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American Academy of Nursing Expert Panel consensus statement on nursing's roles in ensuring universal palliative care access

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Abstract

The purpose of this consensus paper was to convene leaders and scholars from eight Expert Panels of the American Academy of Nursing and provide recommendations to advance nursing's roles and responsibility to ensure universal access to palliative care. Part I of this consensus paper herein provides the rationale and background to support the policy, education, research, and clinical practice recommendations put forward in Part II. On behalf of the Academy, the evidence-based recommendations will guide nurses, policy makers, government representatives, professional associations, and interdisciplinary and community partners to integrate palliative nursing services across health and social care settings. The consensus paper's 43 authors represent eight countries (Australia, Canada, England, Kenya, Lebanon, Liberia, South Africa, United States of America) and extensive international health experience, thus providing a global context for the subject matter. The authors recommend greater investments in palliative nursing education and nurse-led research, nurse engagement in policy making, enhanced intersectoral partnerships with nursing, and an increased profile and visibility of palliative nurses worldwide. By enacting these recommendations, nurses working in all settings can assume leading roles in delivering high-quality palliative care globally, particularly for minoritized, marginalized, and other at-risk populations.

Keywords

Palliative care; Palliative nursing; Hospice care; Hospice nursing; Health disparities; Health inequity; Universal health coverage; Universal palliative care access

Introduction

> *People in all parts of the world live and die with little or no palliative care or pain relief. Staring into this access abyss, one sees the depth of extreme suffering in the cruel face of poverty and inequity. . . The global health community has the responsibility and the opportunity to close the access abyss in the relief of. . . suffering at end-of-life and throughout the life course, caused by life-limiting and life-threatening health conditions. . . palliative care and pain relief are essential elements of universal health coverage. . . [and]*

> *are highly intersectoral. . . We call on academia to promote and incorporate this agenda [for universal palliative care access] across all disciplines including medicine, nursing, and the social sciences.* -The Lancet Commission on Global Access to Palliative Care and Pain Relief (Knaul et al., 2018, pp. 1391, 1444)

Background

Globally, more than 61 million people across the lifespan experience roughly 6 billion days of serious health-related suffering (SHS) every year, and yet palliative care and pain relief services are either significantly lacking or nonexistent in much of the world (Knaul et al., 2018). Based on World Health Organization (WHO). 2020b mortality projections (2016–2060) and estimates of symptom prevalence in twenty medical conditions, the global burden of those who will die with SHS is projected to increase by approximately 87% by 2060. This SHS burden will disproportionately affect those living in the poorest countries, people aged 70 and older, and persons with dementia (Sleeman et al., 2019). Of those individuals experiencing SHS, over 21 million are neonates, infants, children, and adolescents who would benefit from pediatric palliative care, with more than 8 million requiring specialized palliative care services (Connor et al., 2017). The vast majority of children in need live in low- and middle-income countries (LMICs; Knaul et al., 2018), further underscoring global palliative care and health inequities. Palliative care is also required to address the significant needs of families and social support systems related to caregiver strain, bereavement, and complicated grief (Knaul et al., 2018).

Heightened visibility of both SHS and mortality during the coronavirus disease 2019 (COVID-19) pandemic has drawn worldwide attention to the urgent need for universal palliative care access for all people and populations (Radbruch, Knaul et al., 2020). There are critical aspects of palliative care development that require significant policy and practice investments now and in the future (Table 1). There are an estimated 28 million nurses worldwide, accounting for about 59% of the global health and social care workforce (WHO, 2020a). The nursing profession is rooted in an ethical commitment to alleviate SHS and optimize quality of life in philosophical alignment with palliative care (International Council of Nurses [ICN], 2011, 2012a, 2012b). Thus, nurses are key stakeholders to ensure widely available, accessible, and adept palliative care. However, nurses must be equipped to achieve measurable progress toward universal access to palliative care. Access to high-quality palliative nursing care for all individuals, families, and communities is a human right, regardless of age, race, ethnicity, socioeconomic, or other differences. Universal palliative care access can be strategically achieved through increased nurse leadership in intersectoral advocacy and interdisciplinary partnerships at local, national, and international levels.

Palliative care is a holistic and person-centered approach to alleviating SHS across the care continuum, at the end-of-life, and into bereavement (Radbruch, De Lima et al., 2020). Palliative care clinicians support individuals, families and caregivers, and communities when confronting life-limiting illness. Palliative care philosophy emphasizes optimal quality of life and function, mitigation of distressing symptoms, and promotes value concordant care that is either given in conjunction with disease-modifying treatments or comfort-focused (WHO, 2020b). In addition, palliative care involves identifying and addressing myriad ethical questions involving respect for and response to diverse needs and preferences. It balances the benefits and burdens of treatments and services with quality of life within the context of equitable access and distribution of resources (WHO, 2014). The International Association for Hospice & *Palliative Care* (IAHPC) has provided a global three-phase consensus-based definition of palliative care focused on the relief of SHS and relevant to all individuals and communities worldwide, regardless of diagnosis, prognosis, location, point of care, or socioeconomic status (Table 2; IAHPC, 2018; Radbruch, De Lima et al., 2020).

