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## **Pediatric Palliative Care Training to Advance Nurses' Knowledge and Increase Patient Referrals**

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## **Pediatric Palliative Care Training to Advance Nurses' Knowledge and Increase Patient Referrals**

### **Introduction**

#### **Problem Description**

The overall prevalence of children living with life-threatening conditions is increasing due to advances in pediatric medical/surgical care. In addition, the total number of deaths in children with complex illnesses has recently decreased, meaning children with chronic illness and complex health care needs are living longer. Both increased prevalence and increased longevity escalate the demand for pediatric palliative care services (Friebert & Williams, 2015).

Pediatric palliative care is an interdisciplinary collaboration that seeks to improve the quality of life of all children with life-threatening conditions and their families. According to the National Consensus Project for Quality Palliative Care, palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care addresses physical, intellectual, emotional, social, and spiritual needs throughout the continuum of illness (Ferrell et al., 2018).

Palliative care can improve patients' physical and emotional well-being and overall quality of life (Groh et al., 2013; Kaye et al., 2016). Palliative care involvement has been shown to result in better assessment and management of burdensome symptoms (Osenga et al., 2016; WHO, 2018), fewer invasive procedures (Keele et al., 2013), and more integrative and complementary therapies (Osenga et al., 2016). Beneficial outcomes from palliative care involvement also extend to caregivers. Parents of children receiving palliative care have also reported improved quality of life, decreased self-perceived burdens, and less emotional stress

(Groh et al., 2013).

Inadequate healthcare provider training and lack of education have been identified as barriers to providing adequate palliative care, especially pediatrics (Feudtner et al., 2013; WHO, 2018). Specifically, the American Association of Colleges of Nursing (AACN) has identified gaps in palliative care education within nursing programs (AACN, 2019). As a result, there has been a call to educate further healthcare professionals on providing better quality palliative care. According to the literature, expanded education could facilitate more accessible and effective care, which, when provided, has shown to lead to better outcomes for providers, patients, families, and even financial interests (Groh et al., 2013; Osenga et al., 2016; Smith et al., 2014; Szymczak et al., 2018).

### **Rationale for the Intervention: Palliative Care Education**

Education is an essential component of transforming palliative care, and health care professionals, particularly nurses, report that they want more education and training for palliative and end-of-life care (Ferrell et al., 2010). In addition, the literature supports that specific training increases registered nurses' knowledge of palliative and end-of-life care (Balicas, 2018; Bishop et al., 2019; Harden et al., 2017; Haugh, 2015; Haut et al., 2017; O'Shea & Mager, 2019; Whitehead et al., 2010; Widger et al., 2018).

One of the most common curricula noted in the literature was the End-of-Life Nursing Education Consortium (ELNEC). ELNEC provides a core curriculum for palliative care that can be delivered to nursing students, practicing nurses, nurse leaders, and researchers (Ferrell et al., 2015). Further, ELNEC could serve as a platform for inter-professional education for nurses, interns, residents, and other providers in training who may otherwise have limited opportunities to explore palliative content together (McAndrew, 2020).

Several studies on palliative care analyzed patient referrals as an outcome of the intervention (Anderson et al., 2017; McAndrew, 2020; Newton & Sebbens, 2020; Reville et al., 2013; Widger et al., 2018). In these studies, education was not the sole intervention but included in a larger bundle of interventions. Other interventions included standardized screening tools, designated order sets, and a floating hospice team. Authors also found that palliative care training led to better attitudes regarding palliative care (Harden et. al., 2017; Haut et. al., 2017; O'Shea & Mager, 2019), increased comfortability with providing palliative care (Newton & Sebbens, 2020), decreased anxiety (Whitehead et. al., 2010), and better communication skills regarding palliative care (Anderson et. al., 2017; Bishop et. al., 2019).

