SPIRITUAL PAIN, PHYSICAL PAIN, AND EXISTENTIAL WELL-BEING
IN ADULTS WITH ADVANCED CANCER

by

Mary Kathleen Hook

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DEDICATION

To my family, thank you for your never-ending encouragement, for providing snacks while I studied, and rejoicing with me through the process. To my husband, for believing nothing is impossible with God. To my sons, may you dream and achieve above and beyond all you can think or imagine. To my parents, thank you for valuing education and encouraging me every step of the way. To my sisters and their families, thank you for your unconditional support and encouragement along the way.

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ABSTRACT

Nursing care of patients with advanced cancer is challenging because it touches many dimensions of a patient’s life. The study of spiritual pain is relatively new although potentially very important in understanding how to help patients with advanced cancer achieve a sense of well-being. The purpose of this pilot study was to increase scientific knowledge from the participants’ perspectives about experiences of spiritual pain and physical pain, and identify correlates of well-being from the participants’ own perspectives in the context of advanced cancer.

Four research questions were examined in this study:

1. What is the relationship between physical pain and spiritual pain, as perceived by participants who have advanced cancer?
2. What is the relationship between spiritual pain and existential well-being, as perceived by participants who have advanced cancer?
3. What is the relationship between spiritual pain and physical pain in the context of the demographic and health-related variables of age, gender, years of education, and months since diagnosis?
4. What factors do participants with advanced cancer identify as important to their existential well-being?

A descriptive correlational design was used to study the research questions in a convenience sample of 30 adult participants from an outpatient oncology clinic in Southern Arizona. Quantitative data were obtained through interviews using the Providence Saint Vincent Medical Center Pastoral staff’s Spiritual Pain Assessment Tool and Paloutzian and Ellison’s...
(2009) Existential Well-Being Scale, and a Physical Pain Rating scale along with a demographic and health-related form. Qualitative data were also obtained from the participants.

Descriptive, correlational, and content analyses generated results of a significant relationship between Spiritual Pain and Existential Well-Being, and a non-significant relationship between Physical Pain and Spiritual Pain. The following themes (with the first three being most frequently mentioned) were identified as important to the participants’ well-being during their experience of advanced cancer: Meaningful activity, family and friends, and spiritual aspects, followed by health/nutrition, symptom management, and finances. Results warrant continued research into spiritual pain as it relates to existential well-being in persons with advanced cancer.
CHAPTER ONE:

STATEMENT OF THE PROBLEM

Over 1.5 million people in the United States were diagnosed with cancer in 2010 and over one half million people died from cancer in the United States in 2010 according to the American Cancer Society (2010). In other words, over 1500 people die from cancer related deaths every day in the United States (American Cancer Society, 2010). Furthermore, there are over 11.4 million cancer survivors in the United States (“American Cancer Society). Many of these cancer survivors are living with advanced or incurable cancer because of improved treatments (Rose et al., 2009).

Pain or unpleasant symptoms are prevalent in 70% to 90% of people with advanced cancer (Brink-Huis, van Achterberg, & Schoonhoven, 2008; W. Duggleby, 2002; Stromgren et al., 2004; Swarm et al., 2009). The pain in advanced cancer is multifaceted, whether physical, emotional, social, or spiritual and is one of the most feared symptoms of cancer patients (Brink-Huis, van Achterberg, & Schoonhoven, 2008; Stromgren et al., 2004). Spiritual considerations in the realm of advanced cancer are especially important because patients facing life-threatening illness are more prone to disclose aspects of their own spirituality (Surbone & Baider, 2010). Spiritual pain in particular has not been studied adequately but may be a correlate or contributor to the overall pain experience in patients with advanced cancer, as well as increase risk of emotional stress and suicide (McGrath, 2003). Therefore, the focus of this study was spiritual pain and its relationship to physical pain and existential well-being in adults with advanced cancer.
Background and Significance

Advanced cancer is challenging to treat as patients can have a myriad of symptoms, whether caused by the cancer, cancer treatment side effects, or a combination of these events. Pain is included in these symptoms and is one of the most feared cancer symptoms (Brink-Huis, van Achterberg, & Schoonhoven, 2008; Stromgren et al., 2004). Research findings consistently indicate that patients with advanced cancer have better outcomes or longer survival when pain is well controlled (Koenig, 2004; Sulmasy, 2009; Temel et al., 2010).

The National Cancer Institute defines advanced cancer as cancer that has spread to other sites in the body where treatment is not curative (National Cancer Institute: Dictionary of Cancer Terms, 2010). Long-term survival is based on the stage of cancer at the time of diagnosis. For early stage cancer, five years is considered long term survival while two years or longer is considered long term survival for those whose initial diagnosis is that of advanced cancer (Rose et al., 2009).

The concept of pain is multifaceted and includes physical, emotional, and spiritual aspects of pain as the individual experiences it. Physical pain management is accomplished through use of analgesic medications, adjuvant medications, treatment of the cancer, surgical or procedural interventions, and radiation therapies. In addition to management of the physical pain, patients with advanced cancer may have emotional pain secondary to the cancer diagnosis, loss of independence, consideration of death, or inability to perform usual functions within a stable family or support structure (Otis-Green, Sherman, Perez, & Baird, 2002). Often the emotional pain, including depression and anxiety, can be treated pharmacologically. The literature indicates that people facing end of life may also experience spiritual pain distinct from the emotional pain.
of depression or anxiety, which requires a different nursing care approach (Mako, Galek, & Poppito, 2006). When all these aspects of pain are addressed in patients with advanced cancer, outcomes improve (Otis-Green, Sherman, Perez, & Baird, 2002).

Clinically, there are brief and accurate tools to measure physical or emotional pain but clinicians’ knowledge and measures of spiritual pain are not as well developed. The study of this patient experience has the potential to add new knowledge about spiritual pain as well as other potential correlates of well-being among patients who have advanced cancer care. This information may help clinicians to care for patients and make appropriate referrals. If spiritual pain is identified and validated with the patient, the nurse and patient can work together to address this problem, and the nurse may also make referrals to other professionals such as chaplains, social workers, clergy or specially trained spiritual care teams (Surbone & Baider, 2010). At the least, the nurse can use this knowledge to build their nurse-patient relationship through which patient needs are better assessed and treated (Mehta & Chan, 2008; Sutton, Porter, & Keefe, 2002).

Nursing care of patients has included physical, emotional, and spiritual aspects of care since the time of Florence Nightingale, and this continues to be a goal of nursing. The diagnosis of cancer, particularly advanced cancer, often causes people to contemplate their own death and meaning of life and can lead to spiritual distress or crisis, which in turn can have an unfavorable effect on mental or physical health (Anandarajah & Hight, 2001). Furthermore, research has shown that there is more spiritual pain in cancer survivors when compared with those patients with advanced cancer who are enrolled in hospice at the end of life (McGrath, 2003). The notable difference is that hospice treatment addresses the physical, emotional and spiritual needs
of the patient from the time of admission into hospice while traditional cancer treatment, whether palliative or curative, focuses on treating the disease (Murray, 2010) and often does not address the emotional and spiritual changes that are realized with the diagnosis of cancer.

The National Comprehensive Cancer Network (NCCN) has deemed the management of pain associated with cancer as highly significant and subsequently developed the NCCN supportive care guidelines. These NCCN supportive care guidelines include specific guides for pain, palliative care, and distress (National Comprehensive Cancer Network, 2010). These supportive care guidelines are in addition to disease specific guidelines that the NCCN has developed. Multidisciplinary teams developed these NCCN guidelines. These multidisciplinary teams included primarily physicians from various specialty areas, but also nurses, advanced practice nurses, social workers and others. Medicine has recently recognized the importance of including physical, social, emotional, and spiritual aspects of patient care (Anandarajah & Hight, 2001), while nursing has included holistic patient care since the time of Florence Nightingale (Buck, 2006).

Spiritual pain has been associated with negative health outcomes. In addition, spiritual pain may exacerbate or be masked by physical pain. A recent study of patients diagnosed with stage IV nonsmall cell lung cancer showed that those who were treated with simultaneous palliative care and standard care lived longer, with improvement of quality of life and mood, compared with those participants who received standard care alone (Temel et al., 2010). The literature reveals less spiritual pain amongst those with advanced cancer in hospice care compared with survivors with hematologic malignancy, despite advancing cancer (McGrath, 2003). This may be related to the consideration of physical, psychosocial, and spiritual needs by
an interdisciplinary team that holds a holistic perspective of treatment. In the future, development of language and minimum competencies for spiritual health care may contribute to the paradigm of spiritual care in nursing.

The literature suggests that 94% of hospitalized patients believe that spiritual health is as important as physical health and 77% of those agree that spiritual assessment should be part of their medical care (Anandarajah & Hight, 2001). In the outpatient setting a study showed that 40% of patients wanted physicians to discuss pertinent religious issues along with their medical care but only 11% included religious discussions on a regular basis (Anandarajah & Hight, 2001). Other studies have shown a positive association between a religious commitment and illness prevention, and the ability to cope with illness as well as illness recovery (Anandarajah & Hight, 2001). The assessment of spirituality is appropriate for both religious and non-religious persons, but for those with religious preferences, the assessment must be done in the context of their religion (Sulmasy, 2009b).

Regardless of whether spirituality is as important as physical well-being - and many consider it as important - examining the relationship between physical and spiritual pain at end of life is particularly important given both the frequency and complexity of pain in patients with advanced cancer. Spiritual pain may exacerbate, mask, or masquerade as physical pain. Whereas relief of physical pain generally enhances well being or quality of life, in some persons the relief of physical pain may bring on acute awareness of spiritual pain (Mako, Galek, & Poppito, 2006). In addition, Mehta and Chan (2008) suggested that unresolved spiritual issues can contribute to decreased response to pharmacologic treatment of physical pain, raising the question of whether spiritual pain exacerbates or masquerades as physical pain.
In sum, the interest in spiritual care in healthcare is on the rise and the number of articles published on this topic has been rising over the past thirty years (Sessanna, Finnell, & Jezewski, 2007; Swinton, 2006). The identification of spiritual pain can be done through spiritual assessment but a gap has been noted between spiritual assessment and the application of interventions to address those findings (Baldacchino, 2006; van Leeuwen, Tiesinga, Post, & Jochemsen, 2006). In addition, there are many gaps in knowledge, including definitions of spiritual pain, distress, or suffering; optimal interventions for spiritual pain; and the interrelationships between physical and psycho-spiritual pain. Spiritual pain can contribute to negative impacts on healthcare but clarification is needed in this area to provide guidance for optimal spiritual care, including the relief of spiritual pain (Baldacchino, 2006; Lundmark, 2006; van Leeuwen, Tiesinga, Post, & Jochemsen, 2006).

Purpose

The purpose of this study was to: describe the relationships among spiritual pain, physical pain, and existential well-being in patients with advanced cancer in the context of demographic and health-related variables, and to explore factors that participants with advanced cancer report are important to or influence their well-being.

