Advancing Palliative Care in Kenya

KEY WORDS
Education
HIV/AIDS
Malaria
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Tuberculosis

Background: Life-threatening illnesses such as HIV/AIDS, malaria, tuberculosis, and other disorders are prevalent in the developing world, including Kenya.

Objective: The aim of this project was to assist in the development of palliative care throughout Kenya by enhancing the knowledge and skill of faculty members in palliative care so they could integrate this content into existing nursing curricula.

Methods: In an effort to develop palliative care throughout the country, experts from the Kenya Hospices and Palliative Care Association and the Kenyatta National Hospital invited faculty from the End-of-Life Nursing Education Consortium with the United States to adopt the content of its training program to address the needs of nurses and other health care professionals in Kenya. This curriculum was delivered to nursing faculty from throughout Kenya during a 5-day training course that incorporated presentations, case studies, exercises, and other teaching methods.

Results: The course participants completed daily course evaluations in which they rated each session on a scale of 0 = not helpful to 5 = very helpful. All of the sessions were rated very favorably, with scores for all sessions across the 5 days ranging from 4.57 to 4.91.

Conclusion: End-of-Life Nursing Education Consortium provided educational and other support to faculty teaching in nursing schools in Kenya so they could advance palliative care efforts in this country.

Implications for Practice: Nurses working in the United States can share their expertise and learn immense lessons from colleagues in developing worlds.

Kenya is a breathtakingly beautiful country. Located in eastern Africa, it is bordered by Tanzania, Uganda, Sudan, Ethiopia, and Somalia. This is a country of great diversity with more than 40 ethnic groups represented, the most common being Kikuyu, 22%; Luhy, 14%; Luo, 13%; Kalenjin, 12%; and Kamba, 11%. The economy of...
Kenya is primarily agriculturally based, and the most common crops include tea, coffee, corn, wheat, and others. Most living outside Africa know of the beauty of Mount Kilimanjaro and the safaris of the Serengeti and Rift Valley. Despite its natural beauty and exotic wildlife, this country of 39 million people faces extraordinary challenges. Particular challenges include the 40% unemployment rate, with 50% of the population living below the poverty line.\textsuperscript{1,2} Life expectancy is 58 years, yet 1.2 million to 2 million Kenyans are currently living with HIV/AIDS, the leading cause of death.\textsuperscript{3} Cancer is now the third leading cause of death, with 85 000 people living with malignancy. Other common causes of death after HIV/AIDS include respiratory infections, diarrheal diseases, tuberculosis, malaria, stroke, heart disease, perinatal conditions, traffic accidents, and chronic obstructive pulmonary disease.\textsuperscript{4}

Effective palliative care delivery would address the needs of those Kenyans dying of a life-threatening illness, along with those of their family members. There are significant challenges to providing this care, including insufficient numbers of health care professionals. There are approximately 4500 physicians in the country or 1 physician per 10 000 citizens. This is compounded by a severe nursing shortage.\textsuperscript{5} And like many health care professionals throughout the world, most Kenyan physicians and nurses have had little training regarding palliative care.

As one might expect in a country with so many challenges, palliative care and hospice are relatively new additions to health care. Local leaders in this field include the Kenyan Hospice and Palliative Care Association,\textsuperscript{6} a chapter of the African Palliative Care Association (APCA).\textsuperscript{7} Kenya Hospices and Palliative Care Association (KEHPCA) recognizes the need to advance palliative care and has done this through research and training. They are currently directing a study of the quality of life of terminally ill patients, including an assessment of the need for palliative care, and they have fostered numerous training programs throughout Kenya.

Once such training program was the End-of-Life Nursing Education Consortium (ELNEC) held during a training course in Nairobi. In 2008, Dr Zipporah Ali, executive director of KEHPCA, and Dr Esther Munyoro, director of the Palliative Care Program at the Kenyatta National Hospital, contacted the national ELNEC Project Office at City of Hope (COH) to inquire about the possibility of providing an ELNEC-International train-the-trainer course in Nairobi, Kenya. Funds were secured by the Open Society Institute, and the course was held in July 2009. With a vision to reach all of Kenya, both physicians marketed the course country-wide, with representatives from all 8 provinces in attendance. Forty-nine nurses, physicians, nursing faculty, and social workers from various institutions in Kenya attended the 5-day train-the-trainer course.