### **Specific Aims of the Intervention**

The purpose of this evidence-based quality improvement (QI) project was to implement an educational intervention using the ELNEC curriculum with nurses in a PICU. The intervention aimed to improve nurses' knowledge and, subsequently, the number of patients referred for palliative care services.

## **Methods**

### **Setting and Context**

The educational intervention was held with nurses in a 16-bed PICU at a private, independent, not-for-profit children's hospital in eastern Tennessee.

Prior to this intervention, only 13% (N=6) of the nurses had received formal palliative care training. Only one nurse had previously received previous ELNEC training. Years of nursing experience varied, with 14 of the 46 (30%) nursing staff with less than five years of experience and 20 (43%) with more than 10 years of experience.

### **Project Design and Interventions**

The guiding framework selected for this project was the IOWA Model (Iowa Model Collaborative, 2017). The model serves as a framework to improve patient outcomes, enhance nursing practice, and monitor healthcare costs. This evidence-based quality improvement project was a pre-and posttest repeated measures design. Participants consisted of a convenience sample of PICU nurses participating in their quarterly mandatory hospital education requirements.

The intervention for this project was an educational workshop teaching the pediatric content from the End-of-Life Nursing Education Consortium (ELNEC) content, specifically focused on the palliative care content. Educational sessions were held on the hospital campus and offered to all PICU nurses over a 7-day period in 2021. Participants completed a PowerPoint presentation with information guided by ELNEC Pediatric Curriculum, followed by a face-to-face educational session with the lead author. The face-to-face session consisted of two case studies focused on integrative therapies and palliative care services. There was also a discussion about the importance of palliative care and referrals. Following the case studies, participants were educated about how to consult the palliative care team through electronic order entering. The ability for nurses to self-initiate a palliative care referral was a new process in which nurses could consult the palliative care coordinator without a provider's order.

### **Measures**

All participants completed a demographic survey that included gender, highest education, years of nursing experience, and previous palliative care training (Table 1). Nursing knowledge was measured at three time points: pre-intervention, immediate post-intervention, and four weeks post-intervention. The knowledge assessment tool was composed of 16 items taken from ELNEC's pediatric modules (Table 2). These questions were used with permission from Relias Academy, ELNEC's educational forum. These questions measure the application of knowledge.

A total score was calculated, indicating the total number of correct items, with a possible score ranging from 0 (low knowledge) to 16 (high knowledge). Results were expressed as percentages of correct answers.

The number of palliative care referrals pre- and post-intervention was also measured. The data for both PICU admissions and the number of palliative care referrals were collected from the electronic medical record. The patient's eligibility was based on the admission diagnosis being a chronic or life-threatening condition.

The knowledge assessments were graded automatically by the hospital's learning management system. The pre-assessment and post-assessments were matched based on name; however, they were stripped of identifying information prior to data analysis. The list of palliative care referrals was provided by a hospital's palliative care team member. Identifying patient information was removed before analysis.

### **Analysis**

Descriptive statistics were used to detail the sample characteristics, knowledge scores, and the number of palliative care referrals. A Repeated Measures ANOVA was used to test a significant difference between pretest, posttest, and follow-up test four weeks after the intervention. To determine how they differ, pairwise comparisons were conducted. Performances were then compared by years of experience using repeated measures ANOVAs. Chi-square tests were used to compare palliative care referrals pre- and post-intervention. Non-directional statistical tests were performed with the level of significance set at 0.05 for all tests. SPSS version 24 was used to conduct the statistical analysis.

### **Ethical Considerations**

Human subject's protection was ensured through the University and the hospital

Institutional Review Board (IRB). The project was determined to be exempt from IRB review. The pre-and post-knowledge assessments were de-identified before analysis. The excel sheet of PICU admits, and palliative care referrals were stripped of patient names and account numbers before analysis. There were no additional economic implications to consider as participants were required to attend and were paid their hourly wage. There was no additional cost to the hospital or nursing unit. The electronic information was collected and saved in a HIPPA compliant OneDrive. Only members of the project team had access to the data.

