A Project to Improve Nurses’ Knowledge of, and Attitudes Towards, Pain Management at End of Life

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A Project to Improve Nurses’ Knowledge of, and Attitudes Towards, Pain Management at End of Life

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Abstract

Background: Symptom management is essential to the quality of palliative care. The goal of palliative care is to have interventions in place to ensure that the patient is safe and comfortable throughout the disease process and will experience a peaceful death. Providing adequate pain management requires the use of evidence-based interventions to provide pain relief and avoid unnecessary suffering at end of life. Purpose: The purpose of this capstone project was to provide an educational nursing program that addressed misconceptions about opioid use and in the long term, to improve the assessment and treatment of pain for patients at the end of life. Conclusion: The use of an educational intervention aimed at addressing the barriers to adequate pain management was shown to increase nurses’ knowledge, attitude, and skill when assessing for pain and when administering opioids for pain management. Clinical Implications: Clinicians have a responsibility to provide appropriate pain management and to seek education and training necessary to achieve this goal.

Keywords: terminal care, hospice, opioids, knowledge and attitudes, barriers, misconceptions
Introduction and Background

A “good death” is one that avoids distress and suffering for the patient and family by following their wishes while adhering to clinical, cultural and ethical standards (Field & Cassell, 1997, p.4). Pain has been identified as the most distressing and feared symptom at end of life (Morrison & Meier, 2003). However, many clinicians are hesitant to administer opioids for pain management. This reluctance is due to fear of respiratory depression accelerating death (Morrison & Meier, 2003). Despite the lack of evidence-based research supporting this association, clinicians continue to withhold administration of opioids based on the belief that they are accelerating the dying process (HPNA, 2012). The World Health Organization (2015) reported that 6 million people die from cancer without sufficient analgesia or often without any pain management. Deandrea, Montanari, Moja, and Apolone (2008) concluded that the prevalence of untreated cancer pain remains as high as 40% of patients. Undertreatment is well documented and attributed to numerous health care barriers.

Barriers to appropriate pain management include the subjectivity of pain, lack of education, problems converting between opioids and the stigma of opioid use (Spitz et al., 2011). The knowledge and attitudes in relation to addiction and tolerance of opioids were also identified as additional barriers to effective pain management (Fine, 2007; Wells et al. 2001). Yet, Fink and Gates (2010) reported that a lack of scientific data is not a barrier to the mismanagement of pain. Data has been available for decades regarding appropriate pain management for end of life care.

According to the U.S. Census Bureau, older adults are the fastest growing segment of the population (U.S. Department of Health and Human Services, 2001). It is estimated that by the year 2030, individuals > 65 years will make up 19% of the US population compared to 12.9% reported in 2009. Many older adults will spend their aging years in a long-term care facility and
eventually require end of life care (U.S. Department of Health and Human Services, 2001). The percentage of Americans who will die in a long-term care facility is projected to increase from 25% in 1994 to 40% by the year 2040 (U.S. Department of Health and Human Services, 2001). Long term care nurses are at the frontline of patient care; therefore, it is important to determine the knowledge level and attitude of nurses to access whether improvement in patient care is needed. Primo Levi, a Holocaust survivor, physician and philosopher, was once quoted saying “if we know that pain and suffering can be alleviated, and we do nothing about it, we, ourselves become the tormentors” (as cited in DiPiro et al., 2014, p.925). Education and support is needed for long-term care nurses to understand their responsibility to relieve pain and suffering and to attain skill and confidence in the clinical activities that are needed to ensure that this goal is properly meet (HPNA, 2012).

The risk for inadequate pain management among geriatric end of life patients by long-term care clinicians is indicated by a reluctance to administer opioids and results from gaps in specialized education and training on hospice/palliative care. Studies confirm that there is no clinical reason to withhold administration of opioids during end of life care (HPNA, 2012). Research studies consistently identify the need for further education and support for clinicians (Barnett, Mulvenon, Dalrymple, & Connelly, 2010; Wells et al., 2001; White, Coyne, & Patel, 2001; Whitecar, Jonas, & Clasen, 2000). Hutchison, Tucker, Kim, and Gilder (2006) stated that patients have a right to adequate pain management and identified the Pain Assessment in Advanced Dementia (PAINAD) Scale as a useful tool in assessing for the presence of pain in patients who are unable to self-report pain. The PAINAD scale is a five-item observational instrument use to detect possible indicators of pain (see Appendix A) (Warden, Hurley, & Volicer, 2003). However, many long-term facilities do not consistently use the PAINAD scale.
As a result, pain in patients with cognitive impairments continues to be poorly managed.

According to White, Coyne, and Patel (2001), the best practice is to implement education and training for nurses who provide end of life care. These authors stated that the potential for a "good death" is increased when being cared for by competent nurses. Competency means being educationally prepared to perform adequate end of life nursing care. However, few nursing schools have programs incorporating palliative care and continuing education is “minimal and inconsistent” (White, Coyne, & Patel, 2001, p.150). Barriers to continuing education include: lack of accessibility, lack of funding, and lack of value in end of life education. When continuing education is offered, nurses complain that they do not have the time to attend these in-services and there is little to no clinical support after education has been provided.

The Hospice and Palliative Nurses Association (HPNA, 2012) encourages clinicians to utilize analgesic guidelines from the American Pain Society, the American Geriatrics Society, and the National Comprehensive Cancer Network to overcome these barriers in pain assessment and treatment. The Ethics Committee of the American Geriatrics Society (AGS, 2003) further supports this by stating that clinicians have an ethical responsibility to provide pain relief and to avoid unnecessary suffering. The ethical concern of causing harm through the administration of opioids can be eliminated by carefully applying standards and guidelines based on the physiology of pain, the mechanism of drug action, and thorough on-going assessments of the patient’s condition (HPNA, 2013). It is vital that nurses acquire these competencies through academic preparation and continuing education (ANA, 2010).

