



# From Fear to Confidence: Changing Providers' Attitudes About Pediatric Palliative and Hospice Care

## Citation

Beveridge, Christiana White. 2017. From Fear to Confidence: Changing Providers' Attitudes About Pediatric Palliative and Hospice Care. Doctoral dissertation, Harvard Medical School.

## Permanent link

<http://nrs.harvard.edu/urn-3:HUL.InstRepos:41973445>

## Terms of Use

This article was downloaded from Harvard University's DASH repository, and is made available under the terms and conditions applicable to Other Posted Material, as set forth at <http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-of-use#LAA>

## Share Your Story

The Harvard community has made this article openly available.  
Please share how this access benefits you. [Submit a story](#).

[Accessibility](#)

**Harvard Medical School:**  
**Scholarly Report submitted in partial fulfillment of the MD Degree**

**Date:** 21 February 2017

**Student Name:** Christiana White Beveridge

**Title:** From Fear to Confidence: Changing Providers' Attitudes about Pediatric Palliative and Hospice Care

**Mentor Names and Affiliations:**

Tamara Vesel, MD, Department of Medicine, Chief of Palliative Care Division, Tufts Medical Center, Tufts University;

Beth Lown, MD, Department of Internal Medicine, Mount Auburn Hospital, Harvard Medical School

From Fear to Confidence:

## Changing Providers' Attitudes about Pediatric Palliative and Hospice Care

*Background/Aims:* Children have limited access to hospice care: few existing hospice programs have dedicated pediatric teams, and adult hospice providers feel inadequately trained to care for children. The aim of this study is to increase access to pediatric hospice care by empowering adult hospice providers to care for children through a comprehensive education program. Education empowers providers by changing their attitudes from inadequacy to confidence.

*Methods:* We developed a two-day education program to train interdisciplinary teams of adult hospice providers in pediatric care. The curriculum consists of thirteen modules to improve participants' knowledge, skills, and attitudes. Ninety-three providers in Boston, MA, San Francisco, CA, Spokane, WA, and Anchorage, AK learned via multiple teaching methods including lectures, role-plays by professional actors, interviews of bereaved parents, discussions, self-reflections and self-care tips. Learning was evaluated with assessments given before, immediately after, and 6-months following the program. Responses were compared using a one-sided analysis of variation (ANOVA) with a significance level of  $\alpha < 0.05$ .

*Results:* Providers who completed this education program improved their knowledge in twelve of thirteen modules. Self-reported confidence levels with pediatric care improved significantly in all thirteen modules ( $p < 0.05$ ). After this program, 79% of providers reported feeling better prepared to care for pediatric hospice patients. Improvement in confidence with communication skills rather than symptom management correlated with participants' comfort with pediatric hospice care. Qualitative data reinforced that learners felt more prepared to care for pediatric patients.

*Conclusions:* A two-day, high intensity education program can improve adult providers' knowledge of and skill level with pediatric care, leading to a change in attitude from fear to confidence. This model has the potential to dramatically increase access to pediatric hospice care as it utilizes the untapped resource of existing adult hospice infrastructure.

*Funding:* Care Dimensions; Judith Revis Foundation.

## Table of Contents

Section 1: Introduction	Page 4
Section 2: Student role	Page 8
Section 3: Methods	Page 11
Section 4: Results	Page 13
Section 5: Discussion and Limitations	Page 16
Section 6: Conclusions	Page 20
Section 7: Acknowledgements	Page 21
References	Page 22
Tables and Figures	Page 25
Appendices	Page 35

## **Section 1: Introduction**

### **I. Overview:**

Children and their families deserve excellent care at the end of life; they deserve the right to choose where they spend their last days together, to be comfortable, and to die with dignity. These children suffer from severe symptoms at the end of life – ranging from anxiety to pain to dyspnea – and require the expertise of a dedicated hospice or palliative care team to minimize their suffering and the toll it takes on their families.

We know that pediatric hospice care improves children’s quality of life and their families’ quality of life [1]; however, a majority of children do not have access to this necessary level of care [2]. A recent study showed that while over 70% of families would prefer for their child to die at home, only 15-30% of children do [3]. There are many factors leading to low hospice enrollment, but one of the main causes is low access to end-of-life care. Few existing hospice programs have dedicated pediatric teams even though pediatric patients have unique needs at the end of their lives [4] and providers report feeling inadequately trained to care for these children [5]. Therefore, we developed this specialized program to educate providers in pediatric hospice and palliative care and increase access to end-of-life care for pediatric patients.

### **II. Background: what is pediatric hospice and palliative care?**

Over 40,000 children die each year; in addition, over 500,000 children are living with a life-limiting illness. Pediatric palliative care is the field formally developed in the last 20 years to specifically care for this population. According to the American Academy of Hospice and Palliative Care, palliative care is “patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care addresses physical, intellectual, emotional, social and spiritual needs throughout the continuum of illness.” [6] Hospice care is the ultimate step in the palliative care process and is “the model for quality compassionate care for people facing a life-limiting illness ... [it] provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support

is also provided to the patient's loved ones." [7] Hospice care can be provided in several different settings including inpatient, special hospice facilities, and, most often, in the home.

### III. Current State of Pediatric Hospice and Palliative Care

Pediatric palliative care is a relatively new field; the American Academy of Pediatrics (AAP) did not make a formal recommendation about palliative care until 2000, when they recommended that children with a life threatening or terminal condition have access to quality palliative care throughout their illness [8]. The first fellowship in pediatric palliative care was started in the early 2000's at Boston Children's Hospital. Since then, about twenty fellowships have been started in the United States and about 30 pediatricians trained in palliative care graduate each year [9]. Most of these physicians work in the inpatient setting as consultants for teams taking care of children with life-threatening or terminal conditions. About 50% of children's hospitals have palliative care programs, most of which were established in the last ten years [10].

End-of-life care, both in the hospital and at home, requires an interdisciplinary team of providers. There are several programs aimed at teaching nurses pediatric palliative care. The largest, the End of Life Nursing Education Consortium – Pediatric Palliative Care (ELNEC-PPC) was started in 2003. Over 2,000 nurses have attended their "train-the-trainer" courses and returned to their institutions to educate their peers [11]. There are fewer formal pediatric palliative care training programs for other providers including social workers, chaplains, and therapists.

It is certainly a good sign that both palliative care fellowships and nursing training in pediatric palliative care have increased in the last 15 years, but we are still behind in serving the needs of children who are suffering. The Center for Disease Control and Prevention reports in its Annual Summary of Vital Statistics, that in 2014, there were a total of 41,881 deaths in children age 0-19. About half of these (23,215) were infant deaths, and about two-thirds of infant deaths were during the neonatal period [12]. These children's needs are not currently being met: of families of children who have cancer, over 70% report they would prefer for their child to die at home, but only about 15-30% of children do [3]. In many cases, providers are not introducing hospice care early enough as an option; and even when they do, many hospice facilities do not

have teams trained to care for children, so children have limited access to care, especially in rural areas [13].

#### IV. Key Question

Can adult hospice providers improve their knowledge about, ability to, and comfort level with caring for pediatric patients at the end-of-life after participating in an intensive, two-day education program?

#### V. Significance

Children and families suffer unnecessarily at the end of life because they have limited access to hospice care. Few hospice programs have fully dedicated pediatric teams, and the majority of hospices serving children do not have specialized staff to provide pediatric services [7]. Because pediatric patients have needs that require services by specially trained providers, the goal of this program is to train interdisciplinary providers, allowing for the creation of a comprehensive hospice team with all caregivers trained in pediatric care. In order to achieve this goal, this education curriculum is designed for dedicated pediatric hospice and palliative care teams (including physicians, nurses, child life specialists, chaplains, therapists, social workers, and volunteers) and is adapted to their current level of knowledge about pediatric end of life care.

