

# Providing Palliative Care Education: Showcasing Efforts of Asian Nurses

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## ABSTRACT

Most of the world’s population lives in Asia. Prevention and detection of cancer, as well as ensuring equitable access to cancer care for all Asians remains a major public health issue and requires governmental involvement and dedicated resources. Palliative care, a medical and nursing specialty, promotes holistic attention to suffering and provides compassionate and interdisciplinary care to the most vulnerable in all societies—those with serious illness. It is nurses who provide the majority of care for patients with cancer, as no other healthcare professional spends more

time at the bedside or out in the community assessing and managing these patients and their families. The purpose of this article is to showcase nursing leaders throughout Asia who are receiving palliative care education, educating their colleagues in this care, improving clinical practice, participating in the development of healthcare policies, and advocating for this care.

**Key words:** Asia, cancer care, health-care policy, nurses, palliative care

## Introduction

Sixty percent of the world’s population lives in Asia and bears one-half of the global burden of cancer.<sup>[1]</sup> Prevention and detection of cancer, as well as ensuring equitable access to cancer care for all Asians, remains a major public health issue and requires governmental involvement and dedicated resources. Palliative care, a medical and nursing specialty, promotes attention to

suffering and holistic care and provides compassionate care to the most vulnerable in all societies – those with serious illness. The World Health Organization (WHO) has declared that palliative care is a basic human right, and it is nurses primarily who provide consistent care throughout the complex illness trajectory.<sup>[2]</sup> The continent of Asia is a vast land with over 4,473,526,200

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people spread over 31,022,549 km (11,977,868 square miles).<sup>[3]</sup> Consistent with the rest of the world, Asians have a tremendous health-care burden of chronic, debilitating illnesses such as ischemic heart disease, stroke, chronic obstructive pulmonary disease (COPD), lung/trachea/bronchus cancers, diabetes, dementia, diarrheal diseases, tuberculosis, and HIV/AIDS.<sup>[4]</sup> Due to barriers such as denial of death, poor knowledge about hospice and palliative care, governments' failure to fund and promote palliative care, and lack of palliative care education among nursing/medical school faculty, many people are diagnosed with advanced disease and are unable to access supportive care during treatment and at the end of their life. Throughout Asia, nurses faithfully care for these patients and their families. The care is complex and it is vital that nurses be educated about the important role palliative care plays throughout the disease trajectory and their responsibility in implementing and providing the care. Practice can only be improved once nurses are educated as nurses cannot practice what they do not know.

The purpose of this article is to showcase nursing leaders throughout Asia who are receiving palliative care education and then educating their colleagues in this care. In doing so, they are improving clinical practice, participating in the development of health-care policies, and serving as advocates for this very important field of practice.

## Education is Key: A Palliative Care Nursing Education Model

Launched in the year 2000, initially to teach palliative care to nurses in the United States, the End-of-Life Nursing Education Consortium (ELNEC) has today been presented in six of the seven continents and 91 countries in an effort to improve palliative care. The ELNEC project, a partnership between the American Association of Colleges of Nursing (AACN) and City of Hope, is designed to provide undergraduate and graduate nursing faculty, continuing education providers, staff development educators, specialty nurses in pediatrics, oncology, critical care, and geriatrics and other nurses with training in palliative care, so that they can teach this essential information to nursing students and practicing nurses. Through the ELNEC international program, Asian nursing leaders are receiving the education and then returning to their countries to begin translating the curriculum to further disseminate it. In addition, they are providing ELNEC train-the-trainer courses, so other nurses are educated in palliative care and equipped with the resources to go back to their own institutions and educate others. The ELNEC course consists of eight modules [Table 1], case studies, reference lists, and supplemental teaching materials. In addition, there are