Findings from a 2013 study of end of life care demonstrated that little has changed in nearly two decades [from a landmark study published in 1995 called the SUPPORT trial] with regards to pain management in the dying patient (Yao et al., 2013). In 30% of end of life
patients with severe or significant pain at death, only 42.7% actually met the expected pain-related outcome (Yao et al., 2013). These gaps in practice indicate a need to conduct quality improvement interventions aimed at assessing the knowledge and attitudes of clinicians before and after education and support is provided.

**Problem Statement**

Despite over 20 years of evidence-based pain management guidelines, the risk of poor pain management continues among end of life patients. Undertreatment of pain results from lack of knowledge and education of nurses and the myths and misconceptions surrounding opioid use. With an educational in-service, barriers hindering adequate pain management may be reduced or eliminated. Nurses will demonstrate both knowledge and skill when assessing for pain and when administering opioids for pain management.

**Review of the Literature**

A comprehensive search of the literature was conducted to identify and critique existing studies related to pain management at the end of life. The following databases were included: PubMed of the National Library of Medicine and CINAHL. Keywords and Medical Subject Headings (MeSH) terms included a varying combination of the following: terminal care, hospice, opioids, knowledge and attitudes, barriers, and misconceptions. The Hospice and Palliative Nurses Association (HPNA) was explored for resources and guidelines on pain management. The HPNA provides many research articles on pain management to support its position statement that all people have the right to optimal pain relief. Inclusion criteria consisted of full-text articles published in the English language within the past 15 years. Articles were filtered to focus on nurses’ knowledge and perceptions. The search yielded seven articles, each rated for strength of evidence and quality using the John Hopkins research evidence appraisal (The John
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Hopkins Hospital, n.d.). Two qualitative studies, two descriptive studies, one systematic review, one non-randomized controlled study, and an article on clinical practice guidelines were included in this review.

**Lack of Knowledge**

Lack of knowledge related to pain management was identified as a significant barrier to effective pain management. Wells et al., (2001) stated that there still appears to be ‘considerable ignorance’ on the subject of pain assessment and management, although information has been available for 20 years (p.202). In this study, an alarming 34% of 135 nursing and medical staff reported that they had not received any education in pain control and fewer than 43% had received continuing education since being in their current position. Although the study sample was taken from a surgical unit and only a small amount of participants completed both questionnaires, these results still indicate that staff training and education is needed to ensure proper knowledge of pain control and palliation of symptoms. Gardiner et al., (2012) further states that if pain management at end of life is to be achieved, educational opportunities need improvement and an effective plan of care needs to be developed to ensure pain management is optimized.

Nurses are at the frontline of care for end of life patients, however, there are many shortfalls in the professional and continuing education of nurses (American Association of Colleges of Nursing [AACN], 2000). White, Coyne, and Patel (2001) conducted a descriptive study to assess the knowledge of 750 oncology nurses who provide end of life care. Ninety-eight percent of nurses stated that end of life care education is important. However, only 26% reported an “excellent level of preparation to effectively care for a patient and family during the end of life period” (p. 149). These nurses were asked to identify end of life care competencies that
would have been beneficial to learn in nursing school. The top three competencies reported were: (1) talking to patients and families about dying; (2) pain control techniques, specifically opioid dosing and; (3) comfort care-nursing interventions. Proficiency in these areas would equip nurses with the tools to provide quality care at end of life. Although improvements to curricula content have been made, healthcare professionals need to have a better understanding of pain management at end of life. A systematic review of barriers hindering adequate cancer pain management and interventions further supported the need for implementation of a multilevel approach to improve the quality of pain treatment and education (Oldenmenger et al., 2009).

Ferrell, Virani, Grant, Vallerand and McCaffery (2000) examined the amount of content in nursing textbooks related to pain management and end of life care. The goal of their research was to strengthen nursing education regarding pain management at end of life. Fifty textbooks (total of 45,683 pages) were included in this study. Although pain was the most common topic, the 248.5 pages of pain content represented only 0.5% of the total text content. End of life content consisted of 902 pages representing 2% of the total text content. The findings identified the substantial deficiencies in nursing textbooks and demonstrated a need for advances in pain management education into text.

**Myths and Misconceptions**

Poor attitudes as a result of myths and misconceptions on opioid use continue to be a barrier to adequate pain management at end of life. Portenoy et al. (2006) analyzed data from the National Hospice Outcomes Project, a large prospective cohort study involving 13 hospices in the United States. This study was conducted to address concerns that opioids may affect the survival among those with a terminal diagnosis. Data from 725 patients who underwent at least one recorded opioid dose change prior to death were included. Researchers compared outcomes...
of patients receiving usual dose with those receiving high dose therapy. The authors examined
the associations between time of death after the final dose was administered and other variables,
such as the amount of morphine and the percentage of dosage increased. The results of this study
suggest that the final opioid dose has a weak association with overall survival rate and an
extremely low risk of accelerating death among hospice patients. This finding was supported by
the relatively long (time) intervals between the final dose change and death, and the lack of any
indication of higher opioid risk in those subgroups receiving higher doses. The authors conclude
that under-treatment of pain is a much larger concern than the risk of hastening death in
terminally ill patients and healthcare providers should continue to use opioids to manage pain
and suffering at end of life. They also suggested that pain was inadequately treated at end of life
due to the misconception that high doses of opioids hasten death.

