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Pain and Spiritual Distress at End-of-Life

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Purpose/Aims Observations of current hospice practice for spiritual screening and assessment led to the formation of the following research question and area of dissertation study: are hospice patients who have moderate to severe pain within 5 days of admission to hospice compared to those with mild to no pain at increased risk for spiritual distress? Therefore, the purpose of this dissertation study is to 1) describe levels of physical pain, spiritual distress, age, gender, religious affiliation and/or spiritual practice among terminally-ill adults (age 18 and over) within 5 days of admission to hospice; 2) examine the relationship between physical pain and spiritual distress levels in this group; and 3) examine the relationships between and among physical pain, spiritual distress, age, gender, and religious affiliation and/or spiritual practice in this group.

Rationale/Background Pain is a common symptom of EOL care, and interdisciplinary professionals who practice in hospice and EOL are considered specialists in managing pain and the many other potential physical, emotional, and spiritual issues that may arise for patients at EOL. However, while hospice professionals frequently acknowledge the need for an interdisciplinary approach to pain and symptom management, the current Medicare-mandated spiritual screening and assessment process does not account for more timely assessment in patients with unmanaged pain. 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. Or if a patient or family declines a comprehensive spiritual assessment during the initial RN screening, spiritual distress may go unidentified all together at the detriment of a more holistic and comprehensive pain management approach.

Current evidence supports both an increased prevalence of and a positive relationship between increased physical pain and spiritual distress for those with advanced cancer and/or receiving palliative care services. 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 confirmed this high prevalence of pain in over 60% of patients on hospice (Hunnicutt, Tjia, & Lapane, 2017; Teno, Freedman, Kasper, Gozalo, & Mor, 2015). In multiple studies sampling from the cancer population, spiritual distress was reported or identified in 23-44% of patients (Caldeira et al., 2014; Caldeira, Timmins, de Carvalho, & Vieira, 2016, 2017; Hui et al., 2011; Schultz, Meged-Book, Mashiach, & Bar-Sela, 2017). In multiple studies involving patients with advanced cancer, pain has been associated with increased psychological and/or spiritual distress (Delgado-Guay et al., 2016; Henne, Morrissey, & Conlon, 2015; Krok, Baker, & McMillan, 2013). While the cancer or advanced illness population may be similar to the EOL/hospice 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. Additionally, spiritual distress still remains a relatively understudied area, and, in anecdotal experience, assessment and management of physical symptoms often take precedence over interventions for spiritual distress. Further research is needed to determine the relationships between physical pain, spiritual distress, and factors such as age, gender, and religious affiliation/spiritual practice specific to EOL patients assigned to hospice care.

Methods This quantitative study will utilize pre-existing data to examine the relationship between physical pain, spiritual distress, and relevant demographic factors in a group of terminally-ill adults (age 18 and over) within 5 days of admission to hospice. 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 aims 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. Data from the proposed study will serve as a basis for future investigation of more holistic symptom management in this population.

Results Pending

Implications. 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. Therefore, data from the proposed study to explore the relationships between physical pain, spiritual distress, and relevant demographic factors in a group of terminally-ill adults (age 18 and over) within 5 days of admission to hospice will fill current gaps in the knowledge base regarding this area. Findings from this study could ultimately lead to expanded and much-needed multidisciplinary qualitative and quantitative research and changes in practice to ensure the best possible EOL experience for adults at EOL and their caregivers.

Title:
Pain and Spiritual Distress at End-of-Life

Keywords:
Hospice/End of Life, Pain and Spiritual Distress

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Abstract Summary:

Exploring the relationship between moderate/severe pain and spiritual distress in adult hospice patients within 5 days of admission will begin to address current gaps in knowledge that could lead to expanded multidisciplinary research and changes in practice to ensure the best possible EOL experience for adults at end of life.

