Pain and Spiritual Distress at End of Life

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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

PAIN AND SPIRITUAL DISTRESS AT END OF LIFE

by

Kathryn L. Robinson

A dissertation presented to the
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TITLE OF DISSERTATION: Pain and Spiritual Distress at End of Life

DISSERTATION

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Abstract

**Purpose:** The purpose of this study is to examine the relationship between unmanaged pain and spiritual distress in adults newly admitted to hospice.

**Background/Rationale:** Current evidence supports the presence of a positive relationship between increased physical pain and spiritual distress for those with advanced cancer and/or receiving palliative care services. Nonetheless, spiritual distress remains a relatively understudied area; anecdotally, assessment and management of physical symptoms often take precedence over interventions for spiritual distress in patients at end of life (EOL) on hospice. Research is needed to examine the relationships between physical pain, spiritual distress, and other relevant variables specific to EOL patients receiving home hospice care.

**Methods:** Retrospective correlational design. Pre-existing data were extracted from a hospice agency’s electronic health record to examine age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, levels of pain, and spiritual distress in adult patients (age 18 and over) admitted to home hospice services (N=3484). Descriptive, bivariate, and multivariate analyses were conducted.

**Results:** Participants ranged in age from 25 to 107 years, $M = 82 \pm 12.08$, one third were married or had a designated life partner, 16% reported moderate to severe pain; 9.6% experienced spiritual distress. Marital status ($\chi^2 (3, N = 2483) = 20.21, p < .001, \text{Cramer’s} \ V = .09$), hospice diagnosis ($\chi^2 (5, N = 3481) = 22.66, p < .001, \text{Cramer’s} \ V = .08$), pain severity ($\chi^2 (1, N = 3464) = 19.75, p < .001, \text{Cramer’s} \ V = .08$), and age $t (393.17) = 2.84, p = .005, d = .17$ were significantly related to spiritual distress. The logistic model was statistically significant, $\chi^2 (11) = 45.25, p < .001$. Cases indicating the highest odds of
experiencing spiritual distress had pulmonary disease (OR = 1.8, \( p = .02 \)), were single (OR = 1.6, \( p = .02 \)), and had moderate to severe pain (OR = 1.4, \( p = .04 \)).

**Implications:** Moderate to severe pain, marital status, and diagnosis should be considered in a refined spiritual distress screening process. Future research should examine the unique contributions of diagnosis in predicting spiritual distress, particularly pulmonary disease.
Dedications

To all my family, especially:

My beloved husband and best friend, J.B. Robinson,
Your tireless support, encouragement, editing, research-talks, advice, co-parenting, and pouring of wine made this dissertation possible.

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CHAPTER I

INTRODUCTION

Physical, spiritual, psychological, and social pain or distress are common phenomena in end of life (EOL) care, and interdisciplinary professionals who practice in hospice and EOL are considered specialists in managing pain and the other potential physical, emotional, and spiritual issues that may arise for patients at EOL. Hospice and palliative professionals frequently acknowledge the need for an interdisciplinary approach to multidimensional pain and symptom management (Ferrell et al., 2018; Krikorian et al., 2012; Puchalski et al., 2014), however the current Medicare-mandated spiritual screening and assessment process does not account for more timely assessment in patients with unmanaged pain. Consequently, the identification of spiritual distress and needed spiritual or psychosocial interventions may be delayed. This observation led to the following research question: does moderate to severe pain contribute to spiritual distress in patients at EOL? The purpose of this study is to examine the relationship between unmanaged pain and spiritual distress in patient’s newly admitted to hospice. Specific aims: 1) describe age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, levels of pain, and spiritual distress among terminally-ill adults (age 18 and over) within 5 days of admission to hospice; 2) explore the relationships among age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, levels of pain, and spiritual distress in this group. If, as this author hypothesizes, patients who experience higher levels of pain also experience spiritual distress within 5 days after admission to hospice, the study has
significant implications for current practice and future interdisciplinary, multi-method research.

**Background**

Hospice and palliative professionals acknowledge the need for an interdisciplinary approach to complex, multidimensional EOL pain and symptom management (Ferrell et al., 2018; Krikorian et al., 2012; Mako et al., 2006; Puchalski et al., 2014, 2019; Siler et al., 2019). However, the current Medicare-mandated spiritual screening and assessment process does not account for a relationship between unmanaged pain and spiritual distress. In the field of hospice, the current gold standard is to have physical pain managed to a patient’s self-determined acceptable level, or 3 out of 10 or less within 48 hours of admission to hospice. Medicare regulation requires a spiritual care screening by the admitting registered nurse (RN), followed by a more comprehensive spiritual assessment completed by a spiritual counselor, MSW, or other supportive care interdisciplinary team member within 5 calendar days of the hospice admission. The patient (or family) may decline further spiritual assessment during the initial admission screening (Hospice Care, 2017). Given the evidence supporting a positive relationship between pain and spiritual distress in similar populations (Marvin Omar Delgado-Guay et al., 2016; Henne et al., 2015; Krok et al., 2013), this process poses several challenges for adequately addressing spiritual distress in the presence of physical pain.

For instance, in the presence of physical symptoms, many hospice RNs will focus primarily on physical pain interventions, with little consideration for addressing spiritual concerns potentially affecting physical manifestations of the pain experience. Even at a basic level, Caldeira, Carvalho, and Viera (2013) found the current nursing diagnosis of
spiritual distress was not comprehensive enough to meet the defining characteristics found in current literature. Indeed, most are not adequately trained to perform or understand the process and importance of spiritual screenings for identifying spiritual distress (Puchalski et al., 2014; Villagomeza, 2005). Validated screening tools for spiritual distress do not demonstrate consistent accuracy and are generally not utilized during the admission spiritual screening (Bahraini et al., 2020), and Medicare only requires the RN to document whether or not the patient was asked about spiritual or existential concerns (CMS & HQRP, 2018). Even quality measures for palliative care often place emphasis on physical symptoms or adverse therapeutic effects with little to no attention to other elements of suffering, including spiritual distress (Kamal et al., 2014).

In terms of the timeframe for assessments, the delay between the RN spiritual screening and the more comprehensive spiritual assessment by an interdisciplinary team member could delay the identification of spiritual distress and the need for psychosocial interventions by up to 3 days. When considering the urgency of symptom management given the terminal patient prognosis, this delay is an unacceptable prolongation of patient suffering. If a patient or family declines a comprehensive spiritual assessment during the initial screening, spiritual distress may go completely unidentified at the detriment of a more holistic and comprehensive pain management approach.

**Significance**

**Prevalence of Pain and Spiritual Distress**

**Pain.** Physical pain is a prevalent symptom of end of life. This despite freedom from pain is consistently rated as the most important factor of a good death (Smith et al., 2010). Meier et al. (2016) recent literature review with a subsequent call for research
noted across all stakeholders at EOL (patients, family members, and healthcare providers), pain-free status was reported 81% of the time as a top-three theme of a good death.

Alarmingly, Smith et al. (2010) found clinically significant pain steadily increased in the last 4 months of life and was found in approximately 50% of patients in the last month of life. A systematic review of symptom prevalence at EOL supports the presence of pain in 52% of patients in the last two weeks of life (Kehl & Kowalkowski, 2013). In cancer patients receiving active treatment, pain was reported by 66% of patients 60 years and older and up to 81% of patients less than 60 years old (Krok et al., 2013). In cancer patients in the last days or weeks of life, up to 94% of patients were found to experience pain at some point (Renz et al., 2018). Other authors endorsed this high prevalence of pain in over 60% of patients on hospice (Hunnicutt et al., 2017; Teno et al., 2015). From a family perspective, bereaved family members reported unmet pain management needs in up to 25% of EOL patients (Teno et al., 2015).

**Spiritual Distress.** Spiritual distress, a prevalent psychosocial element of EOL care (Marvin Omar Delgado-Guay et al., 2016; Mako et al., 2006), has been studied more extensively with the advanced cancer and/or larger palliative care population as opposed to the smaller subset of those at EOL on hospice. In multiple studies sampling from the cancer population, spiritual distress was reported or identified in 23-67% of patients (Caldeira et al., 2014, 2016, 2017; Hui et al., 2011; Pérez-Cruz et al., 2019; Schultz et al., 2017). In woman with breast cancer undergoing chemotherapy, 39% were experiencing spiritual distress at the time of the study (Caldeira et al., 2016), which is consistent with a larger sample of cancer patients in which the prevalence of spiritual distress was nearly
41% (Caldeira et al., 2017). Delgado-Guay et al. (2016) found 44% of advanced cancer patients reported some level of spiritual pain or spiritual issues. In advanced cancer patients receiving outpatient palliative care, 67% of the total sample reported mild to severe spiritual pain (Pérez-Cruz et al., 2019).

In a sample of hematology and oncology patients, 79% of patients reported at least one spiritual need. Unfortunately, only 2.5-11% of this sample reported inquiry from any healthcare professional regarding their religious or spiritual needs (Astrow et al., 2018). This finding is consistent with findings from bereaved family interviews in which it was identified religion and/or spirituality were not addressed up to 72% of the time for patients during the EOL period. Teno et al. (2015) reported 60% of advanced cancer patients received minimal to no support for their spiritual needs in their last months of life.

**Relationship between Pain and Spiritual Distress**

Given the multidimensional nature of pain, it is not surprising the evidence supports a positive relationship between pain and spiritual distress. In multiple studies involving patients with advanced cancer, pain has been associated with increased psychological and/or spiritual distress (Marvin Omar Delgado-Guay et al., 2016; Henne et al., 2015; Krok et al., 2013; Pérez-Cruz et al., 2019). Delgado-Guay et al. (2016) found in advanced cancer patients spiritual pain was associated with worse physical and emotional symptoms, including pain. The severity of physical symptoms increased with severity of spiritual pain, which suggests spiritual pain may increase expression of physical symptoms, nonetheless more research is needed to better characterize the association and to determine causality (Delgado-Guay et al., 2016).
Gielen, Bhatnagar, and Chaturvedi, et al. (2016) found a statistically significant association between physical pain and spiritual distress. Specifically, spiritually distressed patients were more likely to have severe pain versus less pain in those without spiritual distress. (Gielen et al., 2016). In another study, advanced cancer patients with spiritual distress were more likely to be younger and have pain (Hui et al., 2011). Spiritual distress/pain can even alter a patient’s perception of symptoms and coping. For instance, patients with spiritual pain are more likely to feel spiritual pain made their physical and emotional symptoms worse (Delgado-Guay et al., 2011).

Conversely, spirituality and/or spiritual well-being have been found to increase quality of life and coping, decrease symptom burden, etc. in multiple patient populations. In a sample of black patients receiving treatment for cancer pain, spirituality was associated with overall quality of life; predicted social, emotional, and functional well-being; and decreased pain severity and symptom burden. These findings suggest spirituality may be protective against decreased quality of life (Bai et al., 2018). In their literature review of systematic reviews regarding spiritual interventions for physical pain management, Garschagen et al. (2015) found direct empirical evidence supporting the importance of active coping in maintaining long-term beneficial outcomes for chronic pain management. As noted by the authors, despite the lack of reviews supporting spiritual care in interdisciplinary chronic pain management, it has been associated with increased or more effective coping (Garschagen et al., 2015).

In those with spinal cord injury (SCI), higher levels of pain were associated with spiritual distress and low levels of spiritual well-being were associated with multiple factors, including higher levels of pain-related interference with activities and lower pain
self-efficacy and satisfaction with life. Higher levels of spiritual well-being (including sense of meaning and purpose) protected against psychological distress in the presence of pain and increased a person’s ability to cope with pain (Siddall et al., 2016). Additionally, spiritual well-being (specifically meaningfulness and peacefulness) was found to be related to less depression, less pain interference, lower pain levels, and may be routed in psychopathology. Higher levels of pain were directly related to mood dysfunction and, in turn, reduced spiritual well-being (Nsamenang et al., 2016).

**Gaps in Knowledge**

The evidence reviewed supports a relationship between increased physical pain and spiritual distress for those with advanced cancer or illness and/or receiving palliative care services. Though this population may be similar or related to the EOL population, the specific urgency for symptom management and psychosocial support for those at EOL on hospice are unique, and the timeliness of pain management and spiritual assessment is more pressing. Further research is needed to document the relationship between pain and spiritual distress specific to EOL patients on hospice, which could eventually help address gaps this author believes exist in the current practice. The purpose of the study was to examine the relationship between unmanaged pain and spiritual distress in patient’s newly admitted to hospice.

The research question for this investigation was: Does moderate to severe pain contribute to spiritual distress in patients at EOL? This research question was answered through the following specific aims:

**Aim 1.** Describe age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, levels of pain, and spiritual
distress among terminally ill adults (age 18 and over) within 5 days of admission to hospice.

