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Nursing's role in leading palliative care: A call to action

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Abstract

Palliative care aims to alleviate the suffering of patients with life-limiting illness while promoting their quality of life. In this call to action commentary, we review the ways in which nursing care and palliative care align, describe barriers to nurses engaging in palliative care, and provide specific recommendations for nurses involved in education, training, and administration to assist nurses at all levels of practice to engage in palliative care for their patients.

Keywords

Palliative care; Health policy; Nursing; Workforce; Education

1. Introduction

Palliative care is a healthcare specialty focused on relieving suffering for patients and families of all ages and stages of serious illness. In the past decade, growing evidence demonstrates that palliative care improves patients' and caregivers' quality of life, decreases symptoms, and increases the probability of dying at home. Unlike hospice care that is intended for individuals in the final months or weeks of life, palliative care addresses a breadth of physical, psychosocial, emotional, social, and spiritual needs of patients and their families. According to the National Consensus Project for Quality Palliative Care (2013), the underlying tenets of palliative care include patient-centered care, continuity care across health settings, early introduction of palliative care when diagnosed with a serious illness, interdisciplinary team collaboration, relief from suffering and distress, and equitable access to palliative care. To clarify the distinctions between terms commonly used when describing palliative care, Table 1 lists definitions of common palliative care terminology.

The nursing workforce must be trained in palliative care skills, especially nurses who work with patients with serious illness. In the US, approximately 90 million people live with serious life-threatening illness. About 80% of patients who die need palliative care, and only half of patients admitted to the hospital receive the palliative care they need (Murtagh et al.,

2014). For patients and caregivers (families, friends, and others who provide support to patients) to benefit most from palliative care, it needs to be introduced early and continue throughout the illness trajectory. Nurses in all settings and at all levels of practice are well-positioned to use their skills and position to collaborate interprofessionally to provide palliative care.

The purpose of this paper is to describe the current state of nursing's role in palliative care and address the ways in which nurses in all settings can provide palliative care to patients and caregivers. We identified peer-reviewed manuscripts focused on nursing and palliative care to extract the key ways in which current nursing practice and research conceptualizes and enacts palliative care. We then compared those results to the palliative care framework provided by the National Consensus Project for Quality Palliative Care (2013) to determine the areas in which nursing has opportunities to lead the growing palliative care movement. In this manuscript, we first clarify the scope of palliative care and illustrate three key areas in which nursing care and palliative care overlap. Second, we provide an example of a program of research demonstrating the benefits of nurse-led palliative care. Third, we describe barriers to nurses engaging in palliative care across settings. Finally, we provide specific suggestions to nurse educators and leaders to ensure that nursing's valuable perspective continues to guide the palliative care movement and that nurses take the lead in transforming palliative care.

2. Nursing's Role in Palliative Care

Nurses' professional responsibilities to provide palliative care are grounded in the essence of nursing practice and supported by the American Nursing Association's code of ethics. Both palliative and nursing care emphasize comprehensive care supporting the holistic needs of patients and their caregivers including the assessment and treatment of physical, emotional, and spiritual health. Nurses often recognize changes in patients' health status, and these are the junctures during which palliative care may be introduced. While providing palliative care encompasses several nursing care competencies, all nurses are particularly in the primary aspects of palliative care which include symptom management, communication, and advocacy.

2.1. Symptom Management

One of the major benefits of palliative care is the ability to improve patients' and caregivers' physical and emotional symptoms (Kavalieratos et al., 2016). With the primary goal of supporting patients' quality of life, palliative care emphasizes the management of illness and/or treatment of related symptoms. Similarly, nursing care is aimed at proactively managing symptoms using comprehensive and quality treatments. Nurses produced some of the earliest models for symptom management (Dodd et al., 2001) and are leaders in translating evidence based symptom management strategies into practice. For example, the Oncology Nursing Society's Putting Evidence in Practice resource (in-print and online) synthesizes the state of the science on evidence-based interventions to manage patient-centered outcomes experienced by individuals with cancer and provides nurses with specific evidence based recommendations on symptom management.

2.2. Communication

Skilled and empathetic communication is essential in providing excellent palliative care. Nurses are trained in communication skills that allow them to discuss prognosis, goals of care, advance care planning clinical options, and medical decisions with patients and caregivers. Given their intimate knowledge of patients, nurses can facilitate sensitive conversations in a supportive, non-threatening manner incorporating caregivers' concerns and values into conversations about treatment options and goals. Therefore, nurses are in an ideal position to open a discussion on palliative care if he or she assesses the patient is open to discussing these topics and could benefit from palliative care services.

