

Palliative Care Education For Pediatric Nurses

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Of all the various healthcare professionals that provide care to children and their families facing life's end, no one spends more time at the bedside observing, critically thinking, consulting, and providing direct care than the pediatric nurse. Previous research, however, demonstrates that undergraduate education has not prepared nurses to provide optimum end-of-life (EOL) care (Ferrell, Grant, & Virani, 1999; Ferrell, Virani, & Grant, 1999). Although many reasons have been cited in the literature for this inadequacy, the fact remains that when nurses complete their basic education and enter practice, they often are grossly unprepared to care for children and families in need of end-of-life care (Field & Behrman, 2003).

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The End-of-Life Nursing Education Consortium—Pediatric Palliative Care (ELNEC-PPC) Project, has, to date, reached over 400 pediatric nurses through three national training programs. These nurses have returned to their own institution to teach the ELNEC-PPC curriculum to their colleagues, so they will be equipped to promote excellent palliative/EOL care in their own clinical settings.

Palliative Care Education For Pediatric Nurses

Cameron is a 22-month-old girl who was involved in a motor vehicle accident two weeks ago. She arrived in the emergency room unresponsive with fixed and dilated pupils. Cameron had cerebral edema and was intubated and cared for in the pediatric intensive care unit. The physicians discussed with the family that she would not improve and that her brain was not functioning. The family decided to have Cameron extubated the next morning.

Similar situations as described above occur every day in hospital emergency rooms and neonatal intensive care, pediatric intensive care, and medical/surgical units. Between 75%–85% of children die in institutional settings where many barriers to quality palliative care exist (Field & Behrman, 2003). For example, pediatric nurses witness inappropriate use of aggressive curative treatments that may prolong the dying process (Wolfe et al., 2000), lack of adequate training among health care professionals to provide safe and effective ways to control pain, poor communication with family members, delayed access to pediatric hospice/palliative care services, and inadequate reimbursement for those services (Field & Behrman, 2003). Pediatric nurses are confronted with related occurrences dealing with a myriad of complicated physical, psychological, legal, ethical, social, and spiritual dilemmas. Yet studies show that pediatric nurses are

not equipped to deal with these many difficult issues.

Deficiencies in end-of-life (EOL) content in nursing textbooks and in nursing school curriculum have ill-equipped pediatric nurses to assist children and families facing the end of life (Ferrell, Virani, et al., 1999). Previous researchers have documented that nurses also face ethical dilemmas in the clinical setting, such as conflicts about administering pain medication to patients at the end of life, communicating with patients and families, and nursing involvement in patient decision-making regarding foregoing nutrition and hydration (American Nurses Association, 1992, 1994; Asch, 1996; Ferrell & Coyle, 2002).

In 2002, the Institute of Medicine (IOM) released their report on pediatric palliative care titled "When Children Die: Improving Palliative and End of Life Care for Children and Their Families." This report called for improved professional education to address the care of children at the end of life and their families. The IOM reported that approximately 400,000 children in the United States are living every day with a chronic, life-threatening condition, and that 53,000 of these children die annually (Field & Behrman, 2003). Yet due to the numerous years of educational deficiencies related to EOL care, it became evident that further education must be provided to pediatric nurses. Hence, the End-of-Life Nursing Education Consortium Pediatric Palliative Care (ELNEC-PPC) training program was developed to address these educational deficiencies.

How ELNEC-PPC Began

In 1997, the American Association of Colleges of Nursing (AACN) convened a meeting to outline nursing competencies necessary to provide quality care to patients and families. From this meeting, a consensus document was written and entitled, "A Peaceful Death: Recommended

Competencies and Curriculum Guidelines for End-of-Life Care” (American Association of Colleges of Nursing [AACN], 1997). From 1997-2000, researchers at the City of Hope National Medical Center (COH) conducted a project titled, “Strengthening Nursing Education to Improve End-of-Life Care.” The research conducted during the course of this project demonstrated major deficiencies in palliative care education in nursing school curriculum and nursing textbooks (Ferrell, Grant et al., 1999). For example, only 2% of the content found in 50 commonly used nursing textbooks was dedicated to end-of-life (EOL) care (Ferrell, Virani, et al., 1999). Three out of the 50 reviewed textbooks were commonly used pediatric nursing textbooks. Only 1.3% of the content in the pediatric textbooks was related to EOL care. In addition, nursing faculty stated they felt inadequate in teaching end-of-life content. (Ferrell, Grant, et al., 1999)

Results from similar national studies came to the same conclusion—nurses were not prepared to provide optimum end-of-life care (Ferrell, Virani, Grant, Coyne, & Uman, 2000; Institute of Medicine Report [IOM], 1997, 2002). In 1999, AACN and COH initiated collaboration to develop a national education program on end-of-life care for registered nurses. This national project, End-of-Life Nursing Education Consortium (ELNEC), was launched in February 2000 to assist nurses in reducing the burden and distress of adults facing life’s end and to offer support for the many physical, psychological, social, and spiritual needs of patients and their families (Matzo, Sherman, Penn, & Ferrell, 2003; Sherman, Matzo, Panke, Grant, & Rhome, 2003).

