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Improving Pediatric Nurses Knowledge about Palliative Care Services

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This is to certify that the doctoral study by

Marilia Rivera Camacho

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

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Walden University
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Abstract

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by

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MS, Caribbean University, 2009

BS, University of Puerto Rico, 2005

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Nursing Practice

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February 2022

Abstract

Palliative care knowledge is important for nursing staff caring for children with life-threatening and debilitating illness because it can provide comfort-based interventions to optimize their quality of life. Nurses in pediatric settings can support the patient and family by providing education and evaluate patients who can benefit from palliative care services. If nurses do not have the palliative care education to support this comfort care process, the quality of life for children with life-threatening and debilitating illness may be affected. The purpose of this DNP project was to educate pediatric nurses about pediatric palliative care standards. The educational program resulted in a documented increase in the knowledge of pediatric nurses which addresses an identified knowledge gap about the pediatric palliative care standards of practice. The overall increase in knowledge of the 10 nurses who participated in the program was 20% when the pretest scores were compared with those of the posttest. Additional educational sessions are recommended with a goal of educating 100% of the pediatric nurses at the hospital. The result of this educational program has the potential for positive social change for nurses and children with life-threatening and debilitating illness and their families. Educating nurses about the need for children with life-threatening and debilitating illness and their families to receive palliative care may empower them with knowledge they need to initiate a communication with the palliative care team.

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Dedication

To my dear son Diego José Alamo Rivera- Your life has left a purpose and legacy to continue supporting other children and families living with life-threatening and debilitating illness. Each shared moment has remained sealed in my Heart. It comforts me to know that you rest in peace and that we will continue to be connected by that love that united us since you were in my womb - Because love heals!

To my dear son Daniel José Alamo Rivera, thank you for your patience and supporting mama during this journey. You motivated me every day! How proud I am of you and how you honor and remember your brother every day.

Acknowledgments

I cannot express enough gratitude to my committee for their support and encouragement during this journey. Dr. Robert McWhirt, my committee chair; Dr. Susan Fowler; and Dr. Dr. Aboul-Enein, thank you so much for your time and collaboration.

My completion of this project could not have been achieved without the support of a hospital for woman and children in the state of Indiana, thank you Dr. Laurie Berghoff, Mary Hunt, and Alyssa Doak.

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To Susan Chaplin and Laura Moa, how grateful I am that you have shared your story and your precious child life with me. I admire your strength, dedication and how you help other families through your child's legacy. Thank you Delia Tahimí Artreches Camacho for your collaboration and empathy working on the family impact section.

To my husband Jose Luis, and my parents Ramon and Marilia, for your patience and support during this journey. Thank you for always believing in me and encouraged me to keep trying.

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Section 1: Nature of the Project

The number of children under 18 years old who are living with life-threatening and debilitating illness in the United Stated has increased over the years. According to the American Academy of Hospice and Palliative Medicine (2017), these life-threatening illnesses in children have increased and caused 18, 888 deaths among children ages 1 to 19 (Weaver et al., 2017). These are conditions which cannot be cured and will cause premature death, or where curative treatment is possible but may fail. Children with a life-threatening and debilitating illness suffer distressing symptoms, including pain and long periods of discomfort. Data reveal most distressing symptoms in children with life-threatening and debilitating illness (such as pain, dyspnea, and nausea/vomiting) were not addressed during their end-of-life period, and when treated, therapy was commonly ineffective (Friedrichsdorf & Bruera, 2018). Palliative care can significantly benefit children and families by providing comfort, symptom relief, and noncurative interventions through a life-threatening and debilitating illness.

Nurses are the primary caregivers of patients, and they play an essential role in advocating for palliative care services for individuals and families, whether through direct care delivery or referral processes. According to the American Nurses Association (ANA) Code of Ethics (2015), supportive care is particularly important for patients with chronic conditions and in the end-of-life process to prevent and alleviate suffering, including support to the family to meet the needs in a comprehensive way throughout the continuum of care. Nurses caring for children with life-threatening and debilitating illness should be educated to understand the diverse needs and develop competency in providing timely palliative care, which can help nurses identify which patients may benefit from a referral to these services (Steigleder et al., 2019; as cited in Kim et al., 2020). The purpose of this DNP project was to educate pediatric nurses about pediatric palliative care (PPC) standards. Education is fundamental for improving health care professionals' palliative care knowledge and confidence (Reed et al., 2018).

Problem Statement

A hospital in Northeast Indiana defined a practice gap in nurses' knowledge of pediatric palliative care (PPC) standards. Nurses at the site are the main caretakers of pediatric patients and usually are the first line of contact for patients and their families. Nurses play an essential role in advocating for palliative care services for individuals and families, whether by delivery of direct care or team referral processes (ANA, 2017). A general lack of knowledge has been reported by nurses in several domains of palliative care, including palliative care philosophy and principles, pain and symptom management, and transitions from curative to comfort care (Achora & Labrague, 2019). Nurses at the local hospital site are in a crucial position to provide primary palliative care by advocating for patients and families prior to the end of life, collaborating with the health care team to optimize quality of life, and contributing to enhanced symptom management (DeSanto-Madeya et al., 2020). This project aimed to address the local nursing gap in pediatric palliative care (PPC) standards of practice and provide nurses with the education needed to identify pediatric patients needing palliative care.

Approximately 500,000 children and adolescents are living with life-threatening and debilitating illness and may be amenable to interventions to promote comfort and optimize quality of life (Ananth et al., 2017). The evolution in health care implies that all health professionals, regardless of their clinical specialty, understand the concept of palliative care that changes radically. PPC is a philosophy and an organized method for delivering individualized care to life-threatening and debilitating illness (National Hospice and Palliative Care Organization, 2019). Palliative care focuses on symptom management, support, and coordination of care. Providing comfort care is one of the most important areas within palliative services. Comfort is defined as a state of ease and well-being influenced by the caring actions of nursing, which in turn leads to transcending the circumstances of symptom distress, decreased functional status, and improved quality of life (Lafond et al., 2019). Palliative care assesses the needs of the patient and family to coordinate interventions to manage comfort and offer support during crisis of chronic illness, improving quality of life.

PPC takes a holistic approach to caring for the child's mind and body, while also recognizing the needs and support of the family. Palliative care can significantly benefit children with life-threatening and debilitating illness. According to the Center to Advance Palliative Care (2019) referrals are still generally reserved for end of life or cancer patients, on average nearly one-quarter of all PPC patients had a primary diagnosis of cancer (24.5 %) and a diagnosis of complex-chronic illness (9.6%). Barriers to early PPC initiation include clinician misperceptions, emotional toll on clinicians, and prognostic uncertainty about treatment options and care management strategies (Neuburg, 2020). The delay in referrals may affect the comfort, symptom relief, interpersonal human presence, noncurative interventions and patient-family support provided by PPC.

Furthermore, PPC referrals are crucial for children living with life-threatening and debilitating illness and families experiencing significant challenges in caring for their ill child and can relieve distressing symptoms while optimizing quality of life through the trajectory of the illness. Attitudes toward PPC and lack of education are the most common barriers to timely palliative care referrals (Marell et al., 2019).

The purpose of PPC is to provide competent, compassionate, and consistent care to the patient and family. It is important to reinforce that PPC is not only for the end-of-life process, but also needed to provide continuous support to the patient and family. The process begins by getting to know the family, identifying needs, caring for ongoing symptoms with comfort, and providing support until the end of life and bereavement. The published rates of PPC consultations for children vary widely (4-88%; Stutz et al., 2018). Despite the Institute of Medicine, World Health Organization, National Consensus Project (NCP), and American Academy of Pediatrics (AAP) recommendations, most providers are unaware of the need to refer a child to palliative care at diagnosis of life-threatening and debilitating illness and equate palliative care as hospice and/or end-of-life care consequently making late referrals (Marvicsin et al., 2012).

