Promoting Palliative Care Worldwide Through International Nursing Education

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Abstract
Many challenges exist when providing international education to those who care for people at the end of life. Though issues related to culture and language may vary, the one commonality that crosses all nations is that its people die. In general, societies seek to provide the best care they are trained to give. Many have few resources to provide this care well. Traditions of the past influence norms and dictate policies and procedures of the present. Since its inception in 2000, the End-of-Life Nursing Education Consortium Project has provided palliative care education to nurses and other members of the interdisciplinary team in six of the seven continents. This article describes the efforts of this project to improve education around the globe, with the goal of providing excellent, compassionate palliative care, irrespective of location, financial status, political views, religion, race, and/or ethnicity.

Keywords
palliative care, education, international, nursing, community health, holistic health, transcultural health, baccalaureate programs, continuing education/staff development, graduate studies, patient/client and/or family education, end-of-life care

Introduction
Death is a mysterious phenomenon and though it is a normal process, it is commonly denied across the globe. People are generally not prepared for death. They have not had conversations with family members and health care providers about their final wishes. Cultural norms and misconceptions may prevent a dignified death. Many health care professionals are afraid to give “bad news” about a patient’s impending death, irrespective of the part of the world in which they live. There is a fear that the patient will lose hope and that they will suffer emotionally. Quality-of-life issues at the end of life (EOL) are seldom talked about. In many countries, there are few, if any, resources to provide treatment, including palliative care, which is focused on symptom, pain, and stress relief from serious illnesses (Center to Advance Palliative Care [CAPC], 2012).

Worldwide, nurses spend more time at the bedside and in the community with patients than any other health care professional. Nurses have numerous opportunities to have conversations with patients and their families, clarifying goals of care and explaining different treatment options (Dahlin, 2010).

When providing palliative care to underserved countries, pain is a particular challenge. Pain is seldom addressed and rarely managed, due to a lack of opioids available in these countries. For example, the International Narcotics Control Board (INCB) collects opioid consumption rates from national governments around the world. The 2002 INCB report showed that 27 million grams of morphine were used legally in 2002 with 78% going to six high-income countries (Australia, Canada, France, Germany, the United Kingdom, and the United States). These six countries represent 578 million people (8% of the world’s population; Infoplease, 2011). The 22% of morphine that remained was provided to 142 countries, representing 6.5 billion people (92% of the world’s population; U.S. Census Bureau, 2013). Unfortunately, most of these countries have severe poverty, hunger, dislocation, and violence (Open Society Foundations [OSF], 2010). Nurses in these countries with poor access to opioids and other medications are on the frontlines of...
exactly 15 years and 142 national/international courses later, educators returned to their nursing schools and health care organizations partnered to develop the End-of-Life Nursing Care Recommended Competencies and Curricular Guidelines for Nursing Education (AACN, 1997), which outlined the intent of meeting the specific needs of nurses caring for a wide variety of patients (Table 2).

The Need

For years, the World Health Organization has been advocating for improved palliative care throughout the world and has been promoting resources to provide this care (World Health Organization, 2007). The need for excellent palliative care is growing. However, nurses cannot provide care if they have not been educated, as nurses cannot practice what they do not know. Systems which prohibit or inhibit this care must be identified and changed. A major surge in the number of seriously ill patients will be seen in the near future, as the number of elderly increases. Worldwide, 58 million people die annually with 45 million dying in developing countries. At least 60% (35 million people) of them will have advanced illness and suffering before dying and would benefit greatly
from palliative care. Cancer and AIDS account for the greatest number of deaths for both adults and children in developing countries. Ten million new cases of cancer are diagnosed each year and at least two thirds are not cured, and death generally comes within a year. Death rates from AIDS are expected to grow to four million by 2015. It is estimated that 60% to 90% of patients with advanced cancer have moderate to severe pain (OSF, 2010). Fifty percent of the world’s newly diagnosed cancers are now occurring in developing countries, and 80% will have incurable tumors at the time of diagnosis. Very little attention will be given to pain or symptom control and most will not receive assessment for psychological, social, and/or spiritual distress (De Lima, 2006). However, in each country, patients can greatly benefit from improved palliative care, which addresses holistic care (Coyle, 2010).

In 2005, it became clear to the national ELNEC Project Team that a curriculum specifically aimed at international needs should be developed, to meet the demands described above. In preparing to develop an international curriculum, ELNEC invited a group of nurses and physicians who have a wide range of experience in international palliative care to critique the ELNEC-Core curriculum and to make edits and suggestions on making the curriculum more international in scope. This process took a year to complete.