Theoretical Framework

The multifaceted conceptualization of pain in this study as depicted in Figure 1 is framed within and congruent with a multi-dimensional view of well-being and quality of life, and with the concept of Total Pain. Ferrell and Hassey Dow (1997) examined factors that affect quality of life in survivors of cancer and those with advanced disease in the hospice setting. Their concerns were multi-dimensional, related to four categories: physical, psychological, social (family,
marital, children, and work), and spiritual aspects of a person’s life (Ferrell & Hassey Dow, 1997). These aspects are consistent with the concept of Total Pain as coined by Dame Cicely Saunders (Mehta & Chan, 2008; Saunders, 2000), which provided a conceptual framework for the study of spiritual pain in this study.

The word pain generally refers to physical pain that is associated with tissue damage (Musi, 2003) but this study will use the term *pain* in a multifaceted manner to include physical, emotional, social, and/or spiritual pain. This conceptualization of pain along with results of empirical studies done to date provide a basis for understanding pain for this study, and for proposing a possible relationship between physical pain and spiritual pain, and an inverse relationship between spiritual pain and existential well-being.

![Conceptual Model of Total Pain Experience in Advanced Cancer](image-url)

**FIGURE 1.** Conceptual Model of Total Pain Experience in Advanced Cancer
The pain of advanced cancer is multifaceted and may arise from a variety of physical mechanisms, including nerve pain, bony pain, and visceral pain, all of which can be acute or chronic. Of those with advanced cancer who experience pain, 94% report moderate to severe pain that can diminish quality of life (King & Porreca, 2010). Also, chronic pain is common in 70% to 90% of advanced cancer patients (Brink-Huis, van Achterberg, & Schoonhoven, 2008; Wendy Duggleby, 2002; Stromgren et al., 2004).

The pain of advanced cancer can be controlled 85 to 95% of the time but the main focus in practice has been on the relief of physical pain and not the other factors that can and do contribute the overall pain in patients with advanced cancer (Mehta & Chan, 2008). Beyond the multiple sources of physical pain, the individual may experience additional sources of pain. Often patients do not discern the cause of pain and only verbalize that they hurt.

The total pain framework suggests that many aspects of pain, including the physical, social, psychological, and spiritual, can occur in advanced cancer (Saunders, 2000). Spiritual pain in particular, may be part of the individual’s quest for meaning and sense of well-being in the presence of physical pain and other difficulties faced in advanced cancer.

**Spiritual Pain**

Spiritual pain is addressed in the literature using various terms, including, spiritual pain, spiritual distress, spiritual crisis, and spiritual suffering. The term, spiritual pain, is used in this study. *Spiritual pain* is defined in terms of a diminished or lack of the following human experiences: sense of meaning or purpose in one’s life, sense of connectedness to someone or something, sense of forgiveness of self or others, and hope (Groves & Klauser, 2009). Spiritual pain includes one or more of the following four qualities: loss of meaning, inability to forgive,
loss of relatedness, and hopelessness (Groves & Klauser, 2009). Each of these qualities of
spiritual pain can be analyzed further and defined as meaning or who am I; forgiveness or letting
go of the hurts or soul wounds because we have harmed by cheating, lying, abuse, or having our
expectations dashed; relatedness or having relationship or connectedness and trust with someone;
and hopelessness or loss of the ability to see what is life-giving (Groves & Klauser).

**Spiritual Pain as Related to Other Pain Experiences**

In a study by Mako, Galek, and Poppito (2006), a correlation between spiritual and
physical pain was not found but there was a significant correlation between spiritual pain and
morphine use. In addition, patients’ average pain score was 6 out of 10, which raises the question
of whether the pain score was an indicator of physical pain or something more. Some patients
describe their spiritual pain in terms of physical or emotional experiences and may have a
difficult time differentiating the cause of their pain. For example, Mako, Galek, and Poppito
(2006) discussed the significant overlap between spiritual pain and depression and that
depression can be differentiated from spiritual pain. They suggested viewing pain management
broadly to ascertain the source of pain and whether the cause is biological, emotional, or spiritual
and that each one must be addressed as part of the pain assessment.

Millspaugh (2005) explains that some people try to avoid acknowledging spiritual
suffering or pain and are unaware that acknowledgment of such suffering may facilitate
connection with their inner self, others around them, or the transcendent, or otherwise may
enhance well-being. Mehta and Chan (2008) reported on a case of a patient with advanced cancer
who scored his pain 5 out of 10 with the complaint of a deep pain in his chest. The patient was
treated pharmacologically with narcotic analgesia and subsequently reported total relief from the
physical pain in his chest but he continued to rate his pain at 5 out of 10 on the pain rating scale, prompting further assessment of the patient’s pain. The assessment revealed several sources of underlying pain: Social pain as evidenced by role change from head of household to someone to be cared for; psychological pain in the anguish he felt leaving his two young daughters whose mother had also died; psychological pain over the burden that it placed on his sister who had already assumed most of the care for both her brother who was dying from cancer and his daughters; and spiritual pain because of loss of meaning and purpose in his life, and a feeling of being a burden on others. How the relationships had changed and hope were not discussed. The pain this patient felt is a good example of the complex nature of pain and the potential relationships between various facets of pain in advanced cancer. The literature reveals a relationship between psychological/emotional distress and physical pain but a causal relationship has not been identified (Sutton, Porter, & Keefe, 2002).

**Spiritual Pain and Existential Suffering/Well-being**

Spiritual pain may be related to the concept of existential suffering or alternatively, existential well-being. Chaplains, palliative care nurses, physicians, and pain management physicians identified a connection between existential suffering and pain (Strang, Strang, Hultborn, & Arner, 2004). The investigators recommended distinguishing between the concepts of bodily pain and existential suffering, for better understanding (Strang, Strang, Hultborn, & Arner, 2004).

Spiritual Pain may or may not include the concept of “religious pain.” Some suffering experienced by patients at end of life has been associated with religious pain. It has been suggested that some patients expect suffering for various reasons and may as a result have
Satterly (2001) defines religious pain as “a condition in which a patient is feeling guilty over some violation of the moral codes and values of his or her religious tradition. Patients in religious pain believe that God is keenly disappointed in their past or present behaviors, actions, or thoughts” (p. 4). Religious pain may not make sense to others because it is highly individual and subjective, based upon individuals’ interpretations or self-judgments against the backdrop of their own religions traditions, values, and beliefs.

Religious pain is expressed through guilt, which is coupled with punishment or the anticipation of punishment, which most often is expressed as fear. In patients at end-of-life, this fear may be magnified and be a source of intense anxiety as the patient comes closer to death. Sometimes patients believe they can avoid punishment later if they suffer enough in the present even to the point of refusing pain medication. Religious pain requires the use of an interdisciplinary team. Understanding a person’s religious foundation may help in finding a religious counselor who can address religious pain through the use of rituals, teachings, and traditions familiar or reassuring to the individual patient (Satterly, 2001).

Well-being and Dimensions of Pain: Physical, Emotional, Social, and Spiritual

The multidimensional view of well-being may include physical, emotional, social and spiritual pain. Control of physical pain enhances well-being through improved outcomes and longer survival in those with advanced cancer (Koenig, 2004; Sulmasy, 2009; Temel et al., 2010). Emotional and social changes occur in advanced cancer and include possible loss of independence, the consideration of death, and the decreased or inability to perform usual functions within a stable family or support structure potentially impacting well-being or life satisfaction (Otis-Green, Sherman, Perez, & Baird, 2002). Spiritual pain has unfavorable effects
on physical, and emotional health (Anandarajah & Hight, 2001) that may in turn affect overall well-being. An example from McGrath (2003) indicates life satisfaction or well-being was lower in survivors of hematologic malignancy compared with those with advanced cancer enrolled in the hospice setting. Those in hospice had access to resources to address the physical, emotional, social, and spiritual aspects of their pain whereby those who survived hematologic malignancy may not have had access to those same resources. The potential relationships between these dimensions of pain and well-being are an area of interest.

**Research Questions**

In light of these studies and the conceptual framework, four research questions were identified. Examining the findings in response to these questions may contribute a beginning knowledge base about the nature and significance of the clinical problem of spiritual pain and physical pain in patients who have advanced cancer. The research questions are as follow:

1. What is the relationship between physical pain and spiritual pain, as perceived by participants who have advanced cancer?
2. What is the relationship between spiritual pain and existential well-being, as perceived by participants who have advanced cancer?
3. What is the relationship between spiritual pain and physical pain in the context of the demographic and health-related variables of age, gender, years of education, and months since diagnosis?
4. What factors do participants with advanced cancer identify as important to their well-being?
Definitions of Key Concepts

For purposes of this study, the following are definitions of key concepts in this study.

- **Spiritual pain** is defined as the loss of meaning and purpose in the here and now (Millspaugh, 2005), and includes aspects of meaning, relatedness, forgiveness and hope (Groves & Klauser, 2009). Meaning in life and life’s experiences; Relatedness or having relationship or connectedness and trust with someone; Forgiveness or letting go of the hurts or soul wounds; and Hope or having something positive to look forward to or to anticipate happening (Groves & Klauser).

- **Physical pain** is defined by the National Comprehensive Cancer Network as “a sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage p. 27,” (Pargeon & Hailey, 1999; Swarm et al., 2009). MaCaffery and Pasero’s statement that “pain is whatever the experiencing person says it is, existing whenever he says it does” p. 27 is also pertinent (Pargeon & Hailey, 1999; Vogel, Wilson, & Melvin, 2003).

- **Advanced Cancer** is defined as cancer that has spread to other places in the body and treatment is not curative (National Cancer Institute: Dictionary of Cancer Terms, 2010).

- **Existential Well-being** – this concept is used to study well-being or, alternatively, existential suffering. Existential well-being is defined as having a sense of: general well-being, of life satisfaction and purpose (Paloutzian & Ellison, 2009).

Conclusion and Significance to Advanced Practice Nursing

Spiritual care in the realm of cancer is important because these patients are facing life-threatening illness and are prone to disclose aspects of their own spirituality (Surbone & Baider,
The oncology healthcare provider is in a position to recognize spiritual needs and must remain present and available for patients, treating them in a compassionate manner while acknowledging uncertainties and hopes that come with cancer care. Acknowledging spiritual distress or pain is the first step, and referral to a qualified spiritual advisor is recommended for optimal care. Many oncology care providers feel privileged to share in the spiritual dimension of the patient’s healthcare while others believe it is best left for a chaplain or spiritual advisor. Both agree that spirituality and religiosity should not be imposed in any clinical setting (Surbone & Baider, 2010). Further research into the effects of spirituality and cancer care outcomes is warranted, as is the development of spiritual care assessment and appropriate interventions or referrals based on research findings.

The presence of a nurse at the bedside is helpful for the patient who is experiencing spiritual pain, as the nurse provides care, whether administering medications, changing a dressing, offering words of encouragement, silence, or attending to physical assessment. In addition, the advanced practice nurse has the expertise to sit on interdisciplinary teams to impact future decisions with regard to chronic pain management recommendations/algorithms, and establishment of pain relief programs, as examples of when advanced practice nurses can impact the patients we care for.
CHAPTER TWO:
REVIEW OF THE LITERATURE

This chapter will provide a critical review of empirical, conceptual, and clinical literature with regard to spiritual pain in general as well as spiritual pain in the advanced cancer population. This review will include that few studies with regard to spiritual pain have been published, the concept of spiritual pain including, the description of spiritual pain in patients with advanced cancer in hospice and those who are survivors of hematologic malignancy, application of the concepts, general information in the literature, outcomes and their possible relationship to spiritual pain, and considerations regarding quality of life and spiritual pain.

