

PEDIATRIC ONCOLOGY NURSES' KNOWLEDGE OF PAIN MANAGEMENT
IN THE ACTIVELY DYING CHILD

by

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As members of the DNP Project Committee, we certify that we have read the DNP project prepared by Heather Elizabeth Fydrych, titled Pediatric Oncology Nurses' Knowledge of Pain Management in the Actively Dying Child and recommend that it be accepted as fulfilling the DNP project requirement for the Degree of Doctor of Nursing Practice.

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Final approval and acceptance of this DNP project is contingent upon the candidate's submission of the final copies of the DNP project to the Graduate College.

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DEDICATION

I dedicate this DNP Project to each and every one of my pediatric oncology patients. The past six years as a pediatric oncology nurse have taught me to be humble, kind, and generous to those around me, for they may be fighting a battle I know nothing about. I have experienced intractable laughter, pure joy, sadness, irreversible heartbreak, and devastation but none of that will be in vain. To the children I have cared for in new diagnosis, ongoing treatment, completion of therapy, relapse, and death, you have shown me more than I could ever put into words. To know and care for so many children who were taken from this world too soon because of cancer, I promised myself and them that I would pursue endeavors with this advanced degree that would change the world for the better and this project is one small step in that direction.

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ABSTRACT

Background: Pain is one of the most under treated symptoms among pediatric oncology patients during they dying process. There is a significant lack of pediatric specific studies that identify children's perception and expression of pain. There is currently a lack of studies regarding recognition of pediatric pain in the actively dying child. Through utilization of approved pain scales, medications, and improvement in knowledge about identifying pediatric pain, pediatric oncology nurses can work to improve the quality of care delivered among actively dying children.

Purpose: The purpose of this DNP project was to evaluate potential knowledge gain among pediatric oncology nurses regarding pain identification and management in the actively dying pediatric oncology patient after completion of an evidence based educational presentation.

Methods: The method for this DNP project was a one group pre-test, intervention, post-test method was used. Participants for this DNP project included Pediatric Oncology Registered Nurses employed at Banner University Medical Center-Tucson Campus, on the Pediatric Hematology/Oncology/Bone Marrow Transplant Unit. Recruitment for this project occurred through the units private/secure social media Facebook page.

Results: The sample size for this project was small and consisted of 12 matched and completed pre- and post-tests. Data analysis using paired t-tests showed improvement from the pre-test mean score (79.6%) to the post-test mean score (97.9%). Data analysis revealed statistically significant findings as evidenced by a p-value of 0.000058 (alpha level <0.05).

Discussion: Data analysis through descriptive statistics and paired t-test demonstrated an increase in knowledge among this small group of pediatric oncology nurses' regarding pain

management in the actively dying child. Participants also reported they would utilize the education provided to enhance their pain assessment skills, pain management techniques and delivery of care among actively dying pediatric oncology patients.

INTRODUCTION

Background Knowledge

As the leading cause of disease related death in children, cancer is a complex diagnosis often accompanied by an uncertain outcome (National Institutes of Health [NIH], 2018). Despite significant progress in the treatment of pediatric malignancy, 12% of children diagnosed with cancer do not survive (CureSearch, 2018). Of those 88% who do survive, 60% suffer terminal late-effects such as heart failure, secondary cancers and premature death (CureSearch, 2018). A large proportion of pediatric oncology patients who are dying from their malignancy are suffering and their symptoms are not being adequately managed (Wolfe, 2000). This suffering stems from the fact that death in childhood is rare, expectations of cure are high and healthcare providers are hesitant to make the formal shift to non-cure-directed interventions (NIH, 2018).

Transition to an end-of-life care model may be viewed as abandoning hope among pediatric oncology healthcare providers. This outlook interferes with the quality of care provided to actively dying pediatric oncology patient and appropriate management of their symptoms including fatigue, dyspnea, constipation, nausea, vomiting, and pain (NIH, 2018). There is considerable evidence that pain is the most common symptom experienced by actively dying pediatric oncology patients and the least controlled (Wolfe et al., 2000). Adequate pain therapy in children is limited by the lack of pediatric labeling for drugs, shortage of clinical trials in the pediatric care setting, and pediatric pain management research that has not been effectively translated into routine clinical practice (Mathews, 2011).

It is the responsibility of the pediatric oncology nurse caring for the actively dying pediatric oncology patient to identify pain cues, manage symptom burden and minimize

suffering (Association of Pediatric Hematology/Oncology Nurses [APHON], 2001). Optimizing the quality of care and remaining life among dying children depends on the utilization of evidence-based research to improve the quality of education given to pediatric oncology providers (Hilden et al., 2001).

Local Problem

The uncertainty that lies in a child's prognosis can severely impede the introduction of comfort care and pain management often needed during the dying process. There is a significant lack of pediatric related pain studies that identify children's pain perception (Gregoire & Frager, 2006). Measuring pain in the pediatric population is inherently more difficult especially during the dying process in which typical pain scales may not correctly identify the child's pain severity (Gregoire & Frager, 2006).

Nearly two decades ago, the American Academy of Pediatrics (AAP) and the Institute of Medicine (IOM) called for the integration of palliative care at the time of diagnosis in children with a life-threatening illness (Docherty et al., 2012). This appeal refers to the assimilation of curative therapy and palliative care with a focus on treatment as well as alleviation of unpleasant symptoms (Docherty et al., 2012). With identification of the need for quality supportive care during the dying process, pediatric oncology providers must seek to obtain knowledge of best practice guidelines to identify non-traditional pain cues with a goal of minimizing suffering (Hasheesh et al., 2013).

The core values of nursing focus on human dignity, integrity, autonomy, altruism, and social justice (National League for Nurses [NLN], 2018). With these morals, we must be able to shift our focus from curative treatment to ease of suffering, especially when patients may not be

able to verbalize this request. Ceasing treatment holds a stigma of “giving up,” and often times parents need reassurance that quantity of life should not supersede quality (Wolfe et al., 2000). Palliative care means to relieve the physical, emotional, spiritual, and social distress produced by life-threatening conditions while enhancing quality of life (Docherty et al., 2012).

Diamond Children’s Medical Center Blood and Cancer Program at Banner University Medical Center-Tucson Campus (BUMCT), provides oncology care to over 300 children per year on the pediatric Hematology/Oncology/Hematopoietic Stem Cell transplant unit with approximately 40-50 new diagnosed children annually (Banner Health, 2018). Treatment options on this unit include chemotherapy, radiation, immunotherapy, clinical trials, surgical interventions, and Hematopoietic Stem Cell Transplant (Banner Health, 2018). The Diamond Children’s Medical Center Blood and Cancer Program is one of only two centers in Arizona accredited to perform a majority of those pediatric oncology treatments (Banner Health, 2018). Often times the dying child is admitted to the pediatric hematology/oncology unit for pain control and comfort care. Diamond Children’s Medical Center Blood and Cancer program currently has no formal pediatric palliative care program nor are there established guidelines for standards of comfort care for actively dying pediatric patients. Creating a practice change or policy that focuses on education of pain management in the actively dying child can result in improving the quality of care provided to this unique population.

Significance to Advanced Practice Nursing

Pain is one of the most misunderstood, under diagnosed, and under treated medical problems, particularly in children (Mathews, 2011). As the “fifth vital sign,” pain is a physical and emotional experience with differing perceptions among pediatric patients. Research shows

that pain is so frequently undertreated for several reasons. Of the multiple causes, healthcare providers often misunderstand that pain is perceived and expressed in children different than adults and there is a significant lack of understanding of appropriate pain measures utilized in children (Mathews, 2011).

Recognizing that a child is dying is an opportunity for the practitioner to provide high quality and effective care. Adopting the hospice philosophy of providing comfort care allows the healthcare provider to provide comfort measures for a child with cancer at the end of life (Mathews, 2011). There is a significant amount of research that addresses the dire need for practitioners to recognize and treat pain in the dying child (Mathews, 2011).

Intended Improvement

The purpose of this DNP project was to assess knowledge and evaluate potential knowledge gain among pediatric oncology nurses regarding pain identification and management in the actively dying pediatric oncology patient at Diamond Children's Medical Center, BUMCT. This DNP project used a pre-test, education session, and post-test method. The focus of this DNP project was on providing an evidence-based educational session on pain identification and management in the actively dying pediatric oncology patient. Studies suggest that assessing current knowledge and providing education to pediatric oncology nurses on pain and pain management can improve patient outcomes (Hasheesh et al., 2013). The specific aims for this DNP project were to: 1) assess pediatric oncology nurse's knowledge about pain identification and management in the actively dying pediatric oncology patient through pre-test evaluation; and, 2) assess the pediatric oncology nurses' potential knowledge gain after the provided evidence-based intervention through post-test evaluation. Stakeholders of this DNP

project included pediatric oncology registered nurses, pediatric oncologists, pediatric oncology patients and their families.

Study Question

The study question for this DNP project was: Does an evidence-based educational presentation improve knowledge among pediatric oncology nurses regarding pain identification and management in the actively dying pediatric oncology patient?

Theoretical Framework

ACE Star Model of Knowledge Transformation

The Academic Center for Evidence-Based Practice (ACE) developed the Star Model of Knowledge Transformation (Star Model) (Figure 1) as a framework that organizes the process and approach to evidence-based practice (EBP) (Stevens, 2012). Organized as a five-step design, the Star Model depicts forms of knowledge in a relative sequence, as research evidence is moved through the process and ultimately into practice (Stevens, 2012). The Star Model utilizes nursing's previous EBP work and mainstreams the content into the formal network of EBP. The systematic process is as follows: Point 1. Discovery Research, Point 2. Evidence Summary, Point 3. Translation to Guidelines, Point 4. Practice Integration, Point 5. Process/Outcome Evaluation (Stevens, 2012).

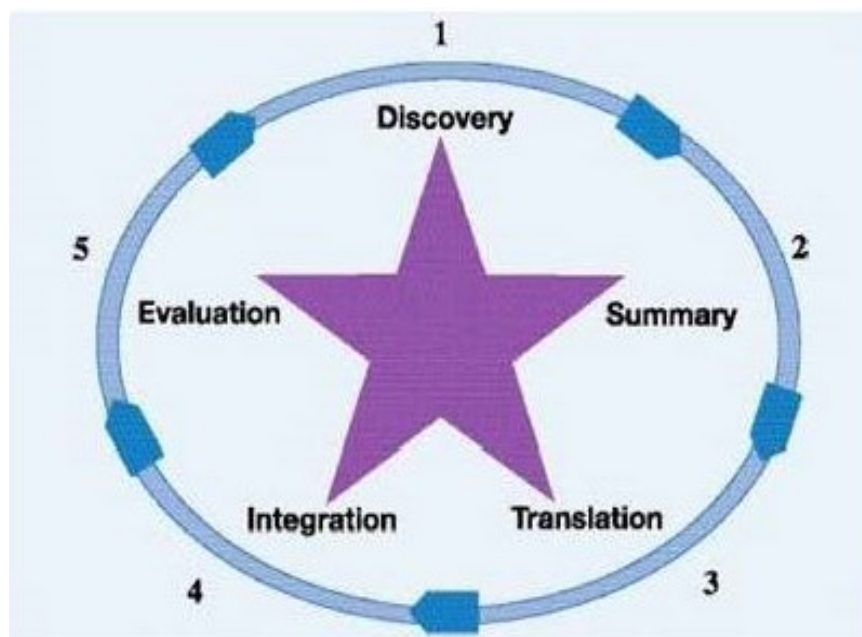


FIGURE 1. ACE star model of knowledge transformation (Stevens, 2004).

Point 1: Discovery Research

In this knowledge generating stage, traditional research methods are used to discover information surrounding the evidence that will be used to change practice (Stevens, 2012). Research results are generated through a primary research study and information may derive from descriptive studies, qualitative studies, or randomized control trials (Stevens, 2012). This stage allows the researcher to build the foundation of evidence as the next step of the Star Model is examined. For this DNP project, point one of the ACE Star Model was the comprehensive search of the current literature on pain identification and management in the actively dying pediatric oncology patient (Appendix A).

Point 2: Evidence Summary

Also identified as a knowledge generating stage, evidence summary is the process in which a single, meaningful statement of the science is quantified (Stevens, 2012). The thorough

evidence summary step differentiates EBP from the former research utilization process (Stevens, 2012). Due in part to the work of the Cochrane Collaboration, significant advancements have been made in systematic reviews utilizing meta-analysis techniques and developing other various statistical summary strategies (Stevens, 2012). Evidence summaries maintain many benefits including: a) summarizing large quantities of evidence into a manageable form; b) identifying consistencies and explaining inconsistencies of findings noted in studies; c) increasing power in proposing a cause and effect relationship; d) reducing bias from systematic error; e) improving reflection of reality; f) increasing efficiency in time between research and practical application; and, e) establishing a platform for continuing updates with new evidence (Stevens, 2012).

Evidence based methods are continually advancing, allowing researchers and implementers the opportunity to use the most rigorous and effective processes to utilize research and drive evidence-based practice. For this DNP project, point two of the ACE Star Model was the synthesis of the current literature on pain identification and management in the actively dying pediatric oncology patient.

Point 3: Translation to Guidelines

Translation to guidelines involves two stages: 1) Translation of evidence into practice recommendations; and, 2) Integration into practice (Stevens, 2012). This process involves translating the summarized evidence from point two into a format where clinicians can review, comprehend, and utilize the evidence in future application (Stevens, 2012). The translated recommendations may be used to shape care standards, clinical pathways, protocols, or algorithms in clinical practice (Stevens, 2012). The Star Model advocates for the development of clinical practice guidelines (CPGs), supported by summarized evidence that outline expected

benefits, anticipated harms, and estimated costs of various decision options (Stevens, 2012). For this DNP project, point three of the ACE Star Model was development of an evidence-based education on pain identification and management in the actively dying pediatric oncology patient.

