serves southeast Missouri and southern Illinois. The medical center was not affiliated with any specific religious organization. This facility has 266 licensed beds and offers a range of services including:

regional heart center, cancer center, brain and spine center, center for women and child services, emergency services, orthopedics and joint replacement center, breast and diagnostic center, and wound care and hyperbaric center. Additional services included the hospital-owned and operated home healthcare and hospice and multiple regional health clinics in the surrounding area. The site was chosen because of its quality as Joint Commission accredited, its array of healthcare services that are provided for a large area with a diverse population, and the researcher's ease of access to this particular facility. The hospital and college where the researcher is employed were affiliated. The proposed research study was presented to the medical center as per request of the hospital's director of education. All questions and concerns were addressed. The researcher worked directly with the hospital's director of education and director of pastoral care to access hospital documents, recruit research participants, and schedule rooms for interviews.

Protection of Human Subjects

Permission to conduct this study was obtained from University of Missouri-Kansas City Institutional Review Board (IRB) and the medical center involved in the study. The medical center was reestablishing their research committee for this process. The researcher remained in contact with the Director of Education at the hospital. A letter of support from the organization is included in the appendices (see Appendix B).

Written consent was obtained from each participant prior to the interview process (see Appendix C). Each participant was informed that participation in the study is strictly voluntary and that they may renounce their participation from the study at any time. As protection against coercion, disclosure of incentive occurred after participants' interest in participation was obtained. Participants were assigned an identification number which was

placed on all interview documents rather than their name. A list identifying participants with their assigned number was stored in a locked drawer in the researcher's workplace office, which was only accessible by the researcher. The digitally audiotaped interviews and transcripts were secured on the researcher's computer or in a locked drawer in the researcher's office until data analysis was complete, after which the audiotapes were destroyed. All verbal and written data were organized and stored in a retrievable database.

Due to the small sample for interviews, interview responses could potentially be identified by hospital personnel who knew the participants and could create repercussions or resentment if something critical was said about the organization or organizational policy, unit, department, or another discipline. Participants could choose to refrain from answering any interview question, request the audio-recorder be turned off, end the interview, or withdraw from the study at any time without penalty.

Data Collection Procedures

Organizational and Provider Level: Document Review

Data collection began with review of hospital documents including: (a) organizational mission, vision, and values; (b) formal hierarchy of the hospital, including chain of command among administration, departments, and units; (c) hospital and departmental policies and procedures that guide patient spiritual care and care of the dying patient; (d) documentation of employee orientation content specific to spirituality and care of the dying patient; (e) job descriptions of professionals to be interviewed; (f) hospital-wide, departmental, and unit specific spiritual assessment and screening tools; (g) patient education materials pertaining to spiritual care of the dying patient.

Mission, vision and values, and policies and procedures were accessed via the hospital intranet. Documents such as job descriptions, interdisciplinary assessment tools, and spiritual screenings were requested through appropriate department directors. The documents were reviewed for content related to a formal prescribed process for spiritual screening, spiritual assessment, diagnosis of spiritual distress, referral, and spiritual care interventions for patients and their families. The criteria for inquiry were selected based upon the spiritual assessment and spiritual care models that were synthesized to form Drury's Compilation of Existing Frameworks, as well as the information needed to address the specific aims of this study (see Tables 2 and 3).

Interviews with Healthcare Professionals

Sample. Upon approval from the University of Missouri-Kansas City's Institutional Review Board, interviews were conducted with key professionals involved in direct patient care, including social workers, chaplains, and registered nurses. The number of professionals to be interviewed from each department included three social workers, three chaplains (this accounts for the whole department), and 12 to 16 registered nurses, including three to four nurses from each of the following four units: intensive care unit, medical-surgical area, inpatient oncology, and cardiac progressive. All interviewees were required to have been an employee at the healthcare institution for a minimum of one year and have experienced the death of at least one patient. The researcher consulted with each department director to develop a plan for recruiting and obtaining consent for staff interviews.

Table 2

Organizational Level Documents

Documents	Criteria for Inquiry
Mission, vision and values	<ul style="list-style-type: none"> • Key terms that indicate that hospital’s plan for addressing the spirituality of their patient’s include: holistic; bio-psycho-socio-spiritual; culture; beliefs, religion. • How does the hospital mission, vision and values define the patient?
Formal hierarchy	<ul style="list-style-type: none"> • Includes a pastoral care department within the formal hierarchy, as well as for nursing and social services. • Is there a relationship between nursing, pastoral care, and social services within the formal hierarchy? If so, what is the relationship?
Policies and procedures	<ul style="list-style-type: none"> • The terms and phrases that identify spirituality as a part of the provision of care, especially the care of dying patients, such as: holistic; culture; beliefs; spirituality; spiritual assessment; spiritual care; spiritual needs; end-of-life; dying; religion or religious beliefs or practices. • Policy review will focus upon organizational structure for providing spiritual care; formal process for delivery of spiritual care; disciplinary roles for spiritual screening, assessment, diagnosis and spiritual needs identification and interventions. • Is there a formal referral process for patients who have spiritual need? If so, what is that process? What disciplines are specifically involved in the process? What is the role of each discipline? Who initiates this process?
Employee orientation content	<ul style="list-style-type: none"> • What information is presented in general employee orientation on spiritual assessment and spiritual care of the dying patient? • Does nursing orientation or department specific orientation include spiritual assessment and spiritual care of the dying patient? If so, for what disciplines? If so, what information is included? • What terminology or language is used in the orientation process in relation to spirituality, spiritual assessment, and spiritual care?
Job descriptions	<ul style="list-style-type: none"> • Does the job description for nurse, chaplain and social worker include spiritual assessment and provision of care specifically for the dying patient? • Do job descriptions include assessment and provision of care for the patient, defined as holistic or bio-psycho-socio-spiritual being?

Documents	Criteria for Inquiry
Spiritual assessment and screening tools	<ul style="list-style-type: none"> • According to the job descriptions, are chaplains required to be board certified? • What tools are used to assess spirituality, spiritual health, or spiritual needs? • What formal language is used for assessing the patient’s spirituality or spiritual needs? • When is spirituality or spiritual needs assessed?
Patient education	<ul style="list-style-type: none"> • What patient education tools exist for dying patients and their families? • Do these tools address spirituality, spiritual needs, or spiritual interventions? • What is the terminology or language used in patient education materials in discussing spirituality, spiritual needs, or spiritual interventions? • What disciplines are responsible for patient education on the spiritual needs of dying patients?

Table 3

Provider Level Documents

Documents	Criteria for Inquiry	Interview Questions
Descriptions of spirituality	<ul style="list-style-type: none"> • How do the definitions provided by the participants compare to the working definition within the study? • What defining characteristics of spirituality are identified by the participants? • What similarities and differences are identified in the language and terminology in defining spirituality among and between nurses, chaplains, and social workers? 	How do you define spirituality?
Descriptions of spiritual distress	<ul style="list-style-type: none"> • How does each participant describe spiritual distress? • What defining characteristics of spiritual distress are identified by the participants? • How do the defining characteristics of spiritual distress compare to the NANDA definition and characteristics? • What similarities and differences are identified in the language and terminology for describing spiritual distress among and between nurses, chaplains, and social workers? 	Describe the indicators of spiritual distress.
Descriptions of spiritual care	<ul style="list-style-type: none"> • What interventions are included in the participant's responses? What are the similarities or differences among the disciplines in the interventions offered to dying patients among and between the disciplines? • What similarities and differences are identified in the language and terminology for describing spiritual care or spiritual interventions among and between nurses, chaplains, and social workers? • What problems are identified by each participant in how spiritual care is delivered within the hospital? Are the identified problems similar or different within the three disciplines? If so, how? 	<p>How do you address spiritual needs of dying patients and their families?</p> <p>What interventions have you used to address the spiritual needs of dying patients and their families?</p> <p>What problems have you identified in how spiritual care is delivered within the hospital?</p>

Documents	Criteria for Inquiry	Interview Questions
Perceived roles in spiritual assessment	<ul style="list-style-type: none"> • Who is responsible for the initial assessment or screening? Ongoing assessment? • What informal process for identifying spiritual needs can be identified among and between the three disciplines? • What other disciplines are identified as key to spiritual assessment for this facility? • How do each of the three disciplines perceive their role and the roles of the other disciplines in assessing spiritual needs? What is consistent in these role perceptions? What is conflicting in these role perceptions? • Do any of the participants openly admit being confused or as not knowing their role or the role of the other disciplines in assessing the spirituality and spiritual needs? • What formal and informal education and training for assessing spirituality are identified for each participant? Discipline? • Are the chaplains board certified? • Does the hospital offer any training for assessing spirituality or spiritual needs? 	<p>How are spiritual needs of dying patients and their families identified within the hospital?</p> <p>Explain your role in identifying needs of dying patients and their families.</p> <p>What do you perceive as the role of nurses in the delivery of spiritual care to dying patients and their families? Hospitalists? Social workers?</p> <p>Who is responsible for the teaching and implementing advanced directives?</p> <p>Who is responsible for the teaching and implementing advanced directives?</p>
Perceived roles in communicating or interfacing with other disciplines about spiritual care needs of patients.	<ul style="list-style-type: none"> • What do participants believe is the process for referral if spiritual needs are identified? • How does the participant's description of the referral process compare to the formal process identified within the hospital's organizational documents? • How does each discipline perceive their role and the roles of other disciplines in addressing spiritual needs? What is consistent among and between the disciplines? What is conflicting among and between the disciplines? 	<p>What has most prepared you for addressing spiritual needs of dying patients and their families?</p> <p>What is the process for referral?</p> <p>What do you perceive as the role of nurses in the delivery of spiritual care to dying patients and their families? Hospitalists? Social workers?</p>

Documents	Criteria for Inquiry	Interview Questions
	<ul style="list-style-type: none"><li data-bbox="577 267 1417 365">• Do any of the participants openly admit being confused or as not knowing their role or the role of the other disciplines in providing spiritual care?<li data-bbox="577 365 1438 428">• How does the perceived roles compare to those identified in the job descriptions and hospital policies?	

Interview procedures. Interviews were scheduled at the convenience of the interviewee immediately before or after their shift. As appointments for interviews were made, the researcher scheduled a private, quiet room through the Education Department. Immediately prior to each interview, information about the study was provided in oral and written form, and UMKC IRB approved written consent was obtained from each participant. The original consent form was retained by the investigator and a signed copy (which also includes the written study information) was provided to the participant (see Appendix C).

Prior to beginning the interviews, participants were asked demographic questions regarding race/ethnicity, number of years in the current profession, educational background including certifications, and religious affiliation. The information sought from professional interviews included:

- participants' definition of spirituality, spiritual care, and spiritual distress,
- examples of what they would consider spiritual needs,
- the number of patient deaths experienced,
- comfort level and perception of their role in assessing for spiritual needs and providing spiritual care to dying patients,
- perception of others' roles in assessing for spiritual needs and providing spiritual care to dying patients,
- perceived barriers to spiritual care within the hospital organization,
- examples of times they have identified spiritual needs and how they have (or have not) responded to those needs,

- specific spiritual interventions that they have used (see Interview Guide in Appendix D).

The interview questions were derived from the spiritual assessment and spiritual care models that formed Drury's Compilation of Existing Frameworks and the information needed to address the specific aims of the study. Interviews were digitally audiotaped and transcribed verbatim. Once interviews were transcribed, the researcher contacted the participants and asked them to review the accuracy of the transcripts.

Data Management and Analysis

Interview transcripts were grouped by disciplines and reviewed and analyzed for overall content (thematic content analysis), for the language used to discuss spirituality, and for process; specifically, what reportedly occurred related to addressing spiritual needs within the institution/discipline/unit (process analysis) (Mason, 2002; Reissman, 2008). Data displays were constructed to organize and compare themes/processes identified from the interviews with related document data, both within each discipline and across disciplines. The organizational and provider level matrices used to guide data collection were compared with the data obtained from the case study in order to identify important characteristics from each organizational and provider level model that support Drury's Compilation of Existing Frameworks.

The perceived roles and processes reported by nurses, chaplains, and social workers were compared to what is written in job descriptions, organizational, and departmental policies and procedures. Perceived roles and "what actually happens" in practice were then compared to existing practice models and to the proposed Drury's Compilation of Existing Frameworks. Although this framework provides a considerable degree of a priori guidance

and categorization for data generation, it is important to clarify that the researcher was inductive in her overall approach, open to findings that did not fit these priori categories and, which may have been “surprises” that enrich insights and findings above the given framework.

This analysis plan was designed to: (a) describe the formal organizational process for identifying and addressing the spiritual needs of patients and families, (b) identify congruities and incongruities between formally defined roles for assessment, diagnosis, and provision of spiritual within the organization and actual behaviors of the staff within the disciplines, (c) identify the language used by the different disciplines in reference to spirituality, spiritual distress, and spiritual care, (d) describe any identified communication patterns between the three disciplines, and (e) identify gaps in the processes related to the provision of spiritual care to dying patients.

Timeline

The timeline for data collection was extended over approximately five months, longer than expected, due to various challenges that occurred throughout participant recruitment and data collection. The hiring of a new hospital administrator and major budgetary concerns made employees apprehensive regarding the perceived changes within the organization. Budget constraints, policy changes, and program cuts were significant and resulted in nurse turnover and lowered morale. Nurses were especially hesitant or disinterested in volunteering to participate in this study, especially if it meant remaining at the hospital an additional 30 minutes to one hour to participate in an interview. Some participants asked if the interview could take place over the phone as opposed to face-to-face; changes to permit the researcher to conduct interviews via phone were proposed and

approved by the IRB. The time allotment for interviews being conducted by phone resulted in the recruitment of participants within the planned range identified in the proposal.

Trustworthiness of the Findings

Rigor is a common term used when evaluating the trustworthiness of qualitative research findings. This study established qualitative rigor through the criteria initially described in Lincoln and Guba's (1985) model of trustworthiness. The four criteria for trustworthiness include: (1) credibility, (2) transferability, (3) dependability, and (4) confirmability (Lincoln & Guba, 1985; Thomas & Magilvy, 2011).

Credibility or "truth value" refers to the degree to which research findings correspond with the participants' interpretations as a whole (Clissett, 2008; Munhall, 2012). Achieving credibility requires that the description or interpretation of the findings accurately illustrate the experience of the participants. To establish credibility, the researcher performed member validation by asking participants to review the interpretations for accuracy in representing their experiences (Thomas & Magilvy, 2011). To further strengthen the credibility, the study findings include excerpts of the participants' verbal responses from the interviews.

Transferability refers to the applicability of the findings in other contexts or with diverse populations (Clissett, 2008; Munhall, 2012; Thomas & Magilvy, 2011). Relevant transferability was promoted by providing a detailed description of the institution and the formal and informal process for spiritual assessment, diagnosis, and spiritual care within the institution, so that readers can make informed comparisons to other institutions based on similarities.

Dependability or “consistency” of the research is the degree to which a duplication of the study with the identical or comparable participants or institution would result in comparable outcomes (Clissett, 2008; Munhall, 2012; Thomas & Magilvy, 2011). To achieve dependability, the researcher provided a comprehensive decision trail that included the purpose of the study, method, rationale for choosing participants, description of the data collection procedure, process for data analysis and interpretation, and a proposed conceptual framework which could provide structure for guiding and comparing data and therefore, should further strengthen the dependability of the research. Given the detail provided, the study could be replicated for comparison in various healthcare settings including acute care, palliative care, long-term care, home-care, outpatient facilities, and religious-affiliated or publicly owned healthcare institutions in both rural and metropolitan areas.

