
CLOSING THE GAP ON PEDIATRIC PALLIATIVE ONCOLOGY DISPARITIES

ERIN R. CURRIE, STEADMAN L. MCPETERS, AND JENNIFER W. MACK

OBJECTIVES: *To describe pediatric palliative care (PPC) in pediatric oncology, the importance of PPC for pediatric oncology patients, disparities within pediatric palliative oncology, innovative strategies for improving PPC access in underserved populations, and implications for oncology nursing practice.*

DATA SOURCES: *Published pediatric oncology and palliative peer-reviewed articles and guidance documents.*

CONCLUSION: *Disparities exist within pediatric palliative oncology. There is much work needed to improve the reach and quality of PPC for pediatric oncology patients, especially those from underserved populations.*

IMPLICATIONS FOR NURSING PRACTICE: *Nurses serve a critical role in advocating for PPC for seriously ill pediatric cancer patients and their families.*

KEY WORDS: *pediatric oncology, pediatric palliative care, telehealth, rural health, vulnerable population.*

The field of pediatric oncology has celebrated many achievements that have increased survival outcomes; however, there is a great need to integrate

supportive care services, such as pediatric palliative care (PPC) to ease the suffering of pediatric, adolescent, and young adult cancer patients.^{1,2} Standard pediatric cancer care is based on three overarching aims: 1) to work toward cure for every child with cancer; 2) to provide high-quality palliative and supportive care throughout illness and survivorship; and 3) to provide high-quality end-of-life care for patients with a terminal diagnosis.³ Even in the most favorable circumstances, where treatment leads to survival, cancer treatments are associated with high symptom burden, resulting in suffering that could be minimized by the early integration of palliative care.^{3,4} The American Society of Clinical Oncology recently published guidelines for all patients with advanced cancer to receive concurrent palliative care services early in their disease.⁵

Erin R. Currie, PhD, RN: Assistant Professor, University of Alabama at Birmingham School of Nursing, Birmingham, AL. Steadman McPeters, DNP, CRNP, CPNP-AC, RNFA: Assistant Professor, University of Alabama at Birmingham School of Nursing, Birmingham, AL. Jennifer W. Mack, MD, MPH: Associate Professor of Pediatrics, Harvard Medical School, Dana-Farber/Boston Children's Cancer and Blood Disorders Center, Boston, MA.

Address correspondence to Erin R. Currie, PhD, RN, Assistant Professor, University of Alabama at Birmingham School of Nursing, 1720 2nd Avenue South, Birmingham, AL 35294. e-mail: ecurrie@uab.edu

© 2018 Elsevier Inc. All rights reserved.

0749-2081

<https://doi.org/10.1016/j.soncn.2018.06.010>

Despite the evidence that supports integrating early PPC with cancer-directed treatment, PPC is often provided very late in the diagnosis or not at all.^{6,7} Childhood death is a tragic, unnatural loss. As a result, parents, children, and clinicians may all wish to pursue aggressive measures to prolong life, and may defer inclusion of palliative care because of the misconception that it is an “either” “or” choice. Underserved pediatric patients from areas with few primary and specialty care providers⁸ are at risk for health disparities, inferior cancer-related outcomes, and suboptimal palliative care and symptom management. Using a search of recently published literature through PubMed and current oncology practice guidelines, this article describes the role, importance, and disparities in PPC in pediatric oncology, innovative strategies for improving PPC access in underserved populations, and implications for oncology nursing practice.

PEDIATRIC PALLIATIVE CARE IN ONCOLOGY

PPC is family-centered, specialized medical care for children with serious illness, such as cancer.⁹ PPC helps relieve physical, emotional, psychosocial, and spiritual suffering for children with serious illness by providing interdisciplinary services that focus on improving quality of life.⁹ The PPC team has specialized training in facilitating informed decision making, assisting with care coordination, and supporting the family through illness and bereavement.¹⁰ As an integral component of comprehensive cancer care, PPC supports the whole person and family regardless of where the patient is in their illness trajectory.² The current recommendation is to integrate PPC at the time of diagnosis for the patient and families to maximize the benefits associated with an added layer of palliative support.^{2,3,11} In this continuum of PPC delivery, hope for cure and life extension may extend through end-of-life care, and hope for comfort and meaning extend through bereavement care (see [Figure 1](#)).

THE URGENT NEED TO INTEGRATE PALLIATIVE AND PEDIATRIC ONCOLOGY CARE

Children with advanced cancer experience substantial suffering at the end of life, with special challenges in management of symptoms such as fatigue, pain, or dyspnea.⁷ Wolfe et al¹² conducted

PediQUEST, a prospective study using the self-assessment of symptoms in pediatric cancer patients. High levels of distress secondary to pain (48%), fatigue (46%), drowsiness (39%), and irritability (37%) among other symptoms were reported at the end of life.¹² Over the last 12 weeks of life, the presence of physical symptoms and distress increased over time.¹² These study results are of particular importance because many studies rely on parent-reported experiences, not first-hand pediatric patient-reported outcomes. Osenga et al¹³ conducted a retrospective chart review and compared circumstances before death in pediatric patients who received PPC and those who did not during an in-patient pediatric hospitalization. Of this chart review, 8% of the patients were diagnosed with cancer and reported dyspnea (36%), seizures (22%), and terminal agitation (22%) at the end of life.¹³ Given the high levels of distress and symptoms in pediatric cancer patients, considerable efforts should be made to improve efforts that enhance quality of life, such as PPC, and gain a better understanding of why these beneficial services may be avoided.

A common perception in pediatric palliative oncology is that patients and their parents wish to avoid palliative care completely or only begin palliative care when death is imminent. A recent study⁴ of attitudes of pediatric patient/parent dyads on early integration of PPC reported that most dyads (98%) did not report opposition to palliative care involvement. Few dyads (1.6%) reported the potential of perceived interference and detrimental effects on their relationship with their oncologist.⁴ Children were significantly more likely than their parents to prefer early palliative care involvement for symptom management.⁴

The use of PPC teams in children's hospitals across the country has increased over time¹⁴; however, little is known about the quality of palliative care outcomes of children who received inpatient PPC. In a retrospective chart review, patients who received PPC had more pain assessments in the last 12–24 hours of admission prior to death, and more documented efforts to manage pain by nursing staff compared with patients who did not receive PPC.¹³ This is highly relevant to providing high-quality care to pediatric patients with advanced cancer because of the known symptom burden commonly experienced by these children. When compared with children who did not receive PPC, children who received palliative care services received fewer invasive procedures and less

Download English Version:

<https://daneshyari.com/en/article/10211357>

Download Persian Version:

<https://daneshyari.com/article/10211357>

[Daneshyari.com](https://daneshyari.com)