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## The Use of a Pediatric Palliative and Hospice Education Module to Enhance the Knowledge and Practice of Emergency Room Providers

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The Use of a Pediatric Palliative and Hospice Education Module to Enhance the Knowledge and Practice of Emergency Room Providers

Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Nursing Practice at the University of Kentucky

By:

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Lexington, KY

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## **Abstract**

**Background:** Palliative and hospice care resources are underutilized in pediatric patients with chronic and life-limiting illnesses. One contributing factor is the lack of formalized education for medical providers regarding the differences and scope of palliative and hospice care models. Without adequate education about these services, providers are not able to effectively utilize otherwise available resources to provide holistic care.

**Purpose:** The purpose of this study was to assess the current perception of knowledge among providers pertaining to pediatric palliative and hospice care. The study investigated improvements in educational outcomes in ten categories after participation in a web-based training. A secondary assessment was made of perceived effectiveness of the training itself.

**Methods:** A prospective cohort study was completed using providers within the University of Kentucky Hospital's Emergency Department. Surveys were distributed to seventy-seven participants which included physicians and advanced practice providers. A pre and post survey using Qualtrics, and a web based educational model were used to analyze clinician knowledge. These surveys used Likert scales, multiple choice, and short answer to evaluate providers' perceptions both before and after the education. Survey topics assessed included prior training, perceptions of educational need, and current knowledge. Categories included in the knowledge assessment and web-based training included ethics, symptom management, grief, use of resources, developmentally appropriate discussion, care planning, and difficult conversations. A paired t-test was used to compare clinician knowledge and attitudes both before and after the

web-based education. As part of the post-survey the participants completed an evaluation of the educational module and a re-assessment of their perception of knowledge.

**Results:** A total of ten participants completed the pre-survey between November 2021 and February 2022. Six participants completed the training and post-survey during the same period. Following the training a statistically significant increase in perception of knowledge was observed in 80% of the categories and 100% of the categories displayed a score increase from the pre-survey ratings. 100% (n=6) of the participants felt that the training was useful and would recommend it to others within their cohort.

**Conclusion:** Literature has confirmed there is a lack of education in pediatric palliative and hospice care in the United States. After a web-based training experience, there was a recorded improvement in perception of education of the same topic among providers in the Emergency Department at the University of Kentucky. Improved Likert scale scores were observed to have statistical significance for nine of ten training categories. Further evaluation with a larger sample size and with different demographics would be useful to determine if this finding is reproducible on a wider scale.

## Acknowledgements

I would like to acknowledge my faculty advisor, Dr. Misty Ellis for her encouragement and wisdom in the last year of my DNP program. While Dr. Ellis took over the track coordinator position late in my program, she ensured we had the knowledge, time, practice, and support to fulfill the rigorous requirements of this program. Her guidance in both practice and professional matters has greatly impacted my path to becoming a nurse practitioner.

I feel fortunate to have 3 influential and admirable women on my DNP committee. Dr. Kathy Isaacs has been influential in getting all the moving parts of my final project together. Dr. Isaacs also graciously accepted a position on my committee about pediatric palliative and hospice despite it not being her specialty. She stepped in to fill a faculty mentor position when it seemed that many other faculty did not have an interest in this specialty at the beginning of my program.

Dr. Adrienne Johnston has been both a mentor and preceptor during my DNP program. Dr. Johnston agreed to partake in my committee and then agreed to take me as a clinical student in my final semester of rotations because she knew about my passion for palliative care and learning how I could expand that passion to others. She has been inspiring, supportive, and greatly encouraged my growth as a new provider.

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expand this project to the rest of KCH and beyond, hoping to encompass many healthcare systems in the future.

Finally, I would like to acknowledge Dr. Amanda Thaxton Wiggins, who played an instrumental role in assisting me with statistical analysis. Her knowledge and expertise in the data analysis and use of SPSS was the guiding light to evaluating my data. Without her, this project would have been much more challenging. Thank you to all of you, who have given me encouragement and made me a better student and future provider.

## **Dedication**

This project is dedicated to my family including my mother, Mary Lynn, father, Jeff, and brother, Ben as well as my fiancé Daniel. This project and the completion of the DNP program has been a 3-year commitment to which they have stood by me through its entirety. My family has always supported my aspirations to pursue the highest levels of education. Their love, encouragement, and constant nudges have been unwavering, especially in times of doubt or stress. My father, an accomplished businessman, author, philanthropist, and role model has provided a guiding light to follow my passion and to strive for excellence even in the smallest ways. His leadership within his work community has fueled my desire to work hard to earn my place, to give back, and remember where I started. My mother, a strong, independent, business manager and leader has provided lessons in responsibility, relationships, and navigating challenges with grace. She has been a cheerleader and a shoulder throughout this program. Along with my parents, my brother has been a constant reminder that I can do anything I set my mind to and that I can be proud of my work. His reminders that he is proud of me as a sister and professional have been steadfast and provided moments of joy when I felt lost. Finally, my beloved fiancé, Daniel. The number of nights he has listened to me panic, cry, or vent are immeasurable. His calm demeanor and affirmations have provided comfort throughout the program. He is a pillar in my life, much like my family, and his stability and love have pushed me through the roughest waters. It is such a blessing to know that he and my family are always there to act as lights in the dark, calm in the storm, and as a rock when nothing seems certain. This project is wholeheartedly dedicated to them for all they have done for me both near and from afar.

## Table of Contents

<b>Abstract.....</b>	<b>2</b>
<b>Acknowledgements.....</b>	<b>4</b>
<b>Dedication.....</b>	<b>6</b>
<b>Background and Significance.....</b>	<b>9</b>
<b>Purpose and Objectives.....</b>	<b>11</b>
<b>Theoretical Model.....</b>	<b>11</b>
<b>Review of Literature.....</b>	<b>12</b>
<b>Summary of Evidence.....</b>	<b>13</b>
<b>Evidence of Gaps in Practice.....</b>	<b>14</b>
<b>Addressing the Gaps.....</b>	<b>15</b>
<b>Methods.....</b>	<b>15</b>
<b>Design.....</b>	<b>15</b>
<b>Setting.....</b>	<b>16</b>
<b>Sample.....</b>	<b>17</b>
<b>Procedure.....</b>	<b>17</b>
<b>Results.....</b>	<b>20</b>
<b>Discussion.....</b>	<b>24</b>
<b>Implications.....</b>	<b>28</b>
<b>Limitations.....</b>	<b>30</b>
<b>Conclusion.....</b>	<b>32</b>
<b>References.....</b>	<b>35</b>

## **List Of Tables**

Table 1. Evidence Table.....	40
Table 2. Characteristics of participants.....	42
Table 3. Categories Perceived as Needed for a Web Based Training.....	43
Table 4. Current Perception of Knowledge and Practices.....	44

## **List of Figures**

Figure 1. Project Plan.....	45
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## **List of Appendices**

Appendix 1. Informed Consent.....	46
Appendix 2. Pre-Survey.....	48
Appendix 3. Post-Survey.....	52

## **Background and Significance**

Hospice and palliative care are among the most underutilized resources for pediatric patients in inpatient healthcare facilities. Historically, pediatric driven hospice and palliative teams have not been regarded as a necessary and cost-effective resource. This is based on the number of rural children's hospitals and the high rates of use in the outpatient setting (Carroll, et al., 2007). Research has shown that palliative and hospice care are just as effective for children and their families as they are for adults (Dingfield et al., 2014). In hospitals without an established children's center, rural settings, emergency rooms (ER), and even in academic settings with smaller children's hospitals, the majority of hospice and palliative providers are not specifically trained to care for pediatric patients (Friedrichsdorf et al., 2019). The main barrier to pediatric palliative and hospice care is the limited training available for pediatric healthcare providers (Friedrichsdorf et al., 2019).