Although the initial eight ELNEC courses, supported by the Robert Wood Johnson Foundation, were designated for nurses who work with patients across the life span, it became evident that the ELNEC curriculum did not meet the distinctive requests of pediatric nurses. Because of the unique needs from the neonate to the adolescent, changes needed to be made to the original ELNEC curriculum. In September 2001, a pediatric-specific ELNEC training course was conceptualized. Twenty invited pediatric palliative care experts attended a 3-day pilot course of the pediatric version of ELNEC in June 2002 where a comprehensive evaluation was conducted. From this pilot and extensive evaluation data, the investigators developed 10 modules

Table 1. ELNEC-PPC Modules and Overviews

Module	Overview
Module 1 Introduction to Pediatric Palliative Nursing	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. Basic principles of pediatric palliative care are presented within a quality-of-life (QOL) framework.
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 pediatric palliative care. 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 pediatric palliative care. 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 event 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.

that were specific to the care of children facing life threatening illness and their families (see Table 1).

The ELNEC-PPC project was developed as a three-day, train-the-trainer program, with the intent that the pediatric nurse educator would return to his/her clinical and/or university settings and disseminate the information to nurses in their facilities through training courses. The 1,000-page ELNEC-PCC curriculum provides the pediatric nurse educator with PowerPoint slides featuring sensitive illustrations (see Figures 1 and 2), “talking points” for each slide, case studies, teaching strategies, and numerous key references for each of the 10 modules.

Embedded within these modules are eight major themes. They include:

- The family as the unit of care
- The important role of the nurse as advocate
- The importance of culture as an influence in palliative care
- The critical need for attention to special populations such as ethnic minorities, the poor, and the uninsured
- The impact of end-of-life issues on all systems of care across all settings
- The influence of critical financial issues on palliative care
- The notion that palliative care is not confined to cancer or AIDS, but rather is essential across all

**Table 2. Number of Activities: Pre and Post ELNEC-PPC Training
(N = 91; 91% response rate)**

Module	Pre-ELNEC-PPC		Post-ELNEC-PPC		p
	(mean)	(SD)	(mean)	(SD)	
Introduction to Pediatric Palliative Nursing	0.64	1.38	1.36	2.25	.004
Communication	0.87	3.23	1.25	2.14	.340
Ethical/Legal Considerations	0.35	1.27	0.73	1.15	.027
Cultural Considerations	0.53	2.80	0.56	0.96	.926
Pain Management	1.22	2.99	1.45	1.77	.518
Symptom Management	0.66	1.59	1.20	1.62	.013
Care at the Time of Death	0.48	1.58	1.02	2.75	.098
Grief, Loss, and Bereavement	0.83	2.90	1.09	1.84	.454
Models of Excellence	0.27	1.20	0.41	1.14	.422

Note: Statistical data is taken from the 12-month up-dates of the first ELNEC-PPC training program. Although 296 nurses have completed the three national ELNEC-PPC courses, these statistics are from data presented from the first cohort only

**Table 3. Number of Attendees: Pre and Post ELNEC-PPC Training
(N = 91; 91% response rate)**

Module	Pre-ELNEC-PPC		Post-ELNEC-PPC	
	(mean)	(SD)	(mean)	(SD)
Introduction to Pediatric Palliative Nursing	14.00	29.27	28.54	49.03
Communication	9.08	22.74	24.51	38.19
Ethical/Legal Considerations	6.02	18.44	20.23	42.86
Cultural Considerations	7.24	29.11	14.37	28.05
Pain Management	15.64	31.35	27.26	37.79
Symptom Management	9.64	22.28	24.45	39.16
Care at the Time of Death	7.79	24.42	15.74	30.55
Grief, Loss, and Bereavement	10.57	22.72	24.85	49.14
Models of Excellence	5.44	23.56	12.60	28.67

Note: Statistical data is taken from the 12-month up-dates of the first ELNEC-PPC training program. Although 296 nurses have completed the three national ELNEC-PPC courses, these statistics are from data presented from the first cohort only

life threatening illnesses and in cases of sudden death

- The importance of interdisciplinary care as essential for quality care at the end of life

Educational Activities of ELNEC-PPC Trainers

To date, over 400 pediatric nurses have attended three national ELNEC-PPC courses, representing 45 states, plus the District of Columbia, British Columbia, and Manitoba. The participants have been in the roles of staff nurse, staff development educator, advanced practice nurse, university faculty, and coordinator/manager. They represent hospitals, hospices, clinics, home health care facilities, and nursing specialty organizations. Fifty-eight percent of the participants have

an advanced degree.

