Palliative Care Nursing

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Palliative Care Nursing

According to the most recent National Vital Statistics Reports, 2,436,652 deaths occurred in 2009, of which 568,688 were due to cancer, second only to heart disease.[1] In 2009, those 65 years or older constituted 39.6 million and represented 12.9% of the US population. By 2030 they will represent 19.3%, with those 85+ representing 15% of the population as early as 2020.[2] In addition to age, illness, and death statistics of those <65, these numbers bear serious consideration regarding the amount of health care that will be required to care for these future patients. Nurses have always been involved in the front lines of care, ensuring that it is delivered safely, effectively, and compassionately. As our society ages, palliative care nurses will be even more vital to providing expert care in meeting the many needs experienced by oncology patients and their families.

Palliative Care Defined

The World Health Organization defines palliative care as the following: "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."[3] In 2004, the National Consensus Project for Quality Palliative Care, comprising 4 major palliative care organizations: the American Academy of Hospice and Palliative Medicine (physician membership), the Center to Advance Palliative Care (palliative care advocacy), the Hospice and Palliative Nurses Association (nursing membership), and the National Hospice and Palliative Care Organization (hospice membership), created and published the Clinical Practice Guidelines for Quality Palliative Care.[4] The Guidelines state that "The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly

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structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care. . ."[4] According to these definitions, providing palliative care necessitates the expertise of an interdisciplinary team, of which nurses are a vital member.

Palliative Care Nurses

Palliative care nurses can be generalists or advanced practice nurses. Nursing is defined by the American Nurses Association (ANA) Scope and Standards of Nursing Practice as "the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human responses and advocacy in the care of individuals, families, communities, and populations."[5] By this definition, nurses, in general, already provide palliative care within the scope of practice in their everyday work setting. However, as palliative care continued to grow as a specialty practice, there arose a need for standards of practice. In 2007, the ANA and Hospice and Palliative Nurses Association collaborated to create the Scope and Standards of Palliative Nursing Practice.[6] These Standards address the specifics of the general and advanced practice levels of palliative care nurses. These Standards also dovetail well with the Clinical Practice Guidelines for Quality Palliative Care. In addition to the need for standards, there has also been an increasing need for advanced practice nurses (APNs) who specialize in palliative care.

Advanced Practice Nurses in Palliative Care

Education and Training

As in other specialty fields in nursing, advanced nursing practice in oncology requires a master's degree level education.[7] Oncology APNs in palliative care have specialty education preparation that enables them to function as experts in this field.[8] In addition to expert knowledge, critical thinking skills, and evidence-based practice, these APNs also have trained communication skills that facilitate patient care in diverse settings regarding patient and family education, psychosocial and spiritual care, and informed decision-making.[9,10] APNs are trained to function in 5 roles that include clinical expertise, clinical consultation, administration, education, and research. As clinicians, oncology APNs in palliative care

manage both acute and chronic symptoms of varying complexities. The clinical consultant provides expertise to colleagues that includes advising, offering resources, assisting with complex clinical issues, and evaluating policies and procedures. Oncology APN administrators deliver leadership that supports and enhances an environment that facilitates and promotes best nursing practice. Oncology APN educators assess and provide patient, staff, and community education; they design, implement, and evaluate educational activities and programs. The oncology APN collaborates on research that is then integrated into clinical practice.[7,9,11-14] Most APNs in palliative care are academically prepared clinical nurse specialists or nurse practitioners.[15]

Vital Member of the Interdisciplinary Palliative Care Team

There is agreement in the literature that APNs are critical to the palliative care team.[12-14,16-18] It is recognized that nurses commonly spend the most amount of time with patients and family members regardless of the setting, and that fact is most true in palliative care. APNs have broad assessment and evaluation skills, which are critical for other team members to contribute their expertise in creating a comprehensive care plan for the patient and family. Members of the palliative care interdisciplinary team vary based on need and resources but usually include physicians, chaplains, social workers, and nutritionists, among other disciplines if available and when needed.[11,18] APNs serve as the primary link between the patient, family, and members of the interdisciplinary palliative care team and are the ones who communicate the team plan with the patient and family.[16]

Palliative Care APN in Action: Case Study

Mrs C is a 55 year old with advanced non-small-cell lung cancer who suffers from shortness of breath, especially on exertion. Recently her disease progressed, and she is now on third-line chemotherapy. Her Eastern Cooperative Oncology Group (ECOG) performance status is 2. She is feeling scared and anxious about the lung cancer becoming worse and also feels like she is losing control. She has been coping well with her disease but is now reluctantly asking for help. Her husband is very supportive but "hovers" over her and causes her to feel "smothered." They have multiple grandchildren (ages 2-16) permanently living with them because of various issues with their 2 sons. Furthermore, she knows she needs to complete an advance directive but her husband "will not go there." Mrs C has a strong faith but feels blindsided by this diagnosis. She

states that she has "done all the right things" and does not understand why God would allow this to happen to her.

The APN had already established a relationship with the patient and several family members, so Mrs C feels comfortable having her case presented to the palliative care team. The APN presented each issue in detail to the team, answered questions, and facilitated discussions of care. A consult was set up with the pulmonary rehabilitation physician who would, among other things, teach her techniques to help her with her shortness of breath. A discussion was facilitated by the APN between the medical oncologist and the pulmonary rehabilitation physicians regarding disease trajectory and potential further treatment as to rehabilitation expectations. Because of the APN's prior assessment, she knew the patient was willing to be seen by a social worker. Details of the patient's home life and concerns were shared and the resulting plan included setting up 2 appointments. The first appointment would be for the patient to talk to the social worker alone about her feelings and concerns and to discuss the advance directive. The second appointment would be held at a time when her husband could accompany her to provide him an opportunity to share his feelings as well. In addition, the APN and social worker connected Mrs C and her husband with a Child Life Specialist to help them cope with the multiple grandchildren at home.

Spiritually, Mrs C's faith was not providing an explanation or a comfort to her regarding her illness. She was experiencing conflicting feelings of believing in God, yet questioning why He would allow this to happen. The APN requested the chaplain visit the patient as well as share with the team how they could best be of help to this patient in this area. The results of this plan were agreeable to the patient and she was seen and continues to be followed by those requested. Her disease is stable on this line of chemotherapy, making it easier to implement the techniques and information provided by pulmonary rehabilitation. She and her husband both shared that their visit with the social worker was very helpful. She has also begun completing her advance directive. Although Mrs C cannot control her adult sons, the Child Life Specialist helped provide her with practical tools to help with her grandchildren. Mrs C appreciated the chaplain's visit and wishes to continue their visits.

In addition to focusing on the whole person to promote quality of life along the illness trajectory, the APN provided continuity of care and coordination of services provided. She followed up with team members providing consults as well as with the patient to evaluate their effectiveness.

Palliative Nursing Care in the Future

In addition to the many patients who have noncancer diseases, the American Society of Clinical Oncology predicted an 81% increase in those living with or surviving cancer by 2020. They also report that there will be a shortage of primary care physicians as well as nurses.[19,20] As palliative care (cancer and noncancer) expands into further medical specialties, such as geriatrics, and increasingly becomes necessary for vulnerable populations, such as those in nontraditional settings, such as prisons, psychiatric care facilities, and homes for the disabled, there will be a significant need for palliative care oncology APNs.[10]

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