Point 4: Practice Integration

Integration is the most familiar practice in healthcare because of the field's demand for current knowledge leading to frequent implementation of innovations (Stevens, 2012). This step allows the implementer to involve stakeholders, both at the individual and organizational level, while changing practice through formal and informal means (Stevens, 2012). The rate of change and adoption of evidence is directly affected by the individual and organization, which are only some of the factors that influence integration of the change into viable systems (Stevens, 2012). Understanding the complexities and unique identifiers of each establishment in which the change will be implemented is vital during the integration process. Point four of the ACE Star Model for this DNP project was an evidence-based educational presentation on pain identification and management in the actively dying pediatric oncology patient.

Point 5: Process and Outcome Evaluation

The final stage of the Star Model focuses on evaluations of endpoints and outcomes (Stevens, 2012). Patient health outcomes, provider satisfaction, patient satisfaction, efficacy, efficiency, economic analysis, and health status impact are reviewed in relation to the EBP change (Stevens, 2012). As new data and information is derived from the five stages of the Star Model, evidence-based quality improvement of health care is identified (Stevens, 2012). For this DNP project, point five of the ACE Star Model was a pre-test/post-test design of an evidence-

based presentation on pain identification and management in the actively dying pediatric oncology patient.

Star Model Practical Application

The ACE Star Model was appropriate for this DNP project based on the aims, measures, and outcomes identifying nurse's knowledge of pain management in the actively dying pediatric oncology patient. The discovery of poor pain management in the dying child with cancer was prevalent with recognition from many research studies addressing the issue of research to assess the efficacy of pain care models, research to assess the efficacy of established and innovative symptom control interventions, and epidemiological research to determine the incidence of pain symptoms in children (Hilden et al., 2001).

As evidence is translated and integrated into practice, aims were created to develop care standards and protocols for nurses to guide their assessment and management of pain in the actively dying pediatric oncology patient. Integrating the evidence into healthcare through utilization of individual and organizational practices will focus on the stakeholders (i.e., patients, parents, nurses, & physicians) (Stevens, 2012). The integration of evidence surrounding pain identification and management can mold a sustainable system of reduction of unwanted symptoms and improved patient comfort during end-of-life care. Finally, after implementation of evidence, evaluation of the effectiveness of patient health outcomes, patient satisfaction, efficacy, efficiency, and overall health status impact will drive the evidence-based quality improvement surrounding the complexities of pain management in the actively dying pediatric oncology patient (Holland & Chertkov, 2001).

Concepts

Pediatric Oncology

Pediatric oncology refers to the process of research and treatment of cancers in children and young adults, typically from birth to age 25 (Rocky Mountain Hospital for Children [RMHC], 2018). The types of cancers that develop in children vary greatly from those that develop in adults therefore oncologists, healthcare professionals that specialize in cancer, must maintain specific knowledge about the development, incidence, and prevalence, and treatment of pediatric cancers (RMHC, 2018). Childhood cancers progress as a result of deoxyribonucleic acid (DNA) changes in cells that occur early in life, potentially before birth whereas adult cancers are linked to environmental exposures and lifestyle risk factors. Although few pediatric cancers have a high cure rate, some children die of their disease or complications related to treatment.

Actively Dying

Actively dying refers to the time in which the patient's physiologic functions begin to wane most often hours or days preceding imminent death (Hui et al., 2014). This includes loss of motor function, increased sleepiness, confusion, delirium, reduced intake of nutrients, changes in breathing patterns, and increased anxiety (Hui et al., 2014). It is important to be aware that the signs and symptoms may be different for each child or young adult and highly dependent on the specific life-limiting condition that is leading to the patient's death (Hui et al., 2014).

Certified Pediatric Oncology Nurse

Because of the rapid scientific and technological advances in cancer care, nurses must maintain current and highly specialized knowledge to provide quality care. Oncology nursing

certification provides validation of the specialized knowledge and experience required for competent performance (Oncology Nursing Society [ONS], 2018). The American Board of Nursing Specialties defines nursing certification as, “the formal recognition of the specialized knowledge, skills, and experience demonstrated by the achievement of standards identified by a nursing specialty to promote optimal health outcomes” (ONS, 2018). Aside from pediatric oncology nurses being notably credentialed to provide healthcare, they are also certified through associations such as the Oncology Nursing Certification Corporation (ONCC) and the Association of Pediatric Hematology/Oncology Nurses (APHON) to provide care specific to pediatric patients affected by cancer (ONS, 2018). Through certified institutions, pediatric oncology nurses participate in a two-day course designed specifically for nurses to learn both the theoretical knowledge and key principles needed to safely, competently, and consistently administer chemotherapy and biotherapy (APHON, 2018). All participants in this project are recognized as pediatric oncology certified registered nurses in the state of Arizona.

Synthesis of Evidence

The first step in identifying gaps in the current evidence was to search the literature (Melnik & Fineout-Overholt, 2005). The databases Medline, CINAHL, Cochrane and Psych Info were searched to identify pain identification and management in the actively dying pediatric oncology patient. The keywords used in the search process were “pediatric pain,” “pain associated with cancer in children,” “nursing knowledge of pain in children,” and “palliative care of children with cancer.” The search was limited to English language, articles within the last 20 years, as research was very limited with a restriction of the last 10 years. A total number of 2,095 articles resulted relating to the search terms, of those 2,095 articles, only 11 were applicable to

pain management in the actively dying pediatric oncology patient (Appendix A). The major themes identified in the review of literature were lack of knowledge of the etiology of pain in children, availability of pain medications with established efficacy in pediatrics, fear of overdose of the dying child, and overall nursing knowledge in advocating for the child actively dying.

Pain and Pain Control

One study on end-of-life pain noted that pain is the most prevalent symptom in children with cancer during the dying process and effective pain control in this population continues to challenge health care providers (Anghelescu et al., 2015). The article also reports that in 76% of cases, parents report their child suffered “a great deal” or “a lot” of pain during the dying process (Anghelescu et al., 2015). Enskar et al. (2017) builds on the seminal work by McCery (1972) and stresses the importance of understanding pain and identifying its magnitude from the nursing perspective. In addition, Enskar defines pain as whatever the experiencing person says it is, existing wherever he or she says it does (Enskar et al., 2007). Unfortunately, research suggests that although this perspective of pain theory has been recognized and adapted by the healthcare field, the actively dying child may not exhibit verbal cues of pain and discomfort placing the responsibility of assessment on the healthcare staff. Enskar et al. (2007) also found that nurses demographic and experiential characteristics shape their attitudes toward care of a dying child and confidence in advocating for pain management (Enskar et al., 2007).

A study on identifying and describing knowledge and attitudes to pain and pain management amongst nurses working with children with cancer, found that the child in pain is often misunderstood due to nurses’ misconceptions and lack of knowledge or experience (Enskar et al., 2007). In a study by Salanterä et al. (1999), there were significant gaps in nursing

comprehension with regards to pharmacological and non-pharmacological pain management in actively dying children. The authors suggest that these gaps were related to the lack of education and exposure nurses receive at their institutions. In Enskar et al. (2007), research found that nurses' attitudes did not hinder effective pain management but rather their underlying misconceptions on the physiology and etiology of pain in children were the primary barrier. Identifying these notable gaps is the first step in addressing the significant issue related to ineffective pain identification and management in the child actively dying from cancer.

Evidence derived from the study by Salanterä et al. (1999), states that there is a need for professional extension training in pain management in children and nurses should be encouraged to actively seek new information. Wolfe et al. (2000), revealed significant discordance between reports of parents and healthcare professionals regarding children's symptoms during end of life care. Suffering often resulted because of a lack of recognition of the problem by the medical team and observations from this study demonstrated that active involvement by care givers committed to palliation alleviated a significant amount of suffering in the dying child (Wolfe et al., 2000).

Strengths of the Current Literature

There is considerable evidence that pain is a common and highly distressing symptom experienced by the actively dying pediatric oncology patient (Snaman et al., 2016). A collective theme among the reviewed studies was consistent in identifying the need for continuing education among oncology providers, increasing exposure to proper end-of-life care and demanding open communication with patients about their symptom management (Hilden et al., 2001).

Weaknesses of the Current Literature

Evidently there were limited strengths as numerous weaknesses were noted in the synthesis of evidence and literature search. Many of the reviewed studies were quasi-experimental, observational, or correlation studies which hold lower internal validity (Winona State University [WSU], 2017). Surveys and case studies are regarded as research designs with the greatest chance of bias in their outcome and therefore present a lower level of evidence (WSU, 2017). With only one systematic review (Level 1), the methodological quality of research is low (WSU, 2017).

Gaps in the Current Literature

Unfortunately, there are significant gaps in the research surrounding the premise that essential data from well-designed clinical trials, practitioners of pediatric palliative care are left to extrapolate from adult studies or to practice anecdotal medicine. The quality of care delivered in any other medical subspecialty under these conditions would be considered substandard. There is no clear plan for remedying the gap of knowledge among providers and research comes largely from adult studies or small cohort pediatric studies (Mathews, 2011). Overall, there is lack of state and federal programs to improve access to palliative care services and appropriate use of symptom control measures despite the many pharmacological advances in pain controlling substances (Mathews, 2011).

Summary of Evidence

A synthesis of evidence was performed to support the notion that identifying pain in the actively dying child is a complex process and healthcare providers, especially nurses, must be properly educated to recognize and manage suffering as it affects the physical, psychological,

social, and spiritual well-being of the child, reducing their quality of life during the dying process (Hooke et al., 2007). Based on this evidence review, there are few published studies on education focused pain management in the actively dying pediatric cancer patient. The few published studies do support the need for evidence-based education for providers on pain management in the actively dying pediatric cancer patient.

METHODS

Design

This DNP project used a one group, pre-test/post-test pre-experimental design to evaluate knowledge increase among pediatric oncology nurses' regarding pain identification and management in the actively dying child. This design was appropriate for the purpose of this DNP project as it involved obtaining a pretest measure relating to the outcome of interest allowing the researcher to examine change as a result of the intervention (Statistics How To, 2018).

Setting

This DNP project was conducted in Tucson, AZ with recruitment of participants through the social media platform, Facebook. A one group in-person session took place at a mid-town coffee shop for participant convenience, with voluntary participation from Pediatric Hematology/Oncology/Hematopoietic Stem Cell Transplant Nurses employed at Banner Diamond Children's Hospital. This 20-bed pediatric inpatient unit serves the pediatric hematology/oncology population of Southern Arizona, Western New Mexico, and Mexico.

Participants

A convenience sample of participants were recruited from the Pediatric Hematology/Oncology Unit at Diamond Children's Medical Center, BUMCT. Recruitment

occurred through the social media platform “Facebook,” of which a verified message was posted to the Diamond Children’s Medical Center Pediatric Hematology/Oncology/Hematopoietic Stem Cell Transplant Private Facebook Page by the researcher of this DNP project (Appendix B). The Facebook posting stated the purpose of the project, details regarding participation, and further instruction for obtaining details of the date, time, and location of the educational session. This posting was approved by the RN Manager of the Pediatric Oncology Unit who identifies as the administrator/owner of the Facebook page. It was reviewed for accuracy and appropriateness of information by the manager prior to posting (Appendix C).

The inclusion criteria for participants included: a) pediatric oncology certified registered nurses, certified through the Association of Pediatric Hematology/Oncology Nurses (APHON), currently employed at Banner Diamond Children’s Hospital Pediatric Hematology/Oncology/Hematopoietic Stem Cell Transplant Unit; b) English speaking/reading; and, c) FTE 0.6 or greater registered nurses who are considered “core-staff” on this unit as identified by Banner Staffing Services HR Department. Exclusion criteria for this study are: a) staff who float or cross-train from other pediatric units who are not identified as “core” staff according to Banner Staffing Services HR Department; b) ancillary staff who do not currently hold an Arizona State Nursing License, such as patient care technicians or medical assistants; and, c) Registered Nurses who do not hold an active certification through the Association of Pediatric Hematology/Oncology Nurses (APHON) Foundation.

Intervention

The intervention for this DNP project was a 20 question pre-test/post-test with a 20-minute, evidence based-education session provided via PowerPoint presentation on pain

identification and management in the actively dying pediatric patient. The introductory segment of the PowerPoint covered the purpose, goal, and significance of the doctoral project as well as key terms with definitions that were covered throughout the presentation. Background information was provided to the participants regarding the importance of the multidisciplinary approach to pain in children with emphasis on the relationship between the pediatric oncology nurse and patient. The presenter then discussed various ways in which children express pain with comparison noted between acute versus chronic pain as well as pain cues expressed by developmental stage.

Four commonly used pediatric pain scales were provided for visual reference and descriptions on their purpose and use were described. Two alternative pain scales not commonly used among the general pediatric population were included as they are specific to either children with cancer or children who have no communicative ability, both of which are relevant to the population of study in this project. Cultural appropriations were briefly discussed as cultural background can influence a family's perception and expression of pain impeding the pediatric oncology nurses' assessment of the actively dying child. The presentation continued with information on the use of non-pharmacological and pharmacological methods of pain control with specifics on commonly used medications, routes of delivery, and dosing. An image of the well-known MD Anderson Cancer Center Cancer Pain-Pediatric (inpatient) Algorithm (2019) was shown to demonstrate one pathway in which the multidisciplinary team caring for the actively dying pediatric oncology patient can evaluate, treat, and reassess pain effectively. Key points were then reviewed on the significance and importance of alleviating pain among actively dying pediatric oncology patients. To conclude, the presenter noted the importance for the

participants to continue their pursuit of educational endeavors regarding pain identification and management in pediatric oncology so that they may provide quality evidence-based driven care to a population that relies on them during the most difficult stage in their life.