Content Outline:

1. Introduction
    1. While hospice professionals frequently acknowledge the need for an interdisciplinary approach to pain and symptom management, the current Medicare-mandated spiritual screening and assessment process does not account for more timely assessment in patients with unmanaged pain. Therefore, the identification of spiritual distress as a component of unmanaged pain may be delayed as well as the need for spiritual or psychosocial interventions.
    2. This observation led to the formation of the following research question and area of dissertation study: are hospice patients who have moderate to severe pain within 5 days of admission to hospice compared to those with mild to no pain at increased risk for spiritual distress?
    3. Purpose:
        1. To describe levels of physical pain, spiritual distress, age, gender, religious affiliation and/or spiritual practice among terminally-ill adults (age 18 and over) within 5 days of admission to hospice.
        2. Examine the relationship between physical pain and spiritual distress levels in this group.
        3. Examine the relationships between and among physical pain, spiritual distress, age, gender, and religious affiliation and/or spiritual practice in this group.
2. Body
    1. Learning Objective #1: To describe current gaps in research on pain and spiritual distress at end of life.
        1. Supporting point #1 (Background): The current Medicare-mandated spiritual screening and assessment process does not account for a relationship between unmanaged pain and spiritual distress.
            1. 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.

        2. If a patient or family declines a comprehensive spiritual assessment during the initial RN screening, spiritual distress may go unidentified all together at the detriment of a more holistic and comprehensive pain management approach.
    2. Supporting point #2 (Significance): The current literature supports both an increased prevalence of and relationship between pain and spiritual distress in the palliative /or advanced illness populations.
        1. 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 confirmed this high prevalence of pain in over 60% of patients on hospice (Hunnicutt, Tjia, & Lapane, 2017; Teno, Freedman, Kasper, Gozalo, & Mor, 2015).
        2. In multiple studies sampling from the cancer population, spiritual distress was reported or identified in 23-44% of patients (Caldeira et al., 2014; Caldeira, Timmins, de Carvalho, & Vieira, 2016, 2017; Hui et al., 2011; Schultz, Meged-Book, Mashiach, & Bar-Sela, 2017).
        3. In multiple studies involving patients with advanced cancer, pain has been associated with increased psychological and/or spiritual distress (Delgado-Guay et al., 2016; Henne, Morrissey, & Conlon, 2015; Krok, Baker, & McMillan, 2013).
    3. Supporting point #3 (Gaps in Knowledge): Further research is needed to determine the relationship between pain, spiritual distress, and relevant demographic factors specific to EOL patients on hospice, which could eventually help address gaps this author believes exist in the current practice.
3. Learning Objective #2: To discuss the chosen study variables and methodological approach of this dissertation study.
    1. Supporting point #1 (Research Design): This is a proposed retrospective correlational study to examine the relationship between unmanaged pain, spiritual distress, and relevant demographic factors in adult patient's newly admitted to hospice.
        1. Data collection will be done through electronic health record (EHR) review of nursing and spiritual assessments within 5 days of admission to hospice.
        2. 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 aims 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.
        3. With this initial data collection, this researcher aims to establish support and validation for further qualitative and quantitative inquiry directly from patients and families.
    2. Supporting point #2 (Study Variables): The main variables of interest for this study are pain and spiritual distress.
        1. For the purpose of this study, verbal pain ratings as documented from the verbal pain scale(s) utilized by the hospice agency will be collected and quantified (as needed) for statistical analysis. Any pain ratings from non-verbal pain scales and/or provider observations will be excluded.
        2. The presence of spiritual distress will be determined based on predefined measures contained in the spiritual assessment completed by the hospice spiritual counselor/chaplain or social worker within 5 days of admission to hospice.
4. Conclusion (Implications of Research Study): By initiating a study to determine the relationship between moderate to severe pain and spiritual distress in hospice patients within 5 days of admission, this author will begin 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 adult hospice patients and their caregiver(s).

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Author Summary: Kathryn Robinson is a Masters-level prepared RN and second-year PhD in Nursing student at the University of San Diego. She began her work in hospice and palliative care in 2009 and has been a Certified Hospice and Palliative Nurse since 2011. Reflective of her deep commitment to hospice and palliative patients and professionals and to the science of nursing, she is dedicated to research and education in multidisciplinary palliative and end of life care.