Purpose Statement

At diagnosis of a life-threatening and debilitating illness, it is important to offer an integrated model of palliative care that continues throughout the course of illness, regardless of the outcome (Lotstein & Lindley, 2019). The lack of education, attitudes, and beliefs of nurses from NICU and PICU at a hospital in Northeast Indiana can be barriers to identify children and families who can benefit from palliative care. Health care professionals' dominant perception of palliative care is that it is hospice and therefore only concerns dying patients (Yu et al., 2020). The purpose of this DNP project was to educate pediatric nurses about PPC standards. Therefore, the practice-focused question was: Will an education program for pediatric nursing staff in a local hospital increase their knowledge of palliative care standards?

Nature of the Doctoral Project

An extensive search through the Walden library using the following sources supported the development of the educational content. Sources included the Center to Advance Palliative Care, National Palliative Care Research Center, National Hospice and Palliative Care Organization Standards of Practice of Pediatric Palliative Care, National Coalition for Hospice and Palliative Care Clinical Practice Guidelines for Quality Palliative Care, Hospice and Palliative Nurses Association, American Nurses Association, and the World Health Organization. Additionally, a search of literature was performed using the following electronic databases: (a) CINAHL, (b) MEDLINE, (c) Google Scholar, and (d) PubMed. The following key terms were used to explore the body of literature: *pediatric palliative care, pediatric end of life, chronic illness and palliative care, pediatric palliative care education, pediatric palliative care at intensive care unit,* and *barriers in pediatric palliative care*.

Local Setting

I initiated communication with the director of a women’s and children’s inpatient services in the state of Indiana that cares for chronically ill children to discuss the nursing gap and develop a plan. The director shared with me that there was a lack of knowledge about PPC standards of practice. We agreed to develop an educational program to be presented to NICU, PICU, and pediatric floor nurses. Approximately 50 registered nurses were expected to participate in the educational program. After I obtained Walden IRB approval (11-09-21-1027081), the nursing director, and the stakeholders from the NICU and PICU at the hospital reviewed the content and gave me permission to present the program to the pediatric nurses. At that time, I was allowed to share the education program flyer at their hospital for the nurses who care for pediatric patients at NICU, PICU, and pediatric floor. The educational content had an identical pre and posttest; this allowed me to determine if there was a difference in the nurse knowledge after participating in the education program. This educational program was reviewed by three content experts: the director of training and educational content of an organization that educates, empowers, and accompanies families and providers who care for children with serious illnesses, a neonatologist and palliative care physician, and a palliative care nurse practitioner from the local hospital. The content experts provided formative evaluation of the PowerPoint presentation and the pre and posttest. I made revisions based on their evaluation and recommendations. The nurses received the information to complete the pretest via SurveyMonkey and a link for the virtual education on the scheduled date and time. I presented the educational content via Teams Meeting to the nurses at the hospital in a 60-minute presentation. The nurses completed a course evaluation and a posttest at the end of the presentation. The pre and posttest were aligned with the learning objectives and content of the educational program. I used descriptive statistics to determine if there was a difference in the mean between the pre and posttest. This information identified if there was a change in the nurses' knowledge after completing the education. Providing this information increased knowledge to address the lack of education of nurses working with children diagnosed with life-threatening and debilitating illness who may benefit from palliative care services to provide comfort, symptom relief, and patient-family support.

Significance

Reducing palliative care to only hospice will continue to delay and prevent referrals, resulting in decreased quality of life and heightened suffering (Neuburg, 2020). Limited access to pediatric-specific palliative care and hospice services deprives children of knowledgeable health care personnel for home-based pain and symptom management. Attitudes toward PCC and lack of education are the most common barriers to timely palliative care referrals (Marell et al., 2019). Through the educational program, I addressed the lack of education, which can also influence the attitude of nurses towards palliative care. According to Kim et al. (2020), an important factor affecting the confidence of nurses in palliative care is a previous education course in hospice, palliative, or end-of-life care. Lack of adequate training and education in palliative care nursing can create negative attitudes that can affect the outcomes of care (Kim et al., 2020). Improving the knowledge of the nurse will impact social change in children diagnosed with life-threatening and debilitating illness because palliative care services can improve their quality of life. Pediatric nurses can increase awareness, educate, and support other clinicians to promote early initiation of PPC in children with life-threatening and debilitating illness (Neuburg, 2020). This project focused on the development and implementation of an education program to increase the knowledge of pediatric nurses who cares for children diagnosed with life-threatening and debilitating illness about palliative care standards of practice so that they can recognize patients who may benefit from palliative care services.

The result of this educational program has the potential for positive social change for nurses and children and families with life-threatening and debilitating illness. Educating nurses about the need of palliative care for children and families with life-threatening and debilitating illness empowered them with the information they need to initiate conversations with the palliative care team. Early referral of children and their family to the palliative care team have the potential to provide them with the guidance and support to facilitate their decision-making process about the care of the child with a life-threatening and debilitating illness, relieve suffering, and improve their quality of life.

Summary

Section 1 discussed the problem statement, purpose, natural of the doctoral project, and significance. A hospital in Northeast Indiana defined a practice gap in nurses' knowledge of PPC standards. To address this gap an educational program was developed and presented to pediatric nurses at the local hospital. The source of evidence to develop and support the education content was the Standards of Pediatric Palliative Care of the National Hospice and Palliative Care Organization. To improve quality of life of children with life-threatening and debilitating illness and to support their families, ongoing and integrated palliative care education programs are essential for nurses to enhance their knowledge, attitude, and confidence. Section 2 provides an overview of the concepts, models and theories that support this educational program. The relevance to nursing practice will provide an overview of the current literature and standards to support the content for the education program.

Section 2: Background and Context

The lack of knowledge about the PPC standards of practice of the nursing staff at a hospital for women and children in the state of Indiana affected pediatric patients who were eligible to receive palliative care services to improve their quality of life. The complex nature of PPC necessitates comprehensive ongoing educational opportunities for nurses working with children with life-threatening and debilitating illness and their families (Akard et al., 2018). The purpose of this DNP project was to educate pediatric nurses about PPC standards. Therefore, the practice-focused question was: Will an education program for pediatric nursing staff in a local hospital increase their knowledge of palliative care standards? Pediatric nurses' lack of education can delay a timely refer for children with life-threatening illness to receive palliative care. Children with life-threatening and debilitating illness can benefit from palliative care services to coordinate interventions to improve their quality of life and receive support through their illness. To provide symptom management, improved quality of life, and advanced care planning, the philosophy of palliative care supports patients and families amid extensive suffering (Ferrell & Coyle, 2008; as cited in Neuburg, 2020). Section 2 provides an overview of the concepts, models, theories, relevance to nursing practice, local background and context, role of the DNP student, and role of the project team to support this educational program that focused on improving nurse's knowledge of palliative care services for children with life-threatening and debilitating illness.

Concepts, Models, and Theories

The use of theory provides the basis for a body of knowledge that is structured and organized to support nursing practice, and which evolves with evidence-based knowledge. Nursing theory improves our care by giving it structure and unity, providing more efficient continuity of care, achieving congruence between process and product, defining the boundaries and goals of nursing actions, and giving us a framework through which to examine the effectiveness of our interventions (Zaccagnini & White, 2017). The social cognitive theory was used to guide this DNP project. In addition, the educational program was guided by the ADDIE model.

Social Cognitive Theory

Albert Bandura’s social learning theory, later called social cognitive theory, provides a theoretical framework for understanding and explaining human behavior; the theory embraces an interactional model of causation and accords central roles to cognitive, vicarious, and self-regulatory processes (Wulfert, 2019). Psychosocial theory can be used as a framework, and although it is not specific to nursing, it can be used to address the lack of nursing education related to palliative care. The social cognitive theory (SCT) proposes that behavior change is affected by personal factors, attributes of one's own behavior and environmental influences (White et al., 2016). This theory allowed to understand the behavior of the nurses and how their personal factors related to the association of palliative care with patients at the end of life or dying may be affected. The SCT by Bandura (1986) provided a framework to conceptualize, promote and evaluate the development of competencies, and served as a guide in the educational project to improve nurse’s knowledge about PPC for children with life-threatening and debilitating illness. Nurses with high self-perceived competence demonstrate higher performance when providing quality care to patients with life-threatening illnesses and their families than nurses with low self-perceived competence (Jean-François et al., 2012). By increasing the knowledge and skills of pediatric nurses, they felt more empowered and trained to collaborate in the patient referral process. Consequently, according to SCT, quality palliative care requires both nursing competence and self-competence to use it effectively. SCT is particularly useful when it comes to educational programs aimed at changing behavior, such as putting new knowledge into practice (White et al., 2016).