There are common themes throughout ELNEC-International which serve as its foundation. They include the family as the unit of care, the vital role of the nurse being an advocate, the importance of honoring culture, critical need for attention to special populations (e.g., children, elderly, socially/economically disadvantaged, homeless, mentally ill, etc.), the importance of assessing and managing not only physical needs but also psychosocial and spiritual aspects of care, the provision of palliative care across all settings (e.g., clinics, acute care, homecare, etc.), the influence of socioeconomic and political issues, and the importance of interdisciplinary care (Ferrell et al., 2009).

The wide range of medications referred to in the Pain, Symptom Management, and Final Hours modules needed to be refined to meet needs of those health care providers who may not have access to all the various medications and other treatment modalities available in the United States. The Cultural Considerations, Communication, Ethics, and Loss/Grief/Bereavement modules needed to be less Western and Judeo-Christian based and a net more widely cast to include a variety of concepts that were more universal. For example, chronic illness, pain, and death are facts in every culture. However, suffering is not always addressed and cultural influences, ethical issues, and family/caregiver needs are not always acknowledged. It was necessary to include these concepts in the ELNEC-International curriculum, as a reminder to nurses to assess these aspects.

The Standards of Practice for Culturally Competent Nursing Care (Douglas et al., 2011) are embedded throughout each of the ELNEC-International modules. For example, promoting social justice (Standard 1) for all citizens is...
emphasized in the Introduction to Palliative Care, Pain and Symptom Management modules. At the beginning of each course, nurses are encouraged to reflect on their own values, beliefs, and cultural history so they understand how these elements can affect their current nursing practice (Standard 2). Nurses are encouraged to participate in developing health care policies and to address gaps in their health care system that prevent the provision of excellent EOL care (Standard 6). ELNEC-International was developed with the realization that a person’s culture plays a critical role in death and dying. This is such a vital issue, that one of the eight modules is dedicated to cultural considerations (Standard 8). Cultural concepts are embedded throughout the remaining seven modules.

**Preparation for International Service**

ELNEC originated with a focus on educating U.S. nurses in palliative care. However, many educators from the United States have had opportunities to provide ELNEC education in various countries because of sabbaticals, fellowships, and/or partnerships with faith-based organizations. The national ELNEC Project Office is contacted frequently by faculty in Schools of Nursing, physicians in developing countries, representatives from hospitals or hospices, and/or Ministers of Health in underserved countries to come to their homeland to present a 3- to 5-day train-the-trainer course.

Planning to go to another country involves understanding the unique culture. It is vital to have conversations with those from the country requesting the education months before the course is taught (Malloy et al., 2011; Paice et al., 2008). What are the cultural and/or religious/spiritual beliefs about caring for those who are dying? What medications are available for use in managing pain and other symptoms? Are there laws that prevent opioids from entering the country? What are the barriers to providing excellent palliative care? What is the status of nurses in this country? How autonomous are the nurses in their clinical practice? It is essential that faculty understand the answers to these questions, including the cultural feasibility of promoting these issues before teaching internationally so they are equipped to provide the education in a culturally sensitive manner. For example, providing a 2-hour lecture on opioid use for intractable pain would be useless if opioids were not available. Understanding the culture is more than just grasping the ethnicity, race and religion of the town, community, or nation. It involves understanding the cultural status of distinct patient groups and factors such as spirituality, religion, gender, age, sexual orientation, and socioeconomic status (Mazanec & Panke, 2010).

In many countries, there are diverse beliefs about ethical or legal issues, such as decision making and patient autonomy (ELNEC, 2012b). In the United Status, there is a large emphasis on patients being informed about making their own health care decisions. Yet patient autonomy may not be the standard practice in other countries around the world. For example, some cultures promote decision making by family members, such as delegating health decisions to the oldest son. There are also diverse beliefs about patients being told they have a serious, life-limiting illness. Families may believe that if their loved one is told their diagnosis, they will give up hope and suffer immensely, or commit suicide, as they do not wish to be a burden to their family. Though these norms and rituals may seem in sharp contrast to their own cultural background, it is vital that nurses respect the decision-making process, beliefs, and values of the country in which they are teaching.

There are other issues, such as discontinuation of life-prolonging therapies, meaning of nutrition and hydration in grave illness, pain and symptom management, and death rituals and mourning practices that need to be understood and respected. It is important to strive to be culturally competent, culturally aware, and culturally compassionate. Becoming culturally competent, aware, and compassionate are ongoing processes developed along a continuum until diversity is accepted as a norm (AACN, 2009a; O’Connell et al., 2007). In turn, the nurse has then acquired greater understanding and capacity in a diverse environment (AACN, 2008, 2009a, 2009b). Nurses bring their own cultural views with them to every situation and they must be aware of how their culture affects their current practice and beliefs.

