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Evaluation, Treatment, and Education In The Hospice Setting By Initiating a Formalized Pain Card

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EVALUATION, TREATMENT, AND EDUCATION IN THE HOSPICE SETTING BY
INITIATING A FORMALIZED PAIN CARD

by

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Bachelor of Science in Nursing
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DEDICATION

I dedicate this quality improvement project first and foremost to my daughters Zoey and Zara. They are my life and the reason that I work hard for everything I do. Next, I am honored to send my dedication, gratitude, and love to my partner in life Sergio Zamorano for the continuous support financially and emotionally. Also, I must dedicate this work to my parents and two sisters for the constant support through the entire process. Lastly, I want to dedicate this work to all the hospice patients and families who allowed me to come into their homes and care for them during their end of life transition.

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ABSTRACT

The purpose of this DNP quality improvement project was to evaluate the use of a formalized pain card that Nurse Practitioners could use to assist clients and caregivers in making the decisions necessary for safe and effective pain management with improving outcomes by using the Brief Pain Inventory Form for measuring: 1) decreased pain, 2) increased pain, 3) pain relief. The appraised evidence suggested that there was a need for a policy standard for patients to notify when pain is unrelieved despite exhausting all other efforts to control pain (Glowacki, 2015). Forty-one (n=41) hospice patients were surveyed pre and post intervention regarding their perception of pain. With a response rate of 100% pre and post intervention, participants reported their highest level of pain over the last 24 hours as 5.56 pre and 5.44 post introduction of the pain card. For pain at its lowest level over the last 24 hours, participants rated their pain at 1.90 pre-pain card and 1.61 post-pain card. For current pain, participants' mean pain score pre-pain card was 3.44 and post-pain card 2.54. Participants reported, over the last 24 hours, that pain medications provided relief 71.95% of the time pre-pain card and 72.68% of the time post-pain card. Parametric and non-parametric matched t-tests for pain variables of participants revealed there was a statistically significant difference for pain over the last 24 hours for parametric matched t-test ($P = .0503$) and not significant for nonparametric test ($P = .0667$), indicating that pain was reduced with the formalized pain card. The results revealed statistically significant differences for current pain from pre to post intervention for both parametric and nonparametric tests ($P = .0002$ and $P < .0001$),

indicating that the formalized pain card decreased current pain. However, the statistical results did not indicate any statistically significant differences from pre to post intervention for pain at its worst over the last 24 hours and for pain relief using medication over last 24 hours, indicating that the pain card was not effective. According to statistical data, pain was not reduced post intervention using the pain card for assessing pain at its worst over 24 hours. For determining the relief of pain using pain medications and treatments within a 24-hour time frame; the formalized pain card did not seem to provide any more pain relief from pre to post intervention. According to McNemar's test, the DNP project results were not statistically significant ($p=.5271$), indicating that the pain card intervention did not produce any differences in pain from pre to post intervention. This project was consistent with the evidence that initiating the formalized pain card provided a quality improvement intervention for patients and caregivers at end of life to promote overall well-being by decreasing overall pain.

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CHAPTER 1

INTRODUCTION

Hospice in the United States is predominantly a home-based entity relying heavily on an informal, unpaid caregiver (Oliver et al., 2013). Approximately 67% of hospice care is provided by informal caregivers (Kelley, Demiris, Nguyen, Oliver, & Wittenberg-Lyles, 2013). Informal caregivers typically include family, friends, and in some circumstances hired non-professionals (Mayahara, Paice, Wilbur, Fogg, & Foreman, 2014). Informal caregivers face many challenges with managing individual's pain being foremost (Kelley, Demiris, Nguyen, Oliver, & Wittenberg-Lyles, 2013; Laguna, Goldstein, Braun, & Enguidanos, 2014).

In a survey of 310 patients with end of life illnesses, patients identified pain management as their number one concern reporting pain 50-90 percent of the time during end of life illness (Woo et al., 2006). Patient maladaptive behaviors exhibited at end of life often arise from pain itself and the fear of ineffective managed pain (Woo et al., 2006). Compounding this concern are barriers in treating hospice patients pain, thus, lead to poorer outcomes (Wells, Pasero, & McCaffery, 2008). Poor outcomes that can occur if pain is not managed adequately can be a suppressed immune system, decreased mobility, feelings of anxiety and depression, loss of appetite, helplessness, and hopelessness (Wells, Pasero, & McCaffery, 2008).

The purpose of this project is to evaluate the use of a formalized pain card that Nurse Practitioners can use to assist clients and caregivers in making the decisions necessary for safe and effective pain management with improving outcomes by using the Brief Pain Inventory Form for measuring: 1) decreased pain, 2) increased pain, 3) pain relief with pain medication, and 4) when to notify the caregiver to administer analgesics. The purpose of this chapter is to describe barriers and best practices to effective pain management among hospice patients.

Statement of the Problem

Barriers to effective pain management include inability to assess pain, reluctance to administer pain medication, fears about narcotic pain medication including overdose or addictions, noncompliance with regimens, hesitancy to report pain to providers, caregiver role strain, and lack of caregiver education (Oliver et al., 2008). When pain is not controlled, it not only affects the patient negatively but also the caregiver (Rudabaugh, Baum, DeMoss, Fello, & Arnold, 2002). For the patient, pain causes an overwhelming amount of suffering leading to depression, sleep issues, fatigue, the need for more assistance with activities of daily living, hopelessness, and anger (Redinbaugh et al., 2002). For the caregiver, pain causes caregivers to feel helpless, burdened, and frustrated (Redinbaugh et al., 2002). In fact, evidence supports a positive linear relationship between patient pain and caregiver depression (Redinbaugh et al., 2002). It follows that effective pain management is vital for both the patient on hospice and the caregiver.

Medication pain management is a complex entity that is usually the responsibility of the caregiver in the home (Lau et al., 2009). However, evidence indicates that caregivers lack educational preparation or training to manage pain (Lau et al., 2012).

Even hospice providers do not educate or train caregivers on effective pain management (Lau et al., 2012). Hospice medications are extremely potent with severe side-effects which require monitoring and other skills that must be taught to the caregiver (Lau et al., 2010).

To date, there are no formalized clinical standards detailing hospice providers' responsibility or process in teaching caregivers how to manage complex medication regimens (Lau et al., 2012). Nurse practitioners play a vital role in the care and management of hospice patients and are in a unique position to educate and train caregivers. According to the American Academy of Nurse Practitioners, nurse practitioners are quickly becoming the preferred provider to patients in all areas of healthcare, including hospice care (Fox, 2014). The purpose of this project is to evaluate the use of a formalized pain card that Nurse Practitioners can use to assist clients and caregivers in making the decisions necessary for safe and effective pain management with improving outcomes by using the Brief Pain Inventory Form for measuring: 1) decreased pain, 2) increased pain, 3) pain relief with pain medication, and 4) when to notify the caregiver to administer analgesics. The aim is to increase caregiver competence and confidence in medication administration resulting in better pain management for the person on hospice.

Significance

Hospice is a highly sought out service for patients especially those needing pain management. It is estimated that 1.5 to 1.6 million patients received some sort of hospice care in 2013 (National Hospice and Palliative Care Organization, 2013). In 2013, there were 5,800 Hospice agencies in all fifty states, the District of Columbia, Puerto Rico,

Guam, and the U.S. Virgin Islands, representing a 41% growth in hospice facilities since 2000 (National Hospice and Palliative Care Organization, 2012; Carlson, Bradley, Du, & Morrison, 2010).

According to the National Hospice and Palliative Care Organization (2012), approximately 45% of all deaths in the United States occurred while patients were in a hospice program. Accounting for the patients' primary diagnoses while in hospice services in descending order are cancer (36.5), dementia (15.2), heart disease (13.4), and lung disease (9.9), other (6.9), unspecified debility (5.4%), stroke or coma (5.2), end stage renal disease (3.0%), liver disease (2.1%), non-ALS motor neuron disease (1.8%), amyotrophic lateral sclerosis (0.4%), and HIV/AIDS (0.2%), (National Hospice and Palliative Care Organization, 2014). Approximately 94% of the hospice care is provided in the patient's home or residence (National Hospice and Palliative Care Organization, 2013). Care is provided by an informal and unpaid caregiver 59% of the time (National Hospice and Palliative Care Organization, 2015).

In South Carolina, approximately 70,000 patients received hospice services in 2015 (Carolina's Center for Hospice & End of Life Care, 2015). In South Carolina, the top three leading causes of death is heart disease (6,629 people), cancer (5,752 people), and stroke (1,951 people) (Lancaster County, SC Health Information, 2007).

In terms of costs and coverage, Congress passed the Medicare hospice benefit in 1982 resulting in at least 84% of hospice services covered by Medicare by 2012 (National Hospice and Palliative Care Organization, 2012). According to the national hospice and palliative care organizations, overall Medicare expenditure on hospice services are approximately \$15.1 billion. However, hospice reduces overall system costs by reducing

hospital readmissions, inpatient deaths, and hospital and ICU days (National Hospice and Palliative Care Organization, 2015). Estimates indicate that hospice care decreased Medicare expenditure by an average of \$2,309 per hospice patient.

Not only does hospice save health care dollars, it also improves quality of care during end of life and increases patient satisfaction. Key quality of life indicators for hospice patients are freedom of pain, effective breathing, and decreased anxiety (Havens Lang, Cabin, Cotten, & Domizio, 2010). Findings from surveys suggest that 73.5% of individuals rated their own or their loved one's hospice service as excellent (National Hospice and Palliative Care Organization, 2014).

In terms of caregiver training, a majority of caregivers lack healthcare training and skills to manage complex diseases and pain levels which makes it difficult for informal caregivers to adequately perceive the individual's level of discomfort and pain control (Mayahara et al., 2014). Informal caregivers are family members, friends, or hired individuals who help individuals that cannot function independently (LA Health, 2010). They typically do not have any healthcare education or licensures (LA Health, 2010). According to Kelly, Demiris, Nguyen, Oliver, and Wittenberg-Lyles (2013), the most often identifiable area of burden to caregivers is the inability to control pain. Inadequate pain management can lead to adverse clinical outcomes, unnecessary suffering, and decreased quality of life (McNeill, Reynolds, & Ney, 2007). Alleviating pain at end of life is of utmost importance and is a national health concern which has been identified as a top research priority (Herr et al., 2010).

Core skill and knowledge areas in administering analgesics include the ability to store medications properly, organize medications properly, recognize pain symptoms,

decide how much and how often to administer analgesics, measure the correct medication dose, and correctly administer the medications (Lau et al., 2010). However, data demonstrates that caregivers are hesitant to administer pain medication (Oliver et al., 2008). Caregivers concerns included tolerance, side effects, and addiction (Oliver et al., 2008). Lau et al. (2010) found that 80% of informal caregivers were administering pain analgesics to without any standard policy, education, training, or procedure. In addition, evidence demonstrates that caregivers focus on cure as opposed to comfort measures and overall, pain management remains a challenge for caregivers (National Institute on Aging, 2016).

In 2010, Medicare created guidelines that required any patient entering into their third hospice benefit period to have a face-to-face encounter with a hospice physician or nurse practitioner (Kennedy, 2012). Nurse practitioners typically do most of the geographically distant face-to-face visits because of the shortage of general practice physicians who usually serve as hospice physicians (Kelly, 2014). Nurse practitioners function by collaborating with a hospice physician to develop a plan of care for pain management (Vallerand, Musto, & Polomano, 2011). By leading the hospice team, nurse practitioners can offer support and empower patients and their families/caregivers to engage in self-management of pain (Vallernd et al., 2011). Empowering strategies include educating the patients and caregivers about the analgesic medications, side effects, dosing, and interactions (Vallerand et al., 2011; Jones, Treiber, & Jones, 2014).

According to Bowen (2016), the ability of an individual to read, understand, and apply concepts heavily determines written and oral education. In addition, poor health literacy is a key factor in medication non-adherence (Jones, Treiber, & Jones, 2014).