This is the first education program we are aware of that aims to train adult hospice providers in pediatric care. Most pediatric palliative care or pediatric hospice education programs discussed in the literature are designed to train providers who already work with children, while most education programs aimed at adult providers focus on adult palliative and hospice care. The two-day structure is also unique: most programs are either in the form of short, focused lectures for specific skills or lengthy, comprehensive training programs including fellowships for pediatricians and social workers. There are two large “train-the-trainer” curricula for pediatric end-of-life care: the End of Life Nursing Education Consortium – Pediatric Palliative Care (ELNEC-PPC), where they estimate 2000 pediatric nurses have completed the training since 2003; and the Education in Palliative and End-of-life Care (EPEC) pediatrics program aimed at a variety of pediatric providers. In ELNEC-PPC, nurses go through a two and a half day training

program with ten modules focused on nursing care at the end of life [11]. In EPEC, providers complete a 26-module course (1 day in person, 20 modules online) [14]. Harvard Medical School developed a comprehensive, 6-day in person and six-month online training program for interdisciplinary providers in palliative care in their Palliative Care Education and Practice (PCEP) program. PCEP has the option for a pediatric track, but its focus is largely on palliative versus hospice care [15]. Each of these programs will certainly improve the number of providers trained in pediatric care, but because they focus on training current pediatric providers, they will struggle to reach the many hospice programs who do not already have dedicated pediatric teams.



## **Section 2: Student role**

I worked with Dr. Vesel and her team over the last four years to 1) complete a needs-assessment for pediatric hospice care; 2) develop a two-day, comprehensive education program for pediatric end-of-life care, 3) create a survey tool to evaluate this education program, and 4) analyze data from participants' surveys to determine the program's effectiveness. Below are further details on the four main components of my work:

### *Phase 1: Pediatric hospice needs-assessment (Spring 2013)*

- 1) Completed local (Boston-area), regional, and countrywide assessment of need for pediatric hospice care based on vital statistics reports of number of pediatric deaths, cause of death, and location of death
- 2) Focused more in-depth on Boston and Massachusetts needs through research on the Massachusetts Pediatric Palliative Care Network.

*Deliverable:* Assessment on need for access to pediatric hospice care in Boston area, Massachusetts, and the United States. Discussion on scope of pediatric palliative care network (PPCN) in Massachusetts.

### *Phase 2: Curriculum development (Summer 2013)*

- 1) Completed needs assessment with providers at an adult hospice organization to understand topics that are most important to learners
- 2) Assisted Dr. Vesel to develop curriculum based on needs assessment and critical pediatric care topics. Curriculum development was based on learning objectives aimed at improving knowledge and skills and changing providers' attitudes.

*Deliverable:* Two-day, 13-module, evidence-based curriculum with specific learning objectives based on knowledge, skills, and attitudes.

*Phase 3: Survey Development (Summer 2013)*

- 1) Wrote questions that accurately corresponded to the program's stated objectives: based on knowledge, skill, and attitude.
- 2) Defined goals of evaluation and aligned questions with these goals in order to obtain meaningful results.

*Deliverable:* Finalized survey by start of education program in fall 2013 (curriculum objectives and survey questions attached)

*Phase 4: Program Evaluation (September 2013 – November 2016)*

- 1) Transferred survey to web-based format with convenient access (google forms)
- 2) Administered survey to participants: The survey is electronic (using google forms) and was sent via email to all participants in our education program 1-2 weeks before, immediately after, and 6 months after completion.
- 3) We received IRB or ethics committee approval or exemption from all institutions we worked with; participants voluntarily completed surveys.

*Deliverable:* Raw data from completed surveys. Raw data was kept on my computer and contained names of participants. I de-identified the data using participant codes before sharing with Dr. Vesel and our research team.

*Phase 5: Data analysis, manuscript writing, conference presentations (summer 2014 – present).*

- 1) Created database of survey results; organized to ease analysis
- 2) Learned and used descriptive statistics to analyze results and determine effectiveness of our program to meet its stated objectives
- 3) Created and presented posters of preliminary analysis for presentations at two international conferences
- 4) Wrote abstract and manuscript to be published in peer-reviewed journal

*Deliverable:* We have presented our findings at two international conferences (2014 International Congress on Palliative Care, Montreal, Canada; 2016 World Research Congress of the European Association for Palliative Care, Dublin, Ireland). We are currently finishing our analysis and writing our manuscript for publication.

In order to understand the scope of my research, I also spent time with Dr. Vesel in clinical situations through both home visits and the Kaplan Family Hospice House in Danvers, MA, an inpatient hospice center. Through these experiences, I was able to interact with providers and patients to understand the importance of communication skills and comfort with pediatrics in caring for children at the end of life.

**Addendum:**

In January 2017, Dr. Vesel was asked to teach our workshops for the first time internationally. I joined, remotely, the international research team to provide the first pediatric palliative care education program in Bhutan. My specific role included:

- 1) Drafting the IRB protocol to evaluate the program
- 2) Modifying the curriculum for inpatient palliative care (hospice does not exist in Bhutan)
- 3) Modifying the survey to include more qualitative data

Over the course of ten days, two separate 2-day workshops were given for a total of 40 participants. Participants completed pre and post workshop surveys and I will administer the survey again in 6 months. I will also be involved in the data analysis and manuscript writing for the first Bhutanese palliative care workshop. The data is not available to include in this report.

## **Section 3: Methods**

### **I. Course Design, Structure, and Content**

The course was designed as a short, high-intensity program in order to be accessible to many providers and not be overly burdensome as a time commitment. Dr. Tamara Vesel, an expert in pediatric end-of-life care, led the curriculum development team. The course consists of 13 modules (see Table 1), each with three objectives: one knowledge-based, one skill-based, one attitude-based. Modules are evidence-based and span a wide breadth of content, ranging from communication with parents and children to symptom management, to goals of care, and self care. Modules are taught using a variety of interactive teaching methods, including the use of actors and role-play, discussions with bereaved parents, and self-reflection. Participants are provided with materials from each module during the workshop, so they are encouraged to actively participate rather than take notes.

### **II. Participant Recruitment**

The education program was taught at existing hospice organizations and tertiary care centers that facilitate hospice referrals with the goal of training interdisciplinary providers to create or strengthen a dedicated pediatric team to care for children at the end of life. Organizations sought out this training program and most agreed to participate in the evaluation. Participant organizations are in Boston, MA, San Francisco, CA, Spokane, WA, and Anchorage, AK. Each organization chose the specific providers who would participate in the education program, including nurses, social workers, chaplains, psychologists, therapists (physical, music, art), child life specialists, bereavement counselors, health aides, and physicians. Each workshop consisted of 15-25 learners.

### **III. Evaluation**

A pre/post survey was developed by the research team in order to test the stated objectives for each module of the curriculum. The questions have not been validated by an

outside researcher, but we believe the questions are accurately testing learners' knowledge, attitudes, and skills. The survey consists of demographic, free response, multiple choice, and Likert-scale questions. A 5-point Likert scale testing participants' self-reported confidence level (or comfort level) was used that ranged from 5 (very high) to 1 (very low). The education program consists of 13 modules (see table 1) with three objectives per module, resulting in a survey of about 39 content questions (see appendix for survey questions).