## **Results**

### **Sample**

A total of 46 nurse participants participated in this educational intervention (Table 1). The demographic survey showed that most participants were female (93.5%). The highest level of education ranged from diploma to doctorate, with the majority having their bachelor's degree (63%). Again, only a small percentage of participants had previous palliative care training (13%), and just one reported ELNEC as the curriculum (2.2%).

### **Knowledge Scores**

The repeated measures ANOVA showed that all time points significantly differed ( $p < .05$ ). There was a significant increase from pretest to immediate posttest ( $p < .05$ ). There was a significant decrease from the immediate posttest to four-week follow-up ( $p < .001$ ). However, the four-week follow-up test was still significantly higher than the original pretest ( $p < .05$ ). The mean scores for all three assessments were pretest (73.2), posttest (91.7), and four-week follow-up (86.4). Three participants did not complete the four-week follow-up test, and therefore their scores were not included ( $n=43$ ). Changes across time did not differ by years of experience

( $p=.857$ ). Changes across time for the variables of gender, education, status, or palliative care training as the frequencies were not evenly distributed.

### **Palliative Care Referrals**

A series of chi-square tests was performed to compare the amount of palliative care referrals both before and after the educational intervention (Table 4). The number of referrals was compared to the total number of PICU admissions. Additionally, referrals were then compared with patients with at least one chronic diagnosis, excluding patients with acute/transient conditions, as palliative care is most appropriate for patients with long-term, chronic conditions. During the pre-intervention period (12/08/21 to 03/08/21), there were 143 total PICU admissions, with 53 having at least one chronic diagnosis. During the post-intervention period (03/09/21 to 06/08/21), there were 185 total PICU admissions, with 68 having at least one chronic diagnosis. The total number of all admitted patients receiving pain/palliative care consults significantly increased from 7.7% (11 patients) pre-intervention to 15.7% (29 patients) post intervention. ( $p=.028$ ). Palliative care referrals also increased for patients having only chronic conditions ( $p=.011$ ). During pre-intervention, 11 out of 53 (20.8%) pre-intervention received palliative care referrals compared to 29 out of 68 (42.6%) during post-intervention ( $p=.011$ ). These consults encompassed multiple types of referrals including strictly pain services, strictly palliative care services, strictly music/massage services, and then any combination of these services.

Of most interest to this project was the number of patients receiving palliative care services. Although pain management services and music/massage therapies are important, they were not the focus of this project, therefore, patients who only received pain evaluations or only music/massage were excluded when examining changes in palliative care services. Palliative

care had to be involved in some capacity inclusion in analysis. For all PICU admissions, 2 out of 143 (1.4%) received palliative care consults pre-intervention, and 14 out of 185 (7.6%) post-intervention received palliative care referrals. This was a significant increase ( $p=.010$ ). Palliative care consults also significantly increased in patients with chronic diagnosis only, with 2 out of 53 (3.8%) receiving consults during pre-intervention, while 14 out of 54 (20.6%) received consults during post-intervention ( $p=.007$ ).

## **Discussion**

### **Interpretation**

Overall, scores for palliative care knowledge increased from pre- to post-intervention. This supports results from previous projects involving the use of an educational intervention to improve nursing knowledge (O'Shea & Mager, 2019; Harden et al., 2017; Haugh, 2015, Widger et al., 2018). In addition, the number of palliative care referrals for PICU patients increased significantly. Increased patient referrals secondary to an educational intervention for nurses was not a measure documented in the literature before this. This specialized training had not been offered at this institution prior to this, but the palliative care team has been pleased with the increased use of its services to meet the needs of patients. Previous literature has found that palliative care involvement can lead to better patient outcomes and more quality care for patients/families. Still, conclusions cannot be drawn from this work due to a lack of time and rigor.

### **Limitations**

This project had several limitations. The sample size was small and took place in one nursing unit at a single institution. The sample had poor variability, with most participants being female and Caucasian. Another limitation is that the knowledge assessments were not proctored.