Nationally, many children's hospitals have a palliative team that rounds on pediatric patients. These teams generally consist of a physician, a nurse practitioner (NP), a pharmacist, a social worker, a chaplain, a case manager, and a child-life representative, however not all team members will have had pediatric training (Friedrichsdorf et al., 2019). While these palliative teams exist, their usage in consultation, and in emergency departments (ED) is notably low on both local level and national levels (Center to Advance Palliative Care, 2020; Liben et al., 2008). The national shortage of education and training for this type of care hinders care for patients and families, and impedes the provider's ability to practice holistic, patient-centered care.

EDs are often the first point of contact for acutely and chronically ill children. ED providers need education on palliative and hospice management because they may encounter a child in need of these services, or one who might already be established with the palliative or

hospice team. Currently, few organizations or research interventions are in place for this issue due to the cost and lack of utilization (Carroll et al., 2007). The National Institute of Health (NIH; 2015) published a pamphlet for families about the difference in palliative care compared to hospice and the resources offered in both. Unfortunately, most of the information about this resource is vague and directed at parents. This resource provides no education or skills aimed towards the providers who manage the care (Moody et al., 2019).

At UKHC there is an established pediatric palliative team (PACT). This team consists of two attending physicians, one nurse practitioner, one social worker, several chaplains, and a member of the child psychology group. It is a split team, so most of the members see both adult and pediatric patients. This is currently the case for most palliative teams nationwide, as a specialized pediatric team is not thought to be cost effective (Dingfield et al., 2014). The PACT team at UKHC has been instrumental in managing complex care needs, providing resources, and organizing care plans for pediatric patients with chronic or life-limiting illnesses. Unfortunately, according to several members of the team, very few teams and units outside of Kentucky Children's Hospital (KCH) are aware of this resource for patients. Because there is no education about the team or their scope, many consults for these children get missed, especially in the ED. One member of the team explained that the team is also limited by an inability to practice to their full scope. This is due to several factors including teams wanting to manage symptoms separately, resources specific to certain teams, and the use of a pain management team instead of the PACT team. The DNP project's training module aimed to educate about pediatric palliative and hospice concepts and distinguish the PACT team as a resource to ED providers.

The aim of this project was to establish an educational module for ED physicians and advanced practice providers (APPs) to complete to enhance their knowledge of pediatric

palliative and hospice care. The educational module focused on concepts that address patient and family care needs in pediatric patients who require palliative or hospice management.

### **Purpose and Objectives**

The purpose of this study was to implement a web-based training (WBT) for providers to complete, emphasizing proper protocols and care planning that should occur when caring for pediatric palliative or hospice patients (Friedrichsdorf et al., 2019). A pre-assessment of prior education and perceptions of knowledge about pediatric palliative and hospice care was conducted followed by a WBT. The target audience was ED physicians and APPs who provide care for pediatric palliative and hospice patients (Sera et al., 2019).

The four aims of this study included:

1. Provide education to providers at the University of Kentucky Emergency Department about pediatric palliative and hospice care through a WBT using evidence-based practices highlighting 10 categories of care concepts.
2. To analyze provider knowledge and confidence surrounding pediatric palliative and hospice care in the ED before and after the training session.
3. To compare pre-survey and post-survey scores about knowledge surrounding the ten categories used in the training.
4. To assess provider's evaluations of the WBT used in the study.

### **Theoretical Model**

The theoretical framework that guided this project was Joyce Travelbee's "Human to Human Relationship Model." This framework was based on a stepwise model of provider and patient encounters from the initial visit to developing rapport in the future (Joyce Travelbee

Interpersonal Theory of Nursing, 2022). The model was built upon the idea that the clinician can provide meaning and empathy to suffering patients and families during times of tragedy or illness (Travelbee, 2020). It was a good fit for this project because of the focus on palliative care; ideally enhancing provider's education and practice in this area of pediatric care can empower them to provide the comfort, support, and empathy during a time of suffering. The concepts that were taken from Travelbee's work include: health being subjective and objective, consideration for all the aspects of health (physical, mental, emotional, and spiritual), building strong rapport between providers and patients, empathy, the use of 'self' to be therapeutic, and assurance (Travelbee, 2020). This framework was used as a guide to build a module with consideration for all aspects of provider to patient care and relationships.

### **Review of Literature**

A literature review was conducted to address the following research question: Does providing a training about pediatric palliative and hospice care to ED providers, enhance their knowledge and comfort in caring for these patients? Several databases were used with varying keywords and search methods. The databases used in this search were: CINAHL, ClinicalKey, PubMed, Cochrane Library, and UpToDate. Several types of searches were conducted including keyword, subject, and MeSH. The keywords used were: pediatric, palliative, hospice, end of life, education, child life, emergency room, emergency department, provider, advanced practice, and palliative care team. A total of 49 articles were reviewed and 37 of those were determined to fit the inclusion of criteria. The articles that best fit the narrowed topic were pared down to 23 (Table 1).

A set of inclusion criteria were used that provided a narrower selection of articles that best fit the study aim, which included age demographic under 18, United States, and publication within the last 20 years. The inclusion criteria also required a specific focus on the pediatric population, i.e. individuals aged 0 to 18 years old. The articles needed to discuss topics or concerns that directly related to a pediatric population that would be different from an adult, and articles that could be found pertaining to pediatric hospice/palliative education. Articles were excluded if the research included anyone over the age of 18, focused solely on symptom management, was conducted outside the US, and/or focused on participants older than 20 years of age.

### **Summary of Evidence**

Several themes emerged from this body of literature. One main finding was the general lack of pediatrics-specific training for providers in hospice/palliative care. In three articles (Carroll et. al., 2007; Friedrichsdorf et. al., 2019; Moody et.al., 2018) the central finding was that providers do not receive specialty training in this topic; this leads to provider discomfort with using palliative care resources for children. It also leads to the generalization of palliative concepts rather than patient-specific and centered care. Compared to the previous articles, Ward-Smith, et.al, (2007) argued for the development of a “palliative team” to manages care, rather than educating providers, despite the centralized role of the physician or APP caring for the patient.

A second theme that arose from this search that providers tend to default palliative/hospice care for children to the adult practice guidelines. Two studies illustrating this were Dingfield et al. (2014), who discussed how children differ from adults in their palliative

needs and Sera et al. (2019), who similarly discussed how the needs of the pediatric patient are more comprehensive than those of adults. The complexity of pediatric patients stems from differing ages, stages, family dynamics, and ethical issues (Sera et al., 2019). Conversely, Barone & Unrungu (2018) and Cuvellio et al. (2019), discussed the barriers that pediatric palliative/hospice patients have encountered from a medical standpoint due to the child's inability to make medical decisions, and the focus being on the family rather than the patient.

Finally, the most important theme that arose was that providers do not feel prepared to care for pediatric palliative/hospice patients without proper training. Several articles including Liben et al. (2018) and Marcus et al. (2020), discussed providers' desire to learn more about this specialty practice, for both personal education and for better patient outcomes. Two research teams also found providers to be willing to attend specialty rotations or educational seminars to gain experience and improve their personal practices (Rossfield et al., 2018; Vesel & Beveridge, 2018).

