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Optimizing the Global Nursing Workforce to Ensure Universal Palliative Care Access and Alleviate Serious Health-Related Suffering Worldwide

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Abstract

Context.—Palliative care access is fundamental to the highest attainable standard of health and a core component of universal health coverage. Forging universal palliative care access is insurmountable without strategically optimizing the nursing workforce and integrating palliative nursing into health systems at all levels. The COVID-19 pandemic has underscored both the critical need for accessible palliative care to alleviate serious health-related suffering and the key role of nurses to achieve this goal.

Objectives.—1) Summarize palliative nursing contributions to the expansion of palliative care access; 2) identify emerging nursing roles in alignment with global palliative care recommendations and policy agendas; 3) promote nursing leadership development to enhance universal access to palliative care services.

Methods.—Empirical and policy literature review; best practice models; recommendations to optimize the palliative nursing workforce.

Results.—Nurses working across settings provide a considerable untapped resource that can be leveraged to advance palliative care access and palliative care program development. Best practice models demonstrate promising approaches and outcomes related to education and training, policy and advocacy, and academic-practice partnerships.

Conclusion.—An estimated 28 million nurses account for 59% of the international healthcare workforce and deliver up to 90% of primary health services. It has been well-documented that nurses are often the first or only healthcare provider available in many parts of the world. Strategic investments in international and interdisciplinary collaboration, as well as policy changes and the safe expansion of high-quality nursing care, can optimize the efforts of the global nursing workforce to mitigate serious health-related suffering.

Keywords

Palliative care; palliative nursing; nursing; global health; global palliative care; serious health-related suffering; universal health coverage

Introduction

While universal access to palliative care has been clearly identified as a core element of the human right to the highest standard of health,¹⁻⁴ there has been minimal discussion specifically about the role of palliative nurses in alleviating the global burden of serious health-related suffering (SHS).⁵⁻⁷ The nursing workforce possesses the expertise, training, and sheer numeric influence to be full partners with interdisciplinary colleagues across medicine, economics, policy, and administration to collaboratively achieve universal access to palliative care if leveraged strategically and sustainably.⁸⁻¹⁰ Importantly, there are an estimated 28 million nurses globally, comprising roughly 59% of the healthcare workforce and account for about 90% of patient and healthcare contact across the continuum.⁴ Indeed, there is no healthcare without nurses.¹¹

Palliative care is a core component of the World Health Organization (WHO) definition of universal health coverage (UHC) and Sustainable Development Goal target 3.8.^{12,13} Thus, it is impossible to achieve UHC without universal access to palliative care. International

policy reports have explicitly noted the invaluable contributions of nurses to achieving cost-effective, high-quality UHC and advancing health equity for all populations, particularly for the poorest and most at-risk groups.^{6,7} Furthermore, the evolving consequences of the COVID-19 pandemic have led to several policy and practice discussions about rapid investment in nursing to strengthen the global COVID-19 response,¹⁴ and how to best leverage the roles of palliative nurses in various practice domains across systems.¹⁵⁻¹⁸

The nursing workforce provides a substantial untapped resource that can be mobilized to expand palliative care access and palliative care program development to address SHS in myriad global contexts and at all stages of serious illness. Although the authors acknowledge the inherent interdisciplinary nature of palliative care, nurses in many parts of the world are often prevented from engaging in leadership opportunities due to hierarchical restrictions, scope of practice limitations, or limited understanding about palliative nurse training and educational background. The purpose herein is to provide a comprehensive, evidence-based overview of how health systems and stakeholders can leverage nursing to fulfill their roles as full members of the interdisciplinary palliative care team.

More specifically, we aim to 1) summarize palliative nursing contributions to the expansion of palliative care access, 2) identify emerging nursing roles in alignment with global palliative care recommendations and policy agendas, and 3) promote nursing leadership development to enhance universal access to palliative care services. To accomplish these aims, the authors provide an empirical and policy review of available literature focused on universal palliative care access and the global nursing workforce. This review is followed by a series of best practice models describing international initiatives that are expanding palliative care service delivery through palliative nursing education and training, policy and advocacy, and academic-practice partnerships. Finally, implications are discussed and accompanied by recommendations to optimize the nursing workforce and identify pragmatic steps forward.

Universal Palliative Care Access & the Global Nursing Workforce

Nurses are trained in a holistic and person-centered model of care that naturally aligns with the integrative perspective of the palliative care field.^{6,15} Nurses are strategically positioned to address major global health agenda items, including the SDGs and UHC.^{6,7,19-23} The World Health Organization (WHO) designated 2020 as the International Year of the Nurse and the Midwife – a time to acknowledge that nurses are often the first and only point of contact with health care in their communities worldwide.²⁴ Universal access to high-quality palliative care will not be possible without strategically optimizing the nursing workforce and integrating palliative care into nursing priorities at the local, national, and international levels.

