Role of the Nurse in the Palliative Care Community

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Introduction to Palliative Care

Palliative care is a person/family-centered approach that focuses on the physical, functional, psychological, social, practical, and spiritual consequences of a serious illness [17]. When offered early in the serious illness trajectory, palliative care has been shown to improve quality of life; decrease symptom burden; facilitate advance care planning by ensuring health care is concordant with patient and family caregiver goals, values, and preferences; and increase survival [1, 7, 16, 36]. Nurses play a paramount role in the palliative care community around the world, a variety of settings, and in diverse roles. This chapter highlights the role of the nurse in the delivery of palliative care.

Palliative Care in Various Settings

Palliative care may be delivered in primary, secondary, or tertiary settings (Fig. 1) [23, 31, 39]. All health-care providers, including nurses, should be able to offer primary palliative care to patients and family caregivers. Primary palliative care includes employing basic pain and symptom management strategies and discussing goals of care in a variety of settings from community hospitals to remote villages around the world. Tertiary palliative care is characteristically provided at tertiary or quaternary academic medical centers by an interdisciplinary team (physician, nurse, social worker, and spiritual care provider). Many of these institutions provide both inpatient and outpatient palliative care consultation, have an inpatient palliative care unit or designated hospice beds, and have access to a palliative home care program. Interprofessional health-care team members in these academic settings, including expert nurses, are often engaged in research and educate other professionals about palliative care through fellowship programs and mentoring. Secondary palliative care, envisioned as a "bridge" between primary and tertiary PC, can be offered by specialist clinicians in community, rural, and other underserved settings.

Hospital-based inpatient palliative care programs, usually located in tertiary or quaternary centers, should be recognized as they have changed the quality of care seriously ill patients receive and end-of-life care should they die during the hospitalization. Improved standards of care, policies and processes, and outcomes' measurement are key to the provision of quality palliative care. The Joint Commission's Palliative

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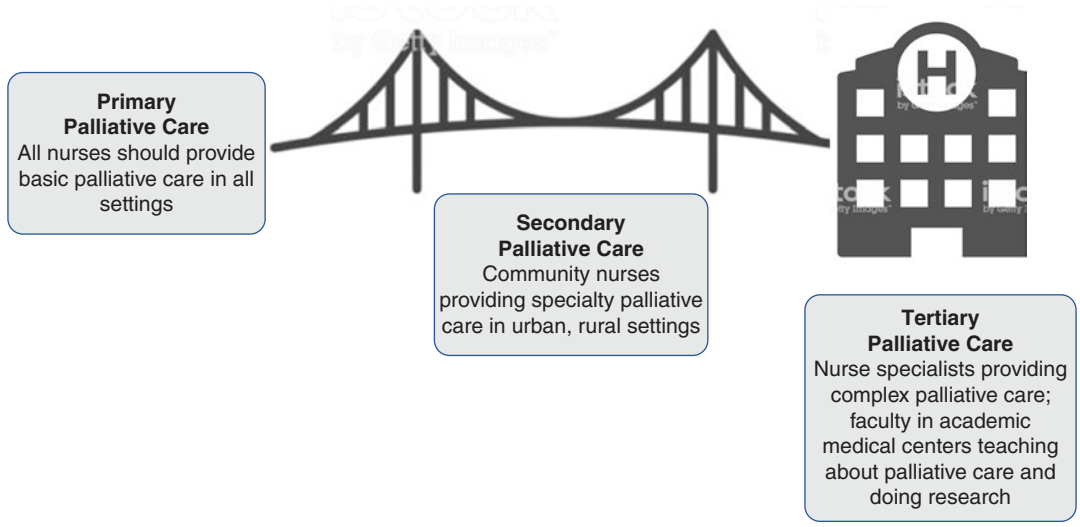

Fig. 1 Primary, secondary, tertiary palliative care: the role of the nurse

Care Certification is intended to distinguish hospital inpatient programs demonstrating exceptional patient- and family-centered care and focuses on optimizing the quality of life for those with serious illnesses [37].

