Pediatric Palliative Care in the Perioperative Period

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Abstract

Purpose of Review The purpose of this review is to familiarize anesthesiologists with the role of the subspecialty of pediatric palliative care and its potential contributions to the management of children with complex and life-threatening illnesses, many of whom may present for operative or diagnostic procedures requiring anesthesia.

Recent Findings Recent publications highlight the benefits of palliative care to patients and families experiencing a wide variety of conditions along the continuum from prenatal application to the management of young adults. Retrospective reports highlight improved quality of life, improved symptom control, an impact on place of care, and an increased rate of achieving the preferred place of death.

Summary Pediatric palliative care is a relatively new subspecialty of pediatrics which utilizes an interdisciplinary team approach to support patients and their families undergoing treatment for life-threatening or life-limiting conditions, addressing physical, emotional, and psychological needs to care for the whole patient.

Keywords Pediatric palliative care and hospice · Perioperative palliative care · Advanced care planning · Goals of care · Life-threatening illness · DNR orders

Introduction

An anesthesia provider, seeing the title of this chapter, might reasonably ask: “What in the world does pediatric palliative care have to do with the practice of pediatric anesthesia?” Anesthesiologists are caring for increasingly ill children presenting for surgical and interventional procedures, both curative and palliative; longer and longer stays in intensive care units are also becoming more common as advances in technology permit extension of life with multi-organ support. This shift in pediatric care toward long, difficult, heroic ICU stays requiring multiple invasive therapies and an army of consultants makes it difficult for families and practitioners alike to navigate the big picture of the illness trajectory. When patients like these, who seem to be approaching end of life, appear on

the operating room schedule, anesthesiologists may feel a sense of dread and futility, further compounded in the setting of an uncertain resuscitation status and unclear goals for the procedure. Hopefully, by the end of this article, the reader will have a better sense of how a palliative care team approach may contribute positively to the perioperative care of complex patients; and further, how colleagues in palliative care might help the perioperative team clarify the patient and family’s goals for the procedure, provide guidance for the management of pain and other symptoms, and ease the care team’s distress at caring for critically ill and unstable patients.

What Is Pediatric Palliative Care? Is It the same as Hospice Care?

Kelley and Morrison defined palliative care as the interdisciplinary specialty focused on improving quality of life for persons with serious illness and their families [1]. The American Academy of Pediatrics Committee on Hospice and Palliative Medicine and the Committee on Hospital Care expanded on that definition, stating that the goal of pediatric palliative care is to “relieve suffering, improve quality of life, facilitate informed decision-making, and assist in care coordination between

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clinicians and across sites of care.” [2] Within pediatrics, pediatric palliative care operates across the age spectrum, helping patients and families from the prenatal period through young adulthood. The child’s life-threatening illness may represent a sudden and serious event in a previously healthy child, the birth of an infant with congenital anomalies at high risk for early death, the recent worsening of a chronic illness in a child with a complex medical history, or a pre-terminal condition. One key aspect of pediatric palliative care is that enhancements in care have resulted in increased survival of the most fragile children, resulting in disease trajectories that are “characterized by slow deterioration and high dependency and debility.” [3] Pediatric specialists have become skilled at delaying death, but at the price of creating a significant burden of care and technology in the home setting. Regardless of the acuity or age of the patient, families are anxious and suffer from the burdens and uncertainties of the illness.

Hospice care is distinct from palliative care. While both specialties provide medical and psychosocial services to patients and families at a time of medical crisis and uncertainty, hospice care is linked to an expectation of death within 6 months from the primary condition; palliative care offers benefits independent of prognosis. In adult medicine, Medicare provisions require that hospice patients relinquish access to disease-altering treatments, but provisions in the Affordable Care Act allow children receiving Medicaid services, up to the age of 21 years, to receive hospice services concurrently with standard care [4]. This concurrent care provision is advantageous for families, in that they may continue to visit trusted caregivers as long as they choose, while giving the hospice team a chance to build relationships prior to the inevitable decline. Over time, in this model, most children spend more time at home than in clinic or in the hospital. One common example of concurrent care would be the oncology patient enrolled in home hospice care who is no longer a candidate for chemotherapy, but who still requires frequent platelet and red cell transfusions to prevent bleeding and to maintain energy levels.