Aim II. Explore the relationships among age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, levels of pain, and spiritual distress in this group.

**Total Pain Model**

Dame Cicely Saunders is widely considered the founder of the modern palliative and hospice movement. For over 60 years, her approaches to the many aspects of EOL care have been foundational to the advent and ongoing evolution of the field and the providers who practice within this specialty. As such, her development of a model addressing the “total pain” experience has greatly influenced the conceptualization and research of this phenomenon for those with advanced illness and/or at EOL. The premise of her foundational model is a multidimensional understanding of and approach to pain, which includes the physical, psychological, social, and spiritual aspects of the unique pain experience. In this model, all of these elements both interact with each other and contribute to the total pain experience (Clark, 1999; Goebel et al., 2009; Greenstreet, 2001; Mehta & Chan, 2008; Saunders et al., 1995).
The simple nature of the model in understanding the many dimensions of the pain experience, including the spiritual element, makes it well-suited for guiding this study. This study will primarily explore the relationship between two elements of total pain: physical pain and spiritual pain/distress. Additional study variables could also address the other elements (social and/or psychological pain) of the total pain experience. Through an enhanced understanding of the relationship between these variables, the study will contribute to the larger consideration of the total pain experience.

**Overview of Research Design**

The nature of a terminal prognosis and admission to hospice services make EOL patients particularly vulnerable research subjects. For this reason, thoughtful
methodology and careful research design is of utmost importance. Additionally, research conducted directly with patients and families at EOL should be thoroughly justified through minimally invasive exploratory studies that establish the need for further and more direct exploration of concepts and phenomena of interest. This study is meant to add further scientific data in support of this justification through a retrospective correlational design to examine the relationship among unmanaged pain, spiritual distress, and select social determinants in patients newly admitted to hospice. Pre-collected data from deceased patients, extracted from the hospice agency’s electronic health record (EHR), provide the basis for statistical analysis and interpretation without any burden or invasiveness to the patient and their families.

**Concepts**

**Spiritual distress.** Spiritual distress is an elusive phenomenon to both conceptualize and operationalize. The concept is often described in the context of impairment of spirituality or spiritual well-being and/or an existential element of pain and suffering (Caldeira et al., 2017; Heyse-Moore, 1996; Villagomeza, 2005). In fact, the literature uses diverse terminology as synonymous with spiritual distress, including spiritual pain or suffering, existential pain or suffering, and psychospiritual pain or suffering (Best et al., 2015; Heyse-Moore, 1996). Mako et al. (2006) defined the term simply as “pain deep in your being that is not physical”. Lack or questioning of the meaning of life, suffering, or purpose is a frequent theme in the spiritual distress literature (Best et al., 2015; Caldeira et al., 2017; Villagomeza, 2005) as is perception of threat to one’s being or self (Heyse-Moore, 1996). Based on the writing of Heyse-Moore (1996), who explored spiritual pain/distress in the dying, spiritual distress at EOL can
theoretically be defined as estrangement from the essence of one’s self. Theoretical attributes of spiritual distress at EOL include meaninglessness, anguish, duality (e.g. isolation, loneliness), and darkness (Heyse-Moore, 1996).

Operationally, spiritual distress at EOL is manifested through physical, psychological, social, and/or spiritual symptoms of conflict in relation to self, in relation to others, and/or in relation the divine (Heyse-Moore, 1996; Mako et al., 2006). Based on this definition, this concept could be measured by identifying the presence, severity, and/or meaningful combination of variables that demonstrate conflict with self, others, and the divine such as lack of meaning or purpose, anguish, isolation, loneliness, regret, anxiety, despair, physical pain, insomnia, fatigue, family concerns, anger, etc. (Caldeira et al., 2017; Fitchett et al., 2019; Heyse-Moore, 1996; Mako et al., 2006).

Given the design for this study, the presence of spiritual distress was identified based on the spiritual assessment completed by the hospice spiritual counselor/chaplain or social worker within 5 days of admission to hospice. The researcher collaborated with multidisciplinary hospice agency leadership to predetermine the measures for spiritual distress contained in the spiritual assessment in the agency’s the electronic health record (EHR). This allowed the researcher to identify the presence of spiritual distress as it is being identified and measured in practice.

**Pain at EOL.** Pain is a multidimensional experience involving the physical, psychological, and/or spiritual aspects of a person’s self (Dobson, 2017; Montes-Sandoval, 1999; Peterson & Mutter, 2010). It is often considered functional in its ability to protect and preserve self, communicate threat or harm, and/or foster a learning experience for the person experiencing pain (Montes-Sandoval, 1999). It is considered
subjective in nature, therefore the description and meaning of the pain experience to the
person experiencing it is an important consideration when conceptualizing, assessing, and
treating pain (IASP Terminology, 2017; Mahon, 1994).

Though frequently viewed and treated in practice as a unidimensional physical
phenomenon, the pain experience is influenced by many domains, including mental,
emotional, spiritual, and ethic-socio-cultural influences (Mehta & Chan, 2008). Ignoring
or failing to recognize the interrelationship between these various domains can ultimately
lead to undertreatment of a person’s pain (Mehta & Chan, 2008; Peterson & Mutter,
2010). This is perhaps most poignant at EOL when a holistic approach to all patient care
is the gold-standard for the EOL multidisciplinary team and of utmost importance to
achieve the “good” death and dying experience for patients and families.

Operationally, there are multiple validated measures of pain. The most common
scales utilized in both general and EOL practice include the Numeric Rating scale (NPS),
the Visual Analogue Scale (VAS), and the Verbal Rating Scale (VRS) (Williamson &
Hoggart, 2005). Though unidimensional in nature, these scales are the most common
initial assessment measurement used by the multidisciplinary team at EOL and are
typically included in each team members initial and ongoing assessments of responsive
patients. So, for the purpose of this study, pain ratings from any of the aforementioned
scales were collected, in addition to the categorized pain severities reported on the
Centers for Medicare and Medicaid Services’ (CMS) Hospice Item Set (HIS). As the
admission nurse records the HIS data according to the admission assessment, the HIS
pain ratings should be reflective of the admission pain ratings (CMS & HQRP, 2018).
Pain ratings from non-verbal pain scales and/or nurse observations were excluded.
Figure 2. Conceptual framework model illustrating the link between age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, levels of pain, and spiritual distress at EOL.

Conclusion

The multidisciplinary and holistic nature of hospice EOL care lends itself well to questions about the interplay between physical, psychological, and spiritual symptoms and the roles multidisciplinary providers play in managing those symptoms. However, given the overall lack of research with hospice patients and families, it is no wonder current practice may not be adequate to address multidimensional symptoms and distress at EOL. Therefore, by proposing a study to identify the relationship between moderate to severe pain and spiritual distress in hospice patients within 5 days of admission, this author begins to address the current gaps in knowledge that could ultimately lead to expanded and much-needed causation, interventional, and qualitative research inquiries.
and changes in practice to ensure the best possible EOL experience for patients and families.
CHAPTER II

REVIEW OF THE LITERATURE

Physical, psychosocial, existential, and/or spiritual pain or distress are common phenomena at end of life (EOL). Management of these complex dimensions of the pain experience is one of the prime directives for the hospice multidisciplinary team whose practice can and should be informed by current evidence and future research.

Exploration of the conceptual, theoretical, and research literature related to the phenomena, the theoretical underpinnings of the study, and the measurement of the concepts will inform the significance of this study in relationship to both existing and gaps in knowledge.

Pain and/or spiritual distress in patients with advanced illness and/or receiving palliative care was a consistent area of study through the late 2000s. A breadth of conceptual, theoretical, and research literature addressing these concepts, either in relation to each other or separately as unique phenomena, was conducted in the late 1990s to early 2000s. But a resurgence of issues related to pain, emotional or spiritual distress, spirituality, and spiritual well-being is increasingly more evident in more recent literature. The focus of this literature review will be on these more current sources, though older literature, particularly conceptual or theoretical, will be cited to support consistency with more recent findings or to present findings for which there is a gap in more current literature. Additionally, due to the universality and prevalence of pain and spiritual distress, international research studies are included in this review. While these studies may not be generalizable to an American and/or Western population, particularly due to potentially significant cultural differences in the origin and nature of spiritual
distress, they still provide insight into phenomena, for cross national, cultural, and ethnic lines.

For this study, the use of end of life (EOL) in relation to a population will generally refer to those with a terminal prognosis of 6 months or less. This prognosis is the hallmark qualification for admission to hospice services, which is the timepoint of interest for the study. Literature referring to EOL patients is not necessarily also referring to patients on hospice and is generally retrospective, meaning the researchers’ application of the term in hindsight is often due to the patient’s demise, not due to admission to hospice.

The concept of pain is complex and multidimensional (Mehta & Chan, 2008). Nevertheless in practice it is often approached with a more one-dimensional assumption of the physical aspect of the phenomenon, even at EOL (Kamal et al., 2014). The measure of pain in this study will be based on rating scales capturing the intensity, not the nature, of the pain experience (Hjermstad et al., 2011). In practice, patients are asked to rate or classify the severity of their “pain,” not their “physical pain.” Whether or not the patient perceives their pain as merely physical or if the subjective pain intensity rating/classification is capturing both the physical and non-physical aspects of the pain experience within the hospice pain assessment will be unknown in this study. Since this study is retrospectively examining pre-collected pain intensity assessments referencing the single word, the term pain as used in practice, as perceived by the patient, and as opposed to its classification as merely physical will stand alone when referenced for this study.
Additionally, this study refers to spiritual distress as opposed to spiritual pain, despite the use of the term spiritual pain in the study’s theoretical underpinnings. This is done for a number of reasons. First, the literature supports the synonymous nature of spiritual distress and spiritual pain and both terms are generally used interchangeably (Best et al., 2015; Henne et al., 2015). Second, the term spiritual distress is the common nomenclature used by nurses and the multidisciplinary team in palliative and EOL practice (Caldeira et al., 2016, 2017). Therefore, this use of the common and practical terminology will support the relatability and applicability of the study’s findings to actual practice. Third, since this study is measuring and using the term pain as it is referred in common practice without qualifying it as just physical, the author aims to better distinguish the two separate concepts being measured. Finally, the term distress coupled with spirituality captures a deeper sense of existential suffering that can’t be confused with an often unidimensional perception of pain (Krikorian et al., 2012; Rhodes & Watson, 1987).

Theoretical Literature Related to Pain and Spiritual Distress

Pain at EOL

Formal conceptual analysis of the general experience of pain or pain at EOL is limited. However, pain throughout historical and current literature acknowledges a complex human experience is often associated with EOL care. As pain is as old as humanity itself, it is referenced throughout historical literature from ancient writings of Aristotle (Aristotle, 2014) and authors from multiple disciplines including Rene Descartes (Descartes, 2014), Florence Nightingale (Nightingale, 1859), and Sigmund Freud (Freud, 1990). It is often described based on its function, whether that be
Perhaps the most relevant source for defining the concept of pain at EOL is Dame Cicely Saunders, considered the founder of the modern hospice movement, who developed a theory of total pain. Grounded in her holistic approach to caring for the whole person at end of life, her total pain theory outlines a holistic understanding of the physical, psychological, and spiritual aspects of the pain experience at EOL. Her approach to “total pain” management and treatment of the whole person requires the recognition and treatment of all, not just physical, aspects of pain to adequately manage and reduce the actual pain experience for palliative patients at EOL (Saunders et al., 1995). Her recognition of the multifaceted nature of pain led to her success as a palliative and EOL practitioner and founder of an approach to EOL care still practiced (Dobson, 2017; Mehta & Chan, 2008).
The International Association for the Study of Pain (IASP) developed a pain taxonomy defining pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (IASP Terminology, 2017).” It highlights the importance of pain as a subjective experience that may or may not be associated with a known pain stimulus. It also includes provisions for recognizing and treating pain in individuals who are unable to communicate. Of particular importance is the recognition that pain experienced in the same way as pain caused by actual tissue damage should be accepted as such regardless of any evidence of a physiological cause (IASP Terminology, 2017).
In one concept analysis, pain is characterized as an uncomfortable, distressful, and multidimensional experience and response to noxious stimuli and/or actual or potential threat to body and/or mind. Additional attributes include the unique and subjective nature of pain, as well as the physical, psychological, and socio-cultural influences and interactions involved in the pain experience. Ultimately, pain is considered a protective mechanism for preservation of self (Montes-Sandoval, 1999). In another conceptual analysis using the phenomenological approach, pain is defined as a personal, unpleasant experience dominating the person’s consciousness, is perceived as never-ending, and could be caused from physiological and/or mental stimuli. Because of the analytic approach used, the emphasis of the defined concept is on the meaning of the pain experience to the person experiencing it (Mahon, 1994).