The SCT posits that individuals learn by direct experiences, human dialogue and interaction, and observation (White et al., 2016). The process begins with meeting the family, identifying needs, taking care of ongoing symptoms with comfort, and providing support through the end of life and grief. Nurses play a critical role in advocating for palliative care services for individuals and families, either through direct care delivery or through the referral processes (ANA, 2017). To address nurses lack of knowledge about PPC for children with life-threatening and debilitating illness, an educational program was developed for nurses. The SCT was applied to the educational program as a framework for behavior change after nurses increased their knowledge of PPC standards of practice. When the focus of a gap is the individual, the resulting educational need may be knowledge and/or interest to the individual learner, it may be related to a new required skill, or it may be a desired behavior change (Jeffery et al., 2016).

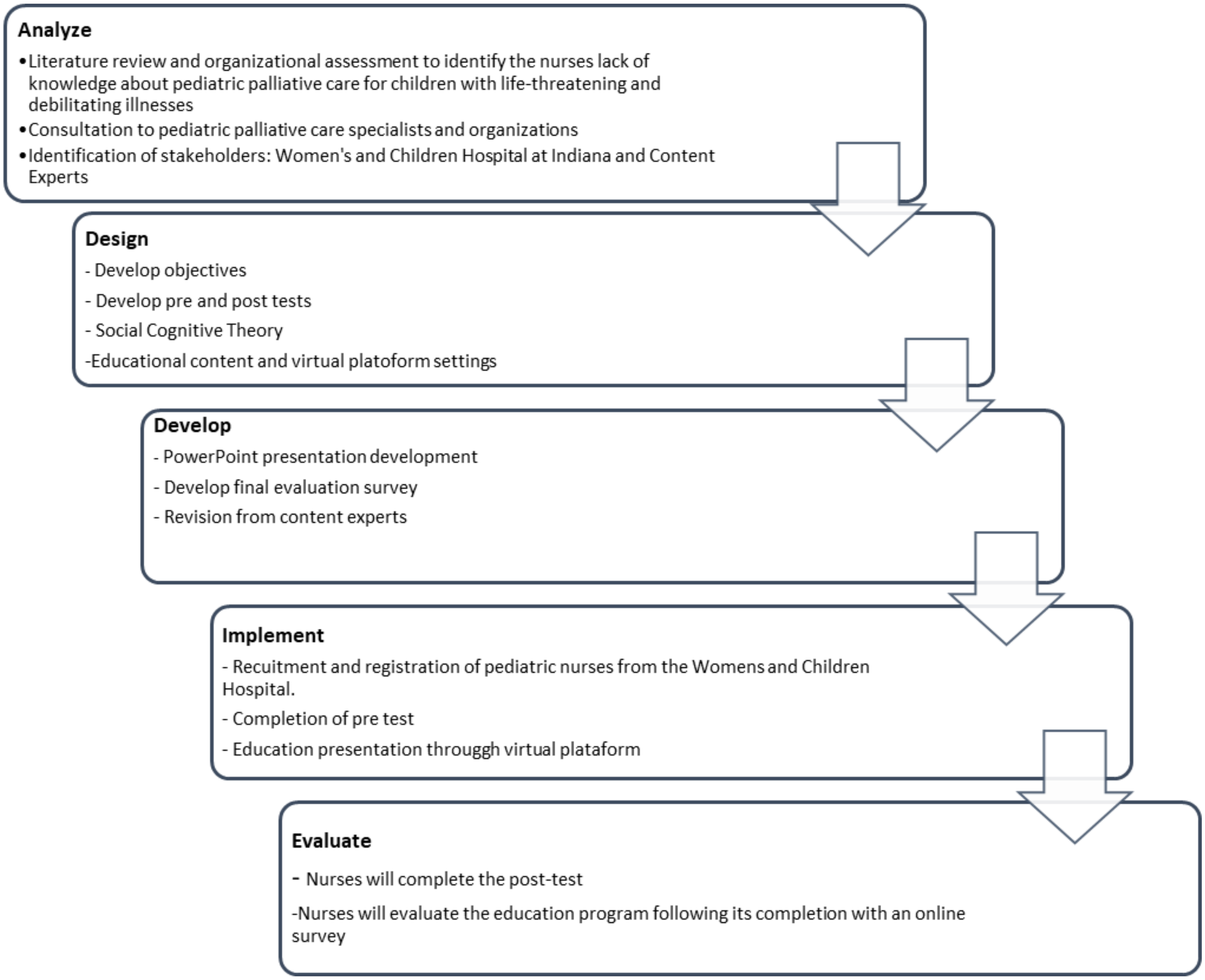
The ADDIE Model

A five steps framework that includes, analysis, design, development, implementation, and evaluation (ADDIE) model was used to plan, develop, implement, and evaluate this educational program because nurses' benefit from education developed based on this instructional design method (Jeffery et al., 2016). This educational program was aimed to increase awareness of palliative care in pediatric nurses so that they can recognize children diagnosed with life-threatening and debilitating illness who can benefit from palliative care services, improving quality of life, and promoting a holistic care. Studies of PPC nursing intervention are beginning to emerge as the state of the science gains momentum and researchers seek to learn new ways to help children and their families cope with life-threatening and debilitating illness (Akard et al., 2018). Nursing leaders can provide education and support the development of future educational programs to help grow PPC services for children with life-threatening and debilitating illness. Nurses are ideally positioned to bridge potential gaps between providers across disciplines, children and their families, researchers and clinicians, students and mentors, communities, and politicians so that we all work together to improve quality of life for children living with life-threatening and debilitating illnesses (Akard et al., 2018). Nursing education is a fundamental element to improve communication between providers and meet the needs of children with life-threatening and debilitating illness.

Educators using the ADDIE model have a standardized approach that ensures a holistic approach to meet the needs of the learner (Jeffery et al., 2016). Through the conversation with the local hospital and the analysis of the current literature, a nursing gap related to lack of knowledge about PPC standards of practice for children with life-threatening and debilitating illnesses was identified. An educational need represents a gap or deficiency between the learner’s current level of competency and a higher level required for effective performance (Jeffery et al., 2016). In the design step, the learning activity was developed to address the lack of knowledge that was identified in the analysis phase (Jeffery et al., 2016). I used the latest evidence from the National Hospice and Palliative Care Organization, learning theories and technological methods to design and develop the educational content. The implementation process included the presentation of the educational program to pediatric nurses. During the evaluation phase, the nurses completed a pre and post-test and final survey to evaluate the content. The evaluation of a learning activity helps to determine whether the activity successfully achieved its purpose and will provide data to establish new interventions (Jeffery et al., 2016). In conclusion, the ADDIE model through its five-step framework (See figure 1) allowed me to build effective learning solutions and organize content to provide quality education and empower nurses to collaborate in improving nursing practice and the care offered.

Figure 1

Application of ADDIE Model



Analyze

- Literature review and organizational assessment to identify the nurses lack of knowledge about pediatric palliative care for children with life-threatening and debilitating illnesses
- Consultation to pediatric palliative care specialists and organizations
- Identification of stakeholders: Women's and Children Hospital at Indiana and Content Experts

Design

- Develop objectives
- Develop pre and post tests
- Social Cognitive Theory
-Educational content and virtual platoform settings

Develop

- PowerPoint presentation development
- Develop final evaluation survey
- Revision from content experts

Implement

- Recuitment and registration of pediatric nurses from the Womens and Children Hospital.
- Completion of pre test
- Education presentation througgh virtual plataform

Evaluate

- Nurses will complete the post-test
-Nurses will evaluate the education program following its completion with an online survey

Note. Adapted from "Staff educator's guide to professional development: Assessing and enhancing nurse competency" by Sigma Theta Tau International Honor Society of Nursing, 2016.

Definition of Terms

The following terms used in this project are defined here.

Holistic Care: Addresses patients' physical, emotional, social, and spiritual needs, restores their balances and enables them to deal with their illnesses, consequently improving their lives (Jasemi et al., 2017).

