Pediatric Palliative Care: A Quantitative Study on the Impact of an Educational In-Service on Nurse Attitudinal Scores

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Abstract

Pediatric palliative care remains largely underutilized despite recommendations by the World Health Organization and American Academy of Pediatrics to involve it from the time of diagnosis for any child with a life-limiting condition. Use of pediatric palliative care improves patient outcomes and satisfaction with care. Barriers nurses encounter in providing pediatric palliative care are well identified in the literature. How to best overcome these barriers has yet to be established. This study is quantitative and utilizes survey methodology. The research setting for this problem is a Pediatric Intensive Care Unit in a nonprofit community hospital. Twenty three nurses working in the unit took an attitudinal survey on pediatric palliative care before and after a pediatric palliative care in-service. The hypothesis was that completing a pediatric palliative care in-service increases nurses’ attitudinal scores on providing pediatric palliative care. Analysis of data, particularly mode and medians, revealed an overall improvement of nurse attitudinal scores post-in-service. Thus, the hypothesis was supported. The researcher recommends that the in-service be offered to new hire nurses and as a yearly update. Further recommendations include improving internal validity by triangulating data and external validity by increasing sample size.
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Chapter 1: Introduction to the Problem

Introduction

Approximately 55,000 children die in America each year. The majority of children who die do so in the Pediatric Intensive Care Unit (PICU) setting (Beckstrand, Rawle, Callister, & Mandleco, 2009). In 1990, the World Health Organization (WHO) initiated the concept of palliative care. The WHO’s aim was and is to improve the quality of life for patients with life-limiting and life-threatening diagnosis and their families. Palliative care was designed to treat the whole person not just in terms of pain but in terms of any physical, psychological, or spiritual problem. Therapies and treatments are tailored to the patient to help them achieve their life goals. It is not used in lieu of curative therapies but rather in conjunction with them to obtain a higher quality of life. Patients do not forgo their primary physicians. Most insurance carriers (including Medicare and Medicaid) now reimburse all or most of costs of palliative care (Center to Advance Palliative Care, 2011). Some states offer full reimbursement for children with life-limiting diagnosis for both palliative care and curative treatments with no time limitations (California Department of Health Care Services, 2012).

In 2000, the American Academy of Pediatrics (AAP) recommended integrating palliative medicine with disease-directed therapy early in any life-limiting diagnosis. Further, in 2003, the Institute of Medicine (IOM) reported that approximately 400,000 children in the United States are living with life-limiting illnesses. This led the IOM to mandate pediatric palliative care and end-of-life care initiatives (Haut, Michael, & Moloney-Harmon, 2012). Despite these recommendations, many pediatric patients with terminal diagnosis enter the PICU without involvement of palliative care. The PICU nurse may suddenly need to provide palliative care to such patients. In addition, children may be admitted to the PICU for one diagnosis and may
sadly develop a new, life-limiting diagnosis related to a disease process or trauma. Providing quality palliative care is essential for the PICU nurse skill set. Many PICU nurses simply do not feel comfortable or competent in providing such care since there is little to no formal education on the topic. Education specifically on pediatric palliative care is lacking in most nursing degree programs, hospital preceptor and mentoring programs, hospital learning programs, and even pediatric critical care certification programs.

This quantitative study evaluated the impact of a pediatric in-service on PICU nurses’ attitudinal scores on providing pediatric palliative care. In this chapter, the problem is presented followed by the research question, hypothesis, significance of the study, and definition of terms. Chapter 2 presents a literature review on pediatric palliative care by theme. In Chapter 3, methodology is presented. Specifically, research design, setting, participants, instruments, data collection, data analysis, and human subject protection are discussed. Findings are presented in Chapter 4 with details of data analysis, results, and interpretation. In Chapter 5, the final chapter, discussion and conclusions are developed. Implications, limitations, and recommendations of the study are offered.

**Problem Statement**

Providing pediatric palliative care can become problematic for PICU nurses. Barriers nurses experience in providing such care are well described in the literature. There are educational barriers, parental barriers, and institutional barriers. The terminally ill child may admit to the PICU in an acute phase of a life-limiting illness without any planning for end-of-life care. This causes much turmoil for the health care staff, family, and patient. In facilities without pediatric palliative care services, the responsibility to provide such care falls wholly on the PICU staff. PICU nurses often do not feel comfortable discussing and providing pediatric palliative
care. They may lack an understanding of what such care entails and how to discuss it with families and patients. American culture traditionally dictates aggressive, curative treatments as loving even if painful and futile. Families may be reluctant to accept a life-limiting diagnosis and well as consider non-aggressive therapies aimed at comfort instead of cure. Nurses may also lack an understanding of how pediatric palliative care can be incorporated into disease directed therapy.

In addition, nurses may be unaware of hospital supports and resources available to them. Many facilities do not provide such services. In 2011, only 63% of hospitals had palliative care programs (Center to Advance Palliative Care, 2011). Out of approximately 3,000 hospice programs in the United States, less than ten percent provide palliative care to children and/or neonates (Romesburg, 2007). Further, as previously mentioned, even children with known life-limiting diagnosis are not properly referred by their physicians for such services. Some nurses may not know if and when it is appropriate to suggest referral of their patient to such services. Nurses may also encounter resistance from families or PICU physicians for a referral or family conference. Generally, physicians (more than nurses) assume that the family is already well informed about treatment choices and that ethical issues are already well discussed amongst the team and with the family (Rushton, Reder, Hall, Comello, Sellers, & Hutton, 2006).

Caring for children with life-limiting or life-threatening diagnoses wears emotionally on nurses. PICU “burnout” and staff turnover rates are high compared to non-intensive care unit rates. Caring for children in the end stages of life can be one of the most trying and emotional endeavors a nurse can face. This grief is magnified when nurses believe they did not provide optimal care for these patients. Many facilities have Employee Assistance Programs that offer grief counseling and debriefing sessions. Although worthy, these programs do not help nurses
overcome barriers they face in trying to provide quality care for their patients. Any process that improves nurses’ attitudes by supporting them in this difficult process is valuable.

**Research Question**

The research question addressed in this study was: *What is the impact of a pediatric palliative care in-service on PICU nurses’ attitudinal scores on providing pediatric palliative care?*

**Hypothesis**

The hypothesis was that completing a pediatric palliative care in-service increases nurses’ attitudinal scores on providing pediatric palliative care.

**Rationale and Significance of the Study**

There are many barriers nurses experience in providing pediatric palliative care. Studying the impact of a pediatric palliative care in-service on PICU nurses’ attitudinal scores on providing pediatric palliative care is beneficial to the field of PICU nursing since the majority of children who die do so in the PICU setting. The IOM has mandated initiatives to improve pediatric palliative care. Doing so not only increases patient and employee satisfaction with care but, ironically, also improves patient outcomes. Given the large nursing educational deficit on pediatric palliative care, an in-service might be a simple method of improving nurses’ attitudinal scores on providing such care. This might ultimately improve palliative care provided to pediatric patients. It might also be useful in terms of improving employee mental health status. Nursing provides more “hands on” care to terminally ill children than another other health care discipline. No doubt these experiences have a profound impact on nurses’ psyches. It is important to support nurses in this difficult process. Not doing so can lead to nurse “burnout,” poor patient care, and can even negatively affect employee attendance and retention rates.
The study assumed that the only independent variable in the time between the pre-in-service survey and the post-in-service survey was the in-service itself. In reality, the world is more complex and less controllable than that. Experiences can also affect attitudinal scores. This study is limited to a single facility and small sample size. Analyzing the inferential statistics would reveal how likely the results from the sample population would be generalizable to the larger population. If the study reveals the impact to be positive, The Manager, Clinical Nurse Specialist, and Nurse Educator at the facility can adopt the in-service as a simple, low cost method of improving PICU nurses’ attitudinal scores on providing pediatric palliative care. It could be offered to new employees along with annual updates for regular staff. Further, the in-service could be adapted and adopted by other units (such as the Neonatal Intensive Care Unit) or even other facilities to improve nursing attitudinal scores about pediatric palliative care.

**Definition of Terms**

*Family/Parents* - those who provide total care for the child regardless of genetic relationship. This includes physical and psychosocial care (EAPC Taskforce Steering Group, 2007).

*Life-limiting diagnosis* - diagnosis in which premature death is expected (EAPC Taskforce Steering Group, 2007).

*Life-threatening diagnosis* - diagnosis in which a premature death is highly probably due to severe illness (EAPC Taskforce Steering Group, 2007)

*Palliative care* - care designed to improve the quality of life of patients and their families facing life-threatening or life-limiting illness through prevention, assessment, and treatment of pain and other physical, psychological, and spiritual problems (World Health Organization, 2002).
Pediatric palliative care - “active and total care of the child’s body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease (World Health Organization, 2002, p. 85).”

