

Running Title: PROMOTING PALLIATIVE CARE INTERNATIONALLY

**Promoting Palliative Care Internationally:
Building Leaders to Promote Education, Practice, and Advocacy**

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The work described in this paper is original, and there are no overlapping publications to report.

Abstract

In February 2000, nine nursing educators, practitioners, and researchers met in Nashville, TN to develop a palliative care curriculum specifically for nurses. The following month, twenty-two advisors from nursing organizations across the United States convened in Washington, DC to review the recommended curriculum development and dissemination plans for end-of-life care throughout nursing schools, hospitals, hospices, homecare, and geriatric settings. The Robert Wood Johnson Foundation (RWJF) provided funding for curriculum and competency development and for 6 national train-the-trainer courses to be held from 2001 to 2003. The curriculum entitled the *End-of-Life Nursing Education Consortium (ELNEC)* was designed to meet the needs of nurses caring for patients with serious and complex illnesses at the end of their lives. This work, beginning in 2000 with the development of the ELNEC curriculum, has been taught in every state across America and in 91 countries around the world and has been translated into 8 languages. Over 21, 400 trainers have returned to their institutions and educated over 642,000 colleagues.

Key Words: palliative care, end of life, interprofessional specialty care, international curriculum

Introduction

In 1997, nursing researchers at the City of Hope (COH) National Medical Center in Duarte, CA began a review of nursing textbooks to determine what content was included on end of life/palliative care. The researchers found that in 50 textbooks, only 2% of content was devoted to educating nurses on caring for patients at the end of their lives. Similarly, nursing faculty lacked resources and education on end of life care. (1) During this same time period, the American Association of Colleges of Nursing (AACN) in Washington, DC, brought healthcare ethicists and palliative care nursing experts together to develop competencies for undergraduate nursing students, entitled *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care*. (2) Because of these two organization's commitment to end of life/palliative care education and practice, they partnered to develop a curriculum specifically for nursing faculty and practicing nurses.

In 2000, the Robert Wood Johnson Foundation provided funding to both COH and AACN to develop the End-of-Life Nursing Education Consortium (ELNEC) curriculum. The goal of ELNEC was then and remains today to educate and provide resources to nursing faculty, to teach the next generation of nurses as well as practicing nurses about palliative care, and to empower all nurses to improve the care of seriously ill patients and their families. The first national ELNEC train-the-trainer course was held in January 2001 in Pasadena, CA, with over 100 nurses attending. The curriculum includes 8 modules and each module includes an overview, objectives, outline, PowerPoint slides, talking points, references, case studies, and supplemental teaching materials (Table 1).

Key Facts about Dying Throughout the World

Palliative care is interprofessional specialty care that provides attention to and management of suffering for the seriously ill and their families. Its focus is on improving quality of life not only physically, but psychologically, socially, and spiritually. (3) In the U.S., 90% of all hospitals with 300 or more beds have access to palliative care, (4) however, world wide, only 14% of seriously ill people receive this specialty care. (5) The World Health Organization estimates that approximately 40 million people desperately need palliative care and 78% of them live in low-/middle-income countries. (5) Over 6 billion people across the globe have poor access to pain medications. (6) There are many barriers to providing palliative care worldwide, including restrictive regulations on essential medications, national policy-makers not being educated about this care, and cultural misconceptions. Lack of education remains a key obstacle to providing this care. (7) While palliative care has been deemed a basic human right by the World Health Organization (WHO), educating healthcare professionals must remain central in efforts to improve care. (8) The care of the seriously and terminally ill will not change or improve until healthcare professionals know and understand the importance of palliative care and realize its ability to decrease suffering.

Meeting Educational Needs: The Development of ELNEC International

In 2005, due to many requests to provide ELNEC worldwide, the national ELNEC Project Team decided to create an international curriculum. A group of nurses and physicians with experience in international palliative care and use of the ELNEC-Core curriculum spent one year developing a curriculum for use around the world. Basic themes of the curriculum were agreed

upon (Table 2). The generic curriculum allowed ELNEC trainers and their teams the ability to include medications in use and available in a specific country, as well as to embed unique and country-specific cultural aspects within the curriculum. The *Standards of Practice for Culturally Competent Nursing Care* was incorporated in each of the ELNEC-International modules. (9) As the International Narcotics Control Board (INCB) statistics indicate, many healthcare professionals care for patients at the end of life without the ability to provide adequate pain relief. (10) Therefore, ELNEC's Pain and Symptom Management modules were made applicable to countries that did not have access to vital pain relief medications. These modules were especially difficult to teach in areas where nurses and other healthcare professionals lacked pain-relieving medications for patients experiencing intractable pain and other symptoms associated with their diseases. In such cases, ELNEC faculty met directly with Ministers of Health and other leaders to encourage more access to pain and symptom medications. When adapting the ELNEC-Core curriculum to an international audience, the ELNEC team had to take into account factors unique in each country, including decision-making and autonomy, religion, spirituality, ethics, and legal issues that could vary region-to-region. Similarly, the translators who translated the various curriculums had to keep many of these same issues in mind.