Study of Spiritual Pain

A search using CINAHL revealed three articles, while Pub Med revealed none under the specific heading spiritual pain and advanced cancer. A Japanese study acknowledged that the structure of spiritual pain has not been established scientifically (Tamura, Kikui, & Watanabe, 2006). Furthermore, spiritual pain in particular is an interest in the literature but has not been studied extensively (Strang, Strang, Hultborn, & Arner, 2004).

Multiple Definitions for Spiritual Pain

Various descriptions of spiritual pain are found across the literature. Lundmark (2006) defines spiritual pain as existential questions and religious conceptions that elicit painful feelings and thoughts while Anandarajah and Hight (2001) report that spiritual distress occurs when an individual cannot access the usual cognitive, experiential, or behavioral components of spirituality because of their present circumstances. Worsening physical and mental health can trigger spiritual distress and spiritual distress can have detrimental effects on physical and mental
health creating a vicious cycle (Anandarajah & Hight, 2001). There is no consensus with regard to the terminology or agreement on the definition for spiritual pain in the literature.

**Description of Spiritual Pain in Survivors and Hospice Patients**

McGrath (2002) conducted a qualitative research study using the phenomenological method to contribute to the development of a language for spiritual pain. This study included 12 patients who survived treatments for hematologic malignancies and revealed that spiritual pain is subjective and arises from a disconnect or break from normal or expected relationships as well as from life satisfaction. When the disconnect with relationships and life satisfaction leads to questioning the meaning of life, it becomes acutely painful and is considered spiritual pain resonating the loss of meaning in the here and now or present time (McGrath, 2002).

McGrath’s (2003) phenomenological study compared two groups of patients, those in hospice and survivors of hematologic malignancy with regard to spiritual pain. There were differences and similarities between the groups. Both the survivors and hospice patients reported painful frustrating and unjust experiences with misdiagnosis, difficulty in obtaining drugs, dealing with side effects of treatment medications, and feeling un-cared for during treatment (McGrath, 2003). Despite sharing of these difficult experiences the hospice patients did not report a disconnect with life or meaning. The study reported that the opposite of spiritual pain is satisfaction with life (McGrath, 2003). Both survivors and those enrolled in hospice reported facing loss of self, relational losses including existential losses (McGrath, 2003). The patients in the hospice were able to find meaning and connection from their life experiences while the survivors were felt challenged to make meaning for their lives while facing the great losses encountered during the treatment and effects from the treatment of their hematologic illness.
(McGrath, 2003). McGrath (2003) reported that suicidal ideation could stem from severe spiritual pain.

This study has a limitation, in that one of the goals of hospice is to prevent spiritual pain and each of the people included in the study chose this particular hospice for their end-of-life care while those survivors may not have had access to the same resources for dealing with spiritual issues. The emphasis of holistic care in the hospice setting may have contributed this difference and may bias understanding as to why such a difference occurs when patients are treated in a curative setting.

Dimensions of Pain: Physical, Psychological, and Spiritual

Mako, Galek and Poppito (2006) used a mixed methods study to differentiate spiritual, physical, psychological pain and illness; and to identify the nature of spiritual pain and interventions that relieve spiritual pain. The study was important because spiritual struggles are associated with poor physical outcomes and increased rates of mortality (Mako, Galek, & Poppito, 2006). Spiritual pain as described by the participants was divided into three categories: intrapsychic, interpersonal, and divine, that was universally experienced by the participants. The study considered the overall expression of pain that includes spiritual as well as physical pain in cancer patients. The study suggests that alleviation of physical pain in patients with advanced cancer allows the patient to differentiate physical from spiritual pain (Mako, Galek, & Poppito, 2006). This reduction of physical pain may allow the clinician to more easily assess underlying spiritual issues that contribute to pain, which can lead to a crisis of spiritual pain in some (Mako, Galek, & Poppito, 2006). The study also differentiated between depression and spiritual pain,
with the realization that depression can be treated through pharmacologic means while spiritual pain requires a different approach (Mako, Galek & Poppito, 2006).

Interventions that were associated with enhanced spiritual well-being aimed at increasing the patient's meaning and dignity for patients in end-of-life with advanced cancer (Mako, Galek, & Poppito, 2006). Examples from this study include patients’ request for prayer and religious rituals, but the majority of patients preferred spending time with healthcare professionals who would listen to their stories (Mako, Galek, & Poppito, 2006).

Furthermore, spiritual pain in people facing death affects relationships and was expressed in terms of meaninglessness, worthlessness, emptiness, loneliness, anxiety, dependence or being a burden. This study revealed that some patients’ quest is to find meaning in the spectrum of their illness, including a struggle to continue to value their sense of self (Georgesen & Dungan, 1996; Mako, Galek, & Poppito, 2006; McGrath, 2002; Strang, Strang, Hultborn, & Arner, 2004; Tamura, Kikui, & Watanabe, 2006).

Rydahl-Hansen (2005) conducted a Giorgi’s phenomenological study with the aim of describing the experience of suffering in hospital patients who have incurable cancer. The study utilized bracketing to remove as much of the researchers pre-understanding of suffering from the study to derive a pure description of the phenomenon. The findings of this study provide a general structure of the suffering phenomena through the lens of hospitalized patients with incurable cancer (Rydahl-Hansen, 2005). The components of the structure include increasing powerlessness, increasing loneliness and isolation, and the eternal unconquerable struggle to maintain or regain control. These three key interactive components are situation specific in relation to the body, consciousness, illness, death, and the cancer treatment. The researchers
found that patients did not express their suffering directly but the interview provided a way for patients to describe their suffering on their own terms (Rydahl-Hansen, 2005). The question arose as to whether participants were aware of their suffering prior to the interview because the participants often described how they experience life and the existence with advanced cancer and not necessarily through the use of the term suffering (Rydahl-Hansen, 2005).

Integrated Psychosocial Spiritual Model for Pain Management

Otis-Green, Sherman, Perez, and Baird (2002) proposed an integrated psychosocial spiritual model for cancer pain management. The premise of this program is that cancer related pain consists of three distinct yet interrelated domains: psychosocial, physical, and spiritual. The physical pain associated with cancer can occur from tumor involvement and treatment side effects. It can have cognitive and emotional impact on the patient that includes negative thoughts and decreased self-esteem. In some cases, physical pain or flares of physical pain may bring about the negative thought that the cancer is progressing. For others the pain experience may be exacerbated by anticipating worsening pain, thereby magnifying their current pain experience (Otis-Green, Sherman, Perez, & Baird, 2002). Physical pain from cancer can be related to emotional distress, including anxiety, depression, fear, anger, hopelessness, and helplessness, with the latter two associated with spiritual pain (Hinshaw, 2005; Saunders, 2000; Strang, Strang, Hultborn, & Arner, 2004). Otis-Green, Sherman, Perez, and Baird, (2002) proposed a model of the pain experience in advanced cancer that defines spirituality as the interconnection with nature, the Transcendent, and others, in the universal desire to understand "how the world works". They proposed that spiritual pain involves a struggle to understand the difference
between beliefs in how the world should work and life experiences in the here and now (Otis-Green, Sherman, Perez, & Baird, 2002).

Otis-Green, Sherman, Perez, and Baird (2002) reported various reasons that some people attribute to pain. These reasons include that some believe that more suffering in the present life increases the odds of going to heaven. Thus, they may choose to forgo pain medications or interventions that might decrease pain and suffering. Others believe that the pain is a form of punishment from God. Moreover, others view pain as challenging their positive thinking, and when diagnosed with cancer their whole belief system is challenged and leads to a sense of failure or the idea that there is a lack of faith or prayers (Otis-Green, Sherman, Perez & Baird, 2002). Future research seeking better understanding of the psychosocial-spiritual aspects of cancer care with regard to spiritual assessment as part of a multidimensional cancer care program may help provide greater understanding of these interrelationships of the individual cancer patient's total pain experience (Otis-green, Sherman , Perez & Baird, 2002).

Goebel et al, (2009) described the use of the total pain theory as a conceptual model in caring for patients with advanced heart failure. They concluded that the application of the theory of total pain with the management of pain associated with advanced heart failure as appropriate because it holistically assesses and manages the overall suffering of these patients (Goebel et al., 2009).

**General Literature on Spirituality in Patients**

Ross (2006) reviewed 14 studies in order to describe and explore nursing perspective and awareness of the spiritual needs of patients and their response to the needs. The study showed that patients often desired spiritual care but often sought friends and family instead of the nursing staff, citing nursing was too busy or disinterested to attend to their spiritual needs (Ross, 2006).
Research recommendations from this article include further exploration and description of the multi-facets of spirituality and spiritual care in order to enhance collaboration with regard to spiritual care on behalf of patients and improved spiritual care education for nurses.

Fisch et al. (2003) examined the relationship between quality of life and spiritual well-being. The literature reveals a relationship between the level of quality of life and spiritual well-being (Fisch et al., 2003), better health outcomes amongst regular religious service attendees (Koenig, 2004; Sulmasy, 2009). A relationship between higher levels of spiritual well-being and longer survival in patients with advanced cancer were also noted.

Conclusions

Findings from the literature strongly support the idea that spirituality in general is relevant to health care, and that spiritual pain in particular is an interest area even though it has not been studied extensively (Strang, Strang, Hultborn, & Arner, 2004). The definition of spiritual pain has not been agreed upon in healthcare. For purposes of this study, spiritual pain is defined as the loss of meaning and purpose in the here and now (Millspaugh, 2005), and includes meaning, relatedness, forgiveness and hope (Groves & Klauser, 2009). There are differences in spiritual pain when comparing cancer survivors and those at end of life with advanced cancer but questions remain. The interplay between physical, psychological and spiritual pain is not known but has been associated with poor physical outcomes and higher mortality. Research is needed to clarify relationships across different experiences of cancer-related pain. Better understanding about spiritual pain and other pain experiences in advanced cancer will enhance healthcare providers’ ability to provide care to the whole person physically, psychologically and spiritually in a transdisciplinary manner.
CHAPTER THREE:

METHOD

This chapter addresses the study design, sample and setting for proposed data collection, a description of the instruments, data collection procedures, and the proposed method of data analysis. In addition, this chapter addresses protection of human subjects as well as measures in place to address pain that may be discovered during the interview process. This research employed a descriptive, correlational pilot study design.

Four research questions were examined in this study:

1. What is the relationship between physical pain and spiritual pain, as perceived by participants who have advanced cancer?
2. What is the relationship between spiritual pain and existential well-being, as perceived by participants who have advanced cancer?
3. What is the relationship between spiritual pain and physical pain in the context of the demographic and health-related variables of age, gender, years of education, and months since diagnosis?
4. What factors do participants with advanced cancer identify as important to their well-being?

Sample and Setting

The setting for the pilot study was an outpatient oncology clinic in Southern Arizona. The convenience sample consisted of 30 adult participants with advanced cancer and who reside in their homes. The sample size provided ample statistical power for a pilot investigation of the proposed relationships and key themes derived from patient perspectives. Participants who
agreed to be in the study were interviewed, in accord with IRB procedures to protect the rights of human subjects. The study lasted five weeks and concluded with the thirtieth interview as required for statistical analysis of a pilot study.

