

ELNEC: Preparing Nurses to be Palliative Care Leaders Around the World

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What is Palliative Care?

“Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”.

WHO, 2018

What is Palliative Nursing Leadership?

- Leadership in palliative care is characterized by leading others with
 - A clear vision of palliative care initiatives
 - Motivation and inspiration to achieve excellence in care
 - Creation of healthy work environments, and changing the behavior of others to work collaboratively in palliative care

Dahlin, 2018

Nursing Leaders Needed to Provide Vision and Direction in Care of the Seriously Ill

All those with serious illness and their families, ideally from the time of diagnosis and across the disease trajectory

| Chronic, Serious Illness | World-wide Percentages |
|--------------------------|------------------------|
| Cardiovascular diseases | 38.5 % |
| Cancer | 34 % |
| Chronic Lung diseases | 10.3 % |
| AIDS | 5.7 % |
| Diabetes | 4.6 % |

Evidence-Based Need for Global Palliative Nursing Leaders

- Every year, > 40 million people with serious illness are in need of palliative care
- Only 14% of those who need palliative care, receive it
- 78% of these reside in low & middle-income (LMI) countries
- 98% of children who need palliative care reside in LMI countries, with nearly ½ in Africa



WHO, 2018 ; WHPCA, 2014

Global Demand for Palliative Care:

Global Atlas 2014 World Map



Global Barriers to Palliative Care



- Lack of education & awareness of palliative care among health care professionals
- Global need increases with rising burden of non-communicable diseases & aging population
- Limited guidelines to establish palliative care programs; many guidelines are only in English
- Overly restrictive regulations on morphine sulfate & other controlled medications – resulting in unnecessary pain & suffering

WHO, 2018 ; WHPCA, 2014

What Can We as Nurse Leaders Do To Address This Need?

- WHO recommends that all health care professionals be educated to provide primary palliative care in their communities
- Nurses have the opportunity to learn palliative care from the End-of-Life Nursing Education Consortium (ELNEC) curricula
- Consider becoming a leader in your country, community to help educate all nurses in the delivery of palliative care



Celebrating 17 Years of Providing Palliative Care Education and Leadership: The History of ELNEC

Partnership between City of Hope (COH)
Nursing Research & Education and the
American Association of Colleges of Nursing (AACN)



www.aacnnursing.org/ELNEC



Results of This Partnership....

- 2000: Curriculum Developed
- 2001: 1st National ELNEC Course
- Currently 9 ELNEC Curricula:
 - ELNEC-Core
 - ELNEC-Geriatric
 - ELNEC-Pediatric Palliative Care
 - ELNEC-Critical Care
 - ELNEC-APRN
 - ELNEC-International
 - Integrating Palliative Oncology Care into Doctor of Nursing Practice (DNP) Education and Clinical Practice
 - ELNEC-Undergraduate
 - ELNEC-Oncology APRN



Accomplishments Since ELNEC's Inception



- Nearly 200 National ELNEC train-the-trainer courses have been held across the US and internationally
- Over 25,000 trainers globally
- Those trainers have gone back to their community and have educated over 670,00 healthcare professionals

Other Accomplishments (cont.)

- 30+ articles published in peer-reviewed journals
- National ELNEC Faculty work on key documents promoting palliative care through major national organizations:
 - Institute of Medicine
 - National Cancer Institute
 - National Consensus Project

Other Accomplishments: Educating Nursing Students → ELNEC-Undergraduate Project

1. Create national standards for undergraduate palliative nursing education
2. Develop a curriculum to meet the AACN Palliative CARES Document
Competencies and Recommendations for Educating Nursing Students
3. Eliminate known barriers to teaching palliative care content: lack of time and space in saturated curricula; lack of faculty prepared to teach this content
4. Prepare all nursing students in primary palliative care by graduation

AACN, 2016

ELNEC-Undergraduate Online Curriculum



Throughout All The ELNEC Curricula: Certain Themes

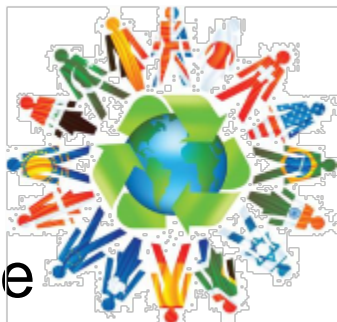
Family as the unit of care



Vital role of the
nurse as advocate

ELNEC Curriculum Themes (cont.)

Importance of honoring culture



Attention to special populations



Palliative care impacts all systems of care



ELNEC Curriculum Themes (cont.)

- Palliative care is for all patients with a serious, or life-threatening illnesses/sudden death and their families
- Palliative care should be provided across the disease trajectory and in all clinical settings
- Interprofessional care is essential for quality palliative care!