As the field of palliative care moves to integrate services earlier into the diagnosis of life-limiting disease, nurses can discuss palliative care resources with the patient and caregivers and emphasize the benefits of including this care early in the disease trajectory. Within the healthcare team, nurses share patient and caregivers' experiences and concerns with other members of the care team and collaboratively work to integrate patient-level information into evidence-based practice. Nursing communication is critical during transitions in patient care, as the turning point from treatment with curative intent to palliative care can often be difficult for patients, caregivers, and healthcare team alike.

2.3. Advocacy

Even as calls for the early integration of palliative care become standard care, cultural and practice barriers to introducing palliative care exist for patients, caregivers, and clinicians. Knowing the patient is central to skilled nursing practice and enhances nurses' ability to develop positive relationships, engage in expert practice, and sets up the possibility for patient advocacy. Nurses are well positioned to advocate for and promote the use of palliative care within various healthcare settings. Nurses are trained advocates, collaborating within the interdisciplinary team to share patients' perspectives and priorities; these skills are particularly needed when the patient has a serious illness. Many patients are not aware of the availability of advance care options, and nurses are primed to discuss palliative care options and connect how palliative care services can address patients and caregivers' medical, psychosocial, and logistical concerns. As members of the care team, nurses can leverage their communication skills to advocate for patients' and caregivers' concerns, worries, and priorities while making treatment decisions.

3. Evidence Supporting Nurse-Led Palliative Care

Research evaluating the impact of nurse-led palliative care demonstrated positive effects on patients' and caregivers' quality of life and healthcare utilization. These nursing interventions, led primarily by Dr. Marie Bakitas's research team and delivered to patients and caregivers in settings with limited access to care (e.g., rural settings), include nurses using telehealth modalities to deliver palliative care coaching sessions and monthly follow-up sessions for patients with incurable cancer. The components of these successful palliative care interventions applied patient activation, decision-making, goal-setting, problem-solving, and symptom management/self-care principles to improve patients' quality of life and symptom burden (Bakitas et al., 2010).

4. Barriers to Nursing's Role in Palliative Care

Despite an overlap between palliative and nursing care and evidence of the benefits of nurse-led palliative care, barriers exist across clinical settings. While research suggests that certified nursing assistants, licensed practical nurses, and registered nurses are comfortable assessing patient symptoms, they report insufficient knowledge of palliative care even though they remain open to training (Unroe et al., 2015). For example, nurses struggle to discuss prognosis and end-of-life planning with their patients (Hjelmfors et al., 2015).

Nurses' reluctance to engage in or lead the palliative care conversation may stem from a lack of clarity regarding interprofessional roles and which aspects of palliative care are within nursing's domain. If nurses do not perceive themselves as having skills in palliative care, they may abdicate their responsibilities to address patients' needs thinking that other healthcare team members will address patients' needs for palliation. For example, Bradley et al. (2001) found that even though neither previous education nor years in practice were associated with more knowledge about palliative care, nurses with specific training in hospice and palliative care services were more likely to practice palliative care with their patients compared to nurses without this training.

In addition to lack of education in palliative care, part of nurses' hesitancy to engage in palliative care may relate to the relationships they build with their patients. Nurses may not recognize when patients are approaching the end of life. Nurses may desire to maintain hope for a cure from the disease rather than assisting patients and caregivers in redefining hope within the context of life-limiting illness. Avoiding emotionally intense conversations may superficially appear to help patients and caregivers cope in the present, but may lead to ethical and moral dilemmas if palliation and end-of-life topics have not yet been previously discussed when urgent decisions are necessary.

5. Call to Action

Given evidence that palliative care practices are already widely used across settings, nurses in all areas of practice across the lifespan require additional training and education to provide palliative care. To gain confidence and an empowered moral agency to practice palliative care, nurses need instruction on the key elements of palliative care, clarity in their role, and administrative support to take on this role. Nurses may avoid discussing these sensitive topics unless they are specifically trained in palliative care skills and equipped and empowered to engage in these conversations with their patients and families. This results in missed opportunities to provide needed, beneficial care to patients.