Confirmability refers to the ability for others to examine all data sources and processes to ensure that the findings are grounded in data and occur with the establishment of credibility, transferability, and dependability (Clissett, 2008; Thomas & Magilvy, 2011). Extensive data tables were created and are shared within the dissertation manuscript along with the processes for examining and interpreting the data, promoting confirmability by readers. These tables include sections of organizational and unit policies related to spiritual assessment, planning, and care as well as direct quotes from interview participants.

CHAPTER 4

RESULTS

Review of Purpose and Aims, Methodology, and Data Sources

During the delicate yet significant end-of-life journey, patients become more aware of their spirituality, spiritual needs, and their desire to have those needs addressed by healthcare professionals tending to them and their loved ones (Blanchard et al., 2012; Daaleman et al., 2008; Puchalski, 2007). This study explored the research questions: How is spiritual care of dying patients and their families addressed at the organizational and provider levels of care within one Midwestern regional medical center?

A case study methodology was used for this study. The purpose of the study was to examine policies and practices at the organizational and provider levels of care to determine potential strengths and gaps in end-of-life spiritual care. The “case” for this study was a single Midwestern 266-bed regional medical center that provided a variety of services throughout the surrounding area. The focus of this study was the delivery of spiritual care to dying patients experiencing spiritual distress. The case study method was fitting for this study because it allowed the researcher to explore in depth a process or experience for which little is known. The case study method uses multiple sources of data, that when pulled together, describe, characterize, and organize aspects of the focus of the study (Lincoln & Guba, 1985; Munhall, 2001; Stake, 2005). It is an exploratory method that can identify future topics needed in a continued research trajectory.

The multiple sources of data used for this study include: (1) major organizational documents – mission, vision, values and philosophy statements; (2) relevant organizational and unit level policies and procedures; (3) job descriptions of social workers, chaplains and

(specific to unit) of nurses; (4) admission, assessment formats, or guides; (5) patient education resources pertaining to the spiritual care of the dying patient; and (6) interviews of three social workers, three chaplains, and twelve nurses from four units (medical-telemetry unit, surgical progressive care and oncology unit, medical-surgical unit and intensive care unit). All interviews explored demographic data (race/ethnicity, number of years in the current profession, educational background including certifications, religious affiliation) and the designated and perceived roles of key professionals in defining, identifying, and addressing spirituality and spiritual distress of dying patients and their families. Strengths and gaps identified within the findings were compared to the proposed Drury's Compilation of Existing Frameworks.

Demographics of Participants

Social Workers

There were three social work participants who ranged in age from 54 to 60 years. Two social workers reported having a Master's degree in social work and the other a Bachelor's degree and licensure in social work. The number of years in their current role ranged from 3 to 21 years. All three reported being affiliated with the Protestant religion; one stated that she attended the Catholic church with her spouse. The number of deaths experienced ranged from three to more than could be recalled. The social worker who reported that she had experienced three deaths stated she had been with many patients who were near death, but she had witnessed only three actual deaths.

Chaplains

The hospital has a pastoral care department that consists of three chaplains. All chaplains participated in the study. They ranged in age from 54 to 69 years of age, with the

number of years in the current role ranging from 10 to 30 years. One chaplain reported having a some college and clinical pastoral education; another had a Bachelor's of Arts degree in education with minors in philosophy and theology, and the third chaplain had a Master's degree in divinity. One chaplain was Protestant, and the other two reported being affiliated with the Catholic religion. The chaplains reported that they had experienced many deaths, with one stating it was "hundreds" and another stated there were too many to count.

Nurses

Twelve nurses were interviewed. They ranged from 25 to 59 years of age. Six nurses reported having a Bachelor's of Science degree in nursing, four reported having an Associate's Degree in nursing, and one had a Master's of Science degree in nursing. The number of years in their current role as a nurse ranged from 1½ to 27 years, with five of these nurses being in the role less than five years. Religious affiliation varied, with three nurses reporting an affiliation with the Lutheran church, three with the Catholic church, three Protestant, one non-denominational, one Christian, and one non-specified. The number of deaths that each nurse had experienced ranged from 3 to 50, with two nurses stating they had experienced more deaths than they could count.

Study Findings

Specific Aim #1: Spirituality and Spiritual Care in Hospital Documents

This section addresses Specific Aim #1, which was to describe how the organization addresses spirituality and spiritual care in major documents, including mission, vision and value statements, departmental policies, job descriptions, various admission and patient assessment forms, and patient education materials.

Organizational and unit level documents. A total of 15 documents were found and reviewed for content relevant to inclusion and definition of spirituality and guidelines for spiritual care. The documents were numbered and listed in Table 2, and included:

- Three core statements for the organization: Mission, Vision, and Values, and Philosophy (#s 1-3)
- The large umbrella policy, the *Plan for Provision of Patient Care*, which includes subdocuments: (#4)
 - Mission, Vision, and Values,
 - Philosophy for the Provision of Patient Care,
 - Definitions of Patient Services, Patient Care, and Patient Support,
 - Patient Care Standards, and
 - The Scope of Services for each department, nursing unit, physician's office and support service
- Nine other various Organizational policies that were chosen for review based on likelihood of spirituality content, (#s 5-13), and
- Two Departmental/Unit level policies likewise chosen for review (#s 14-15).

Table 4 summarizes relevant statements within these documents that focused on spirituality and spiritual care.

Table 4

Spirituality and Spiritual Care in Organizational and Unit Level Documents

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
1. Mission Statement	None	“Together, we make a difference through our commitment to excellence in health care.”
2. Vision	None	“...dedicated to continuous improvement of the Region’s health status in a collaborative cost-effective manner.”
3. Values	None	<p>“...all patients in our care are entitled to quality health services, information and confidentiality about their care, and treatment with dignity and compassion in all of life’s stages”</p> <p>“...strive to balance progress with costs, regulations and competition while always preserving the human touch”</p> <p>“Unity of Purpose</p> <p>Our Health Center family promotes a spirit of cooperation, mutual respect and concern to deliver efficient and coordinated services. We also work to provide patients and families with reassurance, support and care that is sensitive to all their needs”</p> <p>“Service Above Self</p> <p>To demonstrate professionalism, ethics and devotion to duty is our charge. To serve with enthusiasm and compassion is our spirit. Recognizing that technology is in our hands and people are in our hearts, we take pride in giving in our personal best for the benefit of others”</p>
4. Plan for Provision of Patient Care:	“...dedicated to helping patients, families, community and employees to respond to actual and potential health problems; further, we will assist these patients in attaining the highest level	
a. Philosophy for the Provision of		

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
Patient Care	<p>of wellness for which they are capable. This is best achieved by a collaborative approach to patient care. We believe that the physical, psychological, social and spiritual needs of the patients need to be addressed.”</p> <p>The institution “...is committed to providing competent and compassionate care to all individuals throughout their life cycle.”</p> <p>“Age, physical limitations, social, cultural, spiritual and language needs will be considered in the care and services provided.”</p> <p>“Patient care encompasses the recognition of disease and health, patient education and advocacy, recognizing the unique physical, emotional and spiritual, emotional and psychological needs of each person.”</p>	
b. Pastoral Care Scope of Services:	<p>The registered nurse is the professional that is specifically identified as having a role in .”..recognizing the unique physical, emotional and spiritual, and psychological needs of each person” “The Pastoral Care of * provides direct ministry to patients, families, and staff. It provides indirect ministry to clergy and physicians. Where possible, the patient’s own clergy will be contacted on behalf of the patient. The Pastoral Care staff responds to critical care situations such as code blue and imminent death, as well as physician and staff requests for ministry. Seminars and pastoral</p>	

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
5. Organizational Policy: <i>Patient Rights and Responsibilities</i>	educational programs are periodically scheduled for clergy, staff and the community.”	
	“Assignments are made by the Director in the morning and are updated throughout the day according to requests and emergencies. Some of the critical care units in the hospital are regularly assigned to one of staff for greater consistency in ministry.”	
	“New patients who request a visit by Pastoral Care will be seen within 48 hours. Special requests will be accommodated within 24 hours.”	
	“In the event of an emergency or disaster, the pastoral care department deals with the spiritual and emotional needs of patient/family in appropriate crisis intervention.”	
	“The Pastoral Care Department works with all departments providing patient care through a collaborative approach. The staff responds to needs throughout the hospital.”	
	Patient Rights: “Receive care regardless of your age, race, ethnicity, religion, culture, language, physical or mental disability, color, national origin, socioeconomic status, sex, sexual orientation, or gender identity”	Patient Rights: “Receive care in an environment that preserves dignity and supports a positive self image” “Receive compassionate end-of-life care.”
	“Receive healthcare that considers your psychosocial, spiritual, and cultural values.	

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
6. Organizational Policy: <i>Organizational Ethics</i>	<p>“PATIENT CARE: We provide services to those patients for whom we can safely and appropriately provide care, regardless of race, color, national origin, religion, sex, sexual orientation or actual or perceived disability.”</p> <p>“In all circumstances, we will attempt to treat patients in a manner giving reasonable thought to their age, background, culture, religion, and heritage.”</p>	
7. Organizational Policy: <i>Psychosocial, Spiritual and Cultural Values of Patients</i>	<p>“These rights include the accommodation of cultural, religious, spiritual, and personal values as well as to religious and other spiritual practices.”</p> <p>“STANDARD: To guide caregivers to recognize the psychosocial, spiritual, and cultural values that impact the patient’s response to their care.”</p> <p>“Patients have a right to considerate care that safeguards their personal dignity and respects their cultural, psychosocial and spiritual values. These values often influence patient’s perception of care and illness. Understanding and respecting these values guides * Hospital in meeting the patients’ care needs and preferences.”</p> <p>“* Hospital allows patients and their support persons to express their spiritual beliefs and cultural practices as long as these practices do not harm others or interfere with treatment.”</p>	

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
	<p>“* Hospital respects the need for Pastoral care and other Spiritual services. The patient may request support services from Pastoral care or may request a visit from their own Spiritual/Religious Community. * Hospital offers Pastoral Care services 24 hours a day.”</p>	
	<p>“During the registration process patient/support person are asked if they have religious or spiritual preferences.”</p>	
	<p>“During the initial nurse assessment the patient is asked...Would you like the chaplain to visit?” and “Do you have any cultural beliefs that may affect your care or education?”</p>	
	<p>“Cultural or Spiritual practices may include: a. Daily practices like prayer and/or scriptures; b. Practices regarding death and dying; c. Food preferences; d. Practices regarding pregnancy and birth; e. Communication which can include verbal and non-verbal; f. Rituals or Ceremonies; g. Organ donation; h. Pain and/or medications associated with pain; i. Visitors; j. Illness beliefs”</p>	
	<p>“If patients/support person have questions, requests, or comments regarding Cultural or Spiritual practices they can be directed to Pastoral Care and Social Services.”</p>	

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
8. Organizational Policy: <i>Health History</i>	<p>“The responses are entered into the HIS and forwarded to the appropriate department; i.e. Nutrition Services, Discharge Planning, Social Services, Pastoral Care, Respiratory Care, and Cardiac Rehab. The Health History is organized in the functional health pattern format.”</p> <p>“Ask the patient, “Is there anything in your family background or religious beliefs that will help us plan your care and teaching?”</p> <p>Under “Instructions for Documenting the “Discharge Planning Screen Summary” in the HIS “A copy of the screen will automatically print in the Case Management Department and at the location it was entered. Additional copies may print to Respiratory Care, Nutrition Services, Pastoral Care and Cardiac Rehab.”</p>	
9. Organizational Policy: <i>Assessment of Patients</i>	<p>Pastoral care conducts their initial assessment “within 48 hours of request/screen.”</p> <p>Reassessment is “dependent on need expressed at initial assessment.”</p>	
10. Organizational Policy: <i>How Patients’ Care is Planned, Provided and Communicated</i>	<p><u>PASTORAL CARE:</u> The pastoral care of patients is planned on a daily basis. The most urgent situations take precedence; these include: imminent death, critical spiritual/emotional need, family distress, medical-ethical consultation, physician-staff request, code blue, trauma call, etc. The greater part of our time is spent with</p>	

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
	<p>critical care patients and their families. Spiritual and emotional support is given when requested and where the need strongly suggest the same. We also try to contact the pastor of each patient critically in need, when and where that is possible. The patient is always asked if he/she would like our pastoral staff to see him/her, and then asked how we can be of service.”</p>	
<p>11. Organizational Policy: <i>Interdisciplinary Approach to Patient Care: Patient Care Huddles</i></p>	<p>Under the social worker’s responsibilities and role in a Huddle the following is included: “Psycho-social or spiritual concerns/Psychiatric: Any info that would impact care/family support”</p>	<p>“Team members attending the huddles may include: case manager, nurse, social worker, pharmacist, rehab services (PT, OT, or Speech), dietary, diabetic educator, Cardiac rehab services and respiratory therapy. Outside agencies will be invited on a case by case basis and may include LTAC’s, nursing homes, and Home Health companies. A patient/family may request participation but generally information from the rounds is presented to the patient/family by the case manager or social worker.” <i>(Despite statement in column to left, there is no mention of pastoral care here.)</i></p>
<p>12. Organizational Policy: <i>Patient and Family Teaching</i></p>	<p>“Staff nurses and patient educators will consider the following when assessing and planning the patient’s educational needs. Whenever applicable these factors will be reflected in the patient’s plan of care: 1. Cultural and religious factors 2. Emotional barriers...”</p>	
<p>13. Organizational Policy: <i>End-of-life Care/Comfort Care</i></p>	<p>The standard is written as follows, “Comfort and dignity will be optimized during end-of-life care. Each patient experiences and interprets the dying process differently according to personal,</p>	<p>“f. Patient and family support examples include: i. Stay with the patient-talk, watch movies and or read; ii. Allow patient to express fears and concerns about dying; iii. Reminisce about the patient’s life; iv.</p>

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
	<p>cultural, religious, spiritual values and preferences.”</p> <p>The policy is “The patient at or near the end of his/her life has the right to physical and psychosocial comfort. *Hospital provides care that optimizes the dying patient’s comfort and dignity addresses the patient and his or her family’s psychosocial, spiritual, and emotional needs as appropriate, about death and dying.”</p>	<p>Share information-include the patient in discussions and decision making; v. Respect privacy; vi. Reassure the patient that advance directive will be honored; vii. Ask if there is anything else you can do.”</p>
	<p>References in the procedure related to spirituality and spiritual care: “1. To improve communication during the end-of-life the following will be addressed...b. Patient’s religious, cultural, spiritual beliefs and practice”</p>	
	<p>“2. The following end-of-life care resource/support options will be made available to patients and their families that are at or near the end-of-life...d. Spiritual support from pastoral care or members of patient’s faith community</p>	
	<p>“3. The initial patient assessment and reassessment will address end-of-life care and will include the social, spiritual, cultural variables that influence perceptions and expressions of grief by the patient, family members or significant others.”</p>	

Within the first four core documents, with the exception of the *Plan for Provision of Patient Care* (#4), the content lacked any specific mention of the organization's recognition of the patient's spiritual or religious values or beliefs. Two main sections within the *Plan for Provision of Patient Care*, the "Philosophy of Provision of Patient Care" (#4a), and the "Scope of Service for Pastoral Care Services" (#4b) included specific language related to the spirituality and spiritual care of patients.