The information included in the evidence based PowerPoint presentation was assessed and verified by two expert content reviewers who have in-depth knowledge and experience regarding pain management and care of the pediatric oncology patient. The first reviewer (reviewer one) has practiced as a pediatric registered nurse for 14.5 years, 10 in pediatric oncology. Reviewer one currently holds a Certified Pediatric Hematology-Oncology Nurse Accreditation and practices as an advanced practice registered nurse (APRN) family nurse practitioner (FNP) in an outpatient pediatric oncology clinic. Reviewer one found strength in the evidence used to create the educational intervention for this project and strongly agreed with the accuracy of the educational presentation's content, (Appendix D). The second reviewer (reviewer two) is a board-certified pediatric oncologist who has practiced for 15 years as a physician with 12 years in pediatric oncology. Reviewer two found validity in the educational content and agreed with the practicality of information and its alignment with current clinical practice guidelines (Appendix D).

The pre-test for this DNP project included two demographic questions: a) years of nursing experience in pediatric oncology; and, b) highest level of degree obtained (Appendix E). The post-test mirrored the pre-test with omission of the demographic questions and inclusion of four post-intervention evaluation questions (Appendix F). The test content was derived from the well-researched "Knowledge and Attitudes Survey Regarding Pain" Tool (Appendix I). A

disclaimer included within the original tool stated, “You may use and duplicate the tool for any purpose you desire in whole or in part,” (Appendix H) (Ferrell & McCaffery, 2014).

The Knowledge and Attitudes Survey Regarding Pain Tool (pain tool) was developed in 1987 by Betty Ferrell, RN, PhD, FAAN, and Margo McCaffery, RN, MS, FAAN, and has been extensively used throughout the past 30 years. The pain tool has been revised multiple times to reflect changes in pain management practice. The pain tool is a 37-item questionnaire. It contains 21 true or false and 16 multiple choice questions. The purpose of the pain tool is to measure the attitudes and knowledge of caregivers on the subject of pain. The pain tool is provided in Appendix I and the modified version utilized for this study is provided in Appendix E and F.

The original pain tool was revised and questions were omitted as the content of 17 questions were either: a) not specific to the pediatric population; b) not specific to pain management; or, c) not specific to the objective of this project. The pain tool is derived from current standards of pain management such as the American Pain Society, the World Health Organization (WHO), and the National Comprehensive Cancer Network Pain Guidelines (Ferrell & McCaffery, 2014). Test-retest reliability was established ($r > .80$) by repeat testing in a continuing education class of staff nurses ($N=60$) (Ferrell & McCaffery, 2014). Internal consistency reliability was established ($\alpha > .70$) with items reflecting both knowledge and attitude domains.

Data Collection

Data for this DNP project was obtained through the use of pre-/post-tests. The pre-/post-tests were printed single-sided on plain white paper and once all persons were seated at the table, the pre-/post-tests were given to the participants at random, face-down to avoid association of

test numbers/results with partakers by the researcher. Participants were asked to only turn over the pre-test and leave the post-test face down on the table. There was a number on the top right corner of the front page of each test (1-12) so that the pre-/post-test results could be compared for accurate data analysis. The participants had 10 minutes to complete the pre-test including consent to participation and demographic questions, without discussion among one another, and place their test into an envelope labeled “completed pre-tests.”

Once all persons submitted the pre-test, a 20-minute PowerPoint presentation was delivered via laptop as well as printed for each person to review independently during the session. The evidence-based PowerPoint presentation was delivered at an appropriate pace (20 minutes total), with an opportunity for clarifying questions/comments, discretion was noted by the researcher to not answer specific queries correlating to the pre-/post-test, (Appendix G). Participants then had 10 minutes to complete their post-test with survey questions without the use of the PowerPoint presentation informational hand-out and without discussion among one another. Once completed, participants submitted their post-test into a separate folder labeled “completed post-test.” Participants were dismissed from the session after completion.

Data Analysis

Upon completion of the pre-test, intervention, and post-test data were evaluated using descriptive statistics and paired t-test analysis. Descriptive statistics were used to describe the basic features of this DNP project and to provide simple summaries about the sample participants and measures (Keller & Kelvin, 2013). With a paired t-test analysis, the two means found represent two different times (e.g., pre-test & post-test with the intervention between the two time points). This type of analysis was used to determine whether there was statistical evidence

that the mean difference between paired observations on the particular outcome was significantly different from zero (KSU, 2019).

Ethical Considerations

Essential ethical elements to consider when conducting biomedical and behavioral research involving human participants are respect for persons, beneficence, and justice (U.S. Department of Health & Human Services, 2016).

Respect for Persons

Respect for persons was ensured using informed consents/disclosures prior to participation. In accordance with Banner Health and the Non-Research Data Use Committee, participants were responsible for reading and agreeing or disagreeing to a disclosure statement that reports their participation in the doctoral study has no impact on their current or future employment with Banner Health (Appendix E). All study participants were notified of their ability to withdraw from the study at any time without penalty. Pre-/post-tests were entirely anonymous and matched using a numeric identifier to guarantee privacy, confidentiality, and accurate data analysis. All participants were treated with respect and gratitude by the researcher.

Beneficence

It is the responsibility of the researcher to avoid, prevent, or minimize harm to participants while maximizing benefits (Polit & Beck, 2017). Beneficial intent of this project sought to improve nurses' knowledge of pain identification and management in the actively dying child while minimizing potential harm through physical, emotional, social, and financial means (Polit & Beck, 2017).

Justice

Inclusion criteria for this DNP project allowed all FTE (>0.6) pediatric oncology registered nurses who care for pediatric oncology patients at Banner Diamond Children's Hospital an opportunity to participate in the study. To ensure justice, all participants were treated with equal respect and fairness. Anonymity was maintained to avoid discrimination among test performance through the use of black pen and numeric identifiers on each pre-/post-test and submission to a marked folder by the participant.

Committee Approvals and Requirements

Prior to implementation and data collection, approval of the study was confirmed by the University of Arizona College of Nursing Departmental Review Committee and the University of Arizona Institutional Review Board (Appendix L). Banner Health specific ownership and endorsement came from an internal owner of whom is employed through Banner Health and stakes claim in the significance and results of this doctoral project (Appendix J). Approval from the Banner Health Non-Research Data Use Committee (NRDUC) was conferred (Appendix K). Knowledge and training received through the University of Arizona's DNP program guided the development and implementation of this doctoral project.

RESULTS**Data Analysis and Outcomes**

Twelve participants ($n=12$) consented and participated in the pre-test, intervention, post-test process for this DNP project. Each participant met the criteria pursuant to this project: APHON certified pediatric oncology registered nurse, English speaking/reading, employed at 0.6 or greater FTE at Banner University Medical Center-Tucson Campus, Unit D6W: Pediatric

Hematology/Oncology/Hematopoietic Stem Cell Transplant. Of those who participated, three held associate degrees (25%), six held bachelor's degrees (50%), and three held master's degrees (25%) in the field of nursing. There was a wide variety of pediatric oncology nursing experience, with one participant less than a year, six between 1-5 years, three between 5-10 years, one between 10-15, and the last between 20-25 years as reflected in Table 1.

TABLE 1. *Demographic data of participants.*

Characteristic	Sample N=12 (%)
Type of Nursing Degree Held	
• Associate Degree	3 (25%)
• Bachelor's Degree	6 (50%)
• Master's Degree	3 (25%)
Years of Pediatric Oncology Nursing Experience	
• <1	1 (8.3%)
• 1-5	6 (50%)
• 5-10	3 (25%)
• 10-15	1 (8.3%)
• 15-20	0 (0%)
• 20-25	1 (8.3%)

Pre- and Post-Test Descriptive Statistics

The survey intervention consisted of 20 identical pre-test and post-test questions to assess the knowledge of pediatric oncology nurses regarding pain management in the actively dying child. Pre-test scores ranged from 58% to 95%, with a mean of 79.5% and a standard deviation of 2.35. After the 20-minute evidence-based PowerPoint presentation on pain identification and management in the actively dying child, the post-test scores ranged from 95% to 100% correct responses, with a 18.5% increase in the mean test score (98%) and a standard deviation of 0.51. The calculated p-value of 0.000058 (alpha level <0.05) demonstrated statistical significance between the pre-test mean and post-test mean again confirmed knowledge improvement, as outlined in Table 2.

TABLE 2. *Descriptive statistics between pre- and post-tests.*

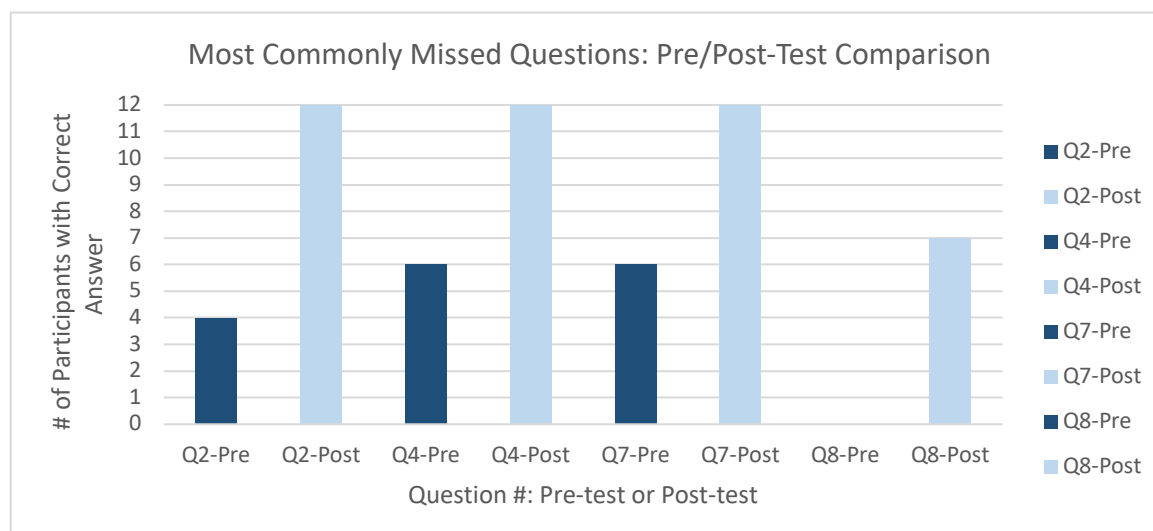
Statistics	Pre-test	Post-test
Mean	79.5	98
Median	85	100
Minimum Score	58	95
Maximum Score	95	100
Standard Deviation	2.35	0.51
P-value	0.000058 (alpha level <0.05)	

Important Findings Among Results

When analyzing the results of the completed pre-/post-test scores, it was noted that the most frequently missed questions were #2, #4, #7 and #8 (Appendix E). Question #2 focused on reliable indicators related to the intensity of pain among pediatric patients of which eight participants reported an incorrect answer of “vital signs” while four participants reported the correct answer of “physical assessment/pain scale.” Upon completion of the intervention, all 12 participants improved their knowledge base and answered the question correctly. When used alone, physiological indicators such as increased heart rate, increased respiratory rate, increased blood pressure, and decreased oxygen saturation are not valid clinical measures of pain as they can be affected by other physiological changes and occur in response to other factors including anxiety, fever, fatigue, dehydration, and medication side effects (Twycross, 2017). Pain assessment tools that incorporate both physiological and behavioral indicators, as well as a child’s self-report should be utilized to measure the most accurate intensity of pain (Twycross, 2017).

Question #4 asked the surveyor to identify the combination of medications that would produce the most optimal analgesic effect in the actively dying child. Question #7 asked which percentage of parents reported their child who died of cancer suffered a great deal from at least

one symptom during the last month of life. Questions #4 and #7 had similar results to question #2 where more than half of participants initially reported the incorrect answer but were able to deduce the correct answer after the interventional PowerPoint presentation. Question #8 created the most significant statistic as no participants (0%) reported the correct answer in the pre-test and only seven participants (58%) were able to identify the correct answer post-intervention. This question asked the participant to identify the dosing of morphine infused per hour among the 6% of children with terminal malignancies who suffered from severe pain. The initial answer reported by 100% of participants was 1mg/kg/hour which equates to a significant dosing to say the least but it has been well documented in a retrospective chart review of 199 children and young adults, in which 6% required “massive” opioid doses, upwards of 100 times the usual dosing of 0.03mg/kg/hour equating to 3mg/kg/hour, the correct answer (Gregoire & Frager, 2006). The important take-away from this question is that “conventional” analgesic doses and routes are effective for the vast majority of children at the end of life but it does not mean that extraordinary measures are not or cannot be taken to relieve the anguish of pain during the dying process (Gregoire & Frager, 2006). Table 3 outlines the commonly missed questions and the noted improvements between pre/post intervention.

TABLE 3. *Most commonly missed questions.*

Results of Paired t-Test

The paired t-test analysis of the data showed that the evidence based educational intervention significantly increased the pediatric oncology nurses' knowledge regarding pain management in the actively dying child. There was a significant difference in the pre-test scores ($M=15.92$, $SD=2.35$) and the post-test scores ($M=19.58$, $SD=0.51$); $p=0.000058$ with notable statistical significance among the reported p-value of 0.000058 (alpha level <0.05). Analysis and interpretation of the project data revealed a significant increase in knowledge among pediatric oncology nurses about pain identification and management in the actively dying pediatric oncology patient after the evidence-based educational session.

