

Nursing perspectives on palliative care 2015

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Abstract: Nurses have an integral role in promoting and providing early palliative care. The provision of palliative care is aligned to the basic tenants of nursing in providing holistic care to individuals and family members. In many parts of the world nurses are the primary health care provider in a community and a primary link between patients and other members of the health care team. Unfortunately, access to accredited palliative care education remains a challenge for nurses.

Keywords: Palliative care; palliative care nursing; nursing education; nursing roles

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Introduction

Palliative care and its place in health care delivery have evolved over the past several decades. From a conceptualization of palliative care being most relevant at the end of life, the emerging conceptualization is one of seeing its relevance from the point of diagnosis of a serious or life-limiting illness and throughout the course of that disease trajectory; and beyond the death of the patient to support the bereaved family members. According to the World Health Organization, palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (1).

A palliative care philosophy and approach can be of benefit throughout an individual's journey with illness, and utilized across many settings of care by all members of the health care team. Historically, much of palliative care knowledge grew from experience with cancer populations. However, the insight and recognition that palliative care can be of value to individuals suffering from other types of life-limiting illness has been growing rapidly. Palliative care is increasingly viewed as an essential component of

comprehensive care throughout the life course and as a fundamental human right (2). Additionally, a person-centered holistic approach to care delivery of health and illness services is cited as a hallmark of a quality health system (3,4).

The need for palliative care is expected to escalate over the next several decades. The world's population continues to grow and many countries will see increases in their older age cohorts. This means the number of individuals who will experience illness, either chronic or life-threatening conditions, live longer with their life-limiting illness because of advances in science and technology, and die from their disease, is anticipated to rise significantly. The mortality from cancer alone is expected to rise from 7.4 million worldwide in 2004 to 12 million by 2030 (5). Globally, 20 million people are in need of palliative care services at the end of life (6); and 80% of these live in low- and-middle resource countries where the health systems are challenged to provide the required care for the rapidly growing populations with non-communicable diseases. As a result, many individuals today are experiencing unnecessary pain and suffering from other severe symptoms during the last days of their lives.

Nurses are the largest workforce in health care globally and are therefore in a strategic position to influence the quality of palliative care delivery throughout the trajectory

of illness (7). Nurses care for patients and families in many settings and for an array of populations. Their presence can play a critical role in reducing the burden of suffering for individuals who are struggling with the impact of illness and who are dying from their disease as well as their careers.

Introducing and implementing a palliative care philosophy and approach, especially with a focus on early intervention in the course of patient care, is not without its challenges. This article will outline the perspectives of nursing regarding early palliative care, highlighting the role nurses can play in the process, the challenges and barriers identified that currently prevent the enactment of these roles, and potential solutions for the barriers.

Nursing in palliative care

The role of nursing has been, and continues to be, integral to the delivery of palliative care. From the time of the Middle Ages to present day, as palliative/hospice care has evolved and finally emerged as a specialty practice, nurses have cared for individuals facing serious and life-threatening illness. The very essence of nursing is focused on caring for the whole person and supporting the family through difficult situations. Not only do nurses require excellent clinical knowledge and skills, but it is also essential that they have expertise in managing interpersonal issues and helping a person diagnosed with a disease and his or her family navigate through the decisions they have to make. Informed by a solid ethical framework, nurses respect and support the individual decisions made.

Today, given that palliative care can be delivered in most practice settings, across all stages of serious illness, and for persons of all ages and their families, nurses with varying levels of education and expertise provide palliative care to greater or lesser degrees. Despite this reality, the delivery, or value, of palliative care is often not recognized or acknowledged, especially in settings such as emergency departments, intensive care units, maternity units, nursing homes, and long-term care agencies. The advent of integrated palliative care across an illness experience, introduced early in the course of life-limiting illness, implies a need for knowledge and specific skills in palliative care by all health care professionals, regardless of practice location.

Nurses as key health care providers

In many parts of the world, nurses are the main health care professional as well as the primary link between the patient

and family and the other multi-professional team members. In some instances, they may be the only visible health care provider in their setting or territory. Although nurses are engaged in leadership roles in palliative care through education, research, management, and advocacy (policy development), the direct delivery of palliative nursing care to individuals and families is the primary role nurses undertake around the world.

According to accepted general nursing standards of professional practice, within a direct patient care role, nurses are accountable for completing a comprehensive health assessment with the individual, providing evidence-based interventions, and evaluating the impact of the care delivered. In particular, providing symptom management, patient education, and emotional support for the patient and family are key responsibilities. The goals of care are to be mutually agreed upon and the approach tailored to the individual's preferences, wishes, and values. Progress toward those desired goals is closely monitored and any necessary adjustments to care made in a timely manner. The unique needs of the person drive the plan of care across physical, psychological, social, emotional, informational, spiritual, financial, and practical domains. Family members and significant others also must be incorporated into the plan as their needs also have to be addressed. The care for family members in their bereavement is an additional focus for nurses.

A holistic approach to nursing practice is a central tenant in most nursing school curricula and will be cited by many individual nurses as a philosophy guiding their daily care provision (8).