The survey was administered electronically through an online survey tool (GoogleForms). The research assistant or a representative from the organization emailed the survey to participants three times: once 2-7 days before the education program, the second time immediately after the completion of the program, and the third time six months later. The research assistant received all results of the survey and de-identifies the data as it is added to the database of results. The research team received IRB or ethics committee approval or exemption from all institutions; participants voluntarily completed surveys and completion of the survey was considered consent to participate in this research.

#### IV. Analysis

Survey results were collected in a database in excel. There were three types of questions: those using Likert scales, multiple choice, and free response. Free response questions were graded as either correct or incorrect based on template answers created by the research team.

The three groups of data (pre, post, and 6-month post) were compared using one-way analysis of variation (ANOVA) tests in Excel. A linear regression model was used with the index question (if participants feel better prepared to care for pediatric hospice patients after this education program) as the dependent variable, and all Likert scale questions as the independent variables to test whether increased comfort levels with any of the skills or situations evaluated would correlate with feeling better prepared to care for pediatric patients at the end of life.

## **Section 4: Results**

### **I. Description of Learners:**

There were a total of 93 participants in the full two-day education program and 19 participants in a shortened, one-day program. The program leadership of the organizations requesting pediatric hospice and palliative care training chose the specific learners in each workshop. Participants' professional roles included nurses, physicians, social workers, chaplains, child life specialists, psychologists, health aides and a variety of therapists (music therapy, physical therapy, massage therapy). They also ranged in their previous experience in hospice, experience in pediatrics, and experience in pediatric palliative care. See Table 2 for a full list of demographics of participants.

The response rate for the pre-workshop survey was 77%, post-workshop survey was 67%, and the six month post-workshop survey was 26% (see Table 3). Respondents to the post and six-month post survey were similar in demographics to the respondents to the pre-survey. At the time of this report, there is one cohort of participants that have not received the six month survey because it has not been six months since their training.

### **II. Overall, learners feel better prepared to care for pediatric patients at the end of life**

In the post-survey, learners were asked if they felt better prepared to care for pediatric hospice patients after completing this education program. 79% of respondents to the post-survey, or 49 providers, either agreed or strongly agreed that they felt better prepared for such pediatric care after this workshop (see Figure 1).

### **III. Improvement in attitudes, skills, and knowledge**

In order to evaluate participants' attitudes and skills, participants were asked about their comfort level in various situations that arise when caring for pediatric patients and confidence levels with various pediatric skills. Providers ranked their comfort or confidence level using a Likert Scale with 1 = very uncomfortable / not at all confident; 2 = uncomfortable / not very

confident; 3 = neutral; 4 = comfortable / confident; 5 = very comfortable / very confident. Table 4 shows the mean results of these Likert scales for thirteen different skills or situations. The mean comfort or confidence level improved significantly for each skill or attitude evaluated with  $p < 0.05$ .

Participants' knowledge was evaluated using multiple choice and free-response questions that were graded as either correct or incorrect. Knowledge also improved in twelve of thirteen modules from the pre- to post-survey, and in all thirteen modules when comparing the pre-survey to the six-month survey. Table 5 and Figure 3 show the percentage of respondents who answered each question correctly in the pre, post, and six month post surveys.

#### IV. Participants left the educational program with confidence similar to those with far greater experience

Figure 2 shows participants' mean comfort or confidence level with pediatric end-of-life care (as assessed by the Likert scale questions discussed above) split by their prior experience in hospice. As seen in the first graph, before the education program, providers who had greater than ten years of hospice experience were significantly more comfortable with each skill or situation assessed than those with less than ten years of hospice experience. However, in the second graph, which shows providers' reported comfort or confidence levels *after* the education program, the gap in comfort level decreases significantly.

#### V. Increased comfort with pediatric hospice correlates with confidence in communication skills

As described above, participants were asked whether they feel better prepared to care for pediatric patients after this education program. A linear regression was run in order to test whether confidence or comfort levels with various skills or situations correlated with perceived preparedness. As seen in Table 6, the one skill that was significantly correlated with feeling prepared to care for pediatric hospice patients is "having difficult conversations with parents and children at the end of life". A higher level of confidence in this difficult situation was correlated with feeling prepared to care for children at the end of life with a  $p < 0.05$ .

## VI. Feedback

Participants valued the teaching methods and structure of this education program greatly. First, they reported that the experiential education methods – the use of actors and role play – were more effective than traditional teaching methods of lectures and discussions. 73% of respondents preferred either actors or role play (38% and 35% respectively) to lectures (15%) and group discussions (12%). Table 7 shows participants’ perceptions of most effective teaching methods. Qualitative feedback supported the value of these experiential teaching methods. For example, one participant noted, “The course's strength lies in its hands-on approach to adult learning. The role plays; the open and inviting conversations were wonderfully challenging and encouraging.”

More important than positive feedback about teaching methods, participants felt empowered for this new role and reinvigorated as end-of-life care providers after this education program. Providers were effusive about the impact this time for learning, reflection, and peer support had on their professional and personal lives. See table 8 for representative examples of participant feedback.



## Section 5: Discussion and Limitations

This is the first education program we are aware of that trains adult providers in pediatric care. In just two days, these providers, many of whom had no previous pediatric care experience, felt generally better prepared to care for pediatric patients, and also improved their knowledge of, skills with, and attitudes toward caring for children. This level of improvement across the board stems from several factors. First, the curriculum was made up of modules that were clearly organized around specific educational objectives; second, innovative teaching methods were used that take advantage of the benefits of experiential training for adult learners; and third, this education program created a safe environment for interdisciplinary providers to learn from each other and faculty.

### I. Curriculum development:

The curriculum for this program was developed based on the core tenets of pediatric palliative and hospice care [16], focusing heavily on communication skills with the child and the family, symptom management at the end of life, addressing ethical challenges, spirituality, and self-care. These modules are similar to descriptions of those taught in other pediatric palliative care training programs like EPEC, PCEP, and ELNEC-PPC, but they highlighted similarities and differences in treating adults as compared with children [17] [14]. In addition, a key differentiator to this curriculum is its focus on experiential learning with live actors and parents who have lost children as faculty, while most other programs use lecture and video formats.

Each module had three objectives that were tied to improving knowledge, skills, and attitudes [18]. For example, in the “Introducing Pediatric Hospice to Children and Families” modules, the objectives were:

*Knowledge:* Learner will be able to identify three ways to address parents’ concerns and ease their anxieties about initiating hospice.

*Skill:* Learner will use developmentally appropriate language for discussing our role with children in partnership with parents.

*Attitude:* Learner will feel confident presenting pediatric hospice to parents, children, and other professionals in a truthful and realistic way.

Organizing the modules in this structured format allowed for improved teaching and evaluation, and ensured the needs of learners were met, as described by several studies [19] [20]. This

curriculum is unique in that it is training providers who are familiar with end-of-life care in adults, but less so in children. The traditional pediatric palliative care topics were refined for this population of learners through a structured conversation with the first group of participants. The tailored curriculum engaged learners and increased the value of the time in the workshop by eliminating redundant material.

In addition to improving participants' knowledge, completing this education program significantly narrowed the difference in comfort levels between those with greater than ten years of hospice experience and those with less experience. Therefore, investing in two days of training for providers gave them close to the same level of increased comfort and confidence that years of experience would have required. One caveat, of course, is that these are self-reported comfort and confidence levels. However, Bandura's Self Efficacy Theory states that when people believe they have the ability to accomplish a task or a goal (i.e. when they self-report high self-efficacy), they are more motivated to learn, and to strive to attain that goal. One may hypothesize that participants in this program who report higher comfort and confidence levels with all 13 skills believe in their own self-efficacy and, therefore, will be motivated to continue to practice and improve those skills clinically [21].