While quality inpatient palliative care is important, it is ideal for patients and their family caregivers to spend the majority of their time outside of the hospital with only an occasional need to be seen by a palliative care specialist. An outpatient team or service can prove helpful, if available, to see patients who are transitioning from hospital to home and have difficulties managing symptoms or emergency needs. Having robust relationships with various community agencies such as home hospice and palliative care can prevent hospital admissions. Having access to freestanding hospice facilities, skilled hospice care within long-term care, and assisted living facilities are other options for those patients who can no longer be cared for by family caregivers in the home setting. In rural communities, home hospice care may not be an option. Visits from nurses employed by community health nursing agencies may be available; however, nurses with palliative care expertise may be scarce. Using telehealth to connect nurses in these settings to tertiary care nursing experts may be the best solution. Regardless of the setting, nurses should be equipped in a variety of roles to deliver palliative care. A description of the various roles is included below.

Nursing Roles

The American Nurses Association along with the Hospice and Palliative Nurses Association recently convened a work group to examine the role of nurses in the provision of palliative care. The report was a Call for Action for nurses to lead and transform palliative care through clinical practice, education, research, and health-care policy [5]. Nurses, being the largest health-care workforce, have an imperative to contribute their holistic and patient/family-centered care to provide quality palliative care. A recent qualitative meta-synthesis found that "Being Available" and "Being Present" were key themes depicting nurses' palliative care roles. Nursing presence is a sacred gift that can be given to patients and family caregivers in times of greatest need.

Nurses' roles in palliative care are diverse and far reaching. They span from the bedside of a patient in a hospital setting, to remote villages with minimal resources, and into classrooms and research labs. They may even be the only health-care resource available in some settings [10].

Table 1 Various nursing roles in palliative care

Nursing role	Role description	Primary palliative care responsibilities
Bedside nurse	Provide direct patient care in the hospital setting	Pain and symptom management as prescribed Communication between disciplines for seamless care delivery Patient/family communication and support Advocacy
Ambulatory nurse	Provide direct patient care to patients in the outpatient setting, such as a clinic, a telephone triage center, or infusion center	Patient/family education Early detection of uncontrolled symptoms and problems Patient/family communication and support
Nurse navigator	Coordinate care from the time of diagnosis through treatment and/or the disease trajectory	Health-care appointment coordination Patient/family education Patient/family communication and support
Case manager	Consult with patients for needs regarding care transitions, community health, and costs of care	Assist in care transitions and with home health or hospice referrals Mobilize community resources as needed Inform about costs of care and treatments
Community health nurse	Provide direct care to patients in the home, school, or long-term care facility	Pain and symptom management in the home or community setting Communication with the physician regarding care needs Patient/family education Patient/family communication and support
Advanced practice nurse	A nurse practitioner, clinical nurse specialist, or certified nurse midwife who has advanced skills in nursing and hold an advanced practice degree	Lead palliative care efforts in some settings Deliver palliative care as a health-care provider Provide disease-modifying treatment Provide pain and symptom management Facilitate advanced care planning and discussion of goals of care
College of nursing faculty	Assistant, associate, or professor at a college of nursing who is responsible for palliative care education of the nursing work	Palliative care curriculum development Palliative care education of the nursing workforce
Nurse scientist	PhD or DNP prepared nurses within a university or health-care setting who conduct palliative care research, quality improvement, and/or promote evidence-based practice	Encourage the use of evidence-based practice in palliative care Discover new knowledge to expand nursing science of palliative care

Table 1 includes a summary of nursing roles in palliative care with further discussion below. The most common roles are listed, although many roles such as patient/family caregiver education and support and advocacy are cross-cutting to some degree across nursing roles.

Bedside Nurses

Seriously ill patients who require hospitalization are often the sickest and most vulnerable. They are in the hospital because they require 24-hour nursing care. Control of pain and other deleterious symptoms is paramount and the focus of palliative care in the hospital setting [12]. Within the clinical setting, nurses are called to improve pain and symptom management through comprehensive assessment, and prompt management through the delivery of both pharmacologic and nonpharmacologic interventions. The goal is to manage symptoms quickly and effectively so that patients can spend more time at home, if preferred. Nurses may need to advocate for patient comfort and easy access to supportive medications [28].

Hospitalized patients may also be in crisis, with progressive disease, medical emergencies, and uncontrolled symptoms. This can often be the reason for hospitalization; admission to the

intensive care unit (ICU) is not uncommon. Disease progression and changes in physical status may warrant a change in the goals of care. These events lead to important conversations, and nurses should be well-equipped in communicating with patients and family caregivers during these crises to ensure goal-concordant care. A survey of 598 ICU nurses found that the majority (88%) engaged in conversations about prognosis, goals of care, and palliative care [6]. Nurses perceived these conversations as important role functions that are critical to quality care.