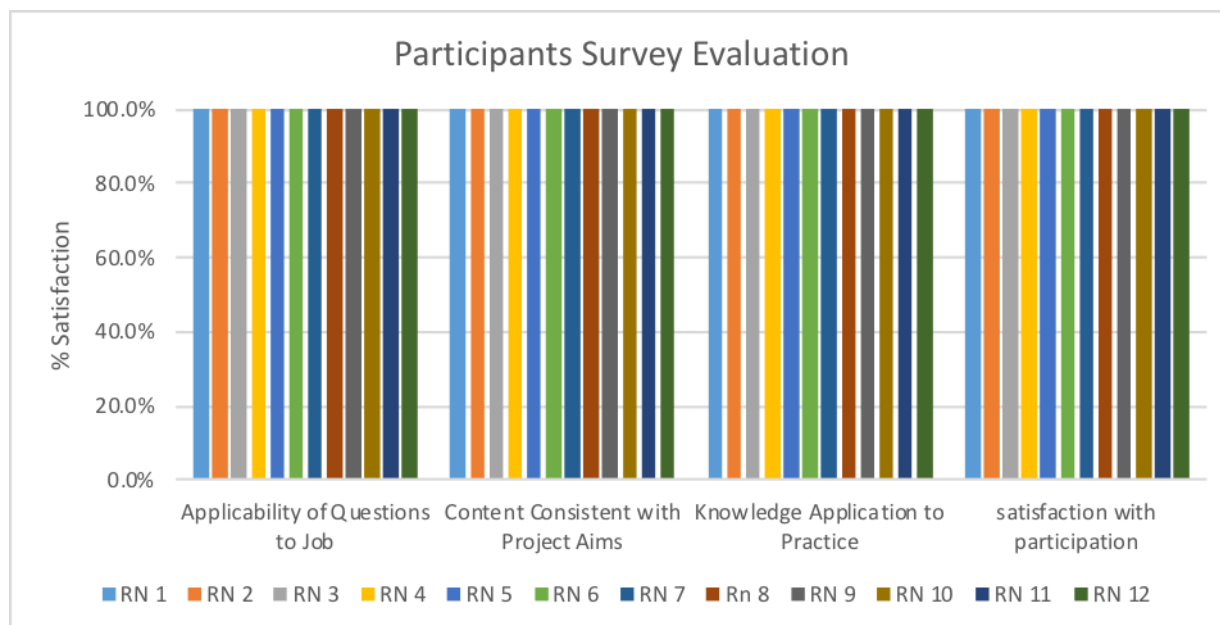
DISCUSSION AND IMPLICATIONS

Impact of Results on Practice

At the end of the post-test, participants were asked to evaluate the intervention with four Likert scale questions (Appendix F). All 12 participants reported they strongly agree (100% satisfaction score) that the topic discussed was applicable to their role as a pediatric RN, that the

education provided during the intervention was consistent with the aims of the project, and as a result they would be able to apply the knowledge gained during the intervention to their clinical practice (Table 4).

TABLE 4. *Participants post-participation evaluation.*



Strengths of Project

Notable strengths of this project were evident by the improvement of post-test scores. Participants clearly understood the content outlined in the PowerPoint and were able to immediately apply it in the post-test capacity. The participants also represented an array of pediatric oncology nursing experience and regardless of degree held and years of exposure to this population, each nurse was able to improve their individual score demonstrating that knowledge does not need to be catered to those who are new or novice in the field.

Another strength of this DNP project was evident in the post-test survey evaluations. The participants felt as though this short educational intervention was useful, practical, and applicable

to their clinical role. This means that as key stakeholders of this topic, the participants could potentially continue to advocate for further educational opportunities or even independently seek evidence on their own accord to positively impact the care they provide to actively dying pediatric oncology patients.

Limitations of Project

With strengths in scholarly projects, there are always notable limitations. This project was conducted at a single site with pediatric oncology nurses specific to that location which creates a potential for selection bias. This means that limitations were fixed based on geographic setting and ability to access a random sample of participants (Price & Murnan, 2004). This could be remediated by expanding the project to other facilities in Arizona with pediatric oncology nurses on staff.

Another weakness was the small sample size of only 12 participants which limits interpretation and generalization of results whereas a larger sample size would be beneficial in identifying significant relationships from the data (Price & Murnan, 2004). Finally, measurements of knowledge gain were conducted immediately following the interventional PowerPoint presentation, it would be conducive to re-evaluate the participants one and six months' post-mediation to assess if knowledge gains were retained.

Future Implications

This small demonstration of knowledge gain speaks volumes to the potential of future implications not only locally on the BUMCT-Peds Hem/Onc/BMT unit but potentially nationally among pediatric oncology units. Research demonstrates the significant need for increased education surrounding pain identification and management in the actively dying pediatric

oncology population. According to Wells et al. (2008), 71% of nurses rate their pain management education as inadequate and 62% rate overall end-of-life care education as inadequate.

Understanding that identification and management of pain is a vital role of the bedside nurse during the dying process, enabling access to education to guide these healthcare providers in relieving a devastating symptom can only enhance the limited quality of life these children have left to experience (Hebert, Moore & Rooney, 2011).

Relevance to DNP Essentials

This DNP project affiliated DNP Essential I: Scientific Underpinnings for Practice. DNP Essential I was utilized to advance knowledge in nursing practice. The project sought to integrate nursing science and apply evidence by providing education to pediatric oncology nurses to solve the clinical problem of pain identification and management in the actively dying pediatric oncology patient. DNP Essential I prompted the need for advancement in the foundational and nursing science of care for the actively dying pediatric oncology patient through incorporation of emerging scientific findings demanded by evolving practice theories. The project also affiliated DNP Essential II: Organizational and Systems Leadership for Quality Improvement, Essential III: Clinical Scholarship and Analytical Methods for Evidence-Based Practice, Essential VI: Inter-Professional Collaboration for Improving Patient and Population Health and Essential VIII: Advanced Nursing Practice.

The DNP project used Essential II to improve patient and healthcare outcomes by designing and evaluating an educational evidence-based intervention and disseminating research into the clinical setting through a care model based in contemporary nursing science. Essential

III was used to design, direct, and evaluate quality improvement among pediatric oncology nurses to ultimately promote safe, timely, effective and efficient patient care. Essentials VI was used to establish interprofessional collaboration among providers in the pediatric oncology domain where input from multiple professions is required to individualize and optimize care for the actively dying pediatric oncology patient. The project used Essential VIII by guiding, mentoring, and supporting other nurses to achieve excellence in nursing practice regarding pain management in the actively dying pediatric oncology patient through evidence-based interventions and evaluations. The project did not use Essential IV: Information Systems/Technology and Patient Care Technology for the Improvement and Transformation of Health Care, Essential V: Health Care Policy for Advocacy in Health Care as it did not address technology or legislation, or Essential VII: Clinical Prevention and Population Health for Improving the Nation's Health.

Conclusion

Cancer is the leading cause of death by disease in children (CureSearch, 2018). Of note, it is responsible for more deaths than all other pediatric diseases combined (CureSearch, 2018). Although great strides have been made in the field of pediatric cancer treatment, over 2,000 children die annually in the United States as a result of their cancer diagnosis (CDC, 2018). These statistics are profound and encompass a multitude of other issues related to pediatric cancer and death. Pain identification and management during the dying process is a topic rarely discussed let alone researched (Sirikia et al., 1998). It is a common misnomer that children do not experience pain at the same magnitude as adults, a grossly false accusation (Mathews, 2011).

With the utilization of verified pain assessment tools and interventions of non-pharmacological and pharmacological management, these children can have the opportunity for quality of life amidst limited quantity (Mathews, 2011). Pediatric oncology nurses at Diamond Children's Medical Center-BUMCT, Diamond 6 West, are specifically trained in the care of children undergoing treatment for their malignancy but receive no formal training in the progression from curative to comfort treatment (APHON, 2011).

In assessing the knowledge of this population regarding pain identification and management among actively dying pediatric oncology patients, it was evident after participating in a short 20-minute evidence-based educational session that there was a significant increase in knowledge gain as noted by the participants improved post-test scores. The implications of this study demonstrate the need for supplemental education concerning the dying process in children, the appropriate tools to assess pain intensity, and ultimately interventions that will provide alleviation of suffering among a population who deserve advocacy, care, and respect.

APPENDIX A:
SYNTHESIS OF EVIDENCE TABLES

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
<p>Angelescu, D. L., Snaman, J. M., Trujillo, L., Sykes, A. D., Yuan, Y., & Baker, J. N. (2015). Patient-Controlled Analgesia at the End of Life at a Pediatric Oncology Institution. <i>Pediatric Blood & Cancer</i>, 62(7), 1237–1244. http://doi.org/10.1002/pbc.25493</p>	<p>Patient controlled anesthesia (PCA) is increasingly used to manage pain in pediatric cancer patients and is important in the treatment of escalating pain at the end of life. The description of the use of opioid PCA in this population has been limited.</p> <ol style="list-style-type: none"> 1. Describe the patient population treated with opioid PCA 2. Describe the morphine-equivalent dose (MED) 3. Describe the pain scores 	Retrospective chart review	<p>44 of 159 (28%) inpatients used opioid PCA during the study time frame</p> <p>(n=44)</p> <p>Female (n=16) Male (n=28)</p> <p>Age at death (years): 0-4 (n=6) 5-7 (n=4) 8-12 (n=6) 13-18 (n=15) >18 (n=13)</p> <p>Mean (13.6 years) Median (14.7 years)</p>	<p>Descriptive statistics were calculated for patient demographic and clinical characteristics. The mean MED between age groups and between diagnosis groups were compared at days 14, 7, 2 and 1, by using the Wilcoxon rank sum test.</p> <p>The mixed effects linear model for repeated measures was used to assess the change in MED and PS over the last 2 weeks and the last week of life for all patients. The mixed effects linear model was also used to assess the change in MED over the last 2 weeks of life within age and diagnosis groups. All analyses were conducted using SAS 9.3 software and all statistical</p>	<p>Benzodiazepines were the most frequently used class of medications concurrently with the opioid PCA. 91% received a benzodiazepine at some point during the last 2 weeks of life, and 28% received benzodiazepines every day. The number of patients receiving benzodiazepines increased toward the end of life, from 35% of patients on day 14 to 77% on day 1.</p> <p>Although mean dose values are generally comparable across studies, individual dose requirements at the end of life are highly variable. This finding is consistently reflected in the large ranges of MED reported, included in the findings of this study.</p> <p>It is important for clinicians to be aware of the need for opioid</p>

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
				comparisons were 2-sided; a P value <0.05 indicated a significant difference.	escalation at the end of life, so that pain and suffering can be aggressively addressed. Pain is identified as a prevalent distressing symptom and further studies of PCA use at the end of life are recommended
Davies, B., Sehring, S. A., Partridge, J. C., Cooper, B. A., Hughes, A., Philp, J. C., . . . Kramer, R. F. (2008). Barriers to Palliative Care for Children: Perceptions of Pediatric Health Care Providers. <i>Pediatrics</i> , 121(2), 282-288. doi:10.1542/peds.2006-3153	Explore barriers to palliative care experienced by pediatric health care providers caring for seriously ill children	Survey *part of a larger survey, this study used self-report questionnaires to examines staff members' perspectives about pediatric end of life care	N=698 UCSF Children's Hospital staff members were mailed the survey A total of 240 providers responded (response rate of 34%) 83% completed by nurses (n=117) and physicians (n=81) 42 surveys completed by	The survey was mailed via campus mail to all pediatric staff members at the University of California, San Francisco (UCSF) Children's Hospital, those who worked >50% of the time providing direct care to pediatric patients were asked to respond.	Of the 26 barriers listed in the questionnaire, only 12 were reported as frequently or almost always occurring by a substantial proportion of respondents (>30%). Surprisingly, many of these identified barriers differed from those reported to be of greatest concern to adult palliative care providers. The results suggest a need for more-widespread education and mentorship in palliative care to address deficits in staff members' knowledge and experience, as well as changes in how hospitals staff their units to provide the time required for the

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
			providers from other disciplines Median age was 37 years (range: 22-70 years)		specialized palliative care need of children. Limitations of note, data was important for the development of the UCSF Children's Hospital pediatric palliative care program, but is not generalizable because they represent data from a single, tertiary care institution. Response rate was low and since anonymity was maintained, it was not possible to determine whether the respondents differed significantly from non-respondents.
Hasheesh, M., AboZeid, S., El-Said, S., & Alhujaili, A. (2013). Nurses' characteristics and their Attitudes toward Death and Caring for Dying Patients in a Public Hospital in Jordan. <i>Health Science Journal</i> , 7(4), 384-394. Retrieved from http://www.hsj.gr/medicine/nurses-characteristics-and-their-attitudes-toward-death-and-caring-for-dying-patients-in-a-public-hospital-in-jordan.pdf	Assess how Jordanian nurses providing care for terminal ill patients feel about death and caring for dying patients as well as examine any relationships between their attitudes and certain nursing characteristics	Quantitative Design	N=155 Nurses N= 93 Females N= 62 Males who directly care for patients in the terminal stage of life. The study was	The nurses' attitudes toward caring for dying patients were measured using the Frommelt Attitude toward Care of the Dying (FATCOD) scale. The nurses' attitudes toward death were measured using the Death Attitude Profile-Revised (DAP-R)	Years of experience as an RN and age are strong indicators of showing positive attitudes toward caring for death and dying patients. Younger RNs tend to report higher levels of fear than do their middle and older subsets of RNs. There was no significant relationship between nurses' attitudes toward

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
			conducted in a public Hospital- the largest governmental hospital in Jordan- Amman.	scale. The t-test and F-test were computed to examine the relationships between nurses' attitudes toward care of dying and death and demographic factors. Official permission was obtained from the Ministry of Health and the selected hospital. Participation from nurses was voluntary and the steps to ensure confidentiality and anonymity were detailed.	care of the dying and gender factor. Lack of training in communication and education resulted in uncomfortable attitude with death. Some limitations of this study include the convenience sample that may not be representative of RNs working with terminal patients at large, there may have been a selection bias that diminish the generalizability of the findings. The study used 2 instruments designed in the American cultural context. Therefore, a content validity of the scales was done.
Hooke, M. C., Grund, E., Quammen, H., Miller, B., McCormick, P., & Bostrom, B. (2007). Propofol Use in Pediatric Patients with Severe Cancer Pain at the End of Life. <i>Journal of Pediatric Oncology Nursing</i> , 24(1), 29-34. doi:10.1177/1043454206296026	Describes the use and effectiveness of adjuvant propofol for pain control for pediatric oncology patients at the end of life.	Retrospective chart review	N=9 patients of which there were 6 girls and 3 boys who received propofol as an adjuvant for pain control	Chart review for all patients who received propofol as an adjuvant for pain control between 1993 and 1999 at Children's Hospitals and Clinics of Minnesota, Department of	All patients experienced severe pain and agitation, not well controlled by continuous infusion opioids and benzodiazepines. Upon starting propofol, most patients had a temporary stabilization in the dose of opioids with subjective