Summary

The majority of children who die do so in the PICU setting. Despite the AAP recommendations and the IOM mandates, children with life-limiting illness often have no palliative care involvement. PICU staff, particularly the nurse, is left with the responsibility of providing such care. Understandably, this is enormously stressful situation for the nurse. To compound the stress, PICU nurses may feel unqualified or unsupported in providing such care. How to best address this problem has yet to be discovered. The researcher hypothesized that an in-service on pediatric palliative care increases nurses’ attitudinal scores on providing pediatric palliative care. In Chapter 2, the researcher presents a literature review on best practices and barriers nurses encounter in providing pediatric palliative care. This clarifies what is already known on the subject.
Chapter 2: Literature Review

Introduction

Research began with a literature review. Various sources such as articles, books, and reports related to the research problem were found by searching databases for keywords. The researcher used several keywords related to their problem statement. In this case the keywords included: pediatric, palliative care, nursing, interventions, perceptions, barriers, family, education, and end-of-life. Western Governors University’s online library of Ovid® Journals (medical sources), CINAHL Plus® (nursing and allied health sources), and MEDLINE® (medical sources) were used. Also used was EBSCO®’s Content Select which is an electronic research database. Keywords were entered in various combinations and Boolean technique and operators “AND” and “NOT” were employed. The search yielded many sources applicable to the research topic. Ultimately, eighteen were selected for review. Best practices for providing pediatric palliative care were revealed. The barriers were categorized into three general types: education related, parent related, and hospital related.

Review of the Literature

Best Practices

Organizations such as the World Health Organization (WHO), the Institute of Medicine (IOM), the Center to Advance Palliative Care, the American Academy of Pediatrics (AAP), and various State Departments of Health Care Services have defined best practices and guidelines for providing quality pediatric palliative care. Since the inception of palliative care in the 1990’s, the WHO has recommended that children with any life-limiting or life-threatening diagnosis receive palliative care in an effort to improve the quality of their lives. In 2002, the landmark book, *National cancer control programmes: policies and managerial guidelines*, was published.
Although the book focused on cancer, an entire chapter was dedicated to pain relief and palliative care. It defined pediatric palliative care in general as well as for pediatrics specifically. Relevance was established by demonstrating that the majority of cancer patients need palliative care at some point as do Acquired Immunodeficiency Syndrome patients and patients with any non-communicable chronic life-limiting disease. Resource allocation was addressed making relief from suffering a priority for health care providers as opposed to an option. It required holistic assessment of patients. Drug availability included recognition of the WHO essential drug list, providing access to narcotics, distribution planning, and professional training. Education of health care employees was strongly emphasized. It required WHO member countries incorporate pediatric palliative care into the national health care system and policy. Priorities for care were pain management, psychological support, and family involvement in care planning. The book was monumental, relevant, and essential for any professional who cares for children or adults with life-limiting illnesses. Its perspective was unique in that is addressed freedom from pain and suffering as a fundamental, human right.

The IOM published the landmark report, *When children die: improving palliative and end-of-life care for children and their families*, in 2003. Like the WHO publication, it defined pediatric palliative care, addressed the need for holistic care, called for better organization, better financing of pediatric palliative care, and integration of palliative care with curative therapies for children. It also called for multidisciplinary and family collaboration for care planning, protocol development, and policy development. It proclaimed a lack of data and professional body knowledge on the subject. This aspect has since improved with many studies ensuing post publication of the report. The report also called for state and federal improvements for pediatric palliative care financing. Like the WHO publication, this report was monumental, relevant, and
essential for professionals caring for children with life-limiting illnesses. It was unique in addressing the growing need for pediatric palliative care in developed countries due to advancements in life prolongation related to technological advancements, medications, vaccinations, sanitation improvements, and safety improvements.

Another landmark academic article defining best practice for pediatric palliative care was the AAP’s article “Palliative care for children” published in *Pediatrics* in 2000. Like the publications by the WHO and the IOM, the article defined pediatric palliative care, addressed the need for a holistic approach, called for the continual integration of palliative care with curative therapies for children with life-limiting diagnoses, and cited the need for a multidisciplinary family collaborated care planning. It declared “the goal is to add life to the child’s years, not simply years to the child’s life” (American Academy of Pediatrics, 2000, p. 353). It was one of the first works to address the barriers to providing palliative care to children such as communications, Medicare and Medicaid barriers, and lack of pediatric specific programs. The work remains relevant in many respects. However, some Medicare and Medicaid barriers have been overcome since publication. Further, the article interestingly made a strong statement that about the organization not supporting euthanasia or any hastening of death which other articles did not address.

Also useful in establishing guidelines for pediatric palliative care is the website for the Center to Advance Palliative Care (www.capc.org). The Center is partnered with the National Palliative Care Research Center and was established at the Mount Sinai School of Medicine in New York City. Since 2000, the Center has assisted over 1300 hospitals in developing palliative care programs. Last updated in 2011, the site offers useful information such as tools and references for starting a palliative care program at a facility. It also offers a “report card”
evaluating access to palliative care with national status as well as state-by-state evaluations along with goals for improvement. Facilities can register as a Palliative Care Leadership Center or with the National Palliative Care Registry. Information on obtaining The Joint Commission Advanced certification is also available. The site offers many seminars, training, and resources which would be useful for any facility interested in investing and meeting best practice standards. This source emphasizes the importance of improved customer satisfaction with palliative care usage and the national shortage of palliative care physicians.

Individual State Departments of Health Care Services websites are also a useful source to determine how to meet best practice for the state in which the child resides. The California Department of Health Care Services has an entire section on pediatric palliative care on its website (www.dhsc.ca.gov/services/ppc). Last updated in 2012, the site continues to offer timely information about the program including history and a program overview. This site is particularly useful in outlining state laws. In the case of California, State Assembly Bill 1745 (The Nick Snow Children’s Hospice and Palliative Care Act of 2006) is described. Forms are available for the physician to complete so that the child may receive palliative care and curative therapies without applying for hospice or declaring the child has six months or less to live.

**Education related barriers**

The first barrier was a general nursing knowledge deficit on pediatric palliative care. There was and is a striking lack of formal education in pediatric palliative care for nurses in nursing degree programs, hospital preceptor and mentoring programs, other hospital educational programs, and even pediatric critical care certification programs. Palliative care was included in Bachelor of Science of Nursing programs but is adult focused and Associate Degree of Nursing programs did not include education for any type of palliative care. Nurses often lacked an
understanding of what exactly pediatric palliative care is. They may also have lacked an understanding of how it could have been incorporated into disease-directed therapy. To further complicate the issue, laws regarding pediatric palliative care and hospice reimbursement differed from those for adults and varied among states. This knowledge deficit was examined in timely, peer reviewed, primary research articles by Haut, Michael, and Moloney-Harmon (2012), Knapp, Madden, Wang, Kassing, Curtis, Sloyer, and Scheckman (2011), and Tubbs-Cooley, Santucci, Kang, Feinstein, Hexem, and Feudtner (2011).

In 2012 research by Haut, Michael, and Moloney-Harmon was published in the Journal of Hospice & Palliative Care. The impact of an online educational program on pediatric and Pediatric Intensive Care Unit (PICU) nurses’ knowledge and attitudes about palliative care was examined. Twenty-five nurses completed Likert style tests before and after completion of an educational program. A modified version of the End-of-Life Nursing Education Consortium Pediatric Palliative Care was offered online to the nurses. Results showed a statistically significant improvement in the nurses knowledge (P=0.02) as well as the nurses attitudes on palliative care (P=0.001) after the intervention. This information was useful in assessing nursing education deficits on the topic as well as measuring the impact of an educational intervention. The authors made a good attempt to establish truth by measuring the effect of the educational program. Analysis of statistical data lent credibility to the study and support to the hypothesis. The study is limited to a small sample of nurses in a single facility. The authors concluded the program was effective in educating nurses on and improving their attitudes about the topic. The intervention can serve as model for all facilities since it is cost-effective and viewed as helpful by participants.
In 2011 research by Knapp et al. appeared in *Pediatric Nursing* examining pediatric nurses’ attitudes on palliative and hospice care. Via email and hard copy mail, 279 pediatric nurses across Florida were surveyed. Results showed a significant difference (p=0.05) in attitudes of those working in a city with a pediatric palliative care program and those not. Being employed in a city with a program increased attitude scores by 0.6 points. The positive attitude statement with the least agreement between the groups was “I think there is a way to reimburse providers in my area for pediatric palliative care prior to the end-of-life.” The negative attitude statement with the least disagreement between the groups was “I think it is difficult to know when, in the course of illness, a child should be referred to palliative care.” This information was useful in assessing nursing education deficits on the topic. The authors made a good attempt to establish truth with a large, diverse sample of nurses by a highly accredited team of researchers. Analysis of statistical data lent credibility to the study and support to the hypothesis. The study was limited to Florida which is one of the few states which did not restrict reimbursement to six months prior to the end-of-life. The authors concluded that training nurses on the topic improved attitude scores, increased referrals, and lead to improved outcomes. Although limited to one state, the palliative care model was more congruent with national goals. The model itself was inspiring and worth advocating for by nurses in terms of health care policy. Unfortunately, the training model has limited applications in many states.

In 2011 research by Tubbs-Cooley et al. appeared in the *Journal of Palliative Medicine*. The team researched pediatric nurses’ assessments of palliative, end-of-life, and bereavement care. A web based questionnaire was completed by 410 nurses in a tertiary children’s hospital. Pain management, maintaining quality of life, and communication were rated the most important interventions by the nurses. The nurses cited lack of debriefing, unclear care goals, and the
health care team’s avoidance in discussing hospice as the largest obstacles to care. Most nurses surveyed (55%) had only one to eight hours of end-of-life education in their careers and most (59%) had cared for one to five children who had died within the last year. Nurses in all units reported collaborating with the palliative care team in 38% of cases involving dying children. The greatest collaboration was by floor units, particularly oncology. This information was useful in assessing nursing education deficits on the topic. The authors made a good attempt to establish truth with a large, specialized group of health care providers. Analysis of cross-sectional data lent credibility to the study and support to the hypothesis. The study was limited to a single facility that has a dedicated pediatric palliative care team. The authors concluded nurses perceived the importance of interventions and problems differently. They also differed in their collaboration with the palliative care team. The need for pediatric care education was clear even in a children’s hospital. The study did not offer a model for education. More children died in Intensive Care Units (ICU’s) than floor units yet ICU’s collaborated less other units. This might have been related to the ICU’s aggressive and often singular focus on curative therapies.