Solutions: Changing One Country at a Time

In 2005, the ELNEC Project received funding from the Open Society Foundations' (OSF) International Palliative Care Initiative to provide palliative care education to nurses throughout Eastern Europe. The first course for Eastern European nurses was held in 2006 at the Austrian American Foundation (AAF) in Salzburg, Austria. Thirty-eight nurses from 12 Eastern European countries attended the initial course. Using the ELNEC curriculum, the week-long course

advocated the use of each country's available opioids, attention to symptom management, clear communication, and encouragement of advocacy. Since the initial course in 2006, five additional courses were held at the AAF (2008, 2011, 2012, 2014, and 2015), using ELNEC to teach not only nurses, but also physicians and social workers. In all, 208 healthcare professionals from 22 Eastern European countries attended one of these six ELNEC train-the-trainer courses (Table 3).

Many who completed the training have returned to their countries and have made significant progress in promoting palliative care education. For example:

- Irena Laska is a nurse at the Mary Potter Palliative Care Center in Korca, Albania. Since 2007, she and her team have worked closely with the Ministry of Health and public health leaders to showcase the value of palliative care education. In October 2015, Ms. Laska organized an ELNEC course for 151 nurses and 25 doctors.
- Maria Aleksandrova is an intensive care nurse at the Kanaker Zeytun Medical Center in Yerevan, Armenia. She works closely with other medical-surgical units to promote palliative care and has provided education to over 30 nurses.
- In Hungary, Nora Ferdinandy, Miklos Lukacs, and Judit Schaffer are renewing the process of accreditation for nursing practice to include 40 hours of ELNEC curriculum training for nurses and social workers. Since 2014, 139 Hungarian healthcare professionals have attended an ELNEC-Core course.
- Understanding the importance of educating nursing students about palliative care, Guljahan Pirnazarova, a nurse practitioner and head of the Nurse Education Department

at the State Medical Institute for Continuing Education, Bishkek, Kyrgyzstan, has used ELNEC to develop a continuing education program for both students and postgraduate nurses. She has worked closely with the Minister of Health and has obtained approval to provide 96 hours for postgraduate education and 80 hours for undergraduate nursing students. (11)

Non-European countries also are providing ELNEC education. For example:

- In September, 2014, six nurses from Panama were competitively chosen to attend an ELNEC train-the-trainer course, held in conjunction with the 18th International Conference on Cancer Nursing (ICCN) in Panama City. These nurses were mentored for nine months after the course by Spanish-speaking ELNEC trainers. They have successfully held two ELNEC courses with over 200 nurses and physicians, from all public and private hospitals throughout Panama City.
- Gassan Abudari is the Palliative Care Clinical Nurse Coordinator at King Faisal Specialist Hospital and Research Centre in Saudi Arabia. While the facility has palliative care services available, Ms. Abundari is committed to increasing palliative care education throughout her organization. To-date, she has educated over 200 nurses, with a goal of teaching ELNEC throughout Saudi Arabia.
- In June 2014, 98 nurses and other interdisciplinary healthcare members from 15 provinces throughout Turkey attended the first ELNEC train-the-trainer course in Ankara, under the leadership of Sultan Kav, PhD, RN, professor at Baskent University, Faculty of Health Sciences. Dr. Kav has joined the task force under the Ministry of Health Director of the Cancer Control Department to develop an educational curriculum, using

ELNEC as its base, to educate at least 800 healthcare professionals working in palliative care units over the next four years with funding from the World Bank. This is particularly significant, as a major proportion of the Turkish population has no access to palliative care.