Because palliative care requires specialized training and skills, some hospitals are providing focused training for bedside nurses. One model hospital in Florida, the USA, has initiated an advanced training program for a select group of nurses. The Palliative Care Resource Nurse is embedded on the nursing unit to provide patient advocacy, discuss goals of care, and help patients discuss advance directives [20]. As hospitals become more focused on palliative versus curative models of care, these nurse-based resources are likely to soar.

Ambulatory Care Nurses

Nurses are key members of the health-care team in ambulatory care settings. Roles include telephone triage, patient education, and provision of infusion therapies such as chemotherapy and blood products [40]. Patients receiving ambulatory care are often more stable than hospitalized patients but have ongoing needs for optimal control of pain and symptoms [28]. Nurses in this setting should ensure optimal quality of life while keeping the patient out of the hospital setting. Early identification for palliative care is another role. Nurses are often the first to recognize uncontrolled pain or symptoms or psychosocial distress, which could warrant a palliative care referral [18].

Ambulatory palliative care programs are also growing and provide an important extra layer of support for many patients. Ambulatory care nurses or advanced practice nurses (APNs) often serve on these teams, providing navigation or coordination of care, which will be further described later. Communication is also important in this role in lieu of discussions about advanced directives and advanced care planning as patients receiving ambulatory care are often well enough to discuss care preferences and personal goals of care [22]. It is important that nurses are equipped and trained to have these discussions when opportunities arise.

Nurse Navigators

Nurse Navigators are often referred to as guides, who walk patients and family caregivers through the care trajectory, from diagnosis through treatment. Because of the relationship established with the patient and family caregiver early in the course of a disease, establishing rapport and trust is often a tremendous benefit when discussions about supportive and palliative care emerge. Nurse navigators serve a variety of palliative care roles including symptom relief, communicating with patients and families about goals of care, and facilitating care transitions with a change in health status. They can also continue to be in touch with families during bereavement [21]. Being a coordinator of care was a top theme identified in one qualitative meta-synthesis of the nurse's role in palliative care [33].

One model program for palliative care navigation is the Billings Clinic Cancer Center, located in Billings, Montana, in the USA. The palliative and supportive care navigator is the link between the ambulatory palliative care team and the patient. The navigator schedules patients for visits with providers, attends palliative care meetings to provide input into care, conducts follow-up phone calls to assess for symptom improvement following palliative care interventions, and fields all phone calls coming into the palliative care service line. Patients and families report high satisfaction with the ability to access palliative care through a known nurse navigator.

Case Managers

Nurses serve as case managers in a variety of settings including hospitals, clinics, and even insurance companies. Their role is to facilitate

coordination of care, care transitions (e.g., from the inpatient hospital setting to home with hospice care), equal access to care, and appropriate use of health-care resources [27]. While these roles are emerging in many health-care settings, opportunity exists for these nurses to be engaged in palliative care and population health management. Patients should have access to a care manager and be informed about how these nurses can support their care. Determining pre-authorization of payment for procedures and medications to advocating for community services, care managers can help support patients and families along the care continuum.

Community Health Nurses

Community health nurses provide palliative care in homes, schools, and in long-term care facilities around the world. A recent survey of 532 home health nurses from 29 countries found that most of the work performed is palliative. Duties included health maintenance, patient and family education, and shared decision-making [10]. In many remote communities, nurses may be the only available health-care professionals, thereby their roles are expansive and of utmost importance. Millions of patients around the globe are living with serious and life-threatening conditions, requiring palliative care. Nurses can close this gap in rural and remote areas [25]. Diligent pain and symptom management, communication with the physician and other team members, communication about advanced directives and goals of care, education about self-care, and emotional support are all important roles of the community health nurse. One qualitative analysis reported four themes that reflected strategies nurses use when providing palliative care in the home: (1) adjusting care around the home environment, (2) helping patients and families discover a balance between self-care, independence, and safe care, (3) guiding patients and family members with changes needed for optimal palliative care at home, and (4) using the time at home to reflect, recuperate, and prepare for end of life [3].

Children experiencing chronic diseases and life-threatening illnesses require palliative care in a variety of settings. One goal for children is to keep them in school to normalize their life as much as possible. While some acute illnesses arise at school, most school nurses spend much of their time providing palliative care. Children with diabetes, cystic fibrosis, and cancer can require supportive care during the school day, and the school nurse is a valuable community health nurse in this setting [2].