What Do Palliative Care Teams Do?

The domain of pediatric palliative care interventions is broad, and includes some or all of the following: discussing patient and family goals of care; facilitating critical decision-making regarding treatment options; managing distressing symptoms including pain, nausea, vomiting, delirium, and anxiety; providing psychosocial and spiritual support; participating in the communication of bad news; discussing end-of-life decisions including resuscitation status; assisting with coordination of care among specialists; assisting with coordination of discharge plans or hospice transfer; and assuring that patients/families are fully informed about the likely trajectory of the

illness (see Table 1). Palliative care interventions are provided by an interdisciplinary team that includes physicians, nurses or nurse practitioners, chaplains, social workers, pharmacists, and bereavement counselors, in addition to administrative support staff. Some teams also include child life specialists, psychologists, physical and occupational therapists, and volunteer support.

Once the primary team consults the palliative care team, the physician and/or advanced practice nurse reviews the medical history, assesses the symptom burden, and makes recommendations to enhance comfort, while the team nurse may provide extra support to bedside nurses and ancillary staff. The palliative care social worker assesses family structure and stressors as well as resource needs and may provide counseling services for the patient, parents, or siblings. The chaplain explores the family’s spirituality and religious faith, helps the child process his/her physical changes/losses as anticipatory grief, assists in the difficult work of “redefining hope,” and helps support the family’s underlying belief system, thereby improving the team’s understanding of the family’s goals of care [6•]. A pediatric psychologist may be very helpful in the assessment and management of pathological behavioral and emotional responses to illness, incorporating cognitive behavioral therapy and introducing techniques such as guided imagery and relaxation [7]. And finally, the palliative care bereavement specialist follows the families of children who have died under the team’s care, identifies parents and siblings at high risk for complicated grief, and makes community referrals when indicated. Most pediatric palliative care is provided in the inpatient setting, although some larger programs have developed strategies for providing continuity of care for their patients in the community or clinic setting [8].

Table 1 Domains of palliative care interventions [5]

Palliative care teams assist patients and families with:

Pain and symptom management
Articulating goals of care
Advanced care planning
Facilitating communication, within the family, with medical team, with caregivers
Critical decision-making
Psychosocial needs of the family
Spiritual support
Emotional support for patient and family, including siblings
Care coordination across specialties and sites
Psychological care
Anticipatory guidance
Memory-making and legacy-planning
End-of-life care
Bereavement support

Another area in which the palliative care team may be helpful is in caring for staff members—trainees, physicians, nurses, and ancillary caregivers—for whom the child’s illness and/or death may induce significant psychological or emotional distress [9•]. Other stressors for bedside caregivers may include contentious interactions with the family, conflicts among team members or consultants, disagreements with the family about the patient’s degree of suffering, or burnout or compassion fatigue. The palliative care team meets with staff members, brainstorms communication strategies that might be helpful in dealing with challenging families, offers emotional support, and encourages healthy self-care.

When Should Practitioners Request a Palliative Care Consult?