## II. Teaching methods:

A critical success factor in this education program is the use of experiential teaching methods in addition to more conventional, didactic teaching methods. According to Lindeman, one of the fathers of adult learning theory, several considerations should be made when teaching adults [22]:

1. Adults are motivated to learn when they experience needs and interests that learning will satisfy
2. Adults' orientation to learning is life-centered and problem-focused;
3. Experience is a rich source for adult learning
4. Adults have a deep need to be self-directed

This education program leveraged all four of these tenets of adult education. First, each of the providers was interested in caring for children, but felt uncomfortable doing so and therefore were motivated to learn. Second, their life events, via their chosen profession to care for those at the end of life gave them the appropriate context within which to understand caring for a child at the end of life. Third, and quite importantly, this program utilized actors and role-play, moving

participants just outside their comfort zones in order to reach the highest level of learning through experience, feedback and reflection. In addition to acting and role-play, in each of the workshops, parents who had lost a child taught the bereavement module and were actively involved throughout both days. Qualitative feedback from participants in this program (see table 8) is similar to findings in a recent study that showed both learners and bereaved parents benefit from this experience [23]. And lastly, adults need to be able to direct their learning – via role play, discussions, question and answer sessions – rather than being told what to learn in didactic sessions.

These experiential education methods are also the best methods for teaching communication skills, arguably the most important component of this educational program. Accurately and compassionately communicating with children and their families during this challenging time is critical for high quality care [14,20,23,6]. Learners were able to practice their communication skills in a safe space, with their peers and with faculty, before having to use them with patients and families.

### III. Supportive and Safe Environment:

Based on qualitative feedback, participants in this program felt valued because their professional leaders and supervisors invested in their development through this education program. They felt empowered by the support they received from peers and faculty. These findings are similar to those seen in employee engagement studies. Employees are more likely to be engaged in their work (to bring their full selves to their roles) if they feel it is meaningful (to themselves, others, and leadership), if it is psychologically safe (or they have the skills and knowledge to decrease fear), and if they are supported physically and emotionally [24]. This program specifically trains interdisciplinary teams of providers in pediatric care to provide peer-to-peer support for the providers. Engaged providers “employ and express themselves physically, cognitively, and emotionally” versus disengaged providers who “withdraw and defend themselves physically, cognitively, or emotionally” (Kahn, p. 694).

Increased engagement with patients, with adequate supports and self-care, improves patient care. It has been shown that the level of compassion needed to care for patients, especially children at the end of life, is not an unlimited resource. In fact, it can be depleted quite quickly without proper training, support, and self-care [25]. The feeling of compassion, or the

ability to feel emotions because of someone else's situation, is modulated by many variables including providers' ability to communicate with patients to elicit their perspective, their desire or ability to take that perspective, their awareness of their own emotions, and their own well-being [25]. This training program reinforced each of these skills. It enhanced communication, increased engagement, provided a safe space to discuss and face emotions, and taught self-care strategies. Focusing on these important skills should lead to increased compassionate care, which benefits both patients and providers.

#### IV. Limitations

There are several limitations to this programmatic evaluation. One of the biggest limitations to this data is that much of the evaluation relies on self-reported comfort or confidence levels rather than actual observation of care provided by participants, or patients' perceptions or quality of life outcomes. Therefore, we do not have concrete data showing improved patient care as a result of this education program. However, according to the Bandura's Self Efficacy Theory, providers who believe that they have certain skills (i.e. have self reported increased comfort levels with pediatric skills) are more motivated to actually attain those skills [21]. This program was able to improve learners' self efficacy, and therefore, according to Bandura, make the difficult task of caring for pediatric patients at the end of life something that learners feel motivated and able to do, rather than something to be avoided.

Another set of limitations pertains to the survey tool used for evaluation. First, the questions used were developed by the research team to be objective and to match directly with an educational objective; however, the questions were not validated by an outside researcher. Second, the same questions were asked at all three time periods – pre, post, and six-months later – resulting in some risk of recall bias resulting in improved scores. However, because participants were not given feedback on their survey results, the level of recall bias is likely low. In addition, there was a low response rate to the six-month survey of 26%. Although there were no noticeable demographic differences between respondents to the pre-survey and those who responded to the post-survey, there could be some responder bias in that those who were more engaged in the program are the ones who chose to respond to the survey after six months. There is also high turnover of hospice employees, so the low response rate is also a factor of loss of contact with some learners.

## **Section 6: Conclusions**

Training adult hospice providers in pediatric care shows promise as a strategy to improve access to underserved children and families at the end-of-life. Providers improved their knowledge, skills, and attitudes in pediatric care over the course of a two-day training program. Improved knowledge and skills were maintained at six-months, and attitude changes continued to improve. The time teams spent together, completing emotionally intense training exercises, led to a context that provided the opportunity to form a collaborative, supportive, interdisciplinary care team that we hope will continue from the workshop into practice.

Based on qualitative feedback from participants, the training program had added benefits for adult – as well as pediatric – care, likely due to emphasis on communication with the team and families. Participants expressed feeling “re-invigorated” and “inspired” after the training program. The time invested in professional development, team building, and self- reflection during this workshop had a positive effect on confirming professional purpose. This outcome has the potential to decrease burnout and intention to leave the profession. The latter has become increasingly important, as the United States faces a significant shortage in palliative care and hospice providers [26].

As the program continues, we will work to clarify objectives in the modules, modify the curriculum based on survey results and qualitative feedback, and provide opportunities for pediatric providers to reconvene for support and continued education. Further research is needed to evaluate the outcomes of 1) increased access to pediatric hospice care; 2) the quality of care provided to pediatric patients by providers who have completed this training program; and 3) patients’ and families’ reports of quality of life and other outcomes important to them.

The existing infrastructure of adult hospice programs is an untapped resource that can be utilized to increase access to pediatric hospice care, both nationally and internationally. Providers who are experienced in end-of-life care can be trained to adapt this knowledge and apply it to the care of pediatric patients. This novel educational model is a critical step towards utilizing the existing resource of adult palliative care providers to provide end-of-life care for children. Increasing the number of providers trained in pediatric hospice and palliative care will improve access to care and decrease unnecessary suffering for children and their families.

## **Section 6: Acknowledgements**

I would like to thank Dr. Tamara Vesel for her unwavering support and mentorship over the last four years. Her deep love of medicine is contagious; the peace and comfort she brings to her patients and to her colleagues is unmatched. I am incredibly lucky to count her as one of my most impactful teachers.

Thank you to Dr. Beth Lown who has jumped into our work with enthusiasm and added immensely to the insights we have been able to learn.

We would like to thank all those who participated in our education program and opened up to what can be a painful topic. Thank you for dedicating your careers to caring for those at the end of life. We very much appreciate you're the time you took to complete our evaluations.