The "Philosophy for the Provision of Patient Care" (#4a) discussed interdisciplinary collaborative care, with the registered nurse named as the one healthcare professional that is specifically identified as having a role in "recognizing the unique physical, emotional and spiritual, emotional and psychological needs of each person" (*Plan for Provision of Patient Care*, p. 2). The "Scope of Service for Pastoral Care Services" (#4b) is comprised of the spiritual ministry to patients, families, and staff.

The few direct or indirect references to spirituality or spiritual needs within the Scope of Standards and descriptions of other departments and units were found only in sections related to Oncology, Hospice, Rehabilitation, and Emergency Units. It was interesting to note that the description of the Oncology Unit included the following statement: "Patients are discharged from this unit to Rehab, home, an extended care facility or heaven" (*Plan for Provision of Patient Care*, p. 19). The hospital's Inpatient Rehabilitation Facility identified one actual or potential major clinical function as that of responding to spiritual distress. The Emergency Department included pastoral care and social services as the two departments that were routinely utilized to facilitate the flow of patients.

Other organizational and unit level policies (# 5-15), that were discovered during the document review on how this healthcare institution addressed spirituality and spiritual care for dying patients, are bulleted below:

- Organizational Policy: *Patient Rights and Responsibilities* (#5)
- Organizational Policy: *Organizational Ethics* (#6)
- Organizational Policy: *Psychosocial, Spiritual and Cultural Values of Patients* (#7)
- Organizational Policy: *Health History* (#8)
- Organizational Policy: *Assessment of Patients* (#9)
- Organizational Policy: *How Patients' Care is Planned, Provided, and Communicated* (#10)
- Organizational Policy: *Interdisciplinary Approach to Patient Care: Patient Care Huddles* (#11)
- Organizational Policy: *Patient and Family Teaching* (#12)
- Organizational Policy: *End-of-life Care/Comfort Care* (#13)
- Unit Level Policy: *Critical Care Policies and Regulations* (#14)
- Unit Level Policy: *Nursing Duties and Responsibilities in Critical Care* (#15)

In nearly all organizational and unit level policies, the reference to spirituality was a general statement, such as, “health care that considers your psychosocial, spiritual, and cultural values,” or “requests regarding culture or spiritual practices can be directed to Pastoral Care or Social Services.” Only four of the twelve policies (# 4, 7, 10 and 13) enumerated in Table 2 offered any detail of what spiritual care might entail.

Details of policy #4, *Plan for Provision of Patient Care*, was discussed in the previous sections. The organizational policy #7, entitled *Psychosocial, Spiritual and Cultural Values of Patients* addressed each patient's right to care that is considerate and respectful of the patient's spiritual, religious, cultural, and personal values. Within the policy was the process for identifying and addressing the psychosocial, spiritual, and cultural values and practices that could influence each patient's overall health and response to care. According to policy #7, upon registration for admission or testing, the patient is asked about their "religious or spiritual preferences" (p. 1). If the patient is admitted for observation or inpatient stay on a nursing unit, a registered nurse will complete an initial assessment and health history that includes the questions: "Would you like the chaplain to visit?" and "Do you have any cultural beliefs that may affect your care or education?" (p. 1). If the patient concurs that a visit from the chaplain is desired, a hospital chaplain is expected to visit the patient within 48 hours. The patient may request Pastoral Care services at any time during hospitalization. Per policy, patients are allowed to express their beliefs and participate in their cultural or spiritual practices within the organization as long as they do not interfere with the care and treatment of others. A list of cultural or spiritual practices was included in the policy and consists of prayer and/or scripture reading, death and dying rituals, dietary preferences, pregnancy and birth practices, verbal and non-verbal communication processes, cultural or spiritual rites or ceremonies, beliefs regarding organ donation, beliefs regarding the treatment and medications administered for pain, visitors, and beliefs regarding illness.

In another policy (#10), *How Patients' Care is Planned, Provided, and Communicated*, the role of pastoral care in the provision of spiritual care to patients within the institution was described. The Pastoral Care department plans patient visits at the

beginning of each day based upon the number of referrals and requests they have received. Those referrals or requests that are deemed most urgent are given priority. Urgent requests include: impending death, critical spiritual or emotional needs of a patient or family, medical-ethical dilemma, response to a healthcare professional's request, code, or trauma call. A greater portion of the pastoral care chaplains' time is spent addressing the needs and concerns of patients and families in the critical care areas. In addition, a request can be made to the hospital chaplain or healthcare professional to contact the patient or family's personal pastor or spiritual leader.

Policy #13, *End-of-life Care/Comfort Care*, addressed the specific needs of the dying patients. The goal of the policy was to optimize comfort and dignity of the dying patient. The policy states, "Each patient experiences and interprets the dying process differently according to personal, cultural, religious, spiritual values and preferences" (Organizational Policy: End-of-life Care/Comfort Care, p. 1). The policy addressed the physical, psychosocial, spiritual, and emotional needs of the patient and their loved ones. The procedure described the assessment process for the dying patient in the following statement: "The initial patient assessment and reassessment will address end-of-life care and will include the social, spiritual, cultural variables that influence perceptions and expressions of grief by the patient, family members or significant others" (p. 1). Interventions included in the procedure address pain, advanced directives, communication, support systems, education, nutrition, and various aids such as music, movies, and reading.

Spirituality and Spiritual Care in Job Descriptions

The job descriptions of pastoral care professionals, social workers, and registered nurses on each unit specific to this study were reviewed (see Table 5).

Table 5

Job Descriptions

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
Official Job Description: Registered Nurse	None	None
Official Job Description: Registered Nurse, Surgical Progressive/Oncology	None	“Demonstrate an understanding of hospice respite and provide care for the patient” under essential duties.”
Official Job Description: Social Worker	None	None
Official Job Description: Cancer Center Medical Social Worker, Social Services	<p>“The role of each team member within the ...Cancer Center is to create a unique healthcare experience for every patient, designed to nurture and inspire as well as add passion, meaning and context to each life we touch. Through teamwork, our focus is to support and guide the aspirations, hopes and needs of our patients and their families throughout their journey.”</p> <ul style="list-style-type: none"> • “Fully engage in each patient and family conversation and each ‘story’ listening closely to increase sensitivity to the patient’s needs and aspirations,” • “Honor and respect the diverse nature, beliefs, values and lifestyles of patients, families and co-workers” • “Recognize the individual and personal needs and aspirations of each patient and individualize interactions to honor and fulfill those needs and aspirations” 	None

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
	<ul style="list-style-type: none"> • “Uphold the symbols and live the Declaration of our promise to patients: <i>My Life, My Hope, Our Journey</i>” • “Support each colleague who works with cancer patients to uplift our spirits, manage our stress and celebrate our lives” • “Provide emotional support and brief counseling to reduce fear and anxiety” 	
<p>Official Job Description: <i>Chaplain Associate</i></p>	<p>“Responsible to assist the Pastoral Care Director in ministry to patients, families, and staff who desire Pastoral Care.”</p> <p>“Works with local clergy in assisting them in ministry to their congregational members.”</p> <p>“Works with Pastoral Care Advisory Committee.”</p> <p>“Assists in providing 24 hour daily on call response to pastoral care requests by patients or staff.”</p>	
<p>Official Job Description: <i>Director</i></p>	<p>“Effectively administers the hospital chaplain service to patients, families and staff desiring pastoral care.”</p> <p>“Works effectively with area clergy.”</p> <p>“Facilitates ongoing clinical pastoral education courses at the hospital as needed.”</p> <p>“Provides continuing education programs for local clergy and staff on hospital pastoral care and ethical issues.”</p> <p>“Effectively oversees and ensures the continuous availability of the Pastoral Care Department on a 24/7 basis.”</p>	<p>“Communication with next-of-kin when a relative is determined critical or if there is a serious emergency or tragedy.”</p> <p>“Family counseling to assist with understanding and dealing with family emergencies and serious illnesses and injuries.”</p> <p>“Family counseling as may be requested by the patient, family or others to deal with difficult issues such as initiation, withholding or withdrawal of life support.”</p> <p>“Assisting family to effectively manage difficult decisions.”</p>

Document	Statements Specific to Spiritual Care	Indirect References to Spiritual Care
	“Effective in communicating the hospital Pastoral Care Process and hospital services to the community.”	“Working closely with, and consulting with the social workers and the employee counselor as needed to assist patients, families and employees.”
	“Establishes standards and procedures for the Pastoral Care Department in accordance with established policies of the hospital.”	“Serve on the Medical Ethics Committee.”
	“Participates in the planning, preparation, and activities associated with the We Can Weekend for cancer patients and their families.”	
	“Coordinating with local or out of town clergy to assist with ministering to sick and injured persons and their families.”	
	“Ministry to the sick, injured, and dying and their families.”	
	“Oversee the daily chapel services.”	

Social workers. Despite the *Interdisciplinary Approach to Patient Care: Patient Care Huddles*, the policy directing referral to Social Workers for spiritual concerns, the job description for medical social workers, with one exception, was devoid of any reference to assessment of the patient's spirituality or addressing the spiritual needs of patients and families. The exception was in the job description of the "Cancer Center Medical Social Worker," which offered some details in guiding spiritual assessment and interventions (Official Job Description, Cancer Center Medical Social Worker, Social Services).

Chaplains. The majority of what was addressed in the Director of Pastoral Care's and Chaplain Associates' job descriptions were qualifications for the job, organizational responsibilities, and communication channels. Of note is that the required qualifications for chaplains at director or associate levels do not include board certification, and associates can be lay persons. Specifically, qualifications for the Director of Pastoral Care Services included being an ordained minister within a denomination that is prevalent in the regional service area of the facility, licensed in the state, experienced as a church pastor, "graduate or post graduate degree in divinity, theology or ministry" and experience in healthcare ministry. The qualifications for Chaplain Associate are "Qualified lay person with a minimum of one unit of Clinical Pastoral Education, denominational endorsement, and two years' experience in religious ministry" (Official Job Description, Chaplain Associate, Pastoral Care, p. 1).

Nurses. The job descriptions for registered nurses, essentially, did not specifically address spiritual assessment or the provision of spiritual care for the dying patient, or any patient. Only the job description of the registered nurse on the Surgical Progressive/Oncology unit offered a single, indirect referral to hospice care.

Specific Aim #2: How Participants Address Spirituality and Spiritual Care

Having presented the findings related to how spirituality and spiritual care was addressed in hospital documents, the next section will address the second aim, how spirituality and spiritual care and related roles are addressed in the language of the healthcare professional participants. Specific Aim #2: Describe how nursing, chaplaincy, and social workers address spirituality and spiritual care in assessment, diagnosis, communication, and implementation of the care for the dying patient including: (a) the language used by the different disciplines in reference to spirituality, spiritual distress, and spiritual care, (b) perceived roles in assessment, diagnosis, and provision of spiritual care to dying patients and families experiencing spiritual distress, and (c) the communication patterns between the three disciplines when addressing spiritual distress and needed spiritual care.

Participant definitions of spirituality and spiritual distress.

Spirituality. As reviewed in Chapter 3, there are a number of definitions of spirituality in the literature (Dossey & Keegan, 2013; Pesut, 2008; Vachon et al., 2009). A working definition was established based upon the concepts most frequently used to describe spirituality within definitions in the literature. For the purpose of this study, spirituality is defined as: the search for meaning and purpose in life based upon the individual's beliefs and connectedness. These beliefs may be founded upon religious, cultural, or other personal values that provide meaning and motivation to transcend beyond stressors of existence and develop the inner strength necessary for the individual to find meaning and purpose in their existence and optimally, physical, psychosocial, and spiritual wellness. Participant responses to the question, "How do you define spirituality?" were thematically analyzed and compared

to this working definition and the key concepts included in the definition (see Table 6). The following themes (in both their presence and absence) were dominant.

Connectedness to a higher being or loved ones or nature. The most frequent key concept included in healthcare professionals' definitions of spirituality included connectedness to a superior being. Language used included a higher being, a higher power, a greater power, god, or in Christian terms, God, or Jesus. Participants referred this as a connection, relationship, or source of strength. In defining spirituality, none of the participants spoke of a connectedness to self, loved ones, the world, or nature.

Religion. Religion and spirituality are terms that often have been connected or even muddled when trying to define spirituality (Dossey & Keegan, 2013; Nardi & Rooda, 2011). Not unlike the variety of interpretations of spirituality and religion in the literature, participants in this study either associated spirituality with religion in their attempt to define spirituality or they made a point to disassociate spirituality from religion. Several participants subtly included religion by using terms that are often associated with Christian beliefs.

Beliefs. Participants identified spirituality as "beliefs." Belief was expressed as a concept that related to spirituality in a variety of contexts. For some of the participants, belief was associated with the higher being (higher power, God, Jesus Christ, Holy Spirit) or simply a presence or the unknown. Other participants associated beliefs with perceived outcomes of spirituality, such as inner strength and comfort.

Table 6

How Nurses, Chaplains and Social Workers Define Spirituality and Spiritual Distress

Characteristics of Spirituality	Participant Response
Christian references to one's connectedness to a higher power.	"As someone, a human that God's created, we have a connection and for me, I find the spiritual connection, the spiritual part of our being is a way for us to connect with Him, with the creator." – Chaplain
Open interpretation of one's higher being.	<p>"I think of spiritual things as I, I relate it all to Christ and my relationship with Jesus." - Nurse</p> <p>"The feel, the connection we have with the power higher than ourselves." – Social Worker</p> <p>"You know, they believe in a higher power and that's where they get their strength from." – Nurse</p> <p>"I guess it's a relationship with something that might be a higher power than you, whether it's God or not, it varies from person to person and it's the third part of us." – Nurse</p> <p>"I think it's an individual, um, relationship that you have with the greater power depending on who that is, God for some, something different for others." – Nurse</p>
Direct relationship between spirituality and religion.	<p>Chaplain: "...an inner part of me *. As someone, a human that God's created, we have a connection * and for me I find the spiritual connection. The spiritual part of our being is a way for us to connect with Him, with the creator. Some would see or explain it differently * but the spiritual part of our being and, I feel we all have it whether we recognize it or not but * for me it's the way that I connect with the creator, God."</p> <p>Nurse: "Uh, spirituality um, for most people they would probably just think of their, whatever religion they're practicing."</p> <p>Nurse: "I mean, it's having religion."</p>
Implied relationship between spirituality and religion.	<p>Nurse: "This is where my spirituality kind of comes from is my faith and um, my relationship with Jesus Christ."</p> <p>Social Worker: "I absolutely believe there is a spirit that I call God. I've been a firm Christian believer in that then there is Jesus Christ and the Holy Spirit."</p>

Characteristics of Spirituality	Participant Response
	<p>Nurse: “Um, just anything, um, you know, that relates to the higher power. Uh, you know. Anything involving God or prayer or you know...”</p> <p>Nurse: “I think of spiritual things as I, I relate it all to Christ and my relationship with Jesus...”</p> <p>Nurse: “...spirituality to me at least, has always been, uh, more of just what you feel as opposed to, you know the uh, ...different things that you go through. The motions that you go through. You know, going to mass, going to church.”</p>
Religion disassociated from spirituality	<p>Nurse: “Um, well it’s, * it’s different from religion. I mean religion is more of an organization type thing...”</p> <p>Chaplain: “To me it’s not a church affiliation.”</p>
Belief in something outside or within themselves	<p>Chaplain: “The dimension of myself that involves belief in the unknown.”</p> <p>Social Worker: “...many people that have the belief that there’s something other than the physical world and presence and from them that is probably what they consider spirituality...”</p> <p>Nurse: “What you believe in after death.”</p> <p>Nurse: “One’s beliefs.”</p> <p>Nurse: “I mean it’s having religion. I believe. Like I have my beliefs and religion...”</p>
Belief that provides a desired outcome	<p>Nurse: “I think it’s where people find their source of strength. You know, they believe in a higher power and that’s where they get their source of strength from.”</p> <p>Social Worker: “Something that you believe in that gives you comfort.”</p>
Search for Meaning and Purpose	<p>Social Worker: “...having a purpose is what I think is important in life and I think spirituality helps bring that sense of purpose to people and so I think people without spirituality or having distress with that, really aren’t sure what has been the meaning of all of this and what has been their purpose so I think there’s just that sense of why?”</p> <p>Chaplain: “I think the spirit gives us meaning, direction and hope...”</p>

Inner strength and spiritual wellness. In defining spirituality, participants identified effects of spirituality as providing faith, comfort, direction, coping, and inner strength. For one nurse participant in particular, spirituality was not so much defined as what it is rather more of what it does “spirituality can also just be uh, whatever helps uh, a patient or even their family, or just anyone in general uh, be able to cope with just, you know, uh day to day instances in their life as well as you know, the hard times, you know things like that. Just anything to kind of help them cope can be a form of spirituality.”

