Editorial

Nursing and the Future of Palliative Care

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Nurses represent the largest group of health-care professionals in the United States of America. Currently, 3.6 million nurses are positioned to contribute to the provision of holistic person-centered care.[1] Internationally, nurses comprise the largest group of health-care providers. Nurses are a vital resource for ensuring the provision of safe and effective care for the global population.[2]

Nurses spend more time with patients and families than any other health professional as they face serious illness.[3] Expert nursing care reduces the distress and burdens of those facing death, and the ability to offer support for unique physical, social, psychological, and spiritual needs of the patients and their families.[3] Collectively, nurses have demonstrated a commitment to palliative care, with some nurses showing even greater initiative in the treatment of end-of-life patients. A 2016 systematic review of palliative care health services found more support for the role of nurses than any other discipline. Of the 98/124 studies that described provider disciplines, nurses were the most common interventionists working in teams or as sole practitioners in 70% of studies.[4,5]

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"Whole Person Care" is Not Just Goals of Care

Palliative care refers to the optimization of quality of life for both the patients with serious illness and their families using special measures to anticipate, treat, and prevent suffering. This care encompasses the continuum of illnesses including physical, psychosocial, emotional, and spiritual needs of seriously ill patients.[6] The Institute of Medicine notes a responsibility to ensure that end of life care is compassionate, affordable, sustainable, and of the best quality possible.[6] Failure to provide holistic care limits the effectiveness of palliative care and can contribute to physical, social, spiritual, and/or emotional suffering.[3,7,8]

Palliative care can be provided concurrently with curative measures.[6] Concurrent care is different than a traditional hospice model, where curative therapy, or life extending measures such as palliative chemotherapy, generally have ceased. The concurrent model of palliative care may be, particularly important in lower and lower middle-income countries where access to curative care is limited. Like geriatrics and hospice, palliative care generally will use a multidisciplinary team that may be made up of nursing,

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social work, spiritual care, and medicine to meet the multifaceted needs of patients with serious illness, or who are at the end of life.[4]

Distinguishing Different Roles of Nurses

The evidence supports that nurses work in a variety of roles. These include as being members of a multidisciplinary consultation team, as individual practitioners in targeted pain and symptom management, or as case managers.[4,6,9,10]

Registered nurses

A registered nurses (RN) educates, give advice, and provides emotional support to patients and their family members. Other duties include physical assessments, health histories, health promotion, counseling, education, medication and treatment administration, wound care, and numerous other personalized interventions. RN's consult and collaborate with a multidisciplinary team and contribute to the plan of care. RN can supervise care delivery by other medical personnel like nurse aides as well as conduct research in support of improved practice and patient outcomes.

Advanced practice registered nurses

Advanced Practice RN (APRN's) can provide excellent service to those suffering from serious life-limiting illnesses. The educational preparation of APRNs allows a "greater depth and breadth of knowledge and ability to synthesize complex data to develop, implement, and coordinate comprehensive, holistic patient-centered plans of care with goals of maximizing health, quality of life, and functional capacity."[11] Depending on state licensure, APRN's may have the ability to practice, furnish medications, and bill independently.

Palliative Care Nursing

Palliative care nursing involves the assessment, diagnosis, and treatment of human responses to actual or potentially life-limiting illness and necessitates a dynamic, caring relationship with the patient and family to reduce suffering. Therefore, palliative nursing is a subspecialty of nursing practice that continues to evolve as the art and science of nursing, and palliative care evolves.[12]

Palliative care nurses work in varied settings including patients' homes, residential hospices, clinics, long-term and skilled care facilities, and acute in-patient facilities.[6] Palliative care should adapt accordingly to meet the physical, emotional, social, and spiritual needs of the patient and their families.[11] Palliative care nurses may be hospice nurses, an advanced practice nurse (APN) with a master's degree or higher, or an acute care RN with additional training. Currently, no standard education for a "palliative care" nurse exists, commitment to caring for a patient with a serious illness is a must. A palliative care nurse could have a wide variety of education, training, and clinical experience.

