



Understanding End of Life Nursing Practices and End of Life Across Cultures

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10.1 Overview

Nurses are the largest group of health and social care professionals globally and they are central to the provision of palliative care. Over 28 million nurses [1] provide care in extremely varied settings, cultures, and under wide-ranging nursing practice models, yet they are united by shared values and a commitment to improved care for the seriously ill and dying [2, 3]. While there is diversity in the scope of practice and education across countries, there are many common areas of palliative nursing care. Nurses are involved in the assessment and management of symptoms, providing bereavement support to patients, caregivers, and communities, offering spiritual support, and managing transitions across settings of care [4]. Nurses are also the clinicians most frequently at the bedside at the time of death, offering critical support when it is most needed to ensure a peaceful death and a supportive, therapeutic presence for grieving families.

Palliative nursing began as a defined nursing specialty with the beginnings of hospice care at St. Christopher's Hospice in London. Access to hospice services has grown exponentially around the world and the development of palliative care has made clear the need to institute the principles of supportive care early in the course of serious illness rather than only at the end of life. The evolution of palliative care has increasingly underscored the critical role of nursing as palliative care extends across the trajectory of illness [5].

The global recognition of universal access to palliative care as an essential element of public health and human rights is reshaping health systems and agendas [4, 6–8]. Numerous factors including an aging society in many nations, pandemics, chronic illnesses, and overburdened health economies all lead to the reality that palliative care is critical for the future and must expand. The number of people who will die from serious illnesses is projected to increase by 87% by the year 2060 [9].

This chapter reviews the development of palliative nursing internationally including major organizational efforts, health policy advances, and developments in nursing education and certification.

10.2 The Urgent Need for Universal Access to Palliative Care

Although the need for palliative care has been recognized worldwide, many countries still lack access and most countries significantly underutilize the full potential of palliative care. In fact, only 20 of the world's 234 countries have successfully incorporated palliative care into their health care systems. Low and middle-income countries (LMICs), in particular, suffer from a lack of palliative care and these are countries who often need it most [10]. Compounding this inequity, these LMICs are faced with the greatest amount of disease and have the least amount of resources to deal with health crises [10]. Nurses play critical roles in all aspects of interdisciplinary professional practice to increase access to primary and specialist

palliative care services and advocate policy changes that promote evidence-based symptom management and psychosocial support [3, 5, 11].

10.3 International Advances in Clinical Practice, Health Policy, Education, and Research

Numerous international efforts from the highest level of health care organizations have supported the need for access to palliative care. A key example has been the United Nations (UN) Sustainable Development Goals (SDGs). This 15-year agenda began in 2016 and recognized key actions needed across dimensions of health and society to strengthen nations [12]. For example, at the (UN) 2019 High-Level Meeting on Universal Health Coverage (UHC), palliative care was officially recognized as a crucial component of achieving UHC, as articulated by SDG 3.8 [6].

In addition to its recognition as an essential element of universal health care, palliative care must be accompanied by both primary and specialty training and this care must be aligned and available to the workforce in each region. There is significant diversity in the workforce across nations ranging from unlicensed nursing staff to doctorally-prepared nurses and in all countries, there is an opportunity to integrate palliative care within the workforce design of each country to reach communities at all junctures of serious illness care.

In 2011, Human Rights Watch recognized palliative care and access to pain relief as a human right [13, 14]. Similarly, WHO passed the Palliative Care Resolution in 2014 encouraging the incorporation of palliative care into national health care systems. The WHO has recognized the need for universal access to palliative care as an essential element of health care [8, 15]. WHO's vision as described in their Global Strategic Directions for Strengthening Nursing and Midwifery is "accessible, available, acceptable, quality and cost-effective nursing and midwifery care for all, based on population needs, in support of universal health coverage and the Sustainable Development Goals" [7, 8, 16].

The more recent Lancet Commission on Global Access to Palliative Care and Pain Relief sought to quantify the burden of serious health-related suffering worldwide and make explicit the role of palliative care in measurably alleviating it, particularly for the poorest and most at-risk populations [4]. The Commission's recommendations include access to an 'Essential Package' that included widespread access to essential medicines, including immediate-release oral and injectable morphine for healthcare workers in all nations to effectively treat moderate to severe pain and dyspnea at end-of-life. Furthermore, they emphasize the need to activate international collective action to address policies that prevent the full integration of palliative care into health systems as a component of comprehensive UHC.