Despite much progress, 64% of countries have no or very limited provision of palliative care.¹⁸ Serious health-related suffering - suffering which limits physical, social, and/or emotional functioning, requires professional intervention, and can be substantially relieved by palliative care - afflicts more than 61 million people globally. Of the 25.5 million people who died in 2015, 45% experienced SHS in their last year of life. Additionally, more

than 80% of the SHS burden is borne by individuals in low- and middle-income countries (LMICs).¹² Among pediatric populations, these disparities are amplified. Of the 2.5 million children (0 – 14 years) who die annually, 98% reside in LMICs. Within LMICs, children account for more than 30% of all deaths associated with SHS, compared to less than 1% in high-income countries (HICs), the majority of which is avoidable.¹⁷

Gaps in palliative care access are only expected to widen and will likely lead to profound consequences for patients, families, and health systems. The SHS burden comes with high costs for vulnerable populations, including increased risk of family impoverishment due to catastrophic healthcare expenditures and increased healthcare expenditures at end of life for health systems that did not prioritize financial protection.¹⁷ In light of this demand, increased palliative care capacity - including palliative nursing - is needed globally.

As an initiative aligned with the WHO Year of the Nurse and the Midwife, the Nursing Now campaign was designed to improve health globally through raising the profile and status of nursing. The campaign was based on the Triple Impact Report published by an all-party group in the UK parliament and led by Lord Nigel Crisp, former chief executive officer of England's National Health System. During his time in office, nurse prescribing was legislated through concerted multidisciplinary advocacy efforts. This evolution in nursing practice and policy informed the Triple Impact Report, which describes how investing in and developing nurses would have the triple impact of improving health, promoting gender equity, and strengthening local economies in alignment with the SDGs.⁶

Nursing Now subsequently helped to take action on the recommendations of the Triple Impact Report and emphasized how investing in nursing and midwifery is the key to the rapid and cost-effective expansion of high-quality UHC. UHC in a subsequent report for the World Innovation Summit for Health.²⁰ This UHC report demonstrated that nurses had a role to play in all aspects of UHC and that they could play a leading role in four areas: long term conditions, primary care, specialist nursing, and public health. Palliative care was a driving factor for the Nursing Now driven report, which emphasized nursing's leadership roles in the SDGs, UHC, chronic and noncommunicable disease management, specialist care services, and policies to promote increased nurse autonomy and engagement at decision-making tables.

The publication of WHO's State of the World's Nursing (SoWN) Report in April 2020, the first ever global survey of nursing, has shown that there is a international shortfall of at least 6 million nurses. Based on survey results, there is urgent action needed to strengthen and develop the profession if UHC – and, therefore, universal palliative care access - is to be achieved by 2030.⁵ The SoWN 2020 Report⁵ emphasized considerable and feasible investments in nursing education, jobs, and leadership, which could positively impact the nursing role in contributing to universal palliative care access. Specifically, the SoWN 2020 Report articulated future directions for nursing workforce policy with a focus on six areas:

- Strengthening the evidence base for planning, monitoring and accountability
- Effective monitoring and responsible, ethical management of nurse mobility and migration

- Developing and supporting the nursing workforce with respect to education, nursing practice, regulation, decent work, and gender and women's rights
- Building institutional capacity and nursing leadership skills for effective governance
- Catalyzing investment for the creation of nursing job opportunities
- Promoting a nurse-led research and evidence agenda

Specifically, there are opportunities to leverage nursing that align with both the recommendations for system-wide palliative care integration from the Lancet Commission on Global Access to Palliative Care and Pain Relief in the domains of stewardship, financing, delivery, and resource generation, as well as advance the future directions for nursing workforce policy from the SoWN 2020 Report (Table 1). In other words, leveraging the nursing role to enhance universal palliative care access dovetails seamlessly with broader global palliative care and global nursing agenda items already underway.

Furthermore, the COVID-19 pandemic has demonstrated the vital role nurses' play in all fields of health care.^{25,26} Throughout COVID-19, palliative nurses have articulated ways to optimize their contributions to advance care planning, goals of care clarification, symptom management planning and evaluation, and ethical guidance amid complex decision-making.^{10,15,27-32} Several international palliative care experts collaborated to provide nursing recommendations to United Nations member states and civil society organizations to improve health and palliative care outcomes globally.¹⁴ Specifically, recommendations included but were not limited to: acknowledging the vital contributions of palliative nurses as critical to the COVID-19 response; integrating palliative nursing planning and treatment competencies as a component of COVID-19 management; and advancing palliative nursing knowledge by promoting supervision and mentorship by palliative nurse specialists in the clinical setting.

