

## Top Ten Tips Palliative Care Clinicians Should Know About Caring for Children

Megan Jordan, MD,<sup>1</sup> Patricia M. Keefer, MD,<sup>2,3</sup> Yu-Lin Amy Lee, MD,<sup>4</sup>  
Kristin Meade, MD,<sup>5</sup> Jennifer M. Snaman, MD, MS,<sup>6</sup> Joanne Wolfe, MD, MPH,<sup>6-8</sup>  
Arif Kamal, MD,<sup>9</sup> and Abby Rosenberg, MD, MS, MA<sup>10,11</sup>

### Abstract

Given the limited number of pediatric-specific palliative care programs, palliative care providers of all disciplines may be called on to care for infants, children, and adolescents with serious illness. This article provides a review of the unique components of pediatric palliative care, including key roles within an interdisciplinary team, pediatric developmental considerations, use of medical technology and complexities of symptom management in children with serious illness, hospice utilization, as well as pointers for discussions with families regarding a patient's quality of life and goals of care.

**Keywords:** pediatric caregiving issues; pediatric chronic illness; pediatric decision making; pediatric palliative care; pediatric prognostication; pediatric symptom management

### Introduction

**P**EDIATRIC PALLIATIVE CARE (PPC) like adult palliative care includes an interdisciplinary holistic patient- and family-centered approach to easing suffering and enhancing well-being. Palliative care is relevant for the hundreds of thousands of children living with serious illness, regardless of their likelihood of long-term survival, including the 42,000 infants, children, and adolescents who die annually.<sup>1</sup> A key difference between adult and PPC is the relative paucity of pediatric-specific programs. For example, 67% of hospitals with more than 50 beds report a palliative care program,<sup>2</sup> and as recent as five years ago there were only 112 PPC programs across the nation.<sup>3</sup> Hence, adult clinicians should expect to be called on to assist with pediatric-aged patients.

The population of children receiving palliative care generally reflects childhood mortality: 41% of patients are <1 year

old, 46% are 2–17 years old, and 13% are ≥18 years old.<sup>4</sup> They have a wide variety of complex illnesses. Most (>55%) have more than one medical problem with principle diagnoses, including genetic/congenital conditions (41%), neuromuscular disorders (39%), and cancer (20%).<sup>5</sup> In some cases, prenatal diagnoses prompt palliative care consultation prior to a child's birth. Patient care needs often involve multiple subspecialties, long-term medical technologies, community support programs, and medications. In addition, typical child developmental processes like gaining motor, speech, social, and cognitive skills continue during the medical experience and influence prognostication, care planning, and decision making. Regardless of age, serious illness and death in childhood is unnatural and has a profound impact on the family and community.<sup>6</sup>

These top 10 tips for palliative care clinicians are meant to provide guidance when caring for a seriously ill infant, child, or adolescent. They were chosen and vetted by pediatric and

<sup>1</sup>Duke Palliative Care, Departments of Medicine and Pediatrics, Duke University, Durham, North Carolina.

<sup>2</sup>Pediatric Palliative Care Program, Department of Pediatrics and Communicable Diseases, C.S. Mott Children's Hospital, Ann Arbor, Michigan.

<sup>3</sup>Department of Internal Medicine, Michigan Medicine, Ann Arbor, Michigan.

<sup>4</sup>Duke Internal Medicine-Pediatrics Primary Care, Departments of Medicine and Pediatrics, Duke University, Durham, North Carolina.

<sup>5</sup>Duke Palliative Care, Department of Medicine, Duke University, Durham, North Carolina.

<sup>6</sup>Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, Massachusetts.

<sup>7</sup>Department of Pediatrics, Boston Children's Hospital, Boston, Massachusetts.

<sup>8</sup>Department of Pediatrics, Harvard Medical School, Boston, Massachusetts.

<sup>9</sup>Duke Cancer Institute, Duke Fuqua School of Business, Durham, North Carolina.

<sup>10</sup>Division of Hematology/Oncology, Department of Pediatrics, Seattle Children's Research Institute, Center for Clinical and Translational Research, University of Washington, Seattle, Washington.

<sup>11</sup>Division of Bioethics and Palliative Care, Department of Pediatrics, University of Washington, Seattle, Washington.

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adult palliative care specialists with the goal of addressing common issues encountered by clinicians.

### The PPC Team Includes Multiple Disciplines, Community-Based Resources, and Family Members

Most children have a community of potential partners who can provide expert advice in their care. This includes the child's primary care physician and/or subspecialists, who often have long-term relationships with the family and want to remain involved.<sup>7</sup> These clinicians provide key insight and expertise regarding the child's medical needs, appropriate medications, and other supportive care recommendations.