The **inclusion criteria** were as follows:

- English-speaking adult males or females
- age 18 and above
- current diagnosis of advanced cancer
- able to participate in answering questions of the study

The **exclusion criteria** were as follows:

- unable to communicate verbally or by writing
- non-English speaking

**Protection of Human Subjects**

Human Subjects Protection approval from The University of Arizona was obtained prior to recruitment or data collection. Site approval was obtained from the participating oncology clinic prior to recruitment or data collection. Informed consent was obtained from each participant prior to participating in the study, each verbalizing their willingness to participate in the study. The participants were reminded that they may withdraw from the study at any time for any reason. None chose this option. Data were de-identified, and data files were password protected. Appendix A contains the forms used for informed consent.

**Instruments and Demographic and Health-related Questionnaire**

Two standardized instruments, to measure Spiritual Pain and Existential Well-Being, were used in the study. In addition, an investigator-developed *Demographic and Health Related*
Form, which included two open-ended questions, was also used. They are displayed in Appendix B. All questions were administered in an interview format for ease of the participant and clarity and completeness of the data.

**Spiritual Pain Assessment Instrument**

The spiritual pain scale was developed by The Pastoral Care staff at Providence Saint Vincent Medical Center in Beaverton, Oregon and adapted from Richard Groves (Groves & Klauser, 2009; Spiritual Pain Assessment Tool, Appendix B). The Spiritual Pain Assessment asks the participant to select one of five responses under each of four categories: meaning, relatedness, forgiveness, and hope. Each area is rated from 1 to 5, and summed for the total score. The total score possible ranges from 4 (indicating lowest level of spiritual pain) to 20 (highest level of spiritual pain). The scale was selected by this investigator after reviewing the literature on psychological and cultural aspects of death and dying, spiritual pain, and considering clinical knowledge in work with patients facing end of life. In particular, Groves and Klauser (2009) identified the four categories as dimensions of spiritual pain and published anecdotal reports of effective use of this instrument with individuals who were facing death. No formal psychometric testing of the instrument is reported in the literature, although reliability was tested in the current sample and found to be adequate (r = .65) according to criteria for internal consistency of a newly developed instrument (Carmines & Zeller, 1979).

**Existential Well-being Subscale from the Spiritual Well-being Scale**

The Existential Well-Being Subscale was used to measure subjective well-being or, alternatively, existential suffering. The *Existential Well-Being Scale* is a subscale of the spiritual well-being scale developed by Ellison and Paloutzian (Ellison & Paloutzian, 1982), has good
reliability and validity, and is widely used in research across ill and well populations. The Existential Well-Being is a subscale of the Spiritual Well-Being Scale and provides a self-assessment of life satisfaction and purpose (Gray, 2006; Paloutzian & Ellison, 2009). The Existential Well-Being is a 10-item questionnaire that was administered as an interview (Paloutzian & Ellison, 2009). Each question is answered on a six-point Likert scale with one meaning strongly disagree and six meaning strongly agree. The total score was calculated from this subscale with 50-60 representing a high level of life’s satisfaction and purpose, 21-49 a moderate level of life satisfaction and purpose, and 10-20 a low level of life satisfaction and purpose (Paloutzian & Ellison, 2009). This is a valid and reliable measure, with Cronbach’s alpha coefficients greater than .75 for internal consistency and reliability in a previous study (Paloutzian & Ellison, 2009).

Demographic and Health-related Questionnaire

The Demographic and Health Related Questionnaire was designed for this study to obtain information directly from the participant. It included demographic information about the participant and the participant’s illness (age, gender, marital status, religious preference, others involvement in their care, years of education, cancer diagnosis and months since diagnosis of cancer). The form also included a one-item rating scale (1 to 10) for physical pain, and two open-ended questions.

Physical Pain Score

A rating scale for physical pain was included in the Demographic and Health-Related Form. The numerical pain rating scale (Physical Pain Score) is a subjective measure of physical pain with a range from zero to 10 with zero indicating no pain and 10 the worst pain (Jensen,
The numerical pain rating scale has been recognized as accurate and reliable in individuals with cancer related pain. The participant rated their pain on a scale from zero to 10 at the time or the interview. The question was quantified by informing the participant that zero was no pain and 10 the worst pain they could imagine. Construct validity was supported by Paice and Cohen (1997) who compared the visual analog scale (VAS), the numeric pain rating scale in 50 patients with cancer. They found strong positive correlation between the VAS and the physical pain scale, using Spearman’s correlation coefficient with statistical significance with $r=0.847$ and $p$ value <0.001 (Paice & Cohen, 1997). Jensen (2003) reviewed a study that found that the physical pain scale was sensitive and specific for detecting meaningful change in pain amongst a sample of 130 patients with the diagnosis of cancer.

Another review of pain rating scales indicates that the physical pain scale is easy to administer while providing data that are as sensitive as the VAS (Williamson & Hoggart, 2005). The difference between the scale and the VAS is that the VAS uses a line that is 10 cm long and the patient is asked to mark their pain level on the line. The left end of the horizontal line represents no pain and the right end of the horizontal line represents the worst imaginable pain. The physical pain scale asks what is your level of pain, with zero no pain and 10 the worst imaginable pain (Jensen, 2003; Paice & Cohen, 1997; Williamson & Hoggart, 2005).

**Open-ended Questions**

In addition, two open-ended questions were asked of the participant: What factors do you identify as important for your sense of well-being? What factors do you identify as important in regulating any pain that you may feel? A follow-up question about type of pain was also asked.
Procedure

The procedure was approved by The University of Arizona Institutional Review Board (IRB). The IRB-approved protocol was followed in recruiting and interviewing participants, as well as in managing the data in a confidential manner.

Quantitative and qualitative data were collected through interviews with each participant. The qualitative data was obtained through a brief open-ended interview (guided by the Demographic and Health-Related Questionnaire), to identify new areas for exploration, and to assist in interpreting the quantitative findings. Quantitative data were obtained using the two brief standardized instruments.

The measures were administered in the following order to build rapport and minimize influence of instruments on participant responses:

1. Administer the Demographic and Health-Related form to establish rapport and obtain data for descriptive analysis.

2. Administer the two open-ended questions to identify any factors that participants think are especially important for their well-being, and then factors relevant to their regulation of pain.

3. Request that the participant rate their Physical Pain Score on a scale using the physical pain scale from zero to 10.

4. Administer the Spiritual Pain Assessment Scale and the Existential Well-Being Scale.

Interaction with participants took place in a private room at the clinic location or at the patient’s home, according to the participant’s preference and at a time convenient for the participant. After informed consent was obtained, the investigator administered the Demographic
and Health-Related Questionnaire, followed by the Spiritual Pain Assessment Tool and the Existential Well-Being Scale. The entire interaction took approximately twenty minutes to complete. The respondents were reminded that they may request a break or another time to complete the interview, or may withdraw from the study entirely, according to the rights of human subjects, but none chose this option. The respondents were reminded that they could be referred to a licensed counselor if they desired assistance. None requested this option. The interview was audio taped to enhance accuracy of transcription of the responses to the open-ended questions and to facilitate attention to and interaction with the participant.

Data analysis consisted of examining the psychometric properties of the instruments, descriptive analyses, correlational techniques, and content analysis for data reduction of qualitative findings.
CHAPTER FOUR:

RESULTS

This chapter addresses the findings of the research according to the research questions. Characteristics of the sample are presented first. The psychometric properties of the instruments were evaluated, with a desired Cronbach’s alpha of .70 minimum and .80 for an established instrument as an indicator of internal consistency reliability. The data were examined for completeness and accuracy. Descriptive statistics were utilized to describe the sample, the pain scores, and spirituality scores. The level of significance was set at .05.

Statistical analysis was performed using the Statistical Package for the Social Sciences 16.0 (SPSS) on the quantitative results, using descriptive statistics, nonparametric, and parametric statistics. The Kolmogorov-Smirnov and Shapiro-Wilk statistics, and the Pearson correlation coefficient and Spearman rho correlation coefficient were used in this study. Content analysis was performed on the qualitative data.

Sample Characteristics

The sample consisted of 30 participants with advanced cancer. Demographic data were collected using a questionnaire designed by the researcher and included age, gender, marital status, ethnicity, religious preference, educational background, cancer diagnosis, length of time since diagnosis, others involved in their care, and numerical pain score. See Table 1 for summary.

The age of participants ranged from 32 to 99 years, with the majority between the ages of 50 and 70. The gender of participants was approximately even, with 16 (53.3%) female and 14
(46.7%) male. Regarding marital status, the majority, 23 (76.7%) were married, followed by three (10%) widowed, two (6.7%) divorced, one (3.3%) single, and one (3.3%) separated.

The ethnicity of the sample was as follows: 27 (90%) were Caucasian, followed by two (6.7%) Hispanic, and one (3.3%) Asian. The religious preference includes 20 (66.7%) Christian, followed by eight (26.7%) with no religious preference, one (3.3%) Jehovah’s Witness, and one (3.3%) Jewish. The educational background was as follows: 10 (33.3%) completing some college, followed by nine (30%) who completed high school; four (13.3%) with a Masters degree; two (6.7%) with a Bachelors degree; two (6.7%) with a Doctoral degree, two (6.7%) with Technical training, and one (3.3%) with GED.

The participants had a variety of cancer types, with the majority of 10 (33.3%) with lung cancer, followed by six (20%) with colon cancer, five (16.7%) with breast cancer, four (13.3%) with multiple myeloma, two (6.7%) with pancreas cancer, one (3.3%) with brain cancer, one (3.3%) with melanoma, and one (3.3%) with prostate cancer. The range in time since diagnosis was from two months to 19 years. Time since diagnoses includes the majority, 13 (43.3%) diagnosed within the past year, followed by six (20%) diagnosed within the past two to three years, three (10%) diagnosed within the past three to four years, three (10%) diagnosed within the past one to two years, one (3.3%) diagnosed within the past four to five years, one (3.3%) diagnosed within the past five to eight years, one (3.3%) diagnosed within the past eight to 10 years, one (3.3%) diagnosed within the past 10 to 15 years, and one (3.3%) diagnosed within the past 15 to 20 years. For the data analysis, these figures were converted to months since diagnosis.
Most participants report having others involved in their care, with 15 (50%) reporting extended family, five (16.7%) reporting their spouse, four (13.3%) reporting family and friends, three (10%) reporting family and clinic staff, two (6.7%) reporting no one involved in their care and one (3.3%) reporting having friends involved in their care.

