



Editorial: A Way Forward for Palliative Care Nursing

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The growing need for palliative care has paralleled the increasing number of people with chronic conditions and ever-rising aging populations around the world. Recently, it was estimated that there are approximately 40 million people in need of palliative care every year.¹ Such increasing demand makes it challenging for health care professionals, including nurses, to serve patients with life-threatening and life-limiting conditions, as well as their families and the health care system as a whole.

In this editorial review, I would like to focus on two main points. Firstly, the key milestones of global efforts for palliative care development will be described, then a way forward for palliative care nursing to support the palliative care development will be highlighted.

Global palliative care movement

Palliative care was first advocated as a universal human right in the 1990s.² The right to palliative care focuses on the right to health and freedom from suffering and ill treatment. Since then, the need for palliative care development has been echoed at international and national levels. In 2007, the WHO proposed a public health model that would enable the development and integration of palliative care into a country's health care system. This consists of a combination of policy development, medication availability, public and professional education, and implementation of palliative care at all levels of care.³ Later on, palliative care was addressed in the WHO global action plan for the prevention and control of NCDs 2013–2020⁴ and in the 2014 World Health Assembly (WHA) resolution 67.19⁵ as an ethical responsibility of the health system and an essential component of comprehensive care throughout one's life span.

Despite an increasing awareness of and growing advocacy efforts for palliative care development worldwide, accessibility to quality palliative care remains poor for many people, particularly those who live in low- and middle-income countries. A disparity in the stage of palliative care development exists across the world, ranging from no known palliative care activity (32% of 234 countries) to an advanced integration of palliative care in the mainstream health care system (8.6% of 234 countries).⁶ Highlighting this variation, a report on the Quality of Death Index (QDI), which reflects the availability of palliative care in 80 countries, described consistent results. The high-income countries were in the top ten positions of the highest QDI. On the contrary, the QDI in both low- and middle-income countries was lower than 60 marks.⁷ Recently, the Lancet Commission on Global Access to Palliative Care and Pain Relief reported that 35.5 people living with life-threatening or life-limiting health conditions experience serious health-related suffering (SHS), and the majority of these people live in low-income and middle-income countries where there is no or little access to pain medications or palliative care.⁸

In order to overcome the issues related to accessibility and equality, the WHO has released a guide on integrating palliative care into primary care. The primary health care setting is considered to be the first place where people can have access to palliative care from the early course of the disease. This practical guide will be useful to planners, implementers and managers to set up the primary palliative care in their health system.⁹ The successful integration of palliative care into the primary health care results in the early identification of patients eligible for palliative care,¹⁰ the decline in emergency visits and hospital admissions, and home deaths.¹¹ Recently, the integration of palliative care into the primary health care was endorsed in the 2018 Astana Declaration at the global conference on primary health care in October.¹²

A way forward for palliative care nursing

Nurses, the largest group of the health workforce, are acknowledged as the backbone of the healthcare system. We can contribute greatly to not only palliative care clients but also the health care system at large. We provide care and support for both patients and their families throughout the illness trajectory. We are always there for them when they are healthy, sick, in deteriorating health, and dying. We are by the side of family members also during the bereavement period. At the public health level, we who work at the frontline of primary care settings orchestrate community-based palliative care by working with communities to increase public awareness on the topic of death and dying and creating compassionate communities that are able to support dying persons at home. According to the International Council of Nurses,¹³ palliative care is a nurse-driven approach, which requires complex decision-making and leadership skills. Nurses collaborate with various stakeholders such as patients, families, health and social care professionals as well as managers, policy makers and planners to advance palliative care.

In an era of growing needs for palliative care, we, as nurses, are at the pivotal position to support a global movement for the advancement of palliative care for all. Notwithstanding the remarkable contributions of nurses to the health care system, several challenges lie in wait. Appropriate responsive strategies to overcome these challenges would result in a flourish for palliative care nursing. Three main strategic recommendations toward that end are addressed here.

