

Best practices for pediatric palliative cancer care: a primer for clinical providers

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Cancer is the leading cause of disease-related death in children and adolescents. Pediatric patients with cancer suffer greatly at the end of life. However, palliative care interventions can reduce suffering and significantly improve the care of these patients and their families. A large percentage of pediatric deaths occur outside of the hospital setting where pediatric palliative resources may not be readily available. Patients in the home setting may be cared for by community hospice programs, which are typically staffed for adult populations. Increasingly, nonpediatric providers are asked to provide palliative care for children and adolescents at the end of life, yet they receive little formal training in this area. This review focuses on the principles of best practice in the provision of palliative care for children and adolescents with cancer. Our intent is to aid clinical providers in delivering optimal care to this patient population. Topics unique to pediatric palliative care that are addressed include: providing pain and symptom management in the broad pediatric range from neonate to adolescent; caring for and interacting with developmentally distinct groups; engaging in shared decision making with parents and adolescents; providing accommodations for prognoses that are often more uncertain than in adult patients; and delivering concurrent disease-directed therapy with palliative care.

Each year, approximately 12,000 children and adolescents in the US are diagnosed with cancer.¹ While cure rates for pediatric cancer have improved dramatically, 20% of children with cancer continue to die from the disease.² Unfortunately, many of these children suffer greatly at the end of life. One study reported that 89% of children with cancer experienced significant suffering in the last month of life.³ Palliative-care (PC) interventions have been demonstrated to reduce suffering and improve care at the end of life for children with cancer.⁴

The benefits of PC can extend far beyond the end-of-life period. The American Society of Clinical Oncology recommends early integration of PC with oncology care for all cancer patients with high-risk disease or high-symptom burden, a recommendation based on strong evidence that early integration of PC improves patient and caregiver outcomes.^{5,6} This recommendation is not unique to the adult population. Early integration of PC with oncology care has been supported by pediatric advocates and experts in the field as the optimal model for high-quality comprehensive care for children with cancer.^{7,8}

Despite the evidence supporting the benefits of PC for cancer patients, there are various barriers to provide optimal PC for pediatric oncology patients. The availability of pediatric palliative care (PPC) resources remain suboptimal with PC services available at less than 60% of Children's Oncology Group centers.⁹ The majority of pediatric hematology oncology fellowship programs do not

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have a PC curriculum.¹⁰ In addition, less than 10% of pediatric oncologists have formal training in PC and tend to use trial and error methods for pain and symptom management.¹¹ While pediatric PC services may be available in the inpatient setting, there has been a shift in recent years toward more patients receiving outpatient therapy and terminal patients choosing to receive care at home.¹² Additionally, in the US, the Accreditation Council for Graduate Medical Education (ACGME) PC fellowship curricula currently includes extremely limited pediatric training usually composed of 2-4 weeks and does not concentrate exclusively on oncology-specific PPC.

PC specialists offer specific expertise to patients who are at risk for complex suffering. These specialists can partner with the patients' primary providers to identify ways to prevent and treat patients' physical symptoms, reduce family distress and dysfunction, resolve conflicts arising while identifying goals of care, and coordinate resources so that children can live in the most appropriate setting. Unfortunately, not all pediatric care systems have access to a robust PPC service. In these situations, when patients have severe symptoms or are trying to access hospice care, these facilities may need to partner with adult-based PC teams to ensure that the patient and family have access to the best available resources. Non-pediatric care providers are increasingly being called upon to care for dying children and adolescents in this setting. Still, these providers may have limited pediatric training. Although these practitioners may be well trained in PC, partnerships with pediatric caregivers are encouraged to ensure they can address pediatric-specific challenges. This article reviews the critical elements of PPC focusing on unique factors inherent to caring for pediatric patients. It also discusses how these principles can be adapted by adult-focused clinicians to provide optimal PC to children and adolescents with cancer.

Children are not little adults

Both pediatric and adult PC focus on identifying, preventing, and treating the stress and symptoms associated with serious illness for patients and their families. This focus also encompasses physical, emotional, social, and spiritual care through the disease course and thereafter. While pediatric and adult PC share many key features, children are not merely small adults.

All types of PC comprise symptom management, goal-oriented decision making, and complex care coordination. Pediatric patients, however, often have unique disease processes with diagnoses and prognoses that may be very distinct from seemingly analogous adult conditions. Pediatric patients are more likely to receive concurrent palliation and disease-directed therapy as well as life-

prolonging treatments, including transfusions. Further, understanding the developmental level of pediatric patients is critical for effective, age-appropriate communication. Pediatric patients also require specific medication dosing considerations that are distinct from adults due to developmental changes in organ function and drug metabolism as well as variability in weight, body mass, volume of distribution, hepatic metabolism and renal excretion. Table 1 outlines some unique aspects and skills that characterize PPC.