Peterson and Mutter (2010) proposed a typology of pain that examines the effect of the pain experience on the domains of a person’s being, the onset and duration of pain, and the process of a person’s ability to make meaning in the experience when deciding how to characterize and treat effectively. Pain or distress in one domain can manifest itself in one or more other domains and thus be misidentified, mischaracterized, and treated ineffectively. They assert the physical, emotional, interpersonal, and spiritual dimensions of pain or distress all contribute in some way to the pain experience and are interrelated when considering the need for a multidimensional and multidisciplinary approach to addressing the pain (Peterson & Mutter, 2010).

Pain is generally and universally acknowledged as multidimensional in nature, it must also be defined and considered in the context of a person’s ethnic-socio-cultural background and experience when assessing and treating the various contributory
domains. In a study exploring the cancer pain experience in American Indians (AIs), the authors acknowledge the AI’s multidimensional perception of pain within the setting of the cultural influences on mindset, approach, and aversion to pain and treatment, as well as the ceremonial and spiritual practices mitigating pain and distress (Haozous & Knobf, 2013). In another study illustrating the effect of the multiple domains of a person’s being within the context of their ethno-cultural background on the pain experience. Bai et al. (2018) found spirituality was associated with decreased pain and improved quality of life in black patients with cancer pain.

**Distress at EOL**

Distress at end of life is a multidimensional (physical, psychosocial, existential, or spiritual) phenomenon involving moderate to severe discomfort, anguish, or suffering due to mental and/or physical upset caused by severely unpleasant symptoms or stressors reported or observed and quantified by the patient, family, or provider. This distress threatens or causes harm and burden to the person or their family/caregiver and ultimately decreases quality of life. Depending on the context, there are multiple ways the term distress has been defined. In the current dictionary definition, Merriam-Webster most relevantly defined distress as “pain or suffering affecting the body, a bodily part, or the mind” or “a painful situation” (“Distress,” n.d.-a). Additionally, the Oxford Dictionary defined the term as “a state of danger or desperate need” and gave the example of a ship in distress (“Distress,” n.d.-b).

The origins of the term date back to 13th century Middle English. It is derived from the Old French noun, “destresce”, and the verb, “destrecier” and is based on the Latin term “distringere” which means to stretch apart (“Distress,” n.d.-b). Chaucer uses
the term in the context of distraining or being distrained, and later examples in the 15th
century begin using it to indicate “pressure employed or applied to produce or restrain
action” (Rhodes & Watson, 1987). In 19th century nursing, Florence Nightingale alludes
to the term as a state of suffering and upset (Nightingale, 1859; Rhodes & Watson, 1987).

Given its multidimensional nature, examples and exploration of the term are
found in medical, nursing, psychological, and spiritual literature. Distress has been
researched extensively in patients diagnosed with cancer with multiple validated
measures of different aspects of distress in that population (Bruera et al., 1991; Portenoy
et al., 1994; Vitek et al., 2007). In EOL care, distress is frequently used to describe a
severe state of physical, psychological (mental or emotional), and/or spiritual discomfort,
Suffering, or pain, and the term is often used interchangeably with stress, discomfort,
suffering, and pain (Krikorian et al., 2012; Rhodes & Watson, 1987).

Distress at EOL is also subjective, observable, and thus best quantified through
multiple sources at EOL, including the patient, family, nurse, etc. Authors assert distress
is unique and subjective to the patient (Blais et al., 2014; McCorkle & Young, 1978; Oi-
Ling et al., 2005; Portenoy et al., 1994). However, there are multiple challenges to
obtaining patient feedback at EOL, noting important benefits of including multiple
measurement as unwillingness or inability of patients to participate in the assessment
process due to severity of illness, symptoms, and compromised cognition and
responsiveness. They argued the most inclusive approach to assessing and understanding
EOL symptoms and distress is through multiple sources. Consideration of subjective
patient report, if available, and observable signs of distress on the part of the family or provider are important aspects of distress in the context of EOL care.

**Spiritual Distress**

Similar to the concept of pain, the terms of spirit, spiritual, spirituality, etc. have ancient language origins including Greek, Sanskrit, Hebrew, Old and Middle French, and Latin. A prevailing meaning for the term spirit involves the vitality, breath, wind, and animation of a being (Heyse-Moore, 1996; Villagomeza, 2005). The noun version of spirituality in Late Latin (*spiritualitatem*) is defined as “a person’s being or essence” (Villagomeza, 2005, p.286). In 2013, building upon consensus definitions from the United States and Europe (Puchalski et al., 2009), international and interdisciplinary healthcare professionals and leaders defined spirituality as “a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred….” (Puchalski et al., 2014, p. 16-17). This and preceding consensus definitions were intentionally developed in a broad and religiously inclusive manner. However, the positive connotation of spirit/spiritual/spirituality is negated when combined with the concept of distress.

The concept of spiritual distress is often used synonymously with multiple other concepts or terms, including spiritual pain. In fact, in his seminal writing examining spiritual pain in the dying, Heyse-Moore (1996) uses both terms interchangeably. In his examination of the concept, he asserts spiritual distress or pain occurs due to estrangement from the essence of one’s self and is manifested physically, psychologically, and/or in spiritual symptoms, for example meaninglessness, anguish, duality, and
darkness. Duality is defined as a feeling of isolation and loneliness, while inner darkness is described in terms of St. John of the Cross’s description of the dark night of the soul and a feeling of being blind-folded and lost. He also emphasized the universal experience of spirituality regardless of any or no religious beliefs or belief in a higher power. Therefore, religious distress is a potential aspect of spiritual distress, but spiritual distress can occur independently from religious belief (Heyse-Moore, 1996).

In a conceptual analysis of spiritual distress in adult cancer patients, the defining attributes of this concept are impairments in 3 or more of the following spiritual constructs: connectedness, value system, sense of self-transcendence, inner strength and energy, sense of inner peace and harmony, sense of meaning and purpose, and faith and religious belief system (Villagomeza, 2005). A systematic review examining spiritual suffering in the cancer context identified the following synonyms of suffering in the cancer context: existential distress, existential suffering, existential pain, spiritual distress, spiritual suffering, spiritual pain, psychospiritual distress, psychoexistential suffering, total pain, and demoralization. Additionally, they identified measures for assessing suffering or one of the aforementioned synonyms. These measures were suffering, hopelessness/demoralization, hope, meaning, spiritual well-being, quality of life where a spiritual/existential dimension was included, distress in the palliative care setting and pain, and distress or struggle of a spiritual nature. This review highlights the multidimensional and contextual context in which a person experiences spiritual suffering and the diversity of language and concepts that help capture the experience (Best et al., 2015).
In two clinical validation studies of the nursing diagnosis of spiritual distress in cancer patients, the authors utilized the Richard Fehring’s Clinical Diagnostic Validity Model to identify and validate defining characteristics of the phenomenon. The most frequent of these characteristics (occurrence rate greater than 80%) were expression of suffering, anxiety, concern about family, alienation, crying, questioning identity, questioning the meaning of life, fear, lack of serenity, insomnia, fatigue, and inability to express creativity. Less frequent, but still valid, characteristics (occurred at least 50% of the time) included questioning the meaning of suffering, hopelessness, lack of meaning in life, and refusal to interact with significant others. Interestingly, the occurrence rate of all items related to religiosity or spiritual practices was less than 50% and considered irrelevant in this sample (Caldeira et al., 2016; 2017).

Mako, Galek, and Poppito (2006) explored spiritual pain among 57 patients with advanced cancer admitted to an inpatient palliative care hospital for symptom crises, 96% of whom reported spiritual pain. Their chaplains asked patients to rate the intensity of their spiritual pain on an 11-point scale (similar to the commonly used numeric pain scale) based on the definition of “pain deep in your being that is not physical” (Mako et al., 2006, p.1108). During the interview, they also asked questions to illicit the nature of spiritual pain in this sample and found while most patients were currently or had experienced spiritual pain, it was expressed in various relational domains. Expression of intrapsychic conflict in relation to self, expressed as despair, isolation, regret, or anxiety, accounted for 48% of those experiencing spiritual pain. Thirty-eight percent of participants expressed their spiritual pain in terms of interpersonal factors in relation to others, such as isolation and regret. Finally, 13% expressed it in relation to the divine
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(e.g. the Transcendent God, Higher Power or Life, Nature), characterized by despair, anxiety, and isolation. In this study, overall spiritual pain was not significantly related to religiosity or religious affiliation (Mako et al., 2006).

Schultz et al. (2017) proposed a model for spiritual distress based on their study examining a distinction between spiritual distress and other measures of general or spiritual well-being or distress. Of the 202 adult cancer patients receiving oncological treatment, 23% reported spiritual distress. They found patient’s perception of a grave clinical condition was a significant predictor of spiritual distress, and the multivariable model for predicting spiritual distress includes not feeling peaceful, feeling unable to accept this is happening, and perceived severity of illness (Schultz et al., 2017). Though this study was conducted in Israel and the cultural influences on spiritual distress limit generalizability of results, the concepts identified in their model are consistent with other literature and seem to reflect some level of universal truth to the concept.

**Total Pain Theory**

Perhaps foundational to the current understanding of pain as a multidimensional experience is Dame Cicely Saunders’s understanding and writings on the total pain experience (Saunders et al., 1995). Her theory of total pain is one of the most influential concepts in modern palliative and EOL practice, policy, and theoretical frameworks (Clark, 1999; Dobson, 2017). It is also consistent with other pain definitions and theories, including the definition from the International Association for the Study of Pain and Gate-Control Theory (Mehta & Chan, 2008). The theory is meant to emphasize a holistic model of care focusing on the whole person by recognizing pain as more than just physical. Other equally important and bidirectional components of total pain include the
unique psychological, social, and spiritual aspects of each individual’s experience (Dobson, 2017; Saunders et al., 1995). The relatively simple model captures the complex and multidimensional experience that is pain at EOL and has shaped the multidisciplinary practice specialty known today (Clark, 1999; Dobson, 2017).

In their frequently cited conceptual analysis of total pain, Mehta and Chan (2008) explore the concept within the context of advanced cancer pain and palliative care. The authors assert the ongoing struggle to master pain management in palliative care is a result of continued inability to fully understand the nature of pain in this population. This is despite the fact the concept of total pain is foundational to the modern palliative care model of understanding and practice. The model case study presented highlights how the non-physical aspects of the total pain experience are easily masked by and manifested as physical pain. Failure to recognize and adequately address the psychological, spiritual, and social aspects of the total pain experience—which are often overlooked when physical pain is the primary focus—result in inappropriate pain interventions (e.g. increasing doses of opioid-analgesic medication) and poor pain control. The ultimate resolution for this case required a combination of psychological and physical interventions to address the complex and equal contributions of the psychological, social, and physical elements of the pain experience for this patient. The authors conclude a multidimensional lens for assessing and managing pain at EOL is critical to adequately addressing pain in this population (Mehta & Chan, 2008).

Similarly, other authors explore the concept of total pain through examination of specific cases. Greenstreet (2001) presents a focused patient care study with a patient experiencing metastatic cancer admitted to hospice with immediate pain management
needs. The author represents the unique multidimensional contributors to the total pain experience, appropriate multidisciplinary and holistic assessment and interventional approaches, and correspondingly asserts the need for a better holistic understanding and approach to EOL pain management (Greenstreet, 2001). Through a case study analysis of a cancer patient at EOL on hospice, Middleton-Green (2008) draws comparable conclusions regarding the need for better understanding, assessment, and subsequent interventions for total pain management, as well as the need for further development of holistic and multidimensional pain assessment tools for patients at EOL.

Although the concept of total pain is frequently applied and discussed within the cancer population, Goebel et al. (2009) apply the theory to research and practice in patients with advanced heart failure. As physical pain is not an anticipated component of the heart failure experience or focus of treatment, as it commonly is in cancer, the non-physical contributors to the total pain model are perhaps even more salient in this population. They apply the theory of total pain through a conceptual model of pain’s impact on quality of life, ultimately drawing the same conclusions as other aforementioned authors: a holistic approach to pain management informed by the total pain theory is crucial for pain control for all patients with advanced illness and/or at EOL (Goebel et al., 2009).

**Additional Research Literature Related to Pain and Spiritual Distress**

Delgado-Guay et al. (2016) conducted a study to explore spiritual pain in advanced cancer patients receiving outpatient palliative care. For the study, the Edmonton Symptom Assessment Scale (ESAS), which includes a measure for pain in addition to other common physical and psychological symptoms, was modified to include a measure
for spiritual pain defined as pain deep in the soul or being that is not physical and rated on a 0 to 10 scale (the ESAS-FS). Upon initial assessment, pain was found in 87% of patients and spiritual pain was identified in 44% of the sample. This prevalence increased to 92% and 57% respectively upon the first follow up visit. Moderate to severe levels of spiritual pain (rated 4 or more out of 10) were positively associated with higher levels of pain intensity. Correlation and logistic regression analysis found no significant association between pain and spiritual pain, although the number of variables factored into the regression underpowered the model based on the sample size. Nonetheless, the authors’ ultimate conclusion is supported by their data: spiritual pain a frequent symptom in this sample, is related to physical and psychological distress, and should be included in screening assessments used among this population (Delgado-Guay et al., 2016).

