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PEDIATRIC PALLIATIVE CARE IN CHILDHOOD CANCER NURSING: FROM DIAGNOSIS TO CURE OR END OF LIFE

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OBJECTIVES: *To describe selected components of pediatric palliative care from diagnosis to cure or end of life that combine to help nurses and other clinicians achieve goals of care for children with cancer and their families.*

DATA SOURCES: *Published articles.*

CONCLUSION: *Pediatric palliative care is characterized by diversity of care delivery models; effect of cancer on the family as the central focus of care; and consideration of culture, spirituality, communication, and ethical standards. End-of-life issues that can be anticipated by nurses and other clinicians include symptoms of cancer or its treatment, the importance of hopefulness, the relevance of trying to be a good parent in decision making, the meaning of legacy making of ill children, and family bereavement.*

IMPLICATIONS FOR NURSING PRACTICE: *Direct nursing care strategies to achieve pediatric palliative care goals are vital to reduce child and family suffering from cancer.*

KEY WORDS: *Pediatric palliative care, pediatric oncology, nursing care, family.*

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THE PURPOSE of pediatric palliative care (PPC) in oncology is to deliver competent, compassionate, and consistent care to children living with cancer and their family members.[1] Pediatric palliative cancer care includes physical, psychological, educational, social, and spiritual goals and is provided concurrently with disease-modifying therapies or as the main goal of care. This care aims to enhance life, decrease suffering, optimize function, and provide opportunities for personal and spiritual growth. Interdisciplinary palliative care includes the child, family, and caregivers from the time of the cancer diagnosis, continuing throughout all cancer treatments into survivorship or cure, or until the end of life. The purpose of this article is to describe selected components of PPC that when combined help nurses and other clinicians achieve goals of care for the ill child and the child's family. Particular emphasis is given to the careful selection of a model of care that matches the culture of the care setting; incorporates essential components of PPC (effect on family, cultural considerations, spirituality, communication, ethical standards) and guides strategies to achieve related goals; anticipates end-of-life issues (symptoms of cancer or its treatment, hopefulness, trying to be a good parent in decision making, legacy making); considers bereavement of family members who experience the death of their child, and the effect of PPC care on the nurse.

MODELS OF PEDIATRIC PALLIATIVE CARE

The task of caring for the estimated 50,000 children who die each year in the United States and the more than 500,000 children who are living with life-limiting conditions is daunting.[2] The growth of PPC programs has significantly increased throughout the United States and internationally since the first programs of the late 1990s.[3] The American Academy of Pediatrics[4] and the Institute of Medicine[5] call for the integration of palliative care early in the process of life-limiting illnesses. However, these calls to action do not define best practice for models of care.

Several models of care delivery exist (Table 1) to guide the highest quality of care in the face of resource limitations, a shrinking health care economic environment, and the overwhelming needs of patients and families. The models differ by the extent to which a PPC team has responsibility for direct care (from consultative only to becoming the primary care providers), the location of the team involvement (inpatient, outpatient, home, or hospice), and the flexibility of the care (limited to a single area or moving with the child across care areas). Each of these models has advantages and disadvantages that must be weighed against the benefits to patients and their families, health care staff, and institutions. These models of care are not mutually exclusive and may exist within a single institution or illness trajectory for any given child. Each institution must determine which program will best meet the needs of its patients, families, and health care teams in the context of health care reform initiatives and available resources.

The choice of the care delivery model should be based on a needs assessment and available resources. Nursing plays an integral role in PPC program development and should be at the forefront of needs assessment. The nurse is a main care provider in each of these care delivery models, yet subtle differences in the nursing role may exist, depending on the institution's vision. Several excellent assessment tools are available through the Center to Advance Palliative Care or other sources, such as the Initiative for PPC Institutional Self-Assessment Tool, which can guide reflection of institutional and unit-based issues and policies.[6,7]

ESSENTIAL COMPONENTS OF PEDIATRIC PALLIATIVE CARE

Effect on the Family

Universal to all delivery models in PPC is care to the seriously ill child, and his or her loved ones. Childhood cancer pervades the life of the entire family unit. Parents, ill children, and siblings have perceived that cancer caused the life of their family to break or fall apart.[8] Fear, uncertainty, chaos, and loneliness replace what was safe, secure, and well known. Family members have reported that they experience fundamental changes in their daily lives. For example, the child with cancer may not be able to attend school as usual, and parents' work routine is altered. Healthy siblings are often cared for by grandparents or friends and often have to go to the hospital to visit their ill sibling or parents. Siblings sometimes assume caregiving or protective roles of caregiver

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