Applicants for the ELNEC-PPC course must fill-out a pre-course evaluation survey and list at least three goals they will work on after attending the course. In addition, a letter of recommendation must be submitted by their administrator, stating support for the trainer in accomplishing these goals after the trainer returns from ELNEC-PPC. At 6-months and 12-months post-training, participants are asked to up-date the ELNEC Project office on the accomplishment of meeting their goals and/or discuss barriers they are having in completing their goals.

Data from the first ELNEC-PPC course, held in August of 2003, showed impressive growth in several areas among the participants. For example:

Number of activities and attendees

who received educational content based on the ELNEC-PPC curriculum increased. (Using 9 out of the 10 ELNEC-PPC modules, nursing educators were asked to document the number of activities and attendees who had received lectures or other educational content based on the ELNEC-PPC curriculum (see Tables 2 and 3). [Module 2: Special Considerations in Pediatric Palliative Care is a supplemental module that focuses on the child's developmental stages and the impact illness has on developmental growth and development and was an optional resource. It was not included in this analysis]. Of particular note were the modules that had a significant rise in both activities as well as attendees, as compared to the previous year. For example, "Introduction to Pediatric

Table 4. Perceived Status of End-of-Life Pediatric Palliative Care Education (N=91; 91% response rate)

Item	Pre X		Post x	
	(mean)	(SD)	(mean)	(SD)
A. Importance of pediatric palliative care content to basic education (0 = not important, 10 = very important)	9.49	.78	9.47	.715
B. Effectiveness of practicing nurses in caring for a dying child and family (0 = not effective, 10 = very effective)	5.12	2.18	7.24	1.81
C. Effectiveness of your own teaching of EOL issues (0 = not effective, 10 = very effective)	7.34	1.88	8.01	1.63
D. Effectiveness of your CE/SD program in teaching pediatric palliative care (0 = not effective, 10 = very effective)	5.36	2.66	7.66	1.80
E. How helpful has the ELNEC-PCC training program been to you in improving palliative care in your CE/SD program? (On a scale of 0 = not helpful, 10 = very helpful)			9.04	1.29

Palliative Care,” “Ethical/Legal Issues,” and “Care at the Time of Death” all experienced at least a 100% increase in the number of educational activities over the past year. Seven out of the 9 modules taught demonstrated over a 100% increase in the number of participants who attended these courses as compared to the same time last year (“Introduction to Pediatric Palliative Care,” “Communication,” “Ethical/Legal Issues,” “Symptom Management,” “Care at the Time of Death,” “Grief, Loss and Bereavement,” “Models of Excellence”). This is a positive finding, particularly given the many constraints on healthcare institutions and university budgets, as well as the nursing shortage. The change is particularly notable given the fact that these changes occurred within the first 12 months of course attendance.

Improvement in EOL education and curriculum led to more effective nursing care. Table 4 depicts results regarding the participants’ perceptions of the status of pediatric palliative care education in their institutions/organizations. Overall, this was an “already converted” group, as they believed, even prior to attending the course, that pediatric palliative care content is very important. In the 12-month post-course evaluation, participants reported significant improvement in the effectiveness of their staff, their own teaching, and their overall curriculum in pediatric palliative care. The participants rated the overall helpfulness of the ELNEC-PPC curriculum at 9.04 (on a scale of 0=not helpful to 10=very helpful).

