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Global Integration of Palliative Nursing Education to Improve Health Crisis Preparedness

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Abstract

Background: COVID-19 has highlighted the need for universal palliative care access. Nurses require palliative care education throughout the trajectory of professional training to effectively achieve this vision.

Method: Review of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care and use of educational exemplars highlight opportunities for improving palliative nursing education in academic and clinical settings.

Results: Consistently applying palliative care principles affects nursing outcomes across myriad domains of person-centered services. All nurses are responsible for delivering primary palliative care, but they cannot practice what they do not know. The End-of-Life Nursing Education Consortium Project offers evidence-based education for nursing students and practicing nurses nationally and globally.

Conclusion: Equipping both nurses and nursing students with palliative care education is critical to improve the overall quality of health care throughout the continuum during COVID-19 and in the face of future health crises.

The 2019 coronavirus disease (COVID-19) pandemic has wreaked havoc on public health systems and placed unprecedented strain on the nursing workforce worldwide. Alongside highly complex ethical dilemmas, a culture of widespread social panic, and severe resource constraints, the suffering of patients and their families has drastically increased (Radbruch, Knaul, et al., 2020). Unequal access to care and COVID-19 interventions have highlighted global health inequities, disproportionately affecting the poor, marginalized, and underserved (Wang & Tang, 2020).

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COVID-19 has required nurses in all specialties to become proficient at many of the skills typically reserved for palliative care clinicians (Rosa & Davidson, 2020). These include symptom management, health care decision making and communication urgent clinical scenarios, and providing care at the time of death. During this public health emergency, global health care systems have seen the demand for palliative care increase exponentially, with the pressing need for palliative care nurses (Etkind et al., 2020; Radbruch, Knaul, et al., 2020). The palliative care nursing role is being redefined to ensure the integration of high-quality, relationship-based, and value-based care for COVID-19 positive patients and their families (Rosa, Gray, et al., 2020).

When considering the likelihood of additional COVID-19 surges and future public health emergencies, it is vital that nurses at all levels of training receive palliative care education. The purpose of this article is to first provide an overview of palliative care and its importance in serious illness care. Second, the authors describe how the consequences of COVID-19 require a palliative care perspective using the U.S.-based National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care (National Coalition for Hospice and Palliative Care [NCHPC], 2018), readily applicable to the global arena. Finally, the article calls for global palliative care education to support nurses, patients, and their families throughout the COVID-19 pandemic and beyond. The End-of-Life Nursing Education Consortium (ELNEC) project offers evidence-based, culturally appropriate curricula as a strategy for international palliative nursing education for both student and practicing nurses. The article recommends a broad approach to academic and clinical education that reframes professional training through a person-centered, palliative care perspective on a global scale while considering the multidimensional effects of COVID-19.

PALLIATIVE CARE: THE BASICS

A new global consensus-based definition of palliative care states it "is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers" (Radbruch, De Lima, et al., 2020, p. 761). Palliative care is appropriate throughout the disease stage alone or in conjunction with disease-modifying treatment; is provided over time based on patients' needs; is offered across all settings and levels of care; is focused on patient, family, and community values and preferences; and is interdisciplinary to ensure the delivery of holistic and individualized services (NCHPC, 2018).

Primary or generalist palliative care should be delivered by all clinicians who care for patients and requires a person-centered approach to improving quality of life through symptom management and tending to psychosocial, mental, emotional, and spiritual needs (NCHPC, 2018). Generalists are also pivotal in identifying the need for specialist input. Specialist palliative care is required for patients with more complex symptoms, to assist in clarifying goals of care for patients and families, to alleviate distress of all types, or to help guide ethical decision making for all involved (NCHPC, 2018). Unfortunately, specialty palliative care resources are limited, especially in countries with few health care resources. Primary palliative care expertise can fill the gaps in quality serious illness care.

CLINICAL PRACTICE GUIDELINES FOR QUALITY PALLIATIVE CARE

The NCP guidelines are intended to guarantee that all patients with any serious illness can access high-quality palliative care in a timely manner (NCHPC, 2018). COVID-19 has underscored the dire gap in primary palliative care skills globally. The NCP guidelines contain eight domains, applicable to palliative care needs in any nation, culture, or context, and they emphasize that all health care professionals must be prepared to provide primary palliative care in all clinical settings, including the community and underserved areas.

A description of how COVID-19 and future public health emergencies relate to each of these eight palliative care domains and the importance of mandatory palliative nursing education is provided below. When considering these domains, it becomes clear that quality nursing care relies heavily on the assurance of quality palliative care. At first glance, many of these domains may appear fundamental to general nursing care. However, evidence exists to support a gap in nursing knowledge related to primary palliative care nursing skills that must be addressed by education (Ferrell et al., 2016; Ferrell et al., 2018).