Palliative Care in the Global Sphere

The WHO (2014, 2018a, 2018b) acknowledges that palliative care should be integrated into all systems across the care continuum as a vital component of universal health coverage (UHC). All United Nations (UN) member states recognized palliative care as fundamental to achieving UHC at the UN Political Declaration of the High-Level Meeting on UHC (UN, 2019) and as essential to Target 3.8 of the Sustainable Development Goals (UN, 2015), which aims to: “Achieve [UHC], including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all”. Inclusive, high-quality, and accessible palliative care for all persons across social, economic, and cultural status or affiliation - without discrimination and with universal respect - is fundamental to protecting the “inherent human dignity of the human person” (UN Office of the High Commissioner for Human Rights, 1966, p. 1).

The state of palliative care is in different stages of development around the globe (Connor, 2020; Knaul et al., 2018). Access to palliative care depends partly on the availability, types, and reimbursement models of palliative care within and across countries. Other considerations include social, environmental, economic, and political health determinants, as well as geographic proximity to health and social care services. Although there is heterogenous access to palliative care, low-income people worldwide consistently have little or no palliative care access (Knaul et al., 2018). From a nursing perspective, palliative care access is largely contingent on palliative care education in nursing school and through continuing education programs in practice settings (Downing, Ben Gal, et al., 2020; Rosa, Gray et al., 2020; Malloy & Davis, 2019).

Of the documented 25.5 million people who died in 2015, about 45% experienced SHS prior to their death (Knaul et al., 2018). International disparities show that over 80% of the global burden of SHS occurs among individuals living in LMICs. Mapping analytics have shown that palliative care provision is available for only 14% of the global population, although there were measurable advancements in palliative care development in 65 countries as of 2017 (Clark et al., 2020). Rurality can lead to palliative care ‘deserts’ and has been shown to predict poor end-of-life outcomes, increased palliative care disparities when compared to urban settings, and the need for palliative care service design that meets the unique needs and resource constraints of rural communities (Cerni et al., 2020; Hawkins-Taylor et al., 2020; Knaul et al., 2018).

In children aged 0 to 14 years, 98% of the 2.5 million who die every year live in LMICs (Knaul et al., 2018). In fact, children account for more than 30% of deaths associated with SHS in LMICs as opposed to less than 1% in high-income countries. At the other end of the age spectrum, older adults age 70 and older are the largest growing segment of the population in need of palliative care. Specifically, older persons diagnosed with cancer and dementia account for the majority of SHS in this age group globally (Sleeman et al., 2019; Sleeman et al., 2020). Nurses have a moral obligation to protect human rights, such as the right to die with dignity and free from pain, through vigilance, advocacy, and exemplary practice (ICN, 2011). Realizing this obligation requires a health equity and social justice model for palliative care delivery.

Palliative Nursing

The philosophical premise of palliative care fundamentally aligns with the holistic, compassionate, and person-centered ideals of the nursing profession (Dahlin et al., 2016; Ferrell & Coyle, 2008; Ferrell & Paice, 2019; ICN, 2012a, 2012b, 2020a). All nurses can and should be educated to deliver *primary* or *generalist palliative care* to decrease symptom burden, improve quality of life, and minimize SHS. *Generalist palliative nursing* includes an understanding of illness trajectories, management of common pain and symptom syndromes, advance care planning, a working knowledge of community resources, and when to bring in a specialist (where available). *Specialist palliative nursing* includes knowledge about specific diseases and their trajectories, complex pain and symptom management, and difficult communications and conversations required in the context of complex legal and ethical, interpersonal and social, psychological/psychiatric, cultural, and/or spiritual/existential/religious dynamics (National Coalition for Hospice & Palliative Care, 2018).

Although there has been some scholarly dialogue regarding the invaluable role of palliative nurses on a global scale to promote access to relevant services, the work and contributions of nurses and nursing has been largely absent from the international policy arena in this context (Downing, Leng, et al., 2016; Malloy et al., 2018; Rosa, Krakauer et al., 2020). A number of national and international experts have highlighted the myriad roles and responsibilities of all nurses and collaborating health and social care workers to ensure the delivery of generalist palliative care across settings (African Palliative Care Association [APCA], 2011; American Nurses Association [ANA] & Hospice & Palliative Nurses Association [HPNA], 2017; Indian Directorate General of Health Services, Ministry of Health & Family Welfare, 2012). However, efforts thus far to build palliative nursing capacity on a global scale have been insufficient.

