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

<table>
<thead>
<tr>
<th>Chronic, Serious Illness</th>
<th>World-wide Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular diseases</td>
<td>38.5 %</td>
</tr>
<tr>
<td>Cancer</td>
<td>34 %</td>
</tr>
<tr>
<td>Chronic Lung diseases</td>
<td>10.3 %</td>
</tr>
<tr>
<td>AIDS</td>
<td>5.7 %</td>
</tr>
<tr>
<td>Diabetes</td>
<td>4.6 %</td>
</tr>
</tbody>
</table>

WHO, 2018
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

Rates for people in need of palliative care:
All ages and both sexes per 100,000 (including adults and children)

- 178.36 - 272.85
- 272.86 - 281.84
- 281.85 - 307.16
- 307.17 - 467.52
- Data not available
- Not applicable

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Sigma

Advancing Palliative Care
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: 1\textsuperscript{st} 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 670,000 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

[Map of the World]
Translation Has Been Key to Providing ELNEC Education

• Currently, ELNEC is translated into 9 languages:
  ❖ Spanish
  ❖ Russian
  ❖ Japanese
  ❖ Korean
  ❖ German
  ❖ Romanian
  ❖ Albanian
  ❖ Chinese
  ❖ Czech
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
Curriculum for Palliative Care Leadership Courses

- Advanced ELNEC education in pain, symptoms, communication, self-care, and final hours
- Characteristics of leaders
- Characteristics of followers
- How to publish
- How to design Q I projects
- Mentoring
- Presentation skills
- Much more
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


