Section 3 | UNDERSTANDING ADULT & PEDIATRIC PALLIATIVE CARE

Palliative care is person- and family-centered care, meant to relieve suffering and enhance the quality of life for patients living with life-threatening or life-limiting conditions. The goal of palliative care for both adult and pediatric populations is the same: bridging the gaps in healthcare to fulfill unmet physical, emotional, spiritual, and concrete needs for patients with serious illness. Though the intent is the same, the delivery of palliative care for pediatric patients may appear different than the delivery of palliative care for adults. Providers of home and community-based adult palliative care should anticipate caring for children at times, in part due to the relative scarcity of pediatric palliative care services in the United States.

Referral
Adult patients referred to palliative care most often have oncologic diagnoses. In contrast, pediatric patients referred to palliative care have a much broader range of diagnoses—including neurological, oncological, metabolic, chromosomal, cardiological, respiratory and infectious diseases, etc.—many of which are considered rare diseases. The most common conditions seen by pediatric palliative care teams are severe neurologic impairment. Specifically, 41% of pediatric palliative care patients have genetic/congenital conditions and 39% carry a diagnosis of neuromuscular disorder, while only 20% have cancer. In pediatrics, much more so than in the adult population, patients face a great deal of uncertainty with a life-limiting or -threatening diagnosis.

The medical complexity and uncertainty which these children face may complicate the palliative care referral process. In some cases, the provider or health plan may not have experience recognizing the medical need for palliative care in children. In others, there may not be a home- or community-based provider willing to accept a pediatric patient with an unfamiliar or rare diagnosis. Further, anecdotally, pediatricians often play a role in providing primary palliative care for their patients and may be hesitant to involve a subspecialty palliative care team to assume that role.

Relationship with Patient, Family, and Community
Palliative care providers treating adult patients often communicate directly with the patient and/or a limited number of adult caregivers. Because children are often referred for palliative care at a very young age and may survive for a long time, pediatric palliative care requires a more longitudinal relationship with both the patient and the patient’s family, which may include siblings and extended family members.

The care network for children extends to include school, developmental supportive services (Regional Center, Blind Babies, PT/OT), tertiary children’s hospital providers, home shift nursing, and community groups. Pediatric physicians and palliative care providers will benefit greatly from being aware of community resources and family connections and using those to best support the needs of the child.

Psychosocial Needs of the Provider
While caring for patients with serious illness can be difficult, some providers find caring for pediatric patients with life-threatening or life-limiting illness uniquely challenging. The unnatural nature of pediatric death can be uncomfortable for providers who are not familiar with caring for children. Even experienced palliative care providers have reported that they are not sure what to say to the family of a child with an advanced illness, or how to communicate directly with the child. Resources are available to aid in navigating this discomfort; Jordan et. al. provide helpful recommendations for communicating with families in the context of pediatric palliative care in their paper “Top Ten Tips Palliative Care Clinicians Should Know About Caring for Children”.

PPC Waiver Transition Resource Guide
© 2019 Coalition for Compassionate Care of California | 06.19.19
Developed with support from the California Health Care Foundation, based in Oakland, CA
Psychosocial Needs of the Patient and Family

PPC providers must navigate important and sometimes difficult conversations with patients across a wide range of ages and developmental abilities. The American Academy of Pediatrics (AAP) encourages the child’s participation in developmentally- and age-appropriate conversations about their illness and treatment options, including conversations about burdens and benefits of management options. Providers must consider the unique psychosocial challenges that patients at every age may face and take care to ensure that conversations with the patient are developmentally appropriate. While pediatric patients should be involved in conversations about their care to the extent possible, most conversations will take place with the child’s guardian(s). PPC providers should also take care to acknowledge any unmet psychosocial needs of siblings, as related to the patient’s illness.

Interdisciplinary/Transdisciplinary Team

A PPC team may have more members than an adult palliative care team. A comprehensive PPC team may consist of a child-life specialist, a pediatric mental health specialist, a pediatric grief specialist, a massage therapist, an art or music therapist, and a care coordinator in addition to the physician, nurse practitioner, RN, chaplain, social worker, and pharmacist. Because many members of a PPC team are part-time, each person on the interdisciplinary team should expect their work to be transdisciplinary. For example, an RN should be familiar with child-life practices and aware of the social work plan for the child so that he or she can be working towards the goals of those two team members even when they are not present.

Clinical - Pain & Symptom Management

Many of the symptom management medications that are used in palliative care are the same for pediatric and adult patients. While safety and efficacy of opioids have largely not been tested in clinical trials for pediatric patients, standard dosing guides are available for common symptoms, including pain. Weight-based dosing should be used for pediatric patients. Using age- and development-appropriate tools for pain and symptom assessment is critical to ensure symptoms are managed properly. Adequate pain management is paramount, as untreated pediatric pain can lead to chronic pain in later years. Pain and symptom management resources are listed in the Resources section of this guide.

Clinical - Medical Technology

The majority of children receiving palliative care require the use some type of medical technology. This may include life-prolonging interventions such as feeding tube placement, oxygen delivery devices, tracheostomy, ventilator, and IV therapies (including TPN). Providers of PPC should familiarize themselves with this technology, using the child’s primary care or subspecialty physician team as a resource when needed.

Clinical - Duration of Palliative Care

The median duration of palliative care for pediatric patients is longer than for adult patients. Unlike adult patients, 70% of pediatric patients are alive one year after initiating palliative care. For this reason, PPC providers should expect to develop a longer-term relationship with the child and his or her family.
Clinical - Prognostic Uncertainty

In pediatrics, many patients are diagnosed with their life-limiting illness at a very early age, and it is unclear how this diagnosis may affect their lives in the future, as some of these diseases are so rare that we do not know the natural course of the disease, and also because children often surprise us with their ability to adapt and to recover from life-threatening or -limiting condition, such as traumatic brain injury. It can, therefore, be difficult to predict what a child’s disease course and trajectory may be in the future, and the role of pediatric palliative care is often times to support families through this uncertainty. PPC providers can support patients and families by ensuring repeated goals of care conversations over time to promote the best quality of life.