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Appraisal of the Pediatric End-of-Life Nursing Education Consortium Training Program

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Major deficiencies continue to exist in pediatric palliative and end-of-life nursing education. The End-of-Life Nursing Education Consortium (ELNEC)-Pediatric Palliative Care (PPC) train-the-trainer curriculum was developed to create a nursing education program to improve care for children and their families confronted with life-threatening illnesses (www.aacn.nche.edu/ELNEC). Two ELNEC-PPC training programs were held in August 2005 and August 2006. The purpose of this article is to present data from the precourse and 12-month postcourse follow-up of participants who attended the two courses. Findings from these assessments demonstrate a positive link between educational initiatives and clinical outcomes.
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THE DEATH OF a child is considered an unnatural event; however, pediatric nurses work with children and their families facing potentially life-limiting illnesses with alarming frequency. In fact, approximately 53,000 children die every year in the United States (Field & Behrman, 2003). Nurses are exposed to infants, children, and adolescents who die suddenly, such as from accidents, murder, or suicide, are diagnosed with 6 months or less to live, such as those with cancer or congenital anomalies, die from chronic illness, such as cystic fibrosis, die at or shortly after birth from congenital defects, prematurity, or sudden infant death syndrome, and die in utero with perinatal death (Sumner, 2006). Between 75% and 85% of pediatric deaths occur in institutional settings (Field & Behrman, 2003). In addition to care of children who die from these causes, there is a very significant number of children living with life-threatening diseases who also require palliative care. It is estimated that 1 million children in the United States live with a serious, chronic medical condition (Levetown, 2000).

Despite the need for palliative care, the services available to children and their families are inadequate. Barriers to pediatric palliative care (PPC) help explain, though not excuse, the lack of services. For example, the failure to acknowledge the limits of medicine and uncertainty of prognosis frequently leads to the initiation or maintenance of futile interventions, resulting in a prolongation of the dying process and exacerbation of physical, emotional, and spiritual distress (Wolfe et al., 2000). In addition, the lack of adequate training or access to training for pediatric nurses combined with the discomfort of many health professionals in communicating bad news and prognoses with children and families contributes to the absence of adequate services.

Nurses spend more time and are more intimately involved with patients and families at end of life than

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all other health professionals do (American Association of Colleges of Nursing [AACN], 1997; Field & Cassel, 1997), yet research has demonstrated that major deficiencies exist in nursing education for end-of-life (EOL) care, resulting in an overall lack of preparation to provide care to children and their families facing life-threatening illness. To understand this deficit, the researchers at City of Hope National Medical Center conducted a 3-year project titled, "Strengthening Nursing Education to Improve End-of-Life Care (AACN, 1997)," which was supported by The Robert Wood Johnson Foundation. From 1997 to 2000, the research demonstrated inadequacy in the general content in nursing texts in EOL care as well as insufficient nursing faculty knowledge related to EOL content (Coyne et al., 2007; Ferrell et al., 2005). For example, only 2% of the content found in 50 commonly used nursing textbooks was dedicated to EOL care (Ferrell, Virani, et al., 1999). Other national studies produced comparable results demonstrating that nurses were not prepared to deliver optimal EOL care (Ferrell, Virani, Grant, Coyne, and Uman, 2000; Institute of Medicine Report, 2003).

As a result of these studies, the End-of-Life Nursing Education Consortium (ELNEC) was launched in February 2000. Although the first eight ELNEC courses, supported by the Robert Wood Johnson Foundation, were targeted to working with patients across the life span, it became apparent that the ELNEC curriculum did not meet the specific needs of pediatric nurses caring for neonates, children, and adolescents facing life-threatening illnesses and that a specific curriculum was required to meet these distinctive needs. In September 2001, a pediatric-specific ELNEC training course was conceptualized. In June 2002, the ELNEC-Pediatric Palliative Care (PPC) curriculum was piloted with 20 PPC experts from around the country in a 3-day course. From this pilot and extensive evaluation data, the ELNEC-PPC course was developed. The first Pediatric ELNEC course was held in 2003 followed by a second one in 2004. Following the success of these first two courses, two more additional courses were held in August 2005 and August 2006. The purpose of this article is to present data from the preassessment and 12-month postassessment follow-up of participants who attended the 2005 and 2006 ELNEC-PPC courses.