The advancement of nurse-led policies and care delivery models to ensure universal access to palliative care services is critical. Because nurses comprise the largest human resource segment of the international health and social care workforce and are frequently identified as the most trusted health and social care workers due to their close relationships with their communities, nurses have vital roles and responsibility to ensure universal access to palliative care services (WHO, 2020a). The assurance of human dignity, the alleviation of suffering, meeting the health and social needs of the public, and just distribution of resources are key, globally relevant tenets of codes of ethics for nurses (ANA, 2015; ICN, 2012b).

Barriers to Universal Palliative Care Access

Several multi-level obstacles to universal palliative care access exist (Table 3). Many countries simply lack a national strategy for palliative care integration, meaning that despite a country's wealth there may be limited palliative care access with substantive need that consequently exacerbates SHS (Connor, 2020). A failure to strategically equip all nurses with palliative care skills, education, and supportive policies will undoubtedly lead to unmitigated SHS worldwide and an increased economic burden on health systems. The dire lack of palliative nursing knowledge and skills may also contribute to the vicarious trauma and moral distress many nurses experience from being unable to "act" to relieve suffering and also from delivering non-beneficial / potentially harmful care (e.g., futile care), something the COVID-19 pandemic has demonstrated across the globe (Horesh & Brown, 2020; Li et al., 2020; Rosa, Gray et al., 2020; Rosa, Schlak, et al., 2020; Rushton, 2018).

Conclusion

There is a clear need to mobilize nursing at local and global levels to increase access to palliative care services for all people confronting SHS and their caregivers across the lifespan. The integration of palliative care throughout the health and social care continuum is a foundational aspect of UHC and a human rights priority. Nurses serve critical roles in the delivery of generalist and specialist palliative nursing care across settings and systems. In Part II of this consensus paper, the authors provide an overview of international responses and policy options that have sought to advance universal palliative care access. Ten key recommendations requiring collective action and multidisciplinary stakeholder engagement are then put forward to address palliative nursing policy, education, research, and clinical practice domains.

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Table 1 –

Aspects of Palliative Care Development Requiring Policy and Practice Investments

- Increased availability of internationally controlled essential medicines (e.g., opioids, benzodiazepines) for distressing symptom relief (Ahmed et al., 2020; Arya et al., 2020; Pettus, Cleary et al., 2020)
- Improved grief and bereavement services (Harrop et al., 2020; Helton et al., 2020; Morris et al., 2020; Wallace et al., 2020)
- Enhanced integration of spiritual and existential care (Emanuel et al., 2020; Ferrell, Handzo, et al., 2020; Puchalski et al., 2020)
- Better ability to navigate the complex moral and ethical challenges common in palliative and end-of-life care scenarios (Ciruzzi et al., 2020)
- Increased access to quality palliative nursing education in all settings (Downing, Ben Gal, et al., 2020; Rosa, Gray et al., 2020)
- More effective palliative care communication, including attention to health literacy (Kidd et al., 2018; Noordman et al., 2019; Roodbeen et al., 2020)
- Advocacy and policy pathways to promote culturally inclusive and equitable palliative care delivery for medically underserved, minoritized, and marginalized/atrisk populations (Elbaum et al., 2020; Elk et al., 2020; Harding et al., 2020; Pettus, de Lima et al., 2020; Rosa, Hannaway et al., 2021; Rosa, Pettus et al., 2021; Skinner et al., 2020)

Table 2 –

The International Association for Hospice & Palliative Care Global Consensus Based Palliative Care Definition*

Palliative care 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.Palliative care:Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence-based.
• Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care.
• Is applicable throughout the course of an illness, according to the patient’s needs.
• Is provided in conjunction with disease modifying therapies whenever needed.
• May positively influence the course of illness.
• Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.
• Provides support to the family and the caregivers during the patient’s illness, and in their own bereavement.
• Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family.
• Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary).
• Can be provided by professionals with basic palliative care training.
• Requires specialist palliative care with a multiprofessional team for referral of complex cases.

*Reprinted with permission from the International Association of Hospice & Palliative Care (Radbruch, De Lima et al., 2020).

Table 3 –

Multi-Level Obstacles to Universal Palliative Care Access[*]

Obstacles to universal palliative care access include but are not limited to:
• Misconceptions of and miscommunications about palliative care
• Absent, underdeveloped, or sub-standard palliative care programs, including hospice services
• Opiophobia, the global opioid addiction epidemic, and restrictive policies pertaining to availability and prescribing of internationally controlled essential medicines
• Lack of specialist palliative care human resources for health
• Stigma related to death and dying
• Marginalization of poor, minoritized, and other at-risk populations
• Lack of palliative care education for all health and social care professionals, particularly models that emphasize care of the family
• Cultural and/or religious obstacles that limit palliative care involvement
• An overemphasis on the biomedical/curative model of care
• Social, economic, political, and health inequalities

[*] (Adapted from Connor, 2020; Daniels & Downing, 2018; Knaul et al., 2018).