### **Evidence of Gaps in Practice**

Overall, a key point was the lack of research about pediatric hospice/palliative care and education for providers. The evidence was moderately strong given the minimal resources available that fit the criteria, which included 4 meta-analyses, 6 systematic reviews, 2 case studies, 1 randomized cohort, and 1 randomized controlled trial (Table 1). Some of the limitations in the evidence included the overall lack of research available and the limited sample from large institutions (Carroll et al., 2007; Downing et al., 2018, ; Marcus et al., 2020). In summary, the articles available provided a comprehensive analysis of the gaps in practice and the need, but do not provide solutions to address how to approach specific needs. The current state of

practice seems to be that providers generalize palliative/hospice concepts from adults to use with children because of a lack of education. The desired state is to provide an educational module to enhanced provider confidence and practice so that pediatric patients can receive appropriate, patient-

\]centered palliative or hospice care. The gaps for practice included the lack of teaching in medical and APP programs of study about this subject and lack of current educational tools.

### **Addressing the Gaps**

The proposed solution to the issue is implementing an educational module directed at providers to improve knowledge and practice guidelines for pediatric palliative and hospice care. The goal is to have providers complete the WBT either in a program of study or at the beginning of their practice to grow their knowledge base of palliative and hospice care for pediatrics. The use of a WBT would ideally improve patient outcomes and personal practice of providers. Increased knowledge and use of evidence-based practice principals are the key to closing the gap of palliative and hospice education for pediatrics with complex or life limiting illness. The more knowledgeable and confident providers are, the better able they are to care for patients and families.

## **Methods**

### **Design**

The design was a prospective cohort study. This study invited all ED providers to participate in a pre-survey, WBT, and a post-survey using Qualtrics. Those who participated in all three activities were included in the study. The study investigated the effect of a WBT about

pediatric-specific hospice/palliative care on the perceived knowledge of physicians and APPs in the ED at UK HealthCare. Their knowledge and confidence about ten care categories were evaluated both before and after they completed the WBT using a Qualtrics survey. The 10 categories addressed included: ethics, difficult conversations, using resources, developmentally appropriate conversations, communication, family and sibling grief, care planning, and symptom management.

### **Setting**

The Mckenna David Pediatric ED is a 21-bed unit dedicated to children and families at UK Healthcare. The Adult Emergency Center at UK HealthCare is equipped with 33 exam rooms consisting of acute, trauma, express, and observational units. The study was completed with providers from both the adult and pediatric ED since providers can cover both adult and pediatric areas. This is the city's only level 1 trauma center which annually sees thousands of patients per year.

The UK HealthCare (UKHC) values are DIReCT (diversity, innovation, respect, compassion, and teamwork). UKHC has a goal of providing compassionate and respectful care to every patient, every time. To support that goal, this project illuminated disparities in hospice/palliative education that would allow providers to better serve patients and families with respect and compassion. The information gathered in this study can be presented to pediatric administrators to guide future strategies for implementing the WBT for all pediatric providers at UKHC.

There were several stakeholders involved in this study. The DNP committee consisted of Dr. Misty Ellis, the chair, Dr. Kathy Isaacs, the faculty mentor, and Dr. Adrienne Johnston, the clinical mentor. Secondly, the enterprise director Dr. Patricia Howard was asked to support the

project. Additionally, Dr. Craig Carter, the pediatric ED chief, and Dr. Roger Humphries, the chair of the adult ED, were involved. Some of the outside facilitators for the project included the commitment and buy in from the administrators, IT support for surveys and data, and the time or availability of the providers who were asked to complete the WBT.

## **Sample**

A purposive sample of all providers within the UKHC ED including physicians and APPs were targeted for the study. Inclusion criteria for this study included:

1. Physician or APP licensure
2. A full-time employee of the ED
3. Any shift day, night, weekend, or mid-shift

Exclusion criteria include:

1. Medical students or APP students
2. Any staff that were not a physician or APP (RN, PCT, RT, etc.)
3. Any part-time or PRN employees
4. Any employee of a different unit than the ED

Subjects for this project were recruited by identifying the providers listed on the UKHC ED providers' page. Initial contact with the providers was made with the PI's UKY email address through the UK email directory, and the provider profiles with the participant's work emails.

There were no in person recruitment interactions with participants and the PI.

## **Procedure**

Before beginning the study, approval was obtained from the Institutional Review Board (IRB) from the UK Medical Center IRB. An approval letter from Dr. Howard, chairperson, for

the ER demonstrating organizational support was obtained for the IRB. Organizational support was also sought through personal emails to Dr. Carter and Dr. Humphries, which described the purpose and method for the study. The data from this study was kept anonymous through survey responses that were kept on a firewall protected and encrypted server that was linked to the server at UK. The intervention was developed based on principles from a randomized controlled trial conducted that used an educational module for advanced providers about pediatric palliative and hospice care (Friedrichsdorf, et al., 2019).

This intervention contained three steps:

- 1.) A Qualtrics pre-module survey to assess baseline confidence, previous education, perception of needs, and current knowledge.

- 2.) The educational module formatted as a web-based training (WBT) created with PowerPoint and Zoom recording, which was created from evidence-based practices derived from the literature.

- 3.) A post-survey to re-assess change to confidence and knowledge after completion. Based on the level of success observed in the post-survey, the WBT could be instituted into all pediatric units in the future.

During the pre- and post-surveys, non-identifying demographic information was collected, including number of years in practice and degree held. A 2-question identifier was used in both the pre- and post-surveys to allow for pairing of the t-test by creating a username. This included car make/model and birth year (ex. Corolla1980 or Chevy1975) which was entered into a cross walk table and spreadsheet. There was no paper documentation for this study. An electronic table and the spread sheet were stored in separate files on the PI's identity authenticated, secure, firewall-protected research folder. The crosswalk was only accessible to

the PI and IRB approved study personnel. The PI followed UKHC's policies for retention, storage, and destruction of the electronic data. Six years after study closure all records will be destroyed by the PI following UK Policies AO5-055 and A13-050.

Measurements for this study were conducted on topics such as prior education, perception of educational needs, and current knowledge. Prior education was evaluated with a yes or no style question and a follow up question about the extent of education for participants who answered "yes." Perception of current needs and knowledge were measured using a Likert scale of 1-10 with higher numbers reflecting strong need or knowledge about a subject. Summary scores were calculated using the same questions on both pre- and post-surveys with higher scores reflecting more knowledge acquisition. Questions also included the number of pediatric palliative/hospice cases seen in a year and where they received prior education if applicable. The total scores were calculated for both pre- and post-surveys and audited to form a final measurement of success for this intervention using SPSS data system.

Pre-and post-surveys were emailed and the WBT intervention was delivered through a link to a recorded Zoom presentation, in both in an email and on the pre-survey. After completing the pre-surveys, the participants interacted with a WBT. Following the training, the participants were prompted to click a link to the post-survey. The questions on the post-survey were identical to the Likert scales assessing knowledge from the pre-survey. Data from the surveys were collected using Qualtrics. Any missing data for this intervention were addressed in a listwise deletion form. If data were missing or only the pre-survey was completed, then the case was ignored in the final collection. Analysis for this intervention was conducted with IBM SPSS software version 26, with an alpha level of 0.05 for statistical significance. To assess

knowledge the scores from both the pre- and post-survey were analyzed and compared using paired sample t-tests.

This DNP project took place over the course of 9 months (Figure 1). IRB approval was obtained in September 2021. The data collection occurred from November 1, 2021, to February 15, 2022. After collection, data analysis occurred from February 15, 2022-March 1, 2022. The writing and presentation for this project occurred from March 1, 2022-April 10, 2022.