COURSE

The ELNEC-PPC course was developed as a 2 and 1/2 day, train-the-trainer program, with the intent that those who trained in ELNEC-PPC would become vital forces in its dissemination by taking the information to clinical and/or university settings. The curriculum consists of 10 modules that are specific to the care of children and their families facing life-limiting illness: Nursing Care in Pediatric Palliative Care, Special Considerations in Pediatric Palliative Care, Communication, Ethical/Legal Issues, Cultural Considerations, Pain Management, Symptom Management, Care at the Time of Death, Loss/Grief/Bereavement, and Models of Excellence in Pediatric Palliative Care. Please refer

Table 1. ELNEC-PPC Modules and Overviews

Module	Overview
Module 1: Introduction to Pediatric Palliative Nursing Care	Creates the foundation for the ELNEC-PPC curriculum. It is an overview of the need to improve care and the role of nurses as members of an interdisciplinary team in providing quality care.
Module 2: Special Considerations in Pediatric Palliative Care	Focuses on the foundation of pediatric palliative care by highlighting the essential elements involved with caring for seriously ill children as well as addressing each child's multifaceted uniqueness.
Module 3: Communication	Emphasizes the importance of good communication in PPC. The complexities of communicating with children and families at this critical time are described along with suggestions for care.
Module 4: Ethical/Legal Issues	Discusses some of the key ethical issues and legal concerns in palliative care for children and provides resources to address these in practice.
Module 5: Cultural Considerations	Reviews dimensions of culture that influence PPC. Assessment of culture is emphasized as essential to adequate communication and in providing culturally sensitive care.
Module 6: Pain Management	Reviews basic principles of pain assessment and management in infants, children, and adolescents with a focus on pain in palliative care.
Module 7: Symptom Management	Builds on Module 6 (Pain Management) by addressing other symptoms common in children with life-threatening illnesses.
Module 8: Care at the Time of Death	Focuses on care at the actual time of a child's death, emphasizing the preparation necessary to ensure the best care at this critical even in the trajectory of illness.
Module 9: Loss/Grief/Bereavement	Addresses the challenging aspects of grief, loss, and bereavement of children and families as well as the loss experiences of health care professionals.
Module 10: Models of Excellence	Focuses on the role of nurses in achieving quality care for children living with life-threatening conditions and their families by reviewing limitations in existing systems and opportunities for change.

to Table 1. Thanks. for a description of the modules. There are eight major themes embedded within each of these modules. They include the following: (a) The family as the unit of care; (b) The important role of the nurse as advocate; (c) The importance of culture as an influence in palliative care; (d) The critical need for attention to special populations such as ethnic minorities, the poor, and the uninsured; (e) Palliative care impacts all systems of care across all settings; (f) Critical financial issues influence palliative care; (g) Palliative care is not confined to cancer or AIDS, but rather it is essential across all life-threatening illnesses and in cases of sudden death; and (h) Interdisciplinary care is essential for quality care at the EOL.

The program begins in the evening with an introduction to the course and an introduction to "Nursing Care in Pediatric Palliative Care," followed by a networking reception. The subsequent days include didactic lectures, case study discussions, role-play, and use of videos to demonstrate educational strategy. At the conclusion of the training, the participant returns to his/her institution fortified with the 1,000-page ELNEC-PPC curriculum, including lecture notes, PowerPoint slides, experiential teaching strategies, case studies, and key references for each of the 10 modules (www.aacn.nche.edu/ELNEC).

PREASSESSMENT

ELNEC-PPC participants are competitively selected with priority given to multiple institutions to best spread the resources given the national need. The extensive application requires applicants to fill out a precourse evaluation survey. In addition to demographics, the precourse assessment evaluates the participant's prior experience in providing palliative care education, as well as how important palliative care content is to continuing nursing education. It asks the participants to identify types of materials they are currently using to teach palliative care (e.g., textbooks, audiovisuals, and case studies). The final portion of the assessment asks about the importance and effectiveness of palliative care as well as barriers encountered in the process of delivering palliative care.