Many pediatric teams also include a breadth of disciplines, including nursing, social work, art/music therapy, psychology, chaplaincy, pharmacy, nutrition, and/or child life. Roles that are more specific to pediatrics include child life specialists, who provide age-appropriate resources to reduce the impact of medical stress and support patient/family adjustment, and art/music therapists who provide additional child-preferred media as supportive care and coping tools.<sup>8</sup> Even when not part of an immediate pediatric clinic or hospital, local pediatric providers may still have access to child-appropriate services such as psychologists, therapists, or nursing to assist with evolving palliative and hospice care needs. When available, these resources should be leveraged.

This comprehensive team is helpful, but not essential for the provision of palliative care. Whether or not pediatric subspecialists are available, providers may find additional assistance through the county, school, and religious communities, who often have resources of their own and are happy to remain engaged in a child's overall care. Most importantly, family members must be identified as key collaborators because they are experts in the child's experiences, symptoms, and corresponding physical and psychosocial needs.<sup>8,9</sup>

### Due to Advancing Technology and Medical Expertise, Children Are Living Longer and with Greater Medical Complexities

Over the last half century, child mortality has declined substantially.<sup>10</sup> With improved survival rates of premature infants and those born with congenital diseases, the prevalence of children with medical complexity (CMC) is increasing.<sup>11</sup> CMC are a heterogeneous group representing ~13%–18% of the total pediatric patient population.<sup>12</sup> By convention, these children have illnesses involving at least two organ systems requiring subspecialist expertise.<sup>10</sup> With advancements in oncology,<sup>13</sup> critical care,<sup>14</sup> surgery, and nutrition,<sup>15</sup> children with serious illnesses are living longer and may become vulnerable to previously underappreciated long-term side effects of treatments and interventions.<sup>16,17</sup> Successes in survivorship have translated to increased utilization of and dependence on medical technology (ventilators, feeding tubes, etc.), intensive hospital and community-based service utilization, and increased care coordination needs.

In light of these changes, advance care planning may be challenging. For example, evolving medical advancements, in combination with a child's long disease course and normative development, make prognostication difficult. Unlike in adult palliative care, 70% of pediatric patients are alive one year after their initial palliative care consult.<sup>5</sup> Therefore, palliative care clinicians should anticipate conducting multiple prognostic and goal-focused conversations, often over many years, regarding a family's concerns and hopes for the future (Table 1).

### Accurate Prognostication in Pediatrics Is Complicated by the Lack of Empirical Research and Heterogeneous Medical Experiences

Children receiving palliative care have diverse underlying medical conditions. Given the variability of illnesses, ages,

TABLE 1. SYNTHESIS OF RECOMMENDATIONS FOR COMMUNICATION

Assessment of QoL	Ask family about child's narrative	"Tell me about Leo"
	Ask family about child's QoL	"What has life been like since his diagnosis?" "Describe to us a typical day for Leo when he is well" "What things bring Leo comfort/joy?"
Assessment of symptoms	Ask parents/patients about symptoms and response to prior treatments	"What does it look like when he is in pain?" "When he has been in pain before, what has helped him?"
Goals of care conversations	Ask family how they make decisions for their child	"Who is involved when you have difficult decisions to make in your family?"
	Ask family how they want to receive information	"How are decisions made in your family?"
	Involve providers who have long-standing relationship with child/family	"What is most important when you are receiving information from the medical team?"
	Ask parents/patients their hopes and worries	"Who are the providers that know Leo best?"
	Ask parents/patient their source of strength	"Would you like us to involve them in caring for him at this time?"
		Ask parents/patients their source of strength
Talking with child	A child's developmental state and family preference determine communication with the child	"In difficult times what gives you strength"
		"How well is that working for you right now"
		Ask the adolescent "We need to discuss next steps in your care, how would you like to receive this information?" Ask parents, "What does Leo know about his illness?" "How can we partner with you in talking to Leo about his illness?"

QoL, Quality of Life.

and corresponding medical trajectories, these patients have equally diverse medical outcomes and survival times.

Prognostication for children is additionally challenged by limited prospective research and small heterogeneous samples, translating to a paucity of normative experiences. The acceptability and frequent use of medical technologies in this population may also heighten uncertainty. For example, children who previously died from hypoxic brain injury and central hypoventilation may now achieve a longer life with tracheostomy. Furthermore, corresponding neurological prognostication is made more difficult by pediatric neuroplasticity. It may take months to years for a child to reach his/her new “neurologic baseline.” When families ask about symptom trajectories or life expectancy, clinicians should provide an estimation of days, weeks, months, or years while also acknowledging uncertainty and the need to continuously revisit the answer over time. Palliative care clinicians must help families accept and navigate this uncertainty while supporting their ongoing assessment of a child’s quality of life (Table 1).