Palliative care competencies for pediatric patients

PPC encompasses both shared competencies with adult PC and distinct competencies that address the unique needs of children and adolescents. General structural principles that ensure developmentally appropriate PC across age groups can facilitate quality PPC. Meeting with the patient and family in a child/adolescent friendly atmosphere, distinct from the setting used for serious discussions or procedures, can be extremely helpful in establishing rapport in or out of a health care setting. This can be accomplished with home visits that allow the patient and family to become more familiar with the team in their personal environment. In the health care setting, the team may meet in the playroom or adolescents-only room and spend time allowing the child or adolescent to share games, toys, and demonstrate individual interests. However, serious discussions and physical examinations of any type must not occur here. This allows pediatric patients to maintain places that are "safe" and free of associations with medical procedures. Assessing and facilitating the family's preferred care environment can be critical for a patient's and family's quality of life.¹² Simply asking children and adolescents what wishes they have and where they want to be and asking the family where they believe their child feels most comfortable and safe can initiate a discussion about quality of life and how to best achieve that in the chosen environment. Creating committed and engaged partnerships with hospice and home-health providers can enable optimal patient-centered continuity of care. It also helps ensure that relationships with the PC and primary teams are maintained across care settings with unified goals of care and optimal advance-care planning.³ A dedicated interdisciplinary team is helpful for integrating and coordinating the involvement of PPC clinicians as well as other disciplines, such as child-life specialists, pediatric psychologists and psychiatrists, music therapists, social workers, pharmacists, and chaplains/faith workers.¹³

It is critical to identify and empower decision makers and key emotional supporters for the patient and family as

TABLE 1 General and competency-based comparison of pediatric and adult palliative care

	General approach	Competencies
Adult and pediatric palliative care	<ul style="list-style-type: none"> Patient- and family-centered care for patients with life-limiting conditions Pain and symptom management, quality of life, care for family Similar end-of-life medications Coordination of complex care Focus on goals of care Proactive anticipation of support needs throughout disease trajectory 	<ul style="list-style-type: none"> Understanding of impact of seriously ill person on family system Knowledge regarding pain and symptom management, importance of proactive pain and symptom management Provision of holistic care in a family context Knowledge regarding signs of impending death and its management Skill with difficult conversations, complex communication Creativity and flexibility
Pediatric palliative care (PPC) specific	<ul style="list-style-type: none"> Integration of palliative care where appropriate independent of expected duration of survival Unique disease entities in childhood / adolescence Unique disease biology and trajectory with varying life expectancy and functional outcomes Age-specific physiologic differences Involvement with palliative care services often for a much more prolonged time period More aggressive disease-directed treatment may be available and / or appropriate Continual developmental changes: physical, cognitive, expressive and receptive communication, emotional and psychosocial needs and coping Continual development of social role: stage of family life, recreational and educational needs Legal competence and ethical decision-making Dual focus on growth / development and potential for death Families can choose hospice and disease-directed treatment: concurrent care 	<ul style="list-style-type: none"> Knowledge base for a wider variety of diseases and conditions in PPC Comfort level interacting with children Capability to deal with emotional impact of providing care to children Age-appropriate medication dosing (Table 5) Understanding of developmental implications and patient understanding Family-centered care competency with young, complex and non-traditional families Ability to utilize surrogate decision makers while seeking the input of the pediatric patient in developmentally appropriate ways

well as to establish clear lines of communication among team members and with family. Facilitation of appropriate engagement of peers, school, community, and faith-based groups can be extremely helpful. For patients and families who are interested, visits to the patient's school, church, or other group by one or more team members to answer questions and provide explanation may help the child as well as peers and community members to feel more comfortable to participate in shared activities. It is especially important in caring for young patients to recognize the needs of the family as a whole, which includes the need for sibling support and considering potential key roles of grandparents and extended family. Child-life specialists at a local school or children's hospital may be able to provide age-appropriate materials and tools to the adult PC team; aid in answering questions; and provide age-appropriate explanations of life-threatening conditions and death. Particularly in cases approaching end-of-life,

anticipation and management of potential complicated grief is highly important to best support the family's need for resources, respite and bereavement services.¹⁴

Anticipatory prevention of compassion fatigue and burnout among care providers is essential. It is important to facilitate opportunities for open discussions during and after challenging cases. For adult PC teams that provide care for limited numbers of pediatric patients, it may be particularly helpful to plan a debriefing for the health care providers after each pediatric death to identify concerns and needs for practice changes or for additional emotional and functional team support. Care providers can also benefit from identifying resources within the local system for legal and ethical guidance in cases with potential decision-making conflict. It is critical to address potential myths regarding children's symptoms and illness experiences; and promote awareness of existing guidelines and resources, as referenced in Tables 2 and 3.