- In May 2015, a U.S. team of 3 advanced practice nurses and 1 physician provided ELNEC training at the Kimbilio Hospice and Palliative Care Center in Kip Karen, Kenya. Under the leadership of Juli Boit, FNP, and Director of Kimbilio, a 3-day course was held. Nurses and physicians from Kenya, as well as from Ethiopia, Swaziland, and Uganda attended. In 2016, the U.S. team returned to Kimbilio Hospice to provide a palliative care leadership course to 12 nurses, physicians, and social workers from throughout Kenya. These leaders will play a key role in promoting palliative care, especially in Kenya's rural, underserved areas.
- In Singapore, ELNEC training courses are providing education to promote better access to palliative care. These courses began in 2012, when U.S. nurses Drs. Carol Long and Roger Strong taught an ELNEC train-the-trainer course in Singapore. Since then, 88 ELNEC courses have been held in Singapore and it is estimated that over 2,600 nurses have received this education in this country alone.

Translation of Curriculum is Key to Dissemination

In order to make ELNEC viable internationally, ELNEC leaders had to ensure that the curriculum was available in other languages. Today, ELNEC has been translated into eight languages: Spanish, Russian, Romanian, Albanian, German, Japanese, Korean, and Chinese (Table 4). Not only was the translation of content important, the capture of the unique

cultural, spiritual, ethical, and legal issues of a specific country was also vitally important. In addition, access to basic palliative care medications vary country to country. Every effort has been made to develop the various curricula with respect to these differences. With the exception of the Spanish and Russian versions, nurses who attended an ELNEC course have translated the other six versions and assumed responsibility for keeping the course curriculum updated regularly. These nurses promote the curriculum's use, as well as insure that the education is translated into practice.

- Because of the extensive number of ELNEC courses that have been taught in Mexico and Eastern Europe, the first two translations were completed in Spanish and Russian in 2005. The remaining translations occurred as ELNEC was taught worldwide. In 2006, the first ELNEC trainer to approach the national ELNEC Project Team about translating the curriculum was Sayaka Takenouchi, PhD, RN, a faculty member at Kyoto University in Kyoto, Japan. Because of Dr. Takenouchi's and her team's vision and leadership, ELNEC-Core, ELNEC-Geriatric, and ELNEC-Critical Care have been translated from English to Japanese. The curricula are used widely throughout Japan in Schools of Nursing and Medicine and over 20,000 healthcare providers have received this education.
- A similar scenario is true for South Korea. Under the leadership of Hyun Sook Kim, PhD, RN, a professor at Chungju National University, she and her team have translated ELNEC-Core, ELNEC-Pediatric Palliative Care, and ELNEC-Geriatric into Korean. Today, over 500 healthcare professionals have received this training.
- In 2007, Nicoleta Mitrea, PhD(c), RN, and her team translated ELNEC into Romanian. This was critical, as Ms. Mitrea and her team were expanding ELNEC education

throughout their workplace, Hospice Casa Sperantei, in Brasov, Romania, and leading much of the palliative care education throughout Eastern Europe.

- Irena Laska, mentioned above, also led her team in translating ELNEC from English to Albanian.
- In 2014, Yuhan Lu, an oncology nurse and leader from Peking Cancer Hospital in Beijing, China, together with a team of seven nurses, translated ELNEC into Chinese. The first national ELNEC-Chinese train-the-trainer course, held in April 2015, provided education to over 50 nurses who were selected from 17 provinces and from various universities and medical centers throughout China. In the first year since curriculum translation into Chinese, almost 1,000 Chinese nurses have attended an ELNEC course.
- Lily Niang-Huei Peng, PhD, Assistant Professor at the College of Nursing at the Central Taiwan University of Science and Technology, and her team translated ELNEC-Pediatric Palliative Care into Chinese. In 2014, the first course was held at the Taichung Tzu Chi Hospital with 450 healthcare professionals in attendance.
- Silke Walter and Bea Werner from Freiburg, Germany, worked to translate ELNEC into German. In 2013, the first ELNEC course was presented in Freiburg, with nurses from Germany, as well as Austria and Switzerland, attending.

Developing Leaders to Promote Palliative Care World-Wide

While educating healthcare professionals about palliative care is essential, building leadership in the field is needed in order for this specialty to grow and be sustained. In 2014 and 2015, the Bristol-Myers Squibb Foundation (BMSF) provided funding, through their

Bridging Cancer Care™ initiative, for workshops to develop palliative care nursing leaders throughout Central and Eastern Europe. Two leadership workshops were held over **ten** days, with participants being hosted by Hospice Casa Sperantei in Brasov, Romania. Nursing leaders from Albania, Armenia, Greece, Hungary, and Romania attended these leadership courses. In 2014, the Hospice Casa Sperantei became a Palliative Care Centre of Excellence. Their mission was to continue to serve, lead, promote, and sustain palliative care throughout Central and Eastern Europe, in an effort to reduce disparities in care and outcomes. The combined efforts of these nursing leaders from throughout this region increased access to quality palliative care for cancer patients. (12) Their work continues, as they develop standardized training at both the basic and specialist levels. Because of the tremendous success of the leadership-building courses in Romania, a similar model has been developed and will be presented in 2016 in Kenya and Hong Kong.