The feasibility for this study came from buy in from the administration of the ER. This study would enhance knowledge for providers pertaining to pediatric palliative and hospice care, which could greatly improve patient and family outcomes aligning with UKHC and Joint Commission values and guidelines. To sustain this project, UKHC would require this WBT to be issued to all newly hired providers and expand to other pediatric units of the hospital. Resources to support this study included personnel, budget, and technology. The PI and committee including Dr. Ellis, Dr. Isaacs, and Dr. Johnston, and administration from the ED provided personnel and administrative support. There was no specified budget allotted to this project. Finally, the PI had access to computer and data analysis software through UK.

## **Results**

A total of 10 participants (Table 2) completed the pre-survey and a total of 6 participants completed the WBT and post-survey. Of the six participants who were included in the study, 50% were MDs, 33.3% were nurse practitioners, and 16.7% were medical residents. Years of experience ranged from 0 to greater than 16 years; 33.3% of participants had greater than 16 years of experience. 50% of the participants had 6-10 years' experience, and 16.7% of participants had 0-5 years of experience. Of the six total participants, 66.7% received no prior

training about pediatric palliative care and hospice during any part of their practice or academic program. Of the 33.3% who did receive training during school or on the job, both participants reported very minimal education pertaining to this subject. The six participants also indicated how frequently they encounter a pediatric palliative or hospice patient in their practice; 16.7% reported encountering them “weekly,” 33.3% reported encountering them “a few times a year,” and 50% stated they “almost never” encounter them. No participants selected “daily,” “monthly,” or “I’ve never seen this.”

The pre- and post-survey contained a “select all that apply” to assess perception of need for eight educational categories pertaining to pediatric palliative care and hospice. The pre-survey asked providers to select the categories they felt were needed in an educational tool. The post-survey re-assessed their perception of need by asking if they felt each category had been appropriately addressed. Table 3 contains the paired t-test data from these responses. Eighty-three-point eight percent of participants selected “difficult conversations” as a necessary educational category in the pre-survey and 100% felt it was appropriately addressed. Sixty-six-point seven percent reported that “using resources” was needed and 50% reported it was addressed appropriately. Fifty percent reported “ethical decision making” as needed and 100% felt that it was addressed appropriately. Fifty percent reported that “developmentally appropriate conversations” was a needed aspect in teaching and 100% felt it was addressed appropriately. Fifty percent felt that overall “communication” was needed and 50% felt it was addressed appropriately. Thirty-three-point three percent felt that “grief for family and siblings” needed addressing and 50% felt it was appropriately taught. Thirty-three-point three percent reported that “care planning” needed to be addressed and 33.3% felt it was addressed appropriately.

Finally, 16.7% felt that “symptom management” needed to be taught and 100% felt it was addressed appropriately (Table 3).

During the pre- and post-survey, the six participants were asked to use an identical Likert scale ranging from no confidence (0) to completely confident (10) to rate their perception of knowledge about ten categories. Table 4 shows the mean and standard deviation (SD) for each category for the pre- and post-survey as well as the  $p$  value for each category. The SD will be depicted in parenthesis following the mean value.

Category 1 was “Understanding the difference in palliative and hospice care as it pertains to a child.” The mean and SD for the pre-education were 4.8 (3.5) and 8.5 (2.3) for the post-education. The  $p$  value for category 1 was 0.63, which was the one of only two non-statistically significant value found amongst the categories.

Category 2 was “Medication management for children on palliative or hospice care.” The mean and SD for the pre-education were 4.0 (2.5) and 7.7 (1.8) for the post-education. The  $p$  value for category 2 was 0.028. This showed a statistically significant improvement in knowledge for this category.

Category 3 was “Adjuvant symptom management for children on palliative or hospice.” The mean and SD for the pre-education were 3.9 (2.7) and 7.8 (1.2) for the post-education. The  $p$  value for category 3 was 0.023. This showed a statistically significant improvement in knowledge for this category.

Category 4 was “Documentation of care plans and management for these patients.” The mean and SD for the pre-education were 4.2 (2.3) and 6.8 (1.5) for the post-education. The  $p$  value for category 4 was 0.057. This showed a non-statistically significant improvement in knowledge for this category, despite a noticeable increase in Likert scores.

Category 5 was “Consultation of the pediatric palliative team.” The mean and SD for the pre-education were 4.8 (3.9) and 8.5 (1.2) for the post-education. The *p* value for category 5 was 0.035. This showed a statistically significant improvement in knowledge for this category.

Category 6 was “Utilizing resources for patient and family (social work, chaplain, grief support groups, etc.)” The mean and SD for the pre-education were 4.3 (2.0) and 8.2 (1.2) for the post-education. The *p* value for category 6 was 0.007. This showed a statistically significant improvement in knowledge for this category.

Category 7 was “Ethical decision making for children on palliative or hospice care (child's wishes vs. family, assent, etc.)” The mean and SD for the pre-education were 3.3 (2.0) and 7.2 (1.2) for the post-education. The *p* value for category 7 was 0.013. This showed a statistically significant improvement in knowledge for this category.

Category 8 was “Having difficult conversations with family and siblings about a diagnosis, quality of life, and end of life.” The mean and SD for the pre-education were 2.8 (1.5) and 7.7 (1.0) for the post-education. The *p* value for category 8 was <0.001. This showed a statistically significant improvement in knowledge for this category.

Category 9 was “Communicating with the child about palliative/hospice/death.” The mean and SD for the pre-education were 1.8 (0.76) and 7.0 (0.89) for the post-education. The *p* value for category 9 was <0.001. This showed a statistically significant improvement in knowledge for this category.

Finally, category 10 was “Multidisciplinary approach to the child on palliative or hospice (pharmacy, RT, social work, case management, palliative team, etc.)” the mean and SD for the pre-education were 4.5 (2.6) and 8.2 (1.5) for the post-education. The *p* value for category 10 was 0.022. This showed a statistically significant improvement in knowledge for this category.

The post-survey culminated with 3 questions about the quality of the WBT. The first question addressed how well they felt that the WBT prepared them to care for a pediatric palliative or hospice patient. Sixteen-point seven percent selected “extremely well” and 83.3% selected “very well.” No participants selected “moderately well”, “slightly well”, or “not at all.” The second question was a fill in the blank, where participants were asked to fill in what they felt should have been included in the module that was not. Only 2 participants submitted a fill in the blank answer. One participant responded with “*more on resources.*” The second response stated “*The PP was helpful, but discussions about pediatric death can be emotional and overwhelming for the provider and parents. Discussion of how to do it and actually doing is very different. Sadly, the best "training" is performing the role as the provider in actual situations.*” The final question on the post-survey asked participants to select an answer how about how likely they would be to recommend the WBT to colleagues. 50% reported that they would be “extremely likely” to recommend it and the other 50% reported that they would be “somewhat likely” to recommend it. No participants selected “neither likely or unlikely” or “not at all likely.”

## **Discussion**

The focus of this study was to analyze provider’s perception of knowledge about pediatric palliative and hospice, evaluating previous education received, and comparing perception of knowledge after a web-based training was implemented. There were minimal differences in previous education demographics. Of the topics that participants selected as “most needed” in a training, some form of communication was consistently selected. Likert scale ratings showed increases in all 10 educational categories in the post-survey, with all but two

being statistically significant increases. The demographic variety showed no association with previous education, perception of need, or current knowledge.

Evidence suggests that providers do not receive adequate or any training about pediatric palliative and hospice care (Friedrichsdorf et al., 2019). The study asked participants the years of experience they had in emergency medicine, and the responses did not show an association with their receipt of training or lack thereof. Evidence also suggests that providers understand that pediatric patients cannot be treated with the same principles as adults receiving palliative or hospice care (Dingfield et al., 2014). The post-survey suggested that providers were most interested in learning about difficult conversations, use of resources, and ethical decision making. Following the top three selected categories, developmentally appropriate conversations and general communication were frequently selected. This evidence indicates that providers feel that various forms of communication pertaining to pediatric palliative and hospice are not addressed well enough in training as well as the differing ethical considerations and resources available to pediatric patients using these resources.