### History of ELNEC-International

In the late 1990s, researchers at the COH, in Duarte, California, were studying deficiencies in nursing knowledge and attitudes related to end-of-life (EOL) care in the United States.\textsuperscript{8,9} At the same time, the American Association of Colleges of Nursing was outlining competencies needed by nurses to provide excellent care to patients and their families experiencing EOL issues. In 1999, COH and the American Association of Colleges of Nursing developed a partnership to develop a national education program on EOL care, specifically for registered nurses. This national project is known today as the ELNEC.\textsuperscript{10-13} Since its inception, ELNEC has been generously supported by grants from the Robert Wood Johnson Foundation, National Cancer Institute, the Aetna, Archstone, California HealthCare Foundations, Open Society Institute, and the Oncology Nursing Foundation.

Educating nurses to improve EOL care has always been ELNEC’s primary aim. Although our initial efforts were focused in the United States,\textsuperscript{14} many ELNEC trainers and faculty have had opportunities to travel internationally and provide this education to nurses and other health care providers throughout the world.\textsuperscript{15} Currently, ELNEC trainers and faculty have traveled to 6 of the 7 continents, representing 61 countries around the globe. Many trainers have provided ELNEC educational courses, whereas others have gone as consultants to work with educators, health administrators, and community leaders to improve care of the dying in their countries. Some trainers are working on translating ELNEC into other languages and adopting it to increase the relevance to other cultures. For example, the ELNEC-International content delivered in Africa and other locations addresses such diseases as malaria, tuberculosis, and other infectious disorders that might be less common in the developed world. Additionally, ELNEC has already been translated into Russian where nursing administrators and faculty are using the curriculum in Eastern Europe. ELNEC has also been translated in Spanish (Core and Pediatric Palliative Care versions) and is being widely disseminated in Mexico, Central America, and parts of South America. The Japanese translation is being used at national ELNEC courses across Japan, and ELNEC is also being translated into Korean.

### Major Emphasis on Educating Nursing Faculty in Palliative Care

The leaders in hospice and palliative care in Kenya understand the importance of educating nursing faculty in excellent EOL care, and that is why they strategically selected outstanding nursing educators from around Kenya to participate in the 5-day ELNEC train-the-trainer course. It is critical that faculty obtain EOL education so they not only can teach students in the classroom, but also implement the care in clinical settings. Of the 49 participants who completed ELNEC training, 27 (55%) were nursing faculty members. The other participants included 12 nurses (24%) working in clinical or administrative roles in hospitals, 6 nurses (12%) from the local hospice, 1 social worker (2%), 1 physician (2%) from hospice, and 2 individuals (4%) from the Kenya Hospice & Palliative Care Association (1 physician and 1 nurse).
The Kenya Medical Training College (KMTC) was targeted to receive this education. It is composed of 28 constituent colleges across Kenya. Faculty from 19 of the 28 KMTC colleges (68%) participated in the first ELNEC train-the-trainer course in Kenya. These various campuses are located in both urban and rural settings, with the intent of not only meeting the needs of all Kenyans, but also allowing students opportunities to be exposed to different clinical settings. Many of these colleges are located close to government hospitals, which provide excellent opportunities for on-site clinical training. The ELNEC course was held at the KMTC headquarters, and the main campus located in Nairobi. Literally next door to KMTC headquarters is Kenyatta National Hospital, the largest referral hospital in east Africa. Kenya Medical Training College has more than 14,000 students who attend one of its campuses and is the largest single contributor to the health care sector in Kenya. Annually, more than 2500 graduates, representing 80% of the hospital workforce, begin work in either the public or private health sector.16

As with any school of nursing, there remain barriers that nursing faculty must overcome to provide palliative care training throughout Kenya. For example, providing more time and content related to palliative care in an already crowded curriculum is a challenge. Looking at existing courses and embedding ELNEC into them are an option. Training sufficient numbers of faculty members in palliative care to provide clinical opportunities for students will be a continuous effort and will take time. But role modeling and mentoring will be key in promoting this care, which has been ongoing for several years. Palliative care began in Africa 25 years ago. Care is generally inconsistent and operates from a few centers of excellence. Delivery of palliative care is generally home based, with pain being severely undertreated. Although the government provides “basic care packages,” these plans exclude palliative care. When looking at patient-doctor ratios throughout Africa, there are just not enough doctors to care for the immense needs of the massive population. In 2004, the World Health Organization recommended that governments develop palliative training in curricula for all students in health care–related programs. In addition, APCA is working in Kenya to support palliative care in core nursing and medical curricula so that these students can be trained in prescribing opioids to treat moderate to severe pain.17