Two hundred eleven pediatric nurses attended the 2005 and 2006 ELNEC-PPC training programs. The demographics of the nurses who attended were primarily Caucasian (85.4%) women (95.6%). Although the majority of the attendees were Caucasian, the ethnicity of the populations served varied: Caucasian (46.6%), followed by Hispanic/Latino (27.3%), African American (16%), Asian (7.3%), American Indian/Alaskan Native (1.2%), and other (1.6%). The ELNEC-PPC participants represented varied nursing positions including staff nurse (31.3%) followed by coordinator/manager (24.1%), advanced practice nurse (20.5%), educator (13.9%), university faculty (5.4%), and other (4.8%). The participants also represented a multitude of health care environments including hospital (60.1%), followed by hospice (22.4%), clinical staff development/continuing education (25.9%), college/university continuing education (16.1%) palliative care (14%), home health (8.4%), clinical/outpatient (6.3%), and independent continuing education provider (3.5%). Many of the participants noted that they worked in multiple settings in different positions (i.e., an advanced practice nurse who worked both in a hospital and taught continuing education programs).

In the precourse assessment, nurses were asked to rate both their perceptions of PPC delivery and PPC education in their institutions. In the precourse surveys, the participants perceived PPC as very important to pediatric nursing (x = 9.8; on a scale of 0 = *not important*, 10 = *very important*) and that their continuing education audience would be very receptive to PPC education (x = 9.0). With regard to care delivery, participants perceived that their own institution was only moderately effective in caring for a dying child and family (x = 6.0) and that their continuing education program was minimally effective in teaching PPC content (x = 5.1).

Participants were also asked whether their institution offered PPC education programs in the previous year and, if so, what subjects were taught. The participants stated that prior to attending the ELNEC-PPC course, no educational programs were dedicated to PPC at their institutions, indicating a significant gap between the apparent need for PPC education and the availability. The participants' perceived barriers to providing PPC

Table 2. Barriers to Providing PPC Education

- Discomfort and fears associated with pediatric death
- Lack of educational materials
- Lack of prepared faculty
- Lack of time in present schedule
- Lack of money and support
- Staff turnover and shortages
- Cultural differences
- Competing and required educational needs
- Small pediatric population

education in their community correlate to those in the research (Sumner, 2006). These barriers can be found in Table 2.

12-MONTH EVALUATION POSTCOURSE

As has been the case with previous ELNEC training programs, 12-month evaluation surveys were conducted to evaluate the effectiveness of the ELNEC-PPC program. The 12-month evaluation data of the two ELNEC-PPC courses held in August 2005 and August 2006 (N = 169) demonstrated highly significant improvements in the ratings before and 12 months postcourse on the perceived effectiveness of a nurse caring for a dying children and their families and the improvement of the institution in teaching PPC. Please refer to Table 3. for a pre- and 12-month postcourse comparison. The ELNEC-PPC participants rated the overall helpfulness of the ELNEC-PPC curriculum at 9.06 (on a scale of 0 = *not helpful* to 10 = *very helpful*). When asked how helpful the ELNEC-PPC training program has been to improving PPC content into staff education, the response was 8.30.

The participants were asked to report the greatest benefits of the ELNEC-PPC training. They consistently stated that a predesigned, highly organized, and flexible curriculum is easily implemented in a multitude of settings. The course itself offered a sound knowledge base from which self-confidence in the implementation of PPC education and care delivery developed. Participants also noted that the networking opportunities at the ELNEC-PPC course increased the comfort level of working with children and their families facing life-threatening illness. As a result of attending the course, participants have built partnerships with hospitals, home health agencies, and chronic care facilities to offer education and clinical support so that children and their families are cared for across the health care continuum. In addition to assessing benefits, the postcourse evaluation also asked for the greatest limitations in implementing the ELNEC-PPC curriculum. The largest barriers were funding and time to implement educational initiatives. In addition, some nursing administrators still consider ELNEC-PPC to be an advanced nursing topic and are not inclined to include it in orientation programs. Fear of caring for dying children is another consistent barrier to implementing the ELNEC-PPC curriculum.