Life-threatening illness: condition for which curative treatment may be feasible, but for which this treatment could also fail, leading to a possibility of dying. Life threatening illnesses are chronic, usually incurable diseases, which have the effect of considerably limiting a person's life expectancy (International Children's Palliative Care Network, 2010 as cited in Brouwer et al., 2020).

Palliative Care: Is a specialized medical care that is focused on providing relief from the symptoms for people living with a serious illness. The goal is to improve quality of life for both the patient and the family (Center to Advance Palliative Care, n.d.).

Standards of Professional Nursing Practice: authoritative statements of the actions and behaviors that all registered nurses, regardless of role, population, specialty, and setting, are expected to competently perform (ANA, 2021).

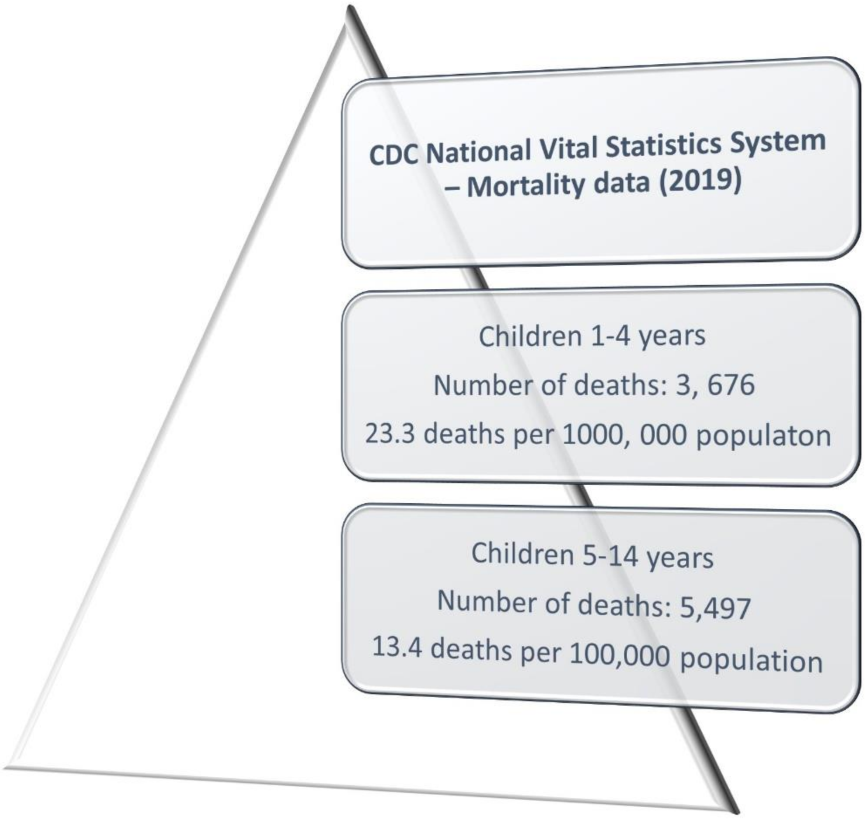
Relevance to Nursing Practice

The survival rate for children with a chronic condition or life-threatening illness has dramatically increased over the past two decades and has demanded a multidisciplinary approach to provide the best optimal care (Himelstein et al., 2004; Himelstein, 2006; Meier & Beresford, 2007; as cited in Marviscin et al., 2012). An estimate of two million children in the United States live with life-threatening and debilitating illness that could benefit from palliative care (Goldhagen et al., 2016; as cited in Lafond et al., 2019). Nurses caring for children with life-threatening and debilitating illness and their families can identify emotional and comfort needs that can benefit from palliative care. The AAP recognized the importance of PPC and the urgent need for timely referral (Newton & Sebbens, 2020). When nurses do not have knowledge about palliative care and how these services can offer a compassionate care, the time of referral is delayed. This lack of knowledge affects collaboration with the healthcare team to optimize quality of life and help improve symptom management for children with life-threatening and debilitating illness. Multiple national initiatives called for system-wide changes to impact early palliative care referral, and the benefits of involving this service early in the disease trajectory are undeniable for patients and their families (Newton & Sebbens, 2020). Early identification of the patients that meet the palliative care criteria for a timely referral to palliative care services can improve overall patient and family quality of life despite the serious health conditions of these patients. To enhance quality of life of children with a life-threatening and debilitating illness and support their needs, an educational program related to the criteria of palliative care is needed to improve the lack of knowledge of nurses. To provide effective and high-quality palliative care, it is necessary to integrate nurses' knowledge, skills, and favorable attitudes toward palliative care (Achora & Labrague, 2019; Sekse et al., 2018; as cited in Kim et al., 2020). In 2017, the American Nurses Association made a call of action to increase the inclusion of palliative care. The purpose of this call for action is to urge nurses in various roles and settings to lead and transform palliative care in practice, education, administration, policy, and research (American Nurses Association, 2017). The goal for this call of action is to enhance and leverage the efforts of all nurses, nursing organizations, and interprofessional teams to promote access and ensure delivery of safe, quality, and person-centered palliative care to all in need (American Nurses Association, 2017). This call of action supports the development of palliative care educational content for nursing programs, continuing education, and national boards.

This DNP project addressed the nursing gap of the local hospital about PPC standards of practice by the development of an educational program to improve the knowledge of pediatric nurses working with children diagnosed with life-threatening and debilitating illnesses.

Figure 2

Statistics Overview



- According to the CDC (2019) (see Figure 2), the trending causes of death includes: Congenital and chromosomal malformations, low birth (Premature), cancer, and accidents (unintentional death).
- According to Ananth et al. (2017) approximately 500,000 more children, and adolescents, are living with life-threatening and debilitating illness that may be amenable to interventions to promote comfort and optimize quality of life (Lafond et al., 2019).

- According to the Center to Advance Palliative Care (2019), palliative care referrals were 24.5 % in cancer and 9.6 % in chronic or complex illness.

Overview of Pediatric Palliative Care

This section introduced the discussion of the concept of PPC and how the quality of life of children with life-threatening and debilitating illness can improve receiving these services.

- Palliative care focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care. Palliative care attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness. Through early integration into the care plan for the seriously ill, palliative care improves quality of life for the patient and the family (National Consensus Project for Quality Palliative Care, 2018).
- Palliative Care is a specialized medical care that is focused on providing relief from the symptoms for people living with a serious illness. The goal is to improve quality of life for both the patient and the family (Center to Advance Palliative Care, n.d.).

The World Health Organization defines palliative care as the prevention and relief of suffering of adult and pediatric patients and their families facing the problems associated with life-threatening illness. These problems include the physical, psychological, social, and spiritual suffering of patients, and psychological, social, and spiritual suffering of family members (World Health Organization, 2020).

Standards of Practice

The Standards of Professional Nursing Practice are “authoritative statements of the actions and behaviors that all registered nurses, regardless of role, population, specialty, and setting, are expected to competently perform” (ANA,2021, p. 4). Nurses have a responsibility to their practice and patients to provide a quality of care that aligns with the scope and standards of practice in their profession. According to the American Nurses Association (ANA) (2021), the nursing scope and standards of practice describe the “who,” “what,” “where,” “when,” “why,” and “how” of nursing practice. In a profession as dynamic as nursing, and with evolving health care demands, changes in scope of practice and overlapping responsibilities are inevitable in our current and future health care system (ANA, 2021). These standards of practice are essential to support the complex and evolving care that nurses provide through palliative care.

This section of the educational program discussed the National Hospice and Palliative Care Organization standards of practice for PPC, including the criteria to identifying children that can benefit from palliative care.

Diagnosis Categories (National Hospice and Palliative Care Organization, 2019)

Shortened life expectancy or suffering from diagnosis in more than one organ system requires specialized care from at least one or more subspecialty providers and have more likelihood of hospital admissions.

Group 1: Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be beneficial alongside attempts at life-prolonging treatment and/or if treatment fails: Advance or progressive cancer or cancer with a poor diagnosis, complex and severe congenital or acquired heart disease, trauma, or sudden severe illness.

Group 2: Conditions where early death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life, allowing participation in normal activities, and maintaining quality of life: Cystic fibrosis, severe immunodeficiency, huma immunodeficiency virus infection, chronic or severe respiratory failure, renal failure, muscular dystrophy, myopathies, neuropathies, severe short gut, TPN dependent.