Barnett, Mulvenon, Dalrymple, and Connelly (2010) conducted a descriptive study to
evaluate nurses’ knowledge, attitudes, and practice patterns regarding titration of opioid
infusions at end of life. The study included 181 nurses from three urban medical centers in the
Midwest. The participants were given a 20 question survey (16 quantitative questions and 4
qualitative questions) in four categories: comfort and confidence in caring for patients requiring
opioid titration; knowledge about symptom management; documentation, education and policy;
and concerns. Although some the results of this study reflect favorably on nursing knowledge
(e.g., 78% of nurses felt comfortable titrating opioids), the authors asserted that there is still a
need for further education and continued training. When nurses were asked about their concerns
about accelerating death with the administration of opioids, 18.2% indicated that they had
concerns, 55.2% had no concerns, and 13.8% were unsure. Despite these percentages, a large
majority (82.9%) of nurses indicated a need for more education. Many revealed that they had
difficulty assessing and documenting symptoms of pain for non-verbal patients and needed more objective data to support a change in opioid dose. The authors identified the importance of established institutional policy and standards and concluded that when evidence based guidelines are followed, there is no evidence to support the fear that increasing opioids for pain management is associated with hastening the dying process.

Morphine is considered the “gold standard” of opioids and the first line treatment for moderate to severe pain in terminally ill patients (World Health Organization, 2016, p.1). Whitecar, Jonas, and Clasen (2000) contend that concerns for the risk for addiction and tolerance in end of life patients is not scientifically based. There is no therapeutic ceiling for morphine, which enables patients to receive a high dosage safety and effectively if titrated properly. Dosages of morphine and other strong opioids can be safely increased by 50% every 24 hours until symptoms are appropriately managed and can also be decreased by 50-75% every 24 hours without causing withdrawal symptoms. Fine (2007) asserts that opioids are the safest and most effective pain medicine for most patients with moderate to severe pain and are much safer than non-steroidal anti-inflammatory medications. He concludes that physicians and nurses have an obligation to avoid this misconception by seeking proper education and failure to do so leads to undertreatment of severe pain or inappropriate and unsafe treatment.

Discussion

There still remains a gap in practice regarding pain assessment and management, despite evidence based pain management guidelines, which have existed for over 20 years (Wells et al., 2001). A high percentage of nurses continue to report the lack of initial and continuing education in pain management. White, Coyne, and Patel (2001) reported that 98% of nurses stated that end of life care education is important. However, the authors identified that this percentage could be
bias due to the sample of nurses having more education than the general population and all the nurses in this study were certified by a specialty organization. These nurses were also older than the average nurse, indicating that they probably had more experience. Further research is needed on nurses with less than 5 years of experience.

Few nursing schools have programs incorporating palliative care and continuing education is inadequate. Textbooks are also lacking content on pain control, especially at end of life (Ferrell, Virani, Grant, Vallerand & McCaffery, 2000). Barnett, Mulvenon, Dalrymple, and Connelly (2010) reported that 82.9% of nurses indicated a need for more education. The authors affirmed that an end of life nursing education program is needed that specifically addresses the use of opioids at end of life and addresses knowledge, attitudes, and practice patterns. These studies indicate the need for further education for nurses who provide end of life care.

Although established pain management guidelines have been available for decades, patients continue to die without adequate pain control due to ongoing misconceptions of opioid use (Yao et al., 2013). The existence of these guidelines and the research dispelling the myths associated with opioid use have led researchers to conclude that a lack of scientific data can no longer be considered a barrier to providing adequate pain management (Fink & Gates, 2010). Portenoy et al. (2006) claims that the final opioid dose has a weak association with survival and an extremely low risk of accelerating death among hospice patients. Whitecar, Jonas, and Clasen (2000) reports that risk for addition and tolerance in end of life patients has not been establish through research. Fine (2007) asserts that opioids are the safest and most effective pain medication for moderate to severe pain. The Hospice and Palliative Nurses Association (2012) encourages clinicians to utilize analgesic guidelines from the American Pain Society, the American Geriatrics Society, and the National Comprehensive Cancer Network to overcome
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these barriers in pain assessment and treatment. Education is needed to address misconceptions of opioid use and to provide nurses with evidence-based guidelines.

**Theoretical Framework**

Kurt Lewin’s Theory of Change (1947) is a simple and practical model for implementing change. Lewin believes that there are two forces at hand when attempting to implement change: driving forces and restraining forces. Driving forces assist in facilitating change by motivating individuals toward the desired goal (Kritsonis, 2004; Lewin, 1947). The driving force in this quality improvement project is creating competent nurses by providing them with education and tools necessary to identify pain and to provide appropriate pain management. Restraining forces counter driving forces by hindering progress and change. The restraining forces in this project include: the fear of respiratory depression accelerating death, the subjectivity of pain, and the stigma of opioid use in relation to addiction and tolerance (Fine, 2007; Spitz et al., 2011; Wells et al. 2001). The goal of Lewin’s change theory is to avoid equilibrium by making the driving force greater than the restraining force. If nurses (1) identify barriers to adequate pain management; (2) understand their obligation to relieve pain and suffering; and (3) achieve skill and confidence in the clinical activities that are necessary to meet this goal, patients will remain safe and comfortable throughout their disease process and will experience a peaceful death.

Lewin’s change theory has three distinct stages: unfreezing, movement, and the refreezing stage. The first step in the process of changing behavior is to unfreeze the current behavior. The need for change must be recognized and wanted before change can be implemented (Kritsonis, 2004). The facility’s director of nursing verbalized that continued education on pain management is needed as evidence by last year’s deficiencies on their state survey. This quality improvement project administered a pre-test, a modified version of the
Nurses’ Knowledge and Attitudes Survey Regarding Pain (NKAS) to identify nursing perceptions on pain management in elderly patients, particularly at end of life (McMillian, 2000). Lewin believes that a successful unfreezing stage can be achieved by making driving forces outweigh restraining forces. If participants are involved in the process of change, they will be more accepting of change.

The second step in Lewin’s change theory is movement. During this phase, there was an in-service to address misconceptions of opioid use and to provide education on evidence-based guidelines for pain management. Lewin believes that persuading participates to agree that the current behavior is not beneficial to them and encouraging them to view the problem from a new perspective is important in this stage (Kritsonis, 2004). During the in-service, nurses had the opportunity to actively participate in the discussion of barriers to adequate pain management and to identify solutions (i.e. pain management tools) most appropriate for their facility and more specifically their unit. Open communication, encouragement and support were important during this stage (Kritsonis, 2004).