Nursing can be integral to address several specific challenges to achieve universal palliative care access. Broadly, obstacles to integrate palliative care include: stigma, lack of knowledge, lack of engagement of individuals and families in treatment decisions; misinterpretation of palliative care and standard medical care as mutually exclusive rather than complementary; lack of appropriate training for providers; competing demands for staff time; emphasis only on specialty care; and failure to apply effective approaches for system or culture change to improve palliative care.³³

However, many barriers exist for nurses to meet global palliative care needs. Scope of practice limitations, licensure constraints, a misunderstanding of nursing role and abilities, nurse migration leading to human resource deficits, poor investments in nurse education, lack of palliative care knowledge and training, among other issues,⁵ all intersect to stall progress toward universal palliative care access. In many countries, restrictive hierarchical healthcare structures often limit the clinical autonomy and leadership capacities of nurses, which are essential to meet the holistic needs of patients, families, and communities experiencing SHS. Ultimately, supporting the nursing profession through a multisector approach is critical to achieve universal palliative care access.

Global Palliative Nursing: Priorities and Best Practice Models

The need to advance universal access to palliative care by leveraging the nursing workforce is evident. This section provides additional background in three priority areas that are critical to achieving universal palliative care access: palliative nursing education and training, policy advancement, and global academic health partnerships. Best practice models for each area are provided and describe current initiatives that are promoting collaboration with interdisciplinary stakeholders to increase palliative care access in a multitude of settings and improve associated outcomes. The models include the End-of-Life Nursing Education Consortium (education and training); nurse prescribing in Uganda (policy); and Partners in Health, Liberia (partnerships).

Palliative Nursing Education and Training

Universities, as well as nursing and medical schools, play an important role in not just preparing future health professionals but in shaping cultural norms and driving advocacy and policy. Ensuring that all health professionals have generalist palliative care knowledge as well as ensuring robust knowledge, skills, and competencies for specialist providers can challenge traditional curricula design and the biomedical organization of curriculum content.³⁴ A systematic review of criteria determining palliative care advancement globally showed that palliative medicine specialization and the inclusion of palliative care content in undergraduate curricula was a strong indicator.³⁵⁻⁴⁰

The integration of palliative care education into the undergraduate and postgraduate nursing curricula is essential to ensure equitable access to palliative care worldwide.^{41,42} In the United States, the American Nurses Association and the Hospice and Palliative Nurses Association (2017) proposed that all professional nurses receive palliative care education to provide generalist palliative care.⁴² Educational content includes assessing and managing pain and illness symptoms, communicating with patients and families about their illness and prognosis, and supporting decision-making and goal setting. In addition, the European Association of Palliative Care (EAPC) recommends three educational levels: basic education for all nursing professionals to understand palliative care principles, intermediary education for nursing professionals who frequently care for patients (adults and children) who require palliative care, and specialized education for nursing professionals working in specialized palliative care areas (adults and children).^{43,44} Despite these guidelines, existing evidence suggests that theoretical and practical palliative care nursing education is often deficient or nonexistent in many global regions.⁴⁵⁻⁴⁷ Barriers to palliative care education include lack of qualified instructors, insufficient time to attend palliative care education activities, lack of integration into the nursing curricula, and lack of funding.⁴⁶

In LMICs, palliative care education must be further adapted to the social, religious, and cultural beliefs of the population and available resources. The meanings ascribed to death and illness may vary widely between ethnic groups as the concept of palliative care is relatively new.^{46,47} Given nurses' trusting relationship with patients, they can engage in dialogue to better understand the role of cultural beliefs in the perceptions of illness and death, as well as provide a family-centered and community-based approach to care. Nurses

need skills to initiate public health programs and raise awareness of palliative and end-of-life care.

Several models of palliative care education and training for nurses have been utilized in different countries. Examples include the work done by Hospice Casa Sperantei in Romania, where post-registration courses are available, accredited by the Order of Nurses in Romania. In the nursing technical schools in Romania, 24 theoretical hours and 96 clinical hours on palliative care are mandatory, with a unified curriculum and training materials. The training materials have also been translated into Armenian, Georgian, Kazak, Russian, Tajik, and Ukrainian.⁴⁸ Similarly, work has been undertaken in Serbia, to integrate palliative care into the undergraduate nursing curriculum, along with nationally accredited continuing education programmes.⁴⁹

Best Practice Model: The End-of-Life Nursing Education Consortium

Partnerships across clinical and academic settings are critically important and this can commonly be supported by professional organizations. The End-of-Life Nursing Education Consortium (ELNEC) project is a national and international education initiative to improve palliative care and is a partnership between the American Association of Colleges of Nursing, Washington, DC and the City of Hope, Duarte, CA.^{50,51} The project provides 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, to teach this essential information to nursing students, practicing nurses, and other healthcare professionals. The ELNEC project prepares health care professionals, administrators, and researchers to work in acute care settings (i.e., medical-surgical and oncology units), clinics, homecare, hospice, and palliative care settings and several national ELNEC- Core courses are held each year.