**Parent related barriers**

Another type of barrier nurses faced in providing pediatric palliative care was parental views. Families are often in a state of crisis when admitted to the PICU. They may have known their child had a terminal illness for sometime or may have found this out on admission. Like parents, caring for children with a life-limiting diagnosis is one of the most trying and emotional endeavors a nurse can face. This makes communication difficult to say the least. Nurses may be reluctant to discuss the topic with families and patients. Many health care providers, including nurses, still use antiquated language when they do discuss the topic. Using such language actually impedes trust and communication amongst the family and health care team as well as
profoundly influences a family’s choice to incorporate palliative care. Parental views were examined in timely, peer-reviewed articles by Beckstrand, Rawle, Callister, and Mandleco (2009), Davies, Sehring, Cooper, Amidi-Nouri, and Kramer (2008), Michelson, Koogler, Sullivan, del Pilar Oretga, Hall, and Frader (2009), and Widger and Picot (2008).

Beckstrand, Rawle, Callister, and Mandleco presented their primary research in the *American Journal of Critical Care* (2009). The topic was critical care nurses’ perceived obstacles and supportive measures to pediatric end-of-life care. A survey was mailed to and completed by 474 critical care nurses across the nation. The study identified barriers with the greatest magnitude as language (17.73) and parental discomfort in withholding or withdrawing care (17.69). Supportive measures of the greatest magnitude were identified as allowing time alone with a deceased child (21.15) and allowing parents to hold a child at the time of withdrawal of support (18.47). This information was useful in assessing nurses’ perceptions on interventions that improve or hinder end-of-life care. The authors made a good attempt to establish truth with a nationwide survey of a large sample of critical care nurses by a highly accredited team of researchers. Analysis of statistical data and magnitude calculations lent credibility to the study and support to the hypothesis. The study has limited application to palliative care specifically since it includes all end-of-life care. The authors concluded that enhancing communication and including palliative care in the treatment of children with life-limiting illness improved end-of-life care. The study addressed the benefit of positive communication and early integration of palliative care to improve the end effect. Specific interventions were listed that nurses could use to improve care.

Davies et al. published their primary research in *Pediatrics* (2008). It was about pediatric health care providers’ perceived barriers to palliative care. A survey was mailed and
completed by 117 nurses and 91 physicians who spent more than half of their time caring for pediatric patients at a children’s hospital. Most frequent barriers were uncertain prognosis (55%), family not acknowledging incurable conditions (51%), language barriers (47%), and time restrictions (47%). Other less frequent barriers included family preferences (40.6%), staff shortages, cultural barriers, no palliative care team, lack of knowledge on pain management, family conflict, staff versus family conflict, and lack of knowledge about palliative care (31%). This information was useful in assessing nursing education deficits on the topic. The authors made a good attempt to establish truth with a diverse, specialized group of health care providers and a highly accredited team of researchers. Analysis of statistical data lent credibility to the study and support to the hypothesis. The study was limited to a single facility. The authors concluded that perceived barriers to pediatric palliative care are different than those for adults. Staff needed to be better educated on the topic and communication skills. Interestingly, nurses and physicians declared similar perceptions including the four most common barriers. Uncertain prognosis is inherent in pediatrics. This made palliative care planning more difficult for nurses.

Michelson et al. published primary research in *Archives of Pediatrics & Adolescent Medicine* (2009). It focused on parental views of critically ill children’s withdrawal of life support. Seventy English and Spanish speaking parents over the age of 17 years whose children where in one of two PICU’s at tertiary hospitals for more than 24 hours and up to one week were interviewed individually. Fifty-seven percent said they could imagine a situation where they would withdrawal support. Factors that would have influenced their decision were suffering (64%), quality of life (51%), physician estimated prognosis (43%), and financial burden (7%). This information could be useful to nurses since they provide the care. The authors made a good attempt to establish truth by conducting the study at multiple centers and with a highly
accomplished team. The open response and one on one format of the interviews allowed for depth in the study. Transcribing verbatim and coding the responses facilitated the grounded theory-based inductive process. This study was limited to a medical focus and hypothetical situations. The authors described various factors that might have influenced consideration of withdrawal of life support. Despite its limitations, the source provided rich insight to parental preconceived perceptions of withdrawal of life support care. Its credibility was diminished by using only hypothetical situations. Most patients survive their PICU stay statistically and it was unlikely that parents realistically conceived of their children not or their child being diagnosed with a life-limiting illness. Only negative terminologies were used for end-of-life care which may have profoundly impacted perceptions.

In 2008, Widger and Picot published their primary research on parental perceptions on the still birth or death of a child in *Pediatric Nursing*. Thirty-eight families whose children died at a tertiary Canadian health care center were surveyed by telephone or in person about their child’s end-of-life-care. Parents were reluctant to report negative experience although they all had a least one. Problem areas included communication with health care providers, relationships with health care providers, care at the time of death, and bereavement follow-up. This information could be useful to nurses since specific interventions they could take to improve care were described. Interventions included team and family communication, being respectful, showing interest, taking photos and hand or foot prints, saving bracelets and locks of hair, post-mortem bathing, and follow up for bereavement support. The team made a good attempt to establish truth by surveying parents whose children actually died about the care they received. The surveys provided depth and richness on the topic. This study was limited to a small sample at a single foreign health care center. The authors concluded there is improvement to be made in
terms of pediatric end-of-life care and presented several interventions that might be used. The article had an overall negative tone despite its usefulness. Most (84.6%) of parents reported being very satisfied with the care they received. Why nurses could not always provide perceived optimal care in this situation may have been related to the innate “wrongness” in a child dying and the profound sensitivity, confusion, and loss parents experienced during this time.

**Hospital related barriers**

The third barrier nurses experienced in providing pediatric palliative care was a general lack of hospital support. Most hospitals lack pediatric palliative care programs, services, and educational programs. Some hospitals have palliative care teams but many teams did not provide pediatric services. In these cases, it is largely the nurse who was left to coordinate and provide the majority of palliative care for her patient. To compound the problem, hospitals often do not account for the interventions and services related to palliative care in assigning nurse case loads. The psychosocial demands alone of these patients make them inordinately time consuming. Add to this the task of coordinating palliative care services and the time requirement multiplied exponentially. Timely, peer reviewed articles by Calabrese (2007), Schmidt (2011), and Ward-Smith, Korphage, and Hutton (2008) were related to these hospital barriers.

In 2007, Calabrese published an article in *Pediatric Nursing* describing the implementation of Aggressive Comfort Treatment (ACT) at a children’s hospital. The need for pediatric palliative care, starting ACT, using ACT, and choosing ACT versus curative therapy were all discussed. Although curative therapy included symptom management, ACT rigorously promoted enhancing the quality of life as opposed to prolonging it. Treatments were non-invasive and home centered allowing for a peaceful death. This information is useful in defining choices for treatment. The author made a good attempt to establish truth by describing
program philosophy. The article was limited to a single case example and was a description of a program rather than a research study. The author concluded that ACT allows parents the choice to aggressively manage symptoms as opposed to making them feel they abandoned their child by choosing palliative care. The verbiage was an interesting way to present a peaceful program. It may be useful in American culture and ICU’s given the competitiveness of these environments. The author presented two diametric choices: ACT or curative therapy. It was unclear if the two could have coincided which may have caused difficulties since often prognosis and life expectancy were unclear.

In *Pediatric Nursing* (2011), Schmidt published an academic article describing the implementation of a pediatric palliative care program in one children’s hospital. The need for pediatric palliative care, a literature review, and resources were identified prior to the start up of the program. The author served as Senior Director for the Pain Management and Palliative Care Program at the hospital. To start the program the author and her team considered which units would benefit from the service, annual hospital deaths, follow-up services for bereavement, and interdisciplinary involvement. The team decided to provide the service as a consult. In addition to clinical consultation, the program offered education and research opportunities. A business plan was used to identify the fiscal impact of the program on the hospital. This information is useful in assessing nurses’ perceptions on interventions that improve or hinder end-of-life care. The author made a good attempt to establish truth by thoroughly describing the start up of the program including challenges as well areas for improvement. The article was limited to a single facility and was a description of a process rather than a research study. The author concluded that after three years, the program successfully cared for 40% of the eligible population with positive feedback from staff and family. No mention was made of what percentage of the
population was cared for prior to the study. Fiscal impact was difficult to access given Medicare reimbursement restrictions. Those patients not at the point of hospice may have incurred additional charges for the service with no shortened length of stay. Medicare reform seemed necessary to ensure financial soundness. Regardless, the quality of patients’ lives seemed to have benefitted immeasurably from the program. Nurses might be likely to endorse this type of program for this reason alone.