Long-term care facilities are common in the USA and their availability is growing in many countries around the world. It is estimated that approximately 40% of all US deaths will occur in long-term care facilities by 2030. Nurses and aides are often the primary care givers within these facilities, providing ongoing palliative care. Older adults comprise the greatest numbers of residents in these facilities, who often have multiple comorbid or life-threatening conditions deeming the majority of these patients eligible for palliative care. Unfortunately, palliative care is often lacking in these facilities. Increasing access to palliative care and improving symptom management, communication, and advanced care planning is critical given the growing need of these facilities [35].

Advanced Practice Nurses

Advanced practice nurses (APNs) including nurse practitioners, clinical nurse specialists, and even nurse midwives play an essential role in the provision of palliative care [30, 32]. While not recognized in all countries around the world, their presence is growing as physician shortages grow more expansive. APNs can be a cost-effective as well as an excellent resource for patients in need of palliative care. Their holistic model of care is focused on disease-modifying care, evidence-based pain and symptom management, expert communication, education, and compassionate end-of-life care [19]. Nurse-led primary palliative care clinics are rapidly emerging in outpatient settings [13].

As noted, with the vast palliative care needs around the globe, APNs are one solution to alleviate care shortages and close the gap on unmet palliative care needs. In order to equip APNs,

significant education and skills are needed. According to a 2017 survey of 556 APNs, 41% perceived that their palliative care training and education was inadequate. Existing programs need to better incorporate palliative care curricula and developing programs should heed to these recommendations [30].

College of Nursing Faculty

Despite palliative care education and training programs, the number of qualified nurse providers remains limited. Major gaps in palliative care access exist for most patient populations in community settings. Nursing Professors and other Nursing Educators have a tremendous responsibility in educating the nursing workforce about palliative care. The needs are diverse, ranging from training APNs in resource-rich countries to training generalist nurses in resource-poor countries [8]. For undergraduate education, the American Association of Colleges of Nursing identified 17 competencies that undergraduate nursing students should achieve by the time they graduate. These are listed in Table 2 [4, 14].

The End-of-Life Nursing Education Consortium (ELNEC)-Core curriculum is one notable program that has been disseminated around the world to over 19,500 nurses in more

Table 2 Competencies necessary for nurses to provide high-quality care to patients and families facing serious illness

1. Promote the need for palliative care for seriously ill patients and their families, from the time of diagnosis, as essential to quality care and an integral component of nursing care.
2. Identify the dynamic changes in population demographics, health-care economics, service delivery, caregiving demands, and financial impact of serious illness on the patient and family that necessitate improved professional preparation for palliative care.
3. Recognize one's own ethical, cultural, and spiritual values and beliefs about serious illness and death.
4. Demonstrate respect for cultural, spiritual, and other forms of diversity for patients and their families in the provision of palliative care services.
5. Educate and communicate effectively and compassionately with the patient, family, health care team members, and the public about palliative care issues.
6. Collaborate with members of the interprofessional team to improve palliative care for patients with serious illness to enhance the experience and outcomes from palliative care for patients and their families and to ensure coordinated and efficient palliative care for the benefit of communities.
7. Elicit and demonstrate respect for the patient and family values, preferences, goals of care, and shared decision-making during serious illness and at end of life.
8. Apply ethical principles in the care of patients with serious illness and their families.
9. Know, apply, and effectively communicate current state and federal legal guidelines relevant to the care of patients with serious illness and their families.
10. Perform a comprehensive assessment of pain and symptoms common in serious illness using valid, standardized assessment tools and strong interviewing and clinical examination skills.
11. Analyze and communicate with the interprofessional team in planning and intervening in pain and symptom management using evidence-based pharmacologic and nonpharmacologic approaches.
12. Assess, plan, and treat patients' physical, psychological, social, and spiritual needs to improve quality of life for patients with serious illness and their families.
13. Evaluate patient and family outcomes from palliative care within the context of patient goals of care, national quality standards, and value.
14. Provide competent, compassionate, and culturally sensitive care for patients and their families at the time of diagnosis of a serious illness through the end of life.
15. Implement self-care strategies to support coping with suffering, loss, moral distress, and compassion fatigue.
16. Assist the patient, family, informal caregivers, and professional colleagues to cope with and build resilience for dealing with suffering, grief, loss, and bereavement associated with serious illness.
17. Recognize the need to seek consultation (i.e., from advanced practice nursing specialists, specialty palliative care teams, ethics consultants, etc.) for complex patient and family needs.

than 85 countries [15]. The modules include both didactic lectures as well as group interaction and discussion. The curriculum has been embedded into undergraduate nursing courses [26] and a graduate ELNEC program exists to educate APNs [14, 29] and educate masters and doctorate nursing practice students in primary palliative care.