The third step of Lewin’s three-step change model is refreezing. The goal in this stage is for nurses on the unit to display integration of effective pain-management as they began to refreeze with new behaviors. Refreezing will occur when nurses appropriately assess for pain and adequately manage symptoms. To reinforce this new pattern, the PAINAD scale was suggested to the facility for daily use during assessments. A post-test was also provided to assess change in perception of pain management after the in-service.

**Project Design and Methods**

Guidelines published by the Agency for Healthcare Research and Quality state that education on safe pain management will prevent undertreatment of pain (Wells, Pasero, &
McCaffery, 2008). The HPNA (2013) further encourages nurses and organizations to advocate for education to better manage pain at end of life. Based on the review of research, the problem solution is to provide an in-service on pain and symptom management to nurses in long-term care settings to address any misconceptions of opioid use and to provide education on end of life care for elderly patients.

**Settings and Resources**

This capstone project took place at a long-term care facility in Western Connecticut. All physical resources (rooms and equipment) were provided by the facility.

**Description of the group, population or community.** This facility was given a 1 star overall rating by The Centers for Medicare and Medicaid Services (CMS), placing it among the lowest 20% of nursing homes in Connecticut. This facility also received 13 deficiencies listed under quality care (CMS, 2015). The percent of short-stay residents who self-report moderate to severe pain at ALHC was 37%, compared to the Connecticut average of 19% and the national average of 18.5% (CMS, 2015). The percent of long-stay residents who self-report moderate to severe pain at ALHC was 18.9%, compared to the Connecticut average of 5.7% and the national average of 7.6% (CMS, 2015). This indicates a significant need for improvement in the quality of care provided to these patients, especially those who cannot self-report pain as they have a greater risk of underassessment and undertreatment (Zwakhalen, Hamers, Peijnenburg, & Berger, 2007). With specialized nursing education and training, patients will receive relief from pain and suffering by competent nurses equipped with the knowledge and skills necessary to identify pain and to provide appropriate pain management.

**Organization analysis of project site.** This facility conducts annual in-services on dementia training for its clinical staff. The staff development coordinator expressed interest and
support in these pain management in-services prior to his dementia training as much of this information overlaps. He believes that this capstone project will prepare nurses for further dementia training by introducing the topic of nonverbal pain and how to properly assess and treat patients who may not always be able to communicate their needs.

**Evidence of stakeholder support.** The key stakeholders include the facility’s administrator, the director of nursing, the staff development coordinator and the facility nurses. A letter of stakeholder’s agreement was drafted and signed by the administrator of the facility. The administration supported this project by providing a room for the in-services and allowing the DNP student access to the facility nurses during and after the intervention to administer the pre- and post-test.

**Project participants.** The participant sample consisted of 13 long-term care registered nurses and licensed practical nurses. Demographics were not collected as this DNP student did not wish to evaluate the differences in demographic measurements.

**Design**

A pre- and post-test design was used to evaluate the effectiveness of the educational program. The DNP candidate administered a pre-test, a modified version of the Nurses’ Knowledge and Attitudes Survey Regarding Pain (NKAS), to assess nurses’ attitudes and perceptions (see Appendix B). At the end of the in-service, a post-test, the same NKAS was administered again to evaluate if the nurses’ attitude and beliefs have changed after receiving education on pain management (see Appendix C).

To prepare for this project, this DNP student attended four in-services conducted by a hospice advance practice registered nurse (APRN) at several long-term care facilities to: (1) be exposed to effective methods for conducting an in-service; (2) identify common questions asked
by long-term care nurses and to (3) identify potential barriers to the planned educational intervention. Prior to the intervention, the DNP student contacted the administrator of a hospice agency in Western Connecticut and requested permission to use copyright material on pain assessment and management (see Appendix D). This educational material was reviewed, a sample pre/post-test was created, and a tentative in-service agenda was completed. The staff development coordinator was contacted and a meeting was scheduled to review the pre- and post-test and educational materials to ensure that it met the facility’s objectives. Two weekdays were scheduled to conduct a thirty-minute in-service, three times during each day to ensure that every nurse from each shift could attend.

**Timeline**

The projected timeline was developed by the DNP candidate to ensure timely completion of this quality improvement project. This timeline was used to guide this project by establishing deadlines and detailing the activities necessary to meet this goal. Each action was sequenced, which communicated accountability for each task while helping to estimate time spent and actual cost (Issel, 2014). The facility’s administrator approved this project proposal in April 2015. The in-services were conducted in October 2015 with project completion by December 2015.

**Expected Goals and Objectives**

- **Goals Related to Program/Intervention/Providers.** The goal was to conduct a pain management in-service for nurses. The expected outcome of this in-service was nurses will feel comfortable and competent in knowledge and skill when assessing for pain and when administering opioids for pain management.

- **Goals Related to the Population.** The goal was for terminally ill patients to be comfortable throughout their disease process. The expected outcome of this project was
patients would no longer be undertreated due to misconceptions and myths regarding opioid use. Instead, patients will receive better end of life care as evidenced by nurses appropriately assessing for signs and symptoms of pain/discomfort and providing appropriate pain management.

The DNP candidate anticipated that the commitment to improved pain management would be reflected by the facility incorporating the PAINAD scale as a tool for nurses to use when assessing pain/discomfort for nonverbal and end of life patients. The final expected outcome was for the facility to implement an annual nursing in-service on pain assessment and analgesic regimens, particularly for opioid use in pain management.