Ward-Smith, Korphage, and Hutton published a primary research source about how funds are spent on children in a palliative care program in *Nursing Economic*$ (2008). Nine exemplar cases of children receiving palliative care services were compared in terms of financial charges to nine exemplar cases of children not receiving palliative care services within an 18 month period at a children’s hospital. Not eligible for the study were children in the Neonatal Intensive Care Unit, those who died within 72 hours of admission, and those who had received palliative care services for less than one month. The mean total cost for those receiving palliative care services was $231,990 and the mean cost for those not was $228,199. For both groups, surgical interventions increased costs more than any other service followed by respiratory treatments. For the palliative care group, the next greatest cost was pharmaceuticals. For the group without care, the next greatest cost was radiology charges. This information is useful in assessing the fiscal impact of a palliative care program. The author made a good attempt to establish truth by thoroughly analyzing the hospital charges for both groups. The study was limited to a single facility and a small sample. The author concluded that the two groups are similar in terms of the number of admissions and the costs for hospitalization. The palliative care group spent more on pharmaceuticals and the control spent more on radiology. A palliative care program may not
have saved money for the hospital which might make it difficult to initiate or continue. Again, the quality of the program would likely have lead to nurse support of it.

**Summary**

Best practices for pediatric palliative care were well described in the literature. Unfortunately, nurses experienced many barriers to providing pediatric palliative care which were also well described in the literature. Revealed were three general types of barriers: education related, parent related, and hospital related. Once the barriers were identified, the knowledge body was enhanced and the opportunity for improvement of care was created. Some literature described attempts to overcome barriers and improve quality of care. The best solution for overcoming barriers to pediatric palliative care was not determined. In this case, the researcher developed an in-service for PICU nurses on providing pediatric palliative care. PICU nurses’ attitudinal scores were measured before and after the in-service. In Chapter 3, the researcher presents methodology for the study.
Chapter 3: Methodology

Introduction

This chapter discusses the methodology for the quantitative study completed by the researcher. The design is described as well as the setting and participants. The instruments and tools for study are presented. Data collection and analysis are, likewise, presented. Finally, protection of human subjects is addressed.

Research Design

The study method was a quantitative study in the form of survey research (Gay, Mills, & Airasian, 2009). The survey was longitudinal because data was collected from the same group at two different times. Based on best practices as well as the barriers identified in the literature review, an in-service was developed by the researcher. Barriers addressed included education related, parent related, and hospital related. An effective way to measure the impact of the in-service was to survey the nurses who complete the in-service before and after completing the in-service. Survey methodology is a preferred methodology in terms of examining attitudes and testing a hypothesis (Gay, Mills, & Airasian, 2009). Like any quantitative study, survey research assumed the world is predictable and the only independent variable is the one manipulated by the researcher. The study took place between August 2012 and October 2012.

Setting

The research setting for this problem was an eight bed Pediatric Intensive Care Unit (PICU) in a nonprofit community hospital with 636 beds. This facility is in a state which allows children with life-limiting diagnosis to receive full reimbursement for palliative care and curative care with no time limitation. The hospital achieved Magnet status last year. Services provided
by the hospital include a neuroscience center, a heart and vascular center, a neonatal intensive care unit, a pediatric unit, a pediatric intensive care unit, a cancer center, a perinatal high risk unit, a stroke center, a bariatric surgery center, and a level II trauma center. Specialty services include a child life team, pet assisted therapy team, and a palliative health care service. Although, there were several specialty services at the hospital, many exclude services for children. This included the palliative care service.

Participants

There were approximately 20 PICU nurses working in the unit. The nurses were both male and female and ranged in age from the 20s to the 60s. Some had only a few years experience in the PICU while others had over 20 years experience. Education levels ranged from Associate Degrees in Nursing to Master of Science of Nursing degrees. Overall, the group was exceptionally dedicated to their patients, their unit, and their community. Several nurses held specialty certifications and had been recognized by the hospital for their clinical excellence. The group as a whole was highly motivated to provide quality care to its patients.

The role of the researcher was largely involved as she had much interaction with the participants. She gained access to the site and secured approval for the study. She set up the survey using the hospital’s SurveyMonkey® account. She requested an email list of PICU nurses from the Department manager. She emailed the survey to the nurses. She followed up on nurse participation or completion as needed. She presented the in-service in person to as many nurses as possible and emailed it to those with whom she did not meet. She then distributed a post-course survey in the same manner as the pre-course survey. She made herself available to the nurses in person, by phone, and by email for questions or feedback.
The role of the participants was to complete the survey pre-in-service, complete the in-service, and complete the survey post-in-service. The sampling method was the entire group due to its small unit size of approximately 20 PICU nurses. The participants were analyzed in terms of demographic groupings such as age, gender, education level, and years of experience. The study was limited to a small sample size and a single facility.

Description of Instruments or Research Tools

Survey

The survey was composed of statements regarding the nurses’ attitudes about pediatric palliative care with accompanying Likert-scale responses (see Appendix A). The Likert items focused on the barriers identified in the literature review. For each Likert item, the participant indicated the level of disagreement or agreement. There were equal amounts of positive and negative positions on the scale from “strongly agree” to “strongly disagree.” The survey was designed to be completed in five minutes or less per Management’s request.

In-service

The in-service consisted of a PowerPoint® presentation on pediatric palliative care created by the researcher (see Appendix B). The presentation addressed the barriers identified in the literature review applicable to the facility as well as methods for overcoming the barriers. The in-service mode was selected as a means of education by Management due to time and budgetary constraints. The in-service was allotted 15 minutes of the employee’s time per hospital guidelines for an in-service presentation. In an effort to make the in-service more active and dynamic, the researcher presented the in-service in person to as many staff as possible. For those unavailable, the presentation was emailed. Questions and discussions were encouraged.
Data Collection

Data were collected via the pre-in-service and post-in-service survey. The surveys were useful tools to collect data to test a hypothesis. The data collected in this case included descriptive data about the nurses such as age, gender, education level, and years of PICU experience. Nurses rated their attitudes on pediatric palliative care via a Likert-scale. The attitudinal statements focused on the barriers (education related, parent related, and hospital related) identified in the literature review. The questionnaire was loaded into a survey template via the hospital’s SurveyMonkey® account and emailed to participants both before and after the in-service. This method of data collection was chosen by Management for the sake of ease and cost effectiveness. The researcher was the only employee with access to the data. After the pre-in-service survey was complete, all data were deleted. After the post-in-service survey was complete, all data were likewise deleted.

Data Analysis

Responses were converted to a number so that attitudes could be measured via use of descriptive statistics. “Strongly disagree” were converted to one, “disagree” to two, “neither disagree nor agree” to three, “agree” to four, and “strongly agree” to five. Percentages of nurses who scored one through five for each item were calculated. In addition, median scores were calculated. The variables were ordinal because rank was established but the distribution was not necessarily equal between units and there was no true zero point. Sample size, return rate, response rate, and percentages were calculated. Descriptive data were presented in tables.

Finally, comparisons between the pre-in-service survey and the post-in-service survey were made. Percentages of nurses who scored one through five for each item were calculated. How much scores had increased or decreased post-in-service was calculated. Descriptive data
were presented in tables. Median scores were also calculated. If the scores increase, the hypothesis was said to be supported by the data. The independent variable was the in-service. The dependent variable was the nursing attitudinal score. Because the study was quantitative, it did not take into account other experiences and interactions that might have affected nurse scores.

**Human Subjects Protection**

After gaining access to the site, the researcher requested Institutional Review Board (IRB) approval for the study from The Evidence Based Practice and Research Council (EBPRC) at the facility. The researcher completed the online course by the National Institutes of Health Office of Extramural Research entitled *Protecting Human Research Participants* (see Appendix C). The EBPRC determined that the project did not require IRB approval and granted permission for the project (see Appendix D). The study met expedited IRB criteria per the IRB at Western Governors University.

The researcher loaded the survey into the institution’s SurveyMonkey® account. A letter explaining the purpose of the study as well as the survey itself was emailed to PICU nurses. Generally, informed consent of participants is needed for research studies. Informed consent may be waived by the IRB if it deems there is no risk. In this case, the educational need for the in-service was well established and the risk to participants was negligent. Therefore, informed consent was deemed as not necessary by the EBPRC which served as the IRB for the facility. The researcher sent out additional requests for participation or completion as needed. After providing the in-service, she distributed a post-in-service survey in the same manner as the pre-in-service survey. The researcher erased all the survey data from the SurveyMonkey® account after it was reviewed.
Summary

Methodology served the research question. The design for this study was quantitative. Survey research was conducted. The setting was a PICU in a 636 bed community hospital. The participants were PICU nurses. The instruments were Likert survey and a PowerPoint® in-service on pediatric palliative care. The survey was presented pre-in-service and post-in-service. Data collection involved converting responses to numerical data for analysis. Protection of human subjects was addressed. Scores revealed if the hypothesis is supported or not. In Chapter 4, the researcher presents the findings of the study.
Chapter 4: Findings

Overview

All twenty four Pediatric Intensive Care Unit (PICU) nurses were asked to participate in the research study. Institutional Review Board approval and informed consent were waived by Evidence Based Practice and Research Council at the institution. An email was sent by the researcher to the nurses in August 2012. The purposes of the study, the participant’s role, and the researcher’s role were described in the email. In addition, a link to the SurveyMonkey® survey was provided. Participation was encouraged but voluntary. Within the same month, two reminder emails were sent to the nurses to complete the survey. Baseline attitudinal scores were collected from this initial survey. In September of 2012, another email was sent to the 24 nurses to participate in the in-service and second survey. The PowerPoint® presentation was included in the email along with a link to the SurveyMonkey® survey. The in-service was presented to the majority of nurses in person by the researcher but some choose to read the PowerPoint® presentation independently. In September and October, the participants were sent two email reminders to complete the in-service and take the survey again.