**Table 1: End-of-Life Nursing Education Consortium-core modules and overviews**

ELNEC module	Overview of the module
#1: Introduction to palliative nursing care	This module creates the foundation for the ELNEC curriculum. It is an overview of the need to improve palliative care and the role of the nurse as a member of an interdisciplinary team in providing quality care. Basic definitions and principles of hospice and palliative care are presented within a QOL framework
#2: Pain management	This module reviews basic principles of pain assessment and management, with a focus on pain at the end of life
#3: Symptom management	This module builds on Module 2: Pain management, by addressing other symptoms common in advanced disease and the role of the nurse in managing these symptoms
#4: Ethical issues in palliative care nursing	This module discusses some of the key ethical issues and legal concerns in end-of-life/palliative care and resources to address these in practice
#5: Cultural and spiritual considerations at the end-of-life	This module reviews dimensions of culture, which influence care in advanced disease. Assessment of culture is emphasized as essential to adequate communication and in providing culturally sensitive care
#6: Communication	This module emphasizes the importance of good communication in end-of-life care. The complexities of communicating with patients and families at this critical time are described along with suggestions for care
#7: Loss, grief, and bereavement	This module addresses the challenging aspects of grief, loss, and bereavement of patients and families as well as the loss experiences of health-care professionals
#8: Final hours	This module focuses on care at the actual time of death, emphasizing the preparation necessary to insure the best care at this critical event in the trajectory of illness

ELNEC: End-of-Life Nursing Education Consortium, QOL: Quality of life

various ELNEC curricula that Asian nurses have translated and taught [Table 2]. These curricula provide education and resources to those working with seriously ill adults, children, older adults, and those in critical care settings. Each of these curricula has been developed and built from the National Consensus Project for Quality Palliative Care, Clinical Practice Guidelines For Quality Palliative Care<sup>[5]</sup> [Table 3].

## Case Study: Mr. Nakata

Mr. Nakata was a 46-year-old banker who lived in Osaka, Japan, with his wife and 3 children, ages 16, 11, and 8. Three months ago, Mr. Nakata noticed he was experiencing shortness of breath when walking from his home to the train station to go to work. He attributed this shortness of breath and fatigue to working long hours and a recent cold. When he did not improve, he went to the doctor who performed tests and determined that Mr. Nakata had stage IV nonsmall cell lung cancer (NSCLC) with widespread metastasis to his lymph nodes and bones. His physician did not recommend any treatment for his aggressive cancer. He and his wife were devastated by the news. Mr. Nakata was left to wonder how he would provide for his family. How would he tell his children about his illness? How long could he work? Who was going to take care of his fatigue, dyspnea, and pain? How would he pay the bills? He also

**Table 2: Overview of various End-of-Life Nursing Education Consortium curricula used throughout Asia**

ELNEC curricula	Asian countries using the curricula	Overview of the curricula
ELNEC-Core	China, Japan, Malaysia, Philippines, South Korea, Vietnam	ELNEC-Core was the first of the ELNEC curricula to be developed and translated, specifically addressing end-of-life needs of Asian adults. This course is aimed at nursing faculty, nursing students, and practicing nurses working in acute care facilities (i.e., medical, surgical, oncology units), home care facilities, hospices, etc.
ELNEC-Geriatric	Japan and South Korea	With life expectancy increasing and the numbers of aging adults growing each day throughout Asia, the health-care system requires nurses to be educated in meeting the palliative care needs of older adults. The ELNEC-Geriatric curriculum addresses the specific educational needs of nurses who provide care to people who reside at home or are being cared for in community-based settings, such as assisted living, nursing communities, skilled nursing settings, hospices, or ambulatory care clinics. Unique features of the course include a focused module on geriatric palliative care that elaborates on physiologic changes in older adults, medications, and chronic conditions using a person-centered approach. Geriatric syndromes are integrated across all nine modules. Patient and family education materials and evidence-based assessment tools are provided to augment pain and symptom management. Undergraduate and graduate nursing faculty finds its supplemental teaching materials and case studies invaluable to their current lectures
ELNEC-Pediatric Palliative Care	Japan and South Korea	Neonates, small children, and adolescents have unique needs when they are seriously ill with a life-threatening illness or injury. This curriculum provides education in assessing and managing children and providing the necessary support to their families
ELNEC-Critical Care	Japan and South Korea	This curriculum has been developed for nurses who work in intensive care, coronary care, burn, dialysis units, emergency departments, and other clinical areas encompassing critical care

ELNEC: End-of-Life Nursing Education Consortium

began to think deeply about the meaning of his life. Had he been a good father? How would he be remembered by his family and friends? Mr. Nakata’s oncology nurse spoke to the oncologist about the opportunity to call the palliative care team to assess him and his family.