Investing in palliative care nursing education

Palliative care education is recommended as one of the four most important public health strategies for the development of palliative care worldwide. WHO recommends that nurses working in primary health care should possess basic palliative care nursing competences and be able to provide primary palliative care to their patients.⁹ However, previous studies have revealed that nurses are not well-prepared for palliative care.^{14,15} Often, nurses report that they feel incompetent and reluctant to care for dying patients and their families, particularly as it regards the aspect of care related to communication. In order to enhance the quality of palliative nursing care, it is essential for nurses to acquire knowledge and skills on these matters. Recently, a call to action with the aim of integrating palliative care content into the undergraduate nursing curricula and preparing the next generation of nurses to care competently for patients at the end-of-life stage has been echoed.¹⁶⁻¹⁸

In addition, professional development programs on palliative care via short-course training or workshops are essential to the enhancement of knowledge and skills required for the advancement of palliative care practices, ensuring patients received up-to-date nursing care. Educational interventions with innovative approaches in order to promote accessibility to palliative care as well as ongoing education and training are also recommended.¹⁹⁻²² Following this strategy, specialist nurses in palliative care can navigate caring for patients with complex palliative care needs while coaching community nurses to provide care for dying patients at home.

Strengthening evidence-based practices in palliative care nursing

Palliative care nursing reflects the quality of palliative nursing care service.²³ As evidence-based practices have promoted better patient care, palliative care delivery should also be incorporated based on evidence. Despite the growing research on palliative care interventions, high quality evidence is limited,²⁴ particularly in low-resource settings.²⁵ Sound intervention research studies are needed to advance the knowledge development regarding palliative care nursing. In addition, it is apparent that assessing palliative nursing care is challenging due to a lack of objective instruments²³ and the complexity of measurements concerning the quality of palliative care.²⁶ Developing tools to measure the quality palliative nursing care is also very much needed. The patient-reported outcome measurements must be sensitive to patient complexity. Mixed methods can be used to comprehensively capture the patients' perspectives related to being cared for both subjectively and objectively. The results from patient-reported outcome reports can help us to identify areas for improvement in palliative nursing care.

Expanding roles of nurses in primary health care

Nurses play crucial roles in primary health care. The call to integrate palliative care into the primary health care has presented us with the opportunity to take actions to lead the care delivery in communities.²⁷ Nevertheless, palliative care at the primary health care level is challenging. Several studies have identified barriers to palliative home care like the complexity of chronic conditions, primary health care providers' incompetences, poor communication and coordination of care, limited accessibility to equipment, services, and medications, and time constraints related to GPs.²⁸⁻³¹ These barriers led to fragmented care and, consequently, result in unmet needs among both patients and caregivers.³²

To bridge the gap in the fragmentation of the care system and to promote a seamless care service able to respond to the complex care needs of patients with chronic illness and their families, the role of nurses at primary care settings has to be expanded and enhanced. The nurse as a navigator is another role that fits the primary health care approach.³³ The nurse navigator model has been implemented in countries like USA, Canada and Australia. This model has had positive impacts on patient outcomes and has improved the care process.³⁴⁻³⁶ In addition, several nursing scholars have proposed that, in the future, nurses delivering primary care will focus more on chronic disease management.^{27, 37} Their responsibilities will include managing patients with chronic conditions, leading complex care management teams to improve the quality of care, and coordinating care between primary care settings and the other levels of care.³⁸ This current trend in enhancing the role of nursing reflects the need to improve the preparation of nurses working in primary care settings. Hence, new curricula and practices that will adequately equip the future nurses to serve as leaders in the organization of the primary care practice as well as play chief roles within inter-professional teams is recommended.²⁷

Conclusion

Nurses play a profound role in palliative care. The high demands for palliative care in the future call for us to take proactive steps in order to affect the development of palliative care. Building the necessary capacities among future nurses by means of palliative nursing education, tailoring rigorous research studies to expand our knowledge regarding palliative care as well as incorporating evidence-based practices in nursing care, and expanding the role of nurses in the primary health care setting are recommended to advance palliative care nursing for all.

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