Of the 24 nurses asked to participate in the initial survey (pre-in-service), 23 did (therefore n=23). The response rate for the initial survey was 95.8%. Of the 23 nurses asked to participate in the second survey (post-in-service), the same 23 did (therefore n=23). The one nurse who did not participate was on a personal leave of absence. Demographic information revealed the majority of participants was in the 51-55 year age group (30.4%), was female (82.6%), held a Bachelor of Science of Nursing (BSN) as the highest nursing degree (56.5%), and had 21-30 years of PICU experience (30.4%).
Statements were rated on a Likert scale by participants before and after the pediatric palliative care in-service. Initial attitudinal scores revealed that most (69.6%) participants disagreed that they received adequate formal pediatric palliative care education. Also, attitudinal scores revealed that most (69.6%) of participants agreed that they understood what pediatric palliative care entails. Initially, most participants (73.9%) agreed that they knew when to suggest pediatric palliative care for their patients. Most (43.5%) of participants agreed that they could competently incorporate pediatric palliative care with curative therapies. Initially, most (60.9%) participants disagreed that they understood their state’s laws regarding pediatric palliative care. Many participants (34.8%) initially disagreed that they could competently discuss pediatric palliative care with patients and parents. Further, 39.1% of participants agreed they could competently discuss pediatric palliative care with the PICU team. Also before the in-service, many participants (43.5%) disagreed that they knew what resources the hospital offers staff providing pediatric palliative care.

Analysis of Data

Demographic information about the participants is presented in Tables 1 through 4. Table 1 represents the age of the participants. The largest percentage of the nurses (30.4%) fell into the 51 to 55 years of age group making this group the mode. The next largest groupings were the 31 to 35 years of age, 46 to 50 years of age, and the 50 to 60 years of age. All were calculated at 13.0%.
Table 1

*Age of Participants*

<table>
<thead>
<tr>
<th>Years of age</th>
<th>Response percent</th>
<th>Response count (n=23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>0.0%</td>
<td>0</td>
</tr>
<tr>
<td>25-30</td>
<td>4.3%</td>
<td>1</td>
</tr>
<tr>
<td>31-35</td>
<td>13.0%</td>
<td>3</td>
</tr>
<tr>
<td>36-40</td>
<td>8.7%</td>
<td>2</td>
</tr>
<tr>
<td>41-45</td>
<td>8.7%</td>
<td>2</td>
</tr>
<tr>
<td>46-50</td>
<td>13.0%</td>
<td>3</td>
</tr>
<tr>
<td>51-55</td>
<td>30.4%</td>
<td>7</td>
</tr>
<tr>
<td>56-60</td>
<td>13.0%</td>
<td>3</td>
</tr>
<tr>
<td>61-70</td>
<td>8.7%</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2 represents the gender breakdown of the participants. There was nearly five times the number of female nurses (82.6%) as there were male nurses (17.4%) in the group.

Table 2

*Gender of Participants*

<table>
<thead>
<tr>
<th>Gender</th>
<th>Response percent</th>
<th>Response count (n=23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>82.6%</td>
<td>19</td>
</tr>
<tr>
<td>Male</td>
<td>17.4%</td>
<td>4</td>
</tr>
</tbody>
</table>
Table 3 depicts the highest level of nursing education of the participants. The group was highly educated with the majority (56.5%) holding BSN’s making it the mode and another 17.4% holding Masters of Science of Nursing. Therefore, a total of 73.9% of the nurses held a BSN or higher degree in nursing. Only 26.1% held Associate Degrees of Nursing as their highest nursing degree.

Table 3

*Nursing Education Level of Participants*

<table>
<thead>
<tr>
<th>Highest nursing degree</th>
<th>Response percent</th>
<th>Response count (n=23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diploma</td>
<td>0.0%</td>
<td>0</td>
</tr>
<tr>
<td>Associate’s degree</td>
<td>26.1%</td>
<td>6</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>56.5%</td>
<td>13</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>17.4%</td>
<td>4</td>
</tr>
</tbody>
</table>

In Table 4, the years of PICU experience of the participants is presented. Clearly, the group was overall very experienced in PICU nursing. The largest percentage of nurses (30.4%) fell into the 21 to 30 years of experience group making it the mode. The next largest grouping was 6 to 10 years of experience (21.7%) followed 11 to 15 years of experience (17.4%).
Table 4

*Years of PICU Experience of Participants*

<table>
<thead>
<tr>
<th>Years</th>
<th>Response percent</th>
<th>Response count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 2</td>
<td>4.3%</td>
<td>1</td>
</tr>
<tr>
<td>2-5</td>
<td>13.0%</td>
<td>3</td>
</tr>
<tr>
<td>6-10</td>
<td>21.7%</td>
<td>5</td>
</tr>
<tr>
<td>11-15</td>
<td>17.4%</td>
<td>4</td>
</tr>
<tr>
<td>16-20</td>
<td>0.0%</td>
<td>0</td>
</tr>
<tr>
<td>21-30</td>
<td>30.4%</td>
<td>7</td>
</tr>
<tr>
<td>More than 30</td>
<td>13.0%</td>
<td>3</td>
</tr>
</tbody>
</table>

Further analysis of the data revealed nurses attitudinal scores on providing pediatric palliative care. The first five statements focused on the nurses’ attitudes about educational barriers to pediatric palliative care. The results are presented in Tables 5 through 9. Table 5 represents the data for Statement 1. The largest group (69.9%) was that which disagreed with this statement “I have received adequate formal pediatric palliative care education” making it the mode. Interestingly, the next largest group for this statement was the group that agreed. However, at only 13.0%, this group is significantly smaller. After the in-service, the disagree group dropped to 43.5%. The biggest change percentage was 26.1% for both the disagree group
and the agree group. The disagree group dropped from 69.9% to 43.5% and the agree group climbed from 13.0% to 39.1% after the survey.

Table 5

Statement 1: I have received adequate formal pediatric palliative care education

<table>
<thead>
<tr>
<th>Level of agreement</th>
<th>Response percent (pre-in-service)</th>
<th>Response count</th>
<th>Response percent (post-in-service)</th>
<th>Response count</th>
<th>Difference percent (post – pre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>8.7%</td>
<td>2</td>
<td>4.3%</td>
<td>1</td>
<td>-4.4%</td>
</tr>
<tr>
<td>Disagree</td>
<td>69.6%</td>
<td>16</td>
<td>43.5%</td>
<td>10</td>
<td>-26.1%</td>
</tr>
<tr>
<td>Neither disagree nor agree</td>
<td>8.7%</td>
<td>2</td>
<td>8.7%</td>
<td>2</td>
<td>0.0%</td>
</tr>
<tr>
<td>Agree</td>
<td>13.0%</td>
<td>3</td>
<td>39.1%</td>
<td>9</td>
<td>+26.1%</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>0.0%</td>
<td>0</td>
<td>4.3%</td>
<td>1</td>
<td>+4.3%</td>
</tr>
</tbody>
</table>

Table 6 represents the data for Statement 2. For this statement “I understand what pediatric palliative care entails,” 69.6% agreed making it the mode. The next largest group is
significantly smaller with 17.4% neither disagreeing nor agreeing. Post-in-service, the disagree group remained at 69.6%. The biggest change for this statement was the strongly agree group which climbed from 0.0% to 17.4% after the in-service.

Table 6

Statement 2: I understand what pediatric palliative care entails

<table>
<thead>
<tr>
<th>Level of agreement</th>
<th>Response percent (pre-in-service)</th>
<th>Response count</th>
<th>Response percent (post-in-service)</th>
<th>Response count</th>
<th>Difference percent (post – pre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Disagree</td>
<td>13.0%</td>
<td>2</td>
<td>4.3%</td>
<td>1</td>
<td>-8.7%</td>
</tr>
<tr>
<td>Neither disagree nor agree</td>
<td>17.4%</td>
<td>4</td>
<td>8.7%</td>
<td>2</td>
<td>-8.7%</td>
</tr>
<tr>
<td>Agree</td>
<td>69.6%</td>
<td>16</td>
<td>69.6%</td>
<td>16</td>
<td>0.0%</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>0.0%</td>
<td>0</td>
<td>17.4%</td>
<td>4</td>
<td>+17.4%</td>
</tr>
</tbody>
</table>
Table 7 represents the data for Statement 3. The mode for this statement “I know when to suggest pediatric palliative care for my patients” was the agree group at 73.9%. The next largest group was (yet again) significantly smaller with 13.0% neither disagreeing nor agreeing. After the in-service the agree group dropped to 47.8%. It and the strongly agree group had the biggest change percentage of 26.1%. The strongly agree group climbed to 30.4% from 4.3%.

Table 7

*Statement 3: I know when to suggest pediatric palliative care for my patients*

<table>
<thead>
<tr>
<th>Level of agreement</th>
<th>Response percent (pre-in-service)</th>
<th>Response count</th>
<th>Response percent (post-in-service)</th>
<th>Response count</th>
<th>Difference percent (post – pre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Disagree</td>
<td>8.7%</td>
<td>2</td>
<td>17.4%</td>
<td>4</td>
<td>+8.7%</td>
</tr>
<tr>
<td>Neither disagree nor agree</td>
<td>13.0%</td>
<td>3</td>
<td>4.3%</td>
<td>1</td>
<td>-8.7%</td>
</tr>
<tr>
<td>Agree</td>
<td>73.9%</td>
<td>17</td>
<td>47.8%</td>
<td>11</td>
<td>-26.1%</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>4.3%</td>
<td>1</td>
<td>30.4%</td>
<td>7</td>
<td>+26.1%</td>
</tr>
</tbody>
</table>
Table 8 represents the data for Statement 4. The mode for this statement “I can competently incorporate pediatric palliative care with curative therapies” was the agree group at 43.5%. The second largest group was the neither disagree nor agree group at 34.8% making this educational statement the one with the least agreement in attitudes. The agree group remained at 43.5% after the in-service. The biggest change was in the strongly agree group which climbed from 0.0% to 13.0%.