### What is Palliative Care?

According to the WHO, palliative care is defined as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems,

**Table 3: National Consensus Project domains and guidelines**

NCP domain	NCP guidelines
Domain 1: Structure and processes of care	Interdisciplinary care Care plan based on patient and family preferences, goals of care, and values Add trained and supervised volunteers Support interdisciplinary education, training, and professional development Develops, implements, and maintains ongoing data with a focus on palliative care outcomes Develop and promote community palliative care resources for use across the care continuum
Domain 2: Physical aspects of care	Pain and symptoms are assessed and managed by the interdisciplinary team, using evidence-based practice
Domain 3: Psychological and psychiatric aspects	This care is provided by an interdisciplinary team A grief and bereavement program must be made available to patients and families, based on their need
Domain 4: Social aspects of care	Interdisciplinary team assesses and manages social aspects of care Interdisciplinary assessment that identifies social strengths, needs, and goals
Domain 5: Spiritual, religious, and existential aspects of care	Interdisciplinary team assesses and manages spiritual, religious, and existential aspects of care Spiritual assessment is performed Religious, spiritual, and cultural rituals are honored, especially at and after the time of death
Domain 6: Cultural aspects of care	Palliative care is provided in a culturally and linguistically sensitive manner
Domain 7: Care of the patient at the end of life	Interdisciplinary team identifies and manages signs and symptoms of impending death, assessing not only physical needs but also psychosocial, spiritual, and cultural needs Provides respectful postdeath care Activates an immediate bereavement care plan for the family
Domain 8: Ethical and legal aspects of care	Person-centered goals of care are respected Palliative care team recognizes complex ethical issues within this care Provision of care is in accordance with professional, state, and federal laws

NCP: National Consensus Project

physical, psychosocial, and spiritual.”<sup>[6]</sup> The WHO highlights other benefits of palliative care:<sup>[6]</sup>

- Provides pain and other distressing symptom relief
- Supports life and sees dying as normal
- Neither hastens nor postpones death
- Incorporates the psychological and spiritual aspects of care
- Provides a support system to assist families to cope with their loved one’s illness as well as their own bereavement
- Promotes interprofessional care
- Enhances quality of life
- Can be used simultaneously with active treatment intended to prolong life (i.e. surgery, chemotherapy, and radiation).

### Nurses Cannot Practice What They Do Not Know

Nurses cannot provide excellent, compassionate care without education.<sup>[7]</sup> Learning how to provide better pain

and symptom assessment and management and how to communicate with the patient, family, and interprofessional team is critical. Understanding the role of grief and bereavement, cultural implications, and ethical dilemmas all play a significant role in providing care to patients with serious illness and their families.<sup>[7]</sup>

Nursing leaders throughout Asia, such as Sayaka Takenouchi, PhD, RN, MPH, Program-Specific Senior Lecturer at the Kyoto University Hospital, Department of Ethics Support in Kyoto, Japan; Hyun Sook Kim, PhD, RN, Professor at the Korea National University of Transportation, Department of Nursing in Jeungpyeong-gun, Chungbuk, Republic of Korea; and Yuhan Lu, RN, MSN, Director of the Oncology Nursing Department at Peking University Cancer Hospital, Beijing, China, have worked with colleagues in their countries to translate ELNEC into their respective languages. Major efforts have been made throughout these countries not only to provide ELNEC education to practicing nurses but also to nursing faculty, so they, in turn, can offer this education to nursing students.<sup>[8-10]</sup>

## Examples of Disseminating End-of-Life Nursing Education Consortium throughout Asia: Japan

Dr. Sayaka Takenouchi was the first ELNEC trainer who requested permission from the national ELNEC Project Office, located at the AACN in Washington, D. C., to translate ELNEC into her language. In 2008, Dr. Takenouchi, with the contribution of Dr. Keiko Tamura, translated ELNEC-Core into Japanese. Due to this translation, the ELNEC-Japan Faculty Development Program was able to offer this education to practicing nurses, in addition to nursing faculty and students, to improve the quality of care of those with serious illness throughout Japan, with generous support from the Japanese Society of Palliative Medicine.<sup>[11]</sup> In 2012, ELNEC-Geriatric, under the leadership of Ms. Miyoko Kuwata, was translated to help meet the country's needs as Japan precedes other countries in experiencing a "super-aging" society.<sup>[11]</sup> To meet these soaring needs, a group of Certified Nurse Specialists in Gerontological Nursing committed to improve the quality of end-of-life care for older Japanese by volunteering to start the ELNEC-Japan Geriatric Project. With the help of a grant from The Sasakawa Memorial Health Foundation, over 1,440 nurses from across Japan who work in home care, nursing homes, and acute care facilities have attended this course (personal correspondence between authors P Malloy and S Takenouchi). Since 2014, this program has been adopted as an official continuing education project by the

Japan Academy of Gerontological Nursing. ELNEC-Critical Care, under the leadership of Dr. Kazuko Nin, was translated in 2015 and has been used in clinical settings throughout Japan (personal correspondence between authors P Malloy and S Takenouchi). ELNEC-Pediatric Palliative Care is being translated in 2017 and will be ready for dissemination in 2018.