Group 3: Progressive conditions without curative treatment options, where treatment is exclusively palliative after diagnosis and may extend over many years: Progressive metabolic disorders, chromosomal disorders, severe osteogenesis imperfecta subtypes, batten disease.

Group 4: Irreversible but non-progressive conditions with complex healthcare needs leading to complications and likelihood of premature death: Severe cerebral palsy, prematurity with multi-organ dysfunction, severe chronic pulmonary disability, disabilities following brain or spinal cord infections, anoxic or hypoxic insult or injury, severe brain malformations.

Patient and Family Centered Care

This section of the educational program discussed the strategy of a family centered care approach that can address this gap-in-practice, and how interdisciplinary management can improve patient outcomes. Also, this section presented patient and family education and advocacy. The palliative care and/or hospice interdisciplinary team provides family-centered care that includes the child and family as one unit of care, respecting individual preferences, values, and cultural beliefs, with the child and family active in decision making regarding goals and plan of care (National Hospice and Palliative Care Organization, 2019). Nurses must assess the needs of the family to develop appropriate interventions and maintain effective communication. Palliative care family-centered care allows to provide a holistic care from diagnosis to the end of life. Families facing serious illnesses need not only medical interventions, but also educational and emotional support to feel confident and receive a holistic care (Weaver, 2017).

Clinical Excellence and Safety

Health professionals providing PPC and/or hospice have the responsibility to pursue comfort aggressively and minimize the child’s physical, psychosocial, and spiritual pain, and suffering in keeping with safe practice, acceptable standards, and patient/family agreement (National Hospice and Palliative Care Organization, 2019). Palliative care provides competent, compassionate, consistent, and holistic care to the patient and family, which may improve their quality of life. This section discussed the collaboration of pediatric specialists to address unique needs of the patient and their family, and how nursing can collaborate to coordinate patient services and referrals. To maintain quality of care and safety, all pediatric providers must complete palliative care educations and competencies annually, as recommended by the National Hospice and Palliative Care Organization.

Nursing Practice

This section of the educational program discussed nursing practice issues related to PPC, educational support, and nursing self-care.

- Nursing education and development of palliative care practice: This section discussed the American Nurses Association call to action in 2017 to increase the inclusion of palliative care. The purpose of this call for action is to urge nurses in various roles and settings to lead and transform palliative care in practice, education, administration, policy, and research (American Nurses Association, 2017). They encourage state boards of nursing with continuing education re-licensure requirements to mandate inclusion of palliative care content. This call of action supports the development of palliative care educational content for nursing programs, continuing education, and national boards.
- Self-care: This section discussed the importance of nursing self-care and strategies to promote the well-being of pediatric nurses who care for chronically ill children. The discussion included resources and how the organization can support nurses and the palliative care team, to develop staff debriefing guidelines.

Local Background and Context

Nursing lack of education about PPC services can impact and prevent the implementation of palliative care for children with life-threatening and debilitating illnesses. A children and women hospital in the state of Indiana identified the need for education about PPC and the importance of nurses to know the standards of practice. This hospital currently has a capacity of 640 beds, with a Neonatal Intensive Care Unit (41 beds) and Pediatric Intensive Care Unit (7 beds), Pediatric floor (20 beds) and Ob-Gyn (40 beds), with a total of 350 nurses. In the educational program, 50 nurses from the NICU, PICU, and pediatric floor were expected to participate. This hospital currently has a palliative care for adult patients that is supporting pediatric areas, when necessary, but the director of the hospital stated that it is not with a pediatric approach. They have currently established a committee in the NICU and are evaluating how to develop a palliative program for children diagnosed with a debilitating and life-threatening illness. They envision a PPC team in the hospital as a resource for standardizing nursing and hospice education and how this can help children and their families provide support and resources. Education is fundamental to understand the diverse needs and develop competent intervention to provide quality of care (Reed et al., 2018). The purpose of this DNP project was to educate pediatric nurses to increase knowledge about palliative care standards of practice so that they can recognize children diagnosed with life-threatening and debilitating illness who can benefit from palliative care services. Through the literature review and the local evidence, this DNP student identified an educational need about palliative care services, which is crucial to offer a quality of care for these patients and their families.

According to Lafond et al. (2019), approximately 500,000 more children, and adolescents, are living with life-threatening and debilitating illness and could benefit from palliative care to improve comfort and optimize their quality of life. Despite the

Institute of Medicine, World Health Organization, National Consensus Project (NCP), and American Academy of Pediatrics (AAP) recommendations, late referrals continue because most providers are unaware of the need to refer a child to palliative care at diagnosis of life-threatening and debilitating illness (Marvicsin et al., 2012). Pediatric nurses can help identify these children and advocate for palliative care services, through direct care delivery or team referral processes (American Nurses Association, 2017). Nurses are in a crucial position to advocate for children and families prior to the end of life, collaborating with the health care team to optimize quality of life, and contributing to enhance their comfort (DeSanto-Madeya et al., 2020). However, nurses have reported a general lack of knowledge in several domains of palliative care, including the philosophy and principles of palliative care, pain and symptom management, and transitions from curative to comforting (Achora & Labrague, 2019). Nurses' lack of education, attitudes, and beliefs have been documented as barriers to timely referral of pediatric patients to palliative care (Marell et al., 2019 & Neuburg, 2020), affecting the coordination of interventions to manage comfort, symptom relief, and support for children with a life-threatening and debilitating illness and their families.

Role of the DNP Student

My professional career as a neonatal and pediatric nurse and as a nursing educator has given me the knowledge and motivation to improve the quality of life for children. As my experience has focused on the care of children in intensive care units and the education of future nurses through courses in maternity and pediatrics, collaboration to improve the knowledge of nurses has always been of interest. The relationship I had with this DNP project was a commitment to improve nurses' knowledge of PPC to help improve the quality of life of children with debilitating and life-threatening illnesses.

As a nursing leader, I am committed to nursing practice and education to develop new research and education to increase the knowledge of pediatric nurses who work with children diagnosed with life-threatening and debilitating illnesses. I recognize the importance of providing support to children and families living with a debilitating and life-threatening illness, and I strongly support that nursing staff is essential to proactively identifying patients who would benefit from this care with an early referral. My role within this DNP project was as developer and presenter of the educational program. In addition, I coordinated the participation of pediatric nurses in the educational program. My participation in this project was active and oriented to achieve a successful result.

My main motivation for this educational project was to improve nursing knowledge about palliative care and to continue expanding these services in the pediatric population. I believe this could result in social change by improving care for children with life-threatening and debilitating illnesses, supporting families, and promoting holistic care through palliative services. The aim of this educational program was to increase the knowledge of pediatric nurses about palliative care and the importance of early referral. My goal was to educate nurses on the current evidence-base practice PPC standards of care for children with life threatening illness.

Role of the Project Team

During the development of this project, three content experts provided a formative evaluation of the PowerPoint presentation and the pre and posttest. The content experts were the director of training and educational content of a national organization that educates, empowers, and accompanies families and providers who care for children with serious illnesses. Two stakeholders at the hospital also provided a formative evaluation, a neonatologist and palliative care physician, and a palliative care nurse practitioner. The selected stakeholders collaborated in the review of the educational content because of their expertise in PPC. This project was implemented in a women and children hospital at Northeast Indiana.

Summary

This educational project was be guided by the Social Cognitive Theory and the ADDIE model. The Social Cognitive Theory allowed to understand the behavior of the nurses and how can affect patient's early referral because of the association of palliative care with end of life or dying patients. I used the ADDIE model as a guide on developing each section of the educational program. This DNP project was relevant to nursing practice because when nurses do not have knowledge about palliative care and how these services can offer a compassionate care, the quality of life of children with life-threatening and debilitating illnesses is impacted. This educational program was developed with a goal, to improve the knowledge and competence of nurses working with children with a life-threatening and debilitating illness, providing the standards of care to identify pediatric patients who can benefit from palliative care services.