Education of nurses in palliative care

The general overarching professional responsibility of nurses is in direct alignment with the tenants of palliative care. However, the principles of palliative care, including good care of the dying, are not introduced and universally taught across nursing schools, even at a basic level. A nurse graduating from an undergraduate or generalist nursing program will not necessarily have been introduced formally to the palliative care philosophy and approach to care. Nursing curricula vary widely around the world regarding the introduction of content and the modes of teaching palliative care.

Despite the overall holistic approach in nursing care, palliative/hospice care is conceptualized as a specialty practice in many parts of the world and requires additional

specific knowledge and skill beyond that possessed by a general nurse. At present, specialty practice can be achieved at various levels through certificate, degree, or advanced practice programs. The approach differs by country and educational setting. Some countries (e.g., United States, Canada) have a certification examination in palliative care nursing that provides a formal designation for the individual practitioner. However, in many settings, nurses pursue a continuing education route to gain knowledge and skills in specialized palliative care and may not have formal certification that recognizes their achievement. In many cases, the learning is garnered through an “on the job” or by experience. This situation results in the learning about palliative care being varied and inconsistent between and among settings.

Emerging roles for nurses

New roles such as clinical nurse specialist, nurse practitioners, nursing navigators, and advanced practice nurses are emerging within the profession and gradually becoming evident within palliative/hospice practices and settings. The incumbents in these roles may be engaged primarily in direct patient care but may also engage in education and research activities. These roles are directed toward ensuring expertise in palliative care is available to patients and to other health care team members. There is also expected that these incumbents will mobilize quality improvement within the care delivery system. They are likely to be change agents and mentors driving toward excellence in patient care. These individuals will often drive the design and implementation of new programs for delivery of palliative care, especially in community, rural, and remote settings. Their capacity for problem-solving and decision-making within an expanded scope of practice, as well as expertise in the prescribing and adjusting of medications, facilitates the provision of palliative care in locations where access to physician support is limited. Creative solutions for accessing physicians by practitioners from rural and remote settings have been designed using teleconference, Internet, and Skype routes. Such solutions allow individual patients to stay within their own communities, near their families and own support networks, yet have access to the necessary expertise in palliative care.

The nursing community within palliative care has indicated support for the notion of early referral to palliative care and, more recently, the incorporation of a palliative care philosophy across the trajectory of a serious or life-

threatening illness (7). The former notion has existed for some time and emerged as an idea when referrals to a formal palliative care service were being made within the last few days of a patient’s life. An earlier referral would allow more time for sorting out the patient’s plan of care and outstanding concerns. The latter notion, integration across the trajectory of illness, has been a more recently articulated idea and speaks to the value of a palliative care philosophy and principles being applied from the time an individual patient learns of a life-limiting illness. It is an approach that would contribute to excellent symptom management, patient and family support, and focus on patient preferences throughout the course of illness. The approach emerged as it was recognized that all patients will not have, nor do they need, access to specialized palliative care services, yet there is a need for “impeccable assessment” (1), astute symptom management, and person-centered care and support throughout the illness provided by the patient’s primary care team.

Despite the stance of supporting an integrated approach to palliative care, nurses in many parts of the world experience challenges in applying this approach. There are significant barriers and influences shaping their experiences in achieving success.

Challenges and barriers to excellence in palliative care nursing

A major worldwide challenge is the financial constraint confronting most health care systems. Availability of, and access to, services are influenced by this factor whether in high, middle or low resource settings. Health care systems are challenged to set priorities for financial budgets given the prevalence of communicable diseases, the growing number of individuals living longer with chronic disease, the changing climate events, and changing population demographics. Financial support for palliative care remains a lower priority in many countries and it is often not yet incorporated into political health care documents.

A major influence on the shape of palliative care nursing is the rapid growth in ageing populations, mainly western countries. In many ways this could dictate who has access to palliative care services; higher expectations from health care service, patients, and family members, will see an increased demand for access to good end of life and palliative care services, as they face the challenge of living longer with life-limiting, chronic illnesses.

The change in health care consumers’ attitudes is evident

and shaping practice. More and more, the expressed aim of individuals is to be in control of the course of illness as long as possible and therefore a demand for structured advance care planning is evident. The use of social media is supporting this, but can also lead to misunderstanding as it is often not overseen by professionals. The wish to control life until the end might also be reflected in the expressed desire for physician-assisted suicide as a way for consumers to have the option of ending unbearable suffering within one's own control. Palliative care nurses have an important role in supporting people and listening to their concerns about maintaining control until the end of life (and beyond for the family). Unfortunately, nurses have reported they are not comfortable with having the conversations with patients and families about death, dying, and end of life issues and approaches (9). Investigations regarding the experiences of nurses caring for individuals with life-threatening illness reveal they can feel moral distress, vicarious trauma, or compassion fatigue, emphasizing the challenges for them when confronted within these situations (10).