Search for meaning and purpose. The search for meaning and purpose is a common task related to spirituality. Yet, meaning and purpose were not a key concept shared among the participants in this study. References to the search for meaning and purpose were limited to those of only one social worker and one chaplain. In defining spirituality, the social worker asserted, “having a purpose is what I think is important in life and I think spirituality helps bring that sense of purpose to people and so I think people without spirituality or having distress with that, really aren’t sure what has been the meaning of all of this and what has been their purpose so I think there’s just that sense of why?” The chaplain more briefly stated, “I think the spirit gives us meaning, direction, and hope...”

Language of spiritual distress among participants. In describing the indicators of spiritual distress, participants described patients having fear or anxiety, and/or being depressed, restless, nervous, distraught, saddened, agitated, emotional, angry, scared, withdrawn, tearful, or crying (Herdman & Kamitsuru, 2014). Each of the NANDA characteristics were identified by at least one participant except fatigue and insomnia. Some participants used emotional states to describe spiritual distress, others described the

questioning that patients experience throughout the dying process, and some expressed that the questions were what brought about the emotional response of patients.

A few participants reported that patients questioned the afterlife and its existence. Other participants described a loss of peace in patients who were experiencing spiritual distress that was expressed through restlessness. One common description of spiritual distress was that of a broken connection. Several participants described this brokenness in relation to their greater power. Two social workers described, in various ways, the loss of connection with one's self. One of the chaplains reported that families of dying patients may experience spiritual distress when they believe their dying loved one lacks the connection with God that will influence their afterlife. One participant identified that a dying patient experiencing spiritual distress may become withdrawn, and another participant related spiritual distress to individuals who were contemplating suicide. It was noted, however, that none of the participants in the study associated spiritual distress with any loss of creativity or interest in nature, arts, or life.

Table 7 illustrates the variety of indicators identified by participants to identify spiritual distress in dying patients and their loved ones. These are placed alongside correlating NANDA-identified causes and characteristics (Herdman & Kamitsuru, 2014). Table 8 lists reported indicators by discipline. Although many "indicators" identified by participants matched "characteristics" described by NANDA, study participants rarely, by name, identified causes of spiritual distress as loss of life purpose, meaning, and connectedness.

Table 7

Indicators of Spiritual Distress

NANDA Characteristics of Spiritual Distress	Participant Responses
<p>Emotions:</p> <ul style="list-style-type: none"> • Anxiety • Crying • Fear 	<p>Chaplain: “Some might be really nervous or * some might be...., depending on what condition they’re in, some might be restless and make a lot of movements even if they can’t communicate verbally. * Sometimes, * you know *, they might * look afraid...”</p> <p>Nurse: “A lot of times I think it is manifested um, through even like emotional distress Um, a lot of times they’ll become like very distraught, um, tearful, um, you know or ...”</p> <p>Nurse: “Oh! A lot of them get agitated and restless, and then some of them will cry but for the most part they are just scared. And, um, they reach out different way. There’s not one person the same. Or, they might withdraw.”</p> <p>Social Worker: “Um, questions that just seem to be, lead into fear. Heaven, hell, asking questions about things like that...”</p> <p>Nurse: “Worried about your, about what’s going to happen after this life.”</p> <p>Nurse: “Somebody who’s, might be very angry or crying, very emotional or somebody who’s very quiet.”</p>
<p>Questioning:</p> <ul style="list-style-type: none"> • Identity • Meaning of life • Meaning of suffering 	<p>Social Worker: “I think there’s an experience of just really trying to come back to themselves and what is their belief or uhm, you know, what’s going to happen after this? A time that they really kind of need to, not necessarily actively push people away but, I think find a way to come to the answers to their questions.”</p> <p>Chaplain: “they might have *, if they can communicate, a lot of questions. They might * be at a point in their life that they’re really searching so they might really wanna ask you a lot of things...”</p> <p>Chaplain: “If there is a God, where are you in my suffering?”</p> <p>Nursing: “Um, just being angry with God and pushing their spirituality away and um, questioning why”</p>

NANDA Characteristics of Spiritual Distress	Participant Responses
Separation from Greater Power	<p>Chaplain: “<u>Feeling alone</u> and <u>abandoned</u>. * If there is a God, where are you in my suffering? * Just an <u>emptiness</u> that I see * and maybe not just, no maybe just emptiness. It’s the <u>lack of that support of a higher being</u> in their time of distress or need and...and <u>they want answers</u>.”</p> <p>Social Worker: “...maybe they were very spiritual by church. That’s one way you can be spiritual. It’s not the only way. But, sometimes they become <u>angry at God</u> or they become <u>angry at just the world</u>.”</p> <p>Nurse: “You know, like I had a patient here recently and she, you know, she was a Christian and she said she got <u>mad at God</u> for some things that had happened and you know, sometimes they turn um, they get <u>angry</u> and kinda <u>turn from their beliefs</u>.”</p> <p>Nurse: “...has <u>no faith in themselves or a higher, a God</u> or anything like that.”</p> <p>Nurse: “...if they have a <u>church, they kinda ward them off</u>. They feel just that lack of...they talk about that <u>lack or void of having God in their life</u> or whatever their spiritual affiliation is. Um, just being <u>angry with God</u> and <u>pushing their spirituality away</u> and um, questioning why.”</p>

Table 8

Language of Spiritual Distress among Healthcare Participants

Nurses	Chaplains	Social Workers
<ul style="list-style-type: none"> • worry • restlessness • crying • lack of peace • sadness • depression • hopelessness • anger • agitation • confusion • withdrawal • isolation from church/ loved ones • cling to life, family, loved ones • fear of abandonment • not yet ready to let go • anger towards higher power • doubting existence of a higher power or afterlife • question Why? Why me? 	<ul style="list-style-type: none"> • nervousness • restlessness • fear • emptiness • feeling alone • feeling abandoned • concerns regarding salvation • perceived lack of support from their higher being • searching for answers to questions • searching for answers regarding the meaning in their suffering 	<ul style="list-style-type: none"> • anxiety • hopelessness • questioning • withdrawal • anger • question beliefs • question what's next • question afterlife • question reasons to live

Perceived Spiritual Assessment and Care Roles

A summary of the perceived professional roles for spiritual assessment and spiritual care are identified in Tables 9 and 10. The summaries include the participants' perspectives on their own roles as well as those of the other professionals.

The role of social workers in assessing spiritual needs. Social worker participants describe their role in assessment from two perspectives. One social worker participant rotates through the facility's outpatient cancer center. This social work participant described their role as assessing the patient and family's needs for resources that could bring a "sense of comfort or hope." When working in the outpatient cancer center, the social worker reported that the social workers in hospice will continue to assess and address the patient and family's needs throughout their service. Another social worker participant described that determining the spiritual needs of dying patients and their families is difficult and while the social workers will ask about their spiritual needs, it is often followed by suggesting a referral to pastoral care.

Each chaplain participant described the role of the social workers in assessing the spiritual needs of patients from a different perspective. One chaplain reported that the social workers approach areas of a patient's life that are not addressed by chaplains. Another chaplain conveyed that social workers are responsible for evaluating the needs of patients who have attempted suicide as well as families who are stricken with a loved one's successful suicide. This chaplain further iterated that while there are social workers who are comfortable with evaluating and addressing the spiritual needs of dying patients and their families, other social workers are more apt to refer assessment of spiritual needs to the chaplains. Even those social workers who are more likely to assess spiritual needs are likely

Table 9

Perceived Professional Roles in Spiritual Assessment

Professional Roles	Participant Responses
<p>Nursing Role As perceived by nurses, social workers and chaplains</p>	<p>Social Worker: “Nursing needs to be probably the key profession in identifying those needs.”</p> <p>Social Worker: “There’s an assessment done by nurses at the time of admission,” however, “it doesn’t have to just be nurses but, that is on their nursing assessment, but anyone who’s in the room um, who notice the patient in distress can ask them, you know, if they would like to talk with someone whether it is a social worker or they may say a counselor or you know, a chaplain or they want someone to contact their own pastor.”</p> <p>Social Worker: “So, I think certainly nurses that just get more experience, you know, have the, have a better ability usually to recognize some things that are happening.”</p> <p>Social Worker: “I think it’s the key role in identifying, in a hospital setting. I mean, that’s who’s got the hands-on time with patients and families. So, if they’re not feeling comfortable about what’s going on then it’s going to be really hard” and went onto say, “So, um, the relationship between the nurses and physicians is the really key so, having good nurses that have the ability to feel comfortable talking to a physician about what’s going on and being able to bring those needs up. So, I think certainly that nurses that just get more experience, you know, have the, have a better ability usually to recognize some things that are happening.”</p> <p>Social Worker: “I think that their main role for all of them would be just to recognize the need, and then how comfortable they feel with going forward with that. I just think that as long as they can recognize the need and get, either they can provide or get someone else to provide.”</p> <p>Nurse: “As the nurse, I am the primary care person so, it’s my job to identify any need that they have and spiritual would be one of them. We’re the ones who really identify the need for it umm, from the very start. We’re the first faces they really see when they enter the hospital so we’re the first ones and usually the last. We’re with them all the time so... We’re the initiators.”</p> <p>Nurse: “I feel like it’s part of holistic care because we don’t just take care of the physical needs of our patients but also the emotional and the mental and the spiritual. I think that is, that to me is holistic care. So it is recognizing signs of distress. A lot of times it is just generalized, angry outbursts towards the end-of-life. People can just generally be angry and you can recognize that as spiritual unrest or sometimes patients are just</p>

Professional Roles
Participant Responses

very tearful and emotional and it's just kind of being intuitive and being able to key in and find out if there is an issue and if they are willing to open up to you then that's, that's something that can really, really help them and not, in those end-of-life situations."

Nurse: "Well I would say that as, you know the staff nurse is talking with the patient, then they're listening for all concerns whether it's physical or emotional or spiritual and you would, you kind of expect, I think the way nurses work is they look for what could possibly go wrong and how can I prevent that from happening. So you anticipate sometimes the person might be into spiritual distress you know, particularly maybe a family of a young child that, who's seriously ill maybe near death."

Nurse: "Um, well any patient that we know that is at imminent death, we know there's a spiritual need but, I think pretty much any patient within the ICU has a spiritual need because they're all critically ill and there's always a chance that, you know they could pass away. So, every patient in the ICU has a spiritual need whether it be the patient or more the family."

Chaplain: "I think often the nurse, the person that's there often, asking, "how are ya? What can I do?" and, has a lot of contact so they're a major part of getting, information to us and letting us know about certain situations. We can usually better minister to people if we know certain things that might help us. So they are very helpful to us, but they add a great deal spiritually too, to the patients also, and family members."

Chaplain: "I see patients and families and nurses, and there's been a death and connection between those nurses and that family, if it's been a few days and they've got to know each other."

Chaplain: "You know years, years ago nurses had far more beside time with the patient. Now we see them less and less be able to take that one on one care of sitting down and talking to them. And so, I think for nurses it's far more difficult and they will call us more and uh, because they see it."

Social Work Role

As perceived by nurses, social workers and chaplains

Social Worker: "It to say, well let's try to figure out what really is going on and how do we address the concerns and bring some sense of comfort or hope. Whatever it might be that's lacking at that time." "I am always comforted myself when I know that we have turned over, say it's an outpatient cancer patient to * hospice that very clearly their needs have been identified and met. I mean sometimes it's just knowing that when I've done a hospice consult that the patient needs a hospital bed that, that specific very concrete need has been identified and met because if you believe in the whole hierarchy of needs, you know you've got to start with where people are before some of those things that are about spirituality are going to be addressed and cognizant that some people are going to say, I'm not going there at all."

Professional Roles

Participant Responses

Chaplain: "...have to go deeper often into certain areas of one's life that sometimes we don't actually get into. They have to find out about care at home, what's available to them and often they find out about the difficulties they're having in certain areas of life not only while they're here but at home. They're a major part of, I think, of that process here also through the team effort of helping and identifying things that maybe areas that we can help either guide 'em to help or, provide resources that will be able to help them."

Chaplain: "Some of them are very spiritual and some of them, and they want to do it themselves, and some of them are not that comfortable and they defer to us but, you know... It has been a contention, we have several that are very much would like to be doing what we're doing so, you know, I hope that's ... That's just the way life is."

Chaplain: "...I think the social workers sometimes start, if they're talking with their patients or their families but, then they'll make referrals back to us."

Nurse: "Social workers are good at identifying needs as well and they can let us know what those needs are there."

(Others paraphrased in text)

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Chaplain Role

As perceived by nurses, social workers and chaplains

Chaplain: "My role is of course, to listen." "...find out what's going on, find out how best I can help, what I can add to help them through whatever situation they're facing. If it be death and dying then of course, what I can do or how best I can help them through this difficult time."

Chaplain: "more mediators, mediators between family members, sometimes conflicts between them. Reassurers to the family that may be in doubt about the spiritual readiness of the dying patient. Always affirming where that person is in their belief journey because it's between they and God..."

Chaplain: "Trying to find peace within the traumatic time they're going through." "Having to go through everything and sometimes that's what compassionate care, comfort care, I think gives the family that peace knowing that they're trying to fulfill what quality of life means for them and spiritually because, sometimes families just fill so guilty because it's like they wanna do everything and yet, there's that part of them that's saying, but I have knowing that they're gonna be at peace, that they're not going to be in such pain physically and spiritually."

Social Worker: "Different families need different things."