**Ethics and Human Subject Protection**

This project administered a modified version the Nurses’ Knowledge and Attitudes Survey Regarding Pain (NKAS) as a pre-test and post-test to access nurses’ attitudes and perceptions before and after the in-service (see Appendix B and C). Three open-ended questions on pain management were included along with a short survey to evaluate the DNP candidate’s performance. The facility nurses were the human subjects involved in this project, which was conducted in accordance with all federal, institutional, and ethical guidelines. At each stage of implementation, no risk to either facility staff or the DNP student were identified. Patient information was not required nor was discussed, which maintained the policies of the Health Insurance Portability and Accountability Act. Confidentially was maintained, as the participants were asked not to put their names on the surveys. The data collected was analyzed, evaluated, and stored at the DNP candidate’s home. Based on the DNP program requirements and the design of this quality improvement project, Institutional Review Board approval was not required.
The American Society for Pain Management Nursing holds the position that all health care providers must advocate for optimal pain and symptom management to alleviate suffering for every patient receiving end of life care. Nurses have a responsibility to use appropriate doses of medication to provide symptom relief and nurses must advocate on all patients’ behalf when the prescribed dosage are not managing pain and other end of life symptoms (Reynolds, Drew, & Dunwoody, 2013). The American Nurses Association’s Nursing’s Social Policy Statement: The Essence of the Profession (ANA, 2010) expresses the social contract between society and the profession of nursing. Nursing interventions are intended to contribute to the goal of quality care and above all, do no harm. All registered nurses are educated in the “art and science of nursing, with the goal of helping individuals, families, groups, communities, and populations to promote attain, maintain, and restore health, or to experience a dignified death” (p.15). Nurses are expected to uphold the principles of autonomy, beneficence, non-maleficence, veracity, confidentiality, fidelity, and justice both before and after the patient’s death.

The American Academy of Pain Medicine (2007) validates the World Health Organization declaration that pain relief is a human right. The Academy advocates strongly for access to high-quality pain care for all persons, seeking to overcome any and all inequities that may exist. The American Medical Association’s statement on disparities affirms that disparities in medical care should be avoided, whether it is based on socio-demographic factors, treatment decisions, differences in income and education, sociocultural factors, or failures by the medical profession. Health care providers should examine their own beliefs and practices to ensure that their prejudice does not affect clinical judgment in medical care.
Education Intervention

The in-service included an evidence-based tool called the Pain Assessment in Advanced Dementia (PAINAD) Scale (see Appendix A). The PAINAD scale was designed to assess the following five items for possible signs of pain: breathing independent of vocalization, negative vocalization, facial expression, body language, and consolability. Each item is scored based on a scale from 0 to 2. These five items are totaled; the final score will range from 0 (no pain) to 10 (severe pain). The American Medical Directors Association has endorsed the PAINAD scale as a useful pain assessment tool for patients with advanced dementia and those at end of life who may no longer be able to verbalize pain (Warden, Hurley, & Volicer, 2003). The PAINAD scale is a simple, valid, and reliable tool used to measure pain in non-verbal patients.

Immediately prior to the in-service, the DNP student administered the pre-test to assess nurses’ attitudes and perceptions (McMillian, 2000). Questions addressed both pharmaceutical and non-pharmacological interventions. After the pre-test, the in-service proceeded by opening with a discussion about perceptions on pain management, especially opioid use at end of life. The in-service continued by presenting evidence-based guidelines on pain management in the elderly patient, particularly at end of life. The nurses’ had the opportunity to ask questions throughout the presentation. Continued discussion explored nurses’ opinions on the facility’s current pain management tools and their concerns about pain assessment and documentation. At the end of the in-service, the same test was administered to all nurses in attendance to evaluate if perceptions changed after education was provided.

Data Analysis

The pre- and post-test was administered using a Likert scale where 1= Strongly Agree and 5= Strongly Disagree. For questions where “Strongly Disagree” was correct, answers of 5
(Strongly Disagree) or 4 (Disagree) were counted as correct, while answers of 3 (Undecided), 2 (Agree), or 1 (Strongly Agree) were counted incorrect. For questions where “Strongly Agree” was correct, answers of 1 (Strongly Agree), or 2 (Agree) were counted as correct, and answers of 3 (Undecided), 4 (Disagree), or 5 (Strongly Disagree) were counted as incorrect. The total pre- and post-test scores were compared using a paired t-test.

**Results**

This education intervention met its goal of successfully addressing the barriers to adequate pain management and providing evidence-based interventions to relieve pain and avoid unnecessary suffering at end of life. The participants indicated improved knowledge and skill when assessing for pain and when administering opioids for pain management.

The pre-test mean score was 7.08, and the post-test mean score was 7.62, which is a mean gain of 0.54 (see Figures 1 and 2). The t-test shows that this gain is not statistically significant. However, it should be noted that a greater number of questions (4) were left blank, and the small sample size may have affected the results (See Appendix E). The purpose of this analysis was to determine if there was an improvement in knowledge and attitudes towards pain management at end of life. The mean scores indicated that the participants’ knowledge and attitudes did improve.
Facilitators and Barriers

The goal was to complete six total in-services on pain management; however, only four in-services were completed. The facility had already conducted a similar pain/dementia in-service, so this in-service was no longer mandatory nor was 6 sessions necessary. The nurses that
attended were those that did not attend the facility's pain/dementia in-service. Even though the turnout was less than expected (<50%), the information was well received and 100% of the participations indicated that their knowledge on end of life care was greatly improved. A hospice APRN was present during all four in-services and further explained the pathophysiology of pain, including personal experiences that were meaningful to the nurses. It was a relaxed environment with extensive discussion.

Nurses may be reluctant to use the PAINAD scale due to adding an additional assessment to their charting. A common barrier may be lack of time due to patient caseload and/or acuity. However, Hutchison et al. (2006) reported that this tool is simple to use, requires less than 1 minute of time and results in clinicians being more comfortable using analgesic to treat pain. Another barrier to this capstone project was the facility’s implementation of the PAINAD scale as it is a corporate facility and it may be difficult to quickly put these interventions in place. Per the director of nursing, there is often an extensive submission and approval process before facility changes can be made. However, the PAINAD scale and other hospice resources have been made available to the nurses and the administrative staff is willing to advocate for these changes, including annual in-services to improve the quality of care for their patients.