In an exploratory study of spiritual pain in patients with advanced cancer receiving outpatient palliative care services in Chile, the authors explored the relationship between spiritual pain (measured by the ESAS-FS), various measures of quality of life, and demographic variables. Of the 208 participants, 10% reported mild spiritual pain, 26% reported moderate spiritual pain, and 31% reported severe spiritual pain. Spiritual pain was independently associated with worse overall quality of life, multiple physical symptoms, symptom burden, and baseline characteristics of gender (female) and age (younger). Pain, though not independently associated with spiritual pain in this study, was significantly associated with lower quality of life. In this sample, spiritual pain was not associated with self-reported spirituality, religiosity, or religious coping (Pérez-Cruz et al., 2019).
In a study conducted among Indian patients with cancer receiving palliative care services, the prevalence and nature of spiritual distress were examined within the context of Indian economic, cultural, and religious factors. As the findings related to the nature of spiritual distress among this sample is contextually limiting in relation to this authors study, those elements will not be reviewed. However, the authors report the presence of spiritual distress in 17.4% of their sample and a significant relationship between spiritual distress and moderate to severe pain scores (Gielen et al., 2017).

A retrospective descriptive study of culturally and linguistically diverse palliative care patients at EOL in Australia found pain to be one of the most common symptoms burdening patients. Symptom management accounted for the majority of inpatient palliative care admissions, with pain recorded for 76% of those admitted. Less than half of the sample reported overall physical comfort in the last seven days of life. Sixty-nine percent of patients were receiving an opioid analgesic in the last 7 days of life; this increased to 86% on the day of death. Psychosocial distress was found in up to 33% of patients in the last 7 days of life though the data showed consistent use of spiritual or pastoral care in this final week (Green et al., 2018).

In concert with Green et al. (2018), research exploring similar or related aspects of pain and/or spiritual distress lend support to a relationship between the physical and non-physical elements of pain or distress. In a study conducted among Australian women exploring the relationship between persistent pain, psychological distress, and the impact on relationships or emotional connectedness, the authors found significant relationships between pain, psychological distress, and an inability to connect to family and friends (Henne et al., 2015). Rawdin, Evans, and Rabow's (2013) exploration of hope, pain, and
psycho-spiritual factors yielded some insight into the mediating effects of mental and spiritual well-being on the ability to maintain hope even in the presence of cancer pain.

A Taiwanese study of cancer patients’ pain management and psychospiritual distress found overall improvement in psychospiritual variables among the two study groups (improved vs. not improved pain levels) within one week of admission to an inpatient palliative care unit. However, a time-dependent association between unmanaged pain and depression was found, suggesting an association between intractable pain and depression. Though a relatively small finding within the context of the overall study, it does support evidence of the relationship between the physical and non-physical pain elements (Lee et al., 2015).

Krok et al. (2013) examined age differences in the presence of pain and psychological distress in adult cancer patients. The prevalence of pain was high in both younger (81% of those less than 60 years old) and older (and 66% of those 60 years or older) participants with a statistically significant difference found between the two groups in terms of prevalence of, severity of, and distress related to pain (all higher in the younger group). Among the measured elements of psychological factors of distress, younger participants reported significantly higher prevalence, severity, and distress in multiple psychological domains. Multivariate analysis found significant predictors of pain include psychological distress variables (difficulty sleeping, feeling irritable), religious activity, and palliative vs. curative treatment in both age groups and female gender in the older adult group. Although the results of the predictor model were underpowered, the authors’ conclusions regarding the high prevalence of pain in this group, the significant differences in the pain and psychological experiences between
younger and older patients, and psychological factors of distress and pain are worth consideration (Krok et al., 2013).

Other authors have explored spirituality or spiritual care as a protective mechanism for pain, distress, and/or well-being in cancer patients. In an Italian sample of terminal cancer patients on hospice, the relationship between spirituality, quality of life, and other demographic and symptom variables, including pain, was studied. Their findings suggest quality of life was negatively associated with pain, but positively associated with spirituality and coping style (Bovero et al., 2016). These findings are supported by Bai et al. (2018), who examined spirituality and quality of life in black cancer patients being treated for pain in an outpatient setting. As in the previous study, spirituality was a significant protective factor for overall quality of life. Conversely, pain severity and interference demonstrated a significant negative association with quality of life (Bai et al., 2018). In a study conducted in South Africa, religious and spiritual care was associated with lower pain scores and less use of morphine in patients with advanced cancer receiving inpatient palliative services (Ratshikana-Moloko et al., 2020).

In a study conducted among Dutch cancer patients receiving curative or palliative treatment, little evidence was found to support the hypothesis spirituality reduced the impact of cancer-related stressors, such as pain, on distress in this sample (Visser et al., 2018). However, the authors themselves recognize their broad measure of distress (measured with the Dutch version of the Hospital Anxiety and Depression Scale) as an outcome variable could explain this finding. Furthermore, differences in culture, location, ethnicity, etc. related to spirituality, religious activity, and spiritual practices must be considered when comparing these studies.
In a case study of unrelieved pain and suffering in patients with advanced cancer, the authors presented 3 cases in which patients’ inpatient hospitalization was complicated by intractable bone pain, severe psychosocial distress, and delirium. All three cases highlight the physical, psychosocial, and spiritual elements of the pain experience and the paramount need for a multidimensional approach to pain assessment and intervention. The authors’ suggested a pain management algorithm addressing the multiple contributing factors to overall pain and suffering in this population (Mori et al., 2012).

Additional research utilizing qualitative inquiry into the phenomenon of pain tends to focus on the experience in a different context or with similar, but still different, populations than those at EOL on hospice. Smith and Osborn (1998; 2015) have used interpretive phenomenological analysis for exploring the experience of chronic lower back pain and the experience of vulval pain. Qualitative research within the context of advanced illness, primarily cancer, focuses heavily on pain and the use of opiates for pain management (Flemming, 2010; Reid et al., 2008). For instance, Coyle (2004) conducted a phenomenological study on the experience of pain and the use of opioids in patients with advanced cancer. Nonetheless, qualitative exploration and description of pain or spiritual distress at EOL is generally lacking.

**Literature on Measurement Tools**

**Pain**

Operationally, there are multiple validated measures of pain. The most common scales utilized in both general and EOL practice include the Numeric Rating scale (NPS), the Visual Analogue Scale (VAS), and the Verbal Rating Scale (VRS; Williamson & Hoggart, 2005). Multiple authors support the adequate validity of these scales (r > .70,
with other single-item pain intensity scales in multiple studies; Chiarotto et al., 2019; Hjermstad et al., 2011; Jensen, 2003). Due to the single-item nature of these scales, reliability testing is limited, but test-retest analysis shows good indications of reliability within short time periods (NPS, \( r = .59 - .93 \) over 2 days; VAS, \( r = .80 \) over 5 minutes to 1 week; VRS = .71 over minutes). Test-retest reliability decreases over longer time frames, but this is not unexpected given the variable nature of pain (Chiarotto et al., 2019; Hjermstad et al., 2011; Jensen, 2003).

It is important to note these scales are single-item measures of pain intensity, not comprehensive measures of pain. Though other valid and reliable comprehensive pain measures are evident in the literature, these scales are generally not used in common practice and would not be available in the preexisting data. The primary investigator (PI) will take into account the limited nature of these single-item scales when interpreting and discussing the results of data analysis.

The HIS is part of the Centers for Medicare and Medicaid Services’ (CMS) Hospice Quality Reporting Program (HQRP). It consists of standardized items intended to capture patient-level data on each hospice admission, including pain severity on admission. Select HIS items can be used to calculate eight National Quality Forum (NQF), though pain severity is not one of those items. Admission pain severity is categorically recorded on the HIS to reflect the admission pain screening as rated on a NPS, VRS, or VAS. Conversions from the 10-point NPS are as follows: 0 equals “none,” 1 to 3 equals “mild”, 4 to 6 equals “moderate”, 7 to 10 equals “severe.” The recorder can also indicate “pain not rated” for pain not assessed or recorded in the admission record.
Therefore, the HIS pain ratings should reflect admission pain ratings (CMS & HQRP, 2018).

**Spiritual Distress**

Given the intangible and often vague nature of spiritual distress and its potential physical, psychological, and/or spiritual manifestations, it can be difficult to measure and operationalize. Recent validation studies of the nursing diagnosis of spiritual distress in cancer patients have sought to operationalize the concept for nurses by characterizing multidimensional and recognizable expressions of the phenomenon, including anxiety, questioning meaning, fatigue, etc. (Caldeira et al., 2016; 2017). Multiple validated instruments exist to measure various constructs of spiritual distress, such as suffering (e.g. the Pictorial Representation of Illness and Self Measure (PRISM)), hopelessness (e.g. the Demoralization Scale), meaning (e.g. Constructed Meaning Scale), or global distress (the Distress Thermometer) (Best et al., 2015; Vitek et al., 2007). Measures of spiritual-wellbeing, for instance the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT–Sp), are often used to identify spiritual distress as it may relate to lack of or compromise in spiritual well-being (Best et al., 2015).

Adequately validated instruments specifically measuring the larger concept of spiritual distress, particularly at EOL, are lacking (Fitchett et al., 2019). Instruments i.e. the Existential Loneliness Questionnaire (ELQ) and the Spiritual Distress Scale (SDS) show promising internal consistency, but require further validation research to establish their utility in measuring this phenomenon (Best et al., 2015; Ku et al., 2010). Furthermore, the number of items in these scales (22 and 30 items respectively) make them impractical for use by the EOL multidisciplinary team and potentially burdensome.
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for research participants who are at EOL. The Spiritual Distress Assessment Tool (SDAT), which has demonstrated adequate psychometric properties in elderly hospitalized patients, appears less cumbersome than the ELQ or SDS but has not been psychometrically tested in the EOL population (Monod et al., 2012).

In 2016, a subscale to the Edmonton Symptom Assessment System (ESAS) was developed to measure spiritual pain in advanced cancer patients receiving care at a supportive palliative care clinic. This new 12-item instrument, termed the ESAS-FS, measures physical and psychological symptoms (including pain) and spiritual pain on a 0-10 scale (0=None to 10=Worst Possible) using the operational definition of spiritual pain as a “pain deep in [a person’s] soul/being that is not physical” (Delgado-Guay et al., 2016). Validation research on this subscale is currently lacking, but this initial study demonstrates face validity and positive associations with multiple physical and psychological symptoms measured in the original 10-item ESAS (Delgado-Guay et al., 2016). If further research validates this new measure, its brevity, familiarity, and ease of use for patients, families, and clinicians lend it well to operationalization as a valuable tool for the multidisciplinary team.

Most recently, Fitchett et al., (2019) developed the PC-7 model with a team of palliative care chaplains. Their model, based on current literature and practice, quantifiably assesses unmet spiritual concerns in hospitalized patients receiving palliative care near EOL. Key concerns identified in the model include need for meaning; need for integrity, legacy, and generativity; concerns about relationships with family or significant others; fear of death or dying; treatment decisions; religious or spiritual struggle. Suggestive indicators of these identified themes are included in the model and include
hopelessness, regret, isolation, loneliness, family concerns, fear, need for reconciliation, etc. The PC-7 model has initially shown promising face validity among content experts, though further reliability and validity testing is still needed (Fitchett et al., 2019).

In this study, the hospice chaplain identifies areas of spiritual concern in the comprehensive spiritual assessment developed by and for the collaborating hospice agency. These areas of concern include spiritual pain, anger, guilt, hopelessness, loneliness, etc. If spiritual pain or multiple other elements of concern are identified, the researcher will note the presence of spiritual distress. Although this assessment measure has not been studied for validity and reliability in measuring spiritual distress, the conceptual literature and previous studies set a precedent for identification of either spiritual pain or multiple other elements of spiritual concern in identifying an overall presence of spiritual distress (Best et al., 2015; Caldeira et al., 2016, 2017).

**State of and Gaps in Knowledge**

The conceptual, theoretical, and research literature clearly support a relationship between the physical and non-physical elements of the multidimensional pain experience. Pain has been found to be associated with spiritual distress, particularly in the palliative care literature. Given the foundation of modern palliative care in Dame Cicely Saunders’s Total Pain Theory, it is no wonder authors and researchers explore and support the relationship between physical pain, spiritual distress/pain, spirituality/spiritual well-being, and/or other non-physical elements of pain.