TABLE 2 Pediatric palliative care Web sites (last accessed December 2012)

Resource	Description	Web site
American Academy of Pediatrics (AAP) Palliative Care Section	US professional society subgroup of pediatricians and subspecialists with interest in palliative medicine; posts include overview and updates in the field	http://www2.aap.org/sections/palliative/
ACT - Association of Children's Palliative Care (Together for Short Lives)	UK-wide charity; online links include practical care pathways and tools for both families and professionals.	http://www.togetherforshortlives.org.uk/
Center to Advance Palliative Care (CAPC) – Pediatric Palliative Care	Provides health care professionals with the tools, training, and technical assistance necessary to start and sustain successful pediatric palliative care programs in hospitals and other health care settings.	http://www.capc.org/palliative-care-across-the-continuum/pediatric-palliative-care/
Children's Hospice and Palliative Care Coalition	US-based nonprofit advocacy organization, with online resources for providers and families.	http://www.chpcc.org/
The Initiative for Pediatric Palliative Care (IPPC)	IPPC is a research, quality improvement, and education effort aimed at enhancing family-centered care for children living with life-threatening conditions.	http://www.ippcweb.org/index.asp
National Network for Pediatric Palliative Care	Regional centers collaborate and share resources for the development and support of pediatric palliative care programs throughout the United States.	http://www.network4pedspallcare.org/
Children's Project on Palliative/Hospice Services (ChiPPS)	NHPCO-based group; excellent newsletter and resources sections.	http://www.nhpc.org/i4a/pages/index.cfm?pageid=3409&openpage=3409
Concurrent Care Toolkit	On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (PPACA) into law enacting a new provision, Section 2302, termed the "Concurrent Care for Children" Requirement (CCCR). The District of Columbia Pediatric Palliative Care Collaborative (DCPPCC) and the National Hospice and Palliative Care Organization (NHPCO) provide this Concurrent Care for Children Implementation Toolkit.	http://www.nhpc.org/i4a/pages/index.cfm?pageID=3689&zbrandid=3022&zidType=CH&zid=4860436&zsubscriberId=750619759&zbdom=http://nhpc.org.informz.net
World Health Organization Essential Medicines List for Children (EMLc); Palliative Care		http://www.who.int/selection_medicines/committees/subcommittee/2/palliative.pdf
EPEC Guidelines on Persisting Pain in Children		http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf

Providers' awareness of how children's disease spectrum and trajectory may differ significantly from adults', and even among pediatric patients of different age, can allow providers to guide anticipatory management throughout the course.⁴ Identification of procedures or interventions that may no longer be necessary or appropriate for patients' disease status or goals of care can promote patients' quality of life. Receptive communication strategies can be enhanced by integrating consideration of pediatric patients' familial and health care cultural context, as well as an assessment of beliefs and mental or emotional states of

all those involved.¹⁴ Clear and transparent communication as well as documentation of discussions and decisions relating to advance care planning can facilitate harmonization of goals. Information sharing and support should be tailored to meet the varying needs of parents, siblings, and extended family members. Such family-directed care can foster trust, consistency, and peace of mind.¹⁵ Disease-management plans can be most effectively developed when providers are able to integrate awareness of pediatric patients' symptoms and disease trajectory with patients' and families' goals. This may involve delaying or

TABLE 3 Pediatric palliative care textbooks

Title	Authors/Publishers
Textbook of Interdisciplinary Pediatric Palliative Care: Expert Consult Premium Edition	Joanne Wolfe, Pamela Hinds, Barbara Sourkes / Saunders: 2011
Palliative Care for Infants, Children, and Adolescents: A Practical Handbook	Brian S. Carter, Marcia Levetown, Sarah E. Friebert / Johns Hopkins University Press: 2004
Pediatric Pain and Symptom Management Algorithms for Palliative Care	Linda, M.D. Wrede-Seaman / Intellicard: 2005
Oxford Textbook of Palliative Care for Children	Ann Goldman, Richard Hain, Stephen Liben / Oxford University Press: 2012
Hospice Care for Children	Ann Armstrong-Dailey, Sarah Zarbock / Oxford University Press: 2008
When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families	Committee on Palliative and End-of-Life Care for Children and Their Families, Marilyn J. Field, Richard E. Behrman / National Academies Press: 2003
Conquering Your Child's Chronic Pain: A Pediatrician's Guide for Reclaiming a Normal Childhood	Lonnie K. Zeltzer and Christina Blackett Schlank / Harper Collins Publishers: 2005
Pediatric Palliative Care in Pediatric Clinics of North America	Kang T, Munson D, Klick J (eds) / Elsevier Health Sciences: 2007
Managing Pain in Children: A Clinical Guide	Alison Twycross, Stephanie Dowden, Liz Bruce; Wiley, John & Sons: 2009

altering medical therapy to facilitate participation in family or school events—or enable travel—so that providers' management may extend beyond the disease to the whole patient. An example might be a transition from optimal IV antibiotic therapy to alternative oral therapy with slightly decreased bioavailability to facilitate mobility for a school event, Make-A-Wish trip, or other important life-enhancing event for the child. Table 4 further outlines some of the specific key clinical competencies for the provision of quality PPC.

