

Pediatric Palliative Care Consultation



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KEYWORDS

- Pediatric palliative care • Elements of consultation • Referral criteria
- Barriers to referral • Value added benefits

KEY POINTS

- PPC consultation can benefit the patient, their family, and the healthcare team by aligning treatment goals with treatment plans, improving the experience of the patient and their family, and enhancing the cooperation of the healthcare team.
- PPC consultation is a process of getting to know a family's goals, values, hopes, priorities, and preferences. It can also include expert opinion and recommendations regarding prognosis, advance care planning, and resources along the continuum of care.
- Children should be referred to PPC at the time of diagnosis with a life-threatening illness or when there is a significant change in health status.
- Families benefit from PPC expertise in pain or other symptoms, spiritual or psychosocial crises, communication challenges, and discussions regarding goals of care.
- Clinicians can look to palliative care when treatment options are challenging or limited, if care invokes moral and emotional distress, or for end-of-life care recommendations.
- Challenges to effective PPC include misconceptions among families and clinicians, uncertainty about benefits and timing of referral, staffing shortages, and challenges in funding programs that save money rather than generate revenue.

INTRODUCTION

Pediatric palliative care (PPC) is a relatively new and quickly growing pediatric subspecialty. This article discusses PPC consultation with specific focus on the added value of PPC, elements of a PPC consultation, and challenges to and opportunities for PPC consultation. Ongoing research, current publication, expert opinion, and institutional experience were compiled for this article.

ADDED VALUE OF PPC

The core concepts of PPC have been present in the practice of many pediatricians for years. These skills are referred to as "primary palliative care," and should be a part of

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all pediatric education.¹ This section outlines the benefits of subspecialist PPC involvement as experienced by different participants in the healthcare interaction. Patient and family, physicians, support staff, and hospitals each benefit in a unique way. The additive result is an overall improvement in care.

Patient and Family

Children and families facing life-threatening conditions have many clinicians on their side. The PPC consultant generally adds support for the family and the team rather than assuming care.^{2,3} Although PPC teams are each unique in composition they are usually a consistent group of clinicians that follow the patient longitudinally.⁴ This continuous relationship over the course of an illness allows the PPC team to readress sensitive topics and significant decisions, such as advance care planning, which may also evolve over time. Often the most therapeutic intervention by PPC teams is impartial listening. A family's desire not to harm a relationship with the primary team may prevent expression of frustration, anger, and disappointment. The PPC team can clarify a family's perspective and help the family interpret medical realities in situations ripe for misunderstanding. Good communication also helps to assess the impact of illness on all members of the family. This information is useful in the process of helping parents navigate decisions and in aiding the family as they deal with their individual emotional, spiritual, and social reaction to the events that are unfolding.

The Primary Care Team

Pediatricians are caring for an increasingly complex group of children.⁵ PPC consultation contributes to the care of these children with specialized knowledge of symptom management, familiarity with common life-limiting scenarios, teaching of primary palliative care, and support in difficult ethical and emotional situations. Life-threatening illness often brings a symptom burden that weighs heavily on children and families.⁶ Attention to symptoms should be a top priority regardless of the goals of care. PPC teams specialize in assessment and treatment of pain, nausea, delirium, insomnia, anxiety, and the myriad of other symptoms common in sick children. Treatment includes pharmacologic and nonpharmacologic methods, with an emphasis on preserving quality of life. Specialized training and experience with uncommon illnesses allows the PPC clinician to be an asset in situations not often encountered by inpatient teams. PPC consultation service is a resource for trainees⁷ and experienced clinicians to gain the PPC and pediatric hospice care (PPC-PHC) skill set recommended for all pediatricians (**Box 1**) by the American Academy of Pediatrics (AAP).^{3(p970)} Every

Box 1

AAP recommended PPC-PHC skills

- Prevent, assess, and manage symptoms
- Communicate in clear, caring, and collaborative manner with patients and families
- Recognize when and how to consult with PPC-PHC specialists
- Communicate effectively the role PPC-PHC specialists play
- Ensure that patient care is consistent with best practices
- Maintain full engagement in well-coordinated care

Adapted from American Academy of Pediatrics. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatrics 2013;132:966–7.

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