**Discussion and Interpretations**

The post-test indicated the most common challenge in assessment of pain to be family and patients’ beliefs on pain and symptom management. Nurses in this study reported that many patients’ religion and/or personal values played a significant role in expression of pain and request for pain medication. Nurses identified further challenges such as lack of time for thorough pain assessment, difficulty assessing a non-verbal patient, unavailability of past medical history documentation, and accuracy of patient’s report of pain.
All nurse participants identified “causing patient harm” as the most common fear when administrating opioids. One participant stated, “Morphine is the death drug”. Another reported the “angel of death feeling”. Many others expressed “not wanting to be the person who gives the last dose before death”. Some mentioned “overdosing” or “respiratory depression” as cause for concern. Post intervention, five participants (38.5%) specifically acknowledged that opioids do not cause death in end of life patients.

Despite the majority of participants stating that the facility had prepared them by providing in-services, 100% still indicated that the information from this in-service gave a greater perspective on assessment and management of pain to care for end of life patients. One participant stated that she had a “greater understanding of the dying process”. Another reported a “deeper explanation of opioid use”.

**Limitations**

This project had several limitations. Demographic variables such as years of experience and educational preparation were not measured, and could have accounted for some of the variation in attitudes and knowledge. Despite 100% completion of the pre- and post-test, the logistics were challenging. Nurses were covering for others to allow for each participant to receive credit for attending the 30-minute session. As a result, some participants came late or had to leave early, missing parts of the presentation. This likely impacted the findings. In addition, several of the post-test were not completed immediately after the in-services, adding a confounding variable and questioning whether the amount of time between the in-service and the post-test had a significant effect on study results.
Suggestions and Future Recommendations

The findings from this project suggest that continued support and education on pain assessment and administration of opioids is needed for all nurses, especially those who provide care to end of life patients. The first implication is the importance of annual in-services on pain assessment and management at long-term care facilities. Without knowledge, nurses are ill equipped to provide care for terminal patients, which may result in increased pain and suffering at the end of the patient’s life. A second implication of this project is the impact that nurses’ perception of opioid use can have on patients who are in pain. Research suggests that fear of accelerating death causes nurses to withhold appropriate treatment (Morrison & Meier, 2003). This data should prompt healthcare administrators to ensure that staff nurses’ are involved in the patient’s care plan meeting where patient and family goals are addressed, including pain management. A clear understanding of the patient’s pain control goals may help alleviate the burden of the nurse responsible for implementing the pain strategy (Parker Oliver et al., 2013). More research is needed that include patient and family members’ knowledge and perceptions of pain at end of life.

Conclusion

Inadequate pain management for patients at the end of their life results from a lack of knowledge, particularly related to misconceptions surrounding opioid use. Nurses have a responsibility to provide appropriate pain management at end of life and to seek education and training necessary to achieve this goal. This quality improvement project provided an in-service on pain and symptom management to nurses in long-term care settings to address any misconceptions of opioid use and to provide education on end of life care for elderly patients. Each nurse was more confident in knowledge and skill when providing pain management for
terminally ill patients. Final evaluation and interpretation of findings was discussed with the administrative staff and evidence based recommendations was provided. This capstone project will be presented at the University of Massachusetts Amherst, College of Nursing Scholarly Presentation day and submitted during the spring of 2016 for DNP degree completion.
References


“I’m not a doctor, and I don’t know if I helped her go faster or slower.” *Journal of Pain and Symptom Management, 46*(6), 1-18. doi: 10.1016/j.jpainsymman.2013.02.011.


Wells, M., Dryden, H., Guild, P., Levack, P., Farrer, K., & Mowat, P. (2001). The knowledge and attitudes of surgical staff towards the use of opioids in cancer pain management: can the Hospital Palliative Care Team make a difference? *European Journal of Cancer Care, 10*(3), 201-211.


Appendix A

Pain Assessment in Advance Dementia (PAINAD) Scale

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
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<tbody>
<tr>
<td><strong>Breathing Independent of Vocalization</strong></td>
<td>Normal</td>
<td>Occasional labored breathing, short period of hyperventilation</td>
<td>Noisy labored breathing, long period of hyperventilation, Cheyne-stokes respirations</td>
<td></td>
</tr>
<tr>
<td><strong>Negative Vocalization</strong></td>
<td>None</td>
<td>Occasional moan or groan, low- level of speech with a negative or disapproving quality</td>
<td>Repeated troubled calling out, loud moaning or groaning, crying</td>
<td></td>
</tr>
<tr>
<td><strong>Facial Expression</strong></td>
<td>Smiling or inexpressive</td>
<td>Sad, frightening, frown</td>
<td>Facial grimacing</td>
<td></td>
</tr>
<tr>
<td><strong>Body Language</strong></td>
<td>Relaxed</td>
<td>Tense, distressed pacing, fidgeting</td>
<td>Rigid, fists clenched, knees pulled up, pulling or pushing away, striking out</td>
<td></td>
</tr>
<tr>
<td><strong>Consolability</strong></td>
<td>No need to console</td>
<td>Distracted or reassured by voice of touch</td>
<td>Unable to console, distract or reassure</td>
<td></td>
</tr>
</tbody>
</table>

(Warden, Hurley, & Volicer, 2003)

Instructions: Observe the patient for five minutes before scoring his or her behaviors. The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3 = mild pain; 4-6 = moderate pain; 7-10 = severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

**Item Definitions**

**Breathing**

1. *Normal breathing* is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. *Occasional labored breathing* is characterized by episodic bursts of harsh, difficult or wearing respirations.
3. *Short period of hyperventilation* is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. *Noisy labored breathing* is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
5. *Long period of hyperventilation* is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. *Cheyne-Stokes respirations* are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