To date, over 1700 nurses have completed ELNEC train-the-trainer courses in all 47 prefectures throughout Japan, with funding from the Japanese Society for Palliative Medicine and the Health and Labor Sciences Research Grant.<sup>[11]</sup> These nurses, who have collectively taught 751 ELNEC courses, have returned to all Japanese prefectures and educated 23,905 nurses and other health-care professionals.<sup>[12]</sup> This widespread nursing education throughout Japan has resulted in increased confidence in teaching end-of-life initiatives and using new and innovative teaching strategies.<sup>[8]</sup>

## South Korea

Translating ELNEC from English to another language is time-consuming and takes a team of people to complete the effort. However, it takes just one person to have the vision and build a coalition to work together until the project is complete. Dr. Hyun Sook Kim has consistently been that visionary and leader who wanted nurses throughout South Korea to be educated in palliative care. Chronic illness is rampant throughout South Korea, as with other Asian countries. Cancer is the number 1 cause of death in South Korea, followed by cardiovascular disease, cerebrovascular disease, pneumonia, and self-harm.<sup>[13]</sup> Currently, hospice nurses see only terminally ill cancer patients and their families. However, today, there is a demand to expand hospice and palliative care services to those with other life-threatening diseases besides cancer.<sup>[10]</sup> The Law on the Hospice and Palliative Care and the Determination of Life-Sustaining Treatment for Terminally Ill Patients, enacted in 2016, will come into effect in August 2017 and will allow hospice and palliative care services to be provided to terminally ill patients with COPD, AIDS, liver disease, and cancer.<sup>[12]</sup> Preparing for this expansion, Dr. Kim and her team have translated not only ELNEC-Core but also ELNEC-Pediatric, ELNEC-Geriatric, and ELNEC-Critical Care curricula in an effort to meet the increasing needs. To date, over 770 nurses throughout South Korea have completed an ELNEC train-the-trainer program (145 trainers in ELNEC-Core, 203 trainers in ELNEC-Geriatric, 191 trainers in ELNEC-Pediatric Palliative Care, and 233 trainers in ELNEC-Critical Care) (personal correspondence between authors P Malloy and HS Kim).



## China

On April 6–8, 2015, 56 nurses representing 16 provinces throughout China attended the first ELNEC course held in China. The 3-day ELNEC course, funded by the Open Society Foundation, was held at the Peking University Cancer Hospital. The course was a tremendous success, mainly due to the leadership of Yuhan Lu and the dedication of seven other nurses from the Peking University Cancer Hospital who spent 14 months translating the ELNEC curriculum from English to Chinese. This course prepared these 56 nurses from across China to provide ELNEC educational courses in their own institutions and their communities throughout the extraordinarily large country of China. To date, over 1,486 oncology nurses have attended an ELNEC training course, sponsored by the Oncology Nursing Committee of Chinese Nursing Association. In addition, over 650 nurses have listened to modules via teleconferencing throughout China (personal communication between authors P. Malloy and Y Lu).

## Singapore

Singapore has received ELNEC training in large part, due to two major teaching efforts. In 2012, Roger Strong, PhD, RN, a nurse practitioner at the San Diego (CA) Veterans Medical Center, traveled to Singapore to teach an ELNEC train-the-trainer course at Dover Park Hospice. Thirty-five nurses attended the course. These nurses, from various health-care facilities across Singapore (i.e. Assisi Hospice, Changi General Hospital, Singapore General Hospital, Ang Mo Kio – Thye Hua Kwan Hospital, Yishun General Hospital, etc.), hold numerous ELNEC training courses each year. In 2016 alone, 18 ELNEC courses were taught, with an estimated 540 nurses attending.