(2 others paraphrased in text)

Table 10

Perceived Professional Roles in Spiritual Care

Nurses	Chaplains	Social Workers
<ul style="list-style-type: none"> • Prayer • Listening • Presence • Recognize patient/family needs • Physical and emotional comfort • Religious articles on patient or at bedside • Contact pastoral care or patient/family's personal minister • Contact family and loved ones • Encourage time with patient • Assist with religious or cultural traditions • Sing with patient/family • Read scripture • Patient/family teaching • Allow for patient/family stories and reflection • Hold a hand, offer a hug or shoulder to cry on 	<ul style="list-style-type: none"> • Prayer • "Stand in the gap" or be available • Listening • Honoring request for religious articles • Allow for patient/family stories and reflection • Accept the patient where they are at • Reading scripture • Music/sounds of nature • Assist with meditation • Offering encouragement to patient/family • Pictures of family, pets, etc. • Emotional comfort • Making contacts with family/loved ones • Guidance • Holy communion • Assisting in finding peace 	<ul style="list-style-type: none"> • Arranging for hospice or home health • Offering emotional support • Pastoral care referrals or contact patient's personal minister • Listening • Counseling • Connecting patient/family with support groups • Assisting with community and online resources and services • Addressing the needs of patient and family in regards to suicide attempts and successes.

to notify the chaplain and report their findings, thus allowing the chaplain the opportunity to go more in-depth with any spiritual issues or concerns.

According to nurse participants, the role of social workers in assessing the spiritual needs seemed to focus more on assessing the discharge needs and developing discharge plans for dying patients to enable patients to return home and remain in their home throughout the dying process. Nurses also recognized that the social workers' role is to assess and provide for the needs of significant others, family members, and friends who have lost a loved one to suicide. However, most nurses verbalized that social workers primarily assessed home care needs so the patient can return home for their last days and referred to pastoral care if a spiritual need was identified.

The role of social workers in providing spiritual care. Social workers are identified in the literature as having a role in addressing the spiritual needs of patients (Brunjes, 2010; Cadge & Bandini, 2015). Each social work participant agreed that they had a role in the provision of spiritual care and primarily that role was putting the family and patient in contact with pastoral care or the patient's personal minister. One social worker discussed the importance of knowing the community resources that are available to ensure that the patient and family are able to access what they need. Other spiritual care interventions identified as within the role of social workers was arranging for hospice, offering support, listening to patients and families, counseling them, and connecting them with support groups as well as online sources of support.

Chaplains seemed to agree that the spiritual care roles of social workers are important, with the primary role of social workers being the identification of resources and making referrals to pastoral care. One chaplain participant identified the unique role of

social workers in addressing the needs of patients who have attempted suicide and the families who remain after a successful suicide. Two of the chaplain participants gave some indication that role conflicts existed between social workers and chaplains. One chaplain stated,

Some of them are very spiritual and some of them, they want to do it themselves, and some of them are not comfortable and they defer to us, but you know... it has been a contention. We have several that very much would like to be doing what we're doing.

Another chaplain stated, "I like to think that as far as the spiritual care, that's our role."

Much like chaplains, nurses identified the spiritual care roles of social workers as that of identifying and connecting dying patients and their families with the resources and services, including home health and hospice. Referrals to pastoral care was identified by some nurse participants as a role of social workers in the general provision of spiritual care as well as with suicidal patients and their families. A few nurse participants stated that social workers offered emotional support to patients and families. One nurse stated, "They, you know, are there to ask questions as far as home needs and that, but in the process they sneak in the emotional support." One nurse stated,

You know they're just there for them to like I said, to listen and cry with and to pray with and uh, you know, it's... Yeah, their specific job may not have [spiritual care] listed under their [duties], but they do it anyway.

Two nurse participants admitted they did not know that social workers had any role in the delivery of spiritual care to patients.

The role of chaplains in assessing spiritual needs. Chaplains were asked to describe their role in identifying the spiritual needs of dying patients and their families. One chaplain emphasized the need to listen to the patient/family describe their situation and then to inquire what is needed to assist them through the crisis. While this chaplain preferred to speak

directly with the patient, this is often not feasible; therefore, identification of spiritual needs is dependent upon discussions with the patient's spouse, family members, or friends.

Mediator was one term used to identify the role of chaplains in assessing spiritual needs of dying patients and their families. Chaplains may need to mediate between family members of the dying patient when conflicts arise. This chaplain explained that families may express doubts regarding the patient's "spiritual readiness" for death. As chaplains, they must support "where the patient is currently at" in their "belief journey, because it's between they and God, not what I think." The language within this statement, like many of the participants, infers the assessment of spiritual needs is for Christian believers or those who believe in God. Within the context of the statement, it appears that interventions such as mediating and reassuring are simultaneously being done along with identification where the person is in their "belief journey."

One chaplain described their role in identifying the spiritual needs of dying patients and their families as it relates to the search for peace during a period of suffering. As families witness the ongoing pain and suffering of their dying loved one, they are often torn between wanting to do everything to extend life; yet knowing death will bring an end to the physical agony, a part of them is ready to let go. This chaplain expressed that patients and families have become more cognizant and forthright about their personal wishes in regards to their quality of life and healthcare choices through advanced directives.

In discussing the roles of chaplains in the delivery of care to dying patients and their families, social worker participants identified assessment roles of chaplains as that of identifying the religious preferences and needs of dying patients and their families. One social worker participant stated that as part of the admission assessment, nurses will ask if the

patient has a desire to speak with a chaplain. While pastoral care will offer their services, if the patient or family are not receptive to a visit from the chaplain, that is respected. For those patients who agree to speak with the chaplain, the spiritual assessment by the chaplain is necessary to identify the unique needs of each patient and their family.

Nursing participants primarily focused on the interventions offered by chaplains, more so than assessment functions of chaplains. One nurse participant from the medical-telemetry area revealed that chaplains make daily rounds to identify spiritual needs of patients in the nursing areas. Another nurse reported that chaplains explore how the patient and family “feel about the situation” and based upon the response, offers support, prayers, or other interventions the patient and family need. Several nurse participants mentioned or inferred that chaplains identify the individual needs of each patient and their family. One difference noted between areas was that a chaplain is specifically assigned to the intensive care unit and therefore is readily available to evaluate and address the spiritual needs of patients and families.

Throughout the interviews with chaplains, social workers, and nurses, there was never any suggestion of any formal assessment of spirituality conducted by chaplains. In reviewing the documentation, the researcher asked if there was any policy or documentation describing the spiritual assessment completed by chaplains when a pastoral care referral was requested. It was indicated that the chaplain allows the patient to take the lead in the discussion, and the assessment is not anything formal. Thus, the documentation would not be a standard form, but would rather be written as a note describing the individualized interaction between the chaplain and patient. This may be the reason that the chaplains’ roles in assessment are vague and sporadic in the responses of all participants, including those of the chaplains.

The role of chaplains in providing spiritual care. A phrase used to describe the role of chaplains in the provision of spiritual care to dying patients and their families was, “standing in the gap,” which was further explained as being available to offer a vast array of spiritual care interventions such as presence, prayer, reading scripture, providing music, or sounds of nature, an atmosphere for meditation, and honoring requests for religious or spiritual objects. The phrase also reflected the philosophy of the chaplain role as a “conduit” between the patient and God, or a greater being. One chaplain described their role as one of listening and asking about the patient’s family to “get the family stories going” and then reflect the stories back to the patient and family. Prayer was not only a spiritual care intervention partaken with the patient and family, but also the chaplain’s prayer for guidance in addressing the spiritual needs of the dying patient and their family. “I use prayer for myself, that I am the instrument that they need. And that’s, sometimes great things happen, sometimes not.” Another chaplain identified getting to know the patient and understanding “what was important to them in life” as an intervention for spiritual care. The importance of accepting the patient’s current spiritual perspective in life is emphasized in the statement,

So, to me it’s walking with them and showing our faith through accepting people wherever they’re at, whatever their relationship is and knowing they’re very important in God’s eyes and, we show that by our acceptance of wherever they are.

One word used to describe a social worker’s perception of the chaplains’ role in the provision of spiritual care was “instrumental.” Offering and providing comfort through the simple presence of pastoral care was identified by one social worker while another social worker was more specific in stating that the chaplains’ role was to offer religious comfort or, “to be aware of the patient’s preference of religion and to try to comfort them with that kind of spiritual reading, prayer, and emotional support.” Other chaplain duties identified by the

social work participants were assisting in making contacts with family members and other loved ones, being present at the bedside of the dying patient, and doing whatever the family needs at the time.

Nurses used adjectives of pivotal, invaluable, powerful, wonderful, and important when describing the roles of chaplains in delivery of spiritual care to dying patients and their families. One nurse stated, “They have hearts for the patients. They truly care.”

Interventions that nurses identified in the role of the chaplains included comfort, offering emotional and spiritual support, prayer, guiding patients and families through the dying process, providing sacraments of Holy Communion, assisting patients and families to find peace of mind, helping them to cope, sitting with patients and families, talking with them, and listening to them. One nurse explained, “I couldn’t imagine as a nurse and you’re dealing with a dying patient, you usually have to deal with the patient as well as the family in a code situation. You’re trying to take care of your patient, but you are also trying to take care of the family and that. Um, pastoral care/chaplain is kind of the bridge between the two of you. You can kind of bring them in to take care of the family while you’re trying to take care of the patient.”

The role of nurses in assessing spiritual needs. Social worker, chaplain, and nurse participants expressed the consensus that the nurse was the primary professional who identifies spiritual distress and spiritual needs of patients and families, because of her/his hands-on time with them. The role of the nurse was to screen for spiritual “needs” upon admission by asking the patient if they would like the chaplain to visit and if they have any cultural beliefs that may affect their care or patient education. This was considered the initial assessment and was included on the formal admission assessment form. The ongoing

assessment for spiritual distress or identification of spiritual needs was based upon informal interactions with patients and could be recognized by any of the hospital staff, physician, patient or family and resulted in a request for pastoral care services from the hospital chaplains or a personal minister.

The nurse participants from all clinical areas agreed that nurses were responsible for the initial assessment and screening for spiritual needs as well as ongoing assessments. The responses from nurse participants included descriptions of situations and behaviors that would indicate the dying patient and/or family were experiencing spiritual distress that needed to be addressed. Nurses reported they assessed spiritual needs by asking questions, spending time with the patient, anticipating needs, discussing of end-of-life wishes with family, and so forth. One nurse stated that she simply lets the patient and family know that pastoral care services are available.

Several nurse participants reported their role as identifying the spiritual needs of patients by recognizing the signs and symptoms of spiritual distress exhibited by the patient and family. Nurses conveyed that they assess the spiritual needs of dying patients upon admission and continue an ongoing assessment for signs of patient or family experiencing spiritual distress. Two of the nurse participants specifically identified their role as being in the forefront as the collaborator of holistic care of dying patients and their families. One ICU nurse participant described the nursing role for identifying spiritual needs as being intuitive.

Two chaplain participants associated the nursing role in identifying spiritual needs with the logic of them being the ones to spend the most actual time at the patient bedside. One chaplain stressed the importance of this time element. Another chaplain described how the contact with patients promotes building a relationship between nurse, patient, and family.

Ironically, the last chaplain participant identified that due to increasing responsibility and less time available to be at the bedside, nurses are becoming more apt to contact the chaplain when a spiritual need is identified rather than responding to the need in any way themselves.

The role of nurses in providing spiritual care. Several nurses stressed the importance of being able to recognize the unique, individualized needs of dying patients and their families before initiating spiritual care interventions. Many of the spiritual care interventions used by these nurses mirrored the interventions used by chaplains. Nine of the nurse participants in this study identified prayer as an intervention used for addressing the spiritual care needs of their dying patients and their families. As one nurse stated,

I, personally, have prayed with patients and families. I have sang with patients and families. I have cried with patients and families. I have just listened. I have read scripture. I have just [done] pretty much anything that is needed.

Teaching the family and patient about the dying process and what to expect was a unique intervention specific to nurses. One nurse told the story of a patient who had progressed to unresponsiveness and the daughters were at the bedside. The nurse spent time with them explaining every step of her nursing care, how each intervention affected the patient, and what to expect. The nurse expressed because of the daughters' understanding of the dying process and what to expect they felt more in control and "were able to have those last moments and then let her (mother) go."

A variety of other interventions were reported by nurses. Some of the interventions had religious orientation, and many reflected presence and maintaining connectedness with loved ones and a higher power. These additional interventions included:

- listening to patients and families as they expressed their concerns, fears or as they reflected on their lives,

- offering comfort,
- asking family to bring the patient's religious articles that are important,
- contacting pastoral care or the patient's personal pastor,
- contacting family members and loved ones regarding imminent death,
- encouraging family to spend time at the bedside with the patient,
- assisting the patient or family with religious or cultural traditions,
- singing with patient,
- reading scripture,
- being available to the patient and family, and
- teaching the family about the dying process and what to expect.

Chaplains reported that nurses played a large role in the delivery of spiritual care to dying patients and family due to the time spent with patients and families. Through the nurse/patient relationship, nurses are able to identify spiritual needs of patients and families and as one chaplain stated,

so they're just a major part of getting information to us and letting us know certain situations. We can usually better minister to people if we know certain things that might help us. So they are very helpful to us, but they add a great deal spiritually too, to the patients also, and family members. I feel they're just a major part of the whole team effort.

One of the chaplains stated that as the connection between nurse and family grows, "It's almost like I want to say, 'You don't need me. You've got it right here. You've got it, you can do it.'" One chaplain identified that through the years, nurses have less time to spend at the bedside and "Now we see them less and less be able to take that one-on-one care of sitting down and talking to them. And so, I think for nurses it's far more difficult and they will call us more."

Like chaplains, social worker participants also identified that nurses are the professionals who recognize what is happening with their patients and patient needs. According to one social work participant, “So, I think certainly that nurses that just get more experience, you know, have the, have a better ability usually to recognize some things that are happening.” Another social worker said about the nurse’s role in spiritual care, “I think that their main role for all of them would be just to recognize the need, and then how comfortable they feel with going forward with that.” This social worker went on to express that as long as the nurse can recognize the patient’s spiritual care need, they can either provide that spiritual care or find someone else to provide it.

Specific Aim #3: Comparing Findings to the Proposed Conceptual Framework

Aim 3 was to compare findings from aims #1 and #2 to the processes described in a proposed conceptual framework developed from a synthesis of existing models for spiritual assessment and care of dying patients and families experiencing spiritual distress. Table 11 illustrates a comparison of the documented organizational and department/unit level structure, and professional roles within this institution to Drury’s Compilation of Existing Frameworks.

In comparing the organizational findings to Drury’s Compilation of Existing Frameworks, it is clear that some spiritual care does occur in this institution, but there are considerable gaps in comparison to more ideal frameworks. In the following chapter the gaps in structure and content of spiritual care are enumerated and discussed in more detail, re-engaging with existing literature.