Domain 1: Structure and Processes of Care

Palliative care is inherently interdisciplinary and rooted in a comprehensive assessment, spirit of family engagement, effective communication, and continuity of care (NCHPC, 2018). Nurses must be prepared with knowledge of palliative care policies and practices within local and national health systems. Requisite palliative nursing education can equip nurses with the skills to understand palliative care resources and introduce palliative services where there are none. Future health crises will require fluency in the structures and processes that affect access to quality palliative care.

Domain 2: Physical Aspects of Care

Palliative care is primarily focused on optimizing quality of life through mitigating troublesome symptoms and improving functionality using a broad range of pharmacological and nonpharmacological interventions (NCHPC, 2018). Nurses should be prepared to attend to physical aspects of care through a palliative perspective: focusing on optimizing comfort, minimizing distress, and promoting quality of life as defined by the patient. In the age of COVID-19, it is critical that nurses be trained to manage common physical symptoms, associated with serious illness, to achieve patient-identified goals; advocate for treatment plans aligned with patient preferences; consult with a broad range of specialties if available; manage chronic pain and other symptom exacerbations while caring for acute needs; and anticipate physical decompensation.

Domain 3: Psychological and Psychiatric Aspects of Care

Palliative care calls for assistance with initial and ongoing psychological and psychiatric assessments, supporting patients and families in developing commensurate plans of care, and providing additional support as needed (NCHPC, 2018). The psychological impacts of COVID-19 will continue to be immeasurable long after the surge has ended. For example, seriously ill individuals, older adults, and individuals with physical limitations or mental health challenges may find psychological symptoms worsening in the context of social

isolation. Palliative care education prepares nurses to confidently screen, intervene, consult specialists, and support patients accordingly in both acute and community-based settings.

Domain 4: Social Aspects of Care

Every aspect of society has been affected by COVID-19 and the breakdown of interpersonal dynamics. Health care visitor restrictions are preventing patients and families from being together in moments of critical need, fear, and worry. Support systems are breaking down. Attending to the family is a palliative care skill required to achieve quality and humanistic care while not losing sight of the individual's goals. Patient-centered, family-focused care is the essence of nursing. In addition, addressing social aspects of care is imperative to removing the structural barriers that perpetuate systemic discrimination against and marginalization of underrepresented populations.

Domain 5: Spiritual, Religious, and Existential Aspects of Care

It is essential to understand the role of spiritual, religious, and existential concerns for patients and families. Nurse trained in palliative care can help to ensure that spiritual and religious needs are identified and that existential anxiety is acknowledged and supported. Understanding these aspects can provide comfort to patients who may be confronting countless changes to their life as they know it.

Domain 6: Cultural Aspects of Care

Palliative care training ensures care is rooted in cultural respect and sensitivity. Nurses must be educated to meet patient needs regarding culture, including rituals, beliefs, and preferences, among other factors. Understanding cultural perspectives may be a key part of assisting patients and families to make meaning of their experience, alleviate unexpressed suffering, and find validation through their own cultural lens.

Domain 7: Care of the Patient Nearing the End of Life

COVID-19 has heightened global transparency about death and dying. Nurses in nearly all specialties and in all care settings are now caring for dying patients with increased frequency. Palliative care education prepares nurses to meet the wide-ranging needs of the dying patient and the grief and bereavement of family members. Nurses trained in palliative care are equipped to guide difficult conversations and to ensure patients and families are emotionally supported and encouraged to care for themselves during the dying process and bereavement.

Domain 8: Ethical and Legal Aspects of Care

Sparse resources, limited workforce capacity, increased work responsibilities, and redeployment to various clinical roles are some of the events reshaping health care during COVID-19. Palliative care education equips nurses to think critically about the ethical and legal aspects of care at all stages of illness; to assist with communication techniques to guide care teams and patients/families toward ethically acceptable resolutions during times of difficult decision making; and to help to identify and manage their own moral suffering related to the ethical consequences of caring for patients during a pandemic.

THE COVID-19 PANDEMIC DEMANDS PALLIATIVE CARE EXPERTISE

Principles of palliative care as defined in the NCP guidelines are essential for managing the COVID-19 pandemic. Unfortunately, due to the spread of the virus, the restrictions have limited patient involvement with interdisciplinary team members. Nurses, who spend the most time at the bedside of patients with COVID-19, must be prepared to provide the essential components of interdisciplinary palliative care. This includes assessing and managing rapidly changing physical symptoms, providing psychological support to patients in isolation, integrating social support to families suffering the distress of not being able to be with their loved ones during hospitalization and at end of life, and providing spiritual support to patients and families navigating this serious illness.