We firmly support the recent statement from the American Nurses Association and the Hospice & Palliative Nurses Association (2017), which calls for nurses to lead and transform palliative care. In this document, the Steering Committee compared standard nurse competencies with those specifically for palliative care nurses, and found that palliative care is a cross-cutting dimension of nursing care with direct implications for every nurse's scope of practice. In addition to being a call for nurses at all levels to lead the culture change in palliative care, this statement serves as an excellent resource for nurses seeking to

advance their knowledge of palliative care by providing a list of resources, organizations, and documents relevant to nursing palliative care.

Aligned with this recent statement, we affirm that nurses in all settings and roles should be confident and empowered to engage in palliative care. We propose the following recommendations to better educate and support nurses to provide palliative care:

1. *Training for practicing nurses.* All nurses regardless of setting should be competent in palliative care.
 - Provide education and build skills in communication, identifying goals of care, end-of-life decision making, and symptom management through brief, evidence-based palliative care training programs such as the End-of-Life Nursing Education Consortium (ELNEC) or the COMFORT communication curriculum.
 - Adapt currently established evidence-based palliative care training programs to ensure they are accessible for nurses across care settings, such as through online training formats with live video conferencing for interaction.
2. *Nursing education.* All graduate nurses should have competency in palliative care.
 - Integrate palliative care competencies into undergraduate and graduate nursing curricula regardless of area of specialization. Continue expanding palliative care into all curricula to ensure a steady nurse workforce that can address palliative care needs across clinical settings.
3. *Administrative support for nurses.*
 - Create healthy work environments that enhance nurses' moral agency. A work environment should support professional nursing practice and allow nurses to practice to their full potential. This could mean the creation of systems for ongoing dialogue about ethical concerns in palliative care.
 - Create a culture that supports nurses to take physical and emotional care of themselves as they provide palliative care. For example, nurses in leadership positions in administration, education, or practice could provide nurses with training in brief coping strategies to diffuse emotional stress from delivering palliative care. Moreover, establishing support groups or debriefing opportunities to encourage peer-to-peer support about their experience providing palliative care may be beneficial. Nurses need institutional support because providing palliative care to patients and families requires a significant amount of compassion and can lead to burnout, caregiver fatigue, and recidivism.

6. Conclusion

To manage patient symptoms and improve patient quality of life, all nurses need to be able to provide palliative care to patients with life-limiting illnesses. The essential elements of delivering palliative care resonate with the essential elements of nursing practice: symptom management, communication, and advocacy. Just as nurses avow being patient advocates and alleviators of suffering, nurses in all positions and across the care continuum must affirm their critical role of providing palliative care regardless of education, role, or setting.

As the pervasiveness of palliative care continues across the country and mounting evidence demonstrates its benefits for patients and families, nursing must demonstrate leadership in embracing and providing high-quality palliative care. This call to action provides actionable items for nurses to address barriers to nursing leading palliative care initiatives across care settings. But these are merely first steps. Through increased evidence-based research, education, and administrative support, all nurses can collaborate with their clinical partners to seamlessly and continuously address the goals of palliative care for their patients and families.

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Table 1

Definitions of terms related to palliative care.

Term	Definition
Palliative care	<p>Patient and family-centered care throughout the continuum of illness that optimizes quality of life by decreasing suffering including eight domains:</p> <ul style="list-style-type: none"> • Structure and process of care • Physical aspects of care • Psychological and psychiatric aspects • Social aspects of care • Spiritual, religious, and existential aspects of care • Cultural aspects of care • Care of the patient at the end of life • Ethical and legal aspects of care
Hospice care	Patient and family-centered care to manage physical, emotional, social, and spiritual needs at the end of life and into bereavement
Advance care planning	A dynamic process where patients anticipate and discuss treatment options in preparation for death, serious illness, and/or potential incapacity; can result in the completion of advance directives and POLST forms
Advance directives	A variety of legal documents (i.e., living will or durable power of attorney) providing details on the patient's future healthcare wishes and goals of care
Living will	Document detailing an individual's healthcare preferences under specific situations, can include information on refusing, limiting, or withholding life-sustaining treatment
Durable power of attorney	Document appointing a health care proxy to make healthcare decisions in the event of decision making incapacity
Healthcare proxy	Individual appointed by the patient to make healthcare decisions when the patient lacks decision making capacity
POLST form	Physicians Orders for Life-Sustaining Treatment (POLST) forms include actionable medical orders for seriously ill patients; meant to be easily modified and used to determine the appropriateness of life sustaining measures in a medical crisis; MOLST, MOST, and POST forms are similar to POLST forms.