The American Academy of Pediatrics has recommended that the palliative care team should be consulted at the time of, or shortly after, the diagnosis of a significant illness [9•]. Even for conditions for which there are now highly effective treatments, like acute lymphocytic leukemia, families benefit from the supportive care offered throughout the treatment journey. Other appropriate times to consult or re-consult the team would be when the child’s typical illness pattern seems to be changing: more frequent hospital admissions, need to add on multiple new medications, obvious deterioration, evidence of cancer recurrence, new symptom burdens, longer hospitalizations, or more difficulty weaning from the ventilator. Any point along the child’s illness journey at which there seems to be a “fork in the road” in terms of possible therapeutic options offers a good opportunity to review the child’s status relative to parental goals. One common example of such an inflection point might be when the medical team is considering tracheostomy for a child with profound neurologic impairment, after one or more failed extubations. Perhaps the medical team is divided about whether or not to offer the tracheostomy. Perhaps they are unsure whether or not parents would want, or be able to take on the added burden of tracheostomy care at home. A frank discussion of the risks, benefits, limitations, lifestyle changes, and alternatives to tracheostomy—presented in light of the parents’ goals and hopes for their child—would help all concerned balance the medical choices going forward. Parents, too, often give hints that they are ready to review goals of care when they make remarks like “it just doesn’t seem like we’re getting back to where she was,” “nothing seems to be working,” or “she just looks miserable all the time.” One of my colleagues says, only half joking, “the time to call palliative care is two months before you thought of it.” (Jared Rubenstein, MD, personal communication).

Barriers to the incorporation of palliative care into disease-directed therapy include the paucity of well-developed

palliative care teams outside major hospitals or academic medical centers. More common is the feeling of some practitioners that families will feel that their physician has “given up” on their child if palliative care is consulted; this hesitancy reflects the physician’s own discomfort with the introduction of palliative care as a benefit to patients.

Which Patients Might Benefit From Palliative Care?

The careful reader might observe that many of the palliative care interventions offered by specialist teams are already incorporated into routine care by colleagues in Pediatric and Neonatal Intensive Care Units (PICU and NICU, respectively) and in Oncology Clinics. This makes sense because the vast majority of children who died in the hospital die in either the NICU or the PICU. Well-trained practitioners in these specialties provide what is known as “primary” palliative care: managing distressful symptoms and communicating effectively with their patients and families, addressing end-of-life issues as they present. However, in more complex situations, it is sometimes both necessary and helpful to have a colleague outside the primary team who meets with the family to assure that they understand what their physicians are telling them, reviews the treatment goals for their child, and provides an extra layer of support in a less rushed setting than is usually possible in the intensive care unit. Sometimes patients who have had a long relationship with a physician hesitate to bring up questions or concerns because they do not want to appear mistrustful of their care team. Sometimes intensivists struggle to communicate with a particular family because of pre-existing mistrust or challenging family dynamics. In these situations, the special training and expertise of the palliative care team may be particularly beneficial.

Primary palliative care is also a fundamental aspect of caring for sick infants in the NICU, with the expectation that the primary treatment team incorporates “symptom management, empathic communication with families, and interprofessional collaboration” into the plan of care [10]. Prognostic uncertainty is one of the most challenging issues to communicate with families in the NICU, made more difficult by the fact that both practitioners and families tend to be overly optimistic about the effectiveness of NICU procedures. The skill with which the palliative care team navigates this tension between prognostic uncertainty and overoptimistic expectations affects the team’s ability to integrate the parents’ goals of care with complex decision-making, and may delay the family from recognizing that their time with their baby may be shorter than hoped for.

Even before birth, perinatal palliative care teams offer support to parents who are expecting an infant with a serious birth defect at high risk for perinatal death. Encouraging the parents

as they “parent in utero” promotes relationship-building with their infant, and helps the parents develop a birth plan reflecting their values and hopes for the baby. What resuscitative procedures do the parents want? What are their goals if the infant survives longer than expected? How can the team best support memory-making, rituals, and family bonding? Palliative care in the perinatal period emphasizes the difficulty of precise prognostication while offering parents the chance to make the most of the time they have with their baby [11]. Planning for transition to hospice if the infant survives to discharge is a key part of any perinatal plan.