The ELNEC project initially focused on providing palliative care education in the United States. In the years following the project's launch, 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 healthcare providers throughout the world. Additionally, trainers have worked as international consultants with educators, health administrators, and community leaders to improve care of the seriously ill in other countries. It is estimated that over 40,000 ELNEC trainers have taught over 1.2 million other professionals. More than 40 U.S.-based and international outcomes papers have been published based on the ELNEC project.⁵²

ELNEC trainers host professional development seminars for practicing nurses, incorporating ELNEC content into nursing curriculum to expand ELNEC's reach into rural and underserved communities, presenting ELNEC at national and international conferences. In recent years, ELNEC has expanded its educational reach by providing its courses online. Over 593 Schools of Nursing have accessed the ELNEC-Undergraduate curriculum initiated in 2017, with more than 56,000 nursing students completing the online course.⁵¹

ELNEC has been translated into Albanian, Chinese, Czech, German, Japanese, Korean, Romanian, Russian. ELNEC has also been translated into Spanish (Core and Pediatric Palliative Care versions) and is being widely disseminated in Mexico, Central America, and parts of South America. ELNEC-Hindi is currently being developed to reach nurses throughout India. Building palliative care leaders has been a major emphasis of the ELNEC leadership team.^{51,52}

Nurses Advancing Palliative Care Policy

The WHO SoWN 2020 Report made several recommendations to change nursing workforce policy. As previously noted, many of the WHO recommendations can be applied to promoting palliative care to achieve UHC (Table 1). These suggestions include developing and supporting the nursing workforce, advancing nursing practice and education, and building institutional capacity and leadership. Countries are encouraged to equip nurses with the competencies to deliver high-quality, integrated person-centered services through education and training programs.⁵ As seen above, curriculums have been developed, at the university and professional level, to train nursing students and practicing nurses. Specifically, these palliative care competencies address person-centered care, communication, and serious illness management.⁵³

Concurrently, nursing practice should enable nurses to work to the full extent of their education and training.⁵ With the need for more providers to conduct goals of care discussions and manage palliative services, the utilization of Advanced Practice Nurses (APNs) or specialist palliative care nurses, has been supported by leaders in palliative care to further serve the needs of patients.⁵⁴ Although high-income countries demonstrate more established APN roles, there are well-noted needs and increased investments in APN development in many LMICs.⁵⁵ Currently, more than 70 countries have or are interested in introducing APN roles. Ensuring that APNs are practicing to the full scope of their education and licensure essential to expand palliative care coverage to a greater population. APNs also play a significant role in pain management and effective medication resource distribution.⁵⁶ Given that APNs do not exist in many parts of the world, health systems must leverage the skills and critical insight of specialist palliative nurses who serve as valuable assets forming trusting relationships with patients and families at the bedside. They can partner with physicians, APNs, palliative specialist nurses, and other healthcare providers to provide pain and symptom management, communicate advanced care planning goals, and advocate for patients and families.

Another critical domain concerns opioid access. Given the challenges discussed previously, nurses in general, and palliative nurses more specifically, should participate in policy changes in governments and regulatory agencies, as well as improving patient and clinician education in pain and analgesic management. Such policy change and role expansion would facilitate opioid access for pain relief, improve safety measures to prevent misuse and diversion, and highlight the needs as well as existing barriers on access in order to generate appropriate demand and quota for the International Narcotics Control Board.

In addition, policy changes that expand APN and nurse prescribing is critical for increasing access in many LMICs. Nurses are prime stakeholders in advocating for opioid access in underserved and rural areas where there are a limited number of licensed prescribers or physicians and other geographic, economic, and social barriers to obtaining opioids for symptom management purposes. Through demonstration and documentation of effective pain assessment and management and the delivery of exemplary clinical care, nurses continue to make the case to expand nurse prescribing privileges.

Nurse leaders need to be on the forefront in decision-making at the regional and global levels.⁴ Policies should reflect patient needs and health system infrastructure. Programs have been created to develop nursing leadership globally including the multi-disciplinary program run by the European Palliative Care Academy and the Palliative Care Nurse Leadership program run in Uganda.⁵⁷⁻⁵⁹ Palliative nursing plays a key role as many LMIC nurses are already performing effective pain and symptom management without recognition or supervision.¹⁵

Best Practice Model: Nurse Prescribing in Uganda

The Ugandan State of the Worlds Nursing country report identified that 80% of the health workforce are nurses.⁵ It was recognized early in the development of palliative care within the country that nurses were crucial to increasing access to palliative care throughout the country. Specifically, in order to ensure patients around the country had access to analgesics such as oral morphine, specially trained palliative nurses would need prescriptive authority due to the low doctor to patient ratio. Thus, the statute was changed in 2004 making it the first country to enable legal nurse prescribing of oral morphine to both adults and children. This policy advancement has made oral morphine freely available to those districts that have specialist palliative care nurses or clinical officers, and morphine has increased in availability within the community and at the village level.