Communication skills are an essential component of palliative care education. Nurses must be able to have conversations about patient treatment preferences with patients who have COVID-19 and their family members upon entry into to an acute care setting. Patients' status can change quickly, and if treatment options such as mechanical ventilation are available, patient preferences must be known so that their wishes can be honored and respected.

Families are relying on the nurse to communicate with them regarding their family members' condition and to facilitate communication between the patient and family. The pandemic has brought to light the importance of nurses knowing how to help family say goodbye to loved ones, even when they cannot be physically present at time of death. Nurses who have had palliative care education have reported being much more comfortable having difficult conversations (Mazanec et al., 2020).

In addition to learning how to care for patients with serious illness and their families, palliative care prepares nurses for the loss, grief, and bereavement issues associated with end of life. One of the major challenges of this pandemic has been that loss and grief have become much more complex. Sudden, unexpected deaths are overwhelming families. The inability to be with loved ones at this most important time of life is devastating and puts family members at high risk for complicated grief. Nurses are being asked to help family members locate a funeral home for mortuary care, and in most situations, memorial ceremonies are not able to be held due to public health restrictions on large gatherings. The dynamics informing bereavement have changed dramatically, leading to alterations in the grieving process. For instance, families are not able to hold the culturally significant death and dying rituals and practices that help them cope with loss.

Nurses are witnessing difficult death experiences, family grief, and cumulative loss and experiencing their own moral distress and compassion fatigue. During the pandemic surges, there is little time for debriefing and supporting each other through these challenges. Without a plan in place for self-care, nurses are at high risk for compassion fatigue and burnout (Kravits, 2019). Nurses need to know that they must take time for self-care, or they will not be able to continue to care for others through the pandemic.

ELNEC: AN EXEMPLAR OF PALLIATIVE NURSING EDUCATION

Created as a partnership between the American Association of Colleges of Nursing (AACN) in Washington, D.C., and the City of Hope in Duarte, California, ELNEC was launched in 2000 to provide palliative care education (http://www.aacnnursing.org/ELNEC). In the 20 years since then, ELNEC has provided palliative care training to undergraduate and graduate nursing faculty; continuing education providers; staff development educators; specialty nurses in pediatrics, oncology, critical care, and geriatrics; and other nurses so they can teach this essential information to nursing students, practicing nurses, and other health care professionals.

Used first as a palliative care education course in the United States, in the years following, ELNEC expanded its focus to train nurses internationally. Currently, ELNEC trainers and faculty have traveled to 100 countries on six of the seven continents to train nurses and other health care providers throughout the world. In answer to the global call for palliative care education, nurses who have attended ELNEC training in the United States returned to their own countries and have taken the lead on translating ELNEC into other languages and adapting it to increase the relevance to their own cultural needs. In addition, ELNEC trainers have worked as international consultants with educators, health administrators, community leaders, and government health ministries to improve care of the seriously ill in other countries. It is estimated that at least 40,000 ELNEC trainers have taught more than 1.2 million nurses and other professionals. ELNEC training is provided not only in courses taught in the United States and internationally but also in an online module format hosted by Relias, a large learning management company.

USING ELNEC IN ACADEMIA

The ELNEC team, in collaboration with the AACN and palliative nursing experts, created the 17 primary palliative care competencies that all undergraduate, prelicensure nursing students should achieve by graduation. The AACN Competencies and Recommendations for Educating nursing Students (CARES) document (2016) was the foundation for the development of an online ELNEC curriculum, ELNEC Undergraduate/New Graduate (available at http://elnec.academy.reliaslearning.com). This curriculum, which is composed of six 1-hour modules, contains video demonstrations of primary palliative care skills, case studies, and text that meets the CARES competencies. Although currently used primarily in the United States, faculty in other countries, such as India, Africa, Eastern Europe, and the Caribbean, are integrating some of the content into their nursing programs. With appropriate cultural modification, this curriculum is appropriate for all nurses learning to provide primary palliative care. As long as there is internet access, this curriculum is available globally. For those countries that have limited internet access, a hard copy of the ELNEC Core curriculum is available to meet the needs of international nursing students and is available in English and 12 other languages (Table 1).

Faculty across the United States requested competencies and a corresponding online curriculum for graduate nursing students attending master's and Doctor of Nursing Practice programs. The ELNEC team created the AACN Graduate Competencies and

Recommendations for Educating nursing Students (G-CARES) document, 13 graduate-level primary palliative care competencies for advanced practice nurses who will fill direct and indirect patient care roles upon graduation (AACN, 2019). This document is the foundation for the online ELNEC Graduate curriculum, which was modeled after ELNEC Undergraduate/New Graduate. The curriculum prepares future advanced practice nurses to provide primary palliative care to all with serious illness. Although it has not been used globally, it is intended to help fill the specialty palliative care gap in the United States and could be used in countries educating nurses at the graduate level.