TABLE 1. Demographics and Health-related Data on the Sample (N = 30)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in Years</strong></td>
<td></td>
</tr>
<tr>
<td>30 - 39</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>40-49</td>
<td>2 (6.7)</td>
</tr>
<tr>
<td>50-59</td>
<td>8 (26.7)</td>
</tr>
<tr>
<td>60-69</td>
<td>7 (23.3)</td>
</tr>
<tr>
<td>70-79</td>
<td>8 (26.7)</td>
</tr>
<tr>
<td>80-89</td>
<td>2 (6.7)</td>
</tr>
<tr>
<td>90-99</td>
<td>2 (6.7)</td>
</tr>
<tr>
<td><strong>Religious Preference</strong></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>20 (66.7)</td>
</tr>
<tr>
<td>None</td>
<td>8 (26.7)</td>
</tr>
<tr>
<td>Jehovah’s Witness</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>Jewish</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td><strong>Educational Background</strong></td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>10 (33.3%)</td>
</tr>
<tr>
<td>Completed High School</td>
<td>9 (30%)</td>
</tr>
<tr>
<td>Masters Degree</td>
<td>4 (13.3%)</td>
</tr>
<tr>
<td>Doctoral Degree</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Bachelors Degree</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Technical Training</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>GED</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td><strong>Type of Cancer</strong></td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>10 (33.3)</td>
</tr>
<tr>
<td>Colon</td>
<td>6 (20)</td>
</tr>
<tr>
<td>Breast</td>
<td>5 (16.7)</td>
</tr>
<tr>
<td>Multiple Myeloma</td>
<td>4 (13.3)</td>
</tr>
<tr>
<td>Pancreas</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Brain</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>Prostate</td>
<td>1 (3.3)</td>
</tr>
</tbody>
</table>
Length of Time Since Diagnosis

<table>
<thead>
<tr>
<th>Duration</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within Past Year</td>
<td>13 (43.3%</td>
</tr>
<tr>
<td>1 to 2 years</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>2 to 3 years</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>3 to 4 years</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>4 to 5 years</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>5 to 8 years</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>8 to 10 years</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>10 to 15 years</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>15 to 20 years</td>
<td>1 (3.3%)</td>
</tr>
</tbody>
</table>

Others Involved in Care

<table>
<thead>
<tr>
<th>Group</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extended Family</td>
<td>15 (50%)</td>
</tr>
<tr>
<td>Spouse</td>
<td>4 (13.3%)</td>
</tr>
<tr>
<td>Family and Friends</td>
<td>4 (13.3%)</td>
</tr>
<tr>
<td>Family and Clinic Staff</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>No One</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Friends</td>
<td>1 (3.3%)</td>
</tr>
</tbody>
</table>

Normality of Distribution of Variables

The normality of distribution for the Physical Pain Score, Spiritual Pain Assessment Score, and Existential Well-Being Score were assessed using Kolmogorov-Smirnov (K-S) and Shapiro-Wilk tests. The K-S and Shapiro-Wilk tests for normal distribution were done by comparing scores from the sample with that of a normally distributed set of scores (Field, 2005). If the K-S or Shapiro-Wilk test result was not significant ($p > 0.05$) then the sample is not significantly different from the normal distribution and is probably normal. If the K-S or Shapiro-Wilk test result is significant ($p < 0.05$) then the sample is significantly different from the normal distribution and is probably not normal (Field). The Existential Well-Being Scores KS ($p = 0.197$) were normally distributed with significance greater than 0.05. The physical pain rating scale score KS and spiritual pain assessment scale KS scores were not normally distributed with $p$ values <0.05. As a result, nonparametric tests of correlation along with the standard parametric
correlation statistic were used in addition to the parametric correlation statistic. The results were the same with each test.

**Research Question One:** What is the relationship between physical pain and spiritual pain, as perceived by participants who have advanced cancer? The scores on each instrument were calculated first, and then correlated.

**Physical Pain Assessment Score.** The mean score for the Physical Pain Assessment Score for this study was 1.62 and the range was 0 to 6, with a possible range of 1 to 10. The majority of numerical scores were zero or no pain at the time of the interview 14 (46.7%) and five scoring a 2. Other scores are listed below in Table 2.

<table>
<thead>
<tr>
<th>Physical Pain Rating Scale Score</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>14 (46.7)</td>
</tr>
<tr>
<td>1</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>2</td>
<td>5 (16.7)</td>
</tr>
<tr>
<td>2.5</td>
<td>3 (10)</td>
</tr>
<tr>
<td>3</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>3.5</td>
<td>11 (3.3)</td>
</tr>
<tr>
<td>4</td>
<td>2 (6.7)</td>
</tr>
<tr>
<td>4.5</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>5</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>6</td>
<td>1 (3.3)</td>
</tr>
</tbody>
</table>

**Spiritual Pain Assessment Score.** The internal consistency of the Spiritual Pain Assessment Instrument for this study was .65 and near acceptable level for internal consistency of .70 according to (Carmines & Zeller, 1979; Field, 2005). The mean score for the Spiritual Pain Assessment Score for this study was 8.43 and a standard deviation of 3.181. The minimum score was 5 and the maximum score was 16. The majority of Spiritual Pain Assessment Scores rated
eight or less, with 20 (66.7%) and the remaining 10 (33.3%) having scores between 9 and 16, with a possible range of 4 to 20 (see Table 3).

TABLE 3. Distribution of Spiritual Pain Assessment Scores in the Sample ($N = 30$)

<table>
<thead>
<tr>
<th>Spiritual Pain Assessment Score</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>3 (10)</td>
</tr>
<tr>
<td>6</td>
<td>6 (20)</td>
</tr>
<tr>
<td>7</td>
<td>8 (26.7)</td>
</tr>
<tr>
<td>8</td>
<td>3 (10)</td>
</tr>
<tr>
<td>9</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>10</td>
<td>3 (10)</td>
</tr>
<tr>
<td>11</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>12</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>13</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>15</td>
<td>1 (3.3)</td>
</tr>
<tr>
<td>16</td>
<td>2 (6.7)</td>
</tr>
</tbody>
</table>

The scores for the individual components of the Spiritual Pain Assessment Scale are noted in Table 4. The mean scores are near the low end of the scale, indicating less pain, however three of the four categories had at least one subject scoring the maximum score of 5, meaning a high amount of pain in that area.

TABLE 4. Mean, Standard Deviation, and Score Range on Each Component in the Spiritual Pain Assessment Instrument

<table>
<thead>
<tr>
<th>Spiritual Pain Assessment Component</th>
<th>Mean Score</th>
<th>Standard Deviation</th>
<th>Minimum score out of 5</th>
<th>Maximum score out of 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning</td>
<td>2.53</td>
<td>1.29</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Relatedness</td>
<td>1.90</td>
<td>1.13</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Forgiveness</td>
<td>2.07</td>
<td>1.23</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Hope</td>
<td>2.17</td>
<td>0.95</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

The frequencies of each individual score of the Spiritual Pain Assessment Scale are noted in Table 5. The majority of responses for the category of meaning, relatedness, and forgiveness were 1, while the majority of answers for Hope were 2.
TABLE 5. Number of Participants on Each Spiritual Pain Level from 1 to 5 within Each Component of the Spiritual Pain Assessment Instrument (Total N = 30)

<table>
<thead>
<tr>
<th>Spiritual Pain Assessment Component</th>
<th>1 = Lowest level of pain</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 = Highest level of pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning</td>
<td>9 (30%)</td>
<td>6 (20%)</td>
<td>6 (20%)</td>
<td>8 (26.7%)</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Relatedness</td>
<td>14 (46.7%)</td>
<td>10 (33.3%)</td>
<td>2 (6.7%)</td>
<td>3 (10%)</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Forgiveness</td>
<td>13 (43.3%)</td>
<td>8 (26.7%)</td>
<td>5 (16.7%)</td>
<td>2 (6.7%)</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Hope</td>
<td>8 (26.7%)</td>
<td>12 (40%)</td>
<td>7 (23.3%)</td>
<td>3 (10%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

The relationship between physical pain and spiritual pain was examined by using both nonparametric testing with Spearman’s rho because of the non-normal distribution but also Pearson r because the Pearson correlation statistic is robust (Field, 2005).

Statistical analysis of the data obtained did not indicate a significant correlation between the Physical Pain Rating Scale score and the Spiritual Pain Assessment Scale score using Pearson $r=.071$ (NS) and Spearman $r=-.026$ (NS). The Pearson correlation statistic was used to uncover relationships between the Physical Pain Score and the individual components of the Spiritual Pain Assessment Scale but were not found to be statistically significant Pearson $r=.061$(NS) with meaning, $r=-.264$(NS) with relatedness, $r=-.273$(NS) with Forgiveness and $r=.183$(NS) with Hope. Significant relationships were noted amongst the questions with Meaning and Relatedness $r=.589 (.001)$, and Relatedness and Forgiveness $r=.454 (.012)$. These relationships support the internal consistency of the instrument. See Table 6 below.
TABLE 6: Pearson Correlations of Physical Pain Score, Spiritual Pain Assessment Score and Individual Components of the Spiritual Pain Assessment Score in the Sample \((N = 30)\)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Spiritual Pain Assessment Score</th>
<th>Meaning</th>
<th>Relatedness</th>
<th>Forgiveness</th>
<th>Hope</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Pain Score</td>
<td>.07</td>
<td>.06</td>
<td>-.26</td>
<td>-.27</td>
<td>.14</td>
</tr>
<tr>
<td>Spiritual Pain Assessment Score</td>
<td>.14</td>
<td>-.06</td>
<td>-.22</td>
<td>-.19</td>
<td></td>
</tr>
<tr>
<td>Meaning</td>
<td></td>
<td></td>
<td></td>
<td>.59**</td>
<td>.31</td>
</tr>
<tr>
<td>Relatedness</td>
<td></td>
<td></td>
<td></td>
<td>.45*</td>
<td>.21</td>
</tr>
<tr>
<td>Forgiveness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.11</td>
</tr>
</tbody>
</table>

**\(p=.001\)**

*\(p=.012\)

Research Question Two: *What is the relationship between spiritual pain and existential well-being among participants who have advanced cancer?*

The internal consistency of the Existential Well-Being Score for this study was adequate, with a Cronbach’s alpha of .77 (Carmines & Zeller, 1979; Field, 2005). The mean score on the Existential Well-Being Score for this study was 45.72, with a standard deviation of 7.425. The minimum score was 30 and the maximum score was 59. The majority of Existential Well-Being Scores indicated a moderate level of life satisfaction 23 (76.7%) and the remaining 7 (23.3%) represented a high level of life satisfaction.

Correlational analysis revealed a significant inverse correlation between Spiritual Pain Assessment Score and the Existential Well-Being Score, using both the Pearson correlation coefficient \(r = -.48 (p = .007)\) and Spearman correlation coefficient \(r = -.54 (p = .002)\). The results indicate that as the Spiritual Pain Assessment Score increased (more spiritual pain), the Existential Well-Being Score decreased (lower level of life
satisfaction and life purpose). Alternatively, those in this sample with less spiritual pain experienced a higher level of existential well-being.