However, research among EOL patients, particularly those on hospice, remains lacking. Though one may argue research with those on palliative care and/or with advanced illness is generalizable or transferable to those at EOL on hospice, the advent of
hospice services marks a unique turning point for this subpopulation of palliative care patients. Particularly in relation to this study, the concrete terminal prognosis (6 months or less) that is a prerequisite to hospice adds a sense of urgency to multidimensional symptom management for patients, families, and practitioners alike. For this reason, further research specific to those at EOL on hospice is greatly needed to better inform and influence a holistic practice and symptom management approach.
CHAPTER III

METHODS

The purpose of the study was to examine the relationship between unmanaged pain and spiritual distress in patient’s newly admitted to hospice. In this chapter a description of the design, sample, data collection, and analytic techniques are presented. The protection of human subjects is also addressed.

The research question for this investigation was: Does moderate to severe pain contribute to spiritual distress in patients at EOL?

This research question was answered through the following specific aims:

Aim 1. Describe age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, levels of pain, and spiritual distress among terminally ill adults (age 18 and over) within 5 days of admission to hospice.

Aim II. Explore the relationships among age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, levels of pain, and spiritual distress in this group.

Research Design

A retrospective correlational design was used to examine the relationship between unmanaged pain and spiritual distress in patient’s newly admitted to hospice. Data were extracted from a hospice agency’s electronic health record (EHR). Due to the sensitive nature of the EOL experience for patients and families, as well as the logistic and ethical challenges of collecting data directly from this population, this research design aimed to
utilize pre-collected assessment data regarding these concepts without instigating the burden of time and additional verbal/physical engagement on the patient and family.

**Study Sample and Setting**

The study sample consisted of hospice patients within 5 days after admission to a hospice program. Participants were at least 18 years old and had at least one nursing and one spiritual assessment completed within the initial 5-day timeframe. Those who were not cognitively able to rate their pain using a verbal scale per hospice program policy (non-verbal pain scale utilized); those who did not have a comprehensive spiritual assessment recorded; a hospice diagnosis of dementia or traumatic brain injury with loss of consciousness; or those less than 18 years old were excluded from analysis.

Per hospice regulation and practice, hospice is provided in any setting the patient designates as their place of residence. This could include a personal or family home or a facility setting. Therefore, the setting for this sample reflects this aspect of having been on hospice services.

**Protection of Human Subjects**

Approval for the conduct of this study was obtained from the Institutional Review Board (IRB) of the University of San Diego (USD) and the executive leadership and research committee at the participating hospice agency. A written letter of support from the participating hospice was obtained. The PI and research assistants (RA) completed the appropriate Human Subjects training as required by USD IRB.

Per the participating hospice agency’s request and for human-subject protection during this vulnerable time in the life and disease trajectory, sample data were limited to deceased patients’ records. Case numbers were assigned to medical record numbers from
the agency’s EHR and the password protected electronic document containing these affiliated numbers are kept separately from other data files. Deidentified data files are also password protected. All files are stored on a password-protected computer and synced to a password-protected cloud storage system.

**Data Collection Procedures**

The PI received study specific data extracted from the EHR of a partnering national hospice agency with offices throughout the continental United States. The information was originally collected and documented by hospice agency staff and multidisciplinary professionals. When a patient is referred to hospice, the agency’s admission staff collects demographic information from medical records provided by the referring provider. The demographic information is verified by the admitting RN and during the social worker’s initial comprehensive assessment. The comprehensive admission assessment, which includes the admitting pain assessment and hospice diagnosis, is collected and documented by a hospice RN. At this agency, the comprehensive spiritual assessment is completed by hospice chaplains, who have met minimum state- and agency-specified qualifications for chaplaincy practice. No interrater reliability data were available for these assessments.

**Data Management**

Data were emailed to the PI in a password-protected Excel file. Patient identifiers were coded in Excel, then the deidentified data was imported to SPSS. All files were password protected and stored on password protected laptop with password protected cloud backup. In addition to protection of human subjects and patient privacy education,
training provided to the RA by the PI included data management procedures according to the data/file organization system established by the PI.

Pre-existing data were collected retrospectively from the EHR of a partnering national hospice agency with offices throughout the continental United States. The PI screened cases based on the exclusion criteria, including use of the Pain Assessment in Advanced Dementia (PAINAD) Scale, lack of a comprehensive spiritual assessment, a dementia or traumatic brain injury with loss of consciousness diagnosis, or age (18 years or younger). Measures of spiritual distress were predefined based on the agency-established comprehensive spiritual assessment. Extracted data included pain scores, categorized pain severity as reported on the HIS, areas of spiritual concern, age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, and hospice diagnosis (provided as ICD-9 or 10 diagnosis codes).

**Study Variables and Measures**

**Spiritual Distress.** Spiritual distress is dependent variable of interest (Table 1). Because the comprehensive spiritual assessment was designed specifically by and for this agency, there is no validity or reliability data. The presence of spiritual distress was based on areas of spiritual concern as documented by the hospice spiritual counselor/chaplain within 5 days of admission to hospice. These areas of concern include anger, coping abilities, denial, family concerns, fear, guilt, hopelessness, indifference, loneliness, loss of control, physical pain, sadness, spiritual pain, and other, all of which are reflected directly or indirectly in the conceptual and research literature. Though narrative data was not available to provide information on the concern marked as “other,” it was included and assumed to be a significant concern identified by either the patient or chaplain.
Additionally, physical pain was included as a possible contributor to spiritual distress as it is specifically denoted as causing spiritual concern when identified in this spiritual assessment.

Based on the literature (Best et al., 2015; Caldeira et al., 2016, 2017) and consultation with content experts and multidisciplinary hospice agency leadership, the researcher identified the presence of spiritual distress based on the identification of spiritual pain (considered either synonymous or a sign of spiritual distress) or multiple other spiritual concerns (Table 2). The number of concerns to be included with spiritual pain to categorize patients with spiritual distress was determined by statistical analysis. For data analysis, each variable was categorized as either identified or not identified as a concern.

**Pain at EOL.** Pain at EOL of life is the primary independent variable of interest (Table 1). Though operationally there are multiple validated measures of pain, the retrospective design of this study limits the ability to choose a desired pain measure. However, general hospice practice utilizes subjective single-item pain intensity scales for patients who are cognitively able to rate or classify the severity of their pain. The most common scales utilized are the Numeric Rating scale (NPS), the Visual Analogue Scale (VAS), and the Verbal Rating Scale (VRS; Williamson & Hoggart, 2005). These measures are widely used and demonstrate strong validity and test-retest reliability (Table 2; Chiarotto et al., 2019; Hjermstad et al., 2011; Jensen, 2003). Therefore, for the purpose of this study, pain ratings from any of the aforementioned scales were collected. Any pain ratings from non-verbal pain scales and/or provider observations were
excluded. Additionally, the pain severity (none, mild, moderate, or severe) as reported on the HIS was collected.

Numeric pain ratings were categorized according to the categorization scheme mandated in the HIS pain severity item (0 = none, 1-3 = mild, 4-6 = moderate, 7-10 = severe). This is the same severity categorization used on the VRS. Once categorized, the HIS was found to reflect a higher proportion of patients in moderate to severe pain than the admission pain ratings. The reason for this warrants further investigation, but for the purpose of this study, in an effort to capture all instances of moderate to severe pain, the HIS pain severity was used for data analysis. The HIS pain severity categories were categorized “no or mild pain” or “moderate to severe pain.”

**Other independent variables.** Potential contributing factors for this study include age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, and hospice diagnosis (Table 1). In a studies exploring the correlates of spiritual distress in the advanced cancer population, spiritual distress was significantly associated with age and gender, specifically younger and female patients were more likely to report spiritual distress (Hui et al., 2011; Pérez-Cruz et al., 2019). In another study examining age differences in the presence of pain and psychological distress in cancer patients, younger patients reported higher levels of pain and psychological distress than older patients and were more likely to report pain if functional limitations were present. For the older adult patients, factors significantly predicting increased likelihood of reporting pain included female gender, receiving palliative treatment, and religious activity (Krok et al., 2013). Conversely, multiple studies and conceptual literature find no relationship between religiosity/spirituality and spiritual distress (Caldeira et al., 2016, 2017; Heyse-Moore,
And though multiple studies examine these phenomena within the context of certain diagnoses (e.g. cancer, heart disease), exploration of significant relationships among various diagnoses is lacking.

Categorizing variables was necessary primarily due to small categorical sample sizes (see tables 1 and 4). For marital status, cases identified as married or having a life partner were grouped together, as were those separated or divorced. Cases documented as unknown for marital status were recoded as missing. Due to small sample sizes, multiple racial/ethnic groups had to be categorized as “other” for the race/ethnicity variable. Similarly, the “other” category for religion or spiritual practice is comprised of multiple religious or spiritual practices. For the purpose of this study, it was important to have categories identifying either a non-religious spiritual practice or no religion/spiritual practice. Therefore, cases identified as having no religion or Atheist were categorized together, those identified as agnostic, “spiritual,” or “non-religious/spiritual.” Diagnoses were provided in individual ICD-9 or 10 codes. For analysis, these ICD codes were recoded to either the ICD categorizing scheme (e.g. all ICD-9 or 10 codes under “Neoplasms” were categorized as cancer in this study) or into the “other” category due to small sample size.

**Statistical Analysis**

All data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 26 software. Descriptive statistics were computed to describe demographic and diagnosis data, pain severity, and the presence of spiritual distress. Statistics for age include sample size, mean with 95% confidence intervals, and range. Statistics for categorical variables include frequency and proportion of the total.
For the bivariate analysis, pain severity and demographic variables (independent variables) were analyzed for a significant relationship with spiritual distress (dependent variable). Bivariate analysis of variance identified significant independent variables to be included in the regression model based on $p$-values < .05. Data were analyzed through chi-square and $t$ tests. The Fisher’s Exact test was used for variables with small categorical sample sizes, particularly due to missing data. Once significant and/or relevant independent variables were identified for use in the predictive regression model, the relationship between significant demographic variables, pain severity, and spiritual distress was further explored and explained through binary logistic regression analysis (Table 3).
The purpose of this study was to examine the relationship between moderate to severe pain and spiritual distress in patient’s newly admitted to hospice. Guided by the Total Pain Model, the study aimed to: 1) describe age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, levels of pain, and spiritual distress among terminally-ill adults (age 18 and over) within 5 days of admission to hospice; 2) explore the relationships among age, gender, marital status, race/ethnicity, religious affiliation and/or spiritual practice, hospice diagnosis, pain severity, and spiritual distress in this group. The results related to these specific aims follow.

Study Sample

The initial study sample consisted of patients within five days of admission to hospice between the years 2015 and 2019. Only cases of deceased patients were provided in the dataset. Based on exclusion criteria, cases were eliminated based on use of a PAINAD scale for the admission pain screening; lack of a comprehensive spiritual assessment; a diagnosis of either dementia or a traumatic brain injury with loss of consciousness; or age less than 18 years (see figure 3). Remaining cases (n=3484) consisted of adults (18 years and older) within five days of admission to hospice who received a RN admission assessment and a comprehensive spiritual assessment by the hospice chaplain. The type of residence for hospice services varied, though the majority resided at home (40%), followed by assisted living facilities (20.9%), skilled nursing or long-term care facilities (25%), and inpatient hospice or hospital settings (14.1%).
Figure 4. Cases assessed for eligibility, excluded based on exclusion criteria, and included in the final analysis.

Descriptive Results

Descriptive data of patients admitted to hospice between the years 2015 and 2019 are presented in table 4. The age range for this sample was 25 to 107 years old with a mean age of 82 (SD = 12.08). Over half of the sample were female and white. One third of the patients were married or had a designated life partner, leaving the majority as either widowed, separated or divorced, or single. The vast majority of patients identified as either Catholic (43%) or Protestant (42.4%). Stroke or other circulatory diseases were the leading hospice diagnoses, followed in order of prevalence by cancer, heart diseases, nervous system diseases, diseases categorized as other (see table 4), and pulmonary diseases.

Some variables had a high number of missing values or a low proportion of the total and/or spiritual distress samples. Marital status had 28.7% missing for both the total
sample and the subset with spiritual distress. For race/ethnicity, the total sample was missing 13.1% of data; the percentage dropped to 10.8% for the spiritual distress group. Additionally, the other category within the race/ethnic variable only accounted for 2.7% of those with spiritual distress. Religion or spiritual practice was missing for 28.3% of the total sample and remained similar in proportion at 25.7% missing for those with spiritual distress. The number of those who identified as agnostic/spiritual/non-religious (2.8%), Jewish (3.2%), or “other” (2.4%) was small among the spiritual distress sample.

