**Doctor of Nursing Practice Inquiry Project**

**Executive Summary**

***Testing a Pediatric Palliative Care Education Workplace Intervention***

**Courtney James**

**Purdue University**

**EXECUTIVE SUMMARY**

**Problem Statement and Significance**

Pediatric palliative care is a beneficial service that aims to improve quality of life for children and their families suffering from serious illness (National Institute of Nursing Research, 2015). Through focus on the needs of the child and family, palliative care has the ability to increase comfort for its recipient (National Institute of Nursing Research, 2015). Despite its benefit, palliative care, in the adult and pediatric setting, is underutilized. An estimated 400,000 children and families who would benefit from palliative care services do not receive them (Center to Advance Palliative Care [CAPC], 2019). Although several barriers have been identified as causes to underutilization, the lack of palliative care provider education is one that directly impacts both providers and patients (Aldridge et al., 2015). Nurses are not exempt from this impact; and while they cannot initiate palliative care consults, nurses who are familiar with palliative care play crucial roles in advocating for this service (Fitch et al., 2015). Palliative care education has shown to be effective in improving knowledge and changing attitudes toward palliative care among nurses (Harden et al., 2017; Hughes et al., 2006; O’Shae & Mager, 2019; McClement et al., 2005). Current palliative care education focuses on adult palliative care. To address this gap in pediatric palliative care training, we created and implemented a brief online education that introduced a general overview of pediatric palliative care. We tested the effectiveness of this training on increasing awareness and improving perceptions of palliative care among registered nurses working in a hospital setting.

**Methodology**

A brief online education video was created to provide a general overview of pediatric palliative care. Eligible registered nurses across six clinical units at an academic pediatric hospital were recruited to complete a pre-test online education, and a post-test. The pre- and post-tests included questions assessing awareness of and perceptions toward palliative care using the Palliative Care Quiz for Nursing (PCQN). (Ross et al., 1996). The questions can be seen in Appendix A. The four questions had the following response options: “true”, “false”, and “I don’t know” (Ross et al., 1996). Three open-ended questions were used to gather qualitative data on hospice and palliative care definitions and the likelihood of suggesting a pediatric palliative care consult (see Appendix B). The project was IRB approved and registered nurses were recruited via email and flyers which included a Qualtrics link to the pre-test, education, and post-test. Data was collected for seven weeks. Descriptive statistics were used to summarize frequencies, central tendencies, and variation of demographic data. McNamar Tests were used to determine if a statistical significance existed between PCQN pre- and post-test responses. Open-ended responses were coded into recurring categories to identify trends before and after the education.

**Results**

In total, 43 out of 244 individuals responded to the survey. Forty-eight percent (n=21) of participants completed the survey. The 21 completed surveys were used for the analysis. Analysis of demographic data using descriptive statistics revealed that 95.2% of participants were female, 85.7% had a Bachelor of Science in Nursing, 85.7% were White, and 0% identified as Hispanic or Latino. Participants ranged in age from 24 to 50 years with a mean age of 30.9 years. Among the 11 practice specialties included in the study, a majority of participants, 61.9%, practiced within the pulmonary specialty. Years of experienced ranged from 1 to 27 years with 66.7% of participants having practiced as a registered nurse for 5 years or less (SD: 6.93). Out of the 66.7% of participants with less than 5 years of practice, 19.1% (n=4) of participants had 0-2 years of nursing practice experience and 47.7% (n=10) of participants had 3-5 years of nursing practice experience. About one third (33.3%) of participants received prior palliative care training, with 28.6% having completed an End-of-Life Nursing Education Consortium (ELNEC) course in the past and 4.6% having received palliative care training in their undergraduate coursework.

There was no statistically significant difference between PCQN question scores pre- and post-intervention. Responses from the three open-ended questions revealed changes from pre- to post-test in how participants defined hospice care and palliative care. Hospice care was defined similarly pre- and post-test; however, more participants included “less than 6 months of life” in the post-test responses. Less variation was seen among post-test responses when defining palliative care. Three recurring topics were mentioned in post-test responses: holistic, early initiation, and quality of life. Participants also reported that they were more likely to encourage a palliative care consult after viewing the palliative care education video. See Appendices C-F for study results.