TABLE 7. Existential Well-being Scale Score and Frequencies in the Sample (N = 30)

<table>
<thead>
<tr>
<th>Existential Well-being Scale Score</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>30</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>35</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>36.5</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>38</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>40</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>41</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>44</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>45</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>46</td>
<td>4 (13.3%)</td>
</tr>
<tr>
<td>47</td>
<td>4 (13.3%)</td>
</tr>
<tr>
<td>49</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>51</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>52</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>53</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>56</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>57</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>58</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>59</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Total</td>
<td>30 (100%)</td>
</tr>
</tbody>
</table>

Table 8 summarizes the overall scores on the three main study variables. A significant relationship was found between Spiritual Pain and Existential Well-Being, but not between any other study variables.
TABLE 8. Means, Standard Deviation, and Range of Scores for Physical Pain, Spiritual Pain Assessment and Existential Well-being in the Sample (N = 30)

<table>
<thead>
<tr>
<th></th>
<th>Physical Pain Score</th>
<th>Spiritual Pain Assessment Score</th>
<th>Existential Well-being Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>1.62 (1.8)</td>
<td>8.43 (3.2)</td>
<td>45.72 (7.4)</td>
</tr>
<tr>
<td>Range Possible.</td>
<td>0-10</td>
<td>4-20</td>
<td>5-60</td>
</tr>
<tr>
<td>Actual Range</td>
<td>0-6</td>
<td>5-16</td>
<td>30-59</td>
</tr>
</tbody>
</table>

**Research Question Three**: *What is the relationship between spiritual pain and physical pain in the context of the demographic and health-related variables of age, gender, years of education, and months since diagnosis?*

Both Pearson and Spearman correlation coefficients were used to determine correlations among the demographic variables and main study variables: age, gender, years of education, months since diagnosis, Physical Pain Score, Spiritual Pain Assessment Score, and Existential Well-Being Score. The analysis using Spearman’s rho generated findings similar to those for the Pearson correlation (Spearman rho =-.54, p=.002). No significant relationships were found between demographic variables and any of the study variables. See Table 9 below. Therefore, multiple regression analyses to examine how each of the pain variables related to each other together with the demographic and health-related variables, was not done.
TABLE 9. Pearson Correlations of Age, Gender, Education, Time since Diagnosis, Physical Pain, Spiritual Pain and Existential Well-being Scores (N = 30)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Gender</th>
<th>Years of Education</th>
<th>Months Since Diagnosis</th>
<th>Physical Pain Score</th>
<th>Spiritual Pain Assessment Score</th>
<th>Existential Well-Being Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>.05</td>
<td>-.21</td>
<td>-.22</td>
<td>-.27</td>
<td>.17</td>
<td>.02</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years of Education</td>
<td>.11</td>
<td></td>
<td>-.12</td>
<td>.11</td>
<td>.13</td>
<td>-.04</td>
</tr>
<tr>
<td>Months Since Diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Pain Score</td>
<td>-.19</td>
<td></td>
<td>.34</td>
<td>.18</td>
<td></td>
<td>-.05</td>
</tr>
<tr>
<td>Spiritual Pain Assessment Score</td>
<td></td>
<td>-.04</td>
<td>-.15</td>
<td>.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Existential Well-Being Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p=.007

**Research Question Four:** What factors do participants with advanced cancer identify as important to their existential well-being?

A content analysis was used in this study to analyze the participant responses to the open-ended questions regarding factors associated with well-being and factors important to regulating pain.

The first question asked was: What factors you identify as important for your sense of well-being? The transcribed answers were compiled and separated by subject number. These answers were then compiled into a master list of responses, with 94 responses identified, and finally placed on 3x5 cards separated by content. These 3x5 cards were then reviewed and placed into categories in an electronic file, based on similar responses, and these similar responses were transcribed into a table and double-checked for accuracy. The categories are summarized in Table 10 below. These six categories are: meaningful activity, family and friends, spiritual aspects, health/nutrition, symptom management, and finances.
In the category of meaningful activity, the 43 (44.8%) responses were further subcategorized (with the number of responses in parentheses) into doing something for myself (13), hobbies (9), having energy (6), household chores (3), having a daily routine (3), exercising (2), caring for pets (2), being independent (1), having quality of life (1), and not just hanging onto life (1).

In the category of spiritual aspects, the 18 (18.8%) responses were further subcategorized into having faith and trust that all is in God’s hands (7), including that He will take care of family, peace that passes understanding that what happens is in God’s hands, allowing God to bear those things that are difficult to handle, and getting to know God. Spiritual activities (7) were meditation, prayer, going to church, studying the Bible, and going to religious services, having spiritual well-being (1), pondering spiritual questions (1), as one participant wondered, “how can people heal and still die”, and no fear of death (2).

In the category of family and friends, the 16 (16.7%) responses were further subcategorized into doing things with family (6), doing things for family (2), having family take care of me (2), naming specific family members who were significant (2), having friends and friends support of choices (1), not feeling alone (1), separation from family because of past hurts (1), and trying to get along with everyone (1).

In the category of health/nutrition, the 11 (11.4%) responses can be further subcategorized into having health (4), having competent, ongoing medical to ensure health (3), keeping a positive attitude about beating cancer (1), eating healthy (1), getting nutrition (1), and gaining weight (1).
In the category of symptom management, the five (5.2%) responses were further subcategorized into pain management (2), ability to breathe (1), nausea control (1), and sleep (1).

In the category of finances, the 3 (3.1%) responses can be further subcategorized into having financial security (1), taken care of (1), and self-supporting (1).

TABLE 10. Frequency (96 Total) of Specific Factors Important to Well-being in the Sample (N = 30)

<table>
<thead>
<tr>
<th>Patient Stated Factors Important to Well-being</th>
<th>Frequency of Responses (% of Total Responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaningful activity</td>
<td>43 (44.8%)</td>
</tr>
<tr>
<td>Spiritual aspects</td>
<td>18 (18.8%)</td>
</tr>
<tr>
<td>Family and friends</td>
<td>16 (16.7%)</td>
</tr>
<tr>
<td>Health/nutrition</td>
<td>3 (11.4%)</td>
</tr>
<tr>
<td>Symptom management</td>
<td>5 (5.2%)</td>
</tr>
<tr>
<td>Finances</td>
<td>3 (3.1%)</td>
</tr>
</tbody>
</table>

The second open-ended question asked during the interview was: What factors do you identify as important in regulating any pain that you may feel? The transcribed answers were compiled and separated by participant number. These answers were then compiled into a master list of responses with individual responses separated and finally placed on 3x5 cards separated by content. These 3x5 cards were then reviewed and placed into categories based on similar responses, and these similar responses were transcribed into a table and double checked for accuracy. Initial categories were identified. These categories include alternative treatments 29 (34.5%), medications 28 (33.3%), and type of medications 27 (32.1%).

The alternative treatment subcategories included distraction seven (24.1%), rest four (13.8%), exercise eight (27.6%), and dealing with it 10 (34.5%).
The next category of medications included taking medication proactively to prevent pain 10 (35.7%), treating pain 14 (50%), and avoiding taking medication unless necessary four (14.3%).

Finally the category of type of medications used, as described by the participants. These responses included, some with multiple medications, included OTC such as acetaminophen seven (23.3%), acetaminophen or ibuprofen two (6.7%), acetaminophen or naproxen one (3.3%), naproxen and loratadine two (6.7%), loratadine one (3.33%), naproxen one (3.33%), and no report of OTC 16 (53.3%). Prescription medications identified included zolpidem one (3.3%), miracle mouthwash two (6.7%), tramadol one (3.33%), “pain medication” two (6.7%), and no report of other prescription medication 24 (80%). Finally narcotic analgesics included long acting or sustained release medications and short acting or immediate release medications. The sustained release medications included sustained release oxycodone two (6.7%) and sustained release morphine sulfate five (16.7%), and 23 (76.7%) reported not using sustained release narcotics. The immediate release medications included hydrocodone/acetaminophen seven (23.3%), oxycodone/acetaminophen six (10%), hydrocodone/acetaminophen or oxycodone/acetaminophen three (10%), immediate release morphine sulfate one (3.3%), hydromorphone one (3.3%), immediate release oxycodone one (3.3%), and 14 (46.7%) reported no use of immediate acting narcotic analgesics. Of the 30 participants in this study, all but one indicated they took some type of medication to assist with pain management, with a variety of agents chosen. Recalling from results for Research Question 1, the pain scores at the time of the interview ranged from zero (no pain) to 6
out of 10, with the majority or 14 (46.7%) of participants reporting no pain at the time of the interview, and five (16.7%) of participants reported 2 out of 10 as a level of pain at the time of the interview.

TABLE 11. Frequency (44 Total) of Types of Medications Used in the Sample (N = 30)

<table>
<thead>
<tr>
<th>Medication</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetaminophen</td>
<td>7 (23.3%)</td>
</tr>
<tr>
<td>Hydrocodone/acetaminophen</td>
<td>7 (23.3%)</td>
</tr>
<tr>
<td>Morphine Sulfate Sustained Release</td>
<td>5 (16.7%)</td>
</tr>
<tr>
<td>Oxycodone/acetaminophen</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Hydrocodone/acetaminophen or Oxycodone/acetaminophen</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Miracle Mouthwash</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Naproxen and Loratadine</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Acetaminophen or Ibuprofen</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Oxycodone Sustained Release</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>“Pain Medication”</td>
<td>2 (6.7%)</td>
</tr>
<tr>
<td>Hydromorphone</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Morphine Sulfate Immediate Release</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Oxycodone Immediate release</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Naproxen</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Loratadine</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Acetaminophen or Naproxen</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Tramadol</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>Zolpidem</td>
<td>1 (3.3%)</td>
</tr>
<tr>
<td>None</td>
<td>1 (3.3%)</td>
</tr>
</tbody>
</table>

The types of pain experienced by the participants were also recorded during the interview (Table 12). Some had more than one complaint of pain. Their types of pain included seven (21.9%) participants with bone pain, four (12.5%) with back pain, four (12.5%) with generalized pain, three (9.4%) with neuropathy pain, two (6.35%) with headache, two (6.3%) with mouth sores, two (6.3%) with right arm and shoulder pain, one (3.1%) with back and leg pain, one (3.2%) who stated can’t breathe, one (3.2%) with cramps, one (3.1%) with intestinal pain, one (3.1%) with leg pain, one (3.1%) with nausea and emesis, and one (3.1%) with shoulder pain.
TABLE 12. Frequency (32 Total) of Type of Pain Identified in the Sample \((N = 30)\)

<table>
<thead>
<tr>
<th>Type of Pain</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>bone pain</td>
<td>7 (21.9)</td>
</tr>
<tr>
<td>back</td>
<td>4 (12.5)</td>
</tr>
<tr>
<td>general</td>
<td>4 (12.5)</td>
</tr>
<tr>
<td>neuropathy</td>
<td>3 (9.4)</td>
</tr>
<tr>
<td>headache</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>mouth sores</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>arm/shoulder</td>
<td>3 (9.4)</td>
</tr>
<tr>
<td>Back and legs</td>
<td>1 (3.1)</td>
</tr>
<tr>
<td>Can’t breathe</td>
<td>1 (3.1)</td>
</tr>
<tr>
<td>Cramps</td>
<td>1 (3.1)</td>
</tr>
<tr>
<td>Intestines</td>
<td>1 (3.1)</td>
</tr>
<tr>
<td>Leg</td>
<td>1 (3.1)</td>
</tr>
<tr>
<td>Nausea/emesis</td>
<td>1 (3.1)</td>
</tr>
<tr>
<td>Shoulder</td>
<td>1 (3.1)</td>
</tr>
</tbody>
</table>
CHAPTER FIVE: DISCUSSION

Healing is measured not by the condition of the body, but by the peace that surrounds and permeates the person. (O’Neill & Mako, p. 45).