**Pain and Spiritual Variables**

The reported HIS admission pain severities indicated approximately 16% of the sample had moderate to severe pain. In the comprehensive spiritual assessment, 26% identified at least one spiritual concern. Regarding indicators of spiritual distress, a Mann-Whitney test indicated the number of spiritual concerns (excluding spiritual pain) was greater for the spiritual pain group (Mdn = 3048.44) than for those without spiritual pain (Mdn = 1659.58), $U = 69,064$, $p < .001$. Additionally, the mean number of spiritual concerns (excluding spiritual pain) for the spiritual pain group was 2.71, which supports the identification of 3 more spiritual concerns (excluding spiritual pain) as an additional indicator of spiritual distress in this sample. Therefore, 6% identified spiritual pain as a spiritual concern and an additional 3.6% identified three or more spiritual concerns (excluding spiritual pain), suggesting a total of nearly 10% of patients experienced spiritual distress.
Relationship among Variables

Bivariate Analysis Results

The bivariate associations among the variables of interest are presented in table 5. A t test to examine the mean differences in age for those experiencing spiritual distress showed significantly lower mean age for spiritual distress (M = 80.43, SD = 13.18) than no spiritual distress (M = 82.57, SD = 11.94), t (393.17) = 2.84, p = .005, d = .17. Of the categorical variables examined using chi-square analysis, marital status (χ² (3, N = 2483) = 20.21, p < .001, Cramer’s V = .09), hospice diagnosis (χ² (5, N = 3481) = 22.66, p < .001, Cramer’s V = .08), and pain severity (χ² (1, N = 3464) = 19.75, p < .001, Cramer’s V = .08) were significantly related to spiritual distress. Gender, race/ethnicity, and religion or spiritual practice were not significant in this sample. For the variables with a high number of missing values and low categorical proportions, a Fischer’s Exact test was run but not significant as no cell within the tables had less than 5 observations.

Specific to the chi-square results, 13.5% of those who were separated/divorced and 14.7% who were single experienced spiritual distress, which was significantly more than expected (observed = 35 and 51, respectively, versus expected = 24.8 and 33.4, respectively). A hospice diagnosis of cancer, pulmonary disease, or a diagnosis categorized as other demonstrated the largest difference between observed (85, 38, 39 respectively) and expected counts (70.7, 26, 30.9 respectively) of spiritual distress, while heart disease (17.4%) demonstrated only a slightly higher observed (58) versus expected (57.2) count. Finally, nearly 15% of those with moderate to severe pain also experienced spiritual distress, which was significantly more than expected (observed = 83 versus expected = 54.5) for this variable.
Multivariate Analysis Results

The multivariate associations among the variables of interest are presented in table 6. The assumptions for a binary logistic regression were met as spiritual distress was a dichotomous categorical variable, categories were mutually exclusive, and independent variables were not required to assume a linear relationship, normal distribution, or equal variance within groups. The binary logistic model was statistically significant, $\chi^2 (11) = 45.25, p < .001$, and accounted for 4% of the variance in the presence spiritual distress ($\text{Nagelkerke } R^2 = 0.04$). The Hosmer and Lemeshow Test indicated the model was a good fit ($\chi^2 (8) = 3.227, p = .919$). The model correctly classified 90.4% of cases. Statistical significance was determined by a two-tailed $p$-value of $<.05$.

Five predictor variables were included in the model. Age, marital status, hospice diagnosis, and pain severity were included due to their significance in the bivariate analysis. Though not significant in the bivariate analysis, gender was also included in the model. Married/life partner was the reference category for marital status, while cancer was the reference category for hospice diagnosis.

Marital status (single), hospice diagnosis (pulmonary disease), and pain severity were the significant predictor variables in the model. Age and gender did not demonstrate statistical significance. Pulmonary disease showed 1.8 times greater likelihood of predicting spiritual distress than cancer ($p = .02$). Those who were single were 1.6 times more likely to experience spiritual distress than those who were married or had a life partner ($p = .02$). Being separated/divorce was not significant in this model, this may be due to inadequate power rather than true lack of actual significance. Finally, those with
moderate to severe pain were 1.4 times more likely to experience spiritual distress than those with no to mild pain ($p = .04$).
CHAPTER V
DISCUSSION

The purpose of the study was to explore the relationship between unmanaged pain and spiritual distress in patient’s newly admitted to hospice. The findings from this study provide additional knowledge to the body of evidence for this population. In terms of prevalence, findings differ from previous research. In this study, 41% of cases reported some level of pain (mild to severe). This is slightly less than previous studies that found pain in 50% or more at EOL (Hunnicutt et al., 2017; Kehl & Kowalkowski, 2013; Renz et al., 2018; A. K. Smith et al., 2010; Teno et al., 2015). Previous studies, primarily in the cancer population, identified 79% of patients report at least one spiritual need (Astrow et al., 2018) and up to 67% were found to have spiritual distress (Caldeira et al., 2014, 2016; M.O. Delgado-Guay et al., 2011; Pérez-Cruz et al., 2019; Schultz et al., 2017). In this sample, 26% of patients identified at least one spiritual concern and only 9.6% were considered to have spiritual distress as designated in this study. However, the measures for spiritual distress varied among previous research and this study, therefore a comparison of prevalence should take that into account.

In terms of the relationship found between pain and spiritual distress in previous studies of similar populations, this study affirms similar findings in hospice patients at EOL. Multiple studies involving cancer patients affirm a relationship between pain and spiritual distress (Marvin Omar Delgado-Guay et al., 2016; Gielen et al., 2017; Henne et al., 2015; Hui et al., 2011; Pérez-Cruz et al., 2019). This association was supported for hospice patients at EOL in this sample. Additionally, this study considered multiple
diagnoses in the relational and predictive analysis and found pulmonary disease to be even more significant than cancer for predicting spiritual distress.

Multiple studies explore spiritual distress in the cancer population and to a lesser extent in those with heart disease (Gillilan et al., 2017; Goebel et al., 2009; Ross & Austin, 2015); however, the current literature lacks exploration of spiritual distress in pulmonary disease at any point in the disease trajectory. Older literature related to pulmonary disease and some element(s) of spirituality or the non-physical generally examines concepts such as spiritual well-being, quality of life, religiosity, or psychological distress (Blinderman et al., 2009; Burker et al., 2004; Lohne et al., 2010; Strada et al., 2013). More recent studies regarding pulmonary disease and EOL care focus heavily on the provision and/or indicators of quality palliative and/or EOL care, physical symptomology and management, and factors related to the healthcare spending and utilization of palliative and/or EOL care (De Schreye et al., 2017; Gainza-Miranda et al., 2018; Iyer et al., 2019; Kendzerska et al., 2019; Maddocks et al., 2017). One recent study explored the clinical indicators of depression and spiritual distress in primary palliative care patients, a small number of whom had a diagnosis of chronic obstructive pulmonary disease (COPD), though results were underpowered and limited by sample size (Velosa et al., 2017). A literature review on addressing spirituality in COPD identified few studies investigate the role of spirituality at any point during the disease process (Gergianaki et al., 2019). To this investigator’s knowledge, there are no current studies exploring spiritual distress and pulmonary disease in hospice patients at EOL. Therefore, the findings related to pulmonary disease are unique and fill a gap in the current literature.
Regarding the sociodemographic variables in this study, findings were generally comparable to 2017 Medicare hospice beneficiaries (National Hospice and Palliative Care Organization, 2018). The study sample consisted of nearly 36% males and 64% females, as compared to 41.6% and 58.4%, respectively, in Medicare beneficiaries who received hospice care in 2017. In 2017, 47.5% of Medicare hospice patients were 85 years or older, 47.3% were between the ages of 65 and 84, and 5.1% were less than 65 years old; similarly, in this sample, 48.1% were 85 years or older, 42.4% were between 65 and 84 years old, and 9.5% were less than 65 years old. Medicare hospice beneficiary reports by race, though categorized slightly differently than this study, were slightly less diverse in 2017 than in this study. In 2017, Medicare hospice beneficiaries were primarily white (82.5% versus 64.8% in this study), followed by African American (8.2% versus 15.9%), Hispanic (6.4% versus 17.1%), Asian (1.7% versus 1.6%), other (0.5% versus 0.004% other, 0.001% Armenian, and .001% Native Hawaiian or Pacific Islander), Native American (0.4% versus 0.0007 Native American or Alaska Native), and unknown (0.3% versus 13.1% missing or unknown in this study). Principle hospice diagnoses in 2017 that compare with this study were cancer (30.1% compared to 21.2% in this sample), circulatory/heart disease or stroke (27% versus 48% categorized in the heart, stroke, or circulatory disease ICD-9 or 10 categories in this study), and respiratory disease (11% versus 7.8% of the total study sample) (National Hospice and Palliative Care Organization, 2018).

Medicare does not report on marital status or religion/spiritual practice within the 2017 hospice dataset. However, in the Religious Landscape Study (RLS) conducted in 2014 by the Pew Research Center, 35,000 Americans were surveyed across the United
States (U.S.). The survey found 47% identified as either evangelical, mainline, or historically black Protestant or orthodox Christian while 20.8% identify as Catholic. Included in Christian faiths were Mormon (1.6%) and Jehovah’s Witness (0.8%). Of non-Christian faiths, 5.9% identified as Jewish, 0.9% as Muslim, 0.7% as Buddhist, and 0.7% as Hindu. An additional 22.8% identified as unaffiliated, including 3.1% atheist and 4% agnostic (Pew Research Center, 2014). This demonstrates far more religious/spiritual diversity in a larger U.S. population than is found in this study, which primarily consists of patients who identify as Protestant (42.4%) and Catholic (43%).

This study supports the relationship between the pain and spiritual distress as identified in previous studies with similar populations. When applied in the context of the Total Pain Model, the causal relationship is less important than the existence of a relationship as both physical and spiritual pain are multidirectional contributors to the total pain experience (Mehta & Chan, 2008; Middleton-Green, 2008; Saunders et al., 1995). If one is identified, such as physical pain, screening for the other factors in the model is warranted in an effort to achieve comprehensive and total pain management. Additionally, all of the variables demonstrating significance in this study seem to support the elements of the Total Pain Model (see figure 3), though diagnosis in particular warrants further investigation to better understand the fit within this model.
Figure 5. The Total Pain Model (Mehta & Chan, 2008). Elements of the total pain experience supported by significant variables in this study. The spiritual distress variable as measured in this study.

Study Implications

Practice

Practice implications relate to the admission spiritual distress screening process. All of the variables included in this study are factors the admitting nurse would either know before or obtain during the admission assessment. Therefore, the presence of the significant variables in this study at the time of admission could prompt the nurse to initiate interdisciplinary intervention sooner to ensure an interdisciplinary pain management approach.

This study found a relationship between marital status, hospice diagnosis, pain, and spiritual distress. Specifically, in this sample, moderate to severe pain was associated
with the presence of spiritual distress and was a statistically significant predictor variable for spiritual distress in the regression model. These findings highlight the importance of spiritual distress screening and may indicate the need for more timely spiritual assessment and intervention by the hospice chaplain for those who are admitted with higher levels of pain. For instance, in conjunction with medical and nursing interventions for pain management, a chaplain assessment would be initiated within 24 hours if a patient is admitted with moderate to severe pain versus a chaplain assessment in up to 5 days after admission.

Additionally, lack of social support has a significant relationship with spiritual distress. In this study, being separated/divorced or single were associated with spiritual distress. This may be due to an actual or perceived lack of social support and/or other psychosocial, emotional, and/or spiritual effects of previously severed relationships or lack of a partner at EOL. Interestingly, being widowed was not significantly related to spiritual distress though this group similarly lacked a spouse or partner at EOL. Perhaps this group is more likely to have expanded social support (e.g. children) and/or emotional/spiritual safeguards against spiritual distress related to their relationship with their deceased partner. For practitioners, this study indicates lack of actual or perceived social support through marital status, specifically being separated, divorced, or single, should be recognized by the admitting nurse as a possible contributor to spiritual distress when coupled with moderate to severe pain and a distressing diagnosis, thus warranting more timely assessment and intervention by the interdisciplinary hospice team.

Finally, hospice diagnosis is a significant factor for the admitting nurse to consider. Multiple diagnoses, including cancer, pulmonary disease, and heart disease, had
a significant association with spiritual distress. However, when examined through the predictive model, pulmonary disease indicated a higher likelihood of predicting spiritual distress than cancer. Given the majority of evidence on spiritual distress at or near EOL is related to the cancer population, this finding is of interest. Pulmonary diseases are typically chronic, highly symptomatic at EOL, and may result from lifestyle choices, such as smoking (Blinderman et al., 2009; Kendzerska et al., 2019; Lohne et al., 2010; Maddocks et al., 2017). Perhaps these factors contribute to the increased risk for experiencing spiritual distress and other elements of the total pain experience at EOL. As diagnosis is one of the primary indicators for hospice appropriateness, it lends itself well as a screening factor for spiritual distress by the admission nurse.