Evaluating providers' current perception of knowledge can help assess barriers pertaining to lack of education about pediatric palliative and hospice. Secondly, educating providers about this topic, can address how these patients are treated in the ED and during hospitalization, which improves patient care and experience. In this study, we used identical Likert-style questions to evaluate provider's perception of knowledge about 10 categories based on previous education. There was demonstrated improvement in all 10 categories from the pre- to the post-survey, and statistically significant improvement in 8. The evidence from these surveys showed that the use of a WBT improved knowledge of providers about this subject. Furthermore, the participants were asked to evaluate the efficacy of the WBT and if they would recommend it to

colleagues. All participants selected the option “very well” or “extremely well” when evaluating how well the WBT prepared them to care for a pediatric palliative/hospice patient. These responses demonstrate the need and success of the WBT despite the small sample size.

The literature reviewed prior to this project suggested that there is minimal to no formal training about pediatric palliative and hospice care for providers. Without this training, provider’s lack adequate knowledge to care for these patients in a holistic way and do not feel comfortable addressing common issues within palliative or hospice care, such as ethics, difficult conversations, and developmentally appropriate communication. In this project, participants were able to provide qualitative and quantitative feedback about their previous knowledge, perception of need, quality of the WBT and recommendation for future use. The quantitative data demonstrated that the WBT was effective in addressing all 10 categories and that the satisfaction with content was high. The qualitative data suggested that there is a gap in knowledge about this subject within all participants, topics that they wanted specific education on, and that satisfaction with the training was high. These data points in both quantitative and qualitative areas highlight the importance of provider education about pediatric palliative and hospice, and its impact on holistic patient care.

Often, patients with chronic or terminal illnesses are already established with the palliative or hospice team or doctor, and they enter the ED with an acute issue requiring hospitalization. Since the ED is often the first point of contact for pediatric patients when they enter the hospital, the project was implemented here. ED providers may not be aware that these patients have an established connection to the palliative or hospice providers, therefore, this aspect of care is often overlooked initially. Unfortunately, these patients may not be recognized until days into their hospitalization if the consult is not placed from the start of their

hospitalization. If ED providers had adequate training in pediatric palliative and hospice concepts, they may feel more comfortable using resources pertaining to this topic or putting in a consult for these teams. With early recognition and use of resources patients would establish appropriate palliative or hospice care sooner. This project suggested that ED providers rarely get trained in this subject and consequently don't feel knowledgeable enough about these concepts to initiate challenging conversations, use resources, or manage symptoms in accordance with palliative and hospice suggestions.

To further the education of providers in the ED and other pediatric units, the pre-survey, WBT, and post-survey could be modified. Future pre-surveys could ask more detailed questions about previous training such as what material was educated on. Pre-surveys could have more options for participants to select from about perceived need topics. Finally, the pre-survey could add educational categories to the Likert style questions to inquire about current knowledge pertaining to these added categories. The WBT would then need to be updated with more information based on these responses, with information gathered from evidence-based resources. The post-survey would be updated to reflect additional categories to be re-assessed and could also include more in-depth evaluation questions about the WBT and suggestions for improvement.

Currently, there is no standard education within the academic community for providers about pediatric palliative and hospice unless a residency or fellowship is pursued in this specialty (Friedrichsdorf et al., 2019 & Moody et al., 2018). Even within these fellowship programs, the focus is usually on adult care with minor training in pediatrics due to the commonly "split" nature of palliative and hospice teams to see both adults and children (Marcus et al., 2020). Participants in this study identified several major themes that they felt needed to be addressed to

adequately educate providers on pediatric palliative and hospice concepts. Participants also demonstrated increased knowledge in all 10 categories after interacting with the WBT. By standardizing this training based on participant responses this WBT could be implemented for all newly hired providers in the ED and all pediatric units. Having a base knowledge of pediatric palliative and hospice concepts would encourage more well-rounded patient care, increase in pediatric palliative and hospice consults, appropriate use of resources, and confidence amongst providers who encounter these patients.

### **Implications**

Literature indicated that additional research needs to be conducted on educational tools for providers about pediatric palliative and hospice as well as the concepts that are most lacking in practice in this area. The literature has also suggested providers would be interested in learning about these concepts and have little understanding about the differences in adult and pediatric patients receiving palliative or hospice care. Evidence has also suggested that these resources are widely underused in this population due to the lack of education amongst providers. The study showed that the participants in the sample showed interest in learning about 8 categories associated with pediatric palliative and hospice care. Following the intervention, the sample participants demonstrated positive increases in perception of knowledge related to all 10 educational categories taught during the WBT.

This study may be used to support future research and efforts to evaluate education associated with pediatric palliative and hospice among providers and increase knowledge in this specialty. Further investigation is needed to gather data on what specific concepts should be educated on as well as how to implement a WBT to all pediatric providers for improved use of

this resource. Although UKHC has a specialty pediatric palliative team, they are often not consulted, not used appropriately, or do not practice to their full scope; this is based on statements from providers on the PACT team during clinical experiences. While no data could be obtained about missed consults in the ED or from other teams, several members of the team verbalized concern that children who could benefit from the PACT team are often missed. Children who may already be established with the PACT team are often not seen until several days into their admission because the ED does not always appropriately place consults for PACT or use them as a resource during their treatment per one of the providers. It was also verbalized by several team members that the use of the pain team and specialty oncology resources has prevented PACT from being consulted on children who could benefit from their resources when they enter the ED. These negative factors have a direct impact on patient care, and many of these concerns could be addressed with provider education.

A more thorough investigation into gaps in provider knowledge about this subject could identify opportunities to develop a successful WBT and create consistent use among all pediatric hospital providers. A comprehensive evaluation of the efficacy of the WBT would support the need for system-wide education related to this topic. Specific provider populations, system needs, resource use, and patient care criteria must be assessed to address the gaps in this area to improve the knowledge of providers and patient care.

Developing process improvements can be amended through collaborative efforts with other hospital systems or educational resources that have spent time and energy to train providers in this area. The few medically based resources such as the Center to Advance Palliative Care (CAPC) could provide additional toolkits to improve provider knowledge across multiple units and facilities (Center to Advance Palliative Care, 2022). Websites such as this provide

interactive modules about certain concepts associated with palliative care for providers, however, most are limited to adult populations or are specific to symptom management.

The CAPC provided a report card by state in 2019 to evaluate palliative care usage, however, this did not include pediatric specific reports (Center to Advance Palliative Care, 2020). According to this report 66.7% of urban hospitals (n=40) in Kentucky had a palliative program and 61.9% of suburban Kentucky hospitals have a palliative program (Center to Advance Palliative Care, 2020). Unfortunately, only 25.9% of rural hospitals had a palliative program. It is important to consider that this only accounts for adult palliative programs and is not inclusive of pediatric patient programs. These figures demonstrated the low usage of palliative care as a resource in the state for adults, and the literature has shown that pediatric programs are drastically lower (Marcus et al., 2020). Amidst other factors such as perceived cost effectiveness, home hospice and palliative care, and insurance, provider education is at the forefront of the lack of use of this resource in pediatric patients.

