3.07 PALLIATIVE CARE AND HOSPICE

Introduction

Pediatric palliative care (PPC) is comprehensive, specialized care for children facing serious or life-threatening illness, with the goal of improving quality of life for the child and the family/caregivers. Palliative care represents both a philosophy and an organized method for delivering care focused on addressing physical, psychosocial, and spiritual needs to prevent and relieve suffering. Pediatric hospice care (PHC) is a particular type of palliative care traditionally provided to patients with a more limited prognosis and carried out by licensed hospice agencies. Pediatric palliative care and PHC are delivered through interdisciplinary collaboration, across care settings, integrated throughout the course of the illness from diagnosis to bereavement, and provided alongside life-prolonging or curative interventions. Patients who may benefit from PPC or PHC are frequently hospitalized; however, PPC resources may be limited and may vary by geographic location. Pediatric hospitalists are often caring for these patients and well positioned to provide basic PPC needs and assist with accessing PPC resources.

Knowledge

Pediatric hospitalists should be able to:

- Compare and contrast between PPC and PHC, attending to scope, patient population, services, optimal timing, and goals of care, among other items.
- Cite key elements of PPC, including facilitation of informed decision-making; enhancing care coordination and communication among medical team members, the child, and family/caregivers; improving comfort through expert symptom management; and optimizing quality of life.
- Review the importance of appropriate timing of PHC referral when the child's expected prognosis is 6 months or less, and list basic steps in the referral process.
- Summarize why PPC and PHC are optimally provided by an interdisciplinary team consisting of a pediatrician, pediatric nurse, social worker, chaplain, and others.
- Describe the value of conducting proactive discussions of goals of care (GOC), which may include forgoing or withdrawing life-sustaining treatment prior to a child becoming critically ill.
- Explain how PPC can be integrated with appropriate medical treatments, including curative and life-prolonging treatment, starting at diagnosis of serious illness.
- Discuss the benefits of items commonly included in a PPC treatment plan such as symptom management, spiritual counseling, and physical therapy, among others.
- Give examples of local, regional, and national resources for PPC and PHC that are accessible to patients, the family/caregivers, and healthcare providers.
- Describe ethical principles related to end-of-life (EOL) care and the role of the hospital ethics committee in these scenarios.
- Describe the processes for writing "allow natural death" (AND), orders, advanced directives, the "Physician Orders for Life-Sustaining Treatment" (POLST) form, pronouncement of death, and completion of a death certificate.

Skills

Pediatric hospitalists should be able to:

- Identify children who may benefit from complex decision-making, advanced symptom management, or higher level psychosocial and spiritual support and refer them to PPC or PHC services.
- Engage in difficult conversations, including communicating "bad news" with compassion.
- Describe and introduce PPC and PHC to patients, the family/caregivers, other subspecialists, and other healthcare providers.
- Lead a basic discussion of prognosis and GOC with patients, the family/caregivers, and the healthcare team.
- Manage ethical dilemmas encountered in the care of the dying patient in the hospital, in collaboration with other healthcare providers as appropriate.
- Provide care that respects the cultural, social, and spiritual preferences of patients and the family/caregivers.
- Screen and provide basic treatment for pain and other distressing symptoms experienced by seriously ill or dying patients, such as dyspnea, nausea, anxiety, delirium, and others.
- Prescribe indicated pharmacologic and non-pharmacologic therapies in collaboration with appropriate consultants, including pain specialists, PPC teams, child-life providers, and integrative therapies.
- Educate healthcare providers and the family/caregivers about symptoms related to active dying.
- Provide counseling regarding life-prolonging interventions, addition of medical technology, and code status.
- Refer patients to other available disciplines for psychosocial and spiritual support, such as pastoral care, social work, and child life, if local PPC and PHC resources are not immediately available.
- Collaborate with an interdisciplinary team including PPC, PHC, nursing, social work, pastoral care, case management, pharmacy, medical/surgical subspecialists, and primary care provider to ensure coordinated, longitudinal care consistent with GOC for this population.
- Manage care needs for this population across facilities where needed, including remotely accessing palliative specialists at tertiary care sites and organizing best plans for patients and the family/caregivers who wish to return for care to their local community center.
- Communicate autopsy and donor options for actively dying children and access immediate support for the family/caregivers and staff related to this decision-making process.

Attitudes

Pediatric hospitalists should be able to:

- Appreciate the key role hospitalists play in ensuring that PPC needs of seriously ill children are addressed.
- Recognize that PPC is appropriate throughout the course of serious illness and should be equitably provided to all children who may benefit from these services.

- Recognize the importance of empathetic, culturally sensitive communication.
- Acknowledge personal attitudes and biases and their influence on care of seriously ill or dying patients from a physical, psychosocial, and spiritual perspective.
- Exemplify ethical behavior in rendering care for these patients and their family/caregivers.
- Reflect on the value of and engage in self-care to cope with the stress of caring for seriously ill patients.
- Realize and address gaps in personal knowledge, skills, and attitudes regarding PPC through professional education.
- Recognize the importance of building therapeutic relationships with seriously ill children and the family/caregivers.
- Recognize that PPC is patient- and family-centered and that treatment plans should be aligned with GOC of patients and the family/caregivers.

Systems Organization and Improvement

In order to improve efficiency and quality within their organizations, pediatric hospitalists should:

- Lead, coordinate, or participate in organizational efforts to provide PPC/PHC education.
- Collaborate with hospital administration and community partners to ensure efficient access to appropriate consultants necessary for success of these programs for children.
- Advocate for development of PPC and PHC resources within the institution and local community.
- Lead, coordinate, or participate in institutional initiatives aimed at improving care of seriously ill children, including improved advanced care planning or symptom management care pathways.

References

1. Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics*. 2013;132(5):966-972. https://doi.org/10.1542/peds.2013-2731.
2. Kang T, Ragsdale LB, Licht D, et al. Palliative Care. In: Zaoutis LB, Chiang VW. Eds. Comprehensive Pediatric Hospital Medicine, 2nd ed. New York, NY: McGraw-Hill Education, 2017:33-38.