The advancement of palliative nursing internationally has also been advanced by rapidly developing technology which has the capacity to provide networking between countries and foster sustained and mutually beneficial academic-practice

partnerships. Emerging telehealth options, while still in low resource countries, has tremendous potential to expand the reach of palliative care [10, 17]. Some examples are E-hospice (<https://ehospice.com>); Palliative Care Network (<https://www.palliativecarenetwork.com>); Palliverse (<https://palliverse.com>); and a range of international and regional palliative care organizations and the roles they play [10]. In addition, the freely available International Association for Hospice and Palliative Care advocacy training program provides pragmatic guidance to interdisciplinary professionals on how to advance palliative care advocacy at local, national, and global levels (<https://hospicecare.com/what-we-do/programs/advocacy-program/>).

In recognition of the WHO-designated 2020 Year of the Nurse and the Midwife, several initiatives were launched to honor the contributions of nursing historically, as well as to identify their roles in meeting the future demands of society. The WHO and the International Council of Nurses established the Nursing Now campaign (2017–2021) to raise the status and profile of nursing. This project and numerous others have called for greater involvement by nurses at all levels of health policy, the need for workforce development, and breaking down barriers that inhibit nurses from practicing to their full potential.

A key development in many nations has been the evolution of Advanced Practice Registered Nursing. Educational preparation, titles, and responsibilities vary by country but in most instances, the Advanced Practice Registered Nurse (APRN) role is focused on primary care delivery with expanded responsibilities in and patient assessment, prescribing of medications [18]. Palliative care APRNs provide leadership skills, advanced knowledge, expanded scopes of practice, and enhanced assessment and treatment competencies that can move palliative nursing forward in clinical practice, education, and policy settings [11].

Nurse midwives, who may be Registered Nurses (RNs) or APRNs depending on the country, have also been key providers of care, especially in countries with high infant morbidity and mortality. The COVID-19 pandemic has served as an example in which APRNs assumed major responsibilities for care across all settings of care from emergency departments, nursing homes, acute care settings, ICUs, and community-based care as the physician workforce was completely incapable of meeting the escalating needs, often in areas that were already vastly overburdened. The APRN role generally includes knowledge and clinical skills in areas such as clinical decision making, communication, ethical conflict resolution, and aggressive symptom management which are vital in a time of pandemic [18].

10.4 Educational Initiatives

Implementation of palliative care on a global scale has been hindered by a shortage of health care professionals trained to deliver it [4]. A phrase often used in describing the need for palliative care education is that nurses can't practice what they do not know [19]. Expecting nurses to provide palliative care requires education and clinical experience that has unfortunately often been absent in many nursing education programs. Preparing nurses to be leading professionals in the

delivery of palliative care demands education in the key domains of palliative care practice including pain and symptom management, communication skills, grief and bereavement of patients, families and staff, psychosocial and spiritual support, and ethical issues associated with serious illness and end of life.

Several global efforts were developed in response to COVID-19 to provide rapid training and resources to support professionals [13, 20, 21]. One example, the Global Palliative Education in the Time of COVID project [22], involves several US institutions, Uganda, and India. One notable aspect of this project is the “Resilience Inspiration Storytelling Empathy Project” which involves online sessions to share experiences of healthcare workers. The program’s objectives include countering isolation, providing connection and community, promoting empathy and understanding, using listening as a form of healing, and increasing resilience and meaning making.

In current times, global issues are local issues as witnessed recently by the rapid transmission of COVID-19 and the resulting universal suffering in every corner of the globe [23–25]. Similarly, palliative nursing which addresses pain and suffering is a shared endeavor of nurses worldwide, as information and communication so easily transcend national boundaries. Cultural exchange, mentorship, training, and curricula made more readily available by technology allow nurses worldwide to learn from one another and share vital information and strategies that contribute to the advancement of palliative care.

10.5 Models of Palliative Nursing Care

The values and goals of palliative nursing care are based on a shared philosophy of nursing globally. Nursing, since its inception as a profession over 200 years ago, was founded on basic ethical principles such as the relief of suffering, whole-person care, and a focus on avoiding harm while providing benefits through attention to physical, psychosocial, and spiritual well-being. These shared values transcend boundaries and cultures and have been fundamental to the growing specialty of palliative nursing (Tables 10.1 and 10.2).