### **Limitations**

Several limitations can be identified in this study. First, the study was limited by a small sample size. There were 77 providers who were invited limited evaluation of this study. Another limitation to this project was the decreased ability to meet for in-services, interactive teaching, and to discuss the project with the participants. These barriers occurred because of several factors, which included, COVID-19 restrictions and differing provider schedules. Virtual technology was available for use; however, either no response was received by department chairs or there was no demonstrated interest in coordinating meetings. Unfortunately, this was likely due to varied schedules and other priorities related to patient care during the COVID-19

pandemic. Being able to meet with stakeholders in person at the start of the project would have likely encouraged more participation and more personal connection to the project. Conducting live in-services and interactive teaching would have created a more personal experience and buy-in for participants.

Another limitation was the selection of a singular unit to implement the study. At the beginning of the study, using one patient care area was encouraged to keep the project manageable. The ED was selected because of their relatively limited exposure to pediatric patients and the concern pediatric specific units were familiar with the palliative team. The ED was also selected because it is often the first contact a patient has when they are acutely ill, and if they are an established palliative or hospice patient, those concepts should be implemented during their time in the ED. Had this project been piloted in the ED and a secondary pediatric specific unit there may have been increased buy in and participation. Increased participation might have been garnered with a larger overall sample size and from increased interest in pediatric providers.

A third barrier to this study was the length of the WBT. Unfortunately, because there is so little education on pediatric palliative and hospice the WBT needed to be long enough to contain all pertinent topics. Had the WBT only covered the top 3 categories that were perceived as lacking, the training would have been shorter. A shorter WBT would have been more inviting and less time consuming for busy providers to engage with. Another way that the WBT could have been modified would have been to not do a voice-over on the PowerPoint. Provider schedules are often chaotic and do not permit extra activities during the shift for more than a few minutes at a time. Having providers complete the WBT at home would also create a barrier

because that is extra work while not on shift. Giving the participants the freedom to interact with the PowerPoint at their pace would likely have encouraged more participation.

Finally, the last limitation in this study was the lack of incentive for fulfilling all the project requirements. Survey projects are historically difficult to conduct due to the time investment. Had an incentive been provided, participants may have been more willing to participate. Prior to IRB approval the incentive of a “badge buddy” was considered. The participants who completed the entire training would receive a badge buddy to denote their participation and education about the project subject. Those with a badge buddy could have been used as a resource for other providers by answering questions, promoting the WBT, and being designated “super-users” for the department should concerns arise. Future piloting of this study will include the badge buddy incentive and in-services to discuss the purpose of the project, interactive engagement, and a revised WBT. To minimize barriers the PI and committee members worked with the unit leaders and administrators to establish a suitable timeline for completion of the pre-test, module, and protest as well as garner support for the project.

## **Conclusion**

Pediatric palliative and hospice care are a significantly underused resource in the community due to several factors, but one of the most significant being the lack of provider education about practice concepts in this specialty (Carroll et al., 2007 & Friedrichsdorf et al., 2019). Literature has shown that pediatric patients benefit from palliative and hospice care in the same way that adults do, but rarely receive adequate specialty care due to lack of provider education (Dingfield et al., 2017). To implement these concepts, any provider who may encounter pediatric patients should be expected to undergo a basic training session either during

school, residency, or on the job to prepare them to render holistic patient care. Evidence has shown that providers are interested in learning about these concepts and acknowledge the differing needs of the pediatric patient compared to an adult when dealing with chronic or terminal illnesses (Moody et al., 2018 & Rossfield et al., 2018).

This study identified barriers and facilitators to provider education about pediatric palliative and hospice care in general, and in a single unit. ED providers at UKHC were asked about previous knowledge and perceived need for education about pediatric palliative and hospice care. This study demonstrated the lack of education provided during academic programs or by employers. The evidence indicated a need for pediatric palliative and hospice education based on increased Likert ratings for all care categories in the WBT from pre- to post-survey. The findings from this study align with the national and local conclusions stating that palliative and hospice care are underutilized resources for pediatric patients due to educational deficit. Overall, the study evidence confirmed that education about these concepts is lacking, there is a perceived need, and that the WBT was effective. By implementing this WBT throughout the system, the provider knowledge base would grow, leading to improved practices and patient care.

The data from this study can be used to ascertain the importance of educating providers about these concepts on a system wide and national level. Despite the small sample size, the data provided concrete evidence that knowledge is lacking, and providers perceive a need for this topic. The efficacy of the WBT was evident through participant responses and shows substantial potential to be a required training module for all providers who interact with pediatric patients. Further research and implementation should be considered within the UKHC network as well as other regional centers, and eventually, with appropriate modifications nationwide. On both a

regional and national level, the use of this WBT could expand the knowledge base about this specialty topic to all pediatric providers, providing confidence, improved patient care, and increased use of hospice and palliative as a resource for children.

The barriers, facilitators, sustainability characteristics, and approach to the study can be addressed in future research to reduce limitations and barriers, strengthen facilitators, and implement other strategies that are not currently in place. These modifications would help encourage and maintain sustainability of this WBT throughout the UKHC network and nationally to furnish further research, interventions, and improved outcomes regarding this specialty topic.

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**Table 1. Evidence Table**

Study Author	Year	Number of Participants	Sample Characteristic That Is pertinent to Study	Study Design	Intervention	Major Finding That Addresses Your Question
Carroll, J. M., Torkildson, C., & Winsness, J. S.	2007	N/A	Lack of education in PPC/barriers	Expert opinion	Integration of PC into the course or tx for terminal children	Ed. and support are low  Need for better Ed/Supp important
Dingfield, L., Casarett, D., Bender, L., & Feudtner, C.	2014	986 children 0-18	Peds specific PC/barriers	Randomized Cohort	Different usage of PC services and need for specialized integrative care	Peds pts likely to use inpatient hospice care r/t resources and diagnoses
Downing, K., Michelson, K., Murday, P., & Arsala, E. G	2018	12 groups 8 bereaved parents 4 non-bereaved parents 18 HCWs	Challenges in PPC/barriers	RCT	Identifying and implementing PPC specific support and resources in non-urban areas	Limited resources for PPC pts and providers  Inadequate information about current education and support decreased  Need for enhancing existing resources through better access, utilization, and quality, and improving care coordination
Friedel, M., Aujoulat, I., Dubois, A. C., & Degryse, J. M.	2019	19 articles selected that met inclusion criteria	Peds specific PC/barriers	SR	Identifying barriers to evaluating outcomes from family and children's perspectives after receiving care	Outcomes from children's perspectives  Multidimensional outcomes from families  Need for better measurements of spiritual, physical, and psychosocial more readily available
Friedrichsdorf, S. J., Remke, S., Hauser, J., Foster, L., Postier, A., Kolste, A., & Wolfe, J.	2019	867 trainers 75 masters 58 countries	Education in PPC/barriers	SR	Creation of module system to identify and eliminate educational barriers to PPC	Current available PPC education  Use of newly developed PPC specific education module patient satisfaction and provider comfort.
Ghirotto, L., Busani, E., Salvati, M., Di Marco, V., Caldarelli, V., & Artioli, G.	2019	16 qualitative studies	Education in PPC/barriers	SR/MA	SR of peds pts insights on treatment and services	Qualitative data available about this is
Goymour, K.-L., Heaton, M., Coombs, S., Kelk, N., Estreich, K., Sarraf, S., Trethewie, S., & Jaaniste, T.	2019	N/A	Education in PPC/barriers	Case Study	Development of a CC cart with resources for pts and families to support them in PPC	CC items and resources available currently which causes barrier to PPC support  Use of the cart feelings of support, education and resources by pts and families.
Kaye, E. C., Abramson, Z. R., Snaman, J. M., Friebert, S. E., & Baker, J. N.	2017	7 organizations	Peds specific PC/barriers	SR	SR of barriers to quantifying or qualifying outcomes for PPC pts	Research currently about the barriers to investigating outcomes and needs of PPC pts  Increase the amount of research going into PPC barriers and the quality and quantity of outcomes will