#### **Understanding a Family’s Narrative About Their Child’s Illness and Their Definition of Quality of Life Is Essential for Effective Goals of Care Discussions**

Understanding the narrative about a patient’s life and illness is critical in palliative care, and some narratives are unique in pediatrics. For example, over a long illness course, many families report hearing a poor prognosis and then “defying the odds.”<sup>18</sup> These experiences may create barriers to later discussions of prognosis and corresponding decision making. Clinicians may be more successful if they validate prior experiences and inherent uncertainties, while also aligning with the parents’ hopes and clearly articulating why the current situation may be different.

In addition, a family’s identity may be tied to the caregiving role for a chronically ill child.<sup>19–21</sup> Parents instinctually feel a need to advocate for their child, translating to potentially adversarial relationships. Parents may have a more pronounced reaction to any perceived threat to their child, and skillfully eliciting goals and establishing a shared goal of comfort or dignity may allow parents to retain their identity and sense of purpose.

Finally, clinicians need to approach questions about a family’s definition of quality of life (QoL) for their child from a perspective of humility and curiosity. For many families, especially those whose children have cognitive impairment or a major disability from birth, QoL is defined by simple successes: being able to smile, laugh, experience joy, know they are loved, etc. It is important to explore and honor these values, even if they differ from provider values (Table 1).

#### **Families of Pediatric Patients Often Choose to Accept the Burdens Involved in the Use of Life-Sustaining Technology for the Benefit of a Longer Life for Their Child**

Eighty percent of PPC patients receive some form of medical technology assistance, most commonly feeding tubes and central venous catheters.<sup>5</sup> Parents often accept medical technologies to ensure the current and future health of their children, in particular those with medical complexity. CMC, including those with extremely limited cognition and

communication, are considered to have an integral and significant role in the family unit. Members of the medical community must avoid making assumptions about patient’s QoL based on limited interactions with the patient or assumptions that QoL is poor due to intellectual disability and/or assistance with medical technology.

CMC are often followed by multiple subspecialties and many receive skilled nursing assistance in the home. Palliative care providers should work together with parents and their subspecialty providers to balance QoL (as defined by the family), with concordant medical interventions. These “blended goals” may include intensive interventions after careful discussion of the potential risks and benefits of the intervention for the child.

#### **Most Symptoms for Pediatric Patients Can Be Managed Analogous to That of Adult Patients; However, Complex Neurologic Symptoms and Feeding Difficulties Are Prevalent and Distinct in Pediatric Population**

Symptom management in the pediatric population follows many of the same principles as in adults. Key differences are linked to pediatric development (Table 2). For example, most medications are dosed based on weight, and clinicians must consider developmental and disease-based differences in metabolism, gastrointestinal absorption, organ maturity, and the ability to tolerate different medication routes.<sup>22</sup> Pragmatically, these differences are most pronounced in the first six months to two years of life. Clinicians should use a pediatric or neonatal specific reference for dosing medications.<sup>22,23</sup>

Younger children often require liquid medications, either due to the limited ability to take pills or the presence of feeding tubes. This may limit the use of longer-acting medications and translate to practical challenges obtaining medication solutions that are uncommonly prescribed outside of children’s hospitals. For example, the only liquid long-acting opioid for children is methadone, which, alongside its pharmacologic properties, makes it a popular choice for pediatric patients with chronic disease-related pain. Patient-controlled analgesia, a popular tool for symptom management, may be challenging to deliver safely and efficaciously when patients themselves are unable to trigger or limit dosing.

Pediatric patients have variable ability to describe symptoms and responses to interventions due to cognitive age and/or language abilities. Hence, clinicians may rely on caregiver insight and physiologic clues. For children with serious neurologic impairment (SNI), a good understanding from caregivers regarding potential pain drivers and typical pain behaviors can be helpful (Table 1). Children with SNI, including those with congenital brain anomalies, hypoxic-ischemic encephalopathy, and some mitochondrial disorders, may also have symptoms of neuroirritability or neurologic “storming” alongside more typical symptoms, such as seizures and spasms.<sup>23</sup> The first can often be treated with careful up-titration of gabapentin; pediatric subspecialty referral may be beneficial to assist nonpediatric trained providers if gabapentin is ineffective. Likewise, pediatric delirium can be difficult to diagnose and treat, even outside the SNI population. Most delirium medications are “off-label” in pediatrics, which can make finding adequate dosing references challenging.