After completing the ELNEC-PPC course, trainers reported at their 12-month follow-up report that the educa-

Table 5. Seeking Palliative Care Professional Development Post ELNEC-PPC (N=91; 91% response rate)

Activities	N (% of participants)
Joined a palliative care organization	28 (31%)
Attended CE/staff development program on palliative care	56 (62%)
Became involved in a palliative care committee, task force, etc	55 (60%)
Subscribed to/read palliative/EOL care publications	48 (53%)
Sought personal clinical experience to increase EOL skills	31 (34%)
Collaborated with other organizations/institutions to implement ELNEC-PPC education	49 (54%)

tion they received empowered them to return to their institution and teach others about pediatric palliative care. They met with other members of the interdisciplinary team to evaluate the current organizational culture, as well as policies and procedures, and sought ways of improving current practice that would meet the complex needs of children and their families facing life-threatening circumstances. Examples of what some of the trainers have accomplished to achieve quality pediatric palliative care through education and how that translates into better care includes:

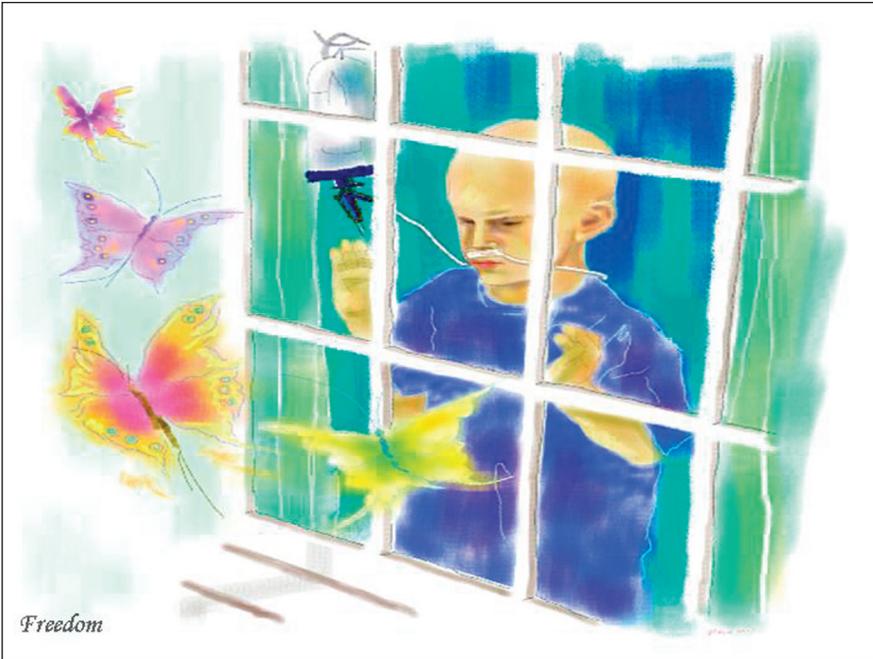
- Developing pediatric oncology palliative care guidelines
- Working with the interdisciplinary team to develop critical pathways and pre-printed orders to address such symptoms as pain, anxiety, dyspnea, fever, and terminal agitation
- Developing and managing a perinatal palliative care program and extending support group meetings to labor and delivery

unit

- Revising neonatal intensive care unit (NICU) palliative care policies and protocols
- Conducting focus groups with bereaved families
- Changing healthcare systems so that home health care providers can be educated in palliative care so transfer from the institution to the home would be more seamless.
- Working on state and national levels to promote changes in pediatric palliative care

ELNEC-PPC trainers committed to continuing education in palliative care and collaboration with other organizations/institutions. Table 5 depicts activities in which ELNEC-PPC trainers participated within 1 year of the course. The purpose of this table is to show the commitment of the ELNEC-PPC trainers, post-course, in taking opportunities to become more involved through a variety of venues in regards to their involvement and collaboration with end-of-life activities. Throughout the

Figure 1. Freedom



Illustrated by Connie Rose. Reprinted with permission.

Figure 2. To Comfort Always



Illustrated by Connie Rose. Reprinted with permission.

course, participants are encouraged to return to their institution and be a change-agent. By becoming better linked to the literature, to organizations that are working to improve palliative care, and to various committees at their workplace, they are many times better prepared to educate others and

to make the changes needed to improve care. Over 50% of the participants attended a program on palliative care, became involved in a palliative care committee/task force, and began to subscribe to and read palliative/EOL care publications. Of particular surprise to the ELNEC Project team was that

54% of the participants had actively collaborated with organizations/institutions other than their own to implement ELNEC-PPC education. This is noteworthy, given the fact that these participants have many educational demands in their own institutions. For example, they coordinate internship/residency programs, provide new employee orientation, review and implement quality improvement initiatives, and over-see the everyday educational needs of their staff. This is a very significant finding as continued commitment to EOL care by the educators is essential to sustaining the training.