## References

- 1 Dickens D. Comparing pediatric deaths with and without hospice support. *Pediatric Blood and Cancer*. 2010 May;54(5):746-750.
- 2 Johnston D, Nagel K, Friedman D. Availability and use of palliative care and end-of-life services for pediatric oncology patients. *Journal of Clinical Oncology*. 2008;26:464-4650.
- 3 Field M, Behrman R. When children die: Improving palliative and end-of-life care for children and their families. Washington, DC: National Academy Press; 2003 Institute of Medicine Committee on Palliative and End-of-Life Care for Children and their Families.
- 4 Jones B. The need for increased access to pediatric hospice and palliative care. *Dimensions of Critical Care Nursing*. 2011 September;30(5):231-235.
- 5 Sheetz M, Bowman M. Pediatric palliative care: an assessment of physicians' confidence in skills, desire for training, and willingness to refer for end-of-life care. *American Journal of Hospice and Palliative Care*. 2008;25:100-105.
- 6 American Academy of Hospice and Palliative Medicine; Center to Advance Palliative Care; Hospice and Palliative Nurses Association; Last Acts Partnership; National Hospice and Palliative Care Organization. National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for quality palliative care, executive summary. *Journal of Palliative Medicine*. 2004;7(5):611-27.
- 7 Friebert S, Williams C. Pediatric Palliative and Hospice Care in America. National Hospice and Palliative Care Organization; 2015.
- 8 American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Medicine. Palliative Care for Children. *Pediatrics*. 2000;106:351-357.
- 9 Friedrichsdorf S. US Pediatric Palliative Care Physician Fellowship Programs. [Internet]. [cited 2017 Jan 30]. Available from: <http://noneedlesspain.org/?s=pediatric+palliative+care+fellowship>.
- 10 Feudtner C, Womer J, Augustin R, Remke S, Wolfe J, Friebert S, Weissman D. Pediatric Palliative Care Programs in Children's Hospitals: A Cross Sectional National Survey. *Pediatrics*. 2013 December;132(6):1063-1070.
- 11 Jacobs H, Ferrell B, Virani R, Malloy P. Appraisal of the Pediatric End-of-Life Nursing Education Consortium training program. *Journal of Pediatric Nursing*. 2009 June;24(3):216-221.
- 12 Kochanek K, Murphy S, Xu J, Tejada-Vera B. Deaths: Final Data for 2014. *National Vital Statistics Reports*. 2016 June;65(4).
- 13 Liben S, Papadatos D, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *The Lancet*. 2008;371(9615):786.

- 14 Friedrichsdorf S, Emanuel L, Hauser J, Wolfe J, Remke S. Pediatrics. [Internet]. 2016 [cited 2017 Jan 30]. Available from: <http://bioethics.northwestern.edu/programs/epec/curricula/pediatrics.html>.
- 15 Harvard Medical School Center for Palliative Care. Palliative Care Education and Practice (PCEP). [Internet]. 2017 [cited 2017 Feb 23]. Available from: <http://www.hms.harvard.edu/pallcare/PCEP/PCEP.htm>.
- 16 Amery J, Lapwood S. A study into the educational needs of children's hospice doctors: a descriptive quantitative and qualitative survey. *Palliative Medicine*. 2004;18:727-733.
- 17 Malloy P, Sumner E, Virani R, Ferrell B. End-of-life nursing education consortium for pediatric palliative care (ELNEC-PPC). *American Journal of Maternal Child Nursing*. 2007 September;32(5):298-302.
- 18 Kern D. *Curriculum Development for Medical Education*. Baltimore (MD): Johns Hopkins University Press; 2009.
- 19 Brenner M, Connolly M, Cawley D, Howlin F, Berry J, Quinn C. Family and healthcare professionals' perceptions of a pilot hospice at home programme for children: a qualitative study. *BMC Palliative Care*. 2016 October 28;15(1):89.
- 20 Browning D, Solomon M. The Initiative for Pediatric Palliative Care: An Interdisciplinary Educational Approach for Healthcare Professionals. *Journal of Pediatric Nursing*. 2005 October;20(5):326-334.
- 21 Bandura A. *Self-efficacy: The exercise of control*. United States: Macmillan; 1997.
- 22 Lindeman E. *The Meaning of Adult Education*. New York (NY): New Republic, Inc.; 1926.
- 23 Snaman J, Kaye E, Cunningham M, Sykes A, Levine D, Mahoney D, Baker J. Going straight to the source: A pilot study of bereaved parent-facilitated communication training for pediatric subspecialty fellows. *Pediatric Blood & Cancer*. 2017 January 1;64(1):156-62.
- 24 Kahn W. Psychological conditions of personal engagement and disengagement at work. *Academy of Management Journal*. 1990;33:692-724.
- 25 Lown B. A social neuroscience-informed model for teaching and practising compassion in health care. *Medical Education*. 2016;50:332-342.
- 26 The American Academy of Hospice and Palliative Medicine Workforce Task Force. Estimate of current hospice and palliative medicine physician workforce shortage. *Journal of Pain and Symptom Management*. 2010;40(6):899-911.
- 27 Levine S, O'Mahony S, Baron A, Ansari A, Deamant C, Frader JLI, Marschke M, Preodor M. Training the Workforce: Description of a Longitudinal Interdisciplinary Education and Mentoring Program in



Palliative Care. *Journal of Pain and Symptom Management*. 2017 January.

28 Fowler K, Poehling K, Billheimer D. Hospice referral practices for children with cancer: a survey of pediatric oncologists. *Journal of Clinical Oncology*. 2006;24:1099-1104.

## Tables and Figures

**Table 1: Curriculum Modules**

Introducing Pediatric Hospice to Parents and a Child
Communication with Children
Pediatric Pain Assessment and Management
Palliative Sedation
Spirituality
Discontinuing Hydration and Nutrition
The Role of the Social Worker in Pediatric Hospice
Understanding Goals of Care at the End-of-Life
Non-Pain Symptom Management
Symptoms at the End-of-Life
Removal from Ventilator Support
Self- Care
Bereavement

**Table 2: Demographics of Learners**

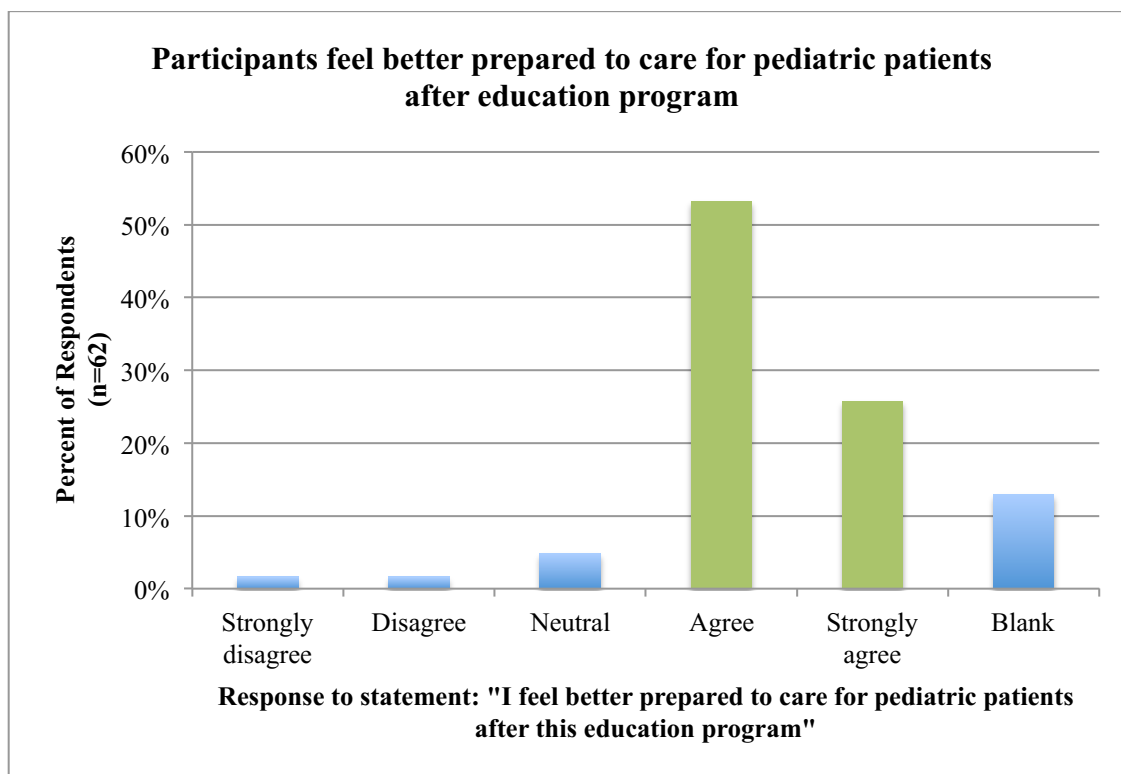
	<u>Number (%)</u>
<b>Health Care Profession</b>	
Chaplain	5 (7)
Child Life Specialist	2 (3)
Health Aide	1 (1)
Nurse	37 (51)
Other	6 (8)
Physician	9 (13)
Social Worker	10 (14)
(blank)	2 (3)
<b>Experience in Hospice Care</b>	
Less than one year	16 (22)
1-5 years	26 (36)
5-10 years	14 (19)
More than 10 years	15 (21)
(blank)	1 (1)
<b>Experience in Pediatric Hospice (# of patients treated)</b>	
None	18 (25)
1-2 patients	13 (18)
2-10 patients	24 (33)
More than 10 patients	16 (22)