**Discussion**

The aim of our study was to examine the impact of a brief, online pediatric palliative care video on nursing awareness and perceptions of palliative care. We anticipated that the pediatric palliative care education video would increase nursing awareness and improve perceptions of pediatric palliative care. Analysis of pre- and post-test PCQN questions revealed no statistically significant difference in nursing awareness and perceptions of pediatric palliative care after the education. However, responses from the open-ended questions did reveal a change in how participants define hospice care, define palliative care, and their likelihood to encourage a pediatric palliative care consult. Although results were not statistically significant, our study suggests that a brief, online pediatric palliative care education video may be clinically significant in increasing nursing awareness of what hospice and palliative care are and improve perceptions of pediatric palliative care. The American Nurses Association advocates for increased pediatric palliative care learning opportunities, such as ours, for nurses in the workplace as it is lacking in nursing curriculums (ANA, 2017). Until nursing curriculums expand to include pediatric palliative care, it is essential that healthcare systems incorporate workplace palliative care education for their nursing staff (ANA, 2017; Kim et al., 2020). Implementation of brief, pediatric palliative care education videos similar to the one in our study may provide a short-term solution to the need for pediatric palliative care education opportunities.

Our study suggests that, without widespread pediatric palliative care education, there may be inconsistencies in how pediatric palliative care is defined, understood, and practiced. These inconsistencies may lead to confusion over when palliative care is appropriate and may decrease the likelihood of encouraging a pediatric palliative care consult. As a result, pediatric patients may miss out on beneficial services such as physical, psychological, social, and spiritual support that is offered in pediatric palliative care (Friebert and Williams, 2015). Incorporation of clear definitions of pediatric palliative care into healthcare organization policies may help to ensure a standardized definition of pediatric palliative care is shared across providers and help providers identify patients who may benefit from pediatric palliative care (Bergstraesser, 2013; CAPC, 2019).

Our study also suggests that nursing practice may be influenced by brief, online pediatric palliative care education videos. The increase in likelihood that participants would encourage a palliative care consult is promising because it reveals that there may be opportunities for culture change in relation to nursing practice. More pediatric palliative care education opportunities are essential as they may, ultimately, impact the quality of care offered to pediatric patients with serious and life-limiting illness and their families (i.e., effective communication, increased clinician confidence) (Pesut & Greig, 2018).

**Implications**

*Systems*

Our study suggests that a brief, pediatric palliative care education video may increase nursing awareness and improve perceptions of pediatric palliative care. Nurses may benefit from palliative care training and education opportunities to increase their awareness and perception of palliative care and, thus, lead to increased advocacy for palliative care implementation (Hagan et al, 2018). Providing routine, required, online trainings that are easily accessible and assigned to each nurse may keep nurses up-to-date on palliative care knowledge. To cater to hands-on learners, offering opportunities to complete rotations with palliative care providers may serve as an additional opportunity for the healthcare system to increase pediatric palliative care exposure. A recent study examined reciprocal shadowing between nurse and resident physician and noted increased understanding of each discipline’s role (Monroe et al., 2021). A program for nurses to shadow palliative care specialists may lead to increased understanding of the role of pediatric palliative care providers and increase their knowledge of the service and potential for suggesting palliative care. However, such trainings and education may not be viewed favorably and/or be sustainable without system-wide support for palliative care and a system-wide culture shift towards mainstreaming palliative care into every hospital unit (Aldridge et al., 2015). To increase awareness and improve perceptions of palliative care among nurses, a culture shift within the healthcare system is warranted.

Responses from the pre-test open-ended questions revealed that some participants were unsure of whether or not they would recommend a palliative care consult for their patients. Integration of a palliative care initiation recommendation form into the Electronic Medical Record (EMR) may serve as another way to help nurses identify patients who would benefit from pediatric palliative care services. Studies have examined the benefit of a palliative care screening tool, leading to an increase in the number of earlier palliative care consults and timely palliative care referrals (Begum, 2013; Paiva et al., 2020). While these studies examined adult palliative care consults, a similar system may be equally useful in the pediatric patient population. As a result of this type of systemic EMR change, nurses may have an improved understanding of when to encourage palliative care and increase the chances that patients and families will receive palliative care.

Our study also indicated varying definitions of palliative care among participants, suggesting widespread misconceptions and misunderstandings of palliative care across health care providers. Implementation of a pediatric palliative care policy at the system level that standardizes information on what palliative care is and who could benefit from it, may provide guidance for implementation and increase the number of palliative care consults. Please see the policy section for more information on how policy at the systems level may impact nurses and patients.

*Policy*

The variation in participant responses when defining palliative care in the pre-test highlights the need for consistency in language when defining palliative care. Hospital-based policies could provide standardized, clear definitions of palliative care. Nurses often reference policies to guide care and, for this reason, policies are easily accessible within the healthcare system. Hospitals should implement pediatric palliative care policies that incorporate a concise definition of pediatric palliative care and provide guidance on the types of pediatric patients that may benefit from palliative care service. The definition must be one that aligns with a current, widely-accepted definition (i.e., the World Health Organization’s [WHO] pediatric palliative care definition).