Nurses Around the World Are Responding To The Needs of Their Seriously Ill Patients

- No other healthcare professional spends more time at the bedside/in the community with patients and their families than the nurse
- Assess and manage care
- Think critically and creatively
- Committed to education
- Desire to contribute to nursing science



Let's Take A Trip Around the World: ELNEC-International

- Presented in 96 countries
- 6/7 continents
- Purpose: To provide education so practice can be improved



We Can Change The World.....
Together



Translation Has Been Key to Providing ELNEC Education

- Currently, ELNEC is translated into 9 languages:
 - Spanish
 - Russian
 - Japanese
 - Korean
 - German
 - Romanian
 - Albanian
 - Chinese
 - Czech



!مرحبا العالم! Hallo Welt!
Hej Värld! Hello World!
Ciao Mondo
ハローワールド!
¡Olá mundo! 世界您好!
Salut le Monde!

You Have To Start Somewhere:



Sayaka Takenouchi, PhD, RN, MPH
First to Translate ELNEC
Kyoto University and Hospital
Kyoto City, Japan



Hyun Sook Kim, PhD, RN, MSW
Korea National University of
Transportation (KNUT)
Seoul, KO

Peking Cancer Hospital Beijing, China



Development of Palliative Nursing Leadership Courses

- Working close with contacts in various regions of the world to identify current/potential leaders
- Obtain funding
- Role modeling
- Mentoring
- Envision “a plan”
- Develop a realistic “plan”



Eastern Europe: Provides a Template for Future Leadership Development

- 5-Year Plan
 - Year 1: ELNEC education
 - Year 2: ELNEC education
 - Year 3: Develop palliative care competencies for schools of nursing and practicing nurses
 - Year 4: Leadership 101
 - Year 5: Leadership 201



Under the vision and leadership of
Nicoleta Mitrea, PhD, RN

2015: Eastern European Leadership Course



Albania, Armenia, Czech Republic, Greece,
Hungary, Romanian, Russia, Serbia

Kenya, 2016: Interprofessional Palliative Care Leadership Course



1st Palliative Care Leadership Course Held in Asia, 2016



China, Japan, Korea, Malaysia, Philippines, Singapore

Lessons Learned in Developing Palliative Nursing Leadership Courses

- You have to have funding
- Respect each culture
- Go humbly—YOU are the visitor
- Seek 2-3 strong leaders who are committed
- It takes more than 1 trip
- Build relationships
- Mentor
- Follow-up with group via SKYPE, email
- Stay in touch through social media
- Assist in making small, achievable, measurable goals
- Listen
- Role model
- Seek more funding

2017 Was a Very Busy/Excellent Year



1st ELNEC-Pediatric Course in Japan, 2017



1st ELNEC-Critical Care Course Held in South Korea, 2017



1st ELNEC-Pediatric Course Held in China, 2017

Shanghai Children's Hospital



1st ELNEC Course Held in Nepal, 2017

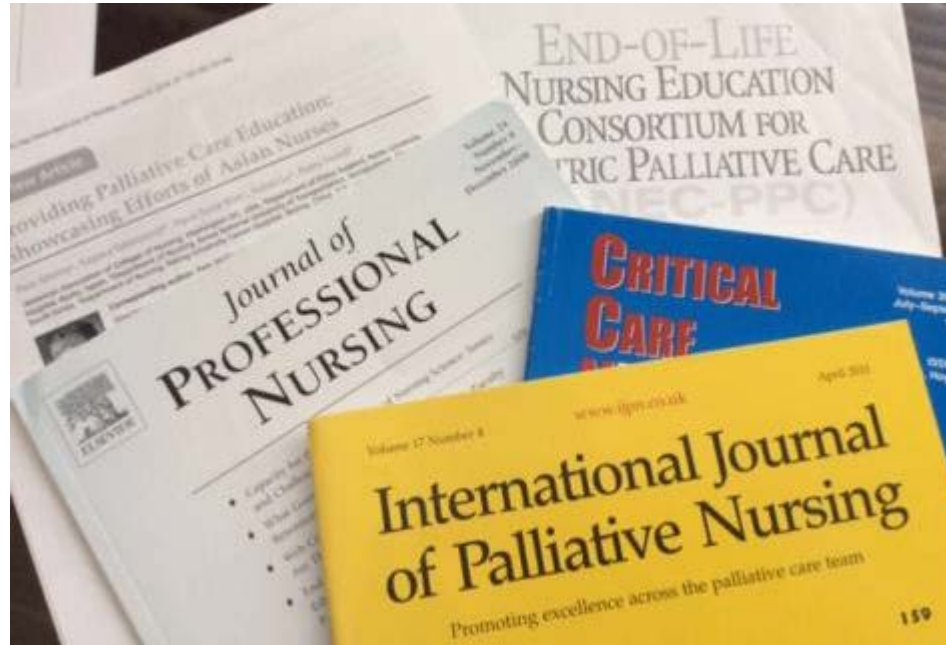


What's Going on in 2018?