Critical factors can promote learning and retention of health information for hospice patients and their caregivers. The first factor is for the nurse practitioner to recognize the patient's or caregiver's level understanding. Key messages to poor understanding include poor compliance with treatments, medication confusion, and constant excuses for not reading written health literacy materials (Bowen, 2016). Second, health literacy materials must be culturally and consumer appropriate using a second grade reading level that avoids health care jargon (Bowen, 2016). Third, providing a succinct message assists with retention. According to research, patients typically retain 50% of information per appointment (Bowen, 2016). Fourth, using the teach-back method increases information retention (Bowen, 2016)

By educating hospice patients and their caregivers, nurse practitioners can empower patients and caregivers to have the best possible outcomes (Jones, Treiber, & Jones, 2014). This practice evaluation project will initiate a pain card to be used with every Hospice patient and caregiver. The idea of the formalized pain card was developed based off an evidence-based algorithm for the treatment of neuropathic pain and adapted to the hospice setting (Finnerup, Otto, Jensen, & Sindrup, 2007). With the introduction of the formalized pain card, it is anticipated that caregivers will feel less hesitancy in administering potent narcotics because they will have a sense of direction and know who to call in a time of need. The formalized pain card has several steps; the initial step is to determine the level of pain the patient is experiencing. There are three scales that can be used and the first scale is the numerical pain scale which is a scale from 0 to 10. According to McCaffery and Beebe (1989), the patient will rate pain with 0 being no pain at all and 10 being the worst pain ever felt. This scale is for the mentally competent

patient who can verbally rate pain (McCaffery & Beebe, 1989). The next scale is the Wong-Baker FACES scale which consists of six faces all depicting different emotions, each of the faces represents a numerical value for pain (Wong & Baker, 1988). With the Wong-Baker FACES scale, the patient will rate pain based on the emotion of the face. The first face is no pain so the pain level is 0. The second face depicts a little bit of pain which is rated at a 2. The third face depicts a little more pain and is rated at a 4. The fourth face shows even more pain which is rated at a 6. The fifth face depicts a lot of pain which is rated at an 8. The sixth face is the worst pain ever experienced which is rated at a 10. The Wong-Baker FACES scale will be used on the nonverbal patient who is mentally competent enough to rate their own pain. The final scale is the face, legs, activity, cry, and consolability scale which is also known as the FLACC scale (National Hospice and Palliative Care Organization, 2002). This scale is formatted into a table and 0-2 points are assigned to each of five categories; these categories include face, legs, activity, cry, and consolability. The total points that can be scored is 10 being the worst pain and 0 being no pain at all. The FLACC scale will be used on the patient who is non-verbal and not mentally capable of rating their own pain. With each of these scales, proper analgesic medications can be administered based on the score that is given to the patient's pain (National Hospice and Palliative Care Organization, 2002). After the patient rates the pain on one of the three scales, the patient is welcomed to describe their pain using descriptive words of their choosing if able. There are some examples listed on the pain card which include aching, burning, tender, numb, piercing, pounding, tight, cramping, pulsing, tingly, gnawing, sharp, stabbing, nagging, shooting, and pinching.

Once the pain is rated and described, pain location should be determined. It is also important for the caregiver to note which pain measure has been previously efficacious or not. Once the caregiver determines the quality of pain, location, and measures of relief, the caregiver can refer to the Card for an algorithm in the selection of the most appropriate pain intervention or notify a healthcare professional for additional assistance.

The algorithm is a step by step process. The first step asks if the pain is currently well controlled which branches to a yes and a no. If the pain is controlled, then the algorithm directs the patient and or caregiver to no further intervention. If pain is not well controlled based on prior questions, the patient or caregiver moves down the algorithm to the next question which asks if analgesics been administered. If no, the algorithm directs the patient or caregiver to administer analgesic medications and re-evaluate pain in 30 minutes to 1 hour. If analgesics have been administered, then the next step is to call the on call number for the county in which the patient resides and give the numerical value based on the scales provided, the pain descriptor words if possible, location of pain if possible, and current medication used for pain management. With the introduction of the formalized pain card, hospice patients should experience less pain because caregivers will have more direction in the administration of analgesics and directions for when and who to call when the analgesic regimens are not effective.

Best Practices

Addressing caregiver pain medication administration is a multifaceted entity requiring special attention. Caregivers must be able to manage all skills associated with medication administration while also understanding how to assess for side effects (Lau et al., 2010). As stated previously, hospice medication regimens are often complicated.

Caregivers are typically unprepared and lack education and training to care for hospice patients. They additionally possess a low health literacy in South Carolina, thus, providers must take steps to empower caregivers to care for hospice patients including pain management.

For example, many adults over the age of 65 years old have a significant lack in reading and comprehension skills (Healthy People 2010, 2010). The literature indicates a strong linear relationship with poor health literacy and advanced age (Healthy People 2010, 2010). For increased adherence to medication regimens in this patient population, it is necessary that written materials be simple and specific, conforming to literacy principles (Healthy People 2010, 2010). The formalized pain card for this practice evaluation project is simple to use and will guide patients and caregivers with ease. It is based on a second grade reading level with arrows to easily guide the patient and caregiver through algorithm.

There is a paucity of literature on formalized pain cards used in the hospice setting, however, a similar tool has been used in a Florida hospice program to educate and treat overall patient pain (Northeast Florida Community Hospice Compassionate Guide). Similar to the pain card for this DNP project, the Florida hospice tool employs the same three scales. The key difference between this practice evaluation pain card and the Florida pain card is the lack of an algorithm in the Florida pain card. The algorithm guides caregivers and patients on medication management and when to notify on call hospice staff for further assistance.

Project Questions and Definitions

The evidenced based practice question is the clinical question which should yield the most current and relevant evidence based practices (Mazurek Melnyk & Fineout-Overholt, 2015). The PICOT is the acronym that defines the terms of the clinical question. The PICOT format is inclusive of (P) population, (I) intervention, (C) comparison intervention, (O) outcome, and (T) time frame. The EBP question for this practice evaluation project is: In adult hospice patients seen by the nurse practitioner, with introduction of a formalized pain card, does pain as measured by the brief inventory form decrease over a time frame of 1 month with the use of a formalized pain card and do caregivers administer analgesics to decrease the patients pain? Table 1 displays the PICOT definitions.

Table 1.1: PICOT Definitions

Population	Intervention	Comparison Intervention	Outcome	Time
Adult patients in hospice services managed by the nurse practitioner	Pain management card that educates the patient when to notify the correct staff for increased pain or pain not relieved by medication	No policy standard for who and what pain situations the patient is to notify: <ul style="list-style-type: none"> <input type="checkbox"/> Correct staff for pain management <input type="checkbox"/> For increased pain <input type="checkbox"/> For pain not relieved by medication 	Pain management as measured by: <ol style="list-style-type: none"> 1. Brief Pain Inventory Form (short form) that identifies: <ol style="list-style-type: none"> a. Decreased pain b. Pain relief with pain medication c. Increased pain • When to notify Caregiver to administer analgesics 	One month

Definitions

1. Adult patient-a person who has gained full strength and maturity ("Free Dictionary," 2003).
2. Brief Inventory Form-a form used to determine the severity of pain and the impact of pain on daily functions ("MD Anderson Cancer Center," 2016).
3. Caregiver- family member or paid helper to care for the sick, elderly, or a child.
4. Hospice-care of terminally ill to focus on comfort and quality of life during end of life transition (National Hospice and Palliative Care Organization).
5. Informal Caregiver-family members, friends, or hired individuals who help individuals that cannot function independently either temporarily or permanently (LA Health, 2010). They typically do not have any healthcare education or licensures (LA Health, 2010).
6. Medication-a drug or other substance used to treat a disease or injury ("Free Dictionary," 2003).
7. Nurse practitioners- is a nurse who has a master's, post-masters, or doctoral degree in a nursing specialty and can generally practice medicine without the supervision of a physician. APRNs help meet the demand for primary and

specialty healthcare practitioners, especially in rural and other areas underserved by physicians ("Graduate Nursing EDU," 2016).

8. Pain-an unpleasant physical, sensory, and emotional experience associated with actual or potential tissue damage, as well as an unpleasant and therefore also an emotional experience (Glowacki, 2015).

Assumptions

1. It is assumed that hospice patients in this project will be in pain.
2. It is assumed that the caregiver will in fact use the formalized pain card provided to them.
3. It is assumed that the caregiver will understand the formalized pain card.
4. It is assumed that the nurse practitioner will understand how to use the brief inventory form.
5. It is assumed that more patients will be female than male.
6. It is assumed that hospice patients will be honest in answering questions related to pain ratings.

Summary

Hospice care is an important part of the health care delivery system that allows clients to die at home with the highest quality of life possible. Since hospice depends on the participation of caregivers who have little or no health care education or training, quality of care can vary. Both clients and caregivers identified pain management as an area of concern. Nurse Practitioners caring for hospice clients on hospice need a

standardized, evidence based method of teaching medication management to clients and caregivers. The purpose of this project is to evaluate the use of a formalized pain card to assist clients and caregivers in making the decisions necessary for safe and effective pain management. Chapter II presents the literature supporting the use of a formalized pain card.

CHAPTER 2

REVIEW OF LITERATURE

The purpose of this project is to evaluate the use of a formalized pain card that Nurse Practitioners can use to assist clients and caregivers in making the decisions necessary for safe and effective pain management with improving outcomes by using the Brief Pain Inventory Form for measuring: 1) decreased pain, 2) increased pain, 3) pain relief with pain medication, and 4) situations that warrant caregiver notification to administer analgesics. The American Nurses Association developed standards and scopes of practices for all practicing clinicians for effective pain management. Standard 5b is health teaching and health promotion which is the impetus for this project (American Nurses Association, 2016). Standard 5b was developed to create a baseline for all practicing nurses to assist them in educating, promoting health, and providing a safe practicing environment. The pain card is a tool that Nurse Practitioners can use to teach patients about pain management. Chapter II presents the search process, a comprehensive literature review and synthesis, conclusions, and the feasibility for conducting this project.

Literature Search

Hospice patients create a unique scenario for Nurse Practitioners in regards to health teaching. Unfortunately, there is a dearth of literature that provides guidance for

educating hospice patients and their caregivers. In fact, there is very minimal research on education methodologies. However, there are many expert opinions.

Following an extensive literature review, 16 articles and psychometric data based tools gave direction for this formalized pain card. Predominant search databases were CINAHL complete, PubMed-Medline, Academic Search Complete, and Joanna Briggs Institute EBP Database. Search terms included “Hospice pain management,” “Nurse practitioner role Hospice Care,” “Hospice pain tools,” “Caregiver teaching,” “Caregiver health teaching,” “Caregiver health pediatric patients, if articles were duplicates, and if the articles did not apply to this project domain. Eleven articles older than 5 years considered classics in the areas of teaching methods and pain management were included. Articles were excluded if they were not English speaking.

Pain Management

Level I Literature

Finnerup, Otto, Jensen, and Sindrup (2007) conducted a randomized, placebo-controlled clinical trial using an evidence-based algorithm for the treatment of neuropathic pain on 110 patients with neuropathic pain. For this study, the algorithm was formulated on the basis of high quality clinical trials (Finnerup et al., 2007). The numbers needed to treat and the numbers needed to harm were used to compare the safety and effectiveness of current neuropathic pain treatments (Finnerup et al., 2007). This article concluded that patients presenting with neuropathic pain are becoming more frequent and that evidence-based treatment options are available and that the evidence-based algorithm is a validated tool in managing neuropathic pain (Finnerup et al., 2007). The algorithm was based on patients with neuropathic pain and was created as a guide in medicating

neuropathic pain (Finnerup et al., 2007). The numbers needed to treat and the numbers needed to harm were calculated as the reciprocal of the 95% confidence interval for the absolute risk difference on the basis of a normal approximation (Finnerup et al., 2007). This algorithm for neuropathic pain gave direction on the creation of the formalized pain card for this project which was adapted to the hospice setting.