This study addressed the relationships among spiritual pain, physical pain, and existential well-being in the context of demographic and other health-related variables. Results from the analysis of the qualitative and quantitative data of this study lend support to the Total Pain framework for this study, which identifies physical, spiritual, emotional, and social realms of pain (Hinshaw, 2005; Saunders, 2000).

Relevance of Spiritual Pain

The study of spiritual pain in patients with advanced cancer is relevant to knowledge development for nursing practice. Spiritual pain is a reflection of how people feel “within” and is a correlate of well-being (O’Neill & Mako, 2011) Groves and Klauser (2009) recommended asking the question that Dame Cicely Saunders posed to her patients: “How are you within?” and then administering the Spiritual Pain Assessment Scale to understand a patient’s level and components of spiritual pain. Their four components of spiritual pain (meaning, forgiveness, relatedness and hopelessness) (Groves & Klauser, 2009) were generally supported in this study, and provide potential areas of intervention for nurses who work with people facing life threatening illness and spiritual pain.

Although spiritual pain is an important human dimension to assess and study, the results from this study did not indicate a significant relationship between spiritual pain and physical pain. This finding is similar to that in two studies found in the literature (Delgado-Guay et al.,
2011; Mako, Galek, & Poppito, 2006). The finding contrasts with the model case by Mehta and Chan (2008) who describe a relationship between spiritual pain and physical pain in a patient with advanced cancer. More research with a larger, more representative sample is needed to help determine the nature and significance of any relationships between physical and spiritual pain. The relevance of spiritual pain, however, may reach beyond a demonstrated relationship to physical pain at any one point in time.

In reference to factors important to pain control, participants identified – at nearly the same percentage – alternative treatments and medications. This may be a reflection of the sample’s relatively low level of pain, with nearly half reporting no pain during the time of the interview. However, 43% reported using a short-acting narcotic medication and 23% reported using a long-acting narcotic medication, for pain relief. Mako and colleagues found a correlation between morphine use and spiritual pain, which may be examined in future research. Another interesting area to pursue in future research is the idea of Mako and colleagues that spiritual pain can hide behind or masquerade as physical pain. A larger sample with more variability in pain level ratings would provide a better sample to study this and the relationship between morphine use and spiritual pain.

This study did not reveal a relationship between spiritual pain and the demographic variables of age, gender, years of education, and number of months since diagnosis. Although there was considerable range of scores on these variables (for example, age ranged from 32 to 99 years), the relatively low level of spiritual pain in the sample may have limited the variability needed to obtain significant relationships. At least 50% or more scored between only a 1 or 2 on Spiritual Pain. In reference to education, the majority (63%) completed high school and some
college, with the remainder educated at higher college levels and technical training. It is possible that education may influence a person’s ability to obtain resources to cope with illness or end of life, but there was no relationship between education and spiritual pain or existential well-being.

In addition, the significant negative correlation between spiritual pain and well-being is supported by similar findings in the literature (King & Porreca, 2010). The qualitative comments derived in this study reflect the themes of relatedness across the physical, spiritual, emotional, and social dimensions of pain and informed the investigator about resources participants were using to attain their moderately high level of existential well-being.

**Existential Well-being**

In this study, the Existential Well-Being Scores were relatively high, with the sample scoring overall in the moderate to high level of well-being. This finding suggests that a sense of well-being is possible, even in the face of life-threatening illness – a perspective supported by many nursing theories and nursing practice experiences. In addition, their qualitative comments regarding factors important to their well-being support the Total Pain framework, and in particular, the spiritual and social dimensions of life as relevant to well-being aspects utilized for this study. The physical dimensions were not as frequently identified, suggesting that the non-physical dimensions may be more important toward the end of life, particularly if the physical care needs have been met. The ability to engage in meaningful activity and to address spiritual aspects of life took precedence over health-related or financial concerns in this sample. These findings corresponded with the four domains of suffering in the concept of total pain as described by Dame Cicely Saunders (Hinshaw, 2005; Saunders, 2000). Ferrell and Hassey Dow
(2007) had similar findings in factors that affect quality of life in survivors of cancer and those with advanced disease. Future researchers should re-examine this to better understand how certain dimensions of the Total Pain framework become more or less important across the trajectory of advanced cancer.

Other researchers, working with different samples in which the pain was higher, had findings congruent with the findings from this study indicating that spiritual pain and life quality or well-being are inversely related. For example, King and Porreca (2010) found that 94% of patients with advanced cancer reported moderate to severe pain that diminished quality of life. Delgado-Guay and colleagues (2011) found that expression of spiritual pain included lower scores in spiritual aspects of quality of life. This study revealed a negative correlation between the Existential Well-Being Score and the Spiritual Pain Assessment Score. This finding is similar to Delgado-Guay and colleagues (2011) and King and Porreca’s (2010) studies, as well as being congruent with what was expected theoretically in terms of an inverse relationship between existential well-being and spiritual pain.

The findings of this study revealed there is a negative relationship between well-being and spiritual pain. This is depicted by a downward pointing arrow next to spiritual pain connected to an upward pointing arrow next to well-being. In addition to this relationship, the participants identified factors that were important to their well-being. These factors are depicted in the diagram, and are included within the circle of well-being with varying sizes to represent the relative importance and frequency as reported by participants. The more frequent responses occupy more space within the largest circle.
that represents well-being and the less frequent responses occupy less space within the largest circle that represents well-being (Figure 2).

**FIGURE 2.** Factors of Well-Being and the Relationship between Existential Well-Being and Spiritual Pain.

**Limitations**

The limitations of this study include a small sample size, use of a new instrument to measure spiritual pain, and non-normal distribution of the Spiritual Pain Assessment Score scores. The sample size of 30 decreased the power of statistical analysis and the variability of scores needed to examine relationships effectively.

While the research and measurement of spiritual pain is relatively new, the Spiritual Pain Assessment Score tool used in this study performed fairly well. The validity and reliability of the questionnaire was not established prior to use, based on searching the literature for an established tool to assess spiritual pain, despite many references to its importance. In light of these
weaknesses, the qualitative comments reflected across the themes lend support to a holistic or “total” perspective of pain and to the significance of spiritual and social factors in well-being in the face of one’s death. The findings of this study provide initial groundwork for a conceptualization and empirical basis for future research and practice with persons facing serious illness or end of life.

**Future Research Implications**

The future research in this area could continue this work on defining the concept of spiritual pain in the context of advanced cancer and relating it to existential well-being. An updated literature review using a CINAHL and Medline search revealed a total of only three articles using spiritual pain and advanced cancer in September 2011. There is need for continued research on this topic.

A larger sample size could enhance statistical power, allow for additional analytic techniques, and overcome the non-normal distribution of study variables. Interviews with a larger number of participants would be useful in confirming or refining aspects important to existential well-being found in this study, as well as what gaining better understanding of what spiritual pain or lack of spiritual pain means to the patient.

In addition, the information gathered from a descriptive study on a larger more representative sample could be used to refine the Spiritual Pain Assessment Score scale and then test reliability and validity of the scale before further use. Further research is necessary to better explain the existence or lack of relationship between physical pain and spiritual pain. Future research designs may also include repeated measures of physical pain score and spiritual pain scores to determine if these scores change over time and if so how and what factors may be
operating to alleviate physical and spiritual pain, whether utilizing medication, alternative treatments, or attention to the patient’s inner life and activities as sources of well-being.

Another dimension for future research includes further exploration of factors important to well-being in patients with advanced cancer. In particular, the factor of symptom management warrants further study, since very few participants identified this as an important factor, in contrast to the emphasis placed on this factor in the literature. Is symptom management, as a factor for well-being in advanced cancer, more relevant when physical pain is less well controlled?

**Clinical Practice for Doctor of Nursing Practice (DNP)**

For a DNP, awareness of the complex needs of an advanced cancer patient is critical. There is a need for theory-based knowledge as well as assessment tools to assist in efficient and reliable assessment and care of the multifaceted dimensions of pain that this population experiences, especially with regard to spiritual pain. The DNP has the expertise to sit on interdisciplinary teams in order to influence future decisions with regard to pain management recommendations/algorithms, to develop the needed instruments to assess the many aspects of pain, including physical and spiritual pain, participate in research, and to be proactive in the implementation of appropriate interventions in the setting of advanced cancer care.

The advanced practice nurse role is multifaceted, just as are the life dimensions of patients who have advanced cancer. The nursing role includes interaction on interdisciplinary committees regarding a variety of considerations to manage pain and enhance well-being. Development and implementation of guidelines can be informed by research and clinical expertise. DNP nurses should participate as change agents in the interdisciplinary development
of pain management guidelines, and implementation of those guidelines in the clinical setting. These guidelines should address the multidimensional view of pain and well-being. In addition, the DNP nurses should develop and conduct research to refine and develop assessment tools that are applicable to research and clinical practice and therefore implement these tools into their clinical practice and research.

**Summary**

In summary, although a relationship between spiritual pain and physical pain was not found, the relationship between spiritual pain and existential well-being was significant. Factors associated with well-being in participants with advanced cancer (who reported a moderately high level of Existential Well-Being) were meaningful activity, family and friends, spiritual aspects, health/nutrition, symptom management, and finances. The concept of total pain was supported by the participant-generated categories identified in this study. The development of a spiritual pain assessment tool that is reliable and valid is needed for use in clinical as well as research settings. Further investigation into the relationship between spiritual pain and physical pain is also indicated, as well as validation of the qualitative themes of well-being identified in this study.
APPENDIX A:

HUMAN SUBJECTS PROTECTION DOCUMENTS
THE UNIVERSITY OF ARIZONA

HSPP Correspondence Form

Date: 05/26/11
Investigator: Mary K. Hook, RN, ANP-C
Advisor: Pamela Reed, Ph.D., RN
Project No/Title: 11-0338-04 Well-Being and Experiences with Pain in Patients with Advanced Cancer
Current Period of Approval: 05/26/11 – 05/25/12

Submit the "FORM Concluding Review Progress Report" no later than 45 days prior to the end of the approval period listed above.

IRB Committee Information

IRB4 – IRB 000004213 Expedited Review – New Project
FWA Number: FW/A00004213

Documents Reviewed Concurrently

<table>
<thead>
<tr>
<th>Status</th>
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<tr>
<td>F200: Application for Human Research Form (received 05/24/11)</td>
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<tr>
<td>Checklists C416 (Waiver of Written Documentation of the Consent Process)</td>
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<tr>
<td>Consent Instruments:</td>
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<tr>
<td>Subject's Disclosure Form (version 05/24/11)</td>
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<tr>
<td>VOTF (received 03/29/11)</td>
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<td>Site Authorizations: Arizona Oncology (dated 05/23/11)</td>
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<tr>
<td>Recruitment Materials: Recruitment Script (in Application) and Recruitment Flyer</td>
</tr>
<tr>
<td>Data Collection Instruments; Interview Questions</td>
</tr>
<tr>
<td>Other (define): CV for PI</td>
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Determination

Approved as submitted effective 05/26/11

Comments

PHI Authorization Form not required. No Protected Health Information (PHI) is being collected in this study.