Symptom assessment and management

The assessment and management of symptoms, including pain, are guided by age-adapted tools and principles as well as specific therapeutic parameters.^{14,16} Many medications for pain and other distressing symptoms have age-group and weight-based dosing, with important differences in pharmacokinetics and pharmacodynamics due to distinct volumes of distribution, hepatic metabolism, and renal excretion. Accordingly, this may for example require adaptation of medication selection and route of administration, where pediatric patients may require an increased dosing interval for some water-soluble or renal-excreted drugs relative to adults.²⁰ Table 5 summarizes the most commonly used medications for pain and other common physical symptoms with typical pediatric dosing information.

In many cases, symptoms are inadequately addressed in pediatric patients receiving PC.¹³ An awareness of potential beliefs that some families and health providers have

regarding the experience and management of symptoms in children and adolescents can help optimize management. Awareness and age-appropriate exploration of patients' emotions and behavioral manifestations, such as irritability, anxiety, or "acting out," could help reinforce healthy patterns of coping and symptom expression in pediatric patients. The following points dispel some of the common beliefs or myths held by families and providers, particularly regarding pain and distressing physical symptoms:

- *Young children do experience pain and distressing symptoms:* Specific age-appropriate measures and encouragement may be needed so that pain and other symptoms can be measured and expressed¹⁴ to reduce the risk of undertreating pain and symptoms in young children.¹⁷
- *Medications for pain and distressing symptoms can be safely administered to pediatric patients:* The safe and effective use of opioids in infants and children is well established.¹⁸ Opioids can also generally be prescribed, as for adults, in accordance with the analgesic ladder principles of the World Health Organization.²⁷ For children and adolescents with advanced cancer, dosing is best guided by the individual needs of the patient. Additionally, opioid requirements per kilogram of body weight can be at least equivalent to those required by adults.²⁸
- *Children can appropriately use Patient-controlled analgesia:* Patient-controlled analgesia (PCA) has been

TABLE 4 Key competencies relevant to pediatric palliative care practices

Key competency	Key components	Examples
Physical domain		
Age-appropriate physical symptom assessment	Awareness and use of age-validated tools. Acknowledge both the valid experience and expression of symptoms in young children.	Pain scales for different ages: - FLACC (2 months to 7 years); - Faces (3 years and up); - Numeric or visual analogue scale (7 years and up) ^{14,16}
Age-appropriate medication selection and dosing	Age group and weight-based dosing. Awareness of general differences between young and older children vs. adults in volume of distribution, hepatic metabolism, renal excretion etc. Appropriate use of non-opioid, opioid, and adjuvant therapies aligned with WHO principles; include appropriate use of scheduled along with as-needed doses for breakthrough pain	Increased dosing interval for some water-soluble or renally-excreted drugs relative to adults ¹⁷ Consider adaptation of medication selection and route based on safety (eg, variable drug distribution in cachectic child) and/or comfort (eg, oral/sublingual may be preferred)
Appropriate use of nonpharmacologic therapies	Awareness and use of adjunctive, multi-modality therapies (cognitive, behavioral, combined)	Skin-to-skin contact for infants-Distraction with blowing bubbles for younger children Relaxation and guided imagery for older children ^{14,16} Fan for breathlessness
Understanding of disease trajectory in pediatric patients	Awareness of how spectrum and trajectory of disease may differ significantly from adult	Supporting parents' anticipatory management near end of life ⁴
Avoidance of un-necessarily invasive / painful procedures or interventions	Anticipatory identification of procedures or interventions that may no longer be necessary or appropriate for a patient's disease status	Reducing number of "routine" blood tests that do not alter patient management and may provoke anxiety
Psychosocial domain		
Age-appropriate behavioral symptom assessment	Awareness and age-appropriate exploration of emotions and behaviors	Recognizing variable basis of irritability, anxiety or "acting out"
Context-appropriate communication	Receptive: Consideration of cultural context, assessment of beliefs, mental/emotional state of family/providers Expressive: Truth-telling in manner appropriate to patient's development, clinical situation, and context elicited above	Clear and transparent documentation of discussions and decisions relating to advance care planning (eg, hospice, do-not-resuscitate orders) ^{4,18}
Patient-appropriate involvement in decision making	Awareness of general age-adapted preferences and capacities for decision-making Awareness of relevant ethical and legal guidelines and resources as appropriate	Local determinant of age of assent and consent Critical individualized decision making and planning based on integrated model ¹⁹ Shared control can also help alleviate anxiety ¹⁶
Holistic family-oriented care	Fostering of trust, consistency and peace of mind ¹⁵	Providing appropriately detailed disease-related and prognostic information
Assessing and supporting goals of care	Developing disease management plan with family that integrates awareness of patient symptoms and disease trajectory with desires and goals of patient and family	Selecting oral chemotherapy course/timing to allow outpatient Make-A-Wish trip