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
			between 1993 and 1999, all of whom were enrolled in hospice programs.	<p>pediatric hematology/oncology</p> <p>The following data, with patient identifiers removed, were collected: age, diagnosis, dose and duration of opioids, and the use of other medications for pain and agitation.</p>	<p>improvement in pain control, increased alertness, and improved ability to interact. Propofol infusions were continued until death in most patients. Two patients received propofol infusions at home. Subsequent increases in opioids in 6 patients and propofol in all patients were required for optimal pain control. Adverse effects included agitation in 5 patients and hallucinations in 2, which were controllable with benzodiazepines. One patient developed severe tetany, requiring propofol interruption; propofol was successfully restarted at a lower dose with an adjuvant benzodiazepine. The authors conclude that propofol is a useful and tolerable adjuvant agent for pain management in pediatric oncology patients at the end of life.</p>
Sanderson, Linda. "Review: Attitudes to and Knowledge about	This study aimed to identify and	Survey	N=106 Registered	Salanterä (1999) instrument on	The aim of this study was to identify and describe

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
<p>Pain and Pain Management of Nurses Working with Children with Cancer: A Comparative Study between UK, South Africa and Sweden.” <i>Journal of Research in Nursing</i>, vol. 12, no. 5, 2007, pp. 517–519., doi:10.1177/1744987107080460.</p>	<p>describe knowledge and attitudes to pain and pain management amongst nurses working with children with cancer and compare the perspectives on pain and pain management of nurses from UK, South Africa and Sweden.</p>		<p>Nurses N=102 Females N= 4 Males</p> <p>In UK, all registered children’s nurses working with children at two pediatric oncology departments in Cardiff (Wales) (n 45) and Bristol (England) (n 45) were approached. Forty-four (20 from Cardiff and 24 from Bristol) of them participated (49%).</p> <p>In South Africa, all registered nurses working on the pediatric</p>	<p>knowledge and attitudes to pain in children was chosen, even though it had to be translated several times. This instrument consists of nine sections with a total of 127 items.</p> <p>A research group in each country collected the data. As a pilot study, prior to the main study, Salanterä’s questionnaire was translated into Swedish and distributed to 47 pediatric nurses in Sweden. The data were analyzed using SPSS for Windows software. The coding in this study was done strictly according to Salanterä’s key. The data were transformed so that a high value (i.e. 5) is interpreted as a higher level of</p>	<p>knowledge and attitudes to pain and pain management among nurses working with children with cancer. In this study the nurses had a fairly good level of knowledge as well as positive attitudes to pain management. Furthermore, the study indicates that a high level of knowledge was correlated to, and the only predicting factor for, more positive attitudes. Pederson and Parran (1997) found no correlation between the nurses’ level of knowledge and their attitudes to pain. But the results in this study show a clear correlation between a high level of knowledge and a positive attitude to pain management. The results from this study could be interpreted that a way to achieve more positive attitudes is to increase the knowledge level among the nurses. On the other hand, Salanterä (1999) investigating the attitudes of Finnish nurses</p>

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
			<p>oncology wards at the two main hospitals in Pretoria were asked to participate in the study (n 55). Although 30 (54%) questionnaires were returned, only 21 of them could be used in the analysis (38%).</p> <p>In Sweden, all 56 nurses working at the two pediatric oncology departments in Gothenburg (n 37) and from the pediatric department at the University of Health Science in Linköping (n 19), were asked to</p>	<p>knowledge or positive attitude to pain management. Likewise, a low value (i.e. 1) is interpreted as a low level of knowledge or a negative attitude to pain management.</p>	<p>(n 303) to children in pain found that negative attitudes in nurses did not hinder effective pain management</p>

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
			participate in the study. Forty-one (23+19) of them participated (73%)		
<p>Salanterä, S., Lauri, S., Salmi, T. T., & Helenius, H. (1999). Nurses Knowledge About Pharmacological and Nonpharmacological Pain Management in Children. <i>Journal of Pain and Symptom Management</i>, 18(4), 289-299. doi:10.1016/s0885-3924(99)00065-2</p>	<p>The purpose of this study was to investigate the knowledge base and practices about pain management in child of Finnish nurses working on children's wards in university hospitals.</p> <p>What do nurses know about nonpharmacological pain management in children?</p> <p>What do nurses know about pharmacological pain management in general and about anti-inflammatory drugs, opioids, and regional anesthesia</p>	Questionnaire	<p>N=265 registered nurses who had at least a bachelor-level education, who worked on children's wards at any of the five Finnish university hospitals, and who primarily worked and had daily contact with children.</p> <p>Response rate was 87%</p> <p>Nurses' ages ranged from</p>	<p>The instrument consisted of a demographic data sheet, nine general questions about nonpharmacological pain alleviation, and 23 questions about pharmacological pain management. In addition, there were 21 questions about different nonpharmacological pain management methods and four questions about the nurse's own opinions of her knowledge and possibilities to manage children's pain. The scores are given as percent of correct answers out of the possible total.</p>	<p>The sample size was quite large, representing one-third of the population. The response rate was also high (87%) and the number of responses excluded because of missing data was very low. Using a questionnaire for data collection allows for anonymity and helps to avoid interviewer bias. The results showed that there remain some gaps in the knowledge base of Finnish university hospital nurses with regard to both pharmacological and nonpharmacological pain management in children. Nurses received higher scores in the area of nonpharmacological pain</p>

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
	<p>in children?</p> <p>What methods of nonpharmacological pain management do nurses use in practice?</p> <p>Do the knowledge base and methods used differ according to nurses' age, time of graduation, education, institute, ward, working experience, or nurses' own opinions of their knowledge?</p>		<p>20 to 59 years, mean (SD) being 39 years</p> <p>Nurses' years of experience ranged from 0.5 to 35 years, with a mean (SD) of 14.5 years</p>	<p>Comparisons were done with nonparametric Kruskal-Wallis analysis of variance (ANOVA). P-values of less than 0.05 were interpreted as significant. The data were entered twice into the program to avoid errors in data input. The SAS system for Windows, release 6.2/1996, was used for data analysis.</p>	<p>management. The nurses themselves were well aware of their lack of knowledge: their evaluations of their own knowledge base were well in line with their actual knowledge scores. The instrument was designed for this study and has not been tested in other populations, as this is a notable limitation.</p>
<p>Tutelman, P. R., Chambers, C. T., Stinson, J. N., Parker, J. A., Fernandez, C. V., Witteman, H. O., . . . Irwin, K. (2017). Pain in Children with Cancer. <i>The Clinical Journal of Pain</i>, 1. doi:10.1097/ajp.0000000000000531</p>	<p>To examine pain prevalence and characteristics, and the pharmacological, physical and psychological pain management strategies used by parents to manage their child's cancer pain.</p>	<p>Survey</p>	<p>Parents of children with cancer currently in treatment or a survivor</p> <p>311 started the survey, 256 completed the survey (82% completion)</p>	<p>Participants were recruited to complete an online survey developed in partnership with the Cancer Knowledge Network, North America's most widely read online cancer resource.</p> <p>Over a 4-week period, the research</p>	<p>Data came from 230 parents (89% mothers) from 10 different countries. Children ranged from 1-18 years (mean=8.93, SD=4.50) and there was an equal ratio of boys to girls. Most parents identified themselves (84.9%) and their children (79%) as Caucasian.</p>

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
			rate) Eligibility criteria: English speaking but no geographic restrictions	<p>team recruited participants by sharing the link to the online survey with their networks of parents of children with cancer via Twitter, Facebook, and professional and patient-directed listservs and blogs.</p> <p>The questionnaire included information about the child's cancer history, child pain characteristics, pain management practices, parent confidence, pain catastrophizing, knowledge of pain assessment, medication attitudes, and demographics</p>	<p>The results of the current study suggest that children with cancer experience a substantial pain burden both during and after treatment. Studies have found that parents of children with cancer do hold misconceptions about pain assessment and management, which impacts their administration of analgesia.</p> <p>The limitations include the design of the study, where data was collected regarding children's pain experiences from their parents, including parents' reports of child pain. Past research has shown that parents and children do not always agree in their reports of pain and parents tend to rate their child's level of pain lower than their children do.</p>
Virdun, C., Lockett, T., Davidson, P. M., & Phillips, J. (2015). Dying in	Identify the five most important	Systematic Review	The included studies came	Databases included the following:	Findings noted that both patients and families note

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
<p>the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. <i>Palliative Medicine</i>, 29(9), 774-796. doi:10.1177/0269216315583032</p>	<p>elements of inpatient end-of-life care as identified by patients with palliative care needs and their families.</p>		<p>from three developed countries in the northern hemisphere: Canada (n=4), United States (n=3), and the United Kingdom (n=1). Seven studies included family with three of these also including patients. One study included patients only. The views from 1141 patients and 3117 families are captured in this review.</p>	<p>EBSCO, OVID, CINAHL, MEDLINE, EMBASE, PubMed, and Cochrane. Search terms used included “dying, death, end of life, terminal care, palliative, patient satisfaction, hospital, experience”. Data were extracted into an electronic preformat in Microsoft Word. Items included the country in which the study was conducted, level of evidence, aim, design, and method, participants and setting, outcomes measures, results and care elements highlighted as important. 1859 articles were found in which 8 were assessed as meeting inclusion criteria.</p>	<p>the importance of expert care, effective communication and shared decision making, respectful care, and confidence in clinicians.</p> <p>The strength of this review lies in the systematic methodology used to limit bias, develop accurate and reliable conclusions and to assimilate large amounts of information to inform future health service development.</p> <p>The limitations of this review note that a single author examined the titles and abstracts and undertook data extraction for included studies. Only descriptive data were reported and therefore should be seen as informative rather than definitive. The narrative approach to synthesis can include some subjectivity in relation to theming and interpretation of data,</p>

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
					although again, group consensus was sought to minimize the risk.
<p>Wolfe, J., Grier, H., Klar, N., Levin, S., Ellenbogen, J., & Salem-Schatz, S. (2000). Symptoms and Suffering at the End of Life in Children with Cancer. <i>New England Journal of Medicine</i>, 342, 326-333. DOI: 10.1056/NEJM200002033420506</p>	<p>Determine the patterns of care among children who die of cancer, the symptoms experienced in the last month of life and the effectiveness of their treatment, and the factors related to suffering from pain at the end of life.</p>	<p>Interview-Questionnaire</p>	<p>Children's Hospital and the Dana-Farber Cancer Institute in Boston</p> <p>Interview conducted of the parents of children who died of cancer between 1990 and 1997</p> <p>Of 165 eligible parents, 103 interviews were conducted with an overall response rate of 62%</p>	<p>Inclusion criteria: English speaking, residing in North America, and having a child who died of cancer more than one year before the study began, and their child's former physician permitted contact.</p> <p>In person and telephone interviews lasting an average of 113 minutes with a mean (+SD) of 3.1+-1.6 years after the death of the child. Parents were asked whether their child had the following symptoms during the last month of life: pain, poor appetite, nausea/vomiting, constipation, diarrhea, dyspnea, or fatigue. They were also asked to rate the</p>	<p>In univariate analyses, factors reported by the parents that were associated with a child's suffering from pain were lack of active involvement by the oncologist in care at the end of life and the perception of receiving conflicting information from care givers. Lack of involvement of the oncologist was also associated with significantly more suffering from pain in a multivariate logistic-regression model, after adjustment for physician clustering, the interval between the child's death and the parental interview, the cause of death, the child's age at death, and the place of death (odds ratio, 2.6; 95 percent confidence interval, 1.0 to 6.7).</p>

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
				degree to which the child appeared to suffer as a result of each symptom on a five-point Likert scale.	The study found that children who died of cancer experienced substantial suffering in the last month of life. According to parental reports, 89 percent of the children experienced substantial suffering from at least one symptom, most commonly fatigue, pain, or dyspnea. The study also found that treatment was seldom successful, even in the case of symptoms that are typically considered to be amenable to treatment. Fewer than 30 percent of parents reported that the treatment of pain was successful, and only 10 percent reported that nausea and vomiting or constipation was controlled.
Wolfe, J., Hammel, J. F., Edwards, K. E., Duncan, J., Comeau, M., Breyer, J., . . . Weeks, J. C. (2008). Easing of Suffering in Children with Cancer at the End of Life: Is Care Changing? <i>Journal of Clinical Oncology</i> , 26(10), 1717-1723.	Determination of whether national and local efforts have led to changes in patterns of care, advanced care planning, and	Respective Cohort Study	Parent survey and chart review data from 119 children who died between 1997 and	Surveys were conducted by telephone, in person, or by paper and pencil format, at the parent's discretion. Parents were	According to parent surveys, children are experiencing significantly less suffering related to prevalent symptoms, such as pain and dyspnea at the end of life, and at least

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
doi:10.1200/jco.2007.14.0277	symptoms control among children with cancer at the end of life.		<p>2004 (follow-up cohort) were compared with 102 children who died between 1990 and 1997 (baseline cohort)</p> <p>Interview of 102 parents of children cared for at the DFCI and CHB, who died of cancer between 1990-1997 and reviewed charts.</p> <p>Interview parents of children who died of cancer between 1997 and 2004.</p>	<p>considered eligible if they were English-speaking, lived in North America, and their child's former oncologist permitted us to contact them.</p> <p>Charts of children whose parents were surveyed were abstracted using the baseline study tool. Data collected included child's sex, diagnosis, dates of birth, diagnosis and death, cause of death, classified as progressive disease or treatment-related complication, use of cardiopulmonary resuscitation, date of termination of last cancer-directed therapy, location of death, and consultation by the CHB pain team.</p>	<p>one indicator of psychological distress, anxiety, also improved.</p> <p>Noted changes in quality of care are likely due to local quality improvement efforts. Increased focus on end-of-life care in the medical field and mass media, and the presence of national recommendations advocating for palliative care as an expected standard of care are likely to have impacted clinical practice at an individual level. In addition, hospital-based palliative care teams such as PACT involve a myriad of strategies that extend beyond direct clinical care.</p> <p>A randomized controlled trial would have been needed to isolate the effects of local from more global efforts. Given the retrospective nature of the study, the child's</p>

Author / Article	Research Question	Design	Sample (N)	Data Collection (Instruments/tools)	Findings Strengths/Limitations
					perspective was not included. Parents remain as the primary voice which is consistent with care approaches thru pediatrics.