Marcus, K., Santos, G., Ciapponi, A., Comande, D., Bilodeau, M., Wolfe, J., & Dussel, V.	2020	11 studies comprised of 2939 cancer patients	Peds specific PC /barriers	SR/MA	SR of research about PPC interventions and impact on QOL	Increased research and education about interventions related to PPC that revolve around QOL needs to better measure the outcomes of the patients and families.
Moody, K., McHugh, M., Baker, R., Cohen, H., Pinto, P., Deutsch, S., Santizo, R. O., Schechter, M., Fausto, J., & Joo, P.	2018	Class of M3s, unspecified number	Education in PPC/barriers	MA	Adding a module about PPC specific tactics for M3 students to increase confidence and provision of care to peds pts at an appropriate level of education	The use of the module during medical school provider confidence and readiness to adequately care for the PPC pt in an inpatient setting, which leads to better pt outcomes and positive feelings of support and education.
Sera, L., Morgan, J., & Mcpherson, M. L.	2019	116 patients	Peds specific PC/barriers	SR	Implementation of PPC specific medication resources instead of the adult regimen	The use of adult regimens pt comfort and stability The use of a PPC specific medication regimen greatly comfort and feelings of support.

Legend to describe Abbreviations

- PPC- pediatric palliative care
- PC- palliative care
- RCT- randomized control trial
- SR- systematic review
- MA- meta-analysis
- CC- comfort care
- QOL- quality of life

**Table 2. Characteristics of participants (N =6)**

<b>Characteristics</b>	<b><i>n</i> (%)</b>
<b>Practice License</b>	
Attending MD/MO	3 (50.0%)
Nurse Practitioner	2 (33.3%)
Resident	1 (16.7%)
<b>Years of Practice in ER</b>	
0-5 years	1 (16.7%)
6-10 years	3 (50.0%)
>16 years	2 (33.3%)
<b>Receipt of Prior Training</b>	
Yes	2 (33.3%)
No	4 (66.7%)

**Table 3. Categories Perceived as Needed for a Web Based Training (n=6)**

<b>Topics Needed for Web Based Training</b>	<b>Pre-education <i>n</i> (%)</b>	<b>Post-education <i>n</i> (%)</b>
<b>Difficult conversations</b>	5 (83.3%)	6 (100%)
<b>Using resources</b>	4 (66.7%)	3 (50.0%)
<b>Ethical decision making</b>	3 (50.0%)	6 (100%)
<b>Developmentally appropriate conversations</b>	3 (50.0%)	6 (100%)
<b>Communication</b>	3 (50.0%)	3 (50.0%)
<b>Grief for family and siblings</b>	2 (33.3%)	3 (50.0%)
<b>Care planning</b>	2 (33.3%)	2 (33.3%)
<b>Symptom management</b>	1 (16.7%)	6 (100%)

**Table 4. Current Perception of Knowledge and Practices (n=6)**

<b>Comfort in addressing category topics</b>	<b>Pre-education Mean (SD)</b>	<b>Post-education Mean (SD)</b>	<b><i>p</i></b>
<b>Understanding the difference in palliative and hospice care as it pertains to a child</b>	4.8 (3.5)	8.5 (2.3)	.063
<b>Medication management for children on palliative or hospice care</b>	4.0 (2.5)	7.7 (1.8)	.028
<b>Adjuvant symptom management for children on palliative or hospice</b>	3.9 (2.7)	7.8 (1.2)	.023
<b>Documentation of care plans and management for these patients</b>	4.2 (2.3)	6.8 (1.5)	.057
<b>Consultation for pediatric palliative team</b>	4.8 (3.9)	8.5 (1.2)	.035
<b>Utilizing resources for patient and family (social work, chaplain, grief support groups, etc.)</b>	4.3 (2.0)	8.2 (1.2)	.007
<b>Ethical decision making for children on palliative or hospice care (child's wishes vs. family, assent, etc.)</b>	3.3 (2.0)	7.2 (1.2)	.013
<b>Having difficult conversations with family and siblings about a diagnosis, quality of life, and end of life</b>	2.8 (1.5)	7.7 (1.0)	<.001
<b>Communicating with the child about palliative/hospice/death</b>	1.8 (0.76)	7.0 (0.89)	<.001
<b>Multidisciplinary approach to the child on palliative or hospice (pharmacy, RT, social work, case management, palliative team, etc.)</b>	4.5 (2.6)	8.2 (1.5)	.022

**Figure 1. Project Plan**

	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr
IRB	█	█	█							
Collection					█	█	█	█		
Analysis								█	█	
Write up & present								█	█	█

## Appendices

### Appendix 1. Informed Consent

#### **The Use of a Pediatric Palliative and Hospice Education Module to Enhance the Knowledge and Practice of ER Providers.**

To Whom It May Concern:

Researchers at the University of Kentucky are inviting you to take part in surveys and an educational module about Pediatric Hospice and Palliative Care. This area of study is not well defined in the provider role and this survey will allow researchers to gauge current thoughts and practices about it. Upon completion of the survey, you will be invited to partake in the module and take a post-survey. Participants are being asked to partake in this study to advance the field of pediatric hospice and palliative medicine, which is the subject for the PI's DNP project. Although you may not get personal benefit from taking part in this research study, your responses may help us understand more about education pertaining to pediatric hospice and palliative care. Some volunteers experience satisfaction from knowing they have contributed to research that may possibly benefit others in the future.

Researchers will review and collect information from your responses based on two identifiers on the survey which will ask you to create a username using your car make/model (Toyota, Malibu, Ford, Rogue, etc.) followed by your birth year. Examples include: Mazda1993 or Corrolla1970. If you do not want to be in the study, there are no other choices except not to take part in the study.

Each survey/questionnaire will take about 5 minutes to complete. The module will take between 30-60 minutes to complete but can be accessed multiple times if you need to leave and come back.

There are no known risks to participating in this study.

Your response to the survey will be kept confidential to the extent allowed by law. Your username will be kept on an encrypted device and will not be shared with anyone and when we write about the study you will not be identified.

We hope to receive completed questionnaires from about 50 people out of the 77 invited, so your answers are important to us. Of course, you have a choice about whether to complete the survey and module but if you do participate, you are free to skip any questions or discontinue at any time. You will not be penalized in any way for skipping or discontinuing the survey.

Please be aware, while we make every effort to safeguard your data once received from the online survey company, given the nature of online surveys, as with anything involving the Internet, we can never guarantee the confidentiality of the data while still on the survey company's servers, or while en route to either them or us. It is also possible the raw data collected for research purposes will be used for marketing or reporting purposes by the survey/data gathering company after the research is concluded, depending on the company's Terms of Service and Privacy policies.

If you have questions about the study, please feel free to ask; my contact information is given below.

Thank you in advance for your assistance with this important project. We are hopeful to have all pre and post surveys completed by December 15<sup>th</sup>, 2021, for those choosing to participate.

Sincerely,

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If you have complaints, suggestions, or questions about your rights as a research volunteer, contact the staff in the University of Kentucky Office of Research Integrity at 859-257-9428 or toll-free at 1-866-400-9428.

## Appendix 2. Pre-survey

### Pre-Module Survey- WBT about pediatric palliative and hospice for APCs

Q1 What practice licensure do you hold?

- Attending MD/DO (1)
- PA (5)
- Nurse Practitioner (6)
- Medical Resident (8)

Q2 How many years have you practiced in Emergency Medicine?