Conclusion

While death and dying will forever be a part of life, nurses throughout the world will continue to advocate for and promote excellent palliative care for patients at the end of life. Recognizing this care as a basic human right for all people, irrespective of race, ethnicity, religion, sexual identity, language, and financial status, nurses must continue to seek to educate themselves and others in providing and promoting this important care. Just as nurses witness the beginning of a new life, they are also privileged to spend sacred final days and hours with patients and their families. This is an important opportunity for nurses and palliative care education is vital to equip them to seize this opportunity.

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Table 1: ELNEC Modules

Module 1: Introduction to Palliative Nursing Care
Module 2: Pain Management
Module 3: Symptom Management
Module 4: Ethical and Legal Issues in Palliative Nursing
Module 5: Cultural and Spiritual Considerations
Module 6: Communication
Module 7: Loss/Grief/Bereavement
Module 8: Final Hours

Table 2: Key Themes of the International Version of ELNEC

- #1: The family is the unit of care
- #2: The key role of the nurse is to be a patient and family advocate
- #3: It is important to honor the patient's/family's culture
- #4: Focus attention on special populations, including children and the elderly, the socially/economically disadvantaged, homeless, those with physical and/or mental disabilities
- #5: Take into consideration the patient's psychosocial and spiritual needs, in addition to his/her physical needs
- #6: Provide palliative care across all settings where patients are seen, such as clinics, acute care, homecare
- #7: The influence of socioeconomic, legal, and political issues are important to keep in mind
- #8: Interdisciplinary care is essential

Table 3: Countries Represented in Six Eastern European Courses

Country	2006	2008	2011	2012	2014	2015
Albania		x		x	X	x
Armenia	x	x		x	X	x
Azerbaijan		x				
Croatia		x				
Czech Republic		x	x			
Estonia	x					
Georgia		x				
Hungary		x	x			
Kazakhstan	x					x
Kosovo	x	x				
Kyrgyzstan	x	x				
Lithuania	x	x				
Macedonia	x					
Mongolia	x					
Poland		x	x			
Romania	x	x	x			
Russia		x	x			
Serbia		x	x			
Slovakia	x	x				
Slovenia	x					
Tajikistan	x			x		
Ukraine		x		x	X	x
TOTAL PARTICIPANTS	38	39	33	31	33	34

Table 4: ELNEC Translations

Language	Leaders in Developing Translation	Countries Using Translation	Number of Trainers
Albanian: ELNEC-Core	Irena Laska and Gerla Koleci	Albania	2,100
Chinese: ELNEC-Core	Team Leader: Yuhan Lu, along with Liyan Zhang, Youhui Gu, Yuhan Lu, and Hong Zhang, (back row, left to right): Min Zhao, Hong Yang, Yiyuan Zhao, and Cuiju Wen.	China	946
ELNEC- Pediatric Palliative Care	Lily Niang-Huei Peng		450
German: ELNEC-Core	Silke Walter and Bea Werner	Germany	55
Japanese: ELNEC-Core ELNEC- Geriatric ELNEC- Critical Care	Sayaka Takenouchi, Keiko Tamura, Megumi Umeda, Sayaka Takenouchi, Miyoko Kuwata, Sachiko Yoshioka, Midori Nishiyama, Kazuko Nin, Yoko Tamura, Akemi Utsunomiya	Japan	20,224
Korean: ELNEC-Core ELNEC- Geriatric ELNEC- Pediatric Palliative Care	Hyun Sook Kim	Korea	539
Romanian: ELNEC-Core	Nicoleta Mitrea, Camelia Ancuta, Roxana Horeica, Teodora Mathe, Gabriela Burlacu	Romanian	6,000
Russian: ELNEC-Core	Translation provided through a grant from the Open Society Foundations	Kazakhstan, Kyrgyzstan, Russia, Tajikistan, Ukraine	500
Spanish: ELNEC-Core	Translation provided through a grant from the American Association of Colleges of Nursing (AACN)	Mexico, Panama	650

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