Table 8

<table>
<thead>
<tr>
<th>Level of agreement</th>
<th>Response percent (pre-in-service)</th>
<th>Response count</th>
<th>Response percent (post-in-service)</th>
<th>Response count</th>
<th>Difference percent (post-pre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>4.3%</td>
<td>1</td>
<td>0.0%</td>
<td>0</td>
<td>-4.3%</td>
</tr>
<tr>
<td>Disagree</td>
<td>17.4%</td>
<td>4</td>
<td>17.4%</td>
<td>4</td>
<td>0.0%</td>
</tr>
<tr>
<td>Neither disagree nor agree</td>
<td>34.8%</td>
<td>8</td>
<td>26.1%</td>
<td>6</td>
<td>-8.7%</td>
</tr>
<tr>
<td>Agree</td>
<td>43.5%</td>
<td>10</td>
<td>43.5%</td>
<td>10</td>
<td>0.0%</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>0.0%</td>
<td>0</td>
<td>13.0%</td>
<td>3</td>
<td>+13.0%</td>
</tr>
</tbody>
</table>
Table 9 represents the data for Statement 5. The mode for this statement “I understand my state’s laws regarding pediatric palliative care” was the disagree group with 60.9%. The next largest group was the neither disagree nor agree group with a significantly smaller score of 21.7%. The disagree group dropped to 17.4% after the in-service. The disagree group and the agree group had the largest percentage change. The agree group climbed from 8.7% to 52.2%.

Table 9

Statement 5: I understand my state's laws regarding pediatric palliative care

<table>
<thead>
<tr>
<th>Level of agreement</th>
<th>Response percent (pre-in-service)</th>
<th>Response count</th>
<th>Response percent (post-in-service)</th>
<th>Response count</th>
<th>Difference percent (post – pre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>8.7%</td>
<td>2</td>
<td>8.7%</td>
<td>2</td>
<td>0.0%</td>
</tr>
<tr>
<td>Disagree</td>
<td>60.9%</td>
<td>14</td>
<td>17.4%</td>
<td>4</td>
<td>-43.5%</td>
</tr>
<tr>
<td>Neither disagree nor agree</td>
<td>21.7%</td>
<td>5</td>
<td>8.7%</td>
<td>2</td>
<td>-13.0%</td>
</tr>
<tr>
<td>Agree</td>
<td>8.7%</td>
<td>2</td>
<td>52.2%</td>
<td>12</td>
<td>+43.5%</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>0.0%</td>
<td>0</td>
<td>13.0%</td>
<td>3</td>
<td>+13.0%</td>
</tr>
</tbody>
</table>
Table 10 represents the data for Statement 6. This statement focused on the nurses’ attitudes about parental barriers to pediatric palliative care. The statement “I can competently discuss pediatric palliative care with patients and families” had the largest percentage (34.8%) in the disagree group making it the mode. Interestingly, the percentages were close to both the next largest group in the neither disagree nor agree group (30.4%) followed by the agree group (26.1%). The disagree group dropped to 17.4% after the in-service. The group along with the agree group and the strongly agree group had the biggest change in percentages. The agree group climbed from 26.1% to 43.5%. The strongly agree group climbed from 0.0% to 17.4%.

Table 10

Statement 6: I can competently discuss pediatric palliative care with patients and parents

<table>
<thead>
<tr>
<th>Level of agreement</th>
<th>Response percent (pre-in-service)</th>
<th>Response count</th>
<th>Response percent (post-in-service)</th>
<th>Response count</th>
<th>Difference percent (post – pre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>8.7%</td>
<td>2</td>
<td>4.3%</td>
<td>1</td>
<td>-4.4%</td>
</tr>
<tr>
<td>Disagree</td>
<td>34.8%</td>
<td>8</td>
<td>17.4%</td>
<td>4</td>
<td>-17.4%</td>
</tr>
<tr>
<td>Neither disagree nor agree</td>
<td>30.4%</td>
<td>7</td>
<td>17.4%</td>
<td>4</td>
<td>-13.0%</td>
</tr>
<tr>
<td>Agree</td>
<td>26.1%</td>
<td>6</td>
<td>43.5%</td>
<td>10</td>
<td>+17.4%</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>0.0%</td>
<td>0</td>
<td>17.4%</td>
<td>4</td>
<td>+17.4%</td>
</tr>
</tbody>
</table>
The last two statements focused on the nurses’ attitudes about hospital barriers to pediatric palliative care. Table 11 represents the data for Statement 7. For the statement “I can competently discuss pediatric palliative care with the PICU team,” the mode was the agree group with 39.1%. The next largest groups (disagree and neither disagree nor agree) were both 30.4%. This statement is the one with the least agreement in attitudes of all the types of statements. After the in-service the agree group had the biggest change climbing from 39.1% to 60.9%. The disagree group changed almost as much by dropping from 30.4% to 8.7%.

Table 11

*Statement 7: I can competently discuss pediatric palliative care with the PICU team*

<table>
<thead>
<tr>
<th>Level of agreement</th>
<th>Response percent (pre-in-service)</th>
<th>Response count</th>
<th>Response percent (post-in-service)</th>
<th>Response count</th>
<th>Difference percent (post-pre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Disagree</td>
<td>30.4%</td>
<td>7</td>
<td>8.7%</td>
<td>2</td>
<td>-21.7%</td>
</tr>
<tr>
<td>Neither disagree nor agree</td>
<td>30.4%</td>
<td>7</td>
<td>13.0%</td>
<td>3</td>
<td>-17.4%</td>
</tr>
<tr>
<td>Agree</td>
<td>39.1%</td>
<td>9</td>
<td>60.9%</td>
<td>14</td>
<td>+21.8%</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>0.0%</td>
<td>0</td>
<td>17.4%</td>
<td>4</td>
<td>+17.4%</td>
</tr>
</tbody>
</table>
Table 12 represents the data for Statement 8. The mode for this final statement “I know what resources the hospital offers staff providing pediatric palliative care” was the disagree group at 43.5%. The next largest group is the agree group with 26.1%. The disagree group had the greatest change dropping to 4.3% after the in-service. The agree group was impacted almost as much climbing to 65.2% after the in-service.

Table 12

Statement 8: I know what resources the hospital offers staff providing pediatric palliative care

<table>
<thead>
<tr>
<th>Level of agreement</th>
<th>Response percent (pre-in-service)</th>
<th>Response count</th>
<th>Response percent (post-in-service)</th>
<th>Difference percent (post-pre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>4.3%</td>
<td>1</td>
<td>0.0%</td>
<td>-4.3%</td>
</tr>
<tr>
<td>Disagree</td>
<td>43.5%</td>
<td>10</td>
<td>4.3%</td>
<td>-39.2%</td>
</tr>
<tr>
<td>Neither disagree nor agree</td>
<td>21.7%</td>
<td>5</td>
<td>21.7%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Agree</td>
<td>26.1%</td>
<td>6</td>
<td>65.2%</td>
<td>+39.1%</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>4.3%</td>
<td>1</td>
<td>8.7%</td>
<td>+4.4%</td>
</tr>
</tbody>
</table>
In addition, to the individual group percentages for each score, median scores pre-in-service and post-in-service were calculated. Central tendency for ordinal data is represented by the median. Fifty percent score higher than the median and fifty percent score lower than the median (Gay, Mills, & Airasian, 2009). The data was presented in Table 13.0. Statements 2 and 3 neither increased nor decreased in points. Statements 1, 4, 6, 7 and 8 each increased by one point. For Statement 5, two points were gained.

Table 13

Median scores for Statements 1-8 pre-in-service and post-in-service

<table>
<thead>
<tr>
<th>Statement</th>
<th>Median (pre-in-service)</th>
<th>Median (post-in-service)</th>
<th>Difference (post – pre)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>+1</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>4</td>
<td>+1</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>4</td>
<td>+2</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>4</td>
<td>+1</td>
</tr>
<tr>
<td>7</td>
<td>3</td>
<td>4</td>
<td>+1</td>
</tr>
<tr>
<td>8</td>
<td>3</td>
<td>4</td>
<td>+1</td>
</tr>
</tbody>
</table>
Results and Interpretation

The original research question (“what is the impact of a pediatric palliative care in-service on PICU nurses’ attitudinal scores on providing pediatric palliative care?”) was considered in interpreting the data and discussing results. Analysis of the data supported the hypothesis that completing a pediatric palliative care in-service increases nurses’ attitudinal scores on providing pediatric palliative care.