- 0-5 years (1)
- 6-10 years (2)
- 11-15 years (3)
- >16 years (4)

Q3 During your training (medical school, NP/PA school, on the job, etc.) did you receive any training about pediatric specific palliative or hospice care?

- Yes (1)
- No (2)

Q4 If you answered YES to Q3 please select the appropriate choices pertaining to your training. (Select all that apply)

- Minimal (1)
- Moderate (2)
- Significant (3)
- During school (4)
- During residency/clinical rotations (5)
- On the job (6)

Q5 What topics do you feel most need to be addressed regarding education about pediatric palliative and/or hospice care? Select all that apply.

- Difficult conversations (1)
- Grief for family/siblings (2)
- Symptom management (3)
- Using resources (4)
- Care planning (5)
- Ethical decision making (6)
- Developmentally appropriate discussions (7)
- Communication (8)
- Other- Please specify here (9) \_\_\_\_\_

Q6 How often do you encounter a pediatric patient OR adult patient treated for a pediatric illness that is on palliative or hospice care?

- Daily (1)
- Weekly (2)
- Monthly (3)
- A few times a year (4)
- Almost never (5)
- I've never seen this (6)

Q7 What topics pertaining to pediatric palliative and hospice care are you most interested in learning about? Please provide a brief answer.

---

Q8 On a scale 0-10 please rate how COMFORTABLE you are currently addressing these topics should a pediatric palliative or hospice patient be in your care. (0 being "no confidence at all" and 10 being "completely confident".)

	0	1	2	3	4	5	6	7	8	9	10
Understanding the difference in palliative and hospice care as it pertains to a child. ()											
Medication management for children on palliative or hospice care. ()											
Adjuvant symptom management for children on palliative or hospice. ()											
Documentation of care plans and management for these patients. ()											
Consultation for pediatric palliative team. ()											
Utilizing resources for patient and family (social work, chaplain, grief support groups, etc.) ()											
Ethical decision making for children on palliative or hospice care (child's wishes vs. family, assent, etc.) ()											
Having difficult conversations with family and siblings about a diagnosis, quality of life, and end of life. ()											
Communicating with the child about palliative/hospice/death. ()											
Multidisciplinary approach to the child on palliative or hospice (pharmacy, RT, social work, case management, palliative team, etc.) ()											

Q11 Would you be willing to participate in a web based training about pediatric palliative and hospice care for a DNP project?

Yes (1)

Maybe (2)

No (3)

Q12 Please create a unique identifier by using your previous or current make or model of car and the year you were born (ex. malibu1965, mustang1988)

---

Q12 Please click or copy and paste the following link to access the zoom training module. At the end of the module there will be a link to click to access the post-survey.

[https://www.icloud.com/icloudrive/0awTZo1fHwd1ITtUve17JNnQ#WBT\\_zoom](https://www.icloud.com/icloudrive/0awTZo1fHwd1ITtUve17JNnQ#WBT_zoom)

## Appendix 3. Post-survey

### Post Survey for Providers About Pediatric Palliative and Hospice

Q1 Please enter the username you created in the pre-survey. (Remember this was formatted as car model followed by birth year; Malibu1980 example)

---

Q2 What topics do you feel were appropriately addressed regarding education about pediatric palliative and/or hospice care in the module? Select all that apply.

- Difficult Conversations (1)
- Grief for Family/Siblings (2)
- Symptom Management (3)
- Using Resources (4)
- Care Planning (5)
- Ethical Decision Making (6)
- Developmentally Appropriate Discussions (7)
- Communication (8)
- Other- Please specify here (9) \_\_\_\_\_

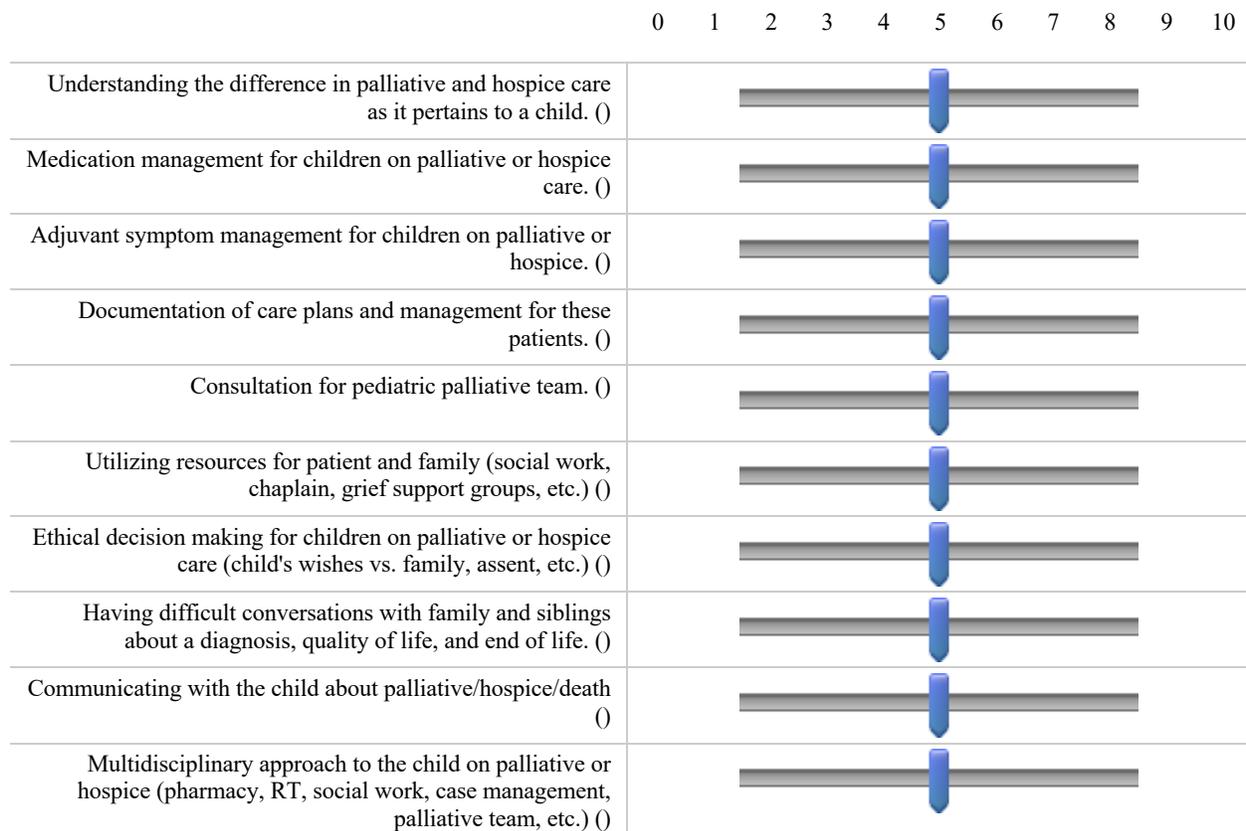
Q3 How well do you feel this module helped prepare you to care for a pediatric palliative or hospice patient?

- Extremely well (1)
- Very well (2)
- Moderately well (3)
- Slightly well (4)
- Not well at all (5)

Q4 What topics pertaining to pediatric palliative and hospice do you feel should have been included in the module? Please provide a brief answer.

---

Q5 On a scale 0-10 please rate how COMFORTABLE you are addressing these topics should a pediatric palliative or hospice patient be in your care AFTER watching the module. (0 being "no confidence at all" and 10 being "completely confident".)



Q7 How likely would you be to recommend this module to colleagues as supplemental training?

- Extremely likely (1)
- Somewhat likely (2)
- Neither likely nor unlikely (3)
- Somewhat unlikely (4)
- Extremely unlikely (5)