Havens Lang, Cabin, Cotton, and Domizio (2010) conducted a randomized controlled trial using six evidence-based instrument scales for pain management: The Functional Assessment Staging Tool, The Palliative Performance Scale, The Numeric Pain Intensity Scale, The Wong-Baker FACES scale, The Pain Assessment in Advanced Dementia Scale, The United Hospice of Rockland Anxiety Scale, and The Modified Borg Scale. These scales were used on 125 hospice patients admitted to United Hospice of Rockland, Inc. In this study, all clinical staff received a laminated hard copy of all instruments and were required to attend an educational program on the utilization of these six tools. All of the instruments were then incorporated into the patient charts and staff, including the hospice nurse practitioner, were required to document using the instruments. Management staff were available 24 hours a day to answer questions and support staff through the new documentation and assessment process. Formal evaluation of the program has not been conducted, but initial data analysis revealed that by introducing evidence-based instruments documentation compliance increased from 25 to 30% as well as patients were comfortable within 24 hours from 85 to 96%. Using evidence based tools on hospice patients, providers improved quality of life by decreasing overall pain (Havens Lang et al., 2010). This article used best practices by

using valid and reliable pain measurement tools. The formalized pain card incorporated the numeric pain intensity scale as well as the Wong-Baker FACES scale.

While Lang, Cabin, Cotton, and Domizio (2010) used multiple evidence-based instrument scales, Herr, Titler, Fine, Sanders, Cavanaugh, Swegle, and Tang (2010) conducted a randomized controlled trial on 399 patients from sixteen hospice agencies using the Cancer Pain Practices Index. The Cancer Pain Practice Index is an index of 11 key indicators which measures provider overall use for evidence based practices for adults with cancer. Areas included on the index were comprehensive pain assessment, focused pain assessment, analgesic use, analgesic side effects, nonpharmacological therapies, and patient education relating to pain management. The Cancer Pain Practice Index was created and refined through a series of reviews by national experts in pain and hospice care. The content validity of the tool was created through expert review processes. Reliability of this tool was established by two trained reviewers on a group of 10 randomly selected patients. The two reviewers were experienced with medical record abstraction. Reliability of the Cancer Pain Practice Index was established at 93%. This randomized controlled trial was conducted in the Midwest, which represented hospice agencies that were small, medium, and large. Inclusion criteria were annual admission of a minimum of 30 patients a year serving mostly older adults (Herr et al., 2010). Data were collected by medical record abstraction over a two-week period after patient admission (Herr et al., 2010). Pain intensity was viewed on three separate occasions during a two-week period; on days 1 or 2, days 3-7, and days 8-14 (Herr et al., 2010). Data obtained through medical records was entered into a database by two specially trained registered nurses. Data entry was considered reliable because any discrepancies in

data entry between the two registered nurses was then sent to a third party for review and final data entry. Data were analyzed using SAS 9.1.3 and a significance level of 5% was used for all tests (Herr et al., 2010). Poisson generalized linear models were applied with the Cancer Pain Practice Index. Data suggested that most patients had pain assessed on admission using a valid pain scale (32%), had components of a comprehensive assessment on admission (52.7%), and had an order for analgesic medication within 48 hours (83.5%). The other components of the physical exam were not documented at all within 48 hours (Herr et al., 2010). Written pain management plans were only documented 0.6% of the time which was low (Herr et al., 2010). Effect of patient, provider, and organizational variables on the Cancer Pain Practice Index were reported. Findings indicated that increased patient age was significant for an increase in reporting pain ($P<0.0001$) and overall race was statistically significant for reporting pain ($P=0.0008$). African Americans were the most statistically significant race to report pain ($P=0.0184$). Findings indicated that hospice size was statistically significant on the Cancer Pain Practice Index score ($P<0.0001$) as well as organizational structure ($P<0.0001$). These findings revealed that the bigger the hospice facility, the better its organizational structure was, as well as a decrease in overall Cancer Pain Practice Index Score thus meaning that the bigger facilities controlled patient pain more effectively. Findings also indicated that nurse variables including nurse certification ($P=0.0114$) and caseload ($P<0.0001$) affected Cancer Pain Practice Index score. The score was higher in patients who had nurses with a lower certification, and higher case load. Findings of this study revealed that although pain is of high priority, evidenced based practices are not always being fully implemented (Herr et al., 2010). The authors concluded that pain is

not being documented appropriately, assessed appropriately, reassessed appropriately, or treated consistently among providers (Herr et al., 2010).

These 2 Level I studies supported the importance of assessment in pain management using evidenced based tools on admission and reassessment for moderate or severe pain during hospice (greater or equal to 5). These studies reveal that complying to evidence based practices to decrease overall pain and suffering among the hospice population is in fact important in hospice patient care.

Level II Literature

Laguna, Goldstein, Braun, and Enquidanos (2014) conducted a retrospective study to investigate racial and ethnic pain differences after inpatient palliative care consultations. This study was conducted in a 240-bed nonprofit health maintenance organization in Los Angeles. There were 421 patient participants of Caucasian, African American, or Latino race. Procedures included inpatient palliative care consultation inclusive of comprehensive pain assessment, pain and symptom relief planning, care planning, and other support services needed by the patients and caregivers. The initial consultation included the physical, psychological, social, and spiritual needs of the patients and their caregivers. Care goals were developed with advanced care planning when possible. Pain and symptom control needs were addressed immediately with analgesics. Palliative care team members frequently visited patients and caregivers to ensure pain was controlled. Data were collected from consultation records. Descriptive data included patient age, sex, race and ethnicity, marital status, primary diagnosis, and number of chronic illnesses. Using an 11-point pain rating scale, the palliative care nurse collected pain data before consultation, 2 hours after consultation, 24 hours after

consultation, and at hospital discharge. Racial and ethnic differences were analyzed using one-way analysis of variance and chi-square testing. Results indicated that among whites ($p < .001$), blacks ($p = .002$), and Latinos ($p < .001$), all experienced significant reduction in pain after the consultation intervention. This study concluded that regardless of race or ethnicity, inpatient palliative care consultation effectively reduces and controls pain. This article further supported the importance of pain assessment using evidence based tools in pain management as found on the formalized pain card which was developed for use on this project. The project pain card called The formalized pain card contains an algorithm for pain management based on assessment that caregivers used. Specifically, findings from this study support the need for a comprehensive pain assessment which the formalized pain card has all of the components of a comprehensive pain assessment. The formalized pain card also has steps for pain and symptom relief which this study suggests is necessary through the use of an algorithm as well as steps to take if pain is unrelieved. Caregivers have round-the-clock support through the use of the pain card and the on-call phone number provided for when pain is unrelieved despite all other efforts.

Level V Literature

An expert opinion article by Wells, Pasero, and McCaffery (2008) described how to improve quality of care through the utilization of quality pain assessment and management. They described the single most important aspect of pain management is regular pain assessment in a formalized fashion. These authors posit that untreated patient pain weakens immune system and produces negative cardiovascular effects, gastrointestinal effects, renal effects, as well as cause anxiety and depression (Wells et al., 2008). According to the authors, estimates of 80% of elderly patients report pain that

is undertreated but only 50% receive pain management (Wells et al., 2008). Moreover, the authors underscore for critical assessment of pain for adequate pain management (Wells et al., 2008). Pain history should include previous pain or ongoing episodes of pain, previous methods for controlling pain, patient and caregiver attitudes toward opioids, patients coping response to pain, caregiver and family expectations concerning pain, patient manifestations, and management preferences for pain (Wells et al., 2008). Examples of appropriate assessment tools were the Numeric Pain Intensity Scale, the Wong-Baker FACES scale, and the FLACC scale (Wells et al., 2008). When patients and caregivers decide on assessment tools it should be a collaborative effort with the provider (Wells et al., 2008). Additional assessments that were of use are location and quality of pain, and aggravating and alleviating factors (Wells et al., 2008). According to the World Health Organization, adequate treatment of pain can be gained through use of opioid analgesics (Wells et al., 2008). These authors also felt that when continued pain is anticipated, a round-the-clock pain regimen should be initiated rather than as needed (PRN) regimens (Wells et al., 2008). Family and caregiver education is of great importance and was found to be a central element to pain control (Wells et al., 2008). Major factors for under-treatment of pain was the lack of providers utilizing evidence-based practices (Wells et al., 2008). This article concluded that education about safe pain management will assist in preventing under treatment of pain (Wells et al., 2008). According to these authors, safety included using the correct tools for pain assessment (Wells et al., 2008).

Multiple recommendations from this article contributed to the DNP project formalized pain card content such as: inclusion of previous methods for controlling pain,

pain location, pain quality, and three pain scales specially designed to meet the needs of any patient under hospice services. The pain scales included were the Numeric Pain Intensity Scale, the Wong-Baker FACES Scale, and the FLACC scale. This article also helped to justify the use of the formalized pain card by the caregiver and caregiver education.

Pain Intensity Measurement Scales

Level III Literature

Garra, Singer, Taira, Chohan, Cardoz, Chisena, and Thode (2009) conducted a convenience study to determine validity of the Wong-Baker FACES pain rating scale in pediatric emergency department patients. Participants were children ages 7-17 years old presenting with painful conditions (Garra et al., 2009). Exclusion criteria were children that possessed any disability (auditory, visual, physical, or mental) that would inhibit their ability to comprehend instructions on how to use the Wong-Baker FACES scale (Garra et al., 2009). Research assistants were available to enroll patients from 9am to midnight Monday-Friday (Garra et al., 2009). The data collection instrument consisted of demographic questions, a visual analog scale, and a reproduced copy of the Wong-Baker FACES scale (Garra et al., 2009). After research assistants obtained demographic information, participants were asked to rate their pain on the Wong-Baker FACES scale and the visual analog scale (Garra et al., 2009). The Wong-Baker FACES scale contains six faces (Garra et al., 2009). Each face corresponds to a numerical value (Garra et al., 2009). The first face is smiling and depicts no pain at all which has a numeric value of 0 (Garra et al., 2009). The second face is smiling, with slightly furrowed brows which depicts hurts a little bit which has a numeric value of 2 (Garra et al., 2009). The third face

has furrowed eyebrows and no smile which depicts hurts a little more which has a numeric value of 4 (Garra et al., 2009). The fourth face has a frown and depicts hurts even more which has a numeric value of 6 (Garra et al., 2009). The fifth face has a larger frown and depicts hurts a whole lot which has a numeric value of 8 (Garra et al., 2009). The sixth face is crying with a frown and depicts hurts worse which has a numeric value of 10 (Garra et al., 2009). A total of 120 patients were assessed with a median age of 13 years (Garra et al., 2009). Given that the visual analog scale is a widely-accepted tool to measure pain intensity and the Wong-Baker FACES scale is highly correlated with it ($p=0.90$; $CI= 0.86$ to 0.93 , the validity of the Wong-Baker FACES scale in measuring pain intensity is supported (Garra et al., 2009).

Paice and Cohen (1997) conducted a convenience study to determine validity of a verbally administered numeric rating scale to measure cancer pain intensity. Participants of the study had documented malignancy, current pain experiences, and were able to understand English (Judith & Cohen, 1997). Demographic information included on patients were age, race, gender, educational level, primary malignancy, and activity level (Judith & Cohen, 1997). The numeric rating scale is a scale included on the DNP formalized pain card. The numeric rating scale is a scale on a 10 cm line anchored at each end by verbal descriptors (Judith & Cohen, 1997). There are numbers range from 0-10 and at 0 the scale reads no pain, at 5 the scale reads moderate pain, and at 10 the scale reads worst possible pain (Judith & Cohen, 1997). Each patient in the study was administered three separate scales; the visual analog scale, the simple descriptor scale, and the numeric rating scale at random order (Judith & Cohen, 1997). After participants completed all three pain scales, they were asked to identify the scale that they preferred to

measure their pain (Judith & Cohen, 1997). A vast majority of patients preferred the numeric rating scale to determine pain severity (Judith & Cohen, 1997). Findings suggest that the numeric rating scale is a reliable and valid tool used to evaluate pain intensity (Judith & Cohen, 1997). Spearman correlation was obtained for each relationship (Judith & Cohen, 1997). There was a strong positive correlation between the visual analog scale and the numeric rating scale ($r= 0.847, p<.001$) (Judith & Cohen, 1997). Given that the visual analog scale is a widely-accepted tool to measure pain intensity and the numeric rating scale is highly correlated with it, the validity of the numeric rating scale in measuring pain intensity is supported (Judith & Cohen, 1997).