The End-of-Life Nursing Education Consortium (ELNEC) project is a national and international education initiative to improve palliative care. ELNEC is a collaboration between City of Hope, Duarte, CA, USA, and the American Association of Colleges of Nursing (AACN), Washington, DC. Since the year 2000, the project, administered by City of Hope, has provided undergraduate and graduate nursing faculty, CE providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in palliative care so they can teach this essential information to nursing students, practicing nurses and other healthcare professionals.

While the initial ELNEC efforts, launched in 2000, were focused in the United States, many ELNEC trainers have had opportunities to travel internationally and provide this education to nurses and other healthcare providers throughout the world [26]. Currently, ELNEC trainers and faculty have traveled to six of the

Table 10.1 Nurses should work to increase accessibility to palliative care locally and throughout the world

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- By working to train nurses and other healthcare professionals in palliative care
 - By disseminating research and information on palliative care's ability to improve quality of life
 - By adapting models of care that can meet the needs of underserved local communities as well as low-income countries throughout the world
 - By forming global partnerships to exchange knowledge, skills, and models of care
 - By rendering culturally sensitive, respectful, and inclusive care to all patients of all backgrounds
 - By advocating for the palliative care nurse's importance to the interdisciplinary care team
 - By advocating for palliative care's vital role in health organizations and systems throughout the country and around the globe
 - By integrating palliative care education into nursing school curricula
-

seven continents, representing 101 countries. Many trainers have provided ELNEC educational courses, while others have gone as consultants to work with educators, health administrators, and community leaders to improve care of the seriously ill in their countries. Some are working on translating ELNEC into other languages and adapting it to increase the relevance to other cultures. As of 2020, ELNEC has been translated into 12 additional languages: Albanian, Armenian, Chinese, Czech, German, Hindi, Hungarian, Japanese, Korean, Romanian, Russian, and Spanish. Some examples of the international ELNEC efforts follow [27, 28].

10.5.1 Japan

The country of Japan was one of the earliest ELNEC collaborations and efforts here have developed into a strong network of ELNEC Trainers providing palliative care education throughout the country [29]. ELNEC JAPAN (https://www.jspm.ne.jp/jspm_eng/el nec.html) celebrated its 10th anniversary in 2019 with now over 3800 trainers who have taught over 44,400 others throughout Japan using the curriculum. Japan's success has been related to full translation of the curriculum, use of each of the specialty curriculum (Core, Pediatrics, Geriatrics, Critical Care) to have broad impact and their organizational structure as a part of the Japan Palliative Medicine Organization [29, 30].

10.5.2 Africa

ELNEC has collaborated with many countries in Africa and with leading organizations such as the African Palliative Care Association (APCA). Africa serves as an example of distinct needs, for example, a much higher level of childhood mortality necessity pediatric-specific content. Roles of nurses and education preparation have been areas of expansion to meet the needs in palliative care and African

Table 10.2 Resources to Support Palliative Nurses' Education, Practice, and Well-Being

