

Pediatric Hospice and Palliative Care: A Little Knowledge Goes A Long Way

Lisa C. Lindley, PhD, RN
Assistant Professor
College of Nursing
University of Tennessee
llindley@utk.edu

The traditional hospice patient is not a 4 year old with multisystem diseases, technology dependence, and complex medication regimens. And yet, a hospital discharge planner, social worker, or nurse may contact your hospice on any given day and ask if you and your staff could care for this child.

Although 15% of Colorado hospices have a designated pediatric program with trained clinical staff, a majority of organizations may find it difficult to provide this level of care (Hospice Analytics, 2015). Pediatric hospice and palliative care provides physical, emotional, social, and spiritual support services to children with a prognosis of 6 months to live and to their families. It is different from adult care in several important ways. First, pediatric diseases are often specific to children and rare, such as neurodegenerative brain iron accumulation disorders. Second, a child often presents at different developmental stages. In fact, using Piaget's theory of development, children can be in any one of 4 developmental stages, while adults present in one stage. Third, the family dynamic can be more complicated for a child. For example, the adult unit of care is often the senior adult, but for children it is the family. The term "family" can have a very broad definition that includes parents, siblings, grandparents, aunts, uncles, and cousins. Additional considerations are made for classmates, pets, and friends. Finally, a child typically enrolls in hospice and palliative care for just a few days compared to adults who often enroll for weeks to months. From a clinical perspective, this means that in 2 or 3 days the staff must learn about new health conditions, assess the child's level of development, understand the family dynamics, and conduct the initial assessment, while caring for the family and for the child who is actively dying. This is no small task.

You may be asking yourself - does it matter? With such short stays in hospice, does providing care to a child offer any benefit? From the parents who receive this care for their child, the answer is YES. Increasingly, parents wish that their child's death could occur in the comfort of their home surrounded by loved ones. Hospice and palliative care enables parents to bring their child home from the hospital to die. Parents express the desire to have their child's pain and other concerning symptoms managed at end of life. One of the cornerstones of hospice and palliative care is effective pain and symptom management. Consequently, children and their families have a need for hospice and palliative care. However, our research has shown that the need often does not match the supply of services (Lindley & Edwards, 2014), even though there is minimal financial impact on hospices (Lindley et al., 2013).

There are a variety of ways that hospices can gain knowledge of providing pediatric care. For example, the National Hospice and Palliative Care Organization has a variety of clinical tools including standards of practice. Additionally, there are pediatric end-of-life clinical training and certification resources through the End-of-Life Nursing Education Consortium (ELNEC) and Hospice and Palliative Nurses Association. Business alternatives can also include subcontracting or hiring temporary staff with pediatric expertise (Lindley, 2013). We hope in the future technology solutions such as mobile apps will assist hospice and palliative clinicians caring for children and families at end of life (Lindley et al., 2014). Obtaining knowledge of pediatric hospice and palliative care takes time and effort. Think about adding this to your in-service curriculum or professional development options. Ultimately, the hospice and palliative care provided for children and families provides comfort to the dying child and eases some of the pain and suffering that comes with losing someone so young. And, ultimately, isn't that the mission of hospices?

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Percent of Hospices Providing Pediatric Service

National Hospice Locator; www.HospiceAnalytics.com