Voepel-Lewis, Zanotti, Dammeyer, and Merkel (2010) conducted a convenience study to determine reliability and validity of the Face, Legs, Activity, Cry, Consolability behavioral tool in assessing acute pain in critically ill patients. Sample study included patients both adults and children who were present in any of the critical care units in the medical center during the study period (Voepel-Lewis, Zanotti, Dammeyer, & Merkel, 2010). Inclusion criteria were if patients could not self-report pain, and if they had an underlying condition associated with pain or were undergoing a procedure known to cause pain (Voepel-Lewis et al., 2010). Exclusion criteria were if patients were prescribed any muscle relaxants (Voepel-Lewis et al., 2010). Three nurses simultaneously, but independently, observed and scored pain behaviors twice in 29 critically ill adults and 8 children prior to administering analgesia medication and then 15 to 30 minutes after administration (Voepel-Lewis et al., 2010). Two nurses used the FLACC scale and the third used either the Checklist of Nonverbal Pain Indicators or the Comfort scale for children (Voepel-Lewis et al., 2010). The FLACC scale includes

behavioral categories and descriptors that are reliably associated with pain in children and adults with cognitive impairment (Voepel-Lewis et al., 2010). The categories included in the FLACC scale are Face, Legs, Activity, Cry, and Consolability (Voepel-Lewis et al., 2010). Under face a score of 0 would depict an individual with no particular expression or smile, a score of 1 would be an individual with occasional grimace, and a score of 2 would be a frequent or constant frown or clenched jaw (Voepel-Lewis et al., 2010). Under legs a score of 0 would depict normal or relaxed position, a score of 1 would reveal uneasy or restless legs, and a score of 2 would reveal kicking or drawn up legs (Voepel-Lewis et al., 2010). Under Activity a score of 0 would reveal a person lying quietly in a normal position, a 1 would depict squirming or shifting, and a score of 2 would depict arched or rigid jerking (Voepel-Lewis et al., 2010). Under Cry a score of 0 would reveal no crying, a score of 1 moans or whimpers, and a score of 2 with steady crying or screams (Voepel-Lewis et al., 2010). Under Consolability a score of 0 would reveal a content and relaxed individual, score of 1 would reveal a person that is reassured by occasional touching or hugging, and a level 2 would reveal a person that is difficult to console or comfort (Voepel-Lewis et al., 2010). After a person is scored in each category, the total number from all of the columns should be added and that provides a numerical value for pain intensity with the highest numerical value of 10 (Voepel-Lewis et al., 2010). There were a total of 73 observations and results revealed that FLACC scores correlated positively with both the Checklist of Nonverbal Pain Indicators and the COMFORT scale- (p=0.963 and 0.849), revealing that the FLACC scale is a valid tool in evaluating pain severity (Voepel-Lewis et al., 2010).

Patient and Caregiver Education

Level II Literature

Mayahara, Paice, Wilbur, Fogg, and Foreman (2014) conducted a 3-day longitudinal study of a convenience sample of home hospice patients and their nonprofessional caregivers. Participants of the study were patients and their informal caregivers who received services from a non-profit hospice program located in Chicago (Mayahara, Paice, Wilbur, Fogg, & Foreman, 2014). Inclusion criteria for patients included the patient received services from a hospice program, received analgesic medications, were able to speak and understand English, and were 18 years or older (Mayahara et al., 2014). Inclusion criteria for informal caregivers were being identified as primary caregiver by patient and at least 18 years or older (Mayahara et al., 2014). Informal caregivers included family, friends, and hired nonprofessionals (Mayahara et al., 2014). Fifty-nine patients and their caregivers were included in the study (Mayahara et al., 2014). Demographic information included age, gender, ethnicity, education level, and caregiver's relationship to the patient (Mayahara et al., 2014).

Informal caregivers were instructed to record a pain and medication diary over three consecutive days (Mayahara et al., 2014). For each patient pain occurrence, the caregiver documented pain intensity and relief measures such as medication, dosage, time of administration, and date of administration (Mayahara et al., 2014). Caregivers were also instructed to document if no medication was given (Mayahara et al., 2014). Patient pain assessment questions for this study were adapted from the Brief Inventory Form (Mayahara et al., 2014). The diary format was adapted from the Daily Pain Management Diary which was developed by Miaskowski and colleagues (Mayahara et al., 2014). Data

collection consisted of two visits to the patient's home, 3 days apart, and a review of their hospice record to identify prescribed analgesic medication regimens (Mayahara et al., 2014). Certified palliative and hospice nurses collected the data (Mayahara et al., 2014). At the first home visit, the nurse explained the study to the patient-caregiver dyad and obtained consent, followed by the questionnaire administration (Mayahara et al., 2014). The nurse asked them to record all analgesics administered for the next three days (Mayahara et al., 2014). Subsequently, the nurse returned and collected the diaries (Mayahara et al., 2014). Descriptive statistics were determined including frequencies, means, and standard deviations (Mayahara et al., 2014).

Chi-Square and t tests were examined to determine the association between demographic variables including age, gender, ethnicity, and education with effective pain management. Chi-square results indicated that hired caregivers had higher education levels than did family caregivers and therefore, pain management was more effective ($P=0.046$). In the 3-day study period, 46 patients reported pain to their caregivers for a total of 422 times which ranged from 1 to 24 times per patient (mean 9.17, standard deviation 6.09). Pearson correlation coefficients were conducted to determine if there was any association between adherence to PRN pain regimens and pain scores. Data revealed that there were significant negative correlations between caregiver adherence and patient pain severity, indicating that as care givers were more adherent to pain regimens, pain severity decreased ($r= -0.31$) (Mayahara et al., 2014). Analyses were also conducted to determine associations between pain scores and medication errors (Mayahara et al., 2014). Data analyses determined that 87% of patients received adequate analgesics for pain, however 49.1% of the time caregivers made medication errors

(Mayahara et al., 2014). Multilevel analysis was used to evaluate differences in pain by seven different medication errors; overall, PRN medication errors were related to higher levels of patient's reported pain ($P=.046$). Based on data analysis, pain scores were higher for the error "gave sedation instead of prescribed analgesics" ($P=.024$). Data analysis also determined that 21.3% of the time patients were experiencing pain, caregivers failed to administer medication at all (Mayahara et al., 2014). This article concluded that understanding the need to medicate when hospice patients experience pain is not only vital, but appropriate interventions from providers needed to occur to help reduce pain among hospice patients (Mayahara et al., 2014).

This article supports the need for having a step by step medication plan for caregivers and patients. The formalized pain card is created in an organized fashion which allows caregivers to easily read and understand. This article also described the need for the formalized pain card to empower caregivers to give analgesic medications to the hospice patient guilt free by incorporating and planning algorithm of medication administration, notifying the healthcare provider, and pain relief intervention measures.

Level III Literature

Lau, Berman, Halpern, Pickard, Schrauf, and Witt (2010) conducted a qualitative study with 23 informal caregivers and 22 hospice providers from 4 hospice agencies using grounded theory. This study was conducted by working with clinical managers at each hospice agency to recruit a convenience sample of caregivers and hospice providers (Lau et al., 2010). Inclusion criteria for caregivers were 18 years old or older, speaking and understanding English, and assisting an elderly hospice patient with at least one hospice prescribed medication (Lau et al., 2010). Inclusion criteria for hospice providers

was at least one year of hospice clinical experience (Lau et al., 2010). Semi-structured, open-ended interview guides were used to address caregivers' medication responsibilities (Lau et al., 2010). Interview questions included: 1. "How do you care for the patient with his/or her medications?" 2. "Who helps you organize and give the medications?" and 3. "Describe a situation when you had trouble organizing or giving medications. What did you find difficult about it? (Lau et al., 2010)" A similar interview guide was developed for hospice providers to share their observations of caregivers' experiences with medication management (Lau et al., 2010). A lead investigator and research assistant conducted the interviews (Lau et al., 2010). Interviews occurred within the patients' private residence (Lau et al., 2010). Hospice provider interviews occurred mainly in the providers' offices (Lau et al., 2010). Interviews averaged about 1 hour and were recorded and transcribed (Lau et al., 2010). Data collection was analyzed by Atlas.ti v-5.2 statistical software (Lau et al., 2010). Data analysis revealed that caregivers and hospice providers identified similar factors that facilitated or impeded medication management (Lau et al., 2010). Facilitating factors were caregivers' life experiences and self-confidence (Lau et al., 2010). Impeding factors were caregivers' negative emotional status, cognitive and physical impairments, low literacy, competing responsibilities, as well as patients' negative emotional states and complex medication needs (Lau et al., 2010). These authors found that knowledge and skills were not the only factors influencing medication management and that other support options may assist informal caregivers in administering analgesics (Lau et al., 2010). Other support options that may facilitate medication administration were assisting with interpersonal relationships between hired and non-hired informal caregivers, providing adequate education based on

literacy level of the caregiver, options for caregivers to positively cope with grief and fatigue, the need for a more comprehensive a round-the-clock medication regimen rather than PRN regimen, and for hospice providers to provide a more open communication between themselves and informal caregivers (Lau et al., 2010). This article helped to create the formalized pain card by recognizing that large populations of individuals have low health literacy.

The DNP project formalized pain card was developed based on a fifth-grade reading level. The pain card also accounts for the patients' medication needs by assessing level and quality of pain as well as guides the caregiver to medicate. The formalized pain card offers opportunity for the hospice nurse practitioner to facilitate open communication when educating on the use of the pain card. This article described the need for collaboration among all involved in the hospice patients care. The formalized pain card has an on-call number for the hospice registered nurse, who then collaborates with the nurse practitioner. Once the nurse practitioner makes recommendations, the medical director is then notified for a need in increased analgesia dosage. The registered nurses directly speak with the family after medication dosage changes have occurred.

Another qualitative study by Lau, Kasper, Hauser, Berdes, Chang, Berman, and Emanuel (2009) studied 22 hospice providers and 23 family caregivers of elderly patients who were receiving home hospice services from 4 hospice agencies using grounded theory. Researchers worked directly with medical directors or clinical managers to identify and recruit study participants (Lau et al., 2009). Inclusion criteria were those providers who had direct clinical contact with patients and caregivers (Lau et al., 2009). Inclusion criteria for caregivers were those that were least 18 years old, could understand

and speak English, and were responsible for assisting elderly hospice patients with medications in the home (Lau et al., 2009). Interviews for this study were guided by a semi-structured, open-ended questionnaire (Lau et al., 2009). For providers, questions were 1. "What should family caregivers know to help a patient with medications at home?", 2. "What concerns have family caregivers expressed about helping with medications", and 3. "What medication-related mistakes do family caregivers make? (Lau et al., 2009)" For caregivers questions included 1. "What medication-related information have you learned or want to learn?", 2. "What worries do you have about helping with medications?", and 3. "Describe how you help the patient with his/her medications and what advice would you give to other family members with similar medication responsibilities? (Lau et al., 2009)" Interviews were conducted by a lead investigator and an assistant (Lau et al., 2009). Interviews with providers were conducted wherever it was convenient for the provider (Lau et al., 2009). All caregivers' interviews were conducted in the patients' private residence (Lau et al., 2009). Interviews averaged about 1 hour in length and were audio recorded with written consent (Lau et al., 2009). Data was analyzed using Atlas.ti v-5.2 statistical software (Lau et al., 2009). Data revealed that providers and caregivers found similar skills to be of importance when dealing with medication management (Lau et al., 2009). That being said, providers emphasized more on technical skills and caregivers emphasized more on management skills (Lau et al., 2009). These authors defined effective medication management as "the ability to effectively relieve symptoms with pharmacological interventions by successfully utilizing caregiving skills in the following five domains: teamwork skills, organization skills, symptom knowledge skills, medication knowledge skills, and

personhood skills” (Lau et al., 2009). This study concluded that providing pain relief with analgesics is of priority for hospice patients and that home hospice patients depend mainly on caregivers to provide analgesics, due to this a comprehensive understanding of medication management skills will better prepare caregivers to provide relief to hospice patients (Lau et al., 2009).