The creation of a consistent definition of palliative care and implementing a hospital policy to use this definition is further supported by Indiana stakeholder groups such as the Indiana Palliative Care and Quality of Life Advisory Council (IPCQLAC). IPCQLAC supports the development of a clear definition of palliative care. Additionally, IPCQLAC also suggests having policies in place to inform patients and families about palliative care services offered, and development of tools that would appropriately identify patients and families who would benefit from palliative care services (2019). As mentioned as a suggestion for a systems-level change, development of a pediatric palliative care trigger within the EMR system along with other system-wide changes are also policy-driven. Such trigger systems at the systems level must be integrated into the hospital policies on when pediatric palliative care is appropriate. Such policy is important to protect/shield nurses from co-workers who do not believe in using palliative care and from co-workers who may shame/blame nurses for suggesting palliative care even when the care is appropriate. Nurses may also feel more empowered to advocate for palliative care when a policy is in place to support their decisions to suggest palliative care.

*Economics*

Our study noted that some participants were unsure or unlikely to recommend a palliative care consult for their patient prior to the education video. Studies suggest that timely palliative care consults may result in cost-savings and reduced length-of-stay (Macmillian et al., 2019). Other nurses throughout the organization may agree with this response if not exposed to or familiar with palliative care. When used appropriately, palliative care identifies a relevant and appropriate treatment plan, utilizes available resources, and reduces hospitalizations resulting in cost savings for the healthcare system (CAPC, 2018). Additionally, palliative care services help healthcare systems achieve quality measures, such as shortened hospital stays and improved patient experiences, which further decrease healthcare costs (CAPC, 2018). In fact, palliative care consultations reduce healthcare costs by more than $3,000 per admission (CAPC, 2018). Increasing awareness and perception of palliative care among nurses and, thus, potentially increasing the likelihood that they will advocate for implementation of these services may indirectly and directly reduce healthcare costs. Integrating palliative care into healthcare systems, via suggestions provided in the systems implications section, may potentially reduce healthcare costs.

*Practice*

Our study suggests that nurse-led education videos may influence nursing perception on healthcare topics, such as palliative care. More opportunities for nurse-led pediatric palliative care discussions and education may impact nursing perceptions of palliative care and the likelihood of encouraging palliative care consults. In fact, nurses may feel more comfortable supporting pediatric palliative care if other nurses are leading efforts to create a more supportive workplace environment around palliative care, and leading efforts to increase quality care through palliative care initiatives (ANA, n.d.; ANA, 2017). When nurses see other nurses leading palliative care education, they may use this as an example to further empower and advocate for nurses to suggest pediatric palliative care. Thus, nurse-led pediatric palliative care education opportunities may empower other nurses to seek additional pediatric palliative care learning opportunities and create an atmosphere where pediatric palliative care inquiries are welcomed.

Nursing practice is also influenced by effective nursing leadership. Self-awareness and inspirational motivation are two effective leadership traits that support a positive work culture for nurses (Hughes, 2019). Nurse leaders, such as unit managers, can advocate for pediatric palliative care education by identifying their own awareness and perception of pediatric palliative care and motivate staff nurses to seek pediatric palliative care education opportunities. By participating in pediatric palliative care education opportunities, nurse leaders may set a positive example for staff nurses and encourage them to advocate for pediatric palliative care education opportunities.

Lastly, incorporating palliative care education into curriculums for pediatric-related certifications or nurse residencies may serve as an ideal way to increase palliative care exposure to nurses. The Institute of Medicine of the National Academies recommends that certifying bodies and healthcare systems require palliative care training in order for graduates to become certified and practice as a nurse (2014). By incorporating this education into requirements for nursing practice, it may help normalize palliative care and, thus, increase advocacy for palliative care. Additionally, exposure to palliative care through the above requirements may increase interest in palliative care and increase the number of nurses who seek extensive palliative care education or training. More trained nurses in palliative care may change perceptions and attitudes toward palliative care, leading to more open discussions among nurses and the health care team about palliative care.

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**Appendix A**

Table 1

*PCQN pre- and post-test questions*

|  |  |
| --- | --- |
| Pre/Post-Test Question 1 | Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration |
| Pre/Post-Test Question 2 | The provision of palliative care requires emotional detachment. |
| Pre/Post-Test Question 3 | The philosophy of palliative care is compatible with that of aggressive treatment. |
| Pre/Post-Test Question 4 | Suffering and physical pain are synonymous. |

**Appendix B**

Table 2

*Pre-/Post-test open-ended questions*

|  |  |
| --- | --- |
| Pre/Post-Test Question 5 | How would you define hospice care? |
| Pre/Post-Test Question 6 | How would you define palliative care? |
| Pre/Post-Test Question 7 | How likely, if at all, would you be to encourage a palliative care consult for your patient if he or she had a serious illness (e.g., cystic fibrosis, cancer, anoxic brain injury)? |