In the PICU population, nearly two-thirds of children who died had a chronic or underlying condition, and a significant proportion were already receiving artificial feedings and some kind of mechanical ventilation at home; it is estimated that as many as 70% of deaths in the PICU are the result of discontinuation of life support [12]. Obviously, this fragile population is one for whom specialist palliative care services could provide extra support and expertise for both families and intensivists. Jones and Carter surveyed Pediatric ICU (PICU) physicians to see how they viewed the collaboration with palliative care teams [13]. They found that intensivists—in general—felt competent to manage most symptoms in the dying child except for more chronic symptoms like constipation and skin breakdown. They felt confident in their communications and in the management of withdrawal of life-sustaining treatments. However, these same physicians felt less confident about how to manage patients whose parents were in denial or were holding on to unrealistic expectations, and viewed those communications as one area in which their palliative care colleagues could be helpful. They also wanted assistance in managing continuity between hospital admissions, and in the coordination of care as patients transitioned home or to hospice care. The PICU physicians viewed the paucity of community-based home hospice programs and the availability of bereavement programs for the families of children who died as major limitations of their resources.

In order to understand the attitudes of intensivists and oncologists regarding palliative care, [14] investigators asked participants to report whether they would incorporate palliative care into the treatment plan, including time of palliative care consult, the reason for the consult, and the reasons why a respondent might not include palliative care using a set of simulated cases. There was no difference in the rate at which the intensivists or oncologists would consult palliative care, but they had different reasons for seeking subspecialist help. Critical care physicians were more likely to seek help with psychosocial needs in complex family situations, whereas oncologists were more likely to consult palliative care for assistance with symptom management, especially toward the end of life. Interestingly, women were more likely than men to incorporate palliative care in the management of their patients

and were also more likely to consult palliative care earlier in the disease process.

Pediatric oncology is one of the specialties with a unique relationship to palliative care because many pediatric palliative care programs were born out of the needs of the oncology patient population. In a review of the oncology literature over a 20-year period, investigators found moderate quality evidence for the early integration of palliative care as a standard approach for children and adolescents diagnosed with cancer, citing significant benefits to patients and families [15]. Authors agree with the early incorporation of palliative care into treatment plans, and propose a three-tiered approach to facilitate a palliative approach for all children with cancer, emphasizing consultation of specialist’s palliative services to children with the highest risk cancers [16]. Some have suggested that “oncologists’ closeness to their patients and the situation may make them less able to perceive suffering,” and also advocate for close collaboration between oncologists and palliative care providers to manage the heavy symptom burden and the uncertainty of the prognosis [17].

Other subsets of pediatric patients provide ideal opportunities for the incorporation of palliative care into standard management. One large group is that of infants and children with genetic disease, congenital anomalies, and neuromuscular disorders, which represents a large proportion of principle diagnoses in one large multi-institutional study [18]. For children with neurologic impairment, progressive debility may be slow and punctuated by episodes of crisis followed by periods of stability; the uncertainties of prognosis create stress, and the caregiving demands on parents quite burdensome. One study showed that after a palliative care consult, a greater percent of parents of children with neuromuscular and severe cognitive impairment elected to avoid life-sustaining treatment interventions, when compared with those with other diagnoses [19]. This suggests that parents welcome the opportunity to discuss the balance between life-sustaining interventions and the suffering their child experiences.

Solid organ transplant patients represent another group that may benefit from palliative care while awaiting transplant, struggling with quality-of-life issues [20]. In a study of lung transplant programs, significant barriers to early introduction of palliative care included unrealistic expectations for survival after lung transplant and transplant physicians’ feeling that transplant goals and palliative care goals were diametrically opposed [21]. Similarly, in a single site review of palliative care for children with end-stage renal failure on dialysis, known to have a very poor quality of life, the authors reported found a high level of emotional distress, concerns about the risks of undergoing and waiting for a renal transplant, and the family’s acknowledgement that even a successfully transplanted kidney has a limited lifespan. The Renal Physicians Association recommends a palliative care plan for all pediatric patients

with ESRD, but this recommendation has been difficult to implement on a national basis [22].