Emanating from these authors’ definition of effective medication management, the DNP project pain card was formalized. The pain card emanates from team work by creating a formalized card that can be used by the nurse practitioner to educate caregivers on critical components regarding medicating hospice patients’ as well as an algorithm for caregivers to use when medicating. This card also incorporates organization and a systematic way to medicate the hospice patient as well as symptoms the patient may be experiencing. The formalized pain card is lacking knowledge on specific medications that can be utilized to control pain, so medication instruction will also need to be provided.

Level IV Literature

An expert opinion article (based on research from the literature) by Hayes (2005) described methods to design effective written medication instruction sheets. Healthy People 2010 devised a goal that 95% of patients who were ordered or prescribed medication received a form of written medication instructions (Hayes, 2010). Another goal was that 95% of patients received counseling on use and risk of medications (Hayes, 2010). Hayes found that declining physical condition, advanced age, and complex medication regimens affect abilities of patients to learn and retain information (Hayes, 2010). Hayes recommended that written materials should use a font of at least 14-point, high illumination in the room, use buff paper to minimize glare, and present health

information with the door closed to reduce distraction (Hayes, 2010). For increased cognitive processing Hayes described the need for health information to be presented in a logical and organized way and at a 5th grade reading level (Hayes, 2010). In regards to literacy, only 33.9% of patients had marginal health literacy meaning that most of the population did not understand and comprehend health materials well (Hayes, 2010). In conclusion, this article described designing written medication instructions as a somewhat difficult task, but stated that materials should be simplistic and contain pertinent specific information (Hayes, 2010). This author stated that teaching points should be bulleted or in a listed format (Hayes, 2010). This author also stated that the provider should present health information verbally and written, and when giving health information verbally, speak slowly and in an organized manner (Hayes, 2010). This article provided guidance in designing the formalized pain card. The formalized DNP project pain card is presented with 14-point font, printed on buff paper, presented in an organized and logical way, written at a fifth grade reading level, specific to hospice patient pain, and information is presented in listed format and algorithm format.

Jones, Trieber, and Jones (2014) described steps to improve medication adherence in an expert opinion article; all were health professionals. In their opinion, the best interventions to assist with medication adherence were caregiver understanding, a comprehensive assessment approach tools tailored to individual patient needs and capabilities, and follow up with the patient (Jones et al., 2014). These authors underscored the importance for health care providers' knowledge level regarding patient consumer health literacy and medication adherence (Jones et al., 2014). These authors suggest that it is important to screen everyone for health literacy, not just individuals who

may be struggling (Jones et al., 2014). Comprehensive assessment approach means that collaboration and involvement of team care providers is necessary (Jones et al., 2014). These authors stated that the providers should use simple words, provide written materials at or below a sixth-grade reading level, keep teaching sessions short, and ask patients what their preferred learning style is (Jones et al., 2014). These authors felt that simplifying medication regimens may illicit better medication adherence; all medications should be reviewed and discontinued if possible, and combination drugs should be used when possible (Jones et al., 2014). Tools to assist with medication adherence are various forms of pill boxes as well as cell phone reminders to take medications at scheduled times (Jones et al., 2014). Accurately assessing and understanding patient learning involves communication with the patient (Jones et al., 2014). Follow up care is essential to improve medication adherence (Jones et al., 2014). In conclusion of this article, these authors found that the trend is for patient self-care in the home, thus, underscoring the need for effective patient and provider communication and education using appropriate health literacy materials (Jones et al., 2014). This article helped to create the DNP project pain card emphasizing appropriate health literacy materials.

Evidence-based pain tools were chosen for this card because each of the scales can be utilized on patients with different cognitive abilities. The Numeric Pain Intensity Scale can be used on patients who are cognitively and verbally intact. The Wong-Baker FACES scale can be used on individuals who are cognitively intact, but verbally incapacitated. The FLACC scale can be used on patients who are not cognitively or verbally intact. Next, it takes a village is utilized because with every hospice patient it is a team collaboration between registered nurses, nurse practitioners, medical directors, case

workers, and more. Next, the education experience is simplified by providing brief questions followed by an easy to follow algorithm. The pain card is written at a fifth-grade reading level. Learning will be assessed on the second visit to the hospice patients home, which is when, follow up will occur as well.

Level V Literature

The purpose of the expert opinion article by Bowen (non-evidence based opinion) (2016) was to present health information retention techniques for low literacy clients. Strategies emphasized were using plain language, focusing the message, using teach back method, and evaluating written materials for health literacy levels (Bowen, 2016). Bowen (2016) stated that healthcare providers are notorious for poorly identifying patients with low health literacy and that often patients with low literacy do not disclose their literacy or reading competency. Clues that may signal low literacy levels are missed appointments, non-compliance with the treatment plan, confusion related to medications, and making excuses for not reading health education materials. The author described plain language as the patient's ability to comprehend verbal conversation. Focusing the message was important in order to improve information retention. The literature has shown that less than 50% is retained during an office encounter (Bowen, 2016). Bowen (2016) stated that limiting key messages to 1-3 per visit was imperative for patient health information retention (Bowen, 2016). The teach back method was a useful tool and asks the patient to recall the information given during the office visit (Bowen, 2016). Written materials can be an efficient way to provide healthcare information to patients, but this information should be at a fifth-grade reading level or lower, and messages in the handout should be limited to 2 (Bowen, 2016). This article assisted in the formation of

the formalized pain card by devising guidelines for patient teaching materials. The DNP project formalized pain card has one key message for controlling patient pain and is written at a fifth-grade reading level.

Brief Inventory Form

Level III Literature

Naegeli, Tomaszewski, and Sawah (2015) conducted a longitudinal study to evaluate the Brief Inventory Form (short form) in patients with moderate to severe systemic lupus erythematosus who were recruited by a free medication monitoring service. The Brief Inventory Form (short form) was administered electronically at baseline visits, week 2 visit, and then week 12 visit (Naegeli et al., 2015). Inclusion criteria were that the patients be at least 18 years old, had a self-reported diagnosis of moderate to severe lupus (Naegeli et al., 2015). Exclusion criteria were if they reported active lupus nephritis or active CNS lupus (Naegeli et al., 2015). Brief Inventory Form (short form) reliability was tested by internal consistency of the items in the form, domain and total score at baseline were measured using Cronbach's alpha coefficient, and acceptable internal consistency is considered with an alpha coefficient >0.70 (Naegeli et al, 2015). For the Brief Inventory Form (short form) Cronbach's alpha >0.90 , indicating that the internal consistency is high and is an acceptable tool (Naegeli et al., 2015). Intraclass correlation coefficients were used to evaluate reliability (Naegeli et al, 2015). The minimum test-retest reliability criteria for attributes that are expected to be stable over time is 0.70 (Naegeli et al, 2015). Test-retest reliability was assessed by correlating responses for the Brief Inventory Form between baseline and week 2 (Naegeli et al., 2015). Validity was determined by the and Systemic Lupus Activity Questionnaire

and a short form health survey version 2 (Naegeli et al, 2015). Construct validity was assessed by Pearson correlation coefficient which was calculated at baseline (Naegeli et al., 2015). The interpretation of the correlation coefficients was categorized as small ($r=0.10-0.23$), medium ($r=0.24-0.36$), and large ($r=0.37$ or greater) (Naegeli et al., 2015). As expected, the Brief Inventory Form (short form) pain severity, pain interference, and total score were highly positively correlated ($r > 0.39$). A total of 122 patients were included in the study (Naegeli et al, 2015). The mean age of participants was 45.7 years and 95.9% of the patients were female (Naegeli et al, 2015). Data analysis revealed that higher scores on the Brief Inventory Form (short form) indicated higher levels of pain (Naegeli et al, 2015). In conclusion, this article revealed that the Brief Inventory Form (short form) is a reliable and valid tool in evaluating pain severity as well as pain interference in a sample of patients with moderate to severe systemic lupus erythematosus (Naegeli et al, 2015).

Level IV Literature

Andres Ares, Cruces Prado, Canos Verdecho, Penide Villanueva, Hoyos, Herdman, Traseira Lugilde, and Valazquez Rivera (2015) conducted a large, noninterventional 3-month follow up study of a single cohort of non-cancer related patients. The primary goal of the study was to determine the evolution of quality of life and pain in patients with moderate to severe non-cancer related pain after 3 months of treatment in pain units throughout Spain (Andres Ares et al., 2015). Inclusion criteria for the study were that patients had to be at least 18 years old, making their first visit to a pain center, have a non-cancer related diagnosis, and score a baseline of at least 4 on a visual analog pain scale (Andres Ares et al., 2015). Patients that were not cognitively

intact were excluded from the study (Andres Ares et al., 2015). Patients were followed for up to 3 months and had three study visits; one at baseline, one month, and then three months (Andres Ares et al., 2015). All patients were administered the Brief Inventory Form (short form) at each visit (Andres Ares et al., 2015). The Brief Inventory Form is designed to evaluate pain severity, pain interference, location of pain through body diagrams, and determination of worst pain experienced in most recent 24 hours (Andres Ares et al., 2015). For this form, patients respond to four 0-10 numeric rating scale questions regarding severity of pain (Andres Ares et al., 2015). Each of the scales presented with a pain question have 0 being no pain at all and 10 with pain as bad as you can imagine (Andres Ares et al., 2015). The pain interference scale asks patients to base interference on enjoyment of life, general activity, walking ability, mood, sleep, normal work, and relations with other people (Andres Ares et al., 2015). Responses are based on a numerical scale with 0 being does not interfere and 10 being interferes completely (Andres Ares et al., 2015). Body diagrams are presented for patients and caregivers to mark location or locations of pain (Andres Ares et al., 2015). Feasibility of the form was tested by calculating the ceiling and floor effects (percentage of patients with the maximum and minimum possible scores) on each item in the questionnaire and for both of the subscales (Andres Ares et al., 2015). The reliability of the subscales was tested by examining the internal consistency of responses on the two scales using Cronbach's (Andres Ares et al., 2015). Ceiling and floor effects of up to 15% and Cronbach's alpha of >0.70 were considered acceptable and through this it was found that the scale was acceptable (Andres Ares et al., 2015). Validity was determined by analyzing capacity to discriminate between patients categorized by response on another scale, the EQ-5D

(Andres Ares et al., 2015). For the study, a total of 3,029 patients with data from baseline to 3-month follow up visits were available for analysis (Andres Ares et al., 2015). For this group of patients mean age was 61.1 years and 67.1% were female (Andres Ares et al., 2015). This study revealed that the Brief Inventory Form (short form) was understood by most patients given that mean maximum pain severity was higher at baseline visit than at 3 month follow up visits (Andres Ares et al., 2015). After 3 months of treatment in pain centers, improvements were seen on both subscales with a standard deviation change of 2.4 points on the pain severity subscale and 2.4 points on the interference subscales (Andres Ares et al., 2015). In conclusion, this article revealed that the Brief Inventory Form (short form) is a reliable form for not only pain severity, but pain interference as well (Andres Ares et al., 2015). This study also reveals that the Brief Inventory Form (short form) is also responsive to changes in health status (Andres Ares et al., 2015).