Special skills of palliative nursing

Palliative care nurses have adjusted their frame of mind from one which revolves around specific tasks such as vital signs, treatments, and interventions, to one of comfort, symptom management, and support.[13] Many nurses involved in palliative care face the challenge of combining the art of caring and the science of medicine into a cohesive model that reflects compassionate, individualized care regardless of the environment.[7] Palliative care nursing demands intense critical thinking, heightened levels of mental functioning, and the ability to utilize complex palliative nursing skills.[14] Palliative care nurses are repeatedly confronted with patients and families who encounter serious end-of-life illness and death.[14,15] These situations are further complicated by complex social situations, difficult diagnoses, challenging symptom management, and challenging communication concerning patient death and grief.[12-16]

Communication

The ability to effectively communicate with patients and families is an important skill for any palliative care nurse. Palliative care nurses must have the ability to explain complex information, as patients are often seeking clarity on disease progression, medications, and plan of care. Palliative care nurses must be able to communicate this information to both the patient and family. It is within the nursing scope of practice to thoroughly explain and educate patients and families on symptoms and treatments through the end of life, including medication regimens.

Compassion

Merriam-Webster[17] defines compassion as "sympathetic consciousness of others' distress together with a desire to alleviate it." Compassion for self can help to prevent burnout, while compassion for patients and families helps to establish a supportive, trusting relationship as symptoms change or worsen or as death approaches.

Human vulnerability

Although the time of on-going disease progression and at the end of life can be distressful, it can also be a time of togetherness for patients and their loved ones. The palliative care nurse has a window into some of the most intimate moments in a person's life. Patients and families tend to remember the nursing response to their needs, which,

through communication, presence, symptom management, and other work within their multidisciplinary team, allows nurses to leave a legacy through care.

Building on Current Roles of Nurses

Primary or generalist palliative care

The generalist nurse has the necessary skills and knowledge to care for dying patients, as well as those with chronic, serious illness; this includes a basic ability to provide relief from pain in addition to symptom assessment and management.

Specialist palliative care

The palliative care RN and APRN specialist has expert knowledge in palliative care, including the pathophysiology of diseases, advanced pain and symptom assessment and management, counseling and communication skills, and advanced care planning. They also have advanced knowledge about caring for individuals with serious, life-threatening illness, as well as those who are imminently dying.[18]

Palliative Oncology Nursing

Although palliative care is useful for a variety of conditions, and much of the high-quality research completed is not unique to medical conditions, the evidence base is strongest for cancer.[4] Early palliative care is particularly beneficial with two recent randomized controlled trials showing that palliative care improves the quality of life of patients with lung cancer and also when they are receiving bone marrow transplant.[8,19,20] Oncology nurses in palliative care will bridge the gap of continuity as they deliver physical and psychosocial care throughout treatment and beyond. Oncology nurses are in a unique position to advocate and address many ethical and legal aspects of care as well as ensure the patient receives palliative care as the patient progresses through illness from curative to palliative treatments.

Methods to Upskill the Current Nursing Workforce

In March of 2017 the American Nurses Association and Hospice and Palliative Nurses Association (HPNA) presented a call to action for nurses to lead and transform palliative care. One of the nursing recommendations included the adoption of End of Life Nursing Education Consortium (ELNEC) curricula (Core, Geriatric, Critical Care, Pediatric, APRN and Online for Undergraduate Nursing Students) as the standard for primary palliative nursing education. ELNEC has also provided education in 90 countries including Japan, Korea, China, Eastern Europe, as well as Kenya. ELNEC has been translated into Spanish, Japanese, Korean, Chinese, Russian, Romanian, Albanian, and German.[8]

There are many educational offerings available for palliative care nurses to improve their knowledge base in palliative and end of life care. Other offerings range from 1 day, simple classes to long, and certifications programs. Certification in Palliative care is offered by the HPNA for Nurse Aides, licensed practical nurse/licensed vocational nurse, RN and APN levels. Colleges offer online and classroom options for certificate programs in palliative nursing. Alternative education including fellowship programs, leadership programs, conferences, and ELNEC courses are also offered.

Of note, for international providers, Stanford offers an online resource, Palliative Care Always (https://lagunita.stanford.edu/courses/Medicine/pc_always/Winter2016/about), which is offered annually and has been used by thousands of participants to gain a fundamental knowledge base about the practice of palliative care.

