Background: In the United States, greater than 40,000 pediatric deaths occur annually (1). Additionally, complex chronic conditions are common, with 15% of children in the US living with one or more chronic health condition (2,3). Many children with life-threatening conditions may have rare conditions that can lead to social isolation and family-life challenges. Palliative care helps seriously ill patients and families with attention to quality of life and comprehensive support during their illness journey (4). This Fast Fact defines pediatric palliative care (PPC) and discusses how PPC can help patients and families with life threatening illness.

Definition: According to the World Health Organization, pediatric palliative care is the active total care of the child’s body, mind, and spirit, and involves giving support to the family (5).

Principles of pediatric palliative care: The American Academy of Pediatrics (AAP) supports an integrated model of palliative care that begins when a life-threatening illness is diagnosed and continues through the disease trajectory (6). PPC often co-occurs with conventional treatments; continues through and after death into bereavement (6); and can be provided in a broad array of settings including hospitals, clinics, or in children’s homes (7-8). PPC is unique in pediatric medicine because of its specific focus on:
1. Enhancing quality of life.
2. Care of the whole child in the context of the family, including the body, mind, and spirit to prevent or diminish suffering.
3. Use of a specialized interdisciplinary care team with the patient and family as its center. Members of the interdisciplinary team may include physicians, advanced practice providers, nurses, social workers, chaplains, counselors, music and art therapists, child life specialists, pharmacists, volunteers, care managers, and bereavement coordinators.
4. Collaboration with other health care providers and community resources.

Roles of Pediatric Palliative Care:

a.) Improve symptom management
PPC teams assist with symptom management, such as alleviating pain, shortness of breath, nausea, vomiting, and anxiety. In addition to medications, non-pharmacologic approaches to symptom control can be implemented, such as acupuncture for pain or placing a bedside fan to alleviate the sensation of dyspnea. Family distress, anxiety and spiritual distress are also among the symptoms that can arise when a family lives with their child’s life-threatening illness.

b.) Enhance communication
The interdisciplinary approach of PPC allows for patients and families to express their needs, hopes, and fears through developmentally appropriate conversation and play. Open, honest communication promotes autonomy and allows patients and families to make decisions and set goals that are consistent with their personal values, traditions, and culture. Children, adolescents, and families should be invited to participate in medical decision making to the degree with which they are comfortable and able. The PPC team assists in coordinating communication among the often-large group of specialists and services caring for children with life threatening conditions.

c.) Facilitate complex medical decision making
PPC teams elucidate patient and family values and goals of care; explain treatments, interventions, and anticipated outcomes in age-appropriate language; and assist in aligning medical recommendations with values and goals to establish a care plan. A common example is technology implementation or cessation (gastrostomy, advanced airway, long-term breathing support, etc.).

d.) Establish an advance care plan
This is the process of establishing goals of care that are consistent with the patient’s and family’s values and that guide decision making in case of worsening illness or at the end of life. Advance care planning may include advance directives, which are documents that specify which treatments and interventions the patient will or will not receive (9). In pediatrics, the team seeks to include the child’s
experience and input at developmentally appropriate levels (9). Goals of care can be shared with the medical team to help facilitate communication and future planning.

e.) **Reduce psychosocial and spiritual suffering**

PPC teams assist caregivers and providers in assessing a patient’s social and spiritual health in a developmentally appropriate manner and make recommendations for interventions if necessary. PPC also support siblings with coping, caregivers with fatigue, and families as they manage competing demands, and financial stressors. PPC teams provide counseling, make referrals, or share resources for coping, grief, and bereavement (10). Additionally, they can assist health care providers experiencing psychosocial and spiritual suffering while caring for children with complex illness.

f.) **Discuss prognosis**

Although prognostication in children is imprecise, PPC practitioners can assist in estimating length of life, anticipating disease course and communicating prognosis to patients and families.

g.) **Coordinate care across continuum**

The PPC team can collaborate and communicate with other providers and the patient’s larger community to provide cohesive, efficient care. The goal for this process is to improve the quality and efficiency of the care received even when pediatric patients undergo care transitions. For example, PPC clinic visits can be coordinated with other healthcare visits with careful planning.

References


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