APPENDIX B:
SOCIAL MEDIA PARTICIPANT RECRUITMENT STATEMENT:
FACEBOOK POST

“Hello all certified pediatric oncology RNs! Are you interested in learning more about pain identification and management in the actively dying pediatric oncology patient? Do you feel as though you could advocate for better care for a child who may be suffering from pain during the dying process? If so, please respond below to participate in an educational session. This informative presentation is for inpatient pediatric oncology RNs employed on D6W, who currently hold their APHON certification, either dayshift/nightshift, part-time/full-time. The survey and presentation will take approximately 30-40 minutes of your time and is delivered by myself, Heather Fydrych. This is the final step in completing my doctoral dissertation and obtaining my credentials as a certified Doctor of Nursing Practice-Pediatric Nurse Practitioner through the University of Arizona, College of Nursing. Participation is entirely voluntary, will not impede on your employment with Banner Health, and compensation will be provided in the form of gratitude. Please comment below with interest and your email address or email me at Hefydrych@email.arizona.edu for detailed information regarding the time/date of this one-time only in-person gathering. No studying required, just bring your inquiring mind.”


BUMCT Peds Hem/Onc BMT
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Search this group



Heather Elizabeth
 Just now



Hello all certified pediatric oncology RNs! Are you interested in learning more about pain identification and management in the actively dying pediatric oncology patient? Do you feel as though you could advocate for better care for a child who may be suffering from pain during the dying process? If so, please respond below to participate in an educational session. This informative presentation is for inpatient pediatric oncology RNs employed on D6W, who currently hold their APHON certification, either dayshift/nightshift, part-time/full-time. The survey and presentation will take approximately 30-40 minutes of your time and is delivered by myself, Heather Fydrych. This is the final step in completing my doctoral dissertation and obtaining my credentials as a certified Doctor of Nursing Practice-Pediatric Nurse Practitioner through the University of Arizona, College of Nursing. Participation is entirely voluntary, will not impede on your employment with Banner Health, and compensation will be provided in the form of gratitude. Please comment below with interest and your email address or email me at Hefydrych@email.arizona.edu for detailed information regarding the time/date of this one-time only in-person gathering. No studying required, just bring your inquiring mind.


 Turn on job features for this post to reach more applicants.

 Like

 Comment


 Write a comment...

APPENDIX C:

PERMISSION TO POST TO PRIVATE CLOSED SOCIAL MEDIA PLATFORMS:

BANNER UNIVERSITY MEDICAL CENTER – TUCSON CAMPUS

DIAMOND CHILDREN'S: PEDIATRIC HEMATOLOGY/ONCOLOGY/BONE MARROW
TRANSPLANT

INTERNAL OWNER/ADMINISTRATOR APPROVAL LETTER

I Taylor Underwood (Taylor Underwood RN, BSN), as the certified administrator of the Banner University Medical Center Pediatric Hematology/Oncology/Bone Marrow Transplant Facebook page state that Heather Fydrych DNP-PNP Student at the University of Arizona, College of Nursing, may be permitted to post information regarding her Doctoral Project for the purpose of recruitment of participants. This is a closed Facebook group that has no direct affiliation with Banner University Medical Center or its legal department.

Signed: Registered Nurse Manager and BUMCT-Peds Hem/Onc/BMT Facebook Page Administrator

Taylor Underwood
Taylor Underwood RN, BSN

4/10/2019
Date

APPENDIX D:
EXPERT CONTENT REVIEWER EVALUATION FORMS FOR POWERPOINT
PRESENTATION

Expert Evaluation Form**PowerPoint Presentation:****“Pediatric Oncology Nurses’ Knowledge of Pain Management in the Actively Dying Child”**Expert Reviewer #1: [REDACTED]**1. The PowerPoint is concise, educational, and appropriate for the targeted audience.**

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

2. The education provided in the PowerPoint is up-to-date and aligns with current practice.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

3. The format in which the information is presented, is easily understood with foreign theories, methods, and tools explained appropriately.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

4. The concepts addressed in the PowerPoint are relevant to the topic of the Doctoral Project.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

5. How many years have you been in practice as a Registered Nurse?

14.5 years

6. How many years have you been in practice as an Advance Practice Registered Nurse?

3.5 years

7. What is your highest degree obtained?

MSN

8. Do you obtain any special certifications that pertain to care of pediatric oncology patients?

Certified Pediatric Hematology-Oncology Nurse (CPHON)

9. In what capacity do you/have you worked with pediatric oncology patients who experience pain?

I have cared for pediatric oncology patients with acute pain related to procedure, chemotherapy side effect, injury. I have cared for patients with chronic pain such as neuropathy, avascular necrosis, or pain related to tumor infiltration. I have cared for the dying child in an inpatient setting as a bedside nurse. I have also managed end of life pain along with palliative care as an NP in the outpatient clinic.

10. Please provide any additional concerns/comments/questions that you have regarding the PowerPoint Presentation you have reviewed.

Great presentation with many resources to understand pain perceptions, rating of pain, and various pain management techniques. I think it is definitely vital for nurses to understand how to manage and properly educate family members about pain management for the child with cancer.

Expert Evaluation Form**PowerPoint Presentation:****“Pediatric Oncology Nurses’ Knowledge of Pain Management in the Actively Dying Child”**Expert Reviewer #2: XXXXXXXXXX**1. The PowerPoint is concise, educational, and appropriate for the targeted audience.**

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

2. The education provided in the PowerPoint is up-to-date and aligns with current practice.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

3. The format in which the information is presented, is easily understood with foreign theories, methods, and tools explained appropriately.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

4. The concepts addressed in the PowerPoint are relevant to the topic of the Doctoral Project.

- a. Strongly agree
- b. Agree
- c. Disagree
- d. Strongly disagree

5. How many years have you been in practice as a Physician?

15 years

6. What is your highest degree obtained?

DO

7. Do you obtain any special certifications that pertain to care of pediatric oncology patients?

Board certified in pediatric oncology

8. In what capacity do you/have you worked with pediatric oncology patients who experience pain, especially related to the dying process?

As a practicing pediatric oncologist for 12 years

9. Please provide any additional concerns/comments/questions that you have regarding the PowerPoint Presentation you have reviewed.

I feel like this is a really great overview of cancer pain and pain in the dying patient. I appreciated the review of basic definitions in the beginning – this is not always done and the learners feel embarrassed to ask questions.

I thought including the pain scales as visuals was very helpful as well.

The most important aspects that were highlighted from my point of view were to remind people of cultural influence on pain and the multidisciplinary approach to pain.

Excellent presentation!

APPENDIX E:
PRE-TEST: MODIFIED “KNOWLEDGE AND ATTITUDES SURVEY REGARDING PAIN”
TOOL

PRE-TEST SURVEY CONSENT/DISCLOSURE FORM

Please respond indicating whether you consent to participate in the study or if you would like to withdraw from the study.

***Please understand that participation or non-participation in this study has no impact on your current or future employment with Banner Health or its affiliates. Your position as a Banner Health RN will not be compromised in any way with your voluntary participation or non-participation. Your answers/feedback will remain entirely confidential and anonymous with no intention of associating completed surveys with their original owners.**

- a. I agree (to participate in study and take pre-test/post-test)
- b. I disagree (to withdraw from study and stop test)

Demographics

Years of Experience in Pediatric Oncology Nursing:

_____ < 1 _____ 1-5 _____ 5-10
 _____ 10-15 _____ 15-20 _____ 20-25

Highest Level of Degree Obtained: _____ Associates _____ Bachelors _____ Masters

Pretest

Modified “Knowledge and Attitudes Survey Regarding Pain” Tool

Questions and content derived from the Knowledge and Attitude Survey Regarding Pain, Care of a Child Dying of Cancer Journal Article, Palliative Care in Pediatric Oncology Textbook, and the Pediatric Palliative Care Consultant: Guidelines for Effective Management of Symptoms Booklet

20 Multiple Choice Questions- Please Circle the Best Answer

1. It has been shown that most patients with progressive cancer do not experience _____ & _____ during the end-of-life period.

- a. pain/thirst
- b. hunger/thirst**
- c. emotion/hunger
- d. pain/emotion

2. What process/method is the most reliable indicator when assessing the intensity of a pediatric patient's pain?
- a. vital signs
 - b. physical assessment/pain scale
 - c. parental report
 - d. physician report
3. All of the following statements are true **EXCEPT**:
- a. Children may sleep in spite of severe pain
 - b. When appropriately administered, strong pain relievers are no more dangerous for children than they are for adults
 - c. Babies as young as six months old can show fear of painful situations, indicating a memory of the unpleasantness of pain
 - d. Children are less sensitive to pain than adults
4. Combining analgesics that work by different mechanisms may result in better pain control with fewer side effects than using a single analgesic agent. Which combination of medications listed below would result in the most optimal analgesic effect?
- a. SSRIs/acetaminophen
 - b. acetaminophen/opioids
 - c. ondansetron/ibuprofen
 - d. opioids/antihistamines
5. Behavioral consequences of untreated pain in children include all of the following EXCEPT:
- a. peacefulness
 - b. agitation
 - c. PTSD
 - d. fear
6. At what age can children begin self-reporting their pain?
- a. 5-6 years old
 - b. 10-11 years old
 - c. 0-1 years old
 - d. 3-4 years old
7. Parents report that ____ of children who died of cancer suffered a great deal from at least one symptom in the last month of life?
- a. 20%
 - b. 60%
 - c. 70%
 - d. 90%

8. 6% of children with terminal malignancy who suffer severe pain require more than _mg/kg of morphine dose equivalent per hour to achieve relief?

- a. 1mg
- b. 3mg
- c. 5mg
- d. 10mg

9. Which option is **NOT** a goal of pain management in the pediatric patient?

- a. relieve pain
- b. minimize side effects
- c. maximize comfort
- d. ignore unwanted symptoms

10. Which of the following is/are useful for treatment of cancer pain?

- a. Ibuprofen (Motrin)
- b. Hydromorphone (Dilaudid)
- c. Gabapentin (Neurontin)
- d. All of the above

11. According to the developmental stages of children, preschool aged children typically report pain by:

- a. crying/struggling/regressing
- b. using appropriate language such as “sore”, “ache”, and “pounding”
- c. tremoring
- d. quantifying pain intensity and location

12. Which verified assessment tool should **NOT** be utilized to assess pain in a child less than 3 years of age during end-of-life care?

- a. CRIES
- b. FLACC
- c. N-PASS
- d. Numeric Scale

13. Which verified pain assessment tool is most effective in assessing pain in an unresponsive and non-verbal pediatric oncology patient during end-of-life care?

- a. Numeric Scale
- b. N-PASS
- c. Colored Analogue Scale
- d. MOPAT (Multidimensional Observational Pain Assessment Tool)

14. Which of the following analgesic medications is considered the drug of choice for the treatment of prolonged moderate to severe pain for cancer patients?

- a. codeine
- b. morphine
- c. acetaminophen
- d. tramadol

15. 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.

16. The most accurate judge of the intensity of the patient's pain is:

- a. the treating physician
- b. the patient's nurse
- c. the patient
- d. the patient's family

17. The time to peak effect for morphine given IV is:

- a. 5 min
- b. 15 min
- c. 60 min
- d. 90 min

18. The time to peak effect for morphine given PO is:

- a. 5-10 min
- b. 10-15 min
- c. 30-60 min
- d. 120-180 min

19. Which of the following describes the best approach for cultural considerations in caring for patients in pain:

- a. There are no longer influences in the U.S. due to diversity of the population
- b. Cultural influences can be determined by an individual's ethnicity
- c. Patients should be individually assessed to determine cultural influences
- d. Cultural influences can be determined by an individual's socioeconomic status

20. Appropriate nonpharmacological interventions for pain management include all of the following **EXCEPT**:

- a. restricting activity
- b. distraction
- c. heat/cold therapy
- d. relaxation

APPENDIX F:
POST-TEST: MODIFIED “KNOWLEDGE AND ATTITUDES SURVEY REGARDING
PAIN” TOOL

POST-TEST SURVEY

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 - c. trembling
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20. Appropriate nonpharmacological interventions for pain management include all of the following **EXCEPT**:

- a. restricting activity
- b. distraction
- c. heat/cold therapy
- d. relaxation

Presentation Evaluation Questions:

1. I felt the survey questions were applicable and/or relevant to my job as a pediatric oncology nurse.

- a. Strongly agree
- b. Agree
- c. Neither/Undecided
- d. Disagree
- e. Strongly disagree
- f. Not applicable

2. The content in the PowerPoint presentation was easily understood and the information was consistent with the topic of the project.

- a. Strongly agree
- b. Agree
- c. Neither/Undecided
- d. Disagree
- e. Strongly disagree
- f. Not applicable

3. I will be able to apply the knowledge gained from this activity in my practice as a pediatric oncology nurse.

- a. Strongly agree
- b. Agree
- c. Neither/Undecided
- d. Disagree
- e. Strongly disagree
- f. Not applicable

4. I was overall satisfied with my participation in this survey/presentation.

- a. Strongly agree
- b. Agree
- c. Neither/Undecided
- d. Disagree
- e. Strongly disagree
- f. Not applicable

Thank you for taking the time to participate in this project!