In addition, Carol Long, PhD, RN, FPCN, FAAN, adapted content for Singapore culture and presented ELNEC-Geriatric at the Hua Mei Training Academy which is part of the Tsao Foundation in Singapore in 2012, in conjunction with the Community Gerontology Nursing Certificate course. In 2017, the course evolved into the Specialist Diploma in Community Gerontology Nursing, currently provided by the School of Health Sciences, Ngee Ann Polytechnic, along with the Tsao Foundation. This course is highly recognized and approved by the Singapore Nursing Board and the Ministry of Education and emphasizes holistic and integrated care across the health-care settings in which older adults are seen. In addition, it promotes further education in health assessment, clinical decision-making, pathophysiology, pharmacology, principles of community gerontology nursing, and palliative care.<sup>[14]</sup> The educational needs of community gerontology nurses are immense as they assess

and manage older persons, many of whom have complex, multiple comorbidities.<sup>[15]</sup>

## Other Asian Countries

ELNEC was first taught in Malaysia at the Perak Palliative Care Society in May, 2016. Since ELNEC is relatively new in Malaysia, Christine Low Seiw, RN and her colleague, Thow Meei Jiun, RN from Hospis Malaysia, offer palliative care in the community for nonhealth-care professionals and are using ELNEC to build a palliative care curriculum for new employee orientation at local hospitals.

In the Philippines, the Ruth Foundation for Palliative and Hospice Care (TRF) has organized annual ELNEC-Core trainings from 2012 to 2016. Much of this work has been developed and overseen by Rumalie Corvera, MD, DPAFP, FPSHPM, DipPalMed and Ayda Nambayan, PhD, RN, who have taught palliative care to over 400 nurses. In 2016, Dr. Nambayan served as the core faculty consultant on the first ELNEC-Pediatric Palliative Care course in the Philippines. Dr. Corvera continues to do outreach work with the Ruth Foundation, having made free home visits to 471 patients and families as of January 2016.

ELNEC was first presented in Vietnam in 2013 by Dr. Roger Strong and he returned in 2015, 2016, and 2017 to continue this work. He has trained over 230 nurses and physicians throughout Vietnam, who provide care at Ho Chi Minh City Oncology Hospital, Lavicet Hospital in Vinheyn City, and University of Medicine and Pharmacy of Ho Chi Minh City.

## Case Study: Mr. Nakata and Palliative Care

Three months after diagnosis of NSCLC with metastasis, Mr. Nakata's symptoms of fatigue, dyspnea, anorexia, and bone pain had worsened. Anxious and experiencing spiritual angst, Mr. Nakata, exhibited alienation from his friends and family, refusing visitors. His physician asked that a home care nurse visit him at home and provides recommendations for end-of-life care. Palliative Care Nurse, Mei, went to Mr. Nakata's home, meeting with him and his family, to assess all of the family's unique needs. She inquired about Mr. Nakata's goals of care and assessed the wife and children for how they were coping and for anticipatory grief, listening to their fears. The palliative care nurse also conducted a physical assessment and made recommendations about providing oxygen for dyspnea and pain medication for metastatic bone pain. She asked what his favorite food was and what sounded appetizing to him. Psychologically, Mei was concerned about his anxiety, knowing that anxiety could contribute to his dyspnea, fatigue, anorexia, sleeplessness, and other symptoms he

was experiencing and recommended that he begin a trial of an anti-anxiety medication. When Mei consulted with Mr. Nakata's physician about increasing his morphine, adding oxygen and an anti-anxiety medication, he agreed with the plan. Mei also suggested that limited visits from friends and family might be helpful and that he might also be better able to deal with his spiritual/existential distress if he spoke to his Buddhist priest. She inquired about rituals and traditions that were important to him and his family. Mei's assessment was aimed not only at Mr. Nakata's physical condition but also his psychological, social, and spiritual suffering. Eight days later, Mr. Nakata died peacefully at his home, with his family and Mei at his bedside.

## Conclusion

Nurses are committed to improving care for those with serious illness and are changing the culture of how people die throughout Asia. Their commitment to education, practice, leadership, advocacy, and research will continue to promote better palliative care. No one spends more time at the bedside or out in the community than the nurse, assessing and managing patients with serious, complex illnesses. Through the ELNEC training courses, nurses throughout Asia will continue to learn and be inspired to commit to this care, respecting and advocating for patients to be honored through their death, in the same measure as was given at their birth. For more information about the ELNEC Project, go to [www.aacnnursing.org/ELNEC](http://www.aacnnursing.org/ELNEC).

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## Conflicts of interest

There are no conflicts of interest.

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