USING ELNEC FOR CONTINUING EDUCATION OF PRACTICING NURSES

ELNEC train-the-trainer courses prepare nurses to teach palliative care to colleagues and other health care professionals with up-to-date, evidence-based ELNEC materials. Over the past 20 years, many institutions have sent nurses to become trainers so that others in their clinical settings can be trained. All ELNEC curricula are composed of modules addressing the following: Introduction to Palliative Care; Pain Management; Symptom Management; Communication; Loss, Grief, and Bereavement; and Care During Final Hours. Trainers offer this education in a format that is user friendly, during lunch-and-learn sessions where one module at a time is covered, half-day conference settings, covering three to four of the modules, or full-day programs covering all six modules in one session.

For institutions that cannot afford to send their nurses to half-day or full-day sessions, online ELNEC curricula are available. Practicing nurses can complete the modules at their own pace and at minimal cost. One large academic medical center successfully piloted a project to educate nurses in medical–surgical, oncology, and critical care settings using ELNEC online. Nurses' knowledge, confidence, and perceived competence in palliative care improved after completing the online curriculum (Bishop et al., 2019). Online curricula available through Relias are ELNEC Core, Critical Care, Geriatric, and Pediatric. ELNEC Communication will be available online by the end of 2020 for an interdisciplinary audience. Nurses are encouraged to enroll in the curriculum that best aligns with their clinical practice population. As is done with inperson training, continuing education credits are awarded, as well as a certificate of completion for the nurses' portfolios.

In the United States, the ELNEC Undergraduate/ New Graduate curriculum can be used to prepare RNs in their first year of practice to provide primary palliative care. Many institutions across all 50 states are integrating the curriculum into nurse residency programs to better prepare new-to-practice nurses to care for patients with serious illness. This education is needed now more than ever before as the 2020 new graduates are experiencing their first year of practice amidst the challenges of the COVID-19 pandemic. Continuing education and staff development educators should consider advocating for integrating this curriculum into orientation for all who are new to nursing.

COVID-SPECIFIC ELNEC EDUCATION FOR ACADEMIA AND CONTINUING EDUCATION

During COVID-19, ELNEC has spearheaded the creation and collation of the only identifiable and readily available resource for primary and specialty palliative nursing across domains of care (http://www.aacnnursing.org/ELNEC/covid-19). ELNEC faculty's combination of video, infographics, webinars, informational slides, pocket guides, and other resources provide accessible and cost-free pathways to ensure all nurses and nursing students are prepared to provide COVID-specific palliative care for patients and their family members. Powerful video demonstrations of how nurses can help families say goodbye to loved ones when they cannot be physically in the hospital with their dying family member, infographics on pain and symptom management related to COVID-19, and the unique issues associated with bereavement and compassion fatigue are examples of resources available online. These palliative care resources can help faculty prepare nursing students for the crisis we are currently experiencing and provide staff development nurses with tools to support practicing nurses.

IMPLICATIONS AND CONCLUSION

Momentum has been growing over the past decade in awareness of the need to integrate palliative care into the curriculum of all health professionals. This is especially true for nursing education, where clinicians will enter practice across all settings of care and in all patient populations that will be significantly affected by COVID-19, as well as future health crises.

Guidelines for quality palliative care are more relevant than ever before, and they demonstrate the application of each domain of quality patient care. Each of the domains of the NCP guidelines are applicable to care of patients with COVID-19, support for their families, and the needs of the clinicians who care for them. Model education programs exist to support nurse educators in ensuring that palliative care content can be well integrated in the educational preparation of the future workforce in nursing, such as ELNEC.

The provision of universal palliative care access is an ethical mandate for all health systems (Knaul et al., 2018; World Health Organization, 2014, 2018). Nurses worldwide must be equipped through education to ensure the delivery of palliative care at primary and specialty levels to ease the most pressing global health dilemmas of our time and in the event of future pandemics (Rosa, Gray, et al., 2020; Rosa, Krakauer, et al., 2020). Global curricular integration of palliative care is needed urgently to properly prepare our global nursing workforce and provide holistic, person-centered care for patients and their families throughout the care continuum.

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TABLE 1

END-OF-LIFE NURSING EDUCATION CONSORTIUM (ELNEC) CURRICULA TRANSLATIONS

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Language	Country of Origin	Type of ELNEC Curricula Available
Japanese	Japan	Core, Pediatric, Geriatric, Critical Care
Korean	South Korea	Core, Pediatric, Geriatric
Chinese	China	Core
German	Germany	Core
Spanish	Mexico, Central America, parts of South America	Core, Pediatric
Russian	Russia	Core
Romanian	Romania	Core, Pediatric, Geriatric
Czech	Czech Republic	Core
Albanian	Albania	Core
Armenian	Armenia	Core
Hindi	India	Core
Hungarian	Hungary	Core, Pediatric