Survey analysis of modal data and median data supported this hypothesis for the overall impact of the in-service. In terms of statements related to educational barriers, the negative groups decreased and the positive statements increased for Statements 1 (“I have received adequate formal pediatric palliative care education”), 2 (“I understand what pediatric palliative care entails”), 4 (“I can competently incorporate pediatric palliative care with curative therapies), and 5 (“I understand my state’s laws regarding pediatric palliative care”) following the in-service. The median scores for each of these statements reflected this by increasing except for Statement 2 which did not change. For Statement 1, the strongly disagree group dropped by 4.4%, the disagree group dropped by 26.1%, the agree group increased by 26.1%, and the strongly agree group increased by 4.3%. For Statement 2, the disagree group decreased by 8.7%, the neutral group increased by 8.7%, and the strongly agree group increased by 17.4%. Although the trend increased overall, the increase was too slight to be captured by the median for Statement 2. Interestingly, Statement 3 (“I know when to suggest pediatric palliative care for my patients”) was unique in that disagree groups increased (by 8.7%), the agree statement decreased (by 26.1%), and the strongly agree group increased (by 26.1%) showing a variance of results. Like Statement 2, Statement 3’s median did not change. This may have resulted from those who were neutral or who agreed shifting their response to disagreed after acquiring new information.
from the in-service. Many health care providers, PICU nurses included, believed that the suggestion is made much later than suggested by national guidelines. For Statement 4, the strongly disagree group decreased by 4.3%, the neutral group decreased by 8.7%, and the strongly agree group increased by 13.0%. The medians for Statements 1 and 4 each increased by one point (from two to three and three to four respectively). For Statement 5, the disagree group decreased by 43.5%, the neutral group decreased by 13.0%, the agree group increased by 43.5%, and the strongly agree group increased by 13.0%. Statement 5’s median had the largest increase at two points (from two to four) likely due to the fact that state laws are not commonly included in the literature. To capture these, individual state legislature must be searched regularly.

Statement 6 (“I can competently discuss pediatric palliative care with patients and parents”) was related to parental barriers. The negative and neutral groups decreased and the positive statements increased in percentage. After the in-service, the strongly disagree group dropped by 4.4%, the disagree group dropped by 17.4%, and the neither disagree nor agree group dropped by 13.0%. The agree group climbed by 17.4% while the strongly agree group climbed by the same percentage. The median score for this statement climbed one point from three to four.

In terms of statements related to hospital barriers, the negative groups decreased and the positive statements increased for Statements 7 (“I can competently discuss pediatric palliative care with the PICU team”) and 8 (“I know what resources the hospital offers staff providing pediatric palliative care”). For Statement 7, the disagree group dropped by 21.7% and the neutral group dropped by 17.4%. The agree group climbed by 21.8% and the strongly agree group by 17.4%. For Statement 8, the strongly disagree group dropped by 4.3% and the disagree group
dropped by 39.2%. The agree group increased by 39.1% and the strongly agree group increased by 4.4%. The median scores increased by one point from three to four for both statements.

**Summary**

From August to October 2012, surveys were conducted to assess nurse attitudes on providing pediatric palliative care before and after and in-service on the topic. Twenty three nurses participated. Statements on educational barriers, parental barriers, and hospital barriers were rated by the nurses pre-in-service and post-in-service on Likert scales. Data were presented in several tables. Analysis of data, particularly mode and medians, revealed an overall improvement of nurse attitudinal scores post-in-service. Thus, the hypothesis that completing a pediatric palliative care in-service increases nurses’ attitudinal scores on providing pediatric palliative care was supported. In Chapter 5, the researcher presents a discussion and conclusions.
Chapter 5: Discussion and Conclusions

Overview

Pediatric Intensive Care Unit (PICU) nurses face many barriers in providing pediatric palliative care. The majority of children who die do so in the PICU setting. Despite the American Academy of Pediatrics (AAP) recommendations and the Institute of Medicine (IOM) mandates, children with life-limiting illness often have no palliative care involvement. PICU nurses, in particular, are left with the stress and responsibility of providing and coordinating such care. In addition to the inherent stress of caring for children with life-limiting diagnoses, PICU nurses are often ill-prepared for and ill-supported in the provision of such care. A review of the literature revealed three main types of barriers to providing pediatric palliative care nurses experience: education related, parent related, and hospital related.

How to best address this problem has yet to be discovered. Given the large nursing educational deficit on pediatric palliative care, an in-service is a simple method of improving nurses’ attitudinal scores on providing such care. The research question was “what is the impact of a pediatric palliative care in-service on PICU nurses’ attitudinal scores on providing pediatric palliative care?” The researcher hypothesized that an in-service on pediatric palliative care would increase nurses’ attitudinal scores on providing pediatric palliative care. This might ultimately improve palliative care provided to pediatric patients by increasing patient satisfaction and patient outcomes. It might also be useful in terms of improving employee mental health status, employee attendance, and employee retention rates.

Discussion

From August to October 2012, surveys were conducted to assess nurse attitudes on providing pediatric palliative care before and after and in-service on the topic. The hospitals’ SurveyMonkey® account was used. The researcher presented an in-service focused on barriers
to the nurses after the initial survey. Twenty three (out of 24) nurses participated. Statements on educational barriers, parental barriers, and hospital barriers were rated by the nurses pre-in-service and post-in-service on Likert scales.

Responses were converted to a number so that attitudes could be measured via use of descriptive statistics. “Strongly Disagree” was converted to 1, “Disagree” to 2, “Neither Disagree nor Agree” to 3, “Agree” to 4, and “Strongly Agree” to 5. Percentages of nurses who scored one through five for each item were calculated. In addition, median scores were calculated. Sample size, return rate, response rate, and percentages were calculated. Descriptive data were presented in tables.

Finally, comparisons between the pre-in-service survey and the post-in-service survey were made. Percentages of nurses who scored one through five for each item were calculated as well the mode. How much scores had increased or decreased post-in-service was calculated. Descriptive data were presented in tables. Median scores were also calculated pre-in-service and post-in-service. Analysis of data, particularly mode and medians, revealed an overall improvement of nurse attitudinal scores post-in-service. Thus, the hypothesis that completing a pediatric palliative care in-service increases nurses’ attitudinal scores on providing pediatric palliative care was supported.

Based on these results, the facility can adopt the in-service as a simple, low cost method of improving PICU nurses’ attitudinal scores on providing pediatric palliative care. It could be offered to new employees along with annual updates for regular staff. Further, the in-service could be adapted and adopted by other units (such as the Neonatal Intensive Care Unit) or even offered to other facilities to improve nursing attitudinal scores about pediatric palliative care.

Implications
Strengths of the project include simplicity and cost-effectiveness. The barriers encountered by nurses are well established in the literature. Once the in-service is created, it can easily be emailed to staff, assigned as a computer based learning module, or presented in poster form as the least expensive means of staff education. The in-service could be updated yearly as feedback is received from participants and to ensure it aligns with current legislature and guidelines.

If the budget allows for more education, in-services can be offered in person. At the very least, the researcher and Nurse Educator could be a resource for staff on the topic. The in-service could be offered to all new employees to the unit and as an annual update for all employees. This could ultimately lead to the facility following AAP recommendations and meeting IOM mandates regarding children with life-limiting illness having palliative care involvement.

The researcher received much positive feedback from staff regarding the in-service’s usefulness. Undoubtedly, the staff is exemplary in their dedication to quality care. This was exhibited by not only their years of experience, specialty certifications, high levels of education, and clinical excellence rewards but also by the response rate of the survey. One of the largest challenges of survey research is getting participants to respond. Participation was voluntary and this group had a 95.8% response rate. The one nurse who did not respond was on a personal leave of absence.

**Limitations**

The study assumed that the only independent variable in the time between the pre-in-service survey and the post-in-service survey is the in-service itself. In reality, the world is more complex and less controllable than that. Experiences could have also affected attitudinal scores.
There had been deaths of children with life-limiting diagnosis unit during the time of the study. Also, there was interaction between the researcher and the participants during the in-service which may have also affected scores.

It would be beneficial for the study and in-servicing to be multidisciplinary. One of the fundamental barriers to pediatric palliative care for children with life limiting diagnosis is lack of physician referral. This project attempted to address that barrier indirectly in terms of the PICU nurses discussing the subject with the PICU team (physicians included). It would likely be worthwhile to have surveying and in-servicing of physicians regarding the topic in addition to nurses.

External validity is determined by how generalizable the results of a study are. This study has low external validity. Generally, inferential statistics are used to reveal how likely the results from the sample population would be generalizable to the larger population. However, inferential statistics are generally not useful for survey designs with a small sample size (Gay, Mills, & Airasian, 2009). Even though the response rate was high (95.8%), the sample size was small (n=23). Larger sample size and replication of the study are essential to establishing external validity.

**Recommendations**

1. **Provide in-servicing on palliative care to nurses upon hire and yearly**

   Internal validity of the research is determined by evaluating if the tool (the survey) actually measures what it was designed to measure (attitudes on pediatric palliative care) (Gay, Mills, & Airasian, 2009). Surveys can be effectively used to collect data about opinions. Given the overall trend of increases in scores, it appears as though the questions were clear and that the in-service was helpful to the PICU nurses.
In the same vein, a multidisciplinary approach throughout surveying and in-servicing may have been useful as the team approach to problems is often utilized in PICU’s. The researcher requested from the facility to have the in-service include a PICU physician, Palliative Care physician, Employee and Assistance Program worker. Each would have presented information on pediatric palliative care and collaboration with nursing. In addition, the researcher wanted to present case scenarios to the participants and the other disciplines. Collectively, the participants would have worked on solutions. Undeniably, adults learn best in dynamic, interactive learning environments. Unfortunately, this would have required much more employee time and, therefore, paid hours, so it was declined by Management.