Ugandan nurses with prescribing licenses require comprehensive training, which is at least nine months in length and provides both practical and theoretical training to registered nurses and clinical officers. It enables or empowers them to carry out palliative care, with a holistic approach, competently and effectively, caring for both the patient and the family. Prescriptive privileges equip palliative nurse specialists to act as key players in developing palliative care in their health unit and community. Initially, palliative nurse specialists were trained through the clinical palliative care course run by Hospice Africa Uganda, but more recently education has also been delivered within the government setting at the Mulago School of Nursing and Midwifery. An additional route to training has been developed through the Diploma/Degree in palliative care run by HAU in conjunction with Makerere University. To date, nearly 200 nurses have been trained as specialists and are able to prescribe, thus enabling access to palliative care throughout the country.

In 2016, an evaluation was undertaken of palliative care nurse prescribing as part of the palliative care nurse leadership program.⁶⁰ The evaluation, which is currently being written up, found that trained nurses are competent to prescribe pain medications in palliative care, demonstrating their ability to assess and manage pain, to give appropriate

medications and reassess and to seek help for complex cases as needed. Minor amendments were recommended to the curriculum and palliative care nurses showed resilience and determination to overcome challenges and improve access to palliative care.

Global Academic-Practice Palliative Nursing Partnerships

One of the key messages of the Lancet Commission report was that international collective action was critical to ensuring that all people, particularly the poor and most at-risk, have access to palliative care services.¹⁷ Inclusive, respectful, mutually beneficial, and long-term global health nursing partnerships are critical to advancing high-quality, cost-effective UHC.^{6,20} Partnerships in both academia and in the practice context are necessary to promote effective capacity building and improve nurse competencies in palliative care. In the clinical setting, qualified nurses (e.g., professional nurses, registered nurses, etc.) are uniquely positioned to identify patients in need of palliative care and to influence the quality of care throughout the illness trajectory. As part of the interdisciplinary team, the nurse is one of the clinicians responsible for the assessment and management of pain and illness-symptoms and the identification of spiritual and psychological needs of the patient and family.⁴² Their role in these assessments may vary based on context and practice setting. Additionally, they support patients' and families' decision-making and goal setting by facilitating advance care planning discussions throughout the serious illness trajectory.

APNs and specialist nurses provide leadership for the interdisciplinary team, assist with advance care planning, promote illness understanding and prepare patients and families to manage disease progression, prescribe needed medication, and implement evidence based palliative care interventions. Through their advanced knowledge, gaps and areas for improvement in palliative care can be identified, especially in resource limited settings. Nurses often lead community and home-based palliative care teams, advancing partnerships with patients, families, and communities.^{61,62} For instance, nurse-led home-based palliative care in rural North India proved cost-effective and allowed individuals to sustain human dignity while living with a serious or incurable disease.⁶³

Interdisciplinary partnerships are also needed to effectively leverage palliative nursing capacity in both low- and high-resource settings. The Nursing Now campaign, as well as several reports,^{5,6,17,20} emphasize that systems and health leaders and policymakers must actively redefine and reconceptualize the role of nursing in health systems and in strategically achieving UHC targets. Antiquated interprofessional hierarchies that marginalize or hinder nurses working to the full extent of their training and licensure commit an ethical disservice to the integrity of quality patient care. Palliative care teams and advocates should call for inclusion of nursing collaboration in organizational strategic planning and patient/family decision making, palliative care development, and optimize their biopsychosocial skillset to improve palliative care delivery. Nurses, and their contribution to health and social care systems, should be included in the policy, practice, and academic decisions that impact their ability to ensure increased palliative care access for all people.

Best Practice Model: Partners in Health, Liberia

A gap in support services for cancer patients was found in Liberia after a two-year internal unpublished Partners in Health (PIH) analysis in 2017 and 2018. Findings showed patients had a high cancer burden with extensive suffering without support. A total of 124 patients with serious illness were referred for assessment and diagnostic testing from multiple district hospitals in geographically restrictive areas. Approximately one-third were diagnosed with a life-threatening condition, and many were advanced in their disease process. In response, PIH - which had implemented community nursing care in Liberia – strove to integrate palliative care services within the noncommunicable disease program. Liberia PIH policy leadership have worked tirelessly with other local and global multisector partners to support policy gaps and form a technical working team in palliative care.