TABLE 5 Common medications and dosing in pediatric palliative care^{14,21-26}

Symptom	Medication	Common pediatric dose (< 60 kg)	Max daily dose
Constipation	Lactulose (can be diluted in water, juices, milk)	< 12 yrs 7.5 mL orally/day, may be repeated after 2 hrs > 12 yrs 15-30 mL orally/day, may be repeated after 2 hrs	60 mL/day
	Polyethylene glycol (mix in 4-8 oz liquid)	1/2 to 1 packet (17 gms) orally every day up to TID	3 packets per day
	Docusate/senna (Senna-S)	2- <6 yrs: 1/2 tab daily 6- <12 yrs: 1 tab daily ≥ 12 yrs: 2 tabs daily	1 tab BID 2 tabs BID 4 tabs BID
Nausea	Ondansetron	0.15 mg/kg/dose orally or IV every 6-8 hr	8 mg/dose
	Promethazine	> 2 yrs: 0.25 mg/kg/dose orally or IV every 6-8 hrs	1 mg/kg/24hr
	Scopolamine (transdermal)	8-15 kg: 1/2 patch every 3 days > 15 kg: 1 patch every 3 days	1 patch every 3 days
Secretions	Hyoscyamine	2-12 yrs: 0.0625-0.125 mg/dose orally or SL every 4 hrs > 12 yrs: 0.125-0.25 mg/dose orally or SL every 4 hrs	2-12 yrs: 0.75 mg/24hr > 12 yrs: 1.5 mg/24hr
	Glycopyrrolate	0.04-0.1 mg/kg/dose orally every 4-8 hrs	1-2 mg/dose or 8 mg/day
Agitation/delirium	Haloperidol	0.01-0.02 mg/kg/dose orally, SL, or PR every 8-12 hrs	0.15 mg/kg/day
Agitation/seizures	Lorazepam [‡]	0.05 mg/kg/dose orally, SL (preferred for seizure), or PR every 4-6 hrs	2 mg/dose
Pruritus	Diphenhydramine [‡]	0.5-1.0 mg/kg/dose orally every 6-8 hrs	5 mg/kg/24hr or 400 mg/24hr
	Hydroxyzine	0.5-1 mg/kg/dose orally every 6 to 8 hrs	4 mg/kg/24hr
Nausea/inflammation	Dexamethasone	2.5-10 mg/m ² /day in divided doses every 6-12 hrs	20 mg/dose
Pain	Acetaminophen (mild pain)	10-15 mg/kg/dose orally every 4-6 hrs	75 mg/kg/24hr
	Ibuprofen (mild pain)	5-10 mg/kg/dose orally every 6-8 hrs	40 mg/kg/24hr
	Oxycodone (moderate pain)	0.1 mg/kg/dose orally every 4 hrs Sustained release formulation available for daily to TID dosing	Patient dependent
	Morphine (moderate pain)	0.3 mg/kg/dose orally, SL, or PR every 3-4 hrs 0.1 mg/kg/dose IV every 2-4 hrs Sustained release formulation available for daily to TID dosing	Patient dependent
	Gabapentin (adjunct for neuropathic pain)	Initially 5-10 mg/kg per day divided TID, increase dose every 3 days	70 mg/kg/24hr or 3600 mg/24hr
	Amitriptyline (adjunct for neuropathic pain)	0.1 mg/kg orally at bedtime, increase by doubling dose every 3-5 days	1 mg/kg/24hr

Severe pain	Recommended infusion starting doses				
	Opioid	Infusion/hour [*]	Boost dose [*]	Interval between boosts	Max
	Morphine	0.02 mg/kg/hr	0.02 mg/kg	15 minutes	NA, titrate to effect
	Hydromorphone	0.004 mg/kg/hr	0.004 mg/kg	15 minutes	NA, titrate to effect
	Fentanyl	0.5 mcg/kg/hr	0.5 mcg/kg	10 minutes	NA, titrate to effect

Abbreviations: BID, twice daily; IV, intravenous; NA, not applicable; PCA, patient-controlled analgesia; PR, per rectum; SL, sublingual; TID, three times daily.

^{*} May consider boosts only for the opioid-naive patient for the initial 12-24 hours.

[‡] Both lorazepam and diphenhydramine may also be used to help manage nausea.

established as a safe and efficacious method in patients aged 6 years or older.²⁰ If children cannot self-administer the analgesics, parents or care providers can safely administer PCA to children.²⁹