**Examples of ELNEC-International Education Programs Around the World**

With a new ELNEC-International curriculum completed, the work of organizing the first international course began. The very first ELNEC-International course, held in 2006 in Salzburg, Austria, was attended by 38 nursing leaders in education and clinical practice, chosen competitively, from 14 Eastern and Central European, former Soviet, and Central Asian countries. A course evaluation was completed by each participant at the end of every day of instruction, using a 5-point Likert-type scale (5 = highest score and 1 = poorest score). The mean score of the conference overall was 4.9 (range of 4.6-4.9; Ferrell et al., 2009). This course was held in collaboration with the Open Society Foundations and the Open Medicine Institute through the Salzburg Seminars program. The goals and objectives of this new endeavor included:

1. Holding a 5-day ELNEC-International educational course
2. Mentoring participants for 1-year postcourse in an effort to increase their palliative care knowledge and confidence
3. Evaluating the impact and effectiveness of this project through e-mail correspondence and a 1-year post-course survey, outlining activities related to palliative care advocacy, applying the principles found in ELNEC-International to their work, and disseminating the curriculum (Ferrell et al., 2009).
During the 5-day course, the eight modules of ELNEC-International were taught. In addition, participants attended a computer lab to assist with literature searches, visited a local hospice, reviewed the World Health Organization foundation measures for palliative care as a public health issue, received instruction on quality improvement efforts, discussed ways to advocate for palliative care, and worked in small groups to set professional goals. At the end of the 5-day course, a graduation ceremony and banquet were held, to honor each participant.

On average, participants scored the course as a 4.7 in relation to meeting their own objectives and expectations. In open-ended questions, participants stated that the strengths of the course included the professional manner of the presenters, appreciation of practical and clinically based content, provision of extensive resources to take back to their country, and the availability of the educators (Paice et al., 2008). Suggestions for improving the next course included more time for work in small groups, more interactive sessions and discussions, and extended content on pediatric palliative care (Paice et al., 2008). These suggestions prompted future courses to include more networking time in smaller groups, review of more case studies for further discussion and clarification, and provision of the ELNEC-Pediatric Palliative Care CD to promote further education in caring for children with serious, life-threatening illnesses.

Twelve-month postcourse outcomes for this 2006 course included the following: organizing a palliative care conference in their community (Armenia, Kazakhstan, Romania), writing a grant to a foundation for funding palliative care services (Kyrgyzstan), speaking with the president of the Palliative Care Association to increase education (Lithuania), writing and publishing an article about palliative care (Russia), speaking to government officials about beginning a palliative care school for health practitioners (Slovenia), and including contents of ELNEC-International into nursing school curricula (Estonia, Kosovo, Slovenia, Slovakia) (Ferrell et al., 2009).

Because of the success of this first ELNEC-International course and the tremendous need, three additional courses (2008, 2011, 2012) have been held in this same facility in Austria, primarily targeting Eastern European nursing leaders in clinical practice and education. Similar responses and evaluations regarding other ELNEC-International courses have been excellent (Ferrell et al., 2009; Kim et al., 2011; Malloy et al., 2011; Paice et al., 2008).

Similar stories can be told in Nairobi, Kenya, where nursing faculty and clinicians from across Kenya came for education. Two Kenyan national and local physician leaders invited five ELNEC faculty (four advanced practice nurses and one physician) to Nairobi to present a 1-week ELNEC-International course. These physicians, Esther Munyoro, MD, from the Kenyatta National Hospice and Palliative Care Team and Zipporah Ali, MD, from the Kenya Hospice and Palliative Care Association (KEHPCA) understand and respect the important role that nurses play in providing and promoting palliative care. They strategically organized the course to include not only nursing faculty but practicing clinical nurses, social workers, and chaplains. Forty-nine health care professionals attended the 5-day train-the-trainer course in 2009. Participants completed evaluations at the end of each day. The evaluations were very favorable with scores ranging from 4.57 to 4.91 (using the Likert-type scale of 5 = very helpful and 1 = not helpful; Malloy et al., 2011). In addition, opportunities to present ELNEC at an all-day palliative care conference and during grand rounds in the critical care areas and on the AIDS unit of the Kenyatta National Hospital in Nairobi were made available throughout the week. All totaled, more than 700 health care professionals received education in at least one ELNEC module in Nairobi alone. After completion of the 5-day ELNEC course, nursing faculty returned to their baccalaureate nursing programs and added 45 hours of palliative care content into their curriculum. Much of this work was promoted by Kenya Hospice and Palliative Care Association, with the support from the Diana Princess of Wales Memorial Fund (Malloy et al., 2011). Comparable stories have also been witnessed throughout Romania, Mexico, Korea, Japan, Tanzania, and many other countries (Table 3).