**Negative Vocalization**

1. *None* is characterized by speech or vocalization that has a neutral or pleasant quality.
2. *Occasional moan or groan* is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. *Low level speech with a negative or disapproving quality* is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. *Repeated troubled calling out* is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. *Loud moaning or groaning* is characterized by mournful or murmuring sounds, wails or laments in much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. *Crying* is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

**Facial Expression**

1. *Smiling or inexpressive*. Smiling is characterized by upturned corners of the mouth, brightening of the eyes and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. *Sad* is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. *Frightened* is characterized by a look of fear, alarm or heightened anxiety. Eyes appear wide open.
4. *Frown* is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. *Facial grimacing* is characterized by a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

**Body Language**

1. *Relaxed* is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. *Tense* is characterized by a strained, apprehensive or worried appearance. The jaw may be clenched. (exclude any contractures)
3. *Distressed pacing* is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. *Fidgeting* is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also be observed.
5. *Rigid* is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding. (exclude any contractures)

6. *Fists clenched* is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.

7. *Knees pulled up* is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (exclude any contractures)

8. *Pulling or pushing away* is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.

9. *Striking out* is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

**Consolability**

1. *No need to console* is characterized by a sense of well being. The person appears content.
2. *Distracted or reassured by voice or touch* is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction with no indication that the person is at all distressed.

3. *Unable to console, distract or reassure* is characterized by the inability to soothe the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.

(Warden, Hurley, & Volicer, 2003, p.14)
Appendix B

Pre-test

Answer the following questions based on the scale listed below.

1= Strongly Agree, 2 = Agree, 3 = Undecided, 4 = Disagree, 5 = Strongly Disagree

1. Vital signs are always reliable indicators of the intensity of a patient’s pain.
2. Patients who can be distracted from pain usually do not have severe pain.
3. Respiratory depression rarely occurs in patients who have been receiving stable doses of opioids over a period of months.
4. Opioids should not be used in patients with a history of substance abuse.
5. Morphine has a dose ceiling (i.e., a dose above which no greater pain relief can be obtained).
6. Elderly patients cannot tolerate opioids for pain relief.
7. Patients should be encouraged to wait until pain is severe before using an opioid.
8. If the source of the patient’s pain is unknown, opioids should not be used during the pain evaluation period, as this could mask the ability to correctly diagnose the cause of pain.

Circle the correct answer.

9. The most likely reason a patient with pain would request increased doses of pain medication is:
   a. the patient is experiencing increased pain
   b. the patient is experiencing increased anxiety or depression
   c. the patient is requesting more staff attention
   d. the patient’s requests are related to addiction

10. The most accurate judge of the intensity of a nonverbal patient’s pain is:
    a. the treating physician
    b. the patient’s primary nurse
    c. the patient
    d. the pharmacist
    e. the patient’s spouse or family

11. What is your biggest challenge in assessment of pain?

12. What is your biggest fear with administration of opioids?

13. How has this facility prepared you to care for end of life patients (prior to this in-service)?
Appendix C

Post-test

Answer the following questions based on the scale listed below.

1 = Strongly Agree, 2 = Agree, 3 = Undecided, 4 = Disagree, 5 = Strongly Disagree

1. Vital signs are always reliable indicators of the intensity of a patient’s pain.
2. Patients who can be distracted from pain usually do not have severe pain.
3. Respiratory depression rarely occurs in patients who have been receiving stable doses of opioids over a period of months.
4. Opioids should not be used in patients with a history of substance abuse.
5. Morphine has a dose ceiling (i.e., a dose above which no greater pain relief can be obtained).
6. Elderly patients cannot tolerate opioids for pain relief.
7. Patients should be encouraged to wait until pain is severe before using an opioid.
8. If the source of the patient’s pain is unknown, opioids should not be used during the pain evaluation period, as this could mask the ability to correctly diagnose the cause of pain.

Circle the correct answer.

9. The most likely reason a patient with pain would request increased doses of pain medication is:
   a. the patient is experiencing increased pain
   b. the patient is experiencing increased anxiety or depression
   c. the patient is requesting more staff attention
   d. the patient’s requests are related to addiction

10. The most accurate judge of the intensity of a nonverbal patient’s pain is:
    a. the treating physician
    b. the patient’s primary nurse
    c. the patient
    d. the pharmacist
    e. the patient’s spouse or family

11. What is your biggest challenge in assessment of pain? Has it changed after this in-service?

12. What is your biggest fear with administration of opioids? Has it changed after this in-service?

13. Do you feel like this in-service was helpful?
    If so, how?
    If not, please explain how it could be better.
Appendix D