(blank)	1 (1)
<b>Experience in General Pediatric (# of patients treated)</b>	
None	11 (15)
1-2 patients	4 (6)
2-10 patients	13 (18)
More than 10 patients	44 (61)

**Table 3: Response rates for pre, post, and 6-month evaluations**

	<b>Number (%)</b>
Pre-survey	72 (77)
Post-survey	62 (67)
6-month survey*	21 (26)

\*81 of 91 learners have received the six-month survey. The last group of learners completed a workshop in November 2016 so will receive the survey in May 2017.



**Figure 1: Participants feel better prepared to care for pediatric patients**

**Table 4: Learners’ self-assessment of confidence or comfort level in pediatric palliative care abilities improved with training**

<u>Attitude or Skill</u>		<u>Mean</u> <sup>a</sup>	<u>S.D.</u>	<u>P-value</u> <sup>b</sup>
Confidence presenting pediatric hospice to parents and children in a truthful and realistic way				<0.001
	Pre	2.87	1.12	
	Post <sup>c</sup>	3.86	0.71	
	6-month <sup>d</sup>	4.06	0.59	
Confidence having a difficult conversation with a teenager and a child without personal bias				<0.001
	Pre	2.96	1.09	
	Post	3.79	0.71	
	6-month	4.06	0.45	
Comfort interacting with pediatric patients and their families in a practical manner				<0.001
	Pre	3.27	1.07	
	Post	3.91	0.80	
	6-month	4.38	0.59	
Confidence discussing with parents removing a child’s body from the home				<0.001
	Pre	3.01	1.10	
	Post	3.85	0.73	
	6-month	4.00	0.62	
Confidence providing guidance and culturally sensitive spiritual / emotional support to families at the end of life				<0.001
	Pre	3.00	1.08	
	Post	3.79	0.82	
	6-month	4.06	0.75	
Confidence working with a child and parents on advanced care planning utilizing the “Five Wishes”				0.001
	Pre	2.79	1.15	
	Post	3.40	1.01	
	6-month	3.75	0.93	
Comfort introducing pediatric social worker to the family under difficult circumstances				<0.001
	Pre	3.69	0.94	
	Post	4.15	0.61	
	6-month	4.44	0.60	
Confidence creating individualized care plans based on goals of care				<0.001

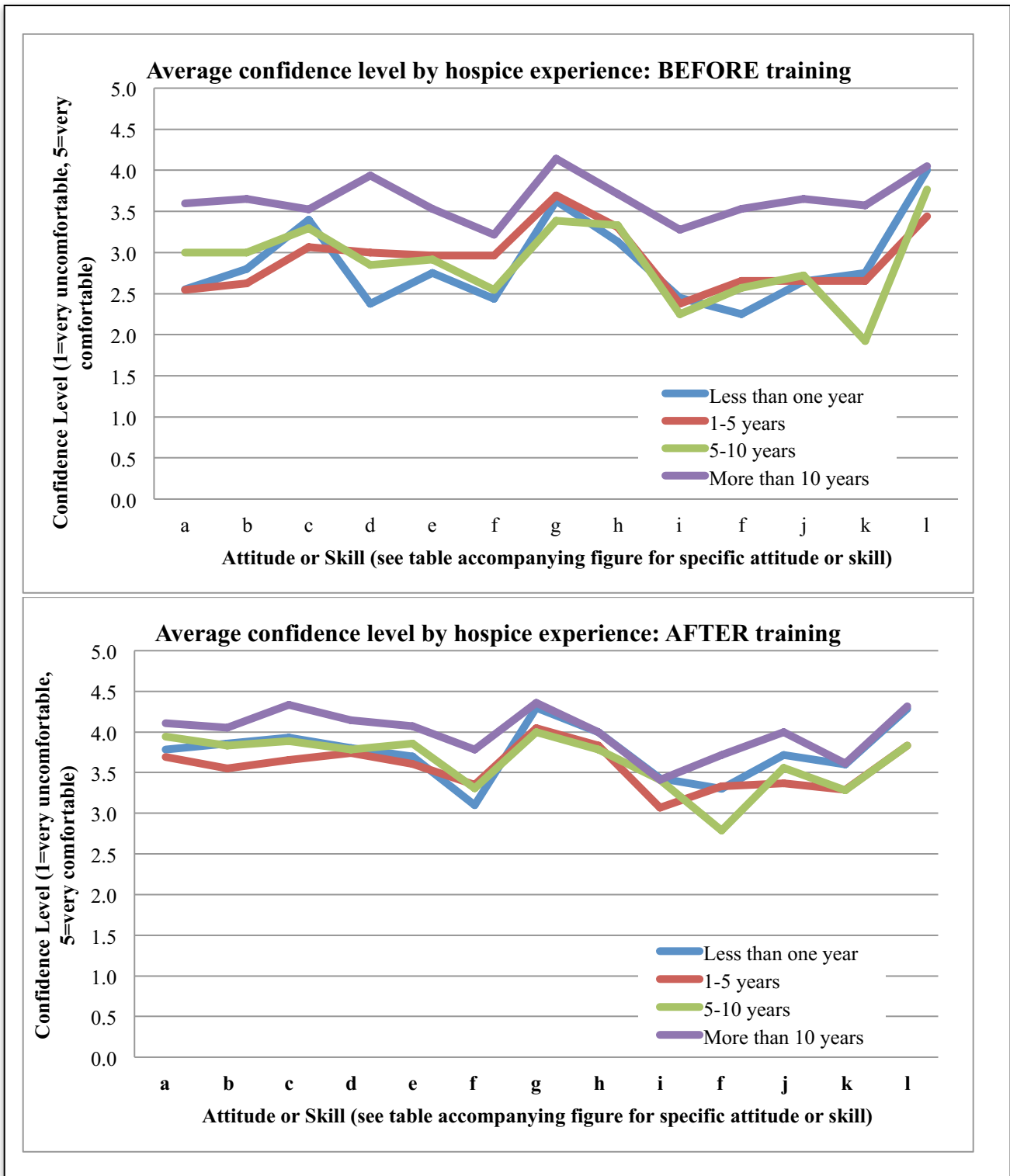
Confidence managing constipation, nausea, and vomiting in a pediatric patient	Pre	3.34	1.10	<0.001
	Post	3.89	0.70	
	6-month	4.13	0.68	
Confidence discussing the prognostication of a child with parents	Pre	2.57	1.18	<0.001
	Post	3.28	0.94	
	6-month	3.13	1.20	
Comfort having difficult conversations with children and parents at the end of life	Pre	2.72	1.06	<0.001
	Post	3.29	0.91	
	6-month	3.75	0.83	
Comfort caring for a child who will be extubated at home	Pre	2.88	1.09	<0.001
	Post	3.62	0.81	
	6-month	4.00	0.60	
Comfort bearing witness to parents' grief through active listening	Pre	2.70	1.20	0.023
	Post	3.41	0.96	
	6-month	3.44	0.98	
	Pre	3.77	0.96	
	Post	4.02	0.88	
	6-month	4.38	0.58	