Organization	Description	Website
<ul style="list-style-type: none"> African Palliative Care Association 	<ul style="list-style-type: none"> Resources to guide palliative care practice in Africa and resource-constrained settings 	<ul style="list-style-type: none"> https://www.africanpalliativecare.org/articles/covid-19-resources/
<ul style="list-style-type: none"> American Academy of Hospice and Palliative Medicine 	<ul style="list-style-type: none"> Tools, networks, and resources to guide self-care and patient education 	<ul style="list-style-type: none"> https://aahpm.org/education/covid-19-resources
<ul style="list-style-type: none"> American Academy of Nursing 	<ul style="list-style-type: none"> Detailed timeline of policy advocacy to protect the public and nurses; links to multiple resources 	<ul style="list-style-type: none"> https://www.aannet.org/news/coronavirus
<ul style="list-style-type: none"> American Association of Critical-Care Nurses 	<ul style="list-style-type: none"> Updates and resources for those in the critical care field, including technical information and content on moral distress in times of crisis 	<ul style="list-style-type: none"> https://www.aacn.org/clinical-resources/covid-19
<ul style="list-style-type: none"> American Association of Nurse Practitioners 	<ul style="list-style-type: none"> Policy and practice updates for nurse practitioners working across settings 	<ul style="list-style-type: none"> https://www.aanp.org/advocacy/advocacy-resource/coronavirus-disease-2019-covid-19-policy-updates
<ul style="list-style-type: none"> American Holistic Nurses Association 	<ul style="list-style-type: none"> Holistic self-care strategies including meditation, movement, nutrition, and other modalities 	<ul style="list-style-type: none"> https://www.ahna.org/Home/Resources/Coronavirus-COVID-19
<ul style="list-style-type: none"> American Nurses Association 	<ul style="list-style-type: none"> Crisis standards of care; nurse preparedness for advocacy, policy, safety, and self, patient, family, and community education 	<ul style="list-style-type: none"> https://www.nursingworld.org/practice-policy/work-environment/health-safety/disaster-preparedness/coronavirus/
<ul style="list-style-type: none"> American Organization for Nursing Leadership 	<ul style="list-style-type: none"> Resources to provide health system and hospital resources, webinars, and education 	<ul style="list-style-type: none"> https://www.aonl.org/updates-and-resources-novel-coronavirus-covid-19
<ul style="list-style-type: none"> American Psychiatric Nurses Association 	<ul style="list-style-type: none"> Tips and resources to support all impacted by COVID-19 and strategies for self-coping 	<ul style="list-style-type: none"> https://www.apna.org/i4a/pages/index.cfm?Pageid=6686
<ul style="list-style-type: none"> Ariadne Labs 	<ul style="list-style-type: none"> Serious illness care program COVID-19 response toolkit for communication and conversation needs 	<ul style="list-style-type: none"> https://www.ariadnelabs.org/coronavirus/clinical-resources/covid-conversations/

(continued)

Table 10.2 (continued)

Organization	Description	Website
<ul style="list-style-type: none"> Center to Advance Palliative Care 	<ul style="list-style-type: none"> Response resources for symptom management, communication, telehealth, among others 	<ul style="list-style-type: none"> https://www.capc.org/toolkits/covid-19-response-resources/
<ul style="list-style-type: none"> End-of-Life Nursing Education Consortium (ELNEC) 	<ul style="list-style-type: none"> ELNEC free resources including training modules, materials to support staff, and other links 	<ul style="list-style-type: none"> https://www.aacnnursing.org/ELNEC
<ul style="list-style-type: none"> European Association for Palliative Care 	<ul style="list-style-type: none"> Updates and resources on the European palliative care response to COVID-19 management 	<ul style="list-style-type: none"> https://www.eapcnet.eu/publications/coronavirus-and-the-palliative-care-response
<ul style="list-style-type: none"> Coalition to Transform Advanced Care 	<ul style="list-style-type: none"> Resources for providers, patients, family caregivers, policy-makers, faith leaders, and foundations 	<ul style="list-style-type: none"> https://www.thectac.org/coronavirus/
<ul style="list-style-type: none"> Hospice and Palliative Nurses Association 	<ul style="list-style-type: none"> Compilation of helpful resources to support both nurse and patient safety and well-being 	<ul style="list-style-type: none"> https://advancingexpertcare.org
<ul style="list-style-type: none"> International Association for Hospice & Palliative Care 	<ul style="list-style-type: none"> Resources relevant for global palliative care in the context of COVID-19 	<ul style="list-style-type: none"> https://globalpalliativecare.org/covid-19/
<ul style="list-style-type: none"> International Council of Nurses 	<ul style="list-style-type: none"> Global platform to share nurses' experiences, learnings, and advice from the frontlines 	<ul style="list-style-type: none"> https://www.2020yearofthenurse.org
<ul style="list-style-type: none"> National Academy of Medicine 	<ul style="list-style-type: none"> Strategies to support the health and well-being of clinicians during COVID-19 	<ul style="list-style-type: none"> https://nam.edu/initiatives/clinician-resilience-and-well-being/clinician-well-being-strategies-during-covid-19/
<ul style="list-style-type: none"> National Hospice and Palliative Care Organization 	<ul style="list-style-type: none"> Shared decision-making tool while considering likelihood of survival, preexisting conditions, and symptoms 	<ul style="list-style-type: none"> https://www.nhpco.org/wp-content/uploads/COVID-19-Shared-Decision-Making-Tool.pdf
<ul style="list-style-type: none"> Robert Wood Johnson Foundation 	<ul style="list-style-type: none"> Updates, guidance, and information on ensuring health equity and supporting a culture of health throughout COVID-19 	<ul style="list-style-type: none"> https://www.rwjf.org