DNP Project Formalized Pain Card

The pain card emanates from the literature and incorporates a tool for caregivers and patients to use for pain management in hospice patients. The formalized pain card algorithm was based off of an evidence-based algorithm for the treatment of neuropathic pain and adapted to the hospice setting. The pain card is a five-item scale to assist caregivers in medicating and identifying patient pain. The first section of the pain card components from three different pain scales, The Numeric Pain Intensity Scale, the Wong-Baker FACES scale, and the FLACC Scale (Havens Lang et al., 2010). For the Verbal pain scale, the patient will verbally state pain with 0 being no pain at all and 10 being the worst pain ever experienced. The second scale, The Wong-Baker FACES scale consists of faces depicting different pain levels. The patients are instructed to point to the

face that corresponds with their pain level and then there are numbers below for the provider to base pain level off of. The first face is a smiling face depicting no pain at all and the last face is crying depicting the worst pain ever experienced. The final scale, the FLACC scale, is a scale that the caregiver utilizes to determine pain level. This scale asks the caregiver to determine facial expression, leg position, if the patient is crying or moaning, and if the patient is consolable. Depending on the caregiver's observations a number is assigned and a total score between 0 and 10 is determined to determine pain level. 0 being no pain and 10 being the worst pain ever experienced. These scales were utilized for the pain card because they each target a different type of patient. All three scales needed to be included to incorporate all patients with pain seen under hospice services. The Numeric Pain Intensity scale was included to target the cognitively and verbally capable patient to rate their pain (Havens Lang et al., 2010). The second scale, the Wong-Baker FACES scale was used for patients who were cognitively intact, but verbally intact (Havens Lang et al., 2010). The final scale, the FLACC scale was incorporated patients that are not verbally or cognitively intact (Havens Lang et al., 2010).

The second portion of the pain card incorporates items for a comprehensive pain assessment. Evidence suggests that pain can be better controlled when a comprehensive pain assessment is conducted on each patient visit (Lang et al., 2010). The pain card asks for pain adjectives, pain location, and previous pain relief measures. Wells, Pasero, and McCaffery (2008) stated that quality of care and pain improvement can occur when quality pain assessments are utilized on a regular basis in a formalized fashion. The pain

card offers a formalized fashion for conducting pain assessment for each patient care contact.

With hospice patients, in addition to needing a comprehensive pain assessment, caregivers also need extra care planning and guidance to care of the hospice patient (Laguna et al., 2014). The final portion of the pain card is an algorithm which guides caregivers to medicate and when to call staff. This algorithm directs care givers to effective pain management by asking questions which proceeds them to the next step based on a “yes” or “no” response. The algorithm provides a step by step guide to caregivers to assist in decision making for effective pain management.

Synthesis

After appraising and evaluating the evidence, the literature synthesis provides supporting evidence for a caregiver formalized pain card for effective pain management among hospice patients. The evidence demonstrated that hospice patients experience uncontrolled pain and using valid tools to assess and treat pain can yield effective pain management. A dearth of literature was noted regarding hospice caregiver education and specific teaching methods for providers to use in the hospice setting for teaching caregivers about hospice care. Evidence based pain assessment tools have demonstrated to improve quality of life as well as decrease overall pain in hospice patients (Havens Lang et al., 2010). Overall, the literature showed that providers are not utilizing these tools for pain assessment or teaching caregivers on the use of pain management in hospice patients (Herr et al., 2010). Nurse practitioners can help to decrease patients’ pain during consultation phase as long as appropriate tools and assessments are utilized (Laguna et al., 2014).

Nurse practitioners serving hospice patients should focus on a 24 hour analgesic regimen as opposed to PRN regimens because caregivers' adherence to pain management was found to be 51% of the time (Mayahara et al., 2015). Also, to improve pain management nurse practitioners should use tools to reduce medication errors by informal caregivers (Mayahara et al., 2014). Tools should be based on fifth-grade reading level or lower, use a 14-16 easily legible font, and include pertinent information specific to the hospice patient population (Hayes, 2010). It is also beneficial for the nurse practitioner to use the feedback and reflection methods when educating patients and caregivers and use medication sheets to facilitate communication (Branch & Paranjape, 2002; Jones et al., 2014). In regard to health information retention it is important to use plain language, focus the message, and use the teach back method while also evaluating all written materials for health literacy, especially for the elderly and other disparate populations (Bowen, 2016; Woodson et al, 2009).

Nurse practitioners are the main providers in regard to analgesic regimens and in this project will be utilized to administer the Brief Inventory Form as well as educate about use of the formalized pain card (Kennedy, 2012). Nurse practitioners in this setting will also be able to educate about safe pain management and thus prevent under-treatment of pain (Wells et al., 2008). It would be beneficial to provide hospice nurse practitioners with the most relevant and evidence based skills to help patients retain health information (Miline & Oliver, 1996). It too would be beneficial for nurse practitioners to provide education further than on skill building and knowledge building such as stress reduction methods for caregivers (Lau et al., 2010). The nurse practitioner is part of the health industry and in the hospice setting the primary role is educating and

communicating with the patients and their caregivers (Radulescu & Cetina, 2011). Based off of Ehde, Nitsch, and Smiley's (2015) article, conclusions were drawn that the Brief Inventory Form is a valid tool for this project and can be utilized effectively. Through this project it is imperative to utilize the most relevant evidenced based literature to create and use the formalized pain card (Glowacki, 2015).

Feasibility

The timeline for this DNP project is one month. A barrier to this project is the available hospice agencies to implement the Formalized Pain Card for an adequate sample. One promising method to overcome available agencies is that this specific hospice agency sees patients all over the state meaning there should be a wide variety of patients and patient demographics for adequate sample size. The hospice agency is one of the largest in the state and has a wide variety of providers from physicians to nurse practitioners available and willing to implement this project. Education will be on a case by case basis depending on which providers will be rounding during the project. All providers rounding with key researcher will have a formal education session on the formalized pain card. If the formalized pain card reveals positive outcomes for patients, then the agency would like to implement formalized training and implementation of the pain card on every patient admitted. All providers for the areas this project will be tested have voiced positive feedback on participation for the project. Data collection will solely be conducted by formalized pain card developer. Cost of the project will include printing of the formalized pain card and gas expenses for travel to patients' primary residence. Total estimated cost for this project is two hundred dollars which will be funded by the key researcher and developer of the formalized pain card. Feasibility for implementation

of this project includes stakeholder support which is essential to the success of this project. Implementation and data analyses was supported by Chief Operating Officer, Volunteer Coordinator, and county Nurse Practitioner. Approval for DNP project was obtained in January 2016 for start in Continual support from hospice staff and stakeholders was essential to the success of this project. Initially staff were concerned about work load and time spent at each patient visit, but when staff took note that key researcher would personally be present at each visit to collect all data and administer tools they agreed to the project processes. The hospice agency chose to wait until the end of the project to decide if they would utilize the DNP formalized pain card on every patient and preferred to wait until that time to decide to train all staff on the use of the card.

Conclusion

The formalized DNP project pain card emanates from the literature. Its purpose is to facilitate assessment and management of pain of hospice patients. The Card provides a guide to caregivers to decision making for medication administration and further staff notification. The pain card includes components of the patients' level of pain over a two-week period, medication administered, if medication was effective, and if patient or caregiver had to call the on-call provider for increase in analgesic medications. The formalized pain card is the intervention and the Brief Inventory Form (short form) is the tool used to measure if the pain card was effective.

A dearth of literature was noted regarding hospice caregiver education and specific teaching methods for providers to use in the hospice setting for teaching caregivers about hospice care. However, evidence based pain assessment tools have

demonstrated to improve quality of life as well as decrease overall pain in hospice patients (Havens Lang et al., 2010). Overall, the literature showed that providers are not utilizing these tools for pain assessment or to teach caregivers pain management in hospice patients (Herr et al., 2010). The formalized pain card was developed based on the most relevant evidenced based practices available for caregiver assessment and pain management and emanates from the Brief Pain Form.

CHAPTER 3

METHODS

Hospice care organizations provide a comprehensive service to patients at end of life. Components include pain management and caregiver support. The purpose of this project is to evaluate the use of a formalized pain card that Nurse Practitioners can use to assist clients and caregivers in making the decisions necessary for safe and effective pain management with improving outcomes by using the Brief Pain Inventory Form for measuring: 1) decreased pain, 2) increased pain, 3) pain relief. This chapter will present the methods to conduct the project. The methods are design, unit of analysis, sample, setting, outcomes to be measured, theoretical framework, description of intervention, strategies to reduce barriers and increase support, instruments, procedures, and data analysis.

Design

A pre-and post-test design is used to examine differences in mean pain scores using the Brief Pain Inventory Scale (DNP Formalized Pain Card) following an educational session for patients and caregivers by a hospice nurse practitioner.

Methods

The nurse practitioner will educate the patient and caregiver regarding pain relief management using the DNP Formalized Pain Card. Following the University of South

Carolina Intuitional Review Board approval, the hospice nurse practitioner will go into each patient's home and first administer the Brief Inventory Form (short form) to determine overall pain severity. The data from the Brief Inventory Form will be collected and entered into an excel spread sheet for subsequent data analyses. The hospice nurse practitioner will then educate the patient and caregiver on the use of formalized pain card and instruct the patient and caregiver to utilize it over the following week. The hospice nurse practitioner will then use role-play with the caregiver and patient to ensure the dyad fully understands how to use the entire DNP project formalized pain card. The pain card consists of three key segments. The first segment provides pain scales for patients to determine overall pain score. The second segment requests adjectives to describe pain, pain location, and what has been done previously to control pain. The final segment of the pain card is an algorithm which assists in guiding the caregiver to medicate if necessary and if a call to staff is warranted for uncontrolled or unrelieved pain. After one week, the hospice nurse practitioner will return to patients' home and re-administer the Brief Inventory Form (short form) to determine if the formalized pain card helped to decrease overall pain. That data will be entered again into an excel spread sheet for subsequent data analyses.

Setting

A hospice care service that manages patients in various settings in the upper part of a southern state will provide entrée and access into the home setting for conducting the DNP project. Data collection and the educational intervention will be implemented in the patient's home. This hospice agency provides four levels of care. The first level is routine home care, which is the most common, and allows patients to continue living in

their home environment with caregivers, hospice providers, and staff providing home care. The second level is respite care, which allows the caregiver to have temporary rest from hospice care duties. The third consists of continuous care that provides care from 8-24 hours per day during crisis periods. The fourth level, the general inpatient care, is for patients in crisis who cannot be managed in the patients' home care setting.

Unit of Analysis

The unit of analysis includes data and mean scores Brief Inventory Form following pre-and post-intervention to determine decreased pain, pain relief with medication, and increased pain. The Brief Inventory form is a form which asks several pain related questions to determine overall pain as well as pain interference for activities of daily living. A data collection Excel spreadsheet tool is used to collect data. The Excel spreadsheet will contain: 1. Visit number, 2. Patient number in study, 3. Age, 4. Gender, 5. Race., 6. Any pain other than minor headaches, sprains, or toothaches today (yes/no), 7. Pain at its worst over the last 24 hours (0-10), 8. pain at its least over the last 24 hours (0-10), 9. Current pain (0-10), and 10. in the last 24 hours how much relief have pain medications/treatments provided (0%-100% which increase by increments of 10).

A second unit of analysis is the formalized DNP project pain card. The pain card documents four items: patients' level of pain over a two-week period, medication administered, if medication was effective, and if patient or caregiver had to call the on-call provider for increase in analgesic medications. Data from the pain cards will be collected after the 2 week period and entered into the excel spreadsheet for analyses and matched with patient number in study.

A third unit will be demographic data of participants such as gender, age, and race. Descriptive statistics will be used to describe the sample.

Protection of Human Subjects

No identifiers will be linked to the patient's name, identification number, or medical record number except for data collection purposes pre-and post-intervention. Subsequently, all identifiers will be removed and a new ID will be keyed for each patient to match patients pre-and post-intervention for statistical analyses. The data will be entered for pre-and post with the same new ID in excel sheet. The data will then be merged for analyzing.