Table 11

Comparison of Drury's Compilation of Existing Frameworks to Findings

Drury's Compilation of Existing Frameworks	Research Findings
<p>Body, mind and spirit of each human being are intertwining inseparable domains. Any positive or negative stressor that influences or alters one domain will affect the other domain ultimately impacting the person as a whole.</p>	<p>Assumptions The cultural, psychosocial and religious/spiritual beliefs of individuals influence perception of illness, its treatment and their response to the care provided (Plan for Provision of Patient Care).</p>
<p>Screening</p> <ul style="list-style-type: none"> • Screening should be completed upon admission by admitting nurse. • Screening may be a question or two maximum. • Opening dialogue regarding spirituality must occur within the first few hours of admission so spiritual distress may be identified and addressed before discharge. • Screening results identify the need for a more comprehensive assessment. 	<p>Screening</p> <ul style="list-style-type: none"> • During the registration process, the patient/support person are asked if they have religious or spiritual preferences. The information is documented on the patient's face sheet. • Screening is completed during the initial nursing assessment. • The health history is to be completed within 8 hours of admission. • Screening includes 2 questions: <ul style="list-style-type: none"> ○ "Would you like a chaplain visit?" ○ "Do you have any cultural beliefs that may affect your care or education?" (Psychosocial, Spiritual and Cultural Values of Patients, p. 1)
<p>Assessment</p> <ul style="list-style-type: none"> • The spiritual assessment may be performed by the nurse or another healthcare professional. • The comprehensive spiritual assessment may or may not be a standard or structured assessment to be effective. • As dialogue about spirituality begins between the healthcare professional and patient, allow the patient to take the lead in the direction that the conversation flows. 	<p>Assessment Nurse: "A registered nurse will assess each patient's needs for nursing care in all settings in which nursing care is provided. Patient care encompasses the recognition of disease and health, patient education and advocacy, recognizing the unique physical, emotional and spiritual, emotional and psychological needs of each person" (Plan for Provision of Patient Care, p. 2). "An assessment will be done on all patients to determine the</p>

Drury's Compilation of Existing Frameworks	Research Findings
<ul style="list-style-type: none"> • The healthcare professional should be cognizant of the verbal and nonverbal cues conveyed by the patient as well as any interactions the patient has with others. • The healthcare professional completing the assessment should request staff input. 	<p>needs of the patient. The assessment will include physical status, pain intensity, psychological status, and social status. This will be an ongoing process done in a systematic manner. The frequency of the reassessment will be determined by the patient's needs and the department/unit structure" (Assessment of Patients, p. 1).</p> <p>"If patients/support person have questions, requests, or comments regarding Cultural or Spiritual practices, they can be directed to Pastoral Care and Social Services" (Psychosocial, Spiritual and Cultural Values of Patients, p. 2).</p> <p>Pastoral Care: "New patients who request a visit by Pastoral Care will be seen within 48 hours. Special requests will be accommodated within 24 hours" (Plan for Provision of Patient Care, p. 81).</p> <p>Reassessment by Pastoral Care is "Dependent on need expressed at initial assessment" (Plan for Provision of Patient Care, p. 122)</p> <p>Social Services: Initial assessment by Social Services occurs following a referral with reassessment determined by the needs of the patient/family or requests from physicians, staff or patient/families (Plan for Provision of Patient Care, p. 122).</p> <p>Organizational Policy #13, <i>End-of-life Care/Comfort Care</i> "The initial patient assessment and reassessment will address end-of-life care and will include social, spiritual, cultural variables that influence the perceptions and expressions of grief by the patient, family members, or significant others" (p. 1).</p>

Drury's Compilation of Existing Frameworks	Research Findings
<ul style="list-style-type: none"> • Spiritual distress and the patient's spiritual needs should be addressed as a section within individualized holistic plan of care. • It is imperative that the plan of care be explored, discussed, and approved by the patient as well as the rest of the healthcare team. 	<p data-bbox="1077 235 1245 264">Plan of Care</p> <p data-bbox="1150 269 1923 337">Organizational Policy #10, <i>How Patients' Care is Planned, Provided and Communicated</i>, <u>"PASTORAL CARE:</u> The pastoral care of patients is planned on a daily basis. The most urgent situations take precedence; these include: imminent death, critical spiritual/emotional need, family distress, medical-ethical consultation, physician-staff request, code blue, trauma call, etc. The greater part of our time is spent with critical care patients and their families. Spiritual and emotional support is given when requested and where the need strongly suggest the same. We also try to contact the pastor of each patient critically in need, when and where that is possible. The patient is always asked if he/she would like our pastoral staff to see him/her, and then asked how we can be of service."</p> <p data-bbox="1150 818 1898 886">Organizational Policy #11, <i>Interdisciplinary Approach to Patient Care: Patient Care Huddles</i> "Team members attending the huddles may include: case manager, nurse, social worker, pharmacist, rehab services (PT, OT, or Speech), dietary, diabetic educator, Cardiac rehab services and respiratory therapy. Outside agencies will be invited on a case by case basis and may include LTAC's, nursing homes, and Home Health companies. A patient/family may request participation but generally information from the rounds is presented to the patient/family by the case manager or social worker." <i>(Despite statement in column to left, there is no mention of pastoral care here.)</i></p>

Social Workers: Under the social worker's responsibilities and role in a Huddle the following is included: "Psycho-social or spiritual concerns/Psychiatric: Any info that would impact care/family support"

Organizational Policy #12: *Patient and Family Teaching*
"Staff nurses and patient educators will consider the following when assessing and planning the patient's educational needs. Whenever applicable these factors will be reflected in the patient's plan of care: 1. Cultural and religious factors 2. Emotional barriers..."

Provision of Spiritual Care

- No single discipline within the healthcare system is exclusively responsible for spiritual care.
- Restoring or improving a patient's spiritual health requires teamwork and collaboration with the patient being a key member of the team.

Organizational Policy #11, *Interdisciplinary Approach to Patient Care: Patient Care Huddles*
"Team members attending the huddles may include: case manager, nurse, social worker, pharmacist, rehab services (PT, OT, or Speech), dietary, diabetic educator, Cardiac rehab services and respiratory therapy. Outside agencies will be invited on a case by case basis and may include LTAC's, nursing homes, and Home Health companies. A patient/family may request participation but generally information from the rounds is presented to the patient/family by the case manager or social worker."

(Despite statement in column to left, there is no mention of pastoral care here.)

Under the social worker's responsibilities and role in a Huddle the following is included: "Psycho-social or spiritual concerns/Psychiatric: Any info that would impact care/family support"

Organizational Policy #13, *End-of-life Care/Comfort Care*
References in the procedure related to spirituality and spiritual care: "1. To improve communication during the end-of-life the following will be addressed...b. Patient's religious, cultural, spiritual beliefs and practice"

"2. The following end-of-life care resource/support options will be made available to patients and their families that are at or near the end-of-life...d. Spiritual support from pastoral care or members of patient's faith community

"f. Patient and family support examples include: i. Stay with the patient-talk, watch movies and or read; ii. Allow patient to express fears and concerns about dying; iii. Reminisce about the patient's life; iv. Share information-include the patient in discussions and decision making; v. Respect privacy; vi. Reassure the patient that advance directive will be honored; vii. Ask if there is anything else you can do."

Departmental/Unit Level Policy #14, *Critical Care Policies and Regulations*

"These units integrate with other hospital departments to provide this specialized care. Integration includes, but is not limited to:

Availability of pastoral care services on a continuous basis..."

"2. The minister of the patient may visit in the critical care visit upon special request (by name) from the family or the patient."

Chaplain Associate Official Job Description:

“Responsible to assist the Pastoral Care Director in ministry to patients, families, and staff who desire Pastoral Care.”

“Assists in providing 24 hour daily on call response to pastoral care requests by patients or staff.”

“Works with local clergy in assisting them in ministry to their congregational members.”

Director of Pastoral Care Official Job Description:

“Effectively administers the hospital chaplain service to patients, families and staff desiring pastoral care.”

“Effectively oversees and ensures the continuous availability of the Pastoral Care Department on a 24/7 basis.”

“Coordinating with local or out of town clergy to assist with ministering to sick and injured persons and their families.”

“Ministry to the sick, injured, and dying and their families.”

“Oversee the daily chapel services.”

“Family counseling to assist with understanding and dealing with family emergencies and serious illnesses and injuries.”

“Family counseling as may be requested by the patient, family or others to deal with difficult issues such as initiation, withholding or withdrawal of life support.”

“Assisting family to effectively manage difficult decisions.”

“Working closely with, and consulting with the social workers and the employee counselor as needed to assist patients, families and employees.”

Organization Structure

- Organizational structure is required for spiritual care to be effective.
 - The process of spiritual assessment and spiritual care should involve a language of spirituality is understood across all disciplines
-

CHAPTER 5 CONCLUSIONS AND IMPLICATIONS

Exploring the Gaps in Spiritual Care

In this chapter, key findings related to the gaps identified in the provision of spiritual care within the case institution are discussed. Recommendations for the institution are identified, as well as larger implications for practice, education, and research. The major gaps or problem areas that are discussed include:

- Lack of an organizational structure for spiritual assessment, planning, and implementation of spiritual care, or communication of the spiritual care plan among healthcare professionals,
- Screening questions that are not relevant in identifying spiritual distress,
- No clear delineation of roles and responsibilities related to spiritual care, leading to tension between some disciplines, and
- No healthcare professional education or training on understanding spirituality, assessing spiritual needs, and responding to spiritual distress.

Lack of Organizational Structure

The lack of a formal process for spiritual assessment and the provision of spiritual care likely has ramifications on the organization's ability to meet the holistic needs of the patients it serves. A formal process would guide healthcare professionals who are expected to provide spiritual care in their communication among other healthcare professionals regarding spiritual assessment findings, developing a holistic plan for the provision of spiritual care to patients experiencing spiritual distress, and providing the care necessary for the patient to experience spiritual peace and comfort (Balboni, Puchalski, & Peteet, 2014). The effective

delivery of spiritual care could positively influence physical symptoms, psychological pain, depression, or anxiety, and heal relationships among patients and loved ones as well as other caregivers.

As described in Chapter 4, within the context of this specific case study, a formal process exists for identifying the religious affiliation of each patient, determining if a patient would like to visit with the chaplain, identifying cultural or religious beliefs that could affect patients' healthcare, and stating the timeframe required for chaplains to respond and assess a patient when a referral has been made. However, the screening and referral process are the extent of the formal organizational process for the delivery of spiritual care in this case study. The absence of a specified organizational process for developing a holistic interdisciplinary plan of care, as well as communicating and documenting the plan of care among the disciplines, clearly makes spiritual care of any patient, including the dying patient, random and variable at best.

One interdisciplinary process is described entitled, "Patient Care Huddles," where professionals have team conferences regarding patients in their care (Organizational Policy: Interdisciplinary Approach to Patient Care: Patient Care Huddles). One solution for defragmenting the organization's process for developing, implementing, and communicating spiritual needs in the patient's holistic plan of care is the inclusion of the chaplain in ongoing patient care huddles. Not unlike what has been identified in the research regarding the usual small size of pastoral care departments within healthcare institutions, the limited number of chaplains is likely a barrier to their participation in patient care huddles on every hospital unit (Blanchard et al., 2012; Emanuel et al., 2012). However, research has linked the provision of spiritual care to terminally ill patients with

improved quality of life, increased patient satisfaction, decreased use of extensive medical interventions, lowered healthcare costs, and increased hospice referrals (Balboni et al., 2013). In today's world, where higher patient satisfaction scores mean increased Medicare reimbursement for patient hospitalization, improved patient satisfaction is a significant reason to consider improving the process for addressing the spiritual needs of patients. The benefits to patients and the healthcare institution would likely outweigh any additional cost attributed to hiring at least one additional pastoral care personnel, or organizing a spiritual care team or spiritual care committee to address the spiritual needs of patients (Hodge, Salas-Wright, & Wolosin, 2016).

Inadequate Screening for Spiritual Distress

While the spiritual screening questions, "Would you like the chaplain to visit?" and "Do you have any cultural beliefs that may affect your care or education?" may meet the Joint Commission's minimal requirements for spiritual assessment, the information obtained from these questions does not identify the presence or absence of spiritual distress. According to Cadge and Bandini (2015), this type of spiritual screening is intended to aid the healthcare professional in determining if spirituality is significant to each patient and if a more in-depth assessment is necessary. A screening that identified the implications of a patient's terminal illness on their personal sense of meaning and purpose would provide an indication of whether the patient was experiencing spiritual distress and the necessity for a more comprehensive spiritual screening (Blanchard et al., 2012).

Koenig (2014) describes an example of better screening questions in a pilot project in which the physician was responsible for the initial spiritual assessment. The purpose of the piloted spiritual assessment was to identify whether the patient has spiritual needs that

warrant the initiation of a referral to a “spiritual care team” and further assessment from a chaplain. The three questions asked by the physician were:

- 1) Do you have a religious or spiritual support system to help you in times of need?
- 2) Do you have any religious beliefs that might influence your medical decisions?
- and 3) Do you have any other spiritual concerns that you would like someone to address? (Koenig, 2014, p. 1165)

When considering the language of spirituality, however, even these screening questions do not determine if the patient’s illness has disrupted what is most meaningful to them, their sense of purpose, or connections with their higher power, loved ones, nature, art, and so forth

Screening questions should identify the implications of a patient’s terminal illness on their personal sense of meaning and purpose or their connections with someone or something significant and sacred. This would provide a better indication of whether the patient is experiencing spiritual distress and thus need a more comprehensive spiritual assessment (Fitchett, 2002). When reviewing the definitions of spirituality, more relevant spiritual screening questions could be simply: (a) How has your illness affected that which is most important to you? (b) How has your illness affected your relationships with those you care about?

Role Clarification and Trepidation

The third gap identified was the **lack of clearly defined professional roles**, in the assessment, planning, and implementation of spiritual care. This lack of clarity in professional expectations was reflected in the participants’ responses about their role and the role of the other disciplines in the spiritual assessment process. Some participants described the spiritual assessment as a nursing role because nurses spend the most time at

the patient's bedside as compared to professionals from other disciplines. In addition, the nurse is cognizant of identifying and anticipating holistic patient needs through ongoing assessment. Two of the chaplains reported that social workers were proficient at digging deeper into the needs of patients, stating that this was part of a team effort because the information identified by the social worker gave chaplains some insight on how to guide the patient and provide resources that might be beneficial for the patient and family.

There were indications of **role conflict** among social workers and chaplains. In the policy describing the interdisciplinary team approach to patient care through patient care huddles, the chaplains were not listed as part of the interdisciplinary team. The social workers' role described in the policy on interdisciplinary team approach was to address the psycho-social and spiritual concerns of patients. Excluding the chaplains and identifying the social workers' role as addressing spiritual concerns may have aided in establishing the role conflict between social workers and chaplains. It was interesting to note that there were no concerns in the overlap of roles between nurses and chaplains, even though there was evidence that these roles overlap on various occasions. One chaplain even seemed to encourage nurses to take charge in the statement,

It's almost like I want to say, 'You don't need me. You've got it right here. You've got it, you can do it... just because I have the label doesn't mean that I'm any better than you are,' because they know, they've observed.

Despite an ill-defined, tolerated sharing of spiritual care, how the roles of chaplains, social workers, and nurses related to one another as part of a team approach was unclear. Blurred boundaries between roles, with some participants expressing concerns over the professional jurisdiction of spiritual care, also put patients more at risk for no one assessing or attending to their spiritual needs.