TABLE 2. SYMPTOM MANAGEMENT PEARLS

Generic pearls for medications in all pediatric patients	Weight based dosing is used until adult dosing is reached The preferred route for medications is liquid administered orally or through feeding tube Intranasal fentanyl and midazolam can be used to avoid PIV placement
Age specific issues for medications	Metabolism changes rapidly in the first two years of life PCA use by children is affected by developmental ability, however often used with assistance of parents and/or nurses Delirium medications are often off-label for use in pediatrics
Opioid specific issues	Given typical need for liquid medications, methadone is the only long-acting option for opioid therapy
Pearls for patients with SNI	Ask caregivers about sources of pain and typical pain behavior Symptoms include seizures, spasticity, neurostorming, and neuroirritability Consider use of gabapentin
Feeding issues and intolerance	Neonates and infants have higher rates of reflux Feeding intolerance may present as abdominal pain, anorexia, retching, and vomiting Constipation is a common problem Management may include adjusting feeding route or regimen, use of motility agents, or considering various feeding tube options

PCA, patient controlled analgesia; PIV, peripheral intravenous line; SNI, serious neurologic impairment.

One last prominent difference in pediatrics is the prevalence of feeding issues and intolerance (Table 2). Neonates and infants naturally have higher rates of reflux, and patients' primary diagnosis or prolonged hospitalizations and interventions may lead to anatomic, physiologic, or functional difficulties with feeding emerging as pain, anorexia, retching, or vomiting. In addition, children can be highly susceptible to constipation, especially depending on their developmental ability to void voluntarily. Initial management often includes titrating feeding rates and varying components of nutrition to optimize growth and minimize symptoms. Providers may need to manage complex feeding plans, motility agents and consider various tube options. It is important to note that feeding challenges may be particularly burdensome for caregivers, as nutrition is often central to the societal perception of "good" parenting.

#### Parents or Other Surrogate Medical Decision Makers Are Generally Given Wide Discretion in Deciding What Is in Their Child's Best Interest

When adults are ill, surrogate decision makers may be tasked with representing the patient's wishes and values. When the ill patient is a child, especially one too young or cognitively unable to participate in decision making, parents (or legal guardians or other surrogates) make decisions, often based on what they believe is in the best interests of their child and/or what aligns most with the family's values. Determining the "best interest" of a child may be difficult, especially when there are intra-family and/or family-clinician differences in perspectives regarding QoL, suffering, and benefit.<sup>24,25</sup> Because parents are presumed to be acting on the child's behalf, they are generally given wide discretion in making these assessments, except in the rare situations where a decision would cause demonstrable harm or danger to the child (e.g., a decision not to treat a curable childhood cancer).<sup>26,27</sup>

Situations may arise where clinicians are asked to provide care that conflicts with their own interpretation of the patient's "best interests."<sup>28</sup> Palliative care teams can play an

invaluable role in these situations of moral distress by helping other medical staff identify and name the cause of their own distress and by underscoring family goals and values. In rare instances, they may also facilitate formal ethics consultation to navigate disagreements. These actions allow clinicians to continue to provide compassionate, family-centered goal-concordant care.

#### Children's Understanding of Illness and Death Evolves Over Time

Children and families experience illness in the context of normal growth and development on multiple levels, including physical, emotional, social, and psychological. To effectively communicate with a child, providers must meet the child at the appropriate developmental level. Therefore, it is important to understand the diverse stages of development in relation to the understanding of illness<sup>29</sup> and death<sup>30-32</sup> (Table 3). These concepts may be influenced by cultural and religious factors. It is essential to note that since children are incredibly observant, providers should be mindful of verbal and nonverbal (body language and facial expression) cues. In addition, just as parents and surrogate decision makers are given leeway in interpreting a child's quality of life, so too should they guide determinations of information delivery and communication to child.<sup>33,34</sup>

#### Children Develop Increasing Decision-Making Capacities as They Get Older and Should Have Increasing Roles in Healthcare Decisions

Just as a child's understanding of illness and its potential mortality evolves with age, so too does his or her capacity to engage in medical decision making. Where parents typically make decisions on behalf of younger children, adolescent patients are often capable of complex decision making, even when discussions involve serious issues like death.<sup>35</sup> Most teens want to be involved in such decisions and acknowledge that, while difficult, participation is helpful in identifying treatment goals, alleviating distress, and communicating with