**Appendix C**

Table 3

*Demographic data results*

|  |  |
| --- | --- |
| ***Age*** | **% (n)** |
| 20 – 30 years | 57% (12) |
| 31 – 40 years | 28.5% (6) |
| 41 – 50 years | 9.5% (2) |
| 50+ years | 0% (0) |
| ***Sex*** |  |
| Female | 95.2% (20) |
| Male | 4.8% (1) |
| ***Degree Status*** |  |
| BSN | 85.7% (18) |
| ASN | 14.3% (3) |
| ***Race*** |  |
| White | 85.7% (18) |
| African American | 4.8% (1) |
| More than one race | 9.5% (2) |
| ***Ethnicity*** |  |
| Not Hispanic or Latino | 100% (21) |
| Hispanic or Latino | 0% (0) |
| ***Practice Specialty*** |  |
| Developmental Pediatrics | 14.3% (3) |
| Endocrine and Metabolism | 9.5% (2) |
| Gastroenterology | 4.8% (1) |
| General Surgery | 9.5% (2) |
| Hematology/Oncology | 4.8% (1) |
| Hospitalist | 4.8% (1) |
| Neurology | 9.5% (2) |
| Neurosurgery | 14.3% (3) |
| Orthopedic | 9.5% (2) |
| Pulmonary | 61.9% (13) |
| Urology | 14.3% (3) |
| ***Years of Experience*** |  |
| 0 – 5 years | 66.7% (14) |
| 0 – 2 years | 19.1% (4) |
| 3 – 5 years | 47.7 % (10) |
| 6 – 10 years | 14.3% (3) |
| 11 – 20 years | 9.5% (2) |
| 21+ years | 9.5% (2) |
| ***Previous Palliative Training/Education*** |  |
| Yes | 33.3% (7) |
| ELNEC | 28.6% (6) |
| Undergraduate coursework | 4.8% (1) |
| No | 66.7% (14) |

**Appendix D**

Table 4

*Recurring topics in open-ended responses: hospice care definition*

|  |  |  |
| --- | --- | --- |
| **Hospice Care Definition / Pre-Test** | **Topics** | **Number of Instances Topic /Phrase Appears in Participant Responses** |
|  | End of Life | 11 |
|  | Less than 6 months of dying | 5 |
|  | Dying/death | 4 |
|  | Comfort | 15 |
|  | Non-curative | 7 |
| **Hospice Care Definition / Post-Test** | **Topic** | **Number of Instances Topic/Phrase Appears in Participant Responses** |
|  | End of Life | 11 |
|  | Less than 6 months of dying | 14 |
|  | Dying/death | 1 |
|  | Comfort | 8 |
|  | Non-curative | 1 |

**Appendix E**

Table 5

*Recurring topics in open-ended responses: palliative care definition*

|  |  |  |
| --- | --- | --- |
| **Palliative Care Definition / Pre-Test** | **Topic/Phrase** | **Number of Instances Topic/Phrase Appears in Participant Responses** |
|  | end of life | 2 |
|  | early/at beginning of diagnosis/throughout illness | 4 |
|  | Comfort care | 8 |
|  | Quality of life | 7 |
|  | Can occur alongside curative treatment | 4 |
|  | Pain control/symptom management | 4 |
|  | “the same as hospice care but life sustaining measures may continue” | 1 |
| **Palliative Care Definition / Post-Test** | **Topic/Phrase** | **Number of Instances Topic/Phrase Appears in Participant Responses** |
|  | Holistic/Encompassing care | 11 |
|  | Early/at beginning of diagnosis/early implementation | 12 |
|  | Quality of life | 11 |

**Appendix F**

Table 6

*Likelihood of Suggesting a Pediatric Palliative Care Consult*

|  |  |  |
| --- | --- | --- |
| **Palliative Care Consult / Pre-Test** | **Topic/Phrase** | **Number of Instances Term/Phrase Appears in Participant Responses** |
|  | Very Likely | 12 |
|  | Likely | 3 |
|  | Not Likely | 1 |
|  | Unsure/Only in certain circumstances (i.e., “if nothing else can be done to cure” or “not something I have previously considered but…probably” | 3 |
| **Palliative Care Consult / Post-Test** | **Topic/Phrase** | **Number of Instances Term/Phrase Appears in Participant Responses** |
|  | Very Likely | 17 |
|  | Likely | 2 |
|  | Not Likely | 0 |
|  | Unsure/Only in certain circumstances (i.e., “I would advocate for palliative care with patients as appropriate.” | 1 |