Sole Practitioners

The highest quality evidence for nurses as independent practitioners has been described in the Education Nurture Advise before Life Ends (ENABLE) studies. The ENABLE intervention included a series of 4 weekly sessions followed by at least monthly follow-up with patients and caregivers until death. Sessions focused broadly on the quality of life relevant issues, communication, and involved pro-active assessment and prevention. ENABLE II showed benefits in quality of life and depression in patients, and the intervention did not directly benefit caregivers. ENABLE III evaluated early versus later nurse intervention; earlier intervention was associated with improved mortality with 63% of patients getting early compared to 48% of patients receiving late palliative care surviving to 1 year.[5,9,10]

Transitions in Health Care

The APRN provides on-going assessment and intervention so he/she can educate and guide the patient and family on a realistic understanding of the disease processes. Not only does this build a trusting relationship with the patient and family but also promotes safe transitions and autonomy, as it allows the patient and family to be an active part of developing a plan of care.[3,7,11]

Conventionally, medical care has focused on cure-oriented care in an acute care setting based on episodic illnesses. However, people have begun to live longer with increasingly complex chronic illness making this type of care insufficient. The service areas should communicate, coordinate, and

work together to care for the person as they promote the goals and wishes of the person.

Care transitions are not only from the hospital to home. Transitions also exist in the type of care which is being delivered to the patient. Points of transition in care include a mix of palliative, cure-oriented or life-prolonging care, a transition to palliative care only, or change to the end of life care.

For patients with longstanding serious chronic illness prognostic uncertainty makes the transition to alternate levels of care difficult. With these multiple transitions nurses must be able to work amidst the transitions and in a multitude of settings.

Nurses Supporting Community Practice Models

People facing serious and end of life illness prefer to be in their own home and community. Palliative care in the community setting (defined here as care outside of the hospital) therefore focuses on providing palliative care through established delivery systems, such as home care and hospice, as well as collaborative partnerships with service agencies and individual clinicians. The point is to maintain a person's life at home or place of residence by maximizing the quality of life, optimizing function and providing care that supports their goals and preferences. In community models, nurses may play a crucial role in coordinating, delivering, and overseeing care in the home and community by working indirectly with lay community health workers.

Home visits

Palliative care nurses can offer specialty consultation in the home setting. This includes some of the complex, time-consuming care coordination, symptom management, and end of life care. Some examples of where home-based palliative care can be utilized include; office visits are a significant hardship, long intensive, or more frequent visits or patients in areas without an available office-based palliative care practice.

Efficient models that utilize nurses, APRN, RN, and social workers, to manage the person's medical, medication, activities of daily living, social and care coordination needs. A nursing palliative care home-visit team may become primary care providers or may co-manage care with other providers.

A home-based palliative care can provide an excellent opportunity to coordinate care, decrease acute care visits, decrease cost, reduce hospital stay, and care for those with serious chronic illness (es) in need of chronic disease management.

Nursing and Interactions with Technology

Use of telehealth

Telemedicine, also known as telehealth, is a rapidly developing application of clinical medicine by which medical information is transferred via telephone, the Internet, video, or other networks for monitoring health status, offering education, consulting, and providing remote medical procedures or examinations. Telemedicine can take place between providers and patients located in clinical settings (clinical video telemedicine) as well as directly with patients in their homes (home telemedicine).

Although there have been no extensive studies of the use of telemedicine for the delivery of palliative care, studies of patients with chronic diseases such as congestive heart failure, chronic obstructive pulmonary disease and diabetes suggest that home telemedicine may reduce rates of hospitalization and emergency department visits, reduce hospital length of stay, improve clinical outcomes, and enhance patient's satisfaction. There are still significant gaps in the evidence base between where telemedicine is used and where high-quality evidence supports its use.

Technology allows providers in palliative medicine to use audio and/or video conferencing with the presence of the patient and provider at the same time. The technology provides a communication link between them that allows a real-time interaction to take place.

Conclusion

Nurses play crucial roles in palliative care, and the evidence supports nurses functioning on palliative care consultation teams or as independent practitioners. Nurses can be active at focused tasks (e.g., pain management) or in broad roles (e.g., case management); although, patients and families with cancer have a spectrum of needs that nurses can play a critical role in alleviating. Evidence supporting independent practice is especially important in lower resourced settings where nurses also may play a crucial role supervising community health and lay workers or volunteers.

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Conflicts of interest

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