Another nationally acclaimed model is one that started with a collaboration between the Middle Eastern Cancer Consortium (MECC), the Oncology Nursing Society (ONS), and the Oman Cancer Association (OCA). The training comprised four parts: Foundations, Advanced Concepts, Leadership, and Research in Palliative Care. The course engages participants using Liberating Structures (ref), which encourage participation by all attendees to brainstorm and develop individualized solutions to local problems [11, 24, 34]. Both ELNEC and this course encourage a "Train the Trainer" approach to increase spread of palliative care philosophy and principles.

A way for hospice and palliative care nurses to be recognized for their palliative care expertise and knowledge is to be certified through the Hospice and Palliative Nurses' Certification Corporation [26]. Competency-based specialty nursing certification is offered to advanced practice nurses, registered nurses, pediatric palliative nurses, nursing assistants, and those caring for patients experiencing perinatal loss. Palliative care preparation courses are offered through the Hospice and Palliative Nurses' Association and many colleges of nursing.

Nurse Scientists

Nurse Scientists provide the conduit for the discovery of new knowledge for the provision of palliative care. High-quality research is essential to build the science around pain and symptom management. While a multitude of options exist, over 65% of patients with advanced cancer and 55% of patients after cancer treatment [38] continue to suffer from pain. Other symptoms are also in need of better management [9]. The management of pain and symptoms is complex and will require nurse scientists to test educational, technological, and multimodal approaches to improve management. Better understanding of patient and caregiver perspectives will be important to gain progress in this area of research [28].

Additional palliative care research topics include best approaches to discuss advance care planning with patients from diverse cultures and backgrounds, better understanding of the complex interplay between health-care systems, health-care professionals, patients, and families, and identifying best approaches to educate patients and family caregivers about palliative care. Nurse-led models of care should further be explored as well, which examine outcomes as well as costs of care. These studies will all require multi-system study approaches. Finally, compassion fatigue and burnout of the nursing workforce are on the rise, and research should consider best approaches to sustain and improve the health of nurses who provide palliative care [5].

Barriers

While nurses work in a variety of roles in primary, secondary, and tertiary palliative care, some barriers exist that prevent quality palliative care, education, and research. First, nurses may not be fully equipped to deliver palliative care due to a lack of preparation and experience. Undergraduate and continuing education of palliative care should be fully supported by nursing leaders across all health-care settings and within every country around the world. Improving the palliative care knowledge of nurses will tremendously expand palliative care access around the globe. Second, nurses may not be practicing at their full scope due to restrictions in prescribing or care within their states or countries. Nurses should advocate for health-care policy that advances the scope of nursing so that patient access to palliative care can be fully expanded and available. Nurses should have a seat at the table to discuss care preferences, goals and care, and advance care plans with patients and families along with other palliative care responsibilities.

Third, nurses report care disparities that result in moral distress. Nurses need to advocate for appropriate pain and symptom management and optimal palliative care and support one another during these crises, in order to alleviate patient and family pain and suffering [5].

Future Directions

Nurses have the ability to both lead and transform palliative care around the globe. As the largest health-care workforce, nurses are often the only ones "present" and "available" to meet the complex physical, psychological, social, and spiritual needs of patients and families who need palliative care. The holistic approach of nursing is conducive to palliative care, and the future is bright, and yet as a profession, nursing will need to better prepare and educate nurses to meet the large demand for palliative care in the future. Education should include didactic material, but most important, it should include simulation to practice skills, discuss case studies, and shadow expert clinicians who can serve as role models. The knowledge of palliative care can be built in a classroom, but the art of palliative care must be through experiential learning and patient engagement.

Permission to reprint these competencies is under consideration.

https://www.aacnnursing.org/Portals/42/ELNEC/PDF/New-Palliative-Care-Competencies.pdf

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