CONCLUSION

The ELNEC-PPC project has been an extremely successful educational endeavor to improve knowledge by nurses in palliative care in caring for dying children and their families. Since its inauguration, 560 pediatric nurses have attended six national ELNEC-PPC courses representing 45 states, plus the District of Columbia and Canada. Another important source of dissemination of ELNEC-PPC has been through ELNEC International efforts. ELNEC has been distributed to more than 45 countries. The ELNEC staff hosted training sessions in October 2006 for representatives from 14 Eastern European countries at a conference convened in Salzburg, Austria and in Tanzania, Africa in August 2007. The high childhood mortality in these countries made the pediatric curriculum very valuable (Malloy, Sumner, Virani, & Ferrell, 2007).

In addition to the wide dissemination of the ELNEC-PPC curriculum, data collected from these two courses demonstrate that nurses are receptive to PPC education and are effective in the dissemination of educational material and achieving their course goals. Data further suggest that nurses are very receptive to palliative care education and are productive in dissemination of educational material and implementation of course goals and objectives. In addition, many educators are teaching the ELNEC content outside of their own institution/

Table 3. Pre/12-Month Postcourse Comparison (Based on a Scale of 0 = *not* to 10 = *very*)

Question	Pre	Post 12 Months	Pre/Post Comparison
How effective do you believe a nurse in your program/agency/setting would be in caring for a dying child and family?	6.05	7.24	$p < .001$
As an educator, how effective do you feel you are in teaching pediatric palliative care content?	6.72	7.66	$p < .001$
How effective do you believe your CE/SD program is in teaching pediatric palliative care content?	5.22	7.34	$p < .001$
Overall, how helpful has the ELNEC-PPC training program been to you in improving palliative care content in your CE/SD program?		8.30	

Note: CE/SD = continuing education/staff development.

Table 4. Case Study

"Danny"

Danny is a 4-year-old boy with primary right shoulder osteosarcoma with metastasis to the spine. His dad reports unusual clinging to him or his mom and difficulty going to sleep. His parents state that Danny does not complain of pain but really does not move that much. They have asked for no further visitation by anyone and just want time alone with him. Danny's parents openly discuss in front of him the fear of disease progression.

Questions	Answers
1. Why do you think Danny is clinging more to his parents?	Clinginess is a developmental characteristic of a child's response to pain. He may be looking for physical comfort for his pain from his parents.
2. What pain assessment scale could be used to assess Danny's pain?	Wong/Baker FACES is probably the most consistently used quantitative pain assessment tool in children, and is the best-documented validated tool. The Poker Chip Tool works well with this age also.
3. What other factors in Danny's case could be contributing to his reluctance to report pain?	Danny may not report pain to his parents because he does not want to distress them more. They have overtly expressed around him their fear that the disease is worsening. He does not want to increase that fear by complaining of pain. Social isolation could also contribute to Danny's perception of pain.
4. What education is needed for Danny and his parents?	Danny needs more information concerning his pain. He needs to be reassured that he has done nothing wrong to cause his pain and that there are steps to relieve his discomfort. Danny's parents need to be educated on children's behavioral responses to pain and the individual behaviors of Danny's that could indicate pain. They should reassure Danny that although they fear he is getting sicker that does not mean they would be upset if he reported his pain.
5. Unfortunately, Danny's disease did progress. He experienced severe right shoulder pain near the end of his life. His parenteral opioid dose was escalated several times with little effectiveness. Several other opioids were attempted but were still unsuccessful in relief of his pain. What could be the intervention for Danny?	Danny could possibly benefit from an epidural. Other invasive procedures or noninvasive treatments may be useful. A consult with a pain or palliative care service might be beneficial to evaluate these options.

agency and are expanding the materials used in their educational efforts. Most importantly, these educators have reported that they are more effective in teaching palliative care because of the ELNEC-PPC curriculum and its impact on better quality care of the dying child and their families (Malloy et al., 2007). Table 4. Thanks. is a case study from the curriculum that demonstrates the use of a highly effective clinical teaching tool resulting in direct improvement in the care of dying children and their families.

Additional information about the ELNEC-PPC project and future courses can be found on the project Web site (www.aacn.nche.edu/ELNEC).

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