APPENDIX G:
INTERVENTION POWERPOINT PRESENTATION SLIDES

Pediatric Oncology Nurses' Knowledge of Pain Management in the Actively Dying Child

Heather Fydych
DNP-PNP Student



1

Purpose and Goal of this Doctoral Project



- The purpose of this doctoral project is to assess the current knowledge of pain management and identification of pain among pediatric oncology nurses in regards to caring for pediatric cancer patients during the dying process.
- The goal of this doctoral project is to share increased knowledge among pediatric oncology nurses regarding pain identification and management post presentation as reflected in their post-test scores.

2

Overview and Significance

- Pain is one of the most misunderstood, under diagnosed, and under treated medical problems, particularly in children?
- Significant lack of pediatric related pain studies that identify children's pain perceptions and reality separate from that of an adult?
- Common misconception that children and infants do not experience pain the same as adults?
- Understand the essence of pain and treat actively, regularly, and prophylactically?
- Death is a painful experience, regardless of age, sex, race, or diagnosis?
- Parents describe the experience of having a child with cancer in pain is unbearable; this creates a feeling of helplessness and lack of control?
- Pain in children who are dying of cancer is complex and may result from:
 - Disturbance or irritation of tissue or bone
 - Inflammation from infection, trauma, or obstruction
 - Side effects from treatment (chemotherapy, surgery, and/or radiation) including nausea/vomiting, organ failure, myelotoxicity, lymphitis, and skin toxicities
 - Neuropathic pain occurs when nerves are injured by tumor infiltration or as a side effect from some chemotherapy drugs or radiation therapy

3

Key Terms and Definitions

- Pediatric:** Of, relating to, or being an infant, child, or adolescent most often under the age of 18
- Pain:** is localized or generalized unpleasant bodily sensation or complex of sensations that clients will to severe physical discomfort and emotional distress and typically results from bodily disorder such as injury or disease. A basic bodily sensation that is induced by a sensory stimulus, is perceived by related nerve endings, is associated with actual or potential tissue damage, is characterized by physical discomfort
- Actively dying:** the focus or days preceding imminent death during which time the patient's physician forecasts death
- Culture:** the customary beliefs, social forms, and material traits of a racial, religious, or social group; the set of shared attitudes, values, goals, and practices that characterize an organization
- Neuropharmacologic pain management:** management of pain without medications, such as use of education, psychological conditioning, hypnosis, distraction, imagery, meditation, music, visualization, biofeedback, bioenergetics, bioenergetics, bioenergetics, bioenergetics
- Pharmacologic pain management:** management of pain with medications such as non-narcotics and narcotics
- Neuroleptics:** encompasses the non-narcotic pain-influencing drugs (propofol, dexmedetomidine, and dexmedetomidine) that produce an anesthetic effect. "Neuroleptics is considered a non-narcotic drug and frequently used in the treatment of chronic pain"
- Opoids:** synthetically (laboratory) made drugs that attach to opioid receptors in the brain decreasing sensation of pain, creates feelings of relaxation, and allows the automatic response of the body such as breathing, memory recall, emotions, feelings, and sensations

4

Multidisciplinary Approach to Pain Management

- Pain is considered the "5th" vital sign and must be assessed by all healthcare staff caring for the child?
- Healthcare staff can include certified nurse anesthetists, respiratory therapists, registered nurses, medical assistants, physical therapists, dietitians, social workers, chaplains, patient navigators, and patient family members
- Children and parents/caregivers are equal partners with members of the health care team in managing the patient's pain?
- Establish realistic treatment goals: the primary goal of pain management is consistent and complete control of pain through the use of appropriate analgesics and adjunct medications, as well as non-pharmacological interventions?
- Both the child and parent/caregiver/relatives/individuals regarding all aspects of pain management at the end of life, or a caregiver may be uncomfortable?
- Some examples of the information/education include:
 - How to recognize and assess pain, including subtle changes
 - Children's perception of pain
 - The factors that influence pain (aging, anger, depression, fear, anxiety, fatigue, culture, age)
 - Impact of the patient's attitudes on a child's pain and suffering
 - Signs, effective pain management options
 - What to expect?
 - Medication issues including anticipating and preventing problems
 - How to tell the body
 - Dispensing fears and misconceptions about pain management (addiction and hastening of death)

5

The Role of the Pediatric Oncology Nurse

- The current role in caring for children who are in pain during the dying process includes assessment, identifying expected outcomes, and planning, performing, and evaluating interventions?
- Assessment: collecting data that leads to the development of an appropriate plan
 - This means communicating with the patient and parent/caregivers on their perception of pain, the child's and caregiver's discomfort, and how the child's and caregiver's discomfort may be related to the disease, collection of objective data such as vital signs, general appearance, and response to touch or movement?
 - Physiological indicators of pain in children:
 - Heart Rate: increases markedly when a pain stimulus
 - Respiratory Rate: significant shift from baseline, increase or decrease, may become rapid and irregular
 - Blood Pressure: increases when a child is in acute pain
 - Oxygen Saturation: decreases when a child is in acute pain
- Identifying Expected Outcomes: with the help of the child, family, and health care team to formulate the goals of care. Together, the appropriate methods of symptom and pain management can be determined. Expected outcomes include the utilization of appropriate methods for pain management and the child's ability to communicate the child's level of comfort to the team?
- Intervention: consistent with the age and cognitive ability of the child these include delivery of pain medication, other non-pharmacological approaches to reduce pain, and education to the child and family. The nurse is also responsible for observing the intervention and the child's response?
- Evaluation: continually assess the response to treatment and compare findings to the expected outcomes. The plan of care is adjusted based on the data collected and the outcome of the health care team?

6

Other Symptoms Expected During the Dying Process

All of these symptoms can contribute to the physical, emotional, and spiritual well-being. They can increase suffering, exacerbate pain, and influence the expected pain of death?

<ul style="list-style-type: none"> Lack of energy/fatigue Dry mouth Swallowing Stomach changes Cough Exhaustion Difficulty urinating Shortness of breath Diarrhea/constipation Weight loss Head issues 	<ul style="list-style-type: none"> Anxiety/irritability Depression Swallowing Stomach changes Headaches Nausea/vomiting Exhaustion/constipation Swallowing Headaches Changes in vision, taste, smell, hearing, and sensation
---	--

7

How Children Express Pain

Some common symptoms outside the dying process?	Some common symptoms during the dying process?
<ul style="list-style-type: none"> Discomfort in physical activity Change in appetite or sleep patterns Avoiding contact with other children Withdrawn, irritable, or angry behavior Nonverbal expressions of pain, sleeping, crying, or howling Planted side Rapid breathing Swallowing Dark eyes Flashing over and over the other 	<ul style="list-style-type: none"> Inability to regulate temperature Swallowing changes Dry mouth Exhaustion Agitation Slurred speech Lack of control of bladder/bowel Redness Decreased or no appetite Difficulty swallowing Drinking

Pain Expression by Developmental Stage?

- 3 Months (0-1): Nonverbal/Behavioral
 - Crying, facial expressions, body posture, movement, breathing patterns, state of arousal
- Toddler (2-3): Nonverbal/Behavioral
 - Facial expressions, body movement, grunting, holding, crying
- Preschooler (4-5): Nonverbal/Behavioral
 - Facial expressions, crying, expressive behavior
- School-aged Children (6-12): Verbal/Quality
 - Crying, withdrawal, expressive behavior
- Adolescent (13-18): Verbal
 - Crying, withdrawal, expressive behavior

8

Pediatric Pain

- Children are capable of self-reporting pain as early as 1 year of age, especially those who have endured chronic pain or treatment related pain previously?
- Infants, toddlers, children, and adolescents present a unique challenge that necessitates consideration of their age, developmental level, cognition and communication skills, previous pain experiences, and associated beliefs?
- Verified pain scales are one of the most reliable ways to assess the intensity of a child's pain?



9

Frequently Used Pediatric Pain Scales

Face, legs, activity, cry, comfortability (FLACC) (ages 2 months-8 years) or Face, legs, activity, cry, comfortability modified scale (FLACC-M) (significantly impaired children ages 0-18 years)

Patients who are unable to self-report should use for 2-8 minutes unattended and responses for patient's/observer activity for frequency and time. Patients who are asleep may also observe for at least 15 minutes unattended and responses for patient's/observer activity for frequency and time.

Category	0	1	2
Face	Relaxed	Worried	Crying
Legs	Relaxed	Worried	Crying
Activity	Relaxed	Worried	Crying
Cry	None	Some	Much
Comfortability	Relaxed	Worried	Crying

10

Frequently Used Pediatric Pain Scales Continued

Wong-Baker FACES Pain Rating Scale (ages 3-18 years)

Wong-Baker FACES Pain Rating Scale (ages 3-18 years) is a visual analog scale that allows children to self-report their pain level. The scale is based on the Wong-Baker FACES Pain Rating Scale (ages 3-18 years) and the Wong-Baker FACES Pain Rating Scale (ages 3-18 years).



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11

Alternative Pediatric Pain Scales

Question-Reworded Child Pain Scale (Question-Reworded Child Pain Scale) (ages 2-8 years)

Question-Reworded Child Pain Scale (Question-Reworded Child Pain Scale) (ages 2-8 years) is a visual analog scale that allows children to self-report their pain level. The scale is based on the Question-Reworded Child Pain Scale (Question-Reworded Child Pain Scale) (ages 2-8 years) and the Question-Reworded Child Pain Scale (Question-Reworded Child Pain Scale) (ages 2-8 years).



Question-Reworded Child Pain Scale (Question-Reworded Child Pain Scale) (ages 2-8 years)

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Question-Reworded Child Pain Scale (Question-Reworded Child Pain Scale) (ages 2-8 years)

Question-Reworded Child Pain Scale (Question-Reworded Child Pain Scale) (ages 2-8 years) is a visual analog scale that allows children to self-report their pain level. The scale is based on the Question-Reworded Child Pain Scale (Question-Reworded Child Pain Scale) (ages 2-8 years) and the Question-Reworded Child Pain Scale (Question-Reworded Child Pain Scale) (ages 2-8 years).



12

APPENDIX H:
KNOWLEDGE AND ATTITUDES SURVEY REGARDING PAIN TOOL:
PERMISSION TO MODIFY AND USE



October 2012

The "Knowledge and Attitudes Survey Regarding Pain" tool can be used to assess nurses and other professionals in your setting and as a pre and post test evaluation measure for educational programs. The tool was developed in 1987 and has been used extensively from 1987 - present. The tool has been revised over the years to reflect changes in pain management practice.

Regarding issues of reliability and validity: This tool has been developed over several years. Content validity has been established by review of pain experts. The content of the tool is derived from current standards of pain management such as the American Pain Society, the World Health Organization, and the National Comprehensive Cancer Network Pain Guidelines. Construct validity has been established by comparing scores of nurses at various levels of expertise such as students, new graduates, oncology nurses, graduate students, and senior pain experts. The tool was identified as discriminating between levels of expertise. Test-retest reliability was established ($r > .80$) by repeat testing in a continuing education class of staff nurses ($N=60$). Internal consistency reliability was established ($\alpha r > .70$) with items reflecting both knowledge and attitude domains.

Regarding analysis of data: We have found that it is most helpful to avoid distinguishing items as measuring either knowledge or attitudes. Many items such as one measuring the incidence of addiction really measures both knowledge of addiction and attitude about addiction. Therefore, we have found the most benefit to be gained from analyzing the data in terms of the percentage of complete scores as well as in analyzing individual items. For example, we have found it very helpful to isolate those items with the least number of correct responses and those items with the best scores to guide your educational needs.

Enclosed for your use is a copy of our instrument and an answer key. You may use and duplicate the tool for any purpose you desire in whole or in part. References to some of our studies which have included this tool or similar versions are included below. We have received hundreds of requests for the tool and additional use of the tool can be found in other published literature. We also acknowledge the assistance of several of our pain colleagues including Pam Kedziera, Judy Paice, Deb Gordon, June Dahl, Hob Osterlund, Chris Pasero, Pat Coyne and Nessa Coyle in the revisions over the years. If using or publishing the tool results please cite the reference as "Knowledge and Attitudes Survey Regarding Pain" developed by Betty Ferrell, RN, PhD, FAAN and Margo McCaffery, RN, MS, FAAN, (<http://prc.coh.org>), revised 2012.

We hope that our tool will be a useful aid in your efforts to improve pain management in your setting.

Sincerely,

A handwritten signature in black ink that reads "Betty R. Ferrell PhD, FAAN".

Betty R. Ferrell, RN, PhD, FAAN
Research Scientist

A handwritten signature in black ink that reads "Margo McCaffery".

Margo McCaffery, RN, MS, FAAN
Lecturer and Consultant

References:

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APPENDIX I:
KNOWLEDGE AND ATTITUDES SURVEY REGARDING PAIN TOOL:
ORIGINAL VERSION

Knowledge and Attitudes Survey Regarding Pain

True/False – Circle the correct answer.