**The Importance of Translation**

Throughout the 12 years of ELNEC, international participants have come to the United States for palliative care education, so they can take the materials back to their country and disseminate and implement the curriculum. Five
ELNEC-International trainers have done exceptional work in creating a vision and a plan to improve palliative care in their country. They knew that they needed to translate the ELNEC modules into their own language.

Sayaka Takenouchi, RN, PHN, MPH, PhD from Kyoto University Graduate School of Medicine, Department of Human Health Services in Kyoto, Japan, attended an ELNEC course 8 years ago in Los Angeles, CA. On completing her graduate work in the United States, she returned to Japan and began working with other nursing and medical professors to translate ELNEC into Japanese. She has worked closely with the Japanese Society of Palliative Medicine, who support ELNEC-Japan by providing a task force and working group within their board of education. Dr. Takenouchi has identified 11 nursing leaders throughout Japan and has educated them to serve as faculty for the national ELNEC-Japan courses. In addition, Dr. Takenouchi and her team translated ELNEC-Geriatric into Japanese in 2012 and ELNEC-Critical Care in 2014. With the increase in older Japanese adults, this curriculum will be critical in educating nurses in a wide variety of settings about palliative care. Since the completion of the translation, Dr. Takenouchi and her team have educated more than 800 train-the-trainers in ELNEC-Japan. In addition, those trainers have returned to their institutions and have educated a total of 1,716 nurses (personal communication).

Hyun Sook Kim, PhD, RN, MSW, Professor, Department of Social Welfare, Chungju National University in Chungju, Korea also attended an ELNEC train-the-trainer course in the United States. She returned to South Korea and identified a team of nursing faculty to assist with the translation of ELNEC-International, ELNEC-Geriatric, and ELNEC-Pediatric Palliative Care into Korean. To date, Dr. Kim and her colleagues have educated 145 nurses in ELNEC-International, 203 nurses in ELNEC-Geriatric, and 191 nurses in ELNEC-Pediatric (personal communication). Dr. Kim has used the Palliative Care Quiz for Nursing to measure knowledge of Korean nurses. Her study showed that nurses’ palliative care knowledge improved after attending an ELNEC course (Kim et al., 2011).

Nicoleta Mitrea, RN, is the Director of Education and National Development at Hospice Casa Sperantei in Brasov, Romania. Ms. Mitrea has been influential in promoting palliative care throughout her hospice, community, and country. She and her team have worked diligently to translate and adapt the ELNEC resources into Romanian. They have shared these materials with their colleagues in Moldova, as they share the same language. In October, 2011, a palliative care conference was held in Bucharest, Romania and the first national ELNEC-Romania course was launched with 56 health care professionals in attendance (Mitrea & Dumitrescu, 2012). Ms. Mitrea has also held four other ELNEC training courses at the Princess Diana Study Center in Brasov, Romania with a total attendance of 200 nurses and other health care providers. She has also travelled to Moldova and educated another 50 participants. In addition, Ms. Mitrea is working with other Eastern European palliative care leaders to develop competencies in the care of those with serious, life-threatening illnesses (personal communication).

Gerhild Becker, MD, teaches staff and cares for patients at Freiburg University in Freiburg, Germany. Dr. Becker has a vision of improving care for those with life-limiting illnesses in German-speaking countries. She knows that will not happen unless staff receives more education. Three years ago, after receiving funding, Dr. Becker contacted the national ELNEC Project Office to explore opportunities to collaborate on a curriculum that would provide palliative care education and yet be sensitive to the specific and unique cultural needs of those living in Germany and other surrounding countries who speak German. She and her staff, Silke Walter, RN, and Bea Werner, RN, have taken the ELNEC-International curriculum and developed it to meet the needs described above. After the translation was completed, Dr. Becker, Ms. Walter, and Ms. Werner decided to strategically train 10 nursing leaders in palliative care at the Freiburg University Hospital in June, 2012. Much of the training took place in small groups, using case studies. The feedback from the participants at this pilot course was outstanding. The next course, was held in Freiburg, Germany in September, 2013 with nurses attending from various parts of Germany. ELNEC-International is also translated into Spanish, Russian, and Armenian. The Chinese translation will be completed by the end of 2014.