**Policy**

At a policy level, the current Medicare-mandated admission spiritual screening process may not be adequate to prompt the needed comprehensive spiritual assessment and subsequent interventions within a smaller timeframe than the current 5-day window. Per Medicare, the nurse must only inquire about spiritual or existential concerns. Depending on the agency, additional information may be obtained, for example religious affiliations or spiritual practices. There is currently no policy to mandate more urgent interdisciplin ary intervention if concerns are identified.

Based upon the findings of this study, information alone may not be adequate to truly identify an increased risk for spiritual distress. However, further exploration of these and additional factors affecting the screening, assessment, and identification of spiritual distress and other elements of the total pain experience and their effect on symptomology and quality of life is warranted. This could inform future policy aimed to increase timely
interdisciplinary intervention for the purpose of comprehensive pain and symptom management and overall comfort at EOL.

**Future Research**

This study prompts many avenues of future research into these phenomena. The results of this exploratory study support the need for further qualitative inquiry, particularly in understanding the total pain experience for patients at EOL including spiritual, psychological, and social elements. This type of inquiry could lay the foundation for future quantitative studies, including development of appropriate screening and assessment measures or psychometric testing of existing measures, such as the PC-7 model (Fitchett et al., 2019) or the Spiritual Distress Assessment Tool (SDAT; Monod et al., 2012), within this population.

Further exploration of precipitating factors of spiritual distress and how admission nurses screen for spiritual and other elements of the total pain experience upon admission to hospice is needed. This could lead to more robust screening measures that prompt more timely and accurate interdisciplinary intervention. Investigation into the screening process could include interventions such as integration of automatic EHR notifications to members of the interdisciplinary team when concerns are identified.

Longitudinal studies of pain and spiritual distress could help identify how time effects these variables at EOL, particularly if physical, spiritual, social, or psychological needs are unmet. One could explore how pain and spiritual needs change over the course of the entire hospice experience, including during times of symptom crisis and/or during the actively dying period. Longitudinal studies increasing our understanding of when interdisciplinary intervention is most needed will inform interventional studies examining
most effective interdisciplinary approaches to total pain management. And given the lack of validated measures for spiritual distress at EOL, these interventional studies should address how spiritual distress is assessed and measured, whether that involves investigating existing instruments validated in other populations or developing validated measures specific to this group and context.

Other avenues of investigation include the differences in the documented admission pain scores and the pain severity reported on the HIS. This raises questions about how nurses are assessing, capturing, and reporting pain upon admission to hospice. In relation to the spiritual distress variable, exploration of the various spiritual concerns identified by this agency’s comprehensive spiritual assessment and how they relate to the spiritual pain concern could shed light on specific psychosocial and/or physical elements contributing to spiritual pain/distress. This exploratory investigation, in addition to qualitative inquiries, could serve as a foundation for future instrument development.

Finally, perhaps the most interesting finding of this study is the significance of diagnosis, particularly pulmonary disease, to spiritual distress. This study uniquely examines various diagnosis categories in relation to pain or spiritual distress at EOL, and it identifies pulmonary disease to be more significant than cancer to predict spiritual distress in this sample. While these phenomena are well documented in the cancer population, pulmonary disease remains largely unexplored, particularly in relation to non-physical elements of pain or distress. Exploratory, longitudinal, interventional, and qualitative investigation specific to this group at EOL would shed light on how this particular diagnosis uniquely shapes the total pain and overall EOL experiences.
Furthermore, as this study categorized diagnosis by type, further investigation of the nature and variance within each diagnosis category may also be warranted.

**Study Limitations**

As a secondary data set, there were limitations to the data obtained. Thus, additional and potentially significant indicators of pain or spiritual distress, including comprehensive pain assessments and narrative data, could not be explored. The data itself is “noisy,” particularly due to lack of interrater reliability. Documentation of pain and spiritual distress will vary among providers based on a number of factors, including skill level, expertise, experience, and general understanding of how to accurately document the variables of interest. Additionally, without the use of a validated measure of spiritual distress at the assessment level, the ability to assess the presence of spiritual distress for the purpose of analysis is weakened. The high proportion of missing and skewed data for some variables is also problematic, though the investigator attempted to account for this in the statistical analysis.

Due to sample sizes, the categorization of certain variables poses challenges to the overall results of the study. For the diagnosis variable, diagnosis codes were categorized based on ICD-9 and 10 categories. This eliminates the variance inherent within each category, such as differences in various types of cancer, pulmonary diseases, etc. The other category for this variable is also problematic as it collapses multiple categories, including potentially distressing diagnoses of HIV, liver, renal, and musculoskeletal diseases. Similarly, the other category for race/ethnicity groups multiple races/ethnicities with vastly different cultures and practices into one, eliminating their possible influence on the results of this study. Finally, the protestant category for religion or spiritual
practice groups 13 different denominations together while the other category groups multiple and vastly different religions and practices. Overall, the inability to capture the variance within these variable categories weakens the results of this study and may warrant future investigation.

Based upon category sample sizes, categories found significant at the bivariate level (e.g. divorced/separated), but not significant in the regression model could be a result of inadequate power versus actual significance. Additionally, although the model is significant and demonstrates a high goodness-of-fit, it only explains 4% of the variance in spiritual distress. This was not unexpected, in the chosen variables were based on what is generally collected during the hospice admission not variables specifically related to spiritual distress. Consequently, further investigation into other, additional, and differing combinations of variables could find models with more predictive power.

As the study is cross-sectional, it does not explore the progression of spiritual distress or pain over the course of hospice admission or length of stay. This snapshot of the phenomena may not be representative of the total experience nor can any cause or effect relationship be explored.

Another limitation is the apparent lack of diversity in religious affiliation and/or spiritual practice reflected in a much larger U.S. sample. However, other sociodemographic variables are relatively consistent with larger samples of Medicare beneficiaries. But in addition to the other limitations, generalizing results of this study to the larger populations should not be considered. Despite these limitations the findings of this study have produced new knowledge regarding spiritual distress and end of life.
Further research is essential to more fully elaborate these and other connections and to design and implement appropriate interventions.

**Conclusion**

Ultimately this study supports the multidimensional nature of pain and spiritual distress for patients at EOL and affirms the Total Pain Model as a guide for multidisciplinary total pain management. Multidisciplinary providers of EOL hospice care must recognize the interrelationship among the physical, spiritual, social, and psychological domains to ensure holistic and comprehensive pain management and the “good” death and dying experience for patients at EOL on hospice. This study describes the relationship between sociodemographic variables, pain severity, and spiritual distress in hospice patients within 5 days of admission and begins to address current gaps in knowledge for EOL care. Expanded and much-needed exploratory, interventional, and qualitative research inquiries are warranted to inform changes in practice that ensure the best possible EOL experience for patients and their families.
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https://doi.org/10.1016/j.jpainsymman.2020.01.019


https://doi.org/10.1089/jpm.2012.0223


https://doi.org/10.1093/annonc/mdm462


https://doi.org/10.1177/1049909117725271


### Tables

#### Table 1

**Variable Table**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Operational Definition</th>
<th>Instrument</th>
<th>Level of Measurement</th>
<th>Descriptive Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spiritual distress/ pain</td>
<td>Presence of spiritual pain or 3 or more other elements of spiritual concern: Anger, Coping abilities, Denial, Family concerns, Fear, Guilt, Hopelessness, Indifference, Loneliness, Loss of control, Physical pain, Sadness, Spiritual pain, Other</td>
<td>Agency-specific comprehensive spiritual assessment: Areas of spiritual concern</td>
<td>Dichotomous (spiritual distress present or not present)</td>
<td>Frequencies and proportions of the total</td>
</tr>
<tr>
<td>Pain</td>
<td>0-10 numeric scale (0 = no pain; 10 = worst pain possible)</td>
<td>Numeric Pain Scale (NPS), Visual Analog Scale (VAS), or Verbal Rating Scale (VRS); categorized as no, mild, moderate, or severe pain on the HIS</td>
<td>Dichotomous (no to mild pain or moderate to severe pain)</td>
<td>Frequencies and proportions of the total</td>
</tr>
<tr>
<td>Demographics or other independent variables</td>
<td>Age, Gender: male/female, Marital status (married/life partner, separated/divorced, single, widowed), Race/ethnicity (black or african american, hispanic or latino, white, other: american indian or alaska native, armenein, asian, native Hawaiian or pacific Islander, other)</td>
<td>N/A</td>
<td>Continuous (age)</td>
<td>Sample size, mean with 95% confidence intervals, median with an interquartile range, minimum values, and maximum values (age)</td>
</tr>
<tr>
<td>Religion or spiritual practice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agnostic/spiritual/non-religious</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Catholic</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Jewish</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Protestant</td>
<td></td>
<td></td>
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<tr>
<td>Other (Bahai, Buddhist, Christian Science, Church of Latter-Day Saints, Hindu, Jain, Jehovah Witness, Mormon, Muslim, Other, Scientologist, Sikh, Unitarian, Wicca/Pagan)</td>
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<td></td>
<td></td>
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<tr>
<td>None/atheist</td>
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</table>

<table>
<thead>
<tr>
<th>Hospice diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
</tr>
<tr>
<td>Nervous system (e.g. ALS or Parkinson’s Disease)</td>
</tr>
<tr>
<td>Heart disease (e.g. congestive heart failure)</td>
</tr>
<tr>
<td>Stroke/circulatory diseases (e.g. peripheral vascular disease)</td>
</tr>
<tr>
<td>Pulmonary (e.g. chronic obstructive pulmonary disease)</td>
</tr>
<tr>
<td>Other (Infectious and parasitic (e.g. HIV); blood and blood forming organs (e.g. anemia); endocrine, nutritional, and metabolic (e.g. protein-calorie malnutrition); digestive system (e.g. liver disease); skin and subcutaneous tissue (e.g. pressure ulcers); musculoskeletal and connective tissue systems (e.g. osteomyelitis); genitourinary system (e.g. renal disease); congenital malformations and chromosomal abnormalities (e.g. Down Syndrome);</td>
</tr>
<tr>
<td>unclassified symptoms or abnormal findings (e.g. dysphagia); injury (e.g. hip fracture)</td>
</tr>
</tbody>
</table>
Table 2

*Instrument Table*

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Description</th>
<th>Items/Subscales</th>
<th>Level of Measurement</th>
<th>Reliability</th>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numeric Pain Scale (NPS)</td>
<td>Range of numbers (e.g. 0-10); 0 represents no pain, 10 represents extreme/worst pain</td>
<td>1 item</td>
<td>Ratio</td>
<td>Test-retest (2-day): $r = .59 - .93$</td>
<td>$r &gt; .70$ (with other single-item pain intensity scales in multiple studies) (Chiarotto et al., 2019; Hjermstad et al., 2011; Jensen, 2003)</td>
</tr>
<tr>
<td>Visual Analogue Scale (VAS)</td>
<td>Line labeled with descriptors of pain intensity (e.g., no pain to extreme pain). Pain score is measurement taken from &quot;no pain&quot; end</td>
<td>1 item</td>
<td>Ratio</td>
<td>Test-retest (5 min to 1 week): $r = .80$</td>
<td>$r &gt; .70$ (with other single-item pain intensity scales in multiple studies) (Chiarotto et al., 2019; Hjermstad et al., 2011; Jensen, 2003)</td>
</tr>
<tr>
<td>Verbal Rating Scale (VRS)</td>
<td>Descriptors/phrases (e.g. none, some, moderate, severe) associated with numeric ratings (e.g. none = 0, severe = 7-10). Score is the number associated with chosen descriptor.</td>
<td>1 item</td>
<td>Ordinal (can convert to ratio)</td>
<td>Test-retest (minutes): $r = .71$</td>
<td>$r &gt; .70$ (with other single-item pain intensity scales in multiple studies) (Chiarotto et al., 2019; Hjermstad et al., 2011; Jensen, 2003)</td>
</tr>
<tr>
<td>Agency-specific comprehensive spiritual assessment</td>
<td>Areas of Spiritual Concern: Anger, Coping abilities, Denial, Family concerns, Fear, Guilt, Hopelessness, Indifference, Loneliness, Loss of control, Physical pain, Sadness, Spiritual pain, Other. Spiritual distress = Presence of spiritual pain or 3 or more other areas of spiritual concern</td>
<td>N/A</td>
<td>Dichotomous (spiritual distress present or not present; spiritual distress care plan opened-yes/no)</td>
<td>None reported</td>
<td>None reported</td>
</tr>
</tbody>
</table>
Table 3