- *Aggressive pain management can be provided in the home setting:* Aggressive pain management, including epidural and peripheral nerve blocks, can also be safely provided in the home setting through collaborative care planning between the hospital and community-based teams.³⁰
- *Children in the PC setting will not commonly become addicted to opioid medications; opioids do not need to be used sparingly for this misperception but should be titrated based on needs.* Significant adverse effects and addiction are very rare events in pediatric patients receiving PC.¹⁷ Cancer-related neuropathic pain may be managed by adjunctive agents such as gabapentin.³¹ Multiple agents are available for the medical management of pediatric patients' distressing physical symptoms, which may be associated with escalated doses of opioids to control pain, such as nausea, vomiting, constipation, and agitation.
- *Age-appropriate nonpharmacologic therapies should be considered for children and adolescents with cancer.* Mixed-modality strategies, ranging from simple distraction to incorporation of technology through virtual reality, can be used to reduce distress.³² These adjunctive therapies can be effective, including use of a fan for anticipated breathlessness; skin-to-skin contact for infants; distraction (eg, blowing bubbles) for younger children; and relaxation and guided imagery for older children and adolescents.^{14,16}
- *Cultural and socioeconomic differences should not be a barrier to effective pain and symptom management:* Pain assessment and management in pediatric patients can be effectively accomplished across cultures and in resource-constrained settings,^{33,34} particularly when providers are familiar with the principles of care¹³ and these are communicated with cultural sensitivity.³⁵ Key strategies to address cultural and language barriers and minimize complicated grief have been voiced by Mexican-American and Chinese-American families. These strategies include allowing sufficient time, medical interpreter services, adequately addressing questions and concerns, and the provision of the best information available.³⁵

Concepts, experiences, and interventions relating to end of life

Given the challenges that may emerge at the end of life in pediatric patients, developmental considerations to help address these patients' unique needs are outlined in Table 6. In

particular, infants to 2-year-olds will need reassurance about parental presence. Children 2- to 6-years old may believe that their disease is a punishment and should be reassured that they did not do anything to "cause" the illness. Children older than 6 years will often have an interest in rituals and death-related details. Deliberately eliciting questions and concerns as well as providing honest answers are critical in this age group. It is imperative to probe more deeply to ensure that the question being answered is actually the one that the child is asking and not merely an adult's instinctive interpretation of the question. Asking for clarification and following up with those that may know the child best can also be helpful. Finally, including children over age 12 in decision making is key. It is essential to promote the concept of open communication and active listening while supporting children and adolescents with cancer who are facing death. Parents and care providers may portray unrealistically optimistic outcomes or avoid discussion of difficult aspects, thereby potentially aggravating patients' fears, increasing their sense of isolation and burden, and inhibiting their adaptive coping.^{38,41} In a study of parents who had lost a child to cancer, 27% of parents who had not spoken with their child about death experienced regret.⁴⁰ None of the parents who had talked with their child openly before his or her death regretted having done so. Regret was more likely if the parents felt that the child wanted to discuss the topic.⁴⁰ Therefore, it may be helpful to respect and acknowledge that children with serious medical illnesses, such as cancer, often have deep insight beyond their years with regards to their health. They also recognize the potential relational and emotionally healing impact of such discussions, particularly among those children showing awareness of their imminent death.⁴²

Young patients are overwhelmingly interested and ready to share their thoughts about end of life.⁴³ Various tools—such as music, visual arts, writing, and digital technology aids—may be used to encourage children to express their thoughts, emotions, and needs. Many children and adolescents also appreciate the specific opportunity to engage in advance planning discussions; documents (ie, *Five Wishes* used for adults as a legal document guiding end-of-life planning in many US states) are valuable tools in young adults.⁴⁴ Analogous "Wishes" documents have also been developed specifically for children and may help guide providers' discussions with patients before the end of life.⁴⁵ *Voicing My Choices* is one such valuable tool recently developed based on input from adolescents and young adults with serious illnesses.⁴⁶

In addition to symptoms such as pain and constipation that typically respond well to treatment, children and adolescents near the end of life may experience more refractory symptoms such as weakness, fatigue, anorexia,

TABLE 6 Overview of concepts, experiences, and interventions relating to end of life across pediatric age groups^{21,36-39}

Age	0-2 years	2-6 years	6-12 years	12-18+ years
Concepts of death and dying	None (death may be cognitively the same as separation)	Death temporary and reversible; death may be caused by thoughts (magical thinking) or as punishment; death not universal (ie, may not happen to everyone); deceased may suffer	Concrete thinking; emerging adult concepts of death Death can be personal Interest in death-related details	Adult concepts (death universal, inevitable, irreversible; causal factors; consequences for dying person and others) Non-physical/metaphysical and abstract associations with death Sometimes sense of invincibility may persist
Potential experiences related to dying	Sensations of pain, discomfort	Potential guilt or wrong perceptions Ritual participation may be valuable	Potential fears of abandonment Engagement in rituals may be valuable	Reflective, seeking personal identity and role, balance of autonomy and dependence, meaning and purpose of life Relationship-based decision making ^{4b}
Potential key interventions: physical and environmental	Optimize physical comfort; promote physical parent-child bonding and consistency of surroundings and objects	Use age-appropriate tools to help monitor symptoms, preferences and response to treatment Facilitate proximity to parents	Facilitate appropriate engagement and decision making relating to symptom management, using age-appropriate tools Support access to peers and social networks	Facilitate active engagement and decision making relating to symptom management, using age-appropriate tools Support access to peers and social networks Support attainment of key short-term activity or life event goals Respect need for privacy
Potential key interventions: emotional and psychosocial	Facilitate close contact with parents; promote consistency and familiarity	Correct wrong associations (eg, fears of sleeping/separation with death) Use clear language (eg, dying)	Address fears; answer questions honestly Engage appropriately in decision making	Facilitate appropriate autonomy and decision making Allow open expression of strong emotions including frustration/anger and support adaptive coping behaviors; promote healthy self-image; assess and support spiritual needs and search for meaning and hope

