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# CONTRIBUTIONS OF PALLIATIVE CARE TO PEDIATRIC PATIENT CARE

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**OBJECTIVES:** *To provide an overview of pediatric palliative care (PPC) as it relates to children and families living with oncologic disease.*

**DATA SOURCES:** *Journal articles, clinical research reports, clinical guidelines, and national statistics.*

**CONCLUSION:** *As new treatment protocols become available, the need for simultaneous supportive PPC, including adequate pain and symptom management, is evident. Further research and PPC program development is necessary for adherence to the current recommendation that PPC should be initiated at the time of diagnosis and continue throughout the course of a child's disease.*

**IMPLICATIONS FOR NURSING PRACTICE:** *Palliative care nursing holds a specific role in the pediatric oncology setting. Registered nurses and advanced practice nurses should be adequately trained in PPC because they are in an optimal role to contribute to interdisciplinary PPC for pediatric oncology patients and their families.*

**KEY WORDS:** *Pediatric oncology, Pediatric palliative care, Nursing*

**O**f the approximately 53,000 children that die each year, approximately 2,200 are from pediatric cancers.<sup>1</sup> Cancer is the leading disease-related cause of death in children and adolescents ages 1 to 19,<sup>1</sup> (referred to collectively as *children* for

the purposes of this article). In 2014 it is predicted that of the 10,450 diagnosed with cancer, 1,350 children are expected to die from their disease.<sup>2</sup> This presents a crucial need for pediatric palliative care (PPC) within pediatric oncology, yet PPC programs are not as common as adult palliative care

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0749-2081/3004-836.00/0.

<http://dx.doi.org/10.1016/j.soncn.2014.08.003>

programs. In fact, although 58% of Children's Oncology Group institutions (an institution that is supported by the National Cancer Institute and is devoted to pediatric cancer research that conducts clinical trials) have palliative care programs, only 6% discuss palliative care at diagnosis.<sup>3</sup> There are several barriers that challenge palliative care delivery in oncology which are both specific and non-specific to pediatrics.

Several barriers exist that prevent sufficient palliative care for children with cancer, including:

- relative rarity of cancer and death in children,
- the developmental stage of the child,
- a lack of evidence-based medicine to define symptoms and causes of death,
- difficulty in symptom management,
- lack of education for healthcare providers about palliative care, and
- reimbursement issues.

All of these barriers contribute to the lack of integration of PPC in pediatric oncology. Utilization of registered nurses (RNs) and advanced practice nurses (APNs), referred to collectively as *nurses* for the purposes of this article, can optimize delivery of PPC within the oncology setting as they are in a unique position to bring together the interdisciplinary team caring for children and families.

Semantics and assumptions have led palliative care to become synonymous with end of life (EOL), death, and hospice, and a lack of a clear definition of PPC often impedes its delivery. For this reason, it is important to define clearly PPC. Several groups, such as the World Health Organization, the American Academy of Pediatrics (AAP), and the Institute of Medicine, have each developed definitions that specifically address PPC. In summary, PPC can be defined as a philosophy of care and an organized program that focuses on total care and enhancement of quality of life of a child and family in the face of life-threatening illness.<sup>4-6</sup>

Different developmental tasks influence how children perceive and cope with illness and possible death, and a crucial aspect of PPC is the consideration of the developmental stage of the child (see [Table 1](#)).<sup>7,8</sup> Children whose disease trajectory spans more than one developmental stage call for constant evaluation and adaptation of the delivery of support and care.<sup>1</sup>

Interventions and approaches should be informed by both the child's chronological age and developmental stage,<sup>9</sup> because they do not

always coincide. It is not unusual for children with advanced illness to either progress or regress in developmental stage. Therefore, when delivering PPC, the child should be considered as a product of their chronological age, developmental stage, medical condition, size, handicap, and cognition.<sup>9</sup> Another barrier is the lack of distinction between PPC and hospice. The use of the terms *palliative care* and *hospice care* interchangeably in the common vernacular has led to confusion in the healthcare field. Although hospice and palliative care share a similar philosophy, they are different entities. Hospice is a part of PPC used for children at later disease stages, whereas the larger palliative care model represents an integrative approach in which care is initiated at diagnosis and delivered through the EOL. Integrative models combining curative care and palliative care enable continuity of care and facilitate a seamless transition to EOL care. It is suggested that palliative care be delivered within disease-focused medical treatment, regardless of curative goals.<sup>10</sup>

## PEDIATRIC PALLIATIVE CARE IN ONCOLOGY

Medical and pharmacologic advances within the last 40 years have drastically improved the survival rate in childhood cancers. Hodgkins and non-Hodgkins lymphoma, Wilms tumors, and acute lymphoblastic leukemia are now considered very curable diseases.<sup>11</sup> Also, survival rates have increased for bone cancer, gonadal cancer, and neuroblastoma.<sup>11</sup> Yet, despite these advances, cancer remains the overall leading cause of pediatric death second to motor vehicle accidents. Metastatic solid tumors and brain tumors continue to be difficult to treat.<sup>11</sup> In short, it is evident that palliative interventions are necessary as suffering is universal for children with cancer and their families.<sup>10</sup> A further examination of definitional clarity, disease trajectory, and symptom management point out the unique obstacles facing PPC delivery in pediatric oncology.

## DEFINING PALLIATIVE CARE

Definitional clarity affects the delivery of PPC in all fields. Although it is recommended that palliative care be offered early in the diagnosis, the various ways in which PPC is defined contributes to incomplete or inadequate interventions. For

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