Section 3: Collection and Analysis of Evidence

The lack of education of the nursing staff of a hospital at Northeast Indiana regarding palliative care standards of practice for children with life-threatening and debilitating illnesses was an obstacle to identify patients who can receive palliative services to improve their quality of life. Parveen et al. (2020) study showed that most of the nurses had limited knowledge of when palliative care should be provided. The purpose of this DNP project was to educate pediatric nurses about PPC standards. To improve the quality of children with life threatening and debilitating illnesses, it is necessary for nurses to have good knowledge and attitude towards palliative care (Parveen et al., 2020). Section 3 provides an overview of the practice focus question, source of evidence, analysis and synthesis of the educational program that focus on improving pediatric nurse’s knowledge of palliative care standards of practice.

Practice-Focused Question

The lack of knowledge of the nursing staff of a hospital for women and children in the state of Indiana about the palliative care standards of practice affected pediatric patients who could benefit from the provision of palliative care services to improve their quality of life. Nurses caring for children with life-threatening and debilitating illness should be educated to develop competencies about PPC. Education focused on palliative care standards of practice can improve patient and family comfort, symptoms management, and quality of life with an early referral. This DNP project was aimed to develop and implement an education program to increase the knowledge of pediatric nurses working with children diagnosed with life-threatening and debilitating illness about the pediatric palliative standards of care. Therefore, the practice-focused question was: Will an education program for pediatric nursing staff in a local hospital increase their knowledge of palliative care standards? The purpose of this project aligned with the practice-focused question because the main goal was to educate nurses about PPC standards of practice to improve their knowledge on palliative care. Enhanced palliative care knowledge may assist in identifying patients that could benefit from these services.

Sources of Evidence

The primary source of evidence for this DNP project was the National Hospice and Palliative Care Organization Standards of Practice of PPC. Education is fundamental for improving health care professionals’ palliative care confidence (Reed et al., 2018). Nurses caring for noncancer patients should be trained to understand the diverse needs and develop competency in providing timely palliative care (Steigleder et al., 2019; as cited in Kim et al., 2020). The National Hospice and Palliative Care Organization Standards of Practice of PPC provide nurses the referral criteria and resources to identify what patients can benefit from palliative care services. Additional sources of evidence were provided through a systematic review of the content literature on PPC. All literature was within the past 9 years, peer reviewed, and written in English. A search of literature was performed through the Walden Library using the following electronic databases: (a) CINAHL, (b) MEDLINE, (c) Google Scholar, and (d) PubMed. The following key terms were used to explore the body of literature: *pediatric palliative care, pediatric end of life, chronic illness and palliative care, pediatric palliative care education, pediatric palliative care at intensive care unit,* and *barriers in pediatric palliative care*.

Evidence Generated for the Doctoral Project

Participants

The participant for the project included all nursing staff employed at NICU, PICU, and a pediatric floor from a hospital in the state of Indiana. Approximately 50 nurses were expected to participate on the educational program and complete the pre and posttest. These participants were relevant as the purpose of this project was to educate pediatric nurses about PPC standards.

Procedures

The nursing director discussed the nurses' lack of knowledge about PPC standards and gave permission to present this educational project. To gain a better understanding of the current knowledge of the staff and to compare the results, the nurses completed a pretest. The pretest included five questions to assess the nurse’s knowledge about pediatric palliative standards of care (see Appendix A). The educational curriculum was based on the content of these five questions. After the presentation of the educational content, the nursing staff completed the same questions as a posttest to compare results and analyze if their knowledge improved. One of the strengths of using a pre and posttest in the assessment process is that it allows nurses' knowledge to be compared. This assessment strategy is useful for educators to assess the learning and skills acquired by nurses (Arrogante et al., 2021).

Educational Program

The education was offered virtually in a 60-minute period, with interactive learning, knowledge checks and post education open questions. The presentation included

Statistics Overview, Overview of Palliative Care, Uniqueness of Pediatric Palliative Care, Standards of Pediatric Palliative Care from the National Hospice and Palliative Care Organization, Nursing Practice, and Family Impact discussion. The topics discussed in the presentation were supported by the evidence-based resource from the National Organization for Hospice and Palliative Care Standards of Practice for Pediatric Palliative Care. At the end of the conference a family impact section was presented to provide nurses current evidence on how children and families can benefit from palliative care. The support of competent, organized, and individualized care from a palliative team is an important factor in promoting well-being and improving the quality of life of families (Winger et al., 2020).

Protections

To ensure ethical protection of the participants, this educational project was developed following the staff education manual and in compliance with the Institutional Review Board (IRB) of Walden University. To protect participants confidentiality, the name of the staff participating were not disclosed. The nursing manager identified all nursing staff that participated. All information or questions discussed and answered in the educational presentation will remain confidential. All participants were informed about their anonymous participation.

Analysis and Synthesis

The educational content was focused on the PPC standards and developed with the ADDIE model. This model allowed me to build effective learning solutions and organize content to provide a quality education. To assure that the content was appropriate and supported the organization needs, two content experts from their facility (a neonatologist and palliative care physician, and a palliative care nurse practitioner) evaluated the presentation and provided feedback. A third content expert also evaluated the educational program, the director of training and educational content of a national organization that educates, empowers, and accompanies families and providers who care for children with serious illnesses. The experts used a six-question questionnaire, using a Likert scale to analyze and validate the specific content of this educational program that was focused on The National Hospice and Palliative Care Organization Standards of Practice of PPC. The Likert scale response categories were as follows: 1 = *Not Applicable*, 2 = *Strongly Disagree*, 3 = *Disagree*, 4 = *Agree*, and 5 = *Strongly Agree*. The questionnaire evaluated purpose, format, evidence, process, and impact of the educational program. The content experts completed the questionnaire in a word document and sent it by email. The educational content was revised as necessary based on the expert panel evaluation and recommendations.

Measuring Knowledge

The education included a pre and posttest that was anonymous through SurveyMonkey. The pre and post-test included five multiple choice questions (Appendix A) related to palliative care definition, diagnosis criteria, patient and family-centered care, family impact, and the National Palliative Care Organization Pediatric Palliative Care Standards.

Data Analysis

To analyze the results, I used descriptive statistics (i.e., frequency and percentage of correct and incorrect answers for each question and total score) with graphical representation. The statistical analysis was performed with SPSS software. This information identified whether there was a change in the nurses' knowledge after completing education. The analysis procedure used in this DNP project addressed the practice-focused question because the purpose was to determine whether there was a difference in the mean number and percentage of correct answers, as well as the rate of change between the pretest and the posttest.

Protection and Privacy

To ensure ethical protection and privacy, this DNP project complied with the Walden Institutional Review Board (IRB), and the approval number was 11-09-21-1027081. Participants were given a consent form for anonymous questionnaires. The organization administrator signed a site agreement form. A consent form for anonymous questionnaires was provided to inform nurses of voluntary participation and that responses to the questionnaires will remain anonymous. By accepting this consent form, they were giving permission to participate in the educational program. Pre- and post-test results will remain anonymous to ensure the privacy of participant responses. The data will be kept on a password protected computer for five years.

Summary

This DNP project developed an educational program about PPC standards of practice to address the lack of knowledge of the nursing staff that cares for children with life-threatening and debilitating illnesses at a hospital for women and children in the state of Indiana. The practice-focused question was: Will an education program for pediatric nursing staff in a local hospital increase their knowledge of palliative care standards of practice? The source of evidence for this DNP project was the Pediatric Standards of Practice of the Hospice and Palliative Care Organization, which provided current evidence and supported the educational program. Section 4 provides an overview of the findings and implications, recommendations, contribution of the doctoral project team, strength and limitations of the educational program that focused on improving pediatric nurse’s knowledge about PPC standards of practice.