weight loss, and limited mobility.⁴⁷⁻⁴⁹ Anticipatory guidance, care planning, coordination, and multidisciplinary psychosocial support are crucial to help ameliorate the distress caused by such symptoms.

Ethical considerations and decision making

In the context of providing PC, ethical considerations abound in the treatment of children with life-threatening illnesses. The central ethical consideration, with unique factors in PPC, is communication and medical decision making. The majority of PPC patients by definition lack capacity for autonomous decision making. In the context of medical research, children as young as 7 years can provide assent for participation. In addition, assent is strongly recommended to enroll adolescents in clinical research.^{44,50} In clinical medicine, however, there is no standard for the involvement of children or adolescents in

medical decision making or advance care planning. Many advocate age-appropriate involvement of children in medical decision making, especially using developmentally appropriate means of communication at the end of life.⁵¹ Children as young as 6 years have participated in complex end-of-life decision making and played an influential role in those decisions when their preferences are considered.^{43,52}

The basis for parental medical decision making on behalf of a child is the premise that parents are best able to judge what is in their child's best interest.⁵³ With regard to decision making for a child with incurable cancer, one study defined a "good parent" as "one who makes informed, unselfish decisions in the child's best interest, meets the child's basic needs, remains at the child's side, shows the child love, protects the child's health, prevents suffering, teaches the child moral values,

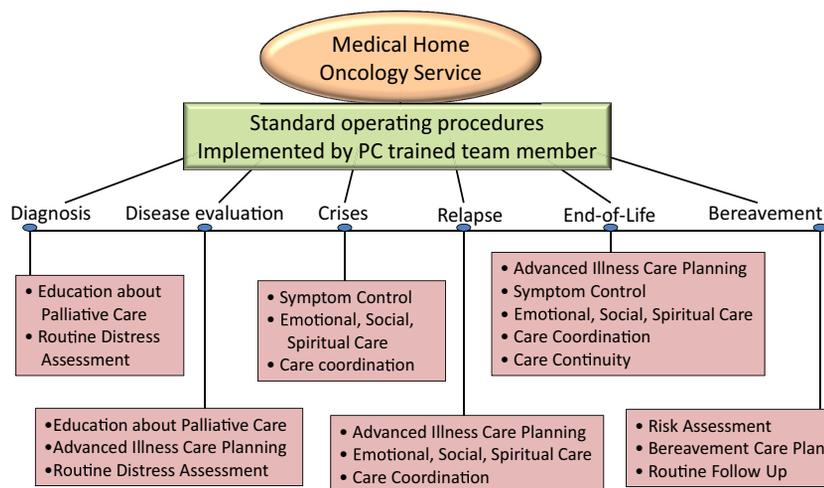


FIGURE The “Embedded Expert” approach to pediatric palliative care.

and advocates for the child.”^{54,55} Considering that parents bear the burden of caring for the child in the context of their family and would be most affected by the child’s outcome, parents may make decisions that might not be solely in the child’s best interest, as parental or familial interests may supersede that of the child. Some maintain that it is well within the parents’ rights to decide on behalf of their child while considering the interests of the family as a whole,⁵⁶ provided that parents are not exposing the child to undue risk for harm.⁵⁷ However, data demonstrate that parents typically do not wish to bear the sole burden of medical decision making and prefer to make medical decisions on behalf of their children in collaboration with their child’s physicians.^{58,59}

The model of shared medical decision making involves physicians presenting parents a range of medically acceptable options and helping the family prioritize and choose a mutually agreeable plan.⁶⁰ Building a relationship with the family and establishing trust is essential to arriving at medically sound and goal-directed care for each patient. Collaborative communication is critical for establishing clarity, understanding common goals, and fostering mutual respect between the providers and family.⁶¹ Clear and concise language as well as full prognostic disclosure can increase clarity and comprehension while maintaining hope.⁶² Physician communication that is both informative and marked by active listening and sensitivity is associated with increased satisfaction of parents with their role in the decision-making process.⁵⁸ Developmentally appropriate communication with the pediatric patient, eliciting both the patient’s preferences and assent, is an important component of this process.¹⁴ For an adolescent or young adult patient, inclusion in medical decision making as well as open communication is especially important to

demonstrate respect for their desire for self-determination and enhance their overall care.⁶³