Regulatory Determinations:

- Criteria for Approval has been met (45 CFR 46.111). The criteria for approval listed in 45 CFR 46.111 have been met for if previously not, have not changed:
  1. Risks to subjects are minimized (b) by using procedures which are consistent with sound research design and which do not unnecessarily expose subjects to risk, and (c) whenever appropriate, by using procedures already being performed on the subjects for diagnostic or treatment purposes; (2) Risks to subjects are reasonably expected to result in evaluating risks and benefits, the IRB should consider only those risks and benefits that may reasonably be expected to result in evaluating risks and benefits, the IRB should consider only those risks and benefits that may result from the research (as distinguished from risks and benefits of therapies subjects would receive even if not participating in the research). The IRB should not consider possible long-range effects of providing knowledge gained in the research (for example, the possible effects of the research on public policy) as among those research risks that fall within the purview of its responsibility; (3) Selection of subjects is equitable: In making this assessment the IRB should take into account the purpose of the research and the setting in which the research will be conducted and should be particularly cognizant of the special problems of research involving vulnerable populations, such as children, prisoners, pregnant women, mentally disabled persons, or economically disadvantaged persons; (4) Informed consent will be appropriately documented, in accordance with, and to the extent required by 46.116; (5) Informed consent will be appropriately documented, in accordance with, and to the extent required by 46.116; (6) When appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of subjects; (7) When appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data; (8) When some or all of the subjects are likely to be vulnerable to coercion or undue influence, such as children, prisoners, pregnant women, mentally disabled persons, or economically or educationally disadvantaged persons, additional safeguards have been included in the study to protect the rights and welfare of these subjects.

Notification: No changes to a project may be made prior to IRB approval except to eliminate approved immediate hazard to subjects.

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Form version 1400/2006
- **Eligible for Expedite Approval (45 CFR §46.110):** Identification or the subjects or their responses (or the resulting procedures involving identification or subjects or their responses) will *MUST* reasonably place them at risk of emotional or civil liability or be damaging to the their financial standing, employability, insurability, reputation, or be stigmatizing, unless reasonable and appropriate protections will be implemented so that risks related to invasion of privacy and breach of confidentiality are no greater than minimal.

- ** Expedite Approval (45 CFR 46.110 Category 6):** Collection of data from voice, video, digital, or image recordings made for research purposes.

- ** Expedite Approval (45 CFR 46.110 Category 7):** Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral, history, focus group, program, evaluation, human factors evaluation, or quality assurance methodologies.

- **Waiver of Documentation of Informed Consent (45 CFR 46.117(c)(2)):** the research involves no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context (Minimal risk one-time interview).

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Ida M. (Ki) Moore, DNSc  
Co-Chair, IRB4 Committee  
UA Institutional Review Board  
IRMM/des

cc: Unit Reviewer

05/26/11  
Date

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- *No changes to a project may be made prior to IRB approval except to eliminate apparent immediate hazard to subjects.*
The University of Arizona Consent to Participate in Research

Study Title:
Well-Being and Experiences with Pain in Patients with Advanced Cancer

Principal Investigator:  Mary Hook DNP candidate, RN, NP-C
Sponsor: None

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to discuss the study with your friends and family and to ask questions before making your decision whether or not to participate.

You may or may not benefit as a result of participating in this study. Also, as explained below, your participation may result in unintended or harmful effects for you that may be minor or may be serious, depending on the nature of the research.

1. Why is this study being done?
This study is being done to gather information about patients’ experiences, particularly experiences of pain when they have cancer. I am also interested in other important experiences that relate to their well-being

2. How many people will take part in this study?
Thirty people will participate in this study.

3. What will happen if I take part in this study?
Participation is voluntary. Any person who agrees to participate in this study agrees to provide demographic information such as age, gender, ethnicity if desired, type of cancer, stage of cancer. A brief interview will be conducted with questions regarding different aspects of pain and well-being, and include open-ended questions as well as brief questionnaires. The interview will be tape recorded to enhance the accuracy of data collection and destroyed after transcription of the interview is complete (transcription will be done by the researcher). The transcript of your interview will not contain your identifying information to protect your privacy. Once the interview is complete, your participation in the study is complete.

4. How long will I be in the study?
The interview will be done on one day and it is expected to last 20 to 30 minutes. Once the interview is concluded, your participation is complete. If for any reason, you want to stop the interview or take a break, you may let the researcher know and she will stop the interview for a break of up to 2 hours then complete the interview or discontinue per your wishes.
5. Can I stop being in the study?
Your participation is voluntary. You may refuse to participate in this study. If you decide to take part in the study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you and you will not lose any of your usual benefits. Your decision will not affect your future relationship with The University of Arizona. If you are a student or employee at the University of Arizona, your decision will not affect your grades or employment status.

6. What risks, side effects or discomforts can I expect from being in the study?
There are no physical risks or side effects although you may experience some anxiety reflecting on your experiences with pain to answer some of the interview questions. If you experience discomfort of any kind during the interview, you are asked to notify the researcher with your concerns and let her know whether or not you want her to notify the staff for assistance.

7. What benefits can I expect from being in the study?
There are no benefits to participating in this study, although some respondents have reported that they experience some relief or positive feelings in talking about their views and experiences regarding their illness with the interviewer.

8. What other choices do I have if I do not take part in the study?
You may choose not to participate without penalty or loss of benefits to which you are otherwise entitled.

9. Will my study-related information be kept confidential?
Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law.

Also, your records may be reviewed by the following groups (as applicable to the research):
- Office for Human Research Protections or other federal, state, or international regulatory agencies
- The University of Arizona Institutional Review Board or Office of Responsible Research Practices
- My Advisory Committee

10. What are the costs of taking part in this study?
There are no costs involved in participating in this study other than 20 to 30 minutes of your time.

11. Will I be paid for taking part in this study?
There will be no monetary compensation for participating in this study.
12. What happens if I am injured because I took part in this study?
It is not likely you will suffer any injury in this particular project. However, if you suffer an injury from participating in this study, you should seek treatment. The University of Arizona has no funds set aside for the payment of treatment expenses for this study.

13. What are my rights if I take part in this study?
If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By participating in the study and responding to the researcher's questions, you are indicating your consent to participate in the study. You do not give up any personal legal rights you may have as a participant in this study.

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled.

An Institutional Review Board responsible for human subjects research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

14. Who can answer my questions about the study?
For questions, concerns, or complaints about the study you may contact Mary Hook, RN, at (520-334-0771).

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at 520-626-6721 or online at http://orec.vpr.arizona.edu/irb

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact Mary Hook, NP-C (phone: 520-334-0771).
May 23, 2011

Principal Investigator: Mary Hook, DNP Candidate, RN, NP-C
University of Arizona
Tucson, AZ

Dear Mary Hook:

I have reviewed your request regarding your study and am pleased to support your research project entitled “Well-Being and Experiences with Pain in Patients with Advanced Cancer”.

Your request to use Arizona Oncology at Rudasill Road in Tucson, Arizona as a recruitment and data collection site is granted. Further, it is understood that the project will be implemented in accordance with The University of Arizona IRB stipulations concerning recruitment of participants, informed consent process, data collection protocol, data management, and confidentiality. Oversight of the project will remain under the University of Arizona IRB. In addition, we understand that your dissertation advisor, Professor Pamela Reed, PhD, RN, FAAN, will be supervising the process. This authorization covers the time period of May 23, 2011 to December 30, 2011.

We look forward to working with you.

Sincerely,

Richard K. Rosenberg, M.D.

www.arizonaoncology.com
APPENDIX B:

DATA COLLECTION INSTRUMENTS
DESCRIPTIVE AND HEALTH-RELATED QUESTIONNAIRE

1. How old are you (in years)?___________
2. Gender: ___Male or ___Female
3. Marital status: Single, Married, Widowed, Separated, Divorced
4. What is your ethnic background?_________________________________________________
5. What is your religious preference?______________________________________________
6. What is your educational background? (e.g. completed high school, years, or degrees of post-high school education?) ________________________________
7. What type of cancer do you have?______________________________________________
8. When were you diagnosed?____________________________________________________
9. Others involved in care: (e.g. Family, loved ones, friends, no one?)
10. On a scale from 0 to 10 with zero being no pain and 10 the most pain please rate your pain at this time (show participant the scale)

   Pain Rating
   0 1 2 3 4 5 6 7 8 9 10

   None-----------------------------------------------------------------------Most

Open-ended questions

1. What factors do you identify as important for your sense of well-being?
   _______________________________________________________________________
   _______________________________________________________________________

2. What factors do you identify as important in regulating any pain that you may feel?
   _______________________________________________________________________
   _______________________________________________________________________

3. A follow-up question about type of pain may be asked. Please describe your pain.
   _______________________________________________________________________
   _______________________________________________________________________

Subject No. ___
Spiritual Pain Assessment Tool

Which statement best describes you at this time. Circle the response.

Meaning:

1. Life is filled with purpose and meaning
2. Life is good, I know what I know what I want to accomplish
3. I feel generally motivated
4. I lack energy to accomplish what I want to accomplish
5. Life has become meaningless.

Comments:

Relatedness:

1. I feel a strong sense of connection with the person and things that matter to me
2. I feel connection to those important to me
3. Most important areas of my life seem balanced
4. I feel some dis-association from key relationships/issues
5. I feel seriously alienated from someone/thing that is important to me

Comments:

Forgiveness:

1. I feel a deep sense of reconciliation towards myself and others
2. I’m unaware of unresolved issues
3. There are no outstanding issues that are calling for forgiveness in my life
4. I know of areas I need to work on to forgive others
5. I feel a strong sense of unforgiving towards myself/others

Comments:

Hope

1. I feel hope-filled and optimistic
2. I sense all will probably work out positive
3. I generally trust what the future holds for me
4. I sometimes question “why me?”
5. I am experiencing deep depression and hopelessness

Comments:

Adapted from the Providence St. Vincent Medical Center, Department of Pastoral Services Spiritual Pain Assessment Tool.

Subject No. ___
Existential Well-Being Scale

For each of the following statements circle the choice that best indicates the extent of your agreement or disagreement as it describes your personal experience:

SA = Strongly Agree  MA = Moderately Agree  A = Agree Disagree  
SD = Strongly Disagree  MD = Moderately Disagree  D = Disagree

1. I don't know who I am, where I came from, or where I'm going.
   SA   MA   A   D   MD   SD

2. I feel that life is a positive experience.
   SA   MA   A   D   MD   SD

3. I feel unsettled about my future.
   SA   MA   A   D   MD   SD

4. I feel very fulfilled and satisfied with life.
   SA   MA   A   D   MD   SD

5. I feel a sense of well-being about the direction my life is headed in.
   SA   MA   A   D   MD   SD

6. I don't enjoy much about life.
   SA   MA   A   D   MD   SD

7. I feel good about my future.
   SA   MA   A   D   MD   SD

8. I feel that life is full of conflict and unhappiness.
   SA   MA   A   D   MD   SD

9. Life doesn't have much meaning.
   SA   MA   A   D   MD   SD

10. I believe there is some real purpose for my life.
    SA   MA   A   D   MD   SD

SWB Scale © 1982 by Craig W. Ellison and Raymond F. Paloutzian.
REFERENCES


McGrath, P. (2002). Creating a language for 'spiritual pain' through research: a beginning. *Supportive Care in Cancer, 10*(8), 637-646.