a. A 5-point Likert scale was used to measure “Confidence or comfort level in ability to perform skill” with 5=Very high confidence (comfort level), 3=Moderate, and 1=Very low;

b. P-values are based on analysis of variation (ANOVA) between the three samples: pre, post, and six-months after completion.

c. All “post” measurements were taken on survey sent to learners immediately following the education program.

d. All “6-month” measurements taken on survey sent to learners six months after completion of the education program.



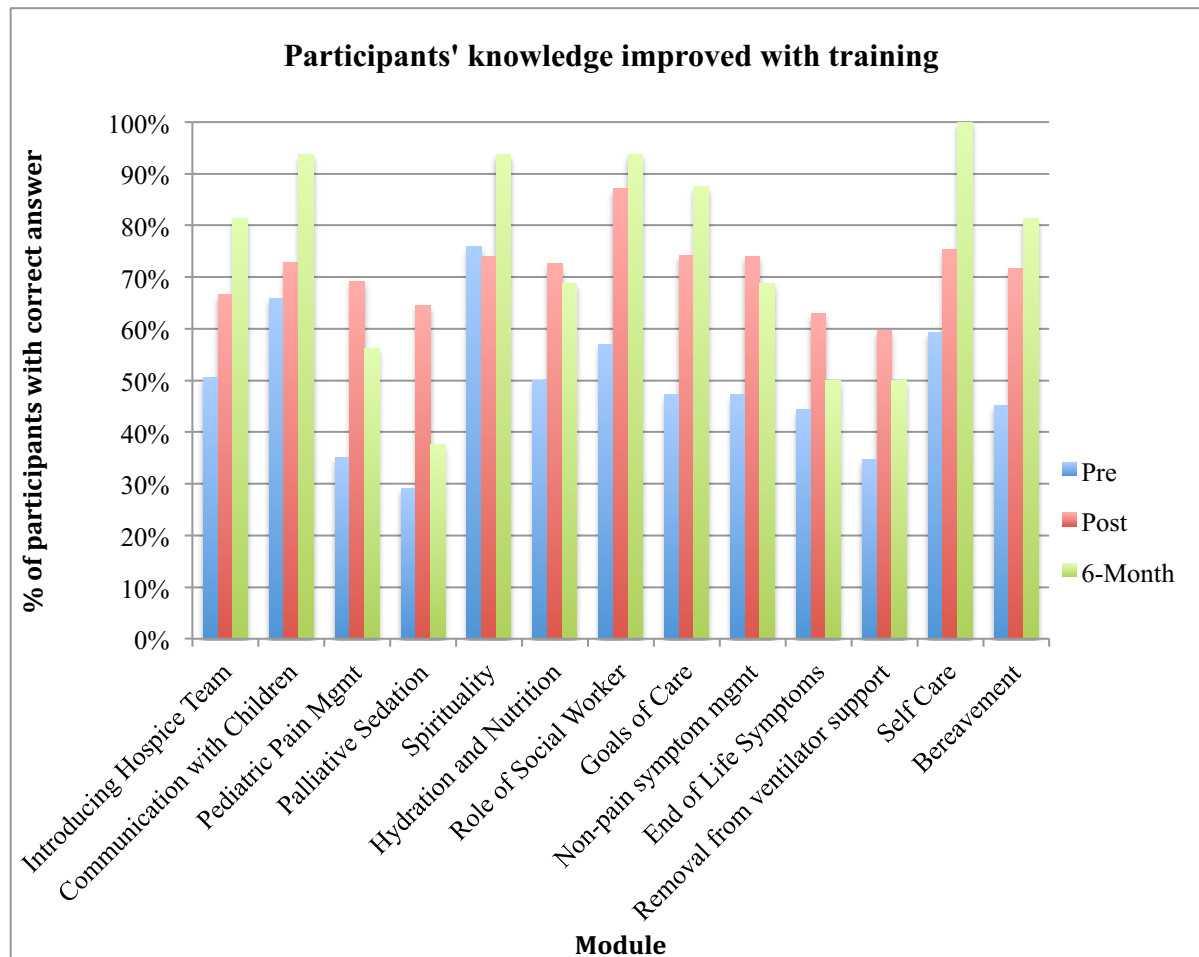
**Figure 2: Average confidence level with pediatric hospice care before and after training: split by level of prior hospice experience**

**Explanation of graph labels:**

<b>ID</b>	<b>Attitude or Skill</b>
a	Presenting pediatric hospice to parents and children in a truthful and realistic way
b	Having a difficult conversation with a teenager and a child without personal bias
c	Interacting with pediatric patients and their families in a practical manner
d	Discussing with parents removing a child's body from the home
e	Providing guidance and culturally sensitive spiritual / emotional support to families at the end of life
f	Working with a child and parents on advanced care planning utilizing the "Five Wishes"
g	Introducing pediatric social worker to the family under difficult circumstances
h	Creating individualized care plans based on goals of care
i	Managing constipation, nausea, and vomiting in a pediatric patient
f	Discussing the prognostication of a child with parents
j	Having difficult conversations with children and parents at the end of life
k	Caring for a child who will be extubated at home
l	Bearing witness to parents' grief through active listening

**Table 5: Participants' knowledge improved with training**

<b>Module</b>	<b>Participants with Correct Responses – n (%)</b>		
	<b>Pre</b>	<b>Post</b>	<b>6-Month</b>
Introducing Hospice Team	36 (51)	41 (67)	17 (81)
Communication with Children	47 (66)	45 (73)	20 (94)
Pediatric Pain Management	25 (35)	43 (69)	12 (56)
Palliative Sedation	21 (29)	40 (65)	8 (38)
Spirituality	55 (76)	46 (74)	20 (94)
Hydration and Nutrition	36 (50)	45 (73)	14 (69)
Role of Social Worker	41 (57)	54 (87)	20 (94)
Goals of Care	34 (47)	46 (74)	18 (88)
Non-pain Symptom Management	34 (47)	46 (74)	16 (69)
End of Life Symptoms	32 (44)	39 (63)	11 (50)
Removal from Ventilator Support	25 (35)	37 (60)	11 (50)
Self- Care	43 (59)	47 (75)	21 (100)
Bereavement	32 (45)	44 (72)	17 (81)