A **team approach** for spiritual care is suggested throughout the literature and as with any team, each member must have designated roles that must be clearly defined (Cadge & Bandini, 2015; Hodge et al., 2016; Koenig, 2014; McSherry, 2006; Puchalski et al. 2009; Puchalski et al., 2014). If the institution were to assimilate a spiritual care team, members of that team could be assigned the responsibility of developing policies and educating staff on spiritual assessment, spiritual care planning, delivery of spiritual care, and discharge planning for patients experiencing or at risk for experiencing spiritual distress. Additionally, the role in meeting the spiritual needs of patients by each healthcare professional on the multi-disciplinary team could also be addressed in these team-developed policies and staff education. Spiritual care would be better approached as a team, each knowing their role, communicating more effectively among team members and impeding further frustration of blurred role boundaries among the disciplines. Furthermore, with the ratio of chaplains to patients being small in this institution, the establishment of interdisciplinary roles could delineate how to most effectively use the chaplains so the spiritual needs of patients are not lacking because of unrealistic expectations of such a small department. As stated in chapter 2, among this group of participants, role conflict in spiritual caregiving was not due to one profession intentionally trying to exclude another. Rather each healthcare discipline is trying to situate itself in developing and understanding the language of spirituality from the perspective of its own profession and professional roles.

Lack of Education and Training on Spiritual Care

Education of healthcare professionals is an essential component for meeting the needs of patients who are experiencing spiritual distress. During data collection of

organizational documents, staff education as well as patient education resources that described the process for providing spiritual care to dying patients and their loved ones were sought. The chaplains, the personnel responsible for staff education, nurses, and social workers could not recall any teaching resources that addressed spirituality. A key concern in this case study was that the language used by the participants lacked attention to the key characteristics of the spirituality definition used in this study, as well as other definitions in the research. Lack of understanding of the basic definition is clear indication of the need for education that would contribute to a shared and appropriate language of spirituality among disciplines.

In healthcare professional interviews, the key characteristic of spirituality, connectedness, was described in relation to religion or God. For some participants, the concern was the lack of connectedness, through the absence of religion or belief in God. However, connectedness to family, self, community, other loved ones, nature, and so forth were not identified among the participants. Because of evidence seen in the study of healthcare professionals' limited language and understanding of spirituality, it would be reasonable to suspect that the spiritual assessment and spiritual care may be limited as well. Determining the effects of this limited language of spirituality in the provision of spiritual care to dying patients and their families is beyond the scope of this study, but continued research could add to the knowledge base for healthcare professionals to better understand spirituality, spiritual assessment practices that best identify spiritual distress and spiritual needs, and spiritual interventions that assist patients in finding peace through their end-of-life journey.

New Progress in the Field

In a 2009 national consensus conference entitled, “Improving the Quality of Spiritual Care as a Dimension of Palliative Care,” a definition of spirituality was agreed upon by the attending participants. This definition was further refined during the 2013 international consensus conference, “On Improving the Spiritual Dimension of Whole Person Care: The Transformational Role of Compassion, Love and Forgiveness in Health Care.” It was recommended that the definition for spirituality be broad so that healthcare professionals could expand their spiritual awareness in recognizing spiritual concerns of patients and become more attentive to the source of each patient’s sense of meaning and purpose (Puchalski et al., 2014). The definition of spirituality, as agreed upon by the 2013 consensus, is as follows:

Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices. (Puchalski et al., 2014)

The 2013 international consensus definition and this study’s working definition recognize meaning, purpose and relationship (connectedness) as key characteristics of spirituality. If healthcare professionals lack insight to these key characteristics, how are they addressing spirituality in its entirety for diverse groups of patients? Filling the educational gap by educating staff on the language and characteristics of spirituality, spiritual distress and their role in the delivery of spiritual care within the organization could significantly enrich the institution by increasing patient satisfaction, lowering healthcare costs, and decreasing readmission rates.

Future of Spirituality in Healthcare

Research concerning the benefits attributed to the provision of spiritual care to patients within the healthcare system has rapidly accumulated over the last decade. Studies continue to indicate that patients who believe their spirituality is addressed by healthcare professionals have a higher satisfaction with the care provided. With the recent changes in healthcare legislation rendering patient satisfaction as a key indicator that drives reimbursement rates from Medicare, as well as regulating agencies' continued focus on spirituality in their standards, healthcare professionals will find it necessary to address the spiritual needs of their patients. Administrators of healthcare organizations have new financial motivation to provide the necessary structures and personnel to provide it, in order to ensure the continued survival and growth of their organization among health systems in the U.S.

Since this study was begun, national and international consensus conferences on enhancing the spiritual dimension of "whole person care" have convened for the purpose of developing strategies for integrating spirituality into healthcare organizations to create more compassionate "systems of care" (Puchalski et al., 2014). These conferences evolved as a result of recognizing that patients are often treated as a "disease that needs to be fixed" promptly with minimal cost. Patients have reported feeling overwhelmed by the onslaught of tests, medications, and treatment options that often reflect a lack of compassion and caring about their stress and burdens secondary to their illness. The initial 2009 national consensus conference, "Improving the Quality of Spiritual Care as a Dimension of Palliative Care," concentrated on spiritual care as a significant element in the provision of "high-quality health-care," particularly in palliative care settings (Puchalski et al., 2014). At the

conclusion of the 2009 conference, an agreement was reached regarding the definition of spirituality, how it can be addressed in palliative care in national healthcare systems, and recommendations for the delivery of spiritual care to palliative care patients.

The 2009 national consensus conference stimulated two additional conferences, the 2012 National Consensus Conference on Creating More Compassionate Systems of Care and 2013 International Consensus Conference on Improving the Spiritual Dimension of Whole Person Care: The Transformational Role of Compassion, Love and Forgiveness in Health Care, for the purpose of developing standards of care, procuring recommendations for implementing the standards of care, and to build upon the 2009 inter-professional spiritual care model and its suggestions for palliative care. The 2013 international conference built upon the standards and recommendations of the 2012 conference to expand the strategies for integrating spiritual care throughout healthcare systems rather than focusing solely on palliative care. These standards and recommendations were created based upon evidence that acknowledges spiritual care as an essential component for quality health-care delivered by compassionate providers. These conferences gave credence to problems similar to those identified in this organizational case study and affirmed the study's recommendations for continued progress in the advancement of spirituality in our healthcare systems. Future initiatives stemming from these national and international conferences are to further refine standards for spiritual care and to integrate these standards in healthcare policies with the ultimate goal of creating "compassionate, person-centered" healthcare systems (Puchalski et al., 2014).

Nursing Practice

As healthcare systems seek to adapt to the legislative changes of the Affordable Healthcare Act (Patient Protection and Affordable Care Act, 2010), Medicare reimbursement based upon patient satisfaction, and regulators dictating the inclusion of spirituality care in healthcare systems, the necessity of including spirituality in the care of patients cannot be ignored. Christine Puchalski's Spiritual Care Implementation Model addressed in this study, was also discussed at the 2009 national consensus conference, and has been supported through various healthcare organizations in the United States. It has been embraced by the National Voluntary Consensus Standards for Palliative and End-of-life Care and implemented in practice in a variety of healthcare systems (Puchalski et al., 2014).

While this model was described in Chapter 2 and integrated into Drury's Compilation of Existing Frameworks, I want to again review this model in terms of implications for practice, acknowledging its ongoing refinement, growing acceptance as an effective model for the provision of spiritual care, not only in palliative care but also in other specialties, and its potential for filling the gaps identified in this specific case study, and, indeed, the "hole" in holistic care.

The Spiritual Care Implementation Model describes a specific process for spiritual screening, completing a spiritual history, spiritual assessment, developing a treatment plan, evaluating the outcomes of the plan, discharge planning, and follow-up. It outlines the roles of each healthcare professional on the interdisciplinary team involved in the spiritual care of hospitalized patients including physicians, nurses, social workers, and chaplains. A board-certified chaplain would be responsible for conducting the spiritual assessment and guiding the interdisciplinary team in the spiritual diagnosis and treatment plan (Puchalski et al.,

2009). If a board-certified chaplain is not available, an expert spiritual care provider would be sought. Due to the small pastoral care department in this study, there would likely be a need for additional chaplains. If the addition of another chaplain is not an option, the facility may consider developing a job description that includes expected qualifications for expert spiritual care providers, use of volunteer ministers from the community, or tweaking the model to meet the needs of the institution.

In the case organization, interdisciplinary communication through patient care huddles already exists within the institution, so the only needed change would be the inclusion of the chaplain or expert spiritual care provider to address the spiritual needs of patients. Collaboration among healthcare team members is a familiar concept, but how often is it applied to spiritual care, and how often are various healthcare professionals educated to fill the “first responder” role for addressing the spiritual needs of patients? According to Puchalski et al.’s model (2009), each member of the team should be educated in the provision of spiritual care, be culturally and spiritually competent, be trained and able to provide compassionate presence and active listening, and be viewed as a valuable asset to the team. The interdisciplinary team continues to be involved in the implementation, ongoing assessment, revisions, and follow-up of the treatment plan. The model indicates that documentation of spiritual care must be included in the patient’s clinical record.

Education

“Knowing is not enough; we must apply. Willing is not enough; we must do.” – Goeth

Lack of training and education is a critical barrier to addressing the spiritual needs of patients as an element of holistic care of the dying patient. The literature substantiates the existence of a spiritual dimension to nursing, and nurses confirm that they have a

responsibility to address the spiritual needs of their patients. However, like any other fundamental role in nursing, training and education are necessary for nurses to truly engage in the role of spiritual caregiver in the delivery of holistic care (Lewinson, McSherry, & Kevern, 2015).

As life expectancy increases, so do the number of people living with chronic and debilitating illness. The next generation of nurses must possess the knowledge and skills necessary to help patients manage the symptoms of chronic, serious, and life-threatening illness, and to renegotiate the meaning and purpose of their lives as they cope with the biophysical, psychosocial, and spiritual changes that occur as the disease progresses (Ferrell, Malloy, Mazanec, & Virani, 2016). These nurses must demonstrate an attitude of caring and compassion, while communicating effectively with patient, families, and healthcare professionals from the time they are first introduced through the families' bereavement period. For the past couple of years, the End-of-Life Nursing Education Consortium (ELNEC) has made great strides in improving the quality of patient care for critically ill patients and their families.

In October 2015, nursing faculty and experts in palliative care assembled to modify the recommendations and guidelines in the original American Association of Colleges of Nursing (AACN) document, *Peaceful Death: Recommended Competencies and Curriculum Guidelines for End-of-Life Nursing Care*, that has directed the preparation of nursing students in their provision of holistic end-of-life care, including spiritual care, for patients and families since 1998 (Ferrell et al., 2016). The revised competencies and recommendations for educating nursing students in the delivery of palliative care were officially accepted by the board of directors of AACN in February 2016. The resulting

document from the February 2016 *Palliative Competencies and Recommendations for Educating Undergraduate Nursing Students* (CARES) includes: 1) a brief history about the palliative care competencies that all graduate nursing students ought to attain throughout their nursing education, 2) recommendations for incorporating the palliative care content into undergraduate nursing curricula throughout the United States, and 3) description of the parallels between the competencies and the *Essentials of Baccalaureate Education for Nursing Practice* (AACN, 2008).

According to nursing faculty, lack of time for developing courses and formulating lesson plans and materials, ongoing academic demands, and lack of knowledge and experience in palliative care hinder the provision of nursing education on delivery of quality palliative care (Institute of Medicine, 2015). A grant through Cambia Health Foundation is funding ELNEC curriculum development that will provide on-line undergraduate education that is vital to improving palliative care for patients and families. The palliative care curriculum is expected to be released in January 2017 and can be solely online or implemented in a face-to-face or blended format, thus offering a variety of options for providing palliative care education to undergraduate nurses in nursing schools across the nation (Ferrell et al., 2016). Through the incorporation of this nationwide curriculum, for nursing education in palliative care, patients who are experiencing critical, life-threatening advanced disease and their families can be assured that nurses will be competent and compassionate in providing holistic care for them during the most life-altering journey of their lifetime.

Research

When comparing this case study to the recommendations from the 2013 international conference, *On Improving the Spiritual Dimension of Whole Person Care: The Transformational Role of Compassion, Love and Forgiveness in Healthcare*, it is reassuring that a model on organizational structure for providing holistic care does exist (Puchalski et al., 2014). Research on the recommendations and model that were modified and established through the 2013 conference is ongoing. Healthcare systems such as the one represented in this case study need to embrace the benefits of spiritual care for its institution and patient populations. In order to gain the attention of healthcare systems, research that relates to the costs of spiritual care as compared to the monetary benefits will likely be necessary for healthcare administrators to take the spiritual care of patients seriously enough to incorporate the recommendations of national and international experts.

Koenig (2014) planned to conduct a pilot study entitled, “Integrating Spirituality into Patient Care” that would establish spiritual care teams to identify and address the spiritual needs patients experiencing spiritual distress in an outpatient physician practice owned by a substantial Protestant healthcare organization in the U.S. The goal of this project was to develop a faith-based model that could be implemented in both outpatient and inpatient settings that would be cost-effective, improve quality of patient care, and promote job satisfaction among healthcare professionals. This pilot project could support another option for an organizational structure that supports the delivery of spiritual care to patients and their families. However, as a faith-based model, the association with religion would need to be evaluated to determine if the model could be applied to spirituality as it is defined by the 2013 international consensus and other sources that view spirituality as a much broader

concept in comparison with religion. At this time, there is no literature discussing the findings from the pilot study, *Integrating Spirituality into Patient Care*. Additional research could take this model one step further by looking at how it could be incorporated into non-denominational healthcare systems.

As the ELNEC curriculum is introduced, future research will be crucial for determining the impact of the curriculum on spiritual assessment and response to spiritual distress in holistic palliative care across the lifespan and in a variety of healthcare settings. Furthermore, satisfaction with the curriculum by student nurses and nursing faculty could provide information for ongoing improvements and advancements of the curriculum as well as the feasibility for expanding the educational program to other healthcare professionals who are key to the delivery of holistic care to patients who are experiencing a chronic, life-threatening or terminal illness and their families. Because nurses currently have a leading role in establishing a holistic plan of care for dying patients, the necessity of palliative care education and ongoing training that includes addressing the spiritual needs is imperative for dying patients who are experiencing spiritual distress, to experience peace and a strong connection to whatever and whoever gives them hope, meaning, and purpose.

Challenges and Limitations

In this study the researcher was unable to observe actual communication between healthcare professionals and patients in assessing and addressing spiritual distress. This aspect of the potential study was not well accepted by the research committee at the hospital who reviewed the proposal, related to HIPAA concerns, likely due to minimal experience with research conducted at the facility. This research committee was recently created, and compared to large metropolitan hospitals, this facility is less accustomed to

research requests. While this limitation made it difficult to directly identify existing spiritual needs that were being missed, this first step in identifying what happens from the organizational standpoint provides an excellent baseline for identifying and conducting further studies which can involve patients and their families. It is also an appropriate scope of study within the limitation of time and resources for this dissertation research.

Since there was a relatively small percentage of total nurses in the hospital who were interviewed in this study, there was a possibility of not reaching saturation of information. The initial plan was to interview three or four registered nurses from each of the four proposed units. Changes within the hospital included budgetary issues resulting in cutting the weekend option program throughout the hospital, increase in staff turnover, poor morale, and various other issues. This resulted in difficulty recruiting a higher number of nurse participants. However, the minimal number of participants established as the goal for this study was attained, and a considerable amount of redundancy was noted among the participants' responses.

Lastly, in the study the pastoral care department consisted of a total of three chaplains: two full-time chaplains and one part-time chaplain. One of the full-time chaplains serves as the director. All chaplains in the department were interviewed. One question in the interview of chaplains addressed the small department size and its effect on the spiritual care of patients – especially those who are terminally ill.

