Integrating Pediatric Palliative Care into the School and Community

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KEYWORDS

- Pediatric palliative care • Chronic illness • Quality of life • School • Transition
- Life-threatening • Life-limiting • Hospice

KEY POINTS

- Common terminology and definitions are needed to ensure a uniform language is used when developing comprehensive pediatric palliative care (CPPC) for children in need of the services and their family members.
- CPPC addresses the physical, psychological, social or emotional, and spiritual needs of children with complex chronic conditions, including some children with special health care needs.
- CPPC should occur at school, worship, athletics, clubs, and organizations where children develop healthy physical, psychological, social or emotional, and spiritual selves.
- Education and civil rights legislation provide a foundation for CPPC services in schools and community settings.
- When a child has an out-of-hospital do-not-resuscitate (OOH DNAR) order, heath care providers (HCPs) should partner with schools to provide support to the child and family, as well as to school professionals, to ensure a positive outcome for all parties. The development of CPPC may aid in enhancing communication between HCPs, families, and schools during the time when an OOH DNAR decision is being considered.

INTRODUCTION

Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. The initiation of palliative care increasingly begins at diagnosis and continues throughout the illness trajectory.[1] Pediatric palliative care (PPC) is provided to children ranging in age from prenatal to young adult or older when receiving treatment of a pediatric diagnosis.[2] Most PPC is provided in a hospital setting; however, community-based PPC (CBPPC) programs are an integral component of assuring access to PPC for children with life-threatening illnesses when provided along with curative or life-prolonging treatment.[3,4]

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Children are dynamic beings who are learning, growing, and developing along a continuum that leads to self-awareness, self-advocacy, and competencies that enable the youngster to become a functional adult. Seriously ill children arrive to PPC at a point along that continuum of development and are very different from adults with serious illnesses. Children have not yet learned to cope with adversity, identified sources of support during a crisis, nor can they answer the question "Who am I?" Children may have encountered serious illness since birth, gradually entered into serious illness, or been thrust suddenly into the chaos. In any case, the focus quickly becomes the child's diagnosis and related challenges; however, that does not halt the child's movement along the developmental continuum as she or he continues to grow, change, and learn about herself or himself and the world. Throughout even the most serious of illnesses, the child continues to be a child and possesses all of the developmental, social, emotional, and spiritual needs of a child. To be effective, PPC must address the child's needs on a developmentally appropriate level for that individual child and provide services in the places where the child lives, learns, grows, and develops. Typically, that place is not the hospital. Rather, it is the child's natural environments of home, school, worship, play, friends, and other interactive activities.

Currently, there is a zeitgeist in our culture that presents an opportunity to change the way PPC is provided to children. Two generations ago, children with serious diagnoses lived in institutions, received minimal medical care, and did not attend school. For example, children with muscular dystrophy, cystic fibrosis,[5] or spina bifida[6] lived only into adolescence, whereas those with cerebral palsy or other neurologic or developmental disabilities were often institutionalized.[7] Today, many of those same youngsters are living into their 20s, 30s, and beyond. Medications, ventriculoperitoneal shunts, central venous access lines, gastrostomy tubes, and ventilators have increased the life expectancy of children with neuromuscular disorders.[8] Care in neonatal intensive care units has improved survival of premature infants[9] and infants with chronic heart or lung conditions, genetic disorders, or birth defects.[10] As children with serious illnesses are often living longer, schools, athletic teams, places of worship, and other venues are developing an understanding of the needs of these children. Thus, participating in school, athletics, and worship are viable options.

With increased survival come unavoidable consequences of significant disability and medical, educational, psychological, social, and spiritual challenges. More children are surviving, resulting in more children who need PPC. These PPC programs should provide coordinated, efficient, and cost-effective care.[11] Health care has opened the doors for seriously ill children to gain entry into activities. Therefore, the interdisciplinary PPC team is called on, in collaboration with adults in the child's natural environments, to engage a broad team of providers to provide a new definition of PPC: comprehensive PPC (CPPC).

This article considers the possibility of developing strong alliances and partnerships between hospitals, CBPPC, schools, athletic teams, places of worship, and other community-based organizations. Partnerships will result in increased knowledge for all caregivers, thus enabling children to have the opportunity to address physical, psychological, social or emotional, and spiritual needs in all of the natural environments where they live, learn, grow, and develop.

SPEAKING THE SAME LANGUAGE

In the interest of developing CPPC services provided across a child's natural environments, it is imperative that all stakeholders use consistent terminology to define the