It is unknown if participants could have collaborated during test-taking. In addition, the lead author only had access to a patient summary (not the entire medical record) that contained only the chief complaint diagnosis. Other chronic diagnoses could have been missed and thus excluded from the data.

### **Conclusion**

This evidence-based educational intervention significantly increased nurses' knowledge and the number of patients receiving palliative care referrals. The improvements suggest that palliative care training for PICU nurses using the ELNEC Pediatric Curriculum can improve nurses' knowledge of palliative care and increase nurse-initiated palliative care referrals. This could lead to improved patient outcomes by connecting patients to services known to improve physical and emotional well-being and overall quality of life.

These findings can be sustained through offering more palliative care training sessions and offering them to the entire organization rather than just one unit. Plans for sustainability also include more interdisciplinary team members, including providers, social workers, and chaplains in educational efforts. Another sustainability strategy includes implementing a standardized palliative care referral tool to be used by bedside nurses. Further studies should include longer timelines and focus on patient/family perspectives, patient outcomes, and cost-analysis.

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**Table 1**

## Demographics

Variable	Options	Count	Percentage
Gender	Female	43	93.5
	Male	3	6.5
Highest Education	Diploma	2	4.3
	ASN	11	23
	BSN	29	63
	Masters	3	6.5
	Doctorate	1	2.2
Years of Experience	Under 5	14	30.4
	5-9	12	28.1
	10+	20	43.5
Previous Training	Yes	6	13
	No	40	86
ELNEC Training	Yes	1	2.2
	No	2	6.5
	Unsure	3	4.3

**Table 2**

## Multiple Choice Knowledge Questions

Question	Description
1	You are the preceptor for Jerry. Which statement by Jerry indicates he needs more training on the principles of palliative care for children?
2	Which of the following levels of listening requires the most energy and involvement?
3	You are working with the Rodriguez family whose 10-year-old daughter has been diagnosed with heart failure. The mother looks at you and says, "I just can't believe that this happened to my family." How should you respond?
4	Which of the following statement about communication is true?
5	What is the act of agreeing with a medical decision that is made by an individual who is not yet of legally binding age?
6	Sam, a 17-year-old boy with Ewing sarcoma, wants to stop chemotherapy and radiation as the doctors have indicated that chances of survival are minimal. His parents though, refuse to stop treatments. What should the palliative care team do?
7	You are working with Zane, a new member of the interdisciplinary team. Which of the following statements by Zane indicates more education on pain assessment in children?
8	What is the number one site of death for children?
9	The ethical principle of justice refers to:
10	What word describes the outward, social expression of a loss?
11	Which should you not do when confronted with conflict?
12	What is typically the appropriate age when a child can be considered for assent?
13	What percentage of children experience pain that is severe enough to interfere with daily functioning?
14	Which of these would be an example of an objective sign of fatigue?
15	True or false: Palliative care teams function to provide both pharmacological and non-pharmalogical treatments for pain?
16	True or false: Palliative care is a cost-effective method of providing care?

Modified tool used with permission ELNEC Section of Relias Learning (2021).

<https://elnec.academy.reliaslearning.com/>

**Table 3**

## Knowledge Scores

Assessment			
	N	Mean Score	p-Value
Pre-intervention	46	73%	
Immediate post-intervention	46	92%	
4-week post-intervention	46	86%	
Pre to immediate post-test	46		.005
Pre to 4-week post-intervention	46		.005
Immediate post-intervention to 4-week post-intervention	46		<.000

**Table 4**

## Palliative Care Referrals

Category	Pre (%)	Post (%)	p-Value
Pain/Palliative (All Admissions)	7.7	15.7	.028
Pain/Palliative (Chronic conditions)	20.8	42.6	.011
Palliative (All Admissions)	1.4	7.6	.010
Palliative (Chronic conditions)	3.8	20.6	.007