**Need for Additional Research in International Palliative Care**

There is much need to increase a robust research agenda, targeting resource-poor countries where disease burden and poverty are high and where health care is limited. Nurses are in a key position to do this, as they are globally advocating for increased awareness of palliative care as a public health issue and a human right, educating citizens about vaccinations and other preventive measures, and consulting in the development of competencies for this care.

Future research questions include the following:

- What are the barriers to pain and other symptom management related to palliative care?
- Why do some resource-poor countries have excellent availability of opioids for medical purposes and other countries do not?
- What role do nurses play in advocacy in promoting palliative care?
- What role does palliative care play in war-torn countries, where conflict and terror are experienced between religious, ethnic, and/or cultural groups?
- What are the needs of dying children and their families in resource-poor countries? What interventions need to be developed/made available to meet these needs?
Conclusion

Nurses play a key role in caring for patients with serious life-threatening illness and their families. People around the world are working together to promote palliative care. There are numerous international hospice and palliative care organizations dedicated to begin and improve palliative care worldwide (Table 4).

Nurses have an exemplary history of meeting challenges and overcoming barriers. Those who provide ELNEC-International training in various parts of the world understand the importance of advocating for changes that will improve palliative care throughout the world. The role of patient advocacy in moving palliative care forward is a goal in all ELNEC-International courses. These nurses advocate in order to promote education, provide encouragement, and sustain support to those living in areas of the world that currently do not practice palliative care. They assess and manage patients in a variety of care settings, including the home, and also provide care across the lifespan. They see and care for patients at the time of diagnosis and throughout their disease trajectory, as well as at the time of death. Though much work has been accomplished in the past few years in educating nurses in palliative care throughout developing countries, there are still more challenges that lie ahead. As nurses across the world become better educated in hospice and palliative care, and continue to use and add to the body of research, the care of the terminally ill will improve. For more information about ELNEC-International, go to https://www.aacn.nche.edu/ELNEC

Table 4. List of Various International Palliative Care Organizations.

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<tr>
<th>Palliative care organization</th>
<th>Overview</th>
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<tr>
<td>African Palliative Care Association (APCA): <a href="http://www.apca.org/ug">http://www.apca.org/ug</a></td>
<td>APCA was formally founded in Tanzania in 2004 to reduce unnecessary pain and suffering from life-limiting illnesses across Africa, working collaboratively with existing and potential providers of palliative care services to help expand service provision and to work with governments and policy makers to ensure that the optimum policy and regulatory framework exist for development of palliative care across Africa.</td>
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<tr>
<td>Asia Pacific Hospice and Palliative Care Network (APHN): <a href="http://aphn.wordpress.com/">http://aphn.wordpress.com/</a></td>
<td>Provides numerous resources, educational opportunities to a wide variety of countries in the Asia Pacific region, including Australia, New Zealand, Singapore, Malaysia.</td>
</tr>
<tr>
<td>European Association for Palliative Care (EAPC): <a href="http://www.eapcnet.eu/">http://www.eapcnet.eu/</a></td>
<td>The EAPC provides a vision of excellence in palliative care that meets the needs of patients and their families, while developing and promoting palliative care in Europe through information, education and research using multiprofessional collaboration.</td>
</tr>
<tr>
<td>International Association of Hospice and Palliative Care (IAHPC): <a href="http://www.iahpc.com">http://www.iahpc.com</a></td>
<td>The IAHPC collaborates and works to improve the quality of life of patients with advanced life-threatening conditions and their families, by advancing hospice and palliative care programs, education, research, and favorable policies around the world. Many helpful palliative care resources are located on website, including essential palliative care practices and medications.</td>
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<tr>
<td>International Children’s Palliative Care Network (ICPCN): <a href="http://www.icpcn.org.uk/">http://www.icpcn.org.uk/</a></td>
<td>ICPCN believes that every child with a life-limiting illness, no matter where he or she lives in the world, deserves excellent palliative care. ICPCN is the only international network of organizations that works with all children’s palliative care services around the world.</td>
</tr>
<tr>
<td>Worldwide Palliative Care Alliance (WPCA): <a href="http://www.thewpca.org/">http://www.thewpca.org/</a></td>
<td>WPCA promotes universal access to affordable, quality palliative care and supports members to develop quality standards in promoting and establishing palliative care. WPCA also promotes advocacy for palliative care to be provided worldwide.</td>
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