2. Improve internal validity for future studies

It would also have been beneficial to triangulate the data from the study. Using a mixed methodology of quantitative and qualitative methods would have added richness to the study. Indeed, complex human interactions are oversimplified in quantitative studies. For instance, the researcher could have attended daily multidisciplinary rounds before and after the in-service in order to observe for any attitude changes regarding the topic in terms of nurse discussion and actions. Referrals to the Palliative Care team could have likewise been investigated by the researcher. Parent surveys could have been developed and used to evaluate parental views on the subject. The researcher could have investigated whether the in-service impacted patient satisfaction. Doing so would have made the study much more time-consuming than the allotted three months and more labor-intensive than one researcher could manage.

3. Improve external validity for future studies

In order to improve the study, it would be necessary to increase the sample size. As all nurses in the unit except for one participated in the study, it would have been necessary to
expand the study to other facility. Further, including another institution would have added validity to study via replication. Data results from various institutions could have been compared to the one another. Once the sample size is increased, inferential statistics could be applied to evaluate external validity.

Conclusions

Caring for children with life-limiting diagnoses presents unique stresses and challenges for nurses. The situation feels inherently “wrong” and in an attempt to correct said “wrongness,” care is often aggressive and completely curative in nature even when it is futile. All too often, the usefulness of pediatric palliative care for these children is overlooked. Barriers to such care are well defined in the literature. This is tragic given that utilizing palliative care in conjunction with curative therapies vastly improves patient satisfaction and outcomes. Patients, families, and staff are more satisfied with cares when palliation is involved. In addition, the AAP has developed recommendations and the IOM has developed palliative care mandates for children with life-limiting diagnoses. Health care facilities must begin to address this deficit. This can be a challenge in terms of budgetary constraints. Indeed, the researcher faced several barriers in this area. Institutional Review Board limits and fees, research project time constraints, and employee time constraints (due to budget constraints) were all barriers the researcher overcame in the completion on this project.

Likert surveys were completed by 23 PICU nurses before and after an educational in-service on pediatric palliative care. Analysis of data, particularly mode and medians, revealed an overall improvement of nurse attitudinal scores post-in-service. Thus, the hypothesis that completing a pediatric palliative care in-service increases nurses’ attitudinal scores on providing pediatric palliative care was supported. The improvement in attitudinal scores along with the
nurses’ dedication to the project were inspiring and rewarding to the researcher. The inherent “wrongness” of children having life-limiting diagnoses cannot be changed. What can be improved is the type of care they receive as well as the support offered to nurses who care for them.
References


Appendix A

Likert Scale Survey of PICU RN's Attitudes on Pediatric Palliative Care

[Image of survey form]

Thank you for taking the time to complete this survey. Pediatric palliative care is an important topic for our unit. This data will be used to help our patients as well as assist me in completing my Master's program.

The survey should take less than 5 minutes to complete. Your responses will be cleared once data has been reviewed.

Thank you again for your participation.

Catherine Thomas

1. What is your age?
   - 20-24
   - 25-30
   - 31-35
   - 36-40
   - 41-45
   - 46-50
   - 51-55
   - 56-60
   - 61-70

2. What is your gender?
   - Female
   - Male

3. What is your level of nursing education?
   - Diploma
   - Associate's Degree
   - Bachelor's Degree
   - Master's Degree

4. How many years of PICU experience do you have?
   - Less than 2
   - 2-5
   - 6-10
   - 11-15
   - 16-20
   - Greater than 30

http://www.surveymonkey.com/s/... 10/20/2012
5. I have received adequate formal pediatric palliative care education.
- strongly disagree
- neither disagree nor agree
- neither agree
- strongly agree

6. I understand what pediatric palliative care entails.
- strongly disagree
- neither disagree nor agree
- neither agree
- strongly agree

7. I know when to suggest pediatric palliative care for my patients.
- strongly disagree
- neither disagree nor agree
- neither agree
- strongly agree

8. I can competently incorporate pediatric palliative care with curative therapies.
- strongly disagree
- neither disagree nor agree
- neither agree
- strongly agree

9. I understand my state’s laws regarding pediatric palliative care.
- strongly disagree
- neither disagree nor agree
- neither agree
- strongly agree

10. I can competently discuss pediatric palliative care with patients and parents.
- strongly disagree
- neither disagree nor agree
- neither agree
- strongly agree

11. I can competently discuss pediatric palliative care with the PICU team.
- strongly disagree
- neither disagree nor agree
- neither agree
- strongly agree

12. I know what resources the hospital offers staff providing pediatric palliative care.
- strongly disagree
- neither disagree nor agree
- neither agree
- strongly agree

Thank you for completing this survey. When you finish, the window will close.

Appendix B

PowerPoint® Presentation on Pediatric Palliative Care

HISTORY
- In 1990, the World Health Organization introduced the concept of palliative care
- WHO's goal was to improve the quality of life for persons with life-limiting or life-threatening illnesses
- Palliative care is designed to treat the whole person, not just in terms of pain but any physical, psychological, or spiritual problems

PEDIATRIC DEFINITION
- WHO defines PPC as "the active and total care of the child's body, mind, and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease"
- It does not require to give up their PMD, to stop curative therapies, to be actively dying, or have an AND/DNR order

NATIONAL GOALS
- In 2000, the American Academy of Pediatrics (AAP) recommended integrating palliative care with disease-directed therapy early for any child with a life-limiting diagnosis
- In 2003, the Institute of Medicine (IOM) mandated PPC and end-of-life care initiatives

THE CURRENT STATE
- Over 55,000 children die in America each year
- The majority do so in the PICU setting
- Most pediatric patients with life-limiting or life-threatening diagnosis have minimal involvement of palliative care

BARRIERS
- Nurses are left to provide largely uncoordinated and aggressive care to their patients creating stress and turmoil for them, as well as the family
- The literature has established numerous barriers nurses experience to PPC including educational, parental, and hospital-related barriers
EDUCATIONAL BARRIERS

- ADN programs have no curriculum on any type of palliative care
- BSN programs have some curriculum on adult palliative care but not on PPC
- Most hospital precepting, learning, and mentoring programs have no curriculum on PPC
- Most certification programs (including CCRN) have no curriculum on PPC

OVERCOMING EDUCATIONAL BARRIERS

- Know when to refer for PPC: Early referral is associated with improved outcomes (itotically), improved patient satisfaction, and improved staff satisfaction

OVERCOMING EDUCATIONAL BARRIERS

- Know how to incorporate PPC with curative therapies: PPC can be planned in multidisciplinary rounds, family conferences, and debriefing sessions. Focus therapies on the patient’s pain, functional goals, mental status, respiratory status, and overall quality of life. It can include pain management, blood transfusions, even surgery, if it helps the patient meet their life goals.

OVERCOMING EDUCATIONAL BARRIERS

- Know state laws: In 2006, California passed the Nick Snow Children’s Hospice and Palliative Care Act which allows children with life-limiting illnesses to receive both PPC and curative therapies in the state of California for with no time limitation. Children receiving hospice care can also receive curative services if life expectancy is 6 months or less as certified by a physician.

PARENTAL BARRIERS

- Many parents do not know what PPC is
- Therapeutic communication is not always used hindering trust of hospital staff
- Language barriers hinder understanding and coordination of care as well as trust
- The term “Do Not Resuscitate (DNR)” has a negative connotation
- Parents often refuse to accept a life-limiting diagnosis and poor prognosis of their child
### OVERCOMING PARENTAL BARRIERS
- Explain PPC to the family: be sincere, honest, and use simple terms
- Communicate therapeutically: use eye contact, open body language, repeat your understanding, validate feelings, allow silences/tears
- Use translator phone and translators
- Use the positive term "Accept Natural Death (AND)" instead of DNR for end-of-life choices
- Do not offer false hope regarding a life-limiting diagnosis or poor prognosis

### HOSPITAL BARRIERS
- MD's are more likely to think that families are well informed and that ethical issues are well discussed within PICU team and with families than nurses are
- Many hospitals have no Palliative Care Teams and even fewer have teams that will provide PPC
- Staffing matrixes rarely account for the psychosocial and coordinating needs of the palliative care patient especially in the active dying phase

### OVERCOMING HOSPITAL BARRIERS
- Know your resources: the PICU team, the Palliative Care Team, LSW, the Child Life Team, the Bioethics Committee, Nurse Educator, Clinical Nurse Specialist
- Advocate for proper staffing: account for the psychosocial demands of the patient as well as coordination of services especially in the active dying phase
- Take care of yourself: healthy relationships, healthy habits/hobbies, the Employee Assistance Program (debriefing, counseling, referrals)

### REFERENCES
Appendix C

National Institutes of Health Office of Extramural Research Certification

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that Catherine Thomas successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 06/16/2012

Certification Number: 937937
Appendix D

Facility Permission for Capstone Project

6/22/12

Western Governors University
Institutional Review Board

The purpose of this letter is to grant Catherine Thomas, a student at the Western Governors University, permission to conduct an Evidence Based Project as her Capstone project on the impact of providing a pediatric palliative care inservice to pediatric intensive care RNs. This project entails a pre-inservice survey of attitudes towards pediatric palliative care, an inservice, and a post inservice survey of attitudes towards pediatric palliative care.

was selected because the organization is the student's employer, and the EBP/Research Council seeks to increase the number of EBP projects conducted at the organization. The Capstone project activities will take place from July 1st through December 31st 2012.

As a Clinical Nurse Specialist and a member of the EBP/Research Council, authorized to act on behalf of on these matters, I do hereby grant permission for Catherine Thomas to conduct this capstone project on attitudes towards pediatric palliative care at