Sample

The sample will consist of hospice patients over ages 18 who receive home care hospice services over a 2-week period. Inclusion criteria are individuals of either gender, age 18 or older, have a formal caregiver, can speak and read English, and are receiving at least one analgesic medication. Based on power and effect size, sample size for this project is estimated at 71 patients.

Outcomes to be Measured

The Brief Inventory Form (short form) is used to collect pain data by patients and caregivers over a two-week period in a pre-and post-test design. The Brief Inventory Form (short form) instrument consists of 9 questions that measures pain or related pain items on a Likert scale ranging from 0-10. With pain rating, 0 is having no pain at all and 10 is having the worst pain ever experienced. With Interference, 0 is no interference on everyday life and 10 is complete interference on everyday life. Psychometric findings in

the literature confirm that this scale has reliability and validity (McDonald et al., 2008). Feasibility of the form was calculated using the ceiling and floor effects (percentage of patients with the maximum and minimum possible scores) on each item in the questionnaire and for both subscales (Ares, 2015). The reliability of the form was tested by examining the internal consistency of responses using Cronbach's which revealed ceiling and floor effects up to 15% and Cronbach's of >0.70 which were considered acceptable (Ares, 2015). The Brief Inventory Form (short form) allows providers to understand if patient experienced overall decreased pain, pain relief with medication, and increased pain.

The formalized DNP project pain card will capture data as it relates to overall pain experienced and relief. It contains 4 items; the pain scales, adjectives to describe pain, pain location, what has been done to help pain previously, and in addition to these questions there is an algorithm for caregivers to use when medicating.

Framework/model of research

Introducing a formalized pain card in the hospice setting requires a sound theoretical framework that has been tested in the clinical setting and has been shown to be valid. Katharine Kolcaba's 1990's Theory of Comfort provides relevance to the topic of pain control and hospice care and pertains directly to this quality improvement project (Vendlinksi & Kolcaba, 1997). This theory includes three important elements. First, the term comfort is derived from a Latin term *comfortare* which means to strengthen greatly (Vendlinksi & Kolcaba, 1997). Second, the process of comforting involves participation of the patient and the caregivers (Vendlinksi & Kolcaba, 1997). Lastly, comfort care consists of the process of comforting and the outcome of enhanced comfort (Vendlinksi

& Kolcaba, 1997). Comfort is described as the experience of being strengthened by having the needs met of relief, ease, and/or transcendence (Vendlinski & Kolcaba, 1997). The four contexts of human experience thought to pertain to comfort are physical, psycho-spiritual, environmental, and social (Vendlinski & Kolcaba, 1997). Relief is defined as “the state of a patient who has had a specific need met (Vendlinski & Kolcaba, 1997).” Ease is defined as “the state of calm or contentment (Vendlinski & Kolcaba, 1997).” Transcendence is defined as “the state in which one rises above one’s problems or pain (Vendlinski & Kolcaba, 1997).”

The first element, the term comfort, created the rationale behind providers enhancing comfort (Vendlinski & Kolcaba, 1997). In this project, the nurse practitioner attempts to enhance comfort by providing a formalized pain card where caregivers and patients notified on call staff if pain was unrelieved despite all other efforts. The second element, the active participation of caregiver and patients involves active involvement between caregivers, patients, and the hospice team (Vendlinski & Kolcaba, 1997). It is ideal that caregivers play an active role in decision-making and medicating of comfort care through the entire process until death (Vendlinski & Kolcaba, 1997). The third element, comfort care, consists of comforting and the outcomes associated (Vendlinski & Kolcaba, 1997). The third element is only meaningful if the desired outcome has been met, in this projects case, productive caregiver education and overall reduction of pain. In most clinical settings, it is difficult for patients to have total comfort, but it is important to have interventions that increase comfort (Vendlinski & Kolcaba, 1997).

In most settings, nurses feel satisfied when interventions they initiate are successful in regards to comfort (Vendlinski & Kolcaba, 1997). This theory has had

limited testing in the hospice setting because death and dying processes are often a sensitive time for patients, caregivers, and families (Vendlinski & Kolcaba, 1997). This project is conducted in a sensitive, theory-driven, and scientific manner, which creates the best possible comfort outcomes for hospice patients.

Strategies to Reduce Barriers

The key stakeholders are the board of directors, medical directors, and hospice clinicians. All of these individuals are part of the hospice agency where the DNP project will be conducted. Barriers to this DNP project were the limited evidence, but the emerging research supports the need for increased education for patients and caregivers in hospice care. The literature reviewed for this study did support the need for a formalized pain card in order to improve patient outcomes, reduce emergency visits, and improve patient satisfaction (Bowen, 2016; Glowacki, 2015; Hayes, 2005; Herr, 2010, Laguna, 2014; Wells, 2005).

Steps to reduce barriers include:

1. Email and have telephone conversation with key stakeholders; inclusive of the board of directors, medical directors, and hospice clinicians from the hospice agency to describe project logistics and literature support for development of the formalized pain card.
2. Have brief telephone conversation prior to first meeting with hospice nurse practitioners involved in project. Describe project and the need for student to attend patient visits to apply intervention. Data collector will be present for all patient visits and data collector will do all entries into Excel personally.

3. Student will obtain access to hospice nurse practitioners to hospice facility managers to set up date and time to provide teaching of tools utilized for DNP project.

Description of Intervention (Formalized Pain Card)

The formalized pain card is developed based on the literature. The pain card compiled items from psychometric validated instruments, and then incorporated items into an algorithm listed on a pain card for patient and caregiver use. The pain card asks patients and caregivers to rate pain based off of three evidence-based pain-rating tools. The second portion of the pain card requests if possible, a description of pain experienced using adjectives. It also requests a location of pain, which is an important element in the pain history. Lastly the pain card asks what has been done previously to help pain and what has and has not worked. This is important as some patients respond differently to methods of analgesia.

The final portion of the pain card is an algorithm which is newly developed and has never been tested in the clinical setting. The algorithm is thought to increase analgesia relief to patients by helping caregivers to medicate. The first question of the algorithm asks if the pain was currently not controlled? If pain is controlled, no further intervention needs to take place. If pain is not well controlled, the next question asks was if pain-relieving medications were given? If the answer is no, the caregiver is directed to administer prescribed analgesia medication and start over using the pain card in 30 minutes-1 hour. If pain relieving medications are administered and reassessed in 30 minutes-1 hour and still results in unrelieved pain, an on-call number is provided and the caregiver is instructed to call for further instruction.

This pain card incorporates all relevant literature in regards to hospice pain control and provides a tool for patients and caregivers to use in medicating. This tool is thought to provide pain management as measured by decreased pain, pain relief with medication, and increased pain.

Procedure

Hospice nurse practitioners will have a brief meeting with lead investigator prior to patient visits to go over all items used for this project. A brief 15-minute presentation of the project is provided during the meeting. The lead investigator will be present for all patient encounters during the project to assist in data collection and dispersion of tools to patients and caregivers. After introductions of the project, the investigator and hospice nurse practitioner will schedule visits over a two-week period and then follow up visits the following two weeks on the same patients.

Patients and caregivers are educated on the formalized pain card and administered the Brief Inventory Form (short form) by the lead investigator as well as the hospice nurse practitioner. The lead investigator begins each patient visit by presenting the Brief Inventory Form (short form) to the patient and caregiver and then the formalized pain card. This intervention is done in the patient's home which can be private residence or facility. Patient access was provided by the hospice agency.

Upon approval from the University of South Carolina Institutional Review Board (IRB), the project will commence in May 2017.

Data collection will occur in an encrypted flash drive using Microsoft Excel. No patient identifiers will be collected from patients or caregivers. No protected health information will be collected. SAS 9.4 software will be used to analyze data.

Data Analysis

Descriptive statistics will be computed on the variables. For categorical variables, the univariate constructions will be included frequency distributions. For continuous variables statistics will be included to measure of central tendency (mean and median) and measure of spread (standard deviation and range). Correlation Pearson will be used to examine the relationship between continuous variables. Matched T-test will be used to test the effect of intervention of outcomes (Brief Inventory Form and The Formalized Pain Card). The level of statistical significance will be set at 0.05. The power calculation showed that we will have at least 80% power with total sample size of 71, for between medium to small effect size, and for $\alpha=.05$.

The data will be provided (or entered) in Excel (2010). SAS (9.4) will be used to analyze the data. All data will be entered and will be kept in a safe place. Several backups will be made for data and programs.

Table 3.1 Required sample size for Pretest-post design

With 80 % and 90 % power, different effect size, and alpha.

Effect Size	Alpha = 0.05		Alpha = 0.01	
	80 %	90 %	80 %	90 %
0.20 (Small)	199	265	296	376
0.3	71	97	115	148
0.4	41	55	66	85
0.50 (Medium)	34	44	51	63
0.80 (Large)	15	19	22	27

Summary

Managing pain in patients at end of life can be a challenging, yet meaningful task. With this intervention, the hope is that patients will reach end of life with pain relief and overall comfort to have the best quality of life as possible in the final days. It takes the cooperation of all involved in care. This includes the medical director, the hospice nurse practitioner, registered nurses, case managers, caregivers, and many more. The formalized pain card is thought to produce an effective tool to help reduce overall pain by giving clear direction on when to medicate, when not to medicate, and when to notify on call staff.

CHAPTER 4

RESULTS

Hospice care organizations provide comprehensive end of life care to terminally ill patients. The purpose of this project was to evaluate the use of a formalized pain card that Nurse Practitioners could use to assist clients and caregivers in making the decisions necessary for safe and effective pain management. The Brief Pain Inventory Form was used for measuring: 1) decreased pain, 2) increased pain, 3) pain relief. This chapter will present the description of the sample, analysis of EBP questions, results, and summary of results.

Description of Sample

The sample consisted of 41 patients, ages 18 years and older, who were receiving hospice services. Each participant had a caregiver. Table 4.1 provides descriptive statistics of the sample. Of the 41 participants, 70.73% were female, 75% white, and 25% black. The majority of participants (73.7%) reported pain at the time of-evaluation (n=60) whereas only 26.83% did not report pain (n=22). The mean age of the sample was 77.54 years with a range of 19 to 98 years of age.

Table 4.1 Participant Descriptive Statistics

Variables	Total
	N %
Gender	
Male	12
Female	29.27
	29
Race	70.73
White	
Black	
	30
Current Pain	75.00
Yes	10
No	25.00
	60
	73.17
	22
	26.83

Analysis of EBP Questions

Participants reported their highest level of pain over the last 24 hours as 5.56 pre and 5.44 post introduction of the pain card. For pain at its lowest level over the last 24 hours, participants rated their pain at 1.90 pre-pain card and 1.61 post-pain card. For current pain, participants' mean pain score pre-pain card was 3.44 and post-pain card 2.54. Participants reported, over the last 24 hours, that pain medications provided relief 71.95% of the time pre-pain card and 72.68% of the time post-pain card. Table 4.2 depicts participants' mean pain scores.

Table 4.2 Frequency distributions of participants' pain

Variables	Pre-pain card			Post-pain card		
	N	Mean	SD	N	Mean	SD
Pain at worst over the last 24 hours	41	5.56	3.11	41	5.44	3.35
Pain at least over the last 24 hours	41	1.90	2.42	41	1.61	2.37
Current pain: 0-10	41	3.44	2.95	41	2.54	2.64

Over the last 24 hours, how	41	71.95	41	72.68
much relief have pain				
medications/treatments	30.76		29.75	
provided.				

Table 4.3 depicts parametric and non-parametric matched t-tests for pain variables of participants. The results showed there was a statistically significant difference for pain over the last 24 hours for parametric matched t-test ($P = .0503$) and not significant for nonparametric test ($P = .0667$), indicating that pain was reduced with the formalized pain card. The results revealed statistically significant differences for current pain from pre to post intervention for both parametric and nonparametric tests ($P = .0002$ and $P < .0001$), indicating that the formalized pain card decreased current pain. However, the statistical results did not indicate any statistically significant differences from pre to post intervention for pain at its worst over the last 24 hours and for pain relief using medication over last 24 hours, indicating that the pain card was not effective. According to statistical data, pain was not reduced post intervention using the pain card for assessing pain at its worst over 24 hours. For determining the relief of pain using pain medications and treatments within a 24-hour time frame; the formalized pain card did not seem to provide any more pain relief from pre to post intervention.