Conclusion

While this case study was limited to one healthcare facility, the findings were expected based upon the literature related to barriers associated with the provision of holistic care, especially that of spiritual care to dying patients and their families. Healthcare

professionals indicate increased interest and knowledge regarding the benefits of spiritual care to their patients as compared to what has been found in the past. However, without the organizational structure and support for healthcare professionals in the provision of spiritual care, the likelihood of patients experiencing holistic care will remain sporadic at best. The ongoing research, recommendations, policy changes, and educational resources may facilitate healthcare professional understanding and awareness of potential needs for spiritual care at end-of-life. An ultimate patient care outcome is to help those who are ending their journey on this earth to know that their life had meaning and purpose and that the connections they have shared with their loved ones will never be forgotten.

APPENDIX A

SPIRITUAL CARE IMPLEMENTATION MODELS

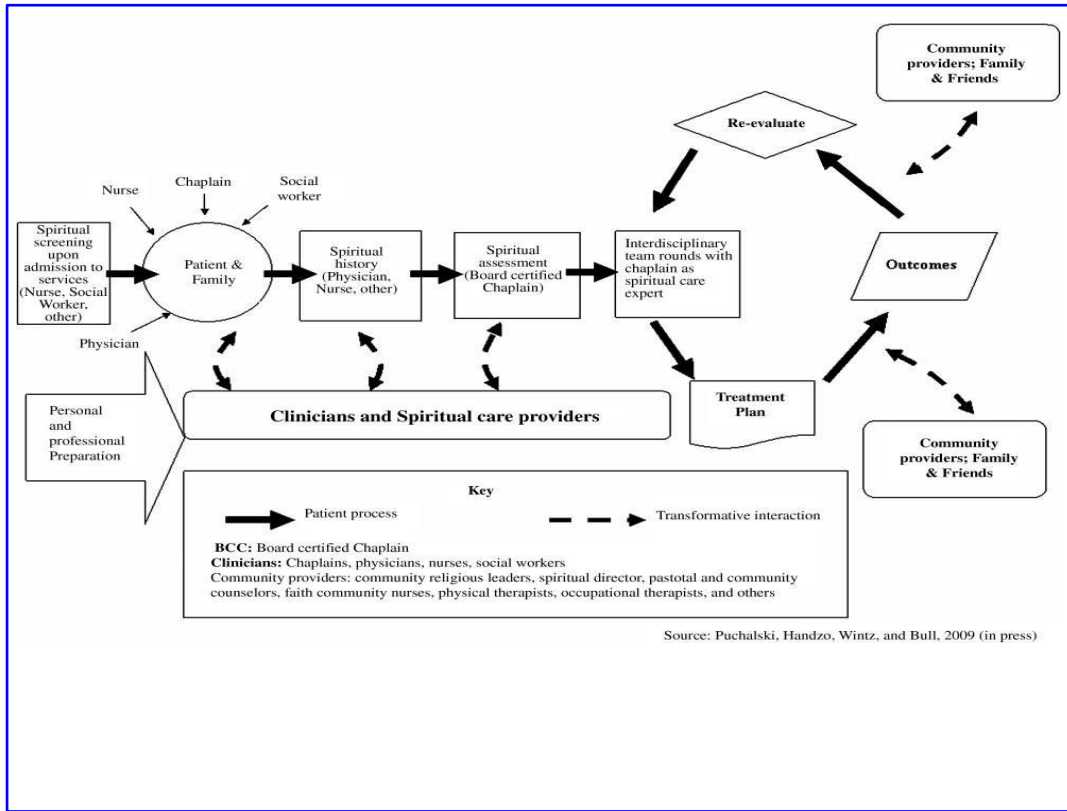


Figure 1. Inpatient spiritual care implementation model

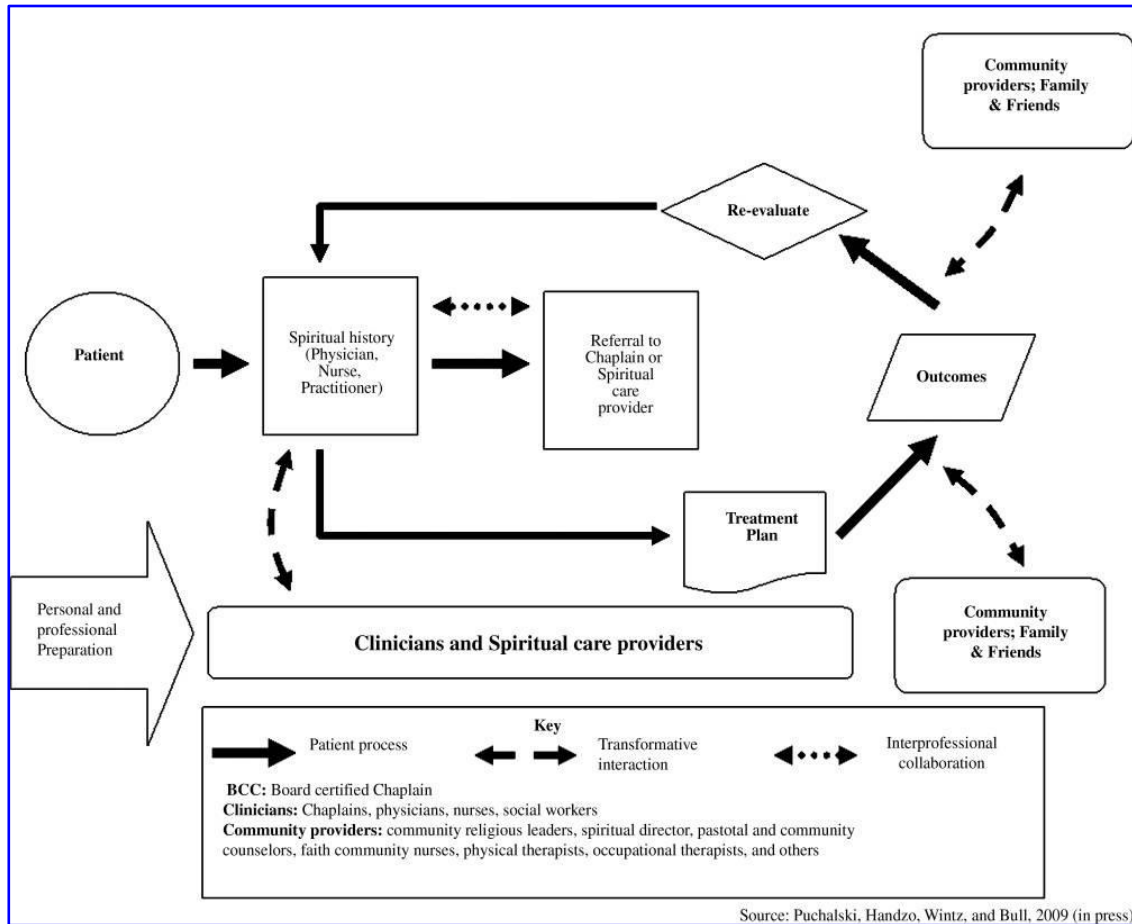


Figure 2. Outpatient spiritual care implementation model

APPENDIX B
LETTER OF SUPPORT



July 23, 2014

To Whom It May Concern:

I am writing as the Chairman of the Institutional Review Board at Southeast Hospital in Cape Girardeau, Missouri to express support, as well as the support of the Southeast Health organization, for the proposed research of Connie Drury. Addressing spiritual needs in healthcare is an area worthwhile for research because of the positive effects on healing and satisfaction of patients and families – especially during the dying process.

Southeast Hospital is a 266 bed regional medical center serving the needs of southeast Missouri and southern Illinois. The hospital is Joint Commission accredited and includes services such as a heart hospital, cancer center, brain and spine center, center for women and children services, emergency services, orthopedics and joint replacement center, breast and diagnostic center, home health, and regional care services. In addition, hospice services are offered through Southeast. The multifaceted services offered by Southeast make it an optimal environment for exploring the spiritual needs of terminally ill patients.

In my position at Southeast, I serve as the Vice President of Physician Services/Chief Medical Officer and currently serve as the Chairman of the Institutional Review Board. I received my Doctor of Osteopathy degree from the University of Health Sciences – College of Osteopathic Medicine in Kansas City, Missouri and am board certified by the American Board of Internal Medicine in Infectious Diseases and Internal Medicine.

I have reviewed Ms. Drury's proposed research and approve the study. Southeast will work with Ms. Drury in order to facilitate her research proposal under the direction and supervision of the UMKC Institutional Review Board.

Sincerely,

A handwritten signature in black ink, appearing to read "D. Shoemaker".

D. Matthew Shoemaker, DO
Vice President of Physician Practices/Chief Medical Officer
SoutheastHEALTH

1701 Lacey Street • Cape Girardeau, Missouri 63701
(573) 334-4822 • www.SEhealth.org

APPENDIX C

CONSENT FOR PARTICIPATION IN A RESEARCH STUDY

Discomfort in Addressing Spiritual Needs: A Hospital-Wide Exploration into the Hole in Holistic Care

Principle Investigator: Connie Drury RN, PhD(c)

Request to Participate

You are being asked to take part in a research study. This study is being conducted at SoutheastHealth, Cape Girardeau, Missouri.

The researcher in charge of this study is Connie Drury. While the study will be run by her, other qualified persons who work with her may act for her.

You are being asked to take part in this research study because you are a registered nurse, chaplain or social worker who has been involved in direct patient care at SoutheastHealth. This document is called a consent form. Please read this consent form carefully and take your time making your decision. The researcher or study staff will go over this consent form with you. Ask her to explain anything that you do not understand. Please read the information below and ask questions about anything that you do not understand before making your decision. This consent form explains what to expect, the risks, discomforts and benefits, if any, if you consent to the study.

Background

Spirituality, with its diverse definitions, is accepted as playing a vital role in the well-being of many people. Nurses and other healthcare providers are now called on to include the spiritual dimension as relevant and within their scope of practice. Nursing, as a discipline focused on human experiences of all kinds, must overcome perceived barriers and attend to the spiritual as well as physical, emotional, social and other dimensions that relate to health and well-being.

You are being asked to take part in this research study because you are a registered nurse, chaplain or social worker who has been involved in direct patient care at SoutheastHealth for at least one year and have experienced the death of at least one patient. The number of subjects to be interviewed from each department are as follows: (a) three social workers; (b) three chaplains (this accounts for the whole department); (c) twelve to sixteen registered nurses, including three to four nurses from each of the following four units: ICU, medical-surgical area, inpatient oncology, and cardiac progressive.

Research Purpose

The purpose of this research is to explore hospital procedures and roles nurses, chaplains, and social workers in defining, identifying, and addressing the spiritual needs of dying patients. This study aims to do that which has not yet been done, that is, look at the entire hospital system to identify professional roles, processes, communication, and language of spiritual care when addressing spiritual distress in dying patients and their families.

Procedure

If you agree to volunteer for this study, we will ask you to participate in a one interview lasting approximately 30 minutes to one hour. You will be asked several questions about your role in providing spiritual care to terminally ill patients. With your permission, the researcher will audiotape the interview so that your responses may be accurately transcribed. You will not be asked to state your name while the interview is being audiotaped. An identification number will be assigned to you and only the researcher will know the identity of each subject in relation to audiotaped interviews, transcribed interview documents, and data analysis documents. The researcher may contact you when the data is analyzed to assure that she understood your responses to the interview questions during the interview.

Participation and Withdrawal

Participation in this study is completely voluntary. You may choose to refrain from answering any question during the interview and may withdraw from the study at any time without penalty. Simply tell the researcher of your desire to withdrawal and no questions will be asked.

Risks

The potential for any risk from participating in this study are minimal. This means that the risks of taking part in this research study are not expected to be more than the risks in your daily life. There may be something in a report of the study that could be potentially identify as your input, due to the small number of people in each unit/department being interviewed. There are no other risks to you if you choose to take part in the study.

Benefits

There may be no benefit from participating in this study. This is an opportunity for you to share your thoughts and stories regarding spiritual care in dying patients.

Fees and Expenses

There are no costs associated with this study.

Confidentiality

While we will do our best to keep the information you share with us confidential. It cannot be absolutely guaranteed. Individuals from the University of Missouri-Kansas City

Institutional Review Board (a committee that reviews and approves research studies), Research Protections Program and Federal regulatory agencies may look at records related to this study to make sure we are doing proper, safe research and protecting human subjects. The results of this research may be published or presented to others. You will not be named in any reports of the results.

You will not be asked to state your name while the interview is being audiotaped. Your actual identity will not be revealed at any time. The individual who transcribes your interview responses know you only by your personal identification number. Once data analysis is complete, the audiotaped interview will be erased. The transcript with your identification number will be kept until research is complete and the dissertation manuscript has been accepted.

Any information pertaining to you will be identified by assigned personal identification number rather than your name. Connie will be the only researcher to have documentation that reveals your name and the identification number assigned to you. This identification list, recordings and transcripts will be maintained in a locked cabinet for which only Connie has access. Once all transcripts have been reviewed for accuracy, the list will destroyed.

After the study is complete, information from the study may be used for future professional journal articles or presentations. Your name and any information that would identify you will not be included in any publication manuscript or presentation.

Contact Information

You should contact the Office of University of Missouri-Kansas City's Social Sciences Institutional Review Board at (816)235-5927 if you have any questions, concerns or complaints about your rights as a research subject. You may call the researcher, Connie Drury at (573)264-4331 if you have any questions or if any problems arise regarding this study.

Voluntary Participation

Taking part in this research study is voluntary. If you choose to be in the study, you are free to stop participating at any time and for any reason. If you choose not to be in the study or decide to stop participating, your decision will not affect any care or benefits you are entitled to. The researchers may stop the study or take you out of the study at any time if they decide it is in your best interest to do so. They may do this for medical or administrative reasons or if you no longer meet the study criteria. You will be told of any important findings developed during the course of this research.

You have read the consent form or it has been read to me. You have been told why this research is being done and what will happen if you take part in the study, including the risks and benefits. You have had the chance to ask questions and you may ask questions at any time in the future by calling Connie Drury at (573)264-4331. By signing the consent form,

you volunteer and consent to take part in the research study. Study staff will give you a copy of the consent form.

Signature (Volunteer Subject)

Date

Printed Name (Volunteer Subject)

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent

APPENDIX D
INTERVIEW GUIDE

Demographical data:

- What is your age?
- How many years have you been practicing in your current role?
- What is your educational background including certifications?
- Describe your ethnic background.
- Describe your religious affiliation.
- How many patient deaths have you experienced?

Defining spiritual needs:

- How do you define spirituality?

Identifying spiritual distress:

- Describe indicators of spiritual distress.

Identifying spiritual needs:

- How are spiritual needs of dying patients and their families identified within the hospital?
- Explain your role in identifying needs of dying patients and their families.

Referral of spiritual needs:

- What is the process for referral?

Addressing spiritual needs:

- How do you address spiritual needs of dying patients and their families?
- What interventions have you used to address the spiritual needs of dying patients and their families?
- What do you perceive as the role of nurses in the delivery of spiritual care to dying patients and their families? Hospitalists? Social workers?
- Who is responsible for the teaching and implementing advanced directives?
- What has most prepared you for addressing spiritual needs of dying patients and their families?
- What problems have you identified in how spiritual care is delivered within the hospital?
- On a scale of 0 to 10, with 0 being very uncomfortable and 10 being very comfortable, how would you rate your comfort level in addressing the spiritual needs of a terminally ill patient?

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VITA

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