The Liberia PIH community response to the integration of palliative care services has shown positive results. Leaders spearheading the program have received positive feedback from providers and community members. For example, a family member of a cancer patient thanked PIH after receiving caregivers' training, spiritual support, social and bereavement support, and timely pain and symptom management. PIH has extended to areas where healthcare is scarce, such as the Ivory Coast and surrounding counties. The example from Liberia also demonstrates the need for programs to be sustainable. Even after the introduction of palliative care in recent years, barriers still exist including access to morphine, training clinical staff, transporting clinicians to community-based patients, distributing adequate funding to programs, and managing space and advanced technology.

To further palliative care in Liberia, government officials have collaborated training efforts with Nigeria and Malawi according to PIH. Plans to disseminate the knowledge gained from this training are ongoing, and a pilot palliative care program is also being assessed in Monrovia. Morphine availability and accessibility is being addressed by a technical working group in collaboration with the Drug Enforcement Agency of Liberia. Specifically, they are working on the control and tracing of morphine after a patient's death for redistribution of the remaining opioid. This is especially important due to the scarcity of liquid morphine throughout the country.

Of note, one specific county in Liberia, Maryland County, has shown significant benefits of an integrated palliative care service. Since 2018, the program has enrolled 31 patients with serious illness. Outcomes have shown that 17 have had comfortable deaths through appropriate pain and symptom management interventions, spiritual and emotional support, and education on end-of-life care; 14 continue in palliative care. The program consisted of eight nurse and physician assistant providers trained by a palliative care specialist using the ELNEC curriculum in May 2019.⁶⁴ Since 2018, the providers have conducted 50 home visits in Maryland County and the surrounding counties of Grand Kru and River Gee. The program has also provided a network to share work experiences and challenges.

The Future: Implications and Recommendations

The care of people experiencing SHS is of interest to government and public policymakers globally. People living with life-limiting illness account for disproportionately high costs to economies and their care is often fragmented, misaligned with patient and family preferences, and results in poor outcomes.^{17,18} Thus, policies should promote increased access to palliative care services and enhanced palliative care training for healthcare clinicians, including nurses.⁶⁵

Palliative care is inherently interdisciplinary and nurses are a key part of the team. However, in many parts of the world, nurses are often not included in decision-making or leadership opportunities. Palliative nurses must engage and be engaged in a number of partnership and leadership action items to increase universal palliative care access on a global scale. For example, they should collaborate with organizations and policymakers to strengthen international nursing optimization initiatives - such as the Nursing Now campaign – to actively raise the profile and status of nursing throughout systems and society at large; adapt models of palliative care education to varied contexts for increased accessibility to recipient populations; engage in fully participatory and respectful interdisciplinary partnerships to enhance palliative care delivery and sustain palliative care program development; and advocate at all levels for scopes of practice that reflect the full extent of their training and skillsets, recognizing them as autonomous clinicians with unique contributions to palliative care team delivery.¹⁰ Nurses will be at the core of innovating health delivery during COVID-19 and far beyond, ensuring that palliative care remains patient-, family-, and community-centered in both low- and high-resource settings.

A multisector and interdisciplinary approach to leveraging palliative nursing is urgently needed. Organizational advocacy is an important foundational step. For instance, the American Academy of Nursing recently completed a consensus paper on nursing's roles and responsibility to ensure universal palliative care access.^{66,67} The paper joined 43 nurse scholars and leaders from diverse fields to put forth globally applicable recommendations for advancing the nursing role in expanding palliative care services (Table 2). The table is organized under the three priority areas previously discussed: education and training, policy and advocacy, and partnerships. Contributing authors currently reside in eight countries (Kenya, Liberia, South Africa, Lebanon, United Kingdom, United States, Canada, Australia) and represented eight expert panels of the Academy (Palliative Care & End-of-Life; Global Nursing & Health; Aging; Bioethics; Child, Adolescent, & Family; Cultural Competence & Health Equity; LGBTQ Health; Quality Health Care). Additional scholarly consultation was given by Julia Downing, PhD, RGN, Chief Executive Officer, International Children's Palliative Care Network and Professor, Makerere University, Uganda. These recommendations for global, national, and local nursing and interdisciplinary stakeholders may be considered a starting point for advancing palliative care access through strategic investment in nursing in the myriad contexts where nurses practice and partner.

Conclusion

Promoting policy, education, capacity building, and research agendas that advance palliative nursing practice and leadership roles are important to fostering the delivery of palliative care services worldwide. With nurses as the largest cadre of healthcare professionals and, in many places, the first or only healthcare professionals available, they contribute significantly to leadership and advocacy efforts that seek to enhance palliative care delivery for all people experiencing SHS in across care settings. Investing in the nursing workforce through palliative care education and training not only optimizes their various roles but also improves their abilities to meet the needs of those with serious illness and optimize their numerous roles as full members of the interdisciplinary palliative care team, thus helping to alleviate the global burden of SHS through expanded access to high-quality palliative care for all.