Table 4.3 P –Value for Matched paired t-test for participants

Pain Variables	Parametric	Non-Parametric
Pain at worst over the last 24 hours	0.5981	0.5917
Pain at least over the last 24 hours	0.0503	.0667
Current pain	0.0002	<.0001
Over last 24 hours, how much relief have pain medications/treatments provided	0.4737	.7813

Table 4.4 depicts McNemar’s test for pre-and post-test surveys. According to McNemar’s test, the DNP project results were not statistically significant ($p=.5271$), indicating that the pain card intervention did not produce any differences in pain from pre to post intervention.

Table 4.4 McNemar’s Test for participants’ pain

Pre Pain	Post-pain	
	No	Yes
No	6 60.00	4 40.00
Yes	6 19.35	25 80.65

Conclusions

Project questions focused on pain severity or interference of pain on everyday life. In summary, only two of the statistical tests yielded statistically significant results. The t-test revealed statistically significant results thus indicating that the pain card reduced pain from pre to post. The McNemar's test did not reveal statistically significant results meaning that overall pain was not reduced after intervention. When reviewing trends in the data it is possible that the pain card reduces pain, but would be beneficial to utilize on a larger and more diverse sample.

Summary

After intervention, frequency and statistical data indicated that use of a formalized pain card on hospice patients does at times prove to decrease pain, but some of the statistical tests did not demonstrate decreased pain. This data is somewhat consistent with evidence-based literature that showed use of the formalized pain card is warranted. In the future, the formalized pain card will need to be tested on a larger more diverse sample size to determine effectiveness in the population.

CHAPTER 5

DISCUSSION

The purpose of this DNP quality improvement project was to evaluate the use of a formalized pain card that Nurse Practitioners could use to assist clients and caregivers in making the decisions necessary for safe and effective pain management with improving outcomes by using the Brief Pain Inventory Form for measuring: 1) decreased pain, 2) increased pain, 3) pain relief. This chapter will present recommendations for practice, recommendations for policy, recommendations for education, recommendations for research, project limitations, and project conclusions.

Recommendations for practice

According to the DNP quality improvement project and consistencies with the literature, the formalized pain card should be utilized on hospice patients (Finnerup et al, 2005). Findings from the literature revealed the need for a policy standard for patients to notify when pain is unrelieved despite exhausting all other efforts to control pain (Glowacki, 2015). The formalized pain card contains the steps necessary for caregivers and patients to medicate effectively and notify providers if pain is unrelieved.

The implementation of the formalized pain card for pain management integrates standards of care in pain management as well as provides an algorithm for caregivers to utilize when medicating hospice patients. By providing patients and caregivers with the formalized pain card it allows patients to be treated in their home environment while

always knowing that a staff member is on call and ready to provide assistance if pain is unrelieved. This process allows better overall quality of life at end of life.

At present, there are challenges to effectively managing hospice patients pain. Barriers to effective pain management include inability to assess pain, reluctance to administer pain medication, fears about narcotic pain medication including overdose or addictions, noncompliance with regimens, hesitancy to report pain to providers, caregiver role strain, and lack of caregiver education (Oliver et al., 2008). Thus, the implementation and utilization of the formalized pain card allowed patients to have overall better pain relief and medical interventions from hospice providers. Participants reported their highest level of pain over the last 24 hours as 5.56 pre and 5.44 post introduction of the pain card. For pain at its lowest level over the last 24 hours, participants rated their pain at 1.90 pre-pain card and 1.61 post-pain card. For current pain, participants' mean pain score pre-pain card was 3.44 and post-pain card 2.54. Participants reported, over the last 24 hours, that pain medications provided relief 71.95% of the time pre-pain card and 72.68% of the time post-pain card. The formalized pain card provided the patients and caregivers with a tool that had clear and concise directions on what to do if the patient was experiencing pain.

Recommendations for Policy

Hospice organizations are continuously required to report performance measure scores to centers for Medicare and Medicaid services, pain control being one of the items to report. Reimbursements rely heavily on these outcome measures. By incorporating the formalized pain card, patients' pain experience overall may decrease and quality of life may increase. For hospice agencies to be effective and continue to provide care to

patients, they need to avoid any decreases in reimbursements from Medicare, especially as it relates to pain management. Hospice organizations must stay current with the evidenced based literature to provide the best methods and tools to patients to control pain. For example, reading current issues of scholarly journals related to pain management with the hospice population, attending seminars, and taking online courses.

Due to the increase in regulations promulgated for 2017 on hospice agencies and their delivery of care, hospice organizations are accountable now for symptom management. As of 2017 hospice agencies are federally mandated to administer surveys to family members and caregivers upon discharge by a third-party organization. These surveys inquire about the delivery of care including pain management. Improved scores on these performance measures will assist hospice agencies to avoid financial sanctions while providing quality care to patients. Of importance, these surveys have the potential to positively or negatively affect patient care satisfaction ratings, marketing perceptions, and referral rates from other providers because scores are made readily available to the public. Enforcing the implementation of the formalized pain card on hospice patients could alleviate poor scores in the realm of pain, thus, increasing the number of hospice patients seeking care.

Recommendation for Education

Based on the literature, evidence indicates that caregivers lack educational preparation or training to manage pain (Lau et al., 2012). Evidence suggests that Hospice providers do not educate or train caregivers on effective pain management (Lau et al., 2012). Hospice medications are extremely potent with severe side-effects which require monitoring and other skills that must be taught to the caregiver (Lau et al., 2010). It is

imperative that hospice providers provide proper medication administration education as well as caregiver/patient education on use of the formalized pain card. Education can be provided through various methods such as reading level appropriate handouts, assistance with using the formalized pain card for the first time, follow up on proper use of the formalized pain card at each visit, as well as requesting constant verbal feedback from patients and caregivers on items taught.

In addition to educating patients and caregivers, providers must be properly educated on the use of the formalized pain card as well as be familiarized with all items pertaining to the pain card. Hospice providers must be able to respond and prescribe in a timely manner if patients or caregivers call with unrelieved pain requests. Hospice providers should fully understand every aspect of the algorithm on the formalized pain card and the steps the patients and caregivers went through to make the phone call to staff. With hospice patients, death is typically imminent, providers must be able to adapt and respond quickly to changes in pain and provide relief to the patients under their care.

Recommendations for Research

The formalized pain card is a tool adapted from an evidence-based algorithm for treatment of neuropathic pain to be utilized in the hospice setting. Further research is warranted to determine the tool's psychometric findings. In this DNP project, the formalized pain card was found to decrease overall pain. Participants reported their highest level of pain over the last 24 hours as 5.56 pre and 5.44 post introduction of the pain card. For pain at its lowest level over the last 24 hours, participants rated their pain at 1.90 pre-pain card and 1.61 post-pain card. For current pain, participants' mean pain score pre-pain card was 3.44 and post-pain card 2.54. Participants reported, over the last

24 hours, that pain medications provided relief 71.95% of the time pre-pain card and 72.68% of the time post-pain card. Further testing on larger samples in more diverse areas will need to be conducted.

End of life is a sensitive time period for patients and caregivers, thus, closing the knowledge gaps through research on pain management is critical for caregivers and patients (Herr et al., 2010). By creating awareness that the formalized pain card is used to help alleviate pain, this may provide more subject participation for further investigation.

Further research should be conducted on the pain card cost savings as it relates to outcomes, ER visits, and quality of life measures. Another key area for future research is the hospice provider response rate to inquiries and calls for pain relief it relates to the formalized pain card and prescribed interventions.

Limitations

This quality improvement project reveals the need for further pain management which is consistent with the evidenced based literature (Kelley et al., 2010). Data obtained were from patients and care givers in home hospice services.

In terms of limitations, the sample size was relatively small (n=41 pre and n=41 post survey). The sample goal for this quality improvement project was 71, but due to timeline constraints sample size was 41. Initially, the project was proposed to occur over a 4 week time period, but was conducted over 6.5 weeks in order to conduct the intervention and to obtain a sample pre and post intervention for comparison. Hospice providers could only accommodate seeing 2-4 patients per visit limiting the overall sample size.

Conclusion

Initiating the formalized pain card provides a quality improvement intervention for patients and caregivers at end of life to promote overall well-being by decreasing overall pain. The pain card is utilized to alleviate distressing pain symptoms in the hospice patient population. Hospice patients with imminent deaths deserve comprehensive pain management. With the introduction of the formalized pain card patients can be treated adequately and have proper pain control. In this population, evaluation of evidence-based literature can promote pain symptom management. Implementation of the formalized pain card can reduce overall pain and suffering during pain symptom crisis. Continuing education for hospice patients, caregivers, and hospice providers is imperative to understanding the full scope of pain management and appropriate alleviating interventions. Adhering to evidence based practice ensures quality patient outcomes, appropriate policy standards, and pathways for future research.

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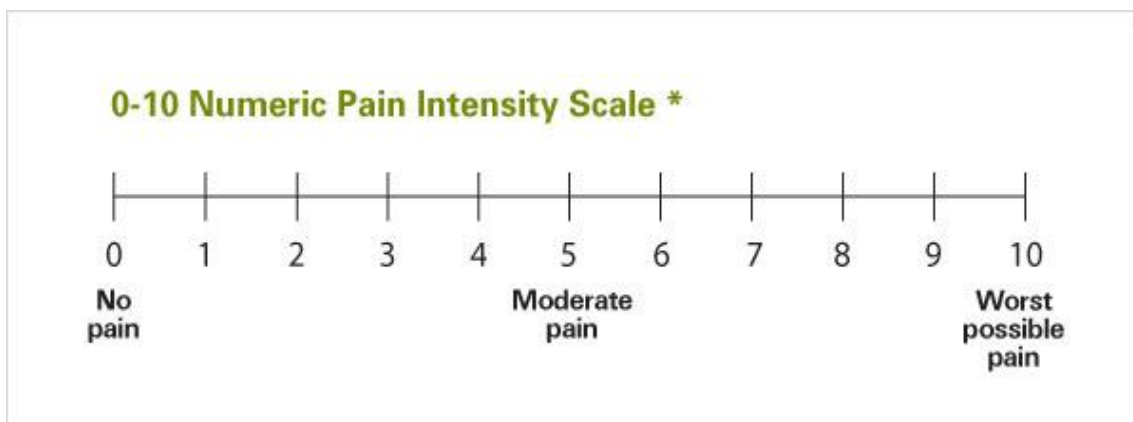
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Appendix A: DNP Project Formalized Pain Card

Pain Card

1. Rate your/your loved one's pain on one of the three scales.
Use this scale if the patient can verbally rate pain on a numeric scale.



- Use this scale if the patient can point to the face that correlates with their pain.*

Wong-Baker FACES™ Pain Rating Scale



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Use this scale if the patient cannot verbally tell you their pain level or point to the face that indicates their pain.

FLACC scale

Behavioral Observation Pain Rating Scale

Categories	Scoring		
	0	1	2
Face	No particular expression or smile; disinterested	Occasional grimace or frown, withdrawn	Frequent to constant frown, clenched jaw, quivering chin
Legs	No position or relaxed	Uneasy, restless, tense	Kicking, or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No crying (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or talking to. Distractable	Difficult to console or comfort
Each of the five categories (F) Face; (L) Legs; (A) Activity; (C) Cry; (C) Consolability is scored from 0-2, which results in a total score between 0 and 10.			

2. *If you or your loved one is able to speak describe the pain using one or more of these descriptive terms: Aching, burning, tender, numb, piercing, pounding, tight, cramping, pulsing, tingly, gnawing, sharp, stabbing, nagging, shooting, pinching, and any others that may describe the pain.*
3. *Please describe where the pain is located if possible*
4. *What has been done to help pain? What has worked, what has not worked?*