Integration with curative therapy

Although frequently misconstrued as being synonymous with end-of-life care, PC focuses on relieving suffering in all its dimensions throughout the entire course of a patient’s illness. As referenced in the introduction, early integration of PC with disease-directed therapy is well supported by the literature, expert opinion, and clinical experience. Early integration of concurrent PC has been shown to alleviate symptoms; improve quality of life and patient satisfaction, reduce caregiver burden, potentially lead to more appropriate referral and utilization of hospice services, reduce inappropriate use of intensive care, and possibly increase survival duration.^{5,6}

The American Academy of Pediatrics supports “an integrated model of PC in which the components of PC are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death” for all children with life-threatening illnesses.⁷ If care teams focus solely on life-extending therapy as opposed to maximizing quality of life, team goals can encourage the use of interventions that may prohibit patients and families from receiving optimal comfort care. PC that is viewed as an abrupt transition from life-prolonging therapy to end-of-life comfort care can alienate clinicians, patients, and families as well as compromise patient care. PPC should be conceptualized as being a part of the care paradigm throughout the course of illness. This will allow the integration of PC resources and expertise into the care plan early on in the illness trajectory. It will also facilitate transitioning to quality of life as a primary goal gradually and intuitively. This would be

based on the needs of the patient and family as well as whether cancer-directed therapy culminates in cure or end of life. Ideally, PC should be offered to all pediatric oncology patients and their families around the time of diagnosis; encompassing medical, social, emotional, and spiritual well-being in a dynamic model that shifts focus based on patient needs at any given time. The result is the achievement of comprehensive, integrated quality care throughout the course of the illness.⁸

Parents demonstrate that they maintain concurrent dual goals of care for their children with progressive illness, prioritizing either disease eradication or alleviation as well as comfort maximization.⁶⁴ This seeming incongruence in reality demonstrates the need to integrate PC into the ongoing care of pediatric patients with serious illness, regardless of the disease-based goals of care. It may be especially beneficial for pediatric patients to have early and ongoing involvement with PPC, as they often have a greater degree of prognostic uncertainty as well as complicated disease trajectories.⁶⁵ Integrated PC services can help maintain focus on the overall goals and coordinate care at critical junctures in the patient's disease course. One model for integrating PPC into the ongoing care of children with cancer involves use of an "embedded" PC expert to integrate PC standard operating procedures (Figure). If implementation of the standard operating procedures does not effectively address the patient and family needs, a consult with a formal PC team is warranted. A model of integrated care teams has been incorporated in adult oncology centers but not yet in the pediatric setting on a large scale.¹⁸

A hallmark of integrating PC with oncology care is concurrent disease-directed therapy with quality-of-life measures. This therapy can include intensive chemotherapy with curative intent, palliative therapy to reduce disease burden, and supportive measures such as transfusions. Pediatric patients can simultaneously receive such comprehensive treatment regimens and be enrolled in hospice and/or PC and for a longer duration than what is typical for adult patients.⁶⁵ Research has demonstrated that when a do-not-resuscitate order is placed for a pediatric patient, there is no significant change in treatment with regard to life-prolonging measures as a result of change in resuscitation status.¹⁹ The recent US legislation of the Affordable Health Care Act supports concurrent disease-directed and quality of life-directed therapy for patients qualifying for hospice services. Familiarity with the concept of concurrent comfort care and disease-directed therapy is therefore essential for providers involved with pediatric patients. Resources, such as the National Hospice and Palliative Care Organization's concurrent care toolkit as well as other resources can be

helpful in understanding and implementing these concepts (Tables 2 and 3).

Conclusion

While PPC differs in some key ways from that of adult patients, both share many fundamental properties. Non-pediatric providers are being increasingly called upon to provide PC for pediatric patients. Many tools, resources, and networks are available to provide support in the unique elements of PPC. The principles and guidance discussed in this article can aid nonpediatric providers in delivering much needed, high quality, integrated PC to pediatric patients and their families.

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Pediatric palliative care should be started at the diagnosis of a life-threatening disease and continue along with curative care. It should not be misinterpreted only as end-of-life care, which it includes, nor faced as precluding the chances of survival.Â Even though parentsâ€™ choices are taken into best account in clinical decisions, physicians are limited by both legal and ethical considerations, standing in a demanding position.¹ The rise of modern medicine and particularly pediatric care have prolonged life expectancy considerably, which represents an increasing number of pediatric patients living with chronic complex conditions.Â Best practices for pediatric palliative cancer care: a primer for clinical providers. J Support Oncol. 2013;11(3):114â€“125. A primer for clinical providers.Â Topics unique to pediatric palliative care that are addressed include: providing pain and symptom management in the broad pediatric range from neonate to adolescent; caring for and interacting with developmentally distinct groups; engaging in shared decision making with parents and adolescents; providing accommodations for prognoses that are often more uncertain than in adult patients; and delivering concurrent disease-directed therapy with palliative care.Â Increasingly, nonpediatric providers are asked to provide palliative care for children and adolescents at the end of life, yet they receive little formal training in this area.