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Key Message

Achieving universal palliative care access is a global social justice priority. Nurses are critical to strategically realizing this vision. Health system leaders, interdisciplinary partners, and policy makers must support nurses to practice to the full extent of their education and licensure to provide high-quality palliative care services for populations worldwide.

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Nursing Roles in System-Wide Integration of Palliative Care at the Intersection of the Lancet Commission Recommendations and the State of the World's Nursing 2020 Future Directions

Table 1

| Lancet Commission Recommendations ¹⁷ | Opportunities to Leverage the Nursing Role to Achieve Universal Palliative Care Access | State of the World's Nursing 2020 Future Directions ⁵ |
|--|--|--|
| Stewardship | | |
| <ul style="list-style-type: none"> 1. A legislative and normative framework is essential to guarantee the integration of palliative care and pain relief into health systems. | <ul style="list-style-type: none"> Nurses should serve as working members on policy and legislative bodies. Nurses are essential to create and disseminate guidelines needed to ensure the integration of generalist and specialist palliative nursing. Advocates for palliative nursing administrators, and educators must be included in workforce strategic planning and curriculum building to ensure palliative care inclusion among institutional and regional priorities. | <ul style="list-style-type: none"> Developing and supporting the workforce (Regulation) Building institutional capacity and leadership skills for effective governance |
| <ul style="list-style-type: none"> 2. Public awareness of and support for palliative care that can drive systemic policies and integration into universal health coverage usually derive from professional groups and non-governmental organizations (NGOs), often in association with international and regional civil society organizations. Government institutions tend to be late adopters of palliative care initiatives. | <ul style="list-style-type: none"> Nurses are ideally positioned to promote relationship-building with patients, families, and communities to identify opportunities for palliative care integration earlier in the serious illness trajectory. Palliative nurses must document patient and family outcomes to inform improved institutional, local, regional, and national policies that recognize and reimburse for palliative nursing services. Nurses must lead/co-facilitate advance care planning conversations to elicit patient and family values and preferences in the context of their illness and SHS. As the profession with the highest proportion of direct patient contact, nurses are critical to advocating for palliative care involvement alongside standard medical care. | <ul style="list-style-type: none"> Developing and supporting the workforce (Nursing Practice, Regulation) |
| <ul style="list-style-type: none"> 3. Feedback between global and national policy making and evidence can drive policy change. | <ul style="list-style-type: none"> Nurses can promote palliative care data exchange between low- and high-resource settings and the role of the nurse. Nursing organizations can promote international data registry on health-related suffering, controlled medicine access, nurse prescriptive privileges, and palliative nursing resources. Palliative nurses can advocate to translate available data into meaningful policy changes. | <ul style="list-style-type: none"> Strengthening the evidence base for planning, monitoring and evaluation Mobility and migration Research and evidence base |
| <ul style="list-style-type: none"> 4. Monitoring and evaluation of palliative care interventions, programs, or policies is uncommon yet essential for effective scale-up. | <ul style="list-style-type: none"> Nurse leaders, clinicians, and community partners must participate in data capture on health systems' performance indicators related to palliative care. Nurse researchers and those working in compliance are integral to strategic planning of palliative care service delivery and evaluation of care quality. | <ul style="list-style-type: none"> Strengthening the evidence base for planning, monitoring and evaluation Research and evidence base |
| Financing | | |