Section 4: Findings and Recommendations

The purpose of my DNP project was to develop an evidence-base educational program about PPC standards of practice to address the lack of knowledge of the nursing staff that cares for children with life-threatening and debilitating illnesses at a hospital for women and children in the state of Indiana. The practice-focused question was: Will an education program for pediatric nursing staff in a local hospital increase their knowledge of palliative care standards of practice? The primary source of evidence for this DNP project was the Pediatric Standards of Practice of the Hospice and Palliative Care Organization, which provided current evidence and supported the educational program. Additional sources of evidence were completed through a systematic review of the content literature on PPC. This DNP project was developed following the staff education manual and in compliance with the IRB of Walden University. To protect participants confidentiality, the name of the staff participating were not disclosed. The presentation included the following sections: Statistics Overview, Overview of Palliative Care, Uniqueness of Pediatric Palliative Care, Standards of Pediatric Palliative Care National Hospice and Palliative Care Organization, Nursing Practice, and Family Impact discussion. The main data of this project were the pretest and posttest used to objectively assess the knowledge of the participants. The pretest was given to the participants prior to the education program to determine a baseline of PPC knowledge, and the posttest was given following the educational program. The scores were documented and analyzed through SurveyMonkey. Section 4 provides an overview of the findings and implications, recommendations, contribution of the doctoral project team, and strengths and limitations of the educational program that focused on improving pediatric nurse’s knowledge about PPC standards of practice.

Findings and Implications

This educational program was completed by 10 nurses from NICU, PICU and pediatric floor at a hospital for women and children in the state of Indiana. All participants reviewed the Walden University consent form for anonymous questionnaires prior to the start of the program and their participation was voluntary. The content of the pre and posttest was developed to evaluate the nurse’s knowledge about pediatric palliative domain and standards of practice. The first question focused on the definition of PPC. The second question focused on the diagnosis categories that can be referred to PPC. The third question focused on the patient and family-centered care. The fourth question focused on how palliative care can impact chronically ill children and their families. The fifth question focused on the National Palliative Care Organization Pediatric Palliative Care Standards. Table 1 includes the average scores of the individual survey questions for pre and posttest. The pretest was completed before the presentation of the educational program. The pretest score ranged from 60% to 100% (see Figure 3); the mean score was 76% with a standard deviation of 13%. Following completion of the education program, the posttest was completed independently by each participant without assistance of any references. The posttest score ranged from 80% to 100% (see Figure 4) with a mean score of 94%, and a standard deviation of 10%. The data indicated an increase in the mean score from 76% to 94% from the pretest to the posttest. As a result of the education program, the average score on the exam increased by 20%. The pre and posttest scores suggest and increased in nurses’ knowledge about PPC standards of practice.

Table 1

Average Pre and Posttest Question Score

Question	Pretest Average Score	Posttest Average Score
1. Pediatric palliative care: a) Focuses on coordination of care for end-of-life process b) Focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care. c) Focuses on chronic pain management d) Focuses on patients diagnoses with cancer	100%	100%
2. The following diagnosis categories can be referred to pediatric palliative care: a) Severe congenital heart disease, severe short gut, cystic fibrosis, chromosomal disorders, extreme prematurity b) Severe congenital heart disease, severe reflux, asthma, blindness c) Cystic fibrosis, dyslexia, developmental delay, severe constipation d) Only cancer diagnosis	90%	100%
3. Patient and family-centered care focuses on the following: a) Patients' preferences only b) Patient needs, treatments, and referrals. c) Supportive care for end-of-life d) Patient and family preferences, cultural believes, values, and goals of care.	80%	100%
4. Select the best example of how palliative care can impact chronically ill children and their families are: a) Psychological support and symptom management. b) Economic resources and treatment trials. c) psychological support and resources during end of life. d) Coordination of care and referral to other providers	30%	70%
5. The National Palliative Care Organization Pediatric Palliative Care Standards focuses on the following: a) Diagnosis criteria, laws, and regulations, and performance measurement b) Clinical excellence, safety, and patient and family-centered care c) Ethical behaviors, patient rights, and organizational excellence d) All the above	80%	100%

Figure 3

Pretest Score Range

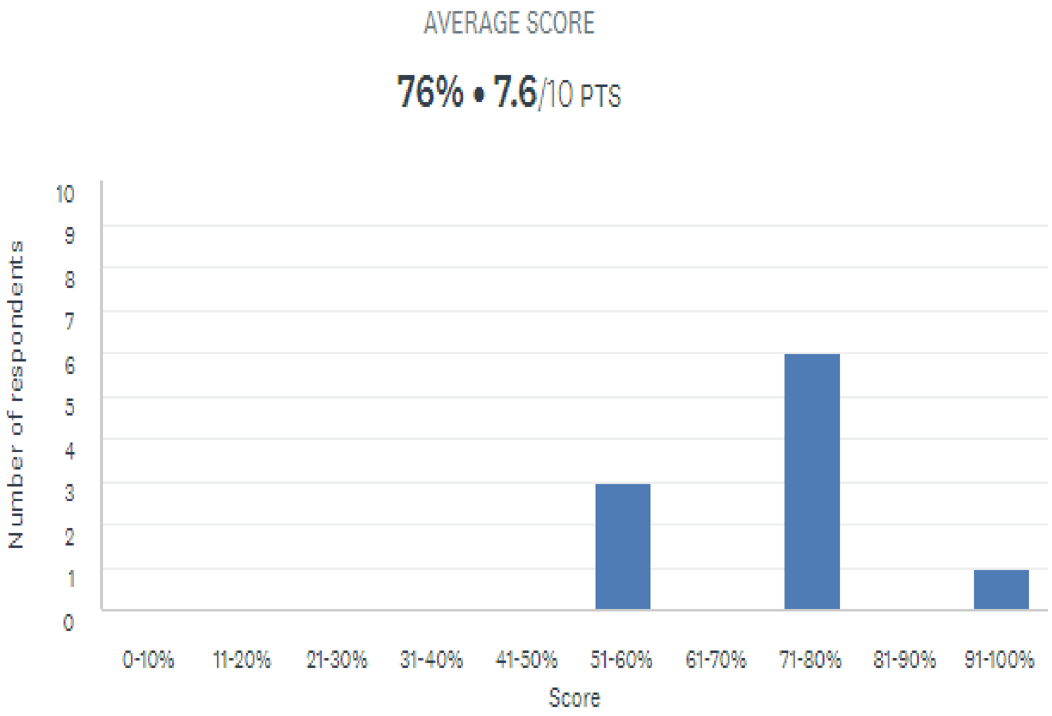
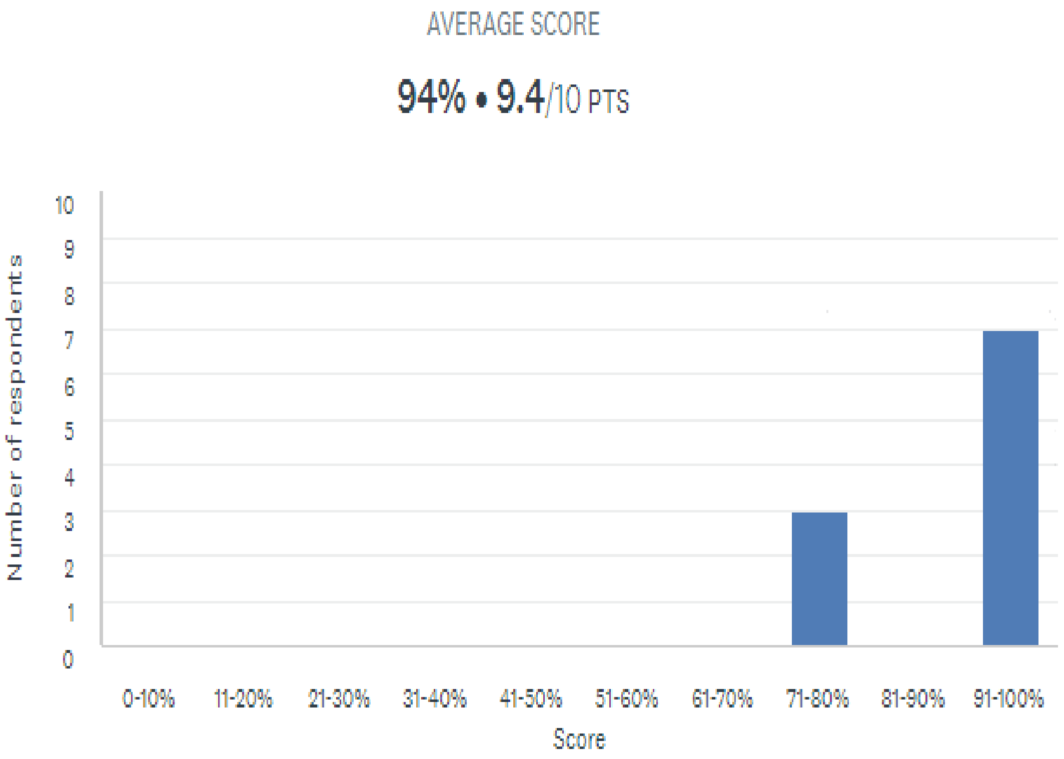


Figure 4

Posttest Score Range



Recommendations

This educational program was provided to 10 registered nurses. After review of the data and initial feedback, additional education sessions are recommended with a goal of educating 100% of the pediatric nurses at the hospital. This education should also be incorporated into new nurse orientation. It is recommended that the hospital implement an annual education to update PPC standards of practice following changes from the National Hospice and Palliative Care Organization. It is recommended to include educational sessions about communication skills, symptom management and referral process. It has been suggested that other healthcare providers can receive this education to improve knowledge and collaboration through the PPC referral process.