(continued)

Table 10.2 (continued)

Organization	Description	Website
<ul style="list-style-type: none"> • Sigma Theta Tau International Honor Society of Nursing 	<ul style="list-style-type: none"> • Relevant free continuing education and series of free expert webinars 	<ul style="list-style-type: none"> • https://www.sigmanursing.org/sigma-is-here-for-you
<ul style="list-style-type: none"> • VitalTalk 	<ul style="list-style-type: none"> • Communication guide and playbook for difficult conversations during COVID-19 	<ul style="list-style-type: none"> • https://www.vitaltalk.org/guides/covid-19-communication-skills/
<ul style="list-style-type: none"> • Worldwide Hospice Palliative Care Alliance 	<ul style="list-style-type: none"> • Internationally based resources for the public, health care professionals, and those working in resource-constrained settings 	<ul style="list-style-type: none"> • https://www.thewhpca.org/covid-19

countries are expanding the basic preparation of nurses in palliative care. Some African countries have expanded to scope of nursing to support nurses prescribing of morphine and several model hospice programs exist [19, 26, 31, 32], (www.africanpalliativecare.org).

10.5.3 Philippines

The Philippines has also served as a model for the development and wide dissemination of efforts throughout the country. As with many nations, initial attention began to the problem of untreated pain but early pain efforts were then extended to a much broader effort to all aspects of palliative care. This is also a country challenged by natural disasters such as tsunamis that have resulted in death in addition to the needs of the chronically ill [33].

10.5.4 Eastern Europe

Eastern Europe has served as a model of regional efforts with collaboration by several countries to make a major impact on nursing and palliative care in a region of the world. Lead by Romania, this has included widespread education throughout the region of nurses, physicians and other clinicians as well as national health policy changes and integration of palliative care in training programs [34, 35]. Several Eastern European countries have also emerged as leaders through the efforts lead by Romania including Albania, Hungary, and Armenia [34, 35].

10.5.5 India

ELNEC India has become a partner over the past 10 years with very important progress in extending palliative care education throughout the country (elnecindia.com). ELNEC INDIA has also used the model of preparing nurses to be ELNEC trainers who can then extend educational efforts. They have also impacted national policy to begin requiring palliative care as a component of basic nursing education. ELNEC India trainers have used technology to create videos for nurses on basic skills such as appropriate use of morphine [36].

Numerous other examples exist around the world depicting outstanding work by nurses to advance palliative care. Uganda has developed training to prepare nurses to prescribe morphine for the relief of suffering in a country with enormous needs [37]. Vietnam has made advances in incorporating training for nurses in palliative care as a component of basic education [5, 37]

10.6 Summary

These many efforts by international health organizations, nursing organizations, and individual countries have contributed substantial progress in palliative care over the past 40 years. The demand for palliative care has however far exceeded the progress in delivering the needed care to reduce human suffering throughout the world.

During this time there has also been rapid advancement as technology has supported research which has created an evidence base of knowledge regarding pain and symptom management as well as psychosocial and spiritual support of seriously ill patients and families. Much of the evidence base for the current field of palliative care has come from the contributions of nurses, working with their interdisciplinary colleagues [11, 38]. Expansion of nursing research will expand the knowledge base of practice yet there are many challenges including limited education or resources for nurse scientists in most countries. There is much that we share as nurses worldwide, but real progress must respect the vast differences across nations and the importance of defining goals for each unique country or region.

Palliative care for older adults, and the oldest old, is a key priority for many developed countries with large populations over the age of 80 and yet is low priority in nations whose mean age of survival remains in the 50s and who still experience very high childhood mortality. Some nations have focused on palliative care in the intensive care unit and protocols for withdrawal of ventilator support while other countries have none of these technologies or systems of care available. Many nations face the reality of war as a key cause of death and many nations continue to experience death from preventable causes and basic needs such as food and clean water. Other nations are challenged now with integrating palliative care into major advances in care which have made diseases such as cancer and heart disease chronic conditions in need of supportive care.

What divides us as nurses across wide geographic, cultural and language divides is so much less than what unites us. Palliative nursing care across all nations is based on fundamental ethical and moral codes of nursing and a commitment to serve people across ages, disease, and settings to relieve suffering.

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