- | | | |
|---|---|--|
| T | F | 1. Vital signs are always reliable indicators of the intensity of a patient's pain. |
| T | F | 2. Because their nervous system is underdeveloped, children under two years of age have decreased pain sensitivity and limited memory of painful experiences. |
| T | F | 3. Patients who can be distracted from pain usually do not have severe pain. |
| T | F | 4. Patients may sleep in spite of severe pain. |
| T | F | 5. Aspirin and other nonsteroidal anti-inflammatory agents are NOT effective analgesics for painful bone metastases. |
| T | F | 6. Respiratory depression rarely occurs in patients who have been receiving stable doses of opioids over a period of months. |
| T | F | 7. Combining analgesics that work by different mechanisms (e.g., combining an NSAID with an opioid) may result in better pain control with fewer side effects than using a single analgesic agent. |
| T | F | 8. The usual duration of analgesia of 1-2 mg morphine IV is 4-5 hours. |
| T | F | 9. Research shows that promethazine (Phenergan) and hydroxyzine (Vistaril) are reliable potentiators of opioid analgesics. |
| T | F | 10. Opioids should not be used in patients with a history of substance abuse. |
| T | F | 11. Elderly patients cannot tolerate opioids for pain relief. |
| T | F | 12. Patients should be encouraged to endure as much pain as possible before using an opioid. |
| T | F | 13. Children less than 11 years old cannot reliably report pain so clinicians should rely solely on the parent's assessment of the child's pain intensity. |
| T | F | 14. Patients' spiritual beliefs may lead them to think pain and suffering are necessary. |
| T | F | 15. After an initial dose of opioid analgesic is given, subsequent doses should be adjusted in accordance with the individual patient's response. |
| T | F | 16. Giving patients sterile water by injection (placebo) is a useful test to determine if the pain is real. |
| T | F | 17. Vicodin (hydrocodone 5 mg + acetaminophen 500 mg) PO is approximately equal to 5-10 mg of morphine PO. |
| T | F | 18. 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. |
| T | F | 19. Anticonvulsant drugs such as gabapentin (Neurontin) produce optimal pain relief after a single dose. |
| T | F | 20. Benzodiazepines are not effective pain relievers unless the pain is due to muscle spasm. |
| T | F | 21. <u>Narcotic/opioid addiction</u> is defined as a chronic neurobiologic disease, characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving. |

Multiple Choice – Place a check by the correct answer.

22. The recommended route of administration of opioid analgesics for patients with persistent cancer-related pain is
☐ a. intravenous
☐ b. intramuscular
☐ c. subcutaneous
☐ d. oral
☐ e. rectal
23. The recommended route administration of opioid analgesics for patients with brief, severe pain of sudden onset such as trauma or postoperative pain is
☐ a. intravenous
☐ b. intramuscular
☐ c. subcutaneous
☐ d. oral
☐ e. rectal
24. Which of the following analgesic medications is considered the drug of choice for the treatment of prolonged moderate to severe pain for cancer patients?
☐ a. codeine
☐ b. morphine
☐ c. meperidine
☐ d. tramadol
25. Which of the following IV doses of morphine administered over a 4 hour period would be equivalent to 30 mg of oral morphine given q 4 hours?
☐ a. Morphine 5 mg IV
☐ b. Morphine 10 mg IV
☐ c. Morphine 30 mg IV
☐ d. Morphine 60 mg IV
26. Analgesics for post-operative pain should initially be given
☐ a. around the clock on a fixed schedule
☐ b. only when the patient asks for the medication
☐ c. only when the nurse determines that the patient has moderate or greater discomfort
27. A patient with persistent cancer pain has been receiving daily opioid analgesics for 2 months. Yesterday the patient was receiving morphine 200 mg/hour intravenously. Today he has been receiving 250 mg/hour intravenously. The likelihood of the patient developing clinically significant respiratory depression in the absence of new comorbidity is
☐ a. less than 1%
☐ b. 1-10%
☐ c. 11-20%
☐ d. 21-40%
☐ e. > 41%
28. 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.
29. Which of the following is useful for treatment of cancer pain?
☐ a. Ibuprofen (Motrin)
☐ b. Hydromorphone (Dilaudid)
☐ c. Gabapentin (Neurontin)
☐ d. All of the above

30. The most accurate judge of the intensity of the 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
31. Which of the following describes the best approach for cultural considerations in caring for patients in pain:
 _____ a. There are no longer cultural influences in the U.S. due to the diversity of the population.
 _____ b. Cultural influences can be determined by an individual's ethnicity (e.g., Asians are stoic, Italians are expressive, etc).
 _____ c. Patients should be individually assessed to determine cultural influences.
 _____ d. Cultural influences can be determined by an individual's socioeconomic status (e.g., blue collar workers report more pain than white collar workers).
32. How likely is it that patients who develop pain already have an alcohol and/or drug abuse problem?
- | | | | |
|------|---------|----------|-----------|
| < 1% | 5 - 15% | 25 - 50% | 75 - 100% |
|------|---------|----------|-----------|
33. The time to peak effect for morphine given IV is
 _____ a. 15 min.
 _____ b. 45 min.
 _____ c. 1 hour
 _____ d. 2 hours
34. The time to peak effect for morphine given orally is
 _____ a. 5 min.
 _____ b. 30 min.
 _____ c. 1 - 2 hours
 _____ d. 3 hours
35. Following abrupt discontinuation of an opioid, physical dependence is manifested by the following:
 _____ a. sweating, yawning, diarrhea and agitation with patients when the opioid is abruptly discontinued
 _____ b. Impaired control over drug use, compulsive use, and craving
 _____ c. The need for higher doses to achieve the same effect.
 _____ d. a and b

Case Studies

Two patient case studies are presented. For each patient you are asked to make decisions about pain and medication.

Directions: Please select one answer for each question.

36. **Patient A:** Andrew is 25 years old and this is his first day following abdominal surgery. As you enter his room, he smiles at you and continues talking and joking with his visitor. Your assessment reveals the following information: BP = 120/80; HR = 80; R = 18; on a scale of 0 to 10 (0 = no pain/discomfort, 10 = worst pain/discomfort) he rates his pain as 8.

A. On the patient's record you must mark his pain on the scale below. Circle the number that represents your assessment of Andrew's pain.

0	1	2	3	4	5	6	7	8	9	10
No pain/discomfort					Worst					
					Pain/discomfort					

B. Your assessment, above, is made two hours after he received morphine 2 mg IV. Half hourly pain ratings following the injection ranged from 6 to 8 and he had no clinically significant respiratory depression, sedation, or other untoward side effects. He has identified 2/10 as an acceptable level of pain relief. His physician's order for analgesia is "morphine IV 1-3 mg q1h PRN pain relief." Check the action you will take at this time.

- _____ 1. Administer no morphine at this time.
 _____ 2. Administer morphine 1 mg IV now.
 _____ 3. Administer morphine 2 mg IV now.
 _____ 4. Administer morphine 3 mg IV now.

37. Patient B: Robert is 25 years old and this is his first day following abdominal surgery. As you enter his room, he is lying quietly in bed and grimaces as he turns in bed. Your assessment reveals the following information: BP = 120/80; HR = 80; R = 18; on a scale of 0 to 10 (0 = no pain/discomfort, 10 = worst pain/discomfort) he rates his pain as 8.

A. On the patient's record you must mark his pain on the scale below. Circle the number that represents your assessment of Robert's pain:

0 1 2 3 4 5 6 7 8 9 10

.....
No pain/discomfort

.....
Worst
Pain/discomfort

- B. Your assessment, above, is made two hours after he received morphine 2 mg IV. Half hourly pain ratings following the injection ranged from 6 to 8 and he had no clinically significant respiratory depression, sedation, or other untoward side effects. He has identified 2/10 as an acceptable level of pain relief. His physician's order for analgesia is "morphine IV 1-3 mg q1h PRN pain relief." Check the action you will take at this time:

- _____ 1. Administer no morphine at this time.
_____ 2. Administer morphine 1 mg IV now.
_____ 3. Administer morphine 2 mg IV now.
_____ 4. Administer morphine 3 mg IV now.

APPENDIX J:

BANNER HEALTH INTERNAL OWNER LETTER OF SUPPORT



Date: 05/21/2019

To: Heather Fydrych RN, BSN
DNP-PNP Student
University of Arizona College of Nursing

From: Sharron Kirby RN, BSN, MHA

|

Re: Pediatric Oncology Nurses' Knowledge of Pain Management in the
Actively Dying Child

I have reviewed your project proposal for implementation potential and appropriateness of the project within Banner University Medical Center-Tucson Campus, Unit Diamond 6 West: Pediatric Hematology/Oncology/Bone Marrow Transplant. From my review I have determined that the project is feasible and congruent with Banner Health initiatives and would be of value to the organization.

Once you receive your NRDUC (Non-Research Data Use Committee) approval letter please forward me a copy. I will continue to be your point of contact at the facility/department level. Results and outcomes will be shared with me so they can be utilized for quality improvement processes as detailed in the proposed project.

Sincerely,
Sharron Kirby RN, BSN, MHA
RN Senior Manager Pediatric Hematology/Oncology/Bone Marrow
Transplant
Banner University Medical Center-Tucson Campus

APPENDIX K:
BANNER HEALTH NON-RESEARCH DATA USE COMMITTEE:
SUPPLEMENTAL QUESTIONNAIRE AND DETERMINATION APPROVAL



**BANNER HEALTH NON-RESEARCH DATA USE COMMITTEE
SUPPLEMENTAL QUESTIONNAIRE**

Principal Investigator: Heather Fydrych

Project # or Title: Pediatric Oncology Nurses' Knowledge of Pain Management
in the Actively Dying Child

Please answer the following questions below; if not applicable please notate with an N/A. If all answers are not completed this could cause a delay in review/approval of your project.

1. Who is the Banner internal owner (Banner employed) of this project (please provide letter of support)?

Sharron Kirby RN, BSN, MHA

RN Senior Manager Pediatric Hematology/Oncology/Bone Marrow Transplant Unit at Banner University Medical Center-Tucson Campus

2. Are you storing any electronic documents with patient identifiers and/or PHI?

No

- a. If yes, where will you be storing this information i.e. on a personal laptop, Banner or UA laptop/desktop, flash drive, UA Box Health (Box@UA), 3rd party storage vendor, REDCap, etc.?

- i. If on a Banner or UA laptop/computer, will it be saved on the C: drive, department drive, share drive, network drive, desktop, etc.?

N/A

- ii. Who has access to this location and the electronic document(s)

N/A

3. Will you have any paper documentation with patient identifiers and/or PHI?

- a. If yes, where will you be securing this information i.e. locked cabinet?

No

- i. Who has access to this secure location?

N/A



4. After your project is completed how do you plan on sharing this data i.e. internally, publishing, QI committee, College class presentation, etc.? (Please include any details on how you will safeguard or de-identify any PHI that is shared externally)

This project and its findings will be used to complete my Doctor of Nursing Practice-Pediatric Nurse Practitioner Degree at the University of Arizona College of Nursing. The information will be presented to my University of Arizona professional committee. Successful defense of the project and its conclusions will meet requirements to graduate as a Doctoral prepared Pediatric Nurse Practitioner. No PHI will be used.

5. Please provide any other pertinent details that relate to the use and disclosure of any data that the Committee may need to know.

Voluntary utilization of the RN staff at Banner will allow me to assess baseline knowledge and post-intervention knowledge pertinent to the topic of this presentation. No patient identifiers/patient data or Banner secure networks will be accessed for the purpose of this project.



June 23, 2019

Heather Fydrych

RE: NRDUC Project:

Protocol Number: 1904575550: Pediatric Oncology Nurses' Knowledge of Pain Management in the Actively Dying Child

New Project UA Determination of Human Research Application Version Jan 2018; forwarded to Non-Research Data Use Committee on 5/23/2019

Non-Research Data Use Committee Evaluation: Approved on 6/21/2019

Dear Heather,

Thank you for your submission of the UA Determination of Human Research Form which outlined the above noted project. On 5/23/19 UA IRB concluded that this project was not research and subsequently forwarded it to the Banner Health Non-Research Data Use Committee (NRDUC) for oversight and review.

The project information you provided was reviewed and subsequently approved on June 21, 2019 by the BH NRDUC. Should you have any questions or concerns please feel free to reach out to the NRDUC chair at any time.

PLEASE NOTE

The NRDUC determination is based on the information you provided to the committee on your application version Jan 2018 and supporting documents forwarded to the NRDUC on 5/23/2019. If the project is modified in any way, including re-analysis of data, the determination is no longer valid. You must resubmit the project to the NRDUC for review and approval.

Please note: As part of continuing process improvement, random audits could be conducted to assess compliance and adherence with submitted/approved applications.

FYI - to be a considered a "quality improvement" activity under HIPAA, information needs to be provided back to Banner for quality/performance improvement purposes. Please make sure you work with the appropriate Banner internal owner or applicable Banner committee to share results.

A copy of this letter will be placed in the NRDUC project file.

Sincerely,

A handwritten signature in black ink, appearing to read "Kristen Eversole".

Kristen Eversole, BS, RHIA, CHPC
Banner Health Privacy Sr. Director/Chief Privacy Officer, NRDUC Chair

APPENDIX L:
THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD (IRB) AND
HUMAN SUBJECTS PROTECTION PROGRAM (HSSP) APPROVAL LETTER



THE UNIVERSITY OF ARIZONA

Research, Discovery
& InnovationHuman Subjects
Protection Program1618 E. Helen St.
P.O. Box 245137
Tucson, AZ 85724-5137
Tel: (520) 626-6721
<http://hspp.arizona.edu/compliance/home>**Date:** May 23, 2019**Principal Investigator:** Heather Elizabeth Fydrych**Protocol Number:** 1904575550**Protocol Title:** Pediatric Oncology Nurses' Knowledge of Pain Management in the Actively Dying Child**Determination:** Human Subjects Review not Required**Documents Reviewed Concurrently:**HSPP Forms/Correspondence: *IRB_Revised_4222019.pdf***Regulatory Determinations/Comments:**

- Not Research as defined by 45 CFR 46.102(l): As presented, the activities described above do not meet the definition of research cited in the regulations issued by U.S. Department of Health and Human Services which state that "Research means a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge. Activities that meet this definition constitute research for purposes of this policy, whether or not they are conducted or supported under a program that is considered research for other purposes. For example, some demonstration and service programs may include research activities. For purposes of this part, the following activities are deemed not to be research."

The project listed above does not require oversight by the University of Arizona.

If the nature of the project changes, submit a new determination form to the Human Subjects Protection Program (HSPP) for reassessment. Changes include addition of research with children, specimen collection, participant observation, prospective collection of data when the study was previously retrospective in nature, and broadening the scope or nature of the study activity. Please contact the HSPP to consult on whether the proposed changes need further review.

The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).

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