Nursing has always enjoyed a reputation for being a mobile profession and no less so in palliative care, where nurses can confidently take up practice in countries where the universal philosophy of palliative care guides practice. It can be argued that while nursing shortages are a worldwide issue (11), it presents opportunities for creativity in developing models of care into the future. Leaders in health care are calling for transformative change in health care delivery and a concerted move to inter-professional or multi-professional team approaches. Transformative change requires intentional and on-going effort as well as astute and committed leadership. The short term nature of budgeting cycles and a notable lack of visionary leadership have been cited as major shortcomings in achieving the desired transformations (4).

A decline in the numbers of young people joining the nursing profession is already evident, as is the lack of retention of new nurses (11). The next generations of nurses working in palliative care will have different expectations of working life, most particularly of their work-life balance. They are more likely to be computer literate, adaptable, eager to advance and seek performance-based rewards, and not necessarily valuing an altruistic worldview. These aspects mean there is even more onuses on employers for creative models of care, especially the further development of senior or expert roles such as practice resource nurses, nurse-led clinics/teams, and nurse practitioner. Exploring complementary roles like personal careers and/or

volunteers, as well as strong community involvement, will also be essential to incorporate into models of care in the support of dying people.

Initiatives by nursing for palliative care advancement

For palliative care nursing to be recognized as its own specialty, there needs to be an evident commitment, quality indicators, and defined outcomes. This requires palliative care nurses to establish evidence-based standards and competencies to support their practice, be actively engaged in educational and research activities, and document the effect of their work for quality control. Nurses need to be able to undertake reflection on their practice and be prepared to take on leadership roles. To advance palliative care as a specialized field within health care settings, these leadership roles need to be implemented independent from other medical specialties.

In using an evidence base, nurses' need easy access to and use of research-based knowledge, but access may be limited due to problems with library and language skills, geographic or physical access to physical and on-line resources, as well as limited ability to interpret and apply the research findings in daily practice (12). These limitations may be particularly evident in resource-poor countries.

The more specialised nurses become, the more they move from relying on others for evidence, to finding discipline specific on-line databases, local protocols, and evidence-based guidelines (12). Specialised nurses require nursing career pathways that straddle clinical work and university-based education, funding for full-time doctoral/post-doctoral positions, and a model of continual development of clinical research skills (13).

Specialist palliative care nurses also need universally consistent and focused education in preparation for their roles, ideally within a multidisciplinary setting to meet the demand for multi-professional clinical collaboration. The International Society of Nurses in Cancer Care developed an educational curriculum which incorporates: global perspectives on death, society and palliative care; experience of the patient and family members; nursing in palliative care; management of clinical symptoms; emergencies; therapeutic communication; care in the last hours of life; loss, grief and bereavement; and ethics at end of life (14).

In addition, work has been undertaken to develop standards for specialist palliative care nursing practice (15-17). In Australia competencies have been developed

around five domains of care: therapeutic relationships; complex supportive care; collaborative practice; leadership; and improving practice. Recently, the International Society of Nurses in Cancer Care has developed a position paper on palliative care for use by nursing groups around the globe to advocate for palliative care nursing, standards, and education (7).

Concurrent with these changes, policy planners, and clinicians have suggested that not all dying people require specialized palliative care services. Thus has developed a catch-phrase: “dying is everybody’s business”, to signify that a dying person needs to have a range of many people involved, both generalist and specialist clinicians, as well as family and community. While palliative care developments in primary health care are evident in many countries, and continue to be developed, Australia has provided leadership in resources and policy development in this area (18).

Examples of innovation

In Australia, primary health care principles have been developed for a range of settings—the community, aged care and general practice in particular—and are aimed at supporting health professionals with general interests in palliative care (19,20), who incorporate care of dying people into their overall workload. This approach is supportive of generalist nurses who work in environments like nursing homes where death occurs on a regular basis, but is not a specialty area of palliative care practice. There are three recognized levels of need in palliative care—primary care, intermediate care or complex care; this is matched to available resources, be they primary care providers (for example, generalist home-care nurses); specialist resources (with some palliative care expertise, for example, oncology or neurology nurses); or specialist palliative care services (home-care or inpatient care). Levels of need and available resources are matched to skills, either primary care or specialist palliative care education and training. Criteria have been developed to clarify when specialized palliative care services need to be initiated. Complexity or instability of the patient and family situation could trigger specific care activities lead by a specialized inter-professional palliative care team.

In Canada, two examples of initiatives to enhance palliative care are worthy of mention. An educational program was designed to enhance the capacity of health care providers to teach palliative care knowledge and skills to their colleagues and is available through www.cancerview.ca.

In British Columbia, a new model for integrating palliative care in the primary sector and working closely with nursing staff has been implemented (21). Because of the belief that the integration of palliative care in daily practice is an important step to achieve adoption of “early palliative care”, this group developed a research group to lay a foundation for early integration of palliative care and initiation of advanced care planning into the primary care setting.

Concluding remarks

Nurses play an integral role in the promotion and advancement of early palliative care for patients and families. When individuals who are living with, or dying from, life-limiting illness have access to nurses who can provide knowledgeable and compassionate care, the burden of suffering will be reduced and the quality of living and dying will be improved. However, access to accredited education about general and specialized palliative care for nurses and the incorporation of innovative nursing roles are critical factors in achieving the desired outcomes in many parts of the world.

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Footnote

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