Beacon Hospice Education Material on Pain Assessment and Management

Table 1: Pain Assessment Tools

(Beacon Hospice, 2010)
Table 2: Comparative Pain Scale

Beacon Hospice Inc. - 1-800-HOSPICE

<table>
<thead>
<tr>
<th>Comparative Pain Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe</td>
</tr>
<tr>
<td>Unimaginable Unspeakable</td>
</tr>
<tr>
<td>10</td>
</tr>
<tr>
<td>Pain so intense you will go unconscious shortly. Most people have never experienced this level of pain. Those who have suffered a severe accident, such as a crushed hand, and lost consciousness as a result of the pain and not blood loss, have experienced level 10.</td>
</tr>
<tr>
<td>Severe</td>
</tr>
<tr>
<td>Unable to engage in normal activities. Patient is disabled and unable to function</td>
</tr>
<tr>
<td>9</td>
</tr>
<tr>
<td>Excruciating Unbearable</td>
</tr>
<tr>
<td>Pain so intense you cannot tolerate it and demand painkillers or surgery, no matter what the side effects or risk. If this doesn't work, suicide is frequent since there is no more joy in life whatsoever. Comparable to throat cancer.</td>
</tr>
<tr>
<td>Severe</td>
</tr>
<tr>
<td>8</td>
</tr>
<tr>
<td>Utterly Horrible</td>
</tr>
<tr>
<td>Pain so intense you can no longer think clearly at all, and have often undergone severe personality change if the pain has been present for a long time. Suicide is frequently contemplated and sometimes tried. Comparable to childbirth or a real bad migraine headache.</td>
</tr>
<tr>
<td>Severe</td>
</tr>
<tr>
<td>7</td>
</tr>
<tr>
<td>Very Intense</td>
</tr>
<tr>
<td>Same as 6 except the pain completely dominates your senses, causing you to think unclearly about half the time. At this point you are effectively disabled and frequently cannot live alone. Comparable to an average migraine headache.</td>
</tr>
<tr>
<td>Moderate</td>
</tr>
<tr>
<td>Interferes with many activities. Requires lifestyle changes but patient remains independent. Unable to adapt to pain.</td>
</tr>
<tr>
<td>6</td>
</tr>
<tr>
<td>Intense</td>
</tr>
<tr>
<td>Strong, deep, piercing pain so strong it seems to partially dominate your senses, causing you to think somewhat unclearly. At this point you begin to have trouble holding a job or maintaining normal social relationships. Comparable to a bad non-migraine headache combined with several bee stings, or a bad back pain.</td>
</tr>
<tr>
<td>Moderate</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>Very Distressing</td>
</tr>
<tr>
<td>Strong, deep, piercing pain, such as a sprained ankle when you stand on it wrong, or mild back pain. Not only do you notice the pain all the time, you are now so preoccupied with managing it that you normal lifestyle is curtailed. Temporary personality disorders are frequent.</td>
</tr>
<tr>
<td>Minor</td>
</tr>
<tr>
<td>Does not interfere with most activities. Able to adapt to pain psychologically and with medication or devices such as cushions.</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>Distressing</td>
</tr>
<tr>
<td>Strong, deep pain, like an average toothache, the initial pain from a bee sting, or minor trauma to part of the body, such as stubbing your toe real hard. So strong you notice the pain all the time and cannot completely adapt. This pain level can be simulated by pinching the fold of skin between the thumb and first finger with the other hand, using the fingernails, and squeezing real hard. Note how the simulated pain is initially piercing but becomes dull after that.</td>
</tr>
<tr>
<td>Minor</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>Tolerable</td>
</tr>
<tr>
<td>Very noticeable pain, like an accidental cut, a blow to the nose causing a bloody nose, or a doctor giving you an injection. The pain is not so strong that you cannot get used to it. Eventually, most of the time you don't notice the pain. You have adapted to it.</td>
</tr>
<tr>
<td>Minor</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>Discomforting</td>
</tr>
<tr>
<td>Minor pain, like lightly pinching the fold of skin between the thumb and first finger with the other hand, using the fingernails. Note that people react differently to this self-test.</td>
</tr>
<tr>
<td>Minor</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>Very Mild</td>
</tr>
<tr>
<td>Very light barely noticeable pain, like a mosquito bite or a poison ivy itch. Most of the time you never think about the pain.</td>
</tr>
<tr>
<td>Minor</td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td>No pain. Feeling perfectly normal.</td>
</tr>
</tbody>
</table>

(Beacon Hospice, 2010)
Table 3: Medications Used for Pain Management

**Mild Pain**
Acetaminophen 325-650mg PO/PR every 4-6 hours as needed or atc
OR
Acetaminophen 500-1000mg PO/PR every 6 hours as needed or atc. Max dose in 24 hours is 4 grams

**Moderate Pain**
Hydrocodone/APAP (various strengths) 1-2 tabs PO every 4-6 ours as needed or atc
OR
Oxycodone/APAP 5/325mg – 1-2 tabs PO every 4-6 hours as needed or atc. Max dose in 24 hours 4 grams.
OR
Oxycodone/APAP 5/500mg—1-2 tabs every PO 4-6 hours as needed or atc. Max dose in 24 hours 4 grams APAP.
OR
Morphine IR—5-10mg PO/PR/SL every 3-4 hours as needed or atc. No Max dose.
OR
Oxycodone—5-10mg PO/PR/SL every 3-4 hours as needed or atc. No Max dose.

**Severe Pain (Intermittent)**
Morphine IR—5-10mg PO/SL every 3-4 hours as needed. No Max dose.
OR
Oxycodone—5-10mg PO/SL every 3-4 hours as needed. No Max dose.
OR
Hydromorphone—2mg PO every 2-3 hours as needed. No Max dose.

**Severe Pain (Continuous) (Can Swallow)**
Morphine LA— PO every 12 hours
OR
Oxycodone LA— PO every 12 hours
OR
Methadone PO every 8 hours

**Severe Pain (Continuous) (Cannot Swallow)**
Morphine LA—PR every 12 hours
OR
Oxycodone LA—PR every 12 hours
OR
Methadone—PR every 8 hours
OR
Transdermal Fentanyl—every 72 hours

If a patient is on LA morphine or LA oxycodone they can be given the IR morphine or Oxycodone as a breakthrough medication if they are experiencing pain before their next dose of LA medication.

(Beacon Hospice, 2015)
### Appendix E

T-test Results

**Paired Samples Statistics**

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<tr>
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<th>N</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
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<tr>
<td>Pre-total</td>
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<td>Post-total</td>
<td>7.6154</td>
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**Paired Samples Correlations**

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**Paired Samples Test**

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<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Std. Deviation</td>
<td>Std. Error Mean</td>
<td>Upper</td>
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<tr>
<td>Pair 1</td>
<td>Pre-total – Post-total</td>
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<td>2.06621</td>
<td>.57306</td>
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**Paired Samples Test**

<table>
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<tr>
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<tr>
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<tr>
<td>Pair 1</td>
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<td>-.940</td>
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