| Lancet Commission Recommendations ¹⁷ | Opportunities to Leverage the Nursing Role to Achieve Universal Palliative Care Access | State of the World's Nursing 2020 Future Directions ⁵ |
|---|---|---|
| <p>5. System-wide integration of palliative care is facilitated by the existence of a national universal health coverage platform and integration into the package of covered services.</p> | <ul style="list-style-type: none"> • Nurse administrators must promote workforce efforts to identify palliative care integration at point of service, during care transitions, and throughout the serious illness care trajectory. • Nurses can raise awareness for national health care budgets to include costs of palliative nursing care interventions. • Nursing schools and universities can develop and finance palliative nurse preceptorships, residencies, and fellowships for all levels of nursing practice. | <ul style="list-style-type: none"> • Developing and supporting the nursing workforce (Nursing Practice, Regulation, Decent Work) |
| <p>Delivery</p> <p>6. The initial adoption of palliative care interventions by governments is usually associated with cancer or HIV disease. Expansion of access to palliative care and pain relief to other health conditions and for children has been slow and is associated with a leap from a disease-specific model to a systemic approach.</p> | <ul style="list-style-type: none"> • Nurses are able to assess SHS, and thus can identify patient groups requiring palliative care beyond HIV and cancer diagnoses. • Palliative nurses can use the global Nursing Now efforts to raise visibility of palliative nursing contributions. • Palliative nurse specialists can lead palliative nursing education efforts and increase the quantity of palliative nurse specialists in acute and community-based settings. | <ul style="list-style-type: none"> • Developing and supporting the nursing workforce (Nursing Practice, Decent Work) • Building institutional capacity and leadership skills for effective governance |
| <p>7. Community involvement in the provision of palliative care is crucial given the limited capacity of health systems in LMICs and the important role of home-based care.</p> | <ul style="list-style-type: none"> • Community nurses are the mainstay of community health care and well-integrated in the community, and thus well-positioned to enlist community stakeholders in community-based models of palliative care. • Nurses can disseminate knowledge to the public and colleagues across the healthcare system about palliative care. • Nurses can lead and co-participate in conversations on goals of care, advance care planning, and values clarification. • Nurses can promote, develop, and lead equitable and person-centered palliative nursing for at-risk and minoritized groups. | <ul style="list-style-type: none"> • Mobility and migration • Developing and supporting the nursing workforce (Nursing Practice) |
| <p>8. Strong small-scale or state-wide programs can be a fulcrum for developing a national palliative care model and achieving systemic integration—especially in delivery.</p> | <ul style="list-style-type: none"> • Nurses can create palliative nursing roles in all settings and countries and at all levels of leadership. • Nursing organizations can advocate for palliative nursing priorities as a part of regional and national nursing agendas globally. | <ul style="list-style-type: none"> • Strengthening the evidence base for planning, monitoring and accountability • Catalyzing investment for the creation of nursing jobs |
| <p>Resource Generation</p> | <ul style="list-style-type: none"> • Nursing organizations and nursing schools can ensure availability of palliative nursing certification and accreditation opportunities. • Nursing organizations and nursing schools can increase access to high-quality palliative nursing education at all levels | <ul style="list-style-type: none"> • Developing and supporting the nursing workforce (Education, Nursing Practice) • Building institutional capacity and leadership skills for effective governance |

| Lancet Commission Recommendations ¹⁷ | Opportunities to Leverage the Nursing Role to Achieve Universal Palliative Care Access | State of the World's Nursing 2020 Future Directions ⁵ |
|--|---|---|
| <p>10. Health systems research and lessons learned from country experiences need to be published and disseminated.</p> | <ul style="list-style-type: none"> • Nurse researchers can ensure that palliative care research is truly interdisciplinary and derive input from industries outside of healthcare from design through dissemination. • Nurse researchers can advance palliative care research across the lifespan and ensure inclusion of nursing-specific considerations. • Nursing schools and universities can empower nurses with research skills to innovate, lead, and create new knowledge. | <ul style="list-style-type: none"> • Catalyzing investment for the creation of nursing jobs • Strengthening the evidence base for planning, monitoring and evaluation • Research and evidence agenda |

Table 2

American Academy of Nursing Expert Panel Consensus-Based Recommendations on Nursing's Roles and Responsibility to Ensure Universal Palliative Care Access (adapted)^{66,67}

| Education and Training | |
|------------------------|---|
| • | Generalist palliative nursing education that is population-informed and inclusive of culturally-appropriate communication and advance care planning education should be supported by global nursing associations and health organizations. |
| • | Continuing education on palliative care skills, advocacy training, nurse mentorship, and technology utilization should be consistently integrated to enhance nursing competency at all levels. |
| • | The education and training of palliative nurses should be leveraged across practice settings, including the rapid expansion of access to palliative nursing services supported by sustainable policies. |
| Policy and Advocacy | |
| • | Governments and health ministries must make fiscal and human resource investments toward palliative nurse specialist development to lead clinical practice, research, workforce development, and policy initiatives. |
| • | There must be increased investment in research and the development/adoption of reimbursement models that pay for palliative nursing care. |
| • | Advocate for palliative nursing to be delivered within a human rights, health equity, and social justice framework to assure dignity, respect, humility, transparency, and ethical care for all persons and populations, particularly the poor, marginalized, and minoritized. |
| Partnerships | |
| • | Palliative nurses must be integrated throughout governments and nongovernmental organization leadership teams to ensure high-quality palliative nursing care and increased social engagement. |
| • | Health and social care decision-making bodies must include palliative nurses on relevant boards and ministries to promote nursing input on needs assessments and program development. |
| • | Nursing collaborations with health and social care, faith-based, and other interdisciplinary professional organizations are critical to expanding palliative care access and improving the public's knowledge of palliative care and palliative nursing. |
| • | Partner with the relevant bodies, local governments, health ministries, and palliative care organizations to mitigate access barriers to internationally controlled essential medications, particularly in LMICs and other resource-poor settings, and develop and enact nurse-led solutions. |