In reviewing further data collected in the 6- and 12-month post-course follow-up, trainers listed specific examples of activities they had provided to other organizations, and of opportunities to expand ELNEC-PPC nationally and internationally. A list of some of these accomplishments include:

- Presenting ELNEC-PPC modules at regional, national, and international conferences.
- Volunteering at the state level to promote changes in pediatric palliative care.
- Working within systems to develop programs to link hospital's end-of-life care programs with the community hospice home care agencies, so that children and their families can return home and receive excellent care.
- Organizing four national ELNEC-PPC courses, sponsored by the Association of Pediatric Oncology Nurses (APON). To date, 225 participants, representing 30 states, Canada, and Sao Paulo have completed one of these four courses. Two additional courses will be offered in 2006.
- Developing, organizing, and releasing on the world-wide web the ELNEC-PPC curriculum on Cure4Kids, an international web-based outreach program at St. Jude Children's Research Hospital. Within the first four months of going "live," 2627 nurses, physicians and other members of the interdisciplinary teams have accessed the ELNEC-PPC curriculum. The majority of those who reviewed the curriculum were from low resource countries.

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. Data

Table 6. Principles of Professional Education

Characteristics of Effective Professional Education	Application to the ELNEC-PPC Curriculum
Education is based on a current, evidence-based curriculum.	The ELNEC-PPC curriculum resulted from extensive input from expert pediatric nurses using best available literature and evidence. The curriculum is up-dated annually with revised versions made available to previous participants.
Adult learning is facilitated by diverse and interactive learning strategies.	The 2 ½ day ELNEC-PPC training program includes approximately 12 hours of lecture time with the remaining time devoted to interactive activities including case studies, small group discussion, role-play, videos, journaling, and non-drug labs (i.e. play, art, spiritual, imagery/relaxation, massage). The syllabus includes the interactive learning activities and materials to facilitate use in dissemination efforts.
Professional education in palliative care recognizes the influence of personal experiences and grief.	The consistent experience across all ELNEC-PPC courses is that many participants have recent or current personal loss and/or illness experiences. Courses include loss exercises and opportunities for personal reflection and individual support.
Training programs acknowledge limited funds are available to educators.	Project funding has been allocated to provide the greatest support to the participants including no cost/minimal cost for course registration and materials (for courses held in 2003, 2004, 2005, 2006).
Success in dissemination efforts is dependent upon access to user friendly, efficient teaching resources.	The ELNEC-PPC materials consist of a 1000+ page syllabus that includes extensive faculty lecture outlines, PowerPoint slides, bibliography, case studies, resource lists, and supplemental teaching guides. All material is provided in hard copy and on CD.
Educational projects require methods of reinforcement.	<i>ELNEC Connections</i> , quarterly newsletter is distributed electronically to all ELNEC-PPC trained nurses. Formal evaluation at 6-and 12-months provides reinforcement. Project staff/investigators are available by e-mail and phone. ELNEC-PPC award winners are announced 1-year post-course. Trainers who have demonstrated exemplary progress in disseminating and implementing the ELNEC-PPC curriculum are provided with these competitive awards. Their work is mentioned in the <i>ELNEC Connections</i> with further details provided on the ELNEC-PPC website. Web site provides updated information and also a network to connect with other trainers by states.
Interdisciplinary collaboration is important in education efforts.	Although ELNEC-PPC has been designed as a nursing education program, the investigators have collaborated closely with colleagues in medical education, primarily through the EPEC project. The ELNEC-PPC curriculum strongly emphasizes interdisciplinary care and has worked collaboratively with other disciplines in regards to EOL education (i.e., medicine, social work, clergy, etc).
Flexibility and continuous improvement is important for educational programs.	The ELNEC-PPC curriculum is a consistent "work in progress." Evolution of the ELNEC-Core project has resulted in separate curriculum and projects, not only for pediatric nursing education, but for undergraduate/CE providers/staff development education, graduate education and oncology. Currently being developed are curricula for nurses who work in critical care and in geriatric settings.
Structured evaluation is necessary to insure quality programs.	Acceptance into an ELNEC-PPC course is by competitive selection based on an extensive application. Formal written evaluation at 6- and 12-months documents outcomes.

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/agency and they 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.

The ELNEC-PPC project is dedicated to educating nurses in all the dimensions of quality of life for children facing death and their families. In addition to the quantitative data reported, the ELNEC-PPC investigators have summarized key principles of professional education in palliative care in Table 6. The sensitivity of pediatric palliative care and the desire to use a variety of teaching methods are crucial to ELNEC-PPC education. Nurses have a unique opportunity to not only help prepare the child and family for the time of death, but also assist with the actual journey of how they get to that final moment (Sumner & Hurula, 1993). Pediatric nurses play a distinctive role in advocating, promoting, and providing excellent care to these children and their families. Education is the key to give pediatric nurses the skills and confidence they need to do this very important work.

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

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