Though there are barriers to obtaining and providing excellent palliative care throughout Kenya, Kenyan nurses are poised to play a key role in caring for those experiencing terminal illness, thanks to the many efforts by World Health Organization, KEHPCA, and APCA. Nursing faculty members in Kenya have begun to become educated in palliative care. Although they have been equipped to provide this education to their nursing students, they have also been empowered to become change agents and to advocate for better laws and practices in providing compassionate care to their most vulnerable citizens.

Evaluation of the ELNEC Training Course

The course participants completed daily course evaluations in which they rated each session on a scale of 0 = not helpful to 5 = very helpful. All of the sessions were rated very favorably, with scores for all sessions across the 5 days ranging from 4.57 to 4.91. Additionally, participants were asked to provide responses to 3 overall evaluation questions rated on a scale of 1 = poor to 5 = excellent. Participants rated the first question, their overall opinion of the conference, at 4.89. When asked if the information was “stimulating and thought provoking regarding palliative care issues,” the rating was 4.97, and when asked “to what extent did the course meet the objectives and your expectations,” the rating was 4.71.

Participants were also given the opportunity to offer suggestions for future training. Comments included a desire for additional small group work, more role play to practice communication skills, and enhanced use of case studies. They also voiced interest in receiving more supplementary materials or textbooks because these are often very limited in their settings.

Since delivering the ELNEC-International course, the institutions providing a bachelor of science in nursing in Kenya have agreed to include 45 hours of palliative care content within the curriculum. The Kenya Hospice and Palliative Care Association, with support from the Diana Princess of Wales Memorial Fund, fostered this effort and continues to encourage this integration of palliative care content within medical schools.

One Final Thought: An Opportunity to Provide More Than Education

While in Kenya, the ELNEC faculty met Joyce Marete, RN, who was working at the Nairobi Hospice in July 2009. Joyce is from Nanyuki, Kenya, and has returned there to start a palliative care and hospice program to serve this region of Kenya. Joyce attended the ELNEC course in Nairobi and shared with the faculty that Nanyuki, with a population of more than 31,000 and the home to a Kenyan Air Force and British Army bases, is in desperate need of palliative care services. The hospital in Nanyuki does not stock morphine or other forms of opioids to treat the pain of the many residents who have cancer, HIV/AIDS, and other chronic life-limiting illnesses. Joyce is working with the government to break through those barriers of obtaining opioids to treat pain and prevent needless suffering. Joyce, the recipient of a grant from the Princess Diana Fund to do research on wound care, has spoken to physicians and nurses at the hospital in Nanyuki and has
began to educate them about the importance of palliative care. Joyce will soon provide palliative care and hospice services at the Nanyuki Clinic. Upon hearing about the need to provide hospice care in this remote village of Nanyuki, the ELNEC Project Team returned to the United States and presented the need for $7000 to ELNEC trainers to begin and sustain this work for 1 year. The ELNEC trainers responded to this opportunity, and today, Joyce is beginning this work.

## Conclusion

The need for effective palliative care throughout Kenya and other developing countries is great. Efforts to educate nursing faculty are essential as they will be training future nurses to provide this care. The ELNEC-International nursing curriculum provides a strong framework of materials and content to facilitate this education. Other programs, including the Educating Physicians in End-of-Life Care and Educating Physicians in End-of-Life Care–Oncology curriculum, are being used successfully to disseminate palliative care information around the world to physician groups in India, Jordan, Egypt, and Saudi Arabia. Excellent resources can also be found through the International Association for Hospice and Palliative Care. Internal organizations and resources are crucial to advance this goal. Champions such as Dr Esther Munyoro from the Kenyatta National Hospital Palliative Care Team and Dr Zipporah Ali from KEHPCA will continue to work to advance palliative care by building on the content delivered through ELNEC.

## References