TABLE 3. DEVELOPMENTAL STAGES AND CONCEPT OF ILLNESS AND DEATH

Age (years)	Characteristics	How child understands illness	How child understands death	Clinical practice implications
2–6	Developing language skills, magical thinking, egocentric, symbolic play	See illness as a form of punishment or attributed to magic/supernatural. They have difficulty differentiating between contagious illnesses and noncontagious illnesses (e.g., cancer)	Temporary or reversible, form of separation, can be caused by thoughts, form of punishment	Minimize separation, correct perceptions of illness/death as punishment, use precise language (dead, dying)
7–12	Concrete thinking	Understand that contagious illnesses occur through physical contact and are capable of differentiating between different illnesses	Gradual awareness that death is irreversible and permanent	Provide concrete details if asked, allow participation in decision making
13–18	Abstract thinking, self-reflection	Understand cause and development of an illness, that exposure to illness may not necessarily result in illness, and aware of psychological forms of illness	Irreversible, universal, and inevitable. May have sense of invincibility.	Allow expression of strong feelings, privacy, access to peers, and participation in decision making

loved ones.<sup>36–38</sup> However, the degree to which they want to be involved may depend on contextual, time, and family factors. Recent studies suggest that illness conditions like phase of treatment and symptom distress predict a child's communication needs more than age.<sup>39</sup> Teens may prefer to hear filtered (rather than complete) medical information from loved ones (rather than medical staff). Finally, although patients become legally responsible for their own medical decisions when they turn 18, it is not uncommon for legally mature young adults to continue deferring to parents as surrogate decision makers.

Palliative care clinicians can navigate these nuances by first asking parents how they prefer to make decisions and how they suggest clinicians communicate with their children (Table 1). With parents' permission, or when the patient is 18 years old or older, clinicians should ask the same questions directly to the patient. These conversations should be repeated periodically, especially when there is a need for key clinical decisions or when clinical circumstances change. In cases where parents explicitly request that clinicians *not* talk directly to an adolescent who may benefit from open communication and shared decision making, thoughtful exploration of parents' worries, values, and goals can be helpful.<sup>40,41</sup>

### Pediatric Hospice Allows for Concurrent Palliative and Disease-Directed Care Under the Patient Protection and Affordable Care Act of 2010

Pediatric end-of-life trajectories are highly variable with respect to their timelines and symptom demands. Likewise, because pediatric disease-directed therapies may alleviate symptoms and align with family goals, both clinicians and parents have historically been reluctant to enroll in hospice care.<sup>43</sup> For these reasons, Section 2302 of the Affordable Care Act of 2010 (ACA) allows pediatric patients to receive disease-directed therapies simultaneously with hospice benefit support.<sup>42</sup> This section is referred to as *concurrent care*. As with the more traditional hospice model, pediatric patients still must have a projected life expectancy of less than 6 months, as determined by referring physicians.<sup>42,44</sup>

A number of stipulations apply to the ACA-endorsed concurrent care, most notably that the application of this law is based on state interpretation. Criteria for inclusion age and specific therapeutic interventions may vary geographically. As this is a federal mandate for funded programs, Medicaid and Children's Health Insurance Programs (CHIP) are the only payers required to participate in concurrent care, and both programs may also adhere to state-level statutes. Private payers may choose not to participate in concurrent care programs; however, many choose to follow local state guidelines.

It is important to be familiar with the interpretation of concurrent care by the Medicaid program in a patient's home state. While disease-directed treatments are often covered, it is important to note that all palliative and symptom-focused evaluation and management are the responsibility of the hospice team, regardless of expense. Most states support only what is necessary based on the legislation, but some have expanded the breadth of pediatric services through Medicaid waiver programs and state plan amendments.<sup>43</sup>

### Conclusion

While PPC serves a unique patient population, the basic tenants of care remain the same, including an interdisciplinary team guided by patient and family values and views of QoL. Care decisions are often based on blended goals of aiding the child to live as well as possible for as long as possible. Partnering with parents to determine goals and communication needs is critical. While prognostication is difficult, providers should remember that many children with complex life-limiting illness live for years. Communication with the child evolves as they grow up and their illness progresses. Achieving relief of physical suffering for the child requires use of appropriately chosen and dosed medications in conjunction with nonpharmacologic, age-based interventions like therapeutic play and/or art therapy. Understanding some of the unique components of pediatrics will prepare palliative care providers to confidently care for children within their practice.

### Author Disclosure Statement

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Address correspondence to:

*Megan Jordan, MD*

*Duke Palliative Care*

*Departments of Medicine and Pediatrics*

*Duke University*

*40 Duke Medicine Circle*

*DUMC Box 3688*

*Durham, NC 27710*

*E-mail: [megan.jordan@dm.duke.edu](mailto:megan.jordan@dm.duke.edu)*