- Bangladesh
- Brazil
- China
- Czech Republic
- India
- Mexico
- New Zealand
- Philippines
- Singapore



9 Articles Published in Peer-Review Journals About ELNEC-International

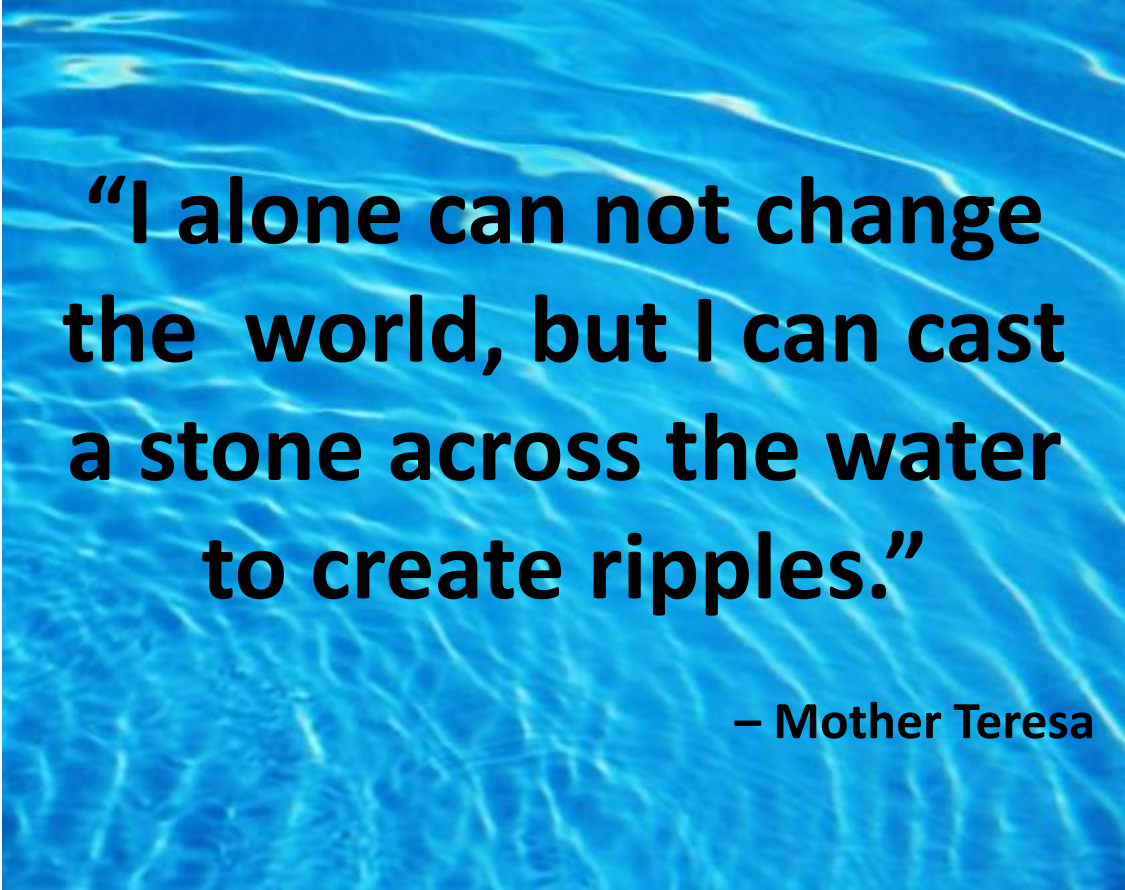


<http://www.aacnnursing.org/ELNEC/Resources>

Your Turn.....

Share Your Experiences of Developing Leaders in Your Community, Country,, Internationally





**“I alone can not change
the world, but I can cast
a stone across the water
to create ripples.”**

– Mother Teresa

References

- American Association of Colleges of Nursing (AACN) (2016). Competencies and recommendations for educating nursing students. www.aacnnursing.org/Portals/42/ELNEC/PDF/New-Palliative-Care-Competencies.pdf
- Dahlin, C. (2018). Palliative nursing leadership intensive. *Journal of Pain and Symptom Management*, (55):2. 548-549.
- World Health Organization (WHO). (2018). Fact sheet. <http://www.who.int/news-room/fact-sheets/detail/palliative-care>
- Worldwide Hospice and Palliative Care Alliance (WHPCA). (2014). Global atlas of palliative care at the end of life files <http://www.thewhpc.org/resources/category/global-atlas-of-palliative-care-at-the-end-of-life>