Contribution of the Doctoral Project Team

The doctoral project team included three content experts who provided a formative evaluation of the presentation and the pre and posttest. The content experts were the director of training and educational content of a national organization that educates, empowers, and accompanies families and providers who care for children with serious illnesses. Two stakeholders at the hospital also provided a formative evaluation, a neonatologist and palliative care physician, and a palliative care nurse practitioner. Their knowledge and collaboration were essential to include relevant information and evidence to present the staff education project. The nursing professional development practitioner of the hospital distributed the education flyer and coordinated with nurses their participation.

Strengths and Limitations of the Project

This project has several strengths and weaknesses. The project was well-developed to meet its objectives. The project materials included a pretest, education presentation, posttest, and program evaluation. The program was able to be completed in one hour, which improves the likelihood of attendance, especially inside intensive care units. Another strength of this project was the use of the National Palliative and Hospice Organization Standards of Care, which can be replicated and provided for nurses in NICU, PICU, and pediatric floor as a main resource to improve patient referral.

The identified limitations of this project include a small sample size and a limited timeframe for implementation. The educational program was planned with a group of 50 nurses. However, only 10 nurses were able to complete the education because of the current situation of COVID pandemic and high census on their intensive care units. This reflects a small sample size of the total nurses expected to complete it. Future education is recommended for nurses who couldn’t participate.

Summary

The education program resulted in a documented increase in the knowledge of pedaitric nurses which addresses an identified knowledge gap about the PPC standards of practice. This gap in practice was addressed through implementation of the evidence-based project. The overall increase in knowledge of the 10 nurses that participated in the program was 20% when comparing pre and posttest scores. Additional educational sessions are recommended with a goal of educating 100% of the pediatric nurses at the hospital. Also, this education should also be incorporated into new nurse orientation to assure the integration of pediatric standards of practice in the pediatric units. Section 5 of the project will elaborate on the dissemination plan following the completion of the project as well as provide an analysis of self and final summary.

Section 5: Dissemination Plan

The purpose of this DNP project was to increase pediatric nursing knowledge by implementing an education program about PPC standards of practice. To continue collaborating and impacting nursing practice, I developed a dissemination plan to share the results, raise awareness, and support the expansion of PPC services. I will be sharing the results of my DNP project through a meeting with the medical director and the nursing professional development practitioner to continue my collaboration and offer this education program to additional nursing staff and to incorporate it into the nursing education curriculum for all new nurses. As part of the dissemination plan, this project will be presented at the Annual Assembly of Hospice and Palliative Care. As a member of the Hospice and Palliative Nurse Association, this will give me the opportunity to collaborate as a leader and educate other nurses about PPC. I will seek to publish my project by March 2022 in the Journal of Hospice & Palliative Nursing, and the Journal of Palliative Medicine. This is an important goal, both professional and personal, giving me the opportunity to share my expertise and contribute to the development of the profession.

Analysis of Self

The DNP prepared nurse makes important contributions to the development and implementation of the science that shapes nursing practice. Through the development of this evidence-based project I have evolved as a practitioner, scholar, and project manager, preparing me for a future leadership role in PPC. As the future leader of DNP, I will continue to collaborate to improve nursing practice, focusing my goals on improving PPC for children with chronic diseases. As an advocate for PPC, this gives me the opportunity to help families receiving palliative care or bereavement support. My interest in PPC comes from my son’s legacy to continue improving access of palliative care for the pediatric chronically ill population.

As I prepare to graduate from this nursing doctoral program, I see myself evolving into a nursing leader who is innovative, confident, and empowered to lead change. The completion of this evidence-based project has also given me a sense of pride and purpose in a personal and professional sense, collaborating as the leader of the nursing practice to increase nurses' knowledge of PPC, and continuing the legacy of my son to help other families with chronically ill children. Reflecting on the academic journey, I have gained the knowledge and skills to be successful as a DNP leader. At first, it was challenging to review the literature and translate the evidence into practice because the field of PPC is still under development. This gave me the opportunity to improve my skills and become more competent. Therefore, working hard to develop this project was an enriching opportunity to prepare myself to be successful as a DNP leader and impact nursing practice with innovative changes.

Summary

This DNP project has resulted in a practice change that will continue to positively impact pediatric nurses and children and families living with life-limiting and debilitating illnesses. Through a dissemination plan, my goal is to impact nursing practice beyond the project site. By implementing a plan to address the knowledge gap of pediatric nurses regarding palliative care, I have been able to empower nurses with the goal being to improve patient care and quality of life.

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Appendix A: Pre and Posttest

Pre and Post-test

The following questionnaire will evaluate nurses' knowledge about pediatric palliative care standards of practice. Read the following questions and choose the best answer based on your knowledge.

1. Pediatric palliative care:

    a. Focuses on coordination of care for end-of-life process

    b. Focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care.

    c. Focuses on chronic pain management

    d. Focuses on patients diagnoses with cancer

2. The following diagnosis categories can be referred to pediatric palliative care:

    a. severe congenital heart disease, severe short gut, cystic fibrosis, chromosomal disorders, extreme prematurity

    b. severe congenital heart disease, severe reflux, asthma, blindness

    c. cystic fibrosis, dyslexia, developmental delay, severe constipation

    d. only cancer diagnosis

3. Patient and family-centered care focuses on the following:

    a. patients' preferences only

    b. patient needs, treatments, and referrals.

    c. supportive care for end-of-life

    d. patient and family preferences, cultural believes, values, and goals of care.

4. Select the best example of how palliative care can impact chronically ill children and their families are:

    a. Psychological support and symptom management.
    b. Economic resources and treatment trials.
    c. Psychological support and resources during end of life.
    d. Coordination of care and referral to other providers

5. The National Palliative Care Organization Pediatric Palliative Care Standards focuses on the following:

a. diagnosis criteria, laws, and regulations, and performance measurement

b. clinical excellence, safety, and patient and family-centered care

c. ethical behaviors, patient rights, and organizational excellence

d. All the above

Total Score ____

Appendix B: Course Evaluation

After the completion of this educational program, the participant will be able to:

- Define pediatric palliative care.
- List 3 differences in adult and pediatric palliative care.
- Review pediatric palliative care standards of practice.
- Identify the need for collaboration with interdisciplinary team members.
- Describe the role of the nurse in providing quality palliative care for children and families.
- Recognize the impact of palliative care services for chronically ill children and their families.

Date & time: November 22, 2021, 1:00 pm

Presented by: Marilia Rivera Camacho MSN, BSN

Participant: Your opinion of the educational content and instructor is important. Please help in evaluating the educational program you have participated in today.

Please evaluate the following criteria:	Very Poor 1	Poor 2	Average 3	Good 4	Very good 5
Understand definition of pediatric palliative care					
List 3 differences in adult and pediatric palliative care.					
Review pediatric palliative care standards of practice					
Identify the need for collaboration with interdisciplinary team members.					
Describe the role of the nurse in providing quality palliative care for children and families					

Recognize the impact of palliative care services for chronically ill children and their families					
The presenter: Marilia Rivera, MSN, BSN was prepared					
The presenter demonstrated expertise and high level of knowledge					
The presenter responded to participant's discussion questions					
Quality of presentation					
Overall rate of this educational program					

Other comments:

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