**Figure 3: Participants' knowledge improved with training**



**Table 6: Linear Regression for Likert Questions**

<b>Linear Regression</b>							
<b>Regression Statistics</b>							
<i>R</i>	0.55602						
<i>R Square</i>	0.30915						
<i>Adjusted R Square</i>	0.0285						
<i>S</i>	0.86683						
<i>Total number of observations</i>	46						
<b>QI = 1.5686 + 0.2849 * Q3 - 0.0815 * Q5 - 0.1496 * Q6 + 0.2120 * Q14 - 0.3310 * Q15 - 0.1031 * Q20 + 0.2888 * Q21 - 0.0154 * Q26 - 0.0848 * Q23 - 0.0541 * Q33 + 0.0253 * Q29 + 0.7110 * Q30 - 0.0606 * Q39</b>							
<b>ANOVA</b>							
	<i>d.f.</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p-level</i>		
<i>Regression</i>	13.	10.75989	0.82768	1.10154	0.39254		
<i>Residual</i>	32.	24.04446	0.75139				
<i>Total</i>	45.	34.80435					
	<i>Coefficients</i>	<i>Standard Error</i>	<i>LCL</i>	<i>UCL</i>	<i>t Stat</i>	<i>p-level</i>	<i>H0 (5%) rejected?</i>
<b>Intercept</b>	1.56863	1.12781	-0.72863	3.8659	1.39087	0.17386	No
<b>Q3</b>	0.28489	0.30525	-0.33689	0.90667	0.93328	0.35766	No
<b>Q5</b>	-0.08153	0.31665	-0.72652	0.56346	-0.25747	0.79846	No
<b>Q6</b>	-0.14963	0.41204	-0.98892	0.68966	-0.36315	0.71888	No
<b>Q14</b>	0.21198	0.32916	-0.4585	0.88245	0.644	0.52417	No
<b>Q15</b>	-0.33103	0.37436	-1.09358	0.43151	-0.88426	0.38315	No
<b>Q20</b>	-0.1031	0.16834	-0.446	0.2398	-0.61243	0.54458	No
<b>Q21</b>	0.28876	0.30556	-0.33363	0.91116	0.94505	0.35172	No
<b>Q26</b>	-0.01538	0.16281	-0.34702	0.31626	-0.09446	0.92534	No
<b>Q23</b>	-0.08483	0.26826	-0.63126	0.46159	-0.31623	0.75388	No
<b>Q33</b>	-0.05405	0.21883	-0.4998	0.3917	-0.247	0.80649	No
<b>Q29</b>	0.02528	0.2035	-0.38924	0.4398	0.12423	0.90191	No
<b>Q30</b>	0.71101	0.33065	0.03749	1.38453	2.15031	0.03919	Yes
<b>Q39</b>	-0.06064	0.20735	-0.483	0.36172	-0.29245	0.77183	No
<i>T (5%)</i>	2.03693						
<i>LCL - Lower value of a reliable interval (LCL)</i>							
<i>UCL - Upper value of a reliable interval (UCL)</i>							

**Table 7: Proportion of participants endorsing effectiveness of education methods**

<u>Education Method</u>	<u>Respondents – n (%)</u>
Actors	23 (38)
Role Play	21 (35)
Lecture	9 (15)
Group Discussion	7 (12)

**Table 8: Feedback from participants**

<b>Feedback on educators and methods</b>
<p>You all radiate integrity. Your presence demands that we pay attention and stay alert. You don't do "o.k." You do "excellent-superb!" The course challenged me to be less intellectually lazy and to improve my overall knowledge about these specific issues in pediatric palliative care.</p> <p>It's actually hard to define the most useful teaching method as all of them you have listed entwined with each other. Lecture and actors alone would not have been as successful without the discussion and role-play of participants. And none of it would have been as effective in a larger group.</p> <p>Having the actors come in was amazing, as was the processing afterwards. Hearing from the couple [who lost a child] directly made a huge impact on me.</p> <p>This is a WONDERFUL program; the reason it is wonderful is because the leaders are all consummate educators. This was the most skilled and worthwhile educational experience in my entire 25-year career in medicine.</p> <p>The course's strength lies in its hands-on approach to adult learning. The role plays; the open and inviting conversations were wonderfully challenging and encouraging!</p> <p>I would like to credit the couple that came forward to talk about the loss of their son and allow us to learn from their loss.</p>
<b>Impact on participants' attitudes about pediatric care</b>
<p>I was terrified at first, and now I LOVE the pediatric patients and would love to have an all-pediatric census for my caseload.</p> <p>I feel I have a skill set now that I didn't feel I had before- I feel like the team appears extremely supportive which would add confidence to any visit I would have to attend with a pediatric patient. I strongly feel I am a better person because of this learning experience. It was a beautiful two days.</p>

I have a greater sense of purpose now; to work in pediatrics and to really pay more attention to the job I do every day.

I have never had training like this and it was highly impacting. I loved all forms of teaching and all of the faculty. I am so appreciative of their work and efforts and feel like my life was impacted by this course.

This program got me really excited about hospice again in general. Everything we learned can be applied to adults too. It was generally nurturing to the soul!

## Appendix 1: Sample of Curriculum Modules, Objectives, and Survey Questions

Module / Section of Survey	#	Learning Objectives	Question	Type of Question
Introducing Pediatric Hospice to Parents and a Child	1	<i>Knowledge:</i> Learner will be able to identify three ways to address parents' concerns and ease their anxieties about initiating hospice.	List three ways to address parents' concerns and ease their anxieties about initiating hospice.	Free Response
Introducing Pediatric Hospice to Parents and a Child	2	<i>Skill:</i> Learner will use developmentally appropriate language for discussing our role with children in partnership with parents.	A five-year-old child was just admitted to hospice. You talk with his parents and receive permission to engage with him. He is playing on the floor with toy car. You introduce yourself to the child. The first thing you should do next is:	Multiple Choice
Introducing Pediatric Hospice to Parents and a Child	3	<i>Attitude:</i> Learner will feel confident presenting pediatric hospice to parents, children, and other professionals in a truthful and realistic way.	How confident do you feel on a scale of 1-5 presenting pediatric hospice to parents, children, and other professionals in a truthful and realistic way?	Likert
Communication with Children	4	<i>Knowledge:</i> Learner will be able to categorize patient's understanding of end-of-life based on developmental stages.	You are talking to an eight-year-old girl enrolled in hospice. In a discussion with you about the end of her life, she probably says...	Multiple Choice
Communication with Children	5	<i>Skill:</i> Learner will be able to demonstrate a difficult conversation with a teenager and school-aged child without personal bias.	On a scale of 1-5, how confident do you feel in your ability to have a difficult conversation with a teenager and a school-aged child without personal bias?	Likert
Communication with Children	6	<i>Attitude:</i> Learner will become comfortable interacting with child and family in a practical manner.	On a scale of 1-5, how comfortable do you feel interacting with pediatric patients and their families in a practical manner?	Likert

Demographics	a	Profession	Multiple Choice
Demographics	b	How long have you worked in hospice care?	Multiple Choice
Demographics	c	How many pediatric patients have you worked with in hospice care?	Multiple Choice
Demographics	d	How many pediatric patients have you worked with in general?	Multiple Choice
Demographics	e	If you do have experience working with pediatric patients what was your role?	Free Response
Demographics	f	What motivated you to be trained in pediatric hospice care?	Multiple Option
Demographics	g	[optional] Please describe your motivation for participating in this training program.	Free Response

---