*Analytic Approach*

<table>
<thead>
<tr>
<th>Statistical test (SPSS v26.0)</th>
<th>Study variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Descriptive statistics&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Demographic data, categorized pain severity, presence of spiritual distress</td>
</tr>
</tbody>
</table>
| Bivariate analysis: t test (age) and Chi-squared<sup>b</sup> | Presence of spiritual distress (yes/no)  
Categorized pain severity  
Age  
Gender  
Marital status  
Race/ethnicity  
Religion or spiritual practice  
Hospice diagnosis |
| Binary logistic regression<sup>b</sup> | Spiritual distress  
Pain  
Other significant variables |

<sup>a</sup> Statistics for continuous variables: sample size, mean with 95% confidence intervals, minimum values, and maximum values. Statistics for discrete variables: frequency and proportion of the total

<sup>b</sup> Significant p-value < .05
Table 4

Descriptive data of patients on hospice from 2015-2019, pain severity, and spiritual distress

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total Sample</th>
<th>Spiritual Distress Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=3484</td>
<td>Proportion (%) or Mean (SD)</td>
</tr>
<tr>
<td>Age (range, 25-107y)</td>
<td>3484</td>
<td>82.36 (12.08)</td>
</tr>
<tr>
<td>Gender</td>
<td>3484</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1247</td>
<td>35.8</td>
</tr>
<tr>
<td>Female</td>
<td>2237</td>
<td>64.2</td>
</tr>
<tr>
<td>Marital Status</td>
<td>2483</td>
<td></td>
</tr>
<tr>
<td>Married/Life partner</td>
<td>747</td>
<td>30.1</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>259</td>
<td>10.4</td>
</tr>
<tr>
<td>Single</td>
<td>348</td>
<td>14</td>
</tr>
<tr>
<td>Widowed</td>
<td>1129</td>
<td>45.5</td>
</tr>
<tr>
<td>Missing</td>
<td>1001</td>
<td>28.7</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>3026</td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>480</td>
<td>15.9</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>517</td>
<td>17.1</td>
</tr>
<tr>
<td>White</td>
<td>1961</td>
<td>64.8</td>
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<tr>
<td>Other**</td>
<td>68</td>
<td>2.2</td>
</tr>
<tr>
<td>Missing</td>
<td>458</td>
<td>13.1</td>
</tr>
<tr>
<td>Religion or spiritual practice</td>
<td>2497</td>
<td></td>
</tr>
<tr>
<td>Agnostic/Spiritual/Non-Religious***</td>
<td>63</td>
<td>2.5</td>
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<tr>
<td>Catholic</td>
<td>1073</td>
<td>43</td>
</tr>
<tr>
<td>Jewish</td>
<td>66</td>
<td>2.6</td>
</tr>
<tr>
<td>Variable</td>
<td>Total Sample</td>
<td>Spiritual Distress Sample</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td></td>
<td>n=3484 Proportion (%) or Mean (SD)</td>
<td>n=334 Proportion (%) or Mean (SD)</td>
</tr>
<tr>
<td>Protestant</td>
<td>1059 42.4</td>
<td>110 44.4</td>
</tr>
<tr>
<td>Other****</td>
<td>81 3.2</td>
<td>6 2.4</td>
</tr>
<tr>
<td>None/Atheist</td>
<td>155 6.2</td>
<td>19 7.7</td>
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<tr>
<td>Missing</td>
<td>987 28.3</td>
<td>86 25.7</td>
</tr>
<tr>
<td>Hospice diagnosis</td>
<td>3481 334</td>
<td>22.662 &lt;.001</td>
</tr>
<tr>
<td>Cancer</td>
<td>737 21.2</td>
<td>85 25.4</td>
</tr>
<tr>
<td>Nervous System</td>
<td>480 13.8</td>
<td>28 8.4</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>596 17.1</td>
<td>58 17.4</td>
</tr>
<tr>
<td>Stroke/Circulatory Diseases</td>
<td>1075 30.9</td>
<td>86 25.7</td>
</tr>
<tr>
<td>Pulmonary</td>
<td>271 7.8</td>
<td>38 11.4</td>
</tr>
<tr>
<td>Other*****</td>
<td>322 9.2</td>
<td>39 11.7</td>
</tr>
<tr>
<td>HIS Admission Pain Severity</td>
<td>3464 334</td>
<td>19.748 &lt;.001</td>
</tr>
<tr>
<td>Pain (no-mild)</td>
<td>2899 83.7</td>
<td>251 75.1</td>
</tr>
<tr>
<td>Pain (moderate-severe)</td>
<td>565 16.3</td>
<td>83 24.9</td>
</tr>
<tr>
<td>Spiritual Distress</td>
<td>334 9.6</td>
<td></td>
</tr>
</tbody>
</table>

SD=Standard Deviation
p-values significant at .05 level
*Bold indicates p <.05.
**American Indian or Alaska Native (N=2), Armenian (N=3), Asian (N=48), Native Hawaiian or Pacific Islander (N=4), Other (N=11)
***Agnostic (n=6), Spiritual (n=9), Non-Religious/Spiritual (n=48)
****Bahai (n=2), Buddhist (n=6), Christian Science (n=3), Church of Latter Day Saints (n=1), Hindu (n=7), Jain (n=1), Jehovah Witness (n=16), Mormon (n=7), Muslim (n=3), Other (n=30), Scientologist (n=1), Sikh (n=2), Unitarian (n=1), Wicca/Pagan (n=1)
*****ICD code disease class: Infectious and parasitic (e.g. HIV; n=48); blood and blood forming organs (e.g. anemia; n=9); endocrine, nutritional, and metabolic (e.g. protein-calorie malnutrition; n=129); digestive system (e.g. liver disease; n=73); skin and subcutaneous tissue (e.g. pressure ulcers; n=3); musculoskeletal and connective tissue systems (e.g. osteomyelitis; n=11); genitourinary system (e.g. renal disease; n=9); congenital malformations and chromosomal abnormalities (e.g. Down Syndrome, n=1); unclassified symptoms or abnormal findings (e.g. dysphagia; n=27); injury (e.g. hip fracture; n=12)
a. Spiritual pain or three or more spiritual concerns (excluding spiritual pain) identified as a concern on the comprehensive spiritual assessment.
Table 5

Variables significantly related to spiritual distress

<table>
<thead>
<tr>
<th>Variables (cases analyzed)</th>
<th>Mean (SD) or proportion (%) with Spiritual Distress</th>
<th>t-statistic (df) or Pearson Chi-Square (df)</th>
<th>p-value*</th>
<th>Cohen’s d or Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (n=3484)</td>
<td>80.43 (13.18)</td>
<td>2.844 (393.171)</td>
<td>.005</td>
<td>.170</td>
</tr>
<tr>
<td>Gender (n=3484)</td>
<td></td>
<td>1.030 (1)</td>
<td>.310</td>
<td>.017</td>
</tr>
<tr>
<td>Male</td>
<td>10.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>9.2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status (n=2483)</td>
<td>20.207 (3)</td>
<td>&lt;.001</td>
<td>.090</td>
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<tr>
<td>Married/Life partner</td>
<td>8.7</td>
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<td></td>
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<tr>
<td>Separated/Divorced**</td>
<td>13.5</td>
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<td></td>
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</tr>
<tr>
<td>Single**</td>
<td>14.7</td>
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<td></td>
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<tr>
<td>Widowed</td>
<td>7.7</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Race/ethnicity (n=3026)</td>
<td>2.281 (3)</td>
<td>.516</td>
<td>.027</td>
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<tr>
<td>Other</td>
<td>11.8</td>
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<tr>
<td>Black or African American</td>
<td>10.2</td>
<td></td>
<td></td>
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<tr>
<td>Hispanic or Latino</td>
<td>8.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>10.1</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Religion or spiritual practice (n=2497)</td>
<td>2.977 (5)</td>
<td>.704</td>
<td>.035</td>
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<tr>
<td>None</td>
<td>12.3</td>
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<td></td>
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<tr>
<td>Agnostic/Atheist/ Spiritual/ Non-Religious</td>
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<tr>
<td>Protestant</td>
<td>10.4</td>
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<td></td>
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<tr>
<td>Catholic</td>
<td>9.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jewish</td>
<td>12.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>7.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospice diagnosis (n=3481)</td>
<td>22.662 (5)</td>
<td>&lt;.001</td>
<td>.081</td>
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</tr>
</tbody>
</table>
### Variables (cases analyzed)  

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean (SD) or proportion (%) with Spiritual Distress</th>
<th>t-statistic (df) or Pearson Chi-Square (df)</th>
<th>p-value*</th>
<th>Cohen’s d or Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer**</td>
<td>11.5</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>ALS/Nervous System</td>
<td>5.8</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Heart Disease**</td>
<td>9.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke/Circulatory Diseases</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pulmonary**</td>
<td>14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other**</td>
<td>12.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Pain Severity</strong> (n=3464)</td>
<td>19.748 (1)</td>
<td>&lt;.001</td>
<td>.076</td>
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<tr>
<td>No to mild</td>
<td>8.7</td>
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<tr>
<td>Moderate to severe**</td>
<td>14.7</td>
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</tr>
</tbody>
</table>

*df=degrees of freedom  
*p-values significant at .05 level  
*Bold indicates p <0.05.  
**Observed count > expected count
Table 6

*Binary logistic regression of hospice patients’ characteristics and pain severity associated with spiritual distress*

<table>
<thead>
<tr>
<th>Variables (n=2472)</th>
<th>β</th>
<th>S.E.</th>
<th>Wald</th>
<th>p-value*</th>
<th>OR</th>
<th>(95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-.010</td>
<td>.006</td>
<td>2.306</td>
<td>.129</td>
<td>.990</td>
<td>(.978-1.003)</td>
</tr>
<tr>
<td>Gender</td>
<td>-.091</td>
<td>.513</td>
<td>10.636</td>
<td>.546</td>
<td>.913</td>
<td>(.680-1.227)</td>
</tr>
<tr>
<td>Marital Status</td>
<td>8.988</td>
<td>.029</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separated/Divorced v. Married/Life Partner</td>
<td>.420</td>
<td>.228</td>
<td>3.382</td>
<td>.066</td>
<td>1.522</td>
<td>(.973-2.382)</td>
</tr>
<tr>
<td>Single v. Married/Life Partner</td>
<td>.486</td>
<td>.206</td>
<td>5.551</td>
<td>.018</td>
<td>1.625</td>
<td>(1.085-2.435)</td>
</tr>
<tr>
<td>Widowed v. Married/Life Partner</td>
<td>-.022</td>
<td>.191</td>
<td>.013</td>
<td>.909</td>
<td>.979</td>
<td>(.673-1.422)</td>
</tr>
<tr>
<td>Hospice diagnosis</td>
<td>16.103</td>
<td>.007</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>ALS/Nervous System v. Cancer</td>
<td>-.491</td>
<td>.276</td>
<td>3.169</td>
<td>.075</td>
<td>.612</td>
<td>(.356-1.051)</td>
</tr>
<tr>
<td>Heart Disease v. Cancer</td>
<td>.135</td>
<td>.230</td>
<td>.344</td>
<td>.557</td>
<td>1.145</td>
<td>(.729-1.798)</td>
</tr>
<tr>
<td>Stroke/Circulatory Diseases v. Cancer</td>
<td>.047</td>
<td>.211</td>
<td>.049</td>
<td>.825</td>
<td>1.048</td>
<td>(.693-1.583)</td>
</tr>
<tr>
<td>Pulmonary v. Cancer</td>
<td>.609</td>
<td>.255</td>
<td>5.681</td>
<td>.017</td>
<td>1.838</td>
<td>(1.114-3.033)</td>
</tr>
<tr>
<td>Other v. Cancer</td>
<td>.437</td>
<td>.245</td>
<td>3.184</td>
<td>.074</td>
<td>1.547</td>
<td>(.958-2.500)</td>
</tr>
<tr>
<td>Moderate to severe pain</td>
<td>.364</td>
<td>.174</td>
<td>4.410</td>
<td>.036</td>
<td>1.440</td>
<td>(1.025-2.023)</td>
</tr>
</tbody>
</table>

\(\chi^2(11) = 45.25, p<.001, R^2=0.04\)

Hosmer and Lemeshow Test: \(\chi^2(8) = 3.227, p = .919\)

OR = odds ratio. CI = confidence interval.

*p-values significant at .05 level

*Bold indicates \(p <0.05\).*
Appendix A

IRB #: IRB-2019-477
Title: Pain and Spiritual Distress at End of Life
Creation Date: 6-24-2019
End Date:
Status: Approved
Principal Investigator: Kathryn Robinson
Review Board: USD IRB
Sponsor:

Study History

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Key Study Contacts

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<th>Member</th>
<th>Role</th>
<th>Contact</th>
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<tbody>
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