Another underserved group of patients who could benefit from early incorporation of palliative care services are older teens and young adults (YA's), for whom chronic life-threatening or life-limiting diseases may interrupt this group's tasks of establishing independence and developing intimate relationships, complicating their ability to make complex decisions as they transition to adult caregivers [23•]. Vulnerability, dependence, and the uncertainty of prognosis increase social isolation and depression, further compounding anticipatory grief. The complex issues presented by YA's medical, psychosocial, and developmental needs offer challenges and opportunities for palliative care teams to bridge the care gaps for this vulnerable population.

Advanced Care Planning

Advanced care planning is the term used to describe discussions balancing patient or parental goals with therapeutic choices, usually prompted by a change in the child's condition. The practitioner leading the discussion should first ascertain what the parents understand about their child's current status, then share any new information that might signal a change in the child's prognosis. Only when parents are well informed about their child's condition will they be receptive to a discussion of the changes or challenges the team believes may be in their child's future (see Table 2). Key to advanced care planning is asking the question, "What if?" *What if* his kidney function does not recover, *what if* his neurologic exam

does not improve when the sedation wears off, *what if* his blood pressure remains low despite three vasopressors? Honest discussion of the therapeutic choices and physician's recommendations, along with the risks, burdens, and limitations of those choices, offers the parents the chance to balance their goals and hopes with decisions for what they see as their child's best interests.

Another key point in advanced care planning is that difficult decisions are rarely possible after one meeting. Parents need time to digest the information privately, formulate follow-up questions, and discuss their feelings and concerns with family members or spiritual leaders. Most advanced care planning requires repeated discussions over several days or weeks, depending on the urgency of the decision.

What About DNR Orders? Can Palliative Care Providers Help With These?

Leading discussions about resuscitation status is one of the core competencies of palliative care physicians. Sometimes, the patient's primary attending initiates a code discussion, while in other situations, the primary team consults palliative care if the team is uncomfortable broaching the topic or if prior attempts resulted in the demand to "do everything" in the face of what the medical team sees as a futile situation. In this circumstance, the palliative care team may revisit and reframe the code discussion, once again starting with the parents' goals of care, reviewing the likely outcomes and the suffering for the child. Some medical teams prefer that the palliative care team initiates the code discussion, believing that if the primary team introduces the topic, the family may lose hope and trust in their caregivers.

Code discussions, like advanced care planning, challenge parents to think ahead, to imagine the worst, and to decide what is most important to them if their child cannot survive the illness. Allowing parents to make choices about individual components of resuscitation (agreeing to fluids and medications, but refusing chest compressions or reintubation, for instance) maintains some sense of control for parents, and may indicate a gradual acceptance of the child's decline. Statements like "We will continue to hope for the best with you, while we plan for the worst" help families feel that their team is continuing to care for their child.

Palliative Care in the Perioperative Period

Pediatric surgeons and surgical subspecialists may find themselves in one of two situations when caring for critically ill and unstable children. They may have a long-term relationship with the patient and family extending over many years; or, they may have just been consulted to perform an invasive

Table 2 Best practices for advanced care planning discussion [24]

Use of a private room
Assuring that there are enough chairs for all participants to sit
Invitation to attend for all interested/involved participants
Cell phones/pagers given to colleagues not in the room
Introduction of all attendees
Statement of the purpose of the meeting
Sitting at eye level with the patient and family
Review of the patient's current condition
Avoidance of medical jargon
Listening to the patient/family without interruption
Asking questions for clarification
Repeating what the patient/family said
Using the words death/dying if applicable
Offering specific recommendations for care going forward
Inviting questions
Allowing silence if grief or other strong emotions are expressed
Summarizing key points from the meeting

procedure on a patient whose family they do not know, whose understanding and goals about the patient's illness are unknown to the clinician. In both situations, the participation of palliative care may be beneficial. In the first case, it is possible for the surgeon's close relationship with the family to affect his/her judgment, recommending repeated surgical interventions that may not be helpful for the child's condition long-term, if he or she has not explored the parents' goals of care as the child's condition has deteriorated. In the second scenario, the complexity and urgency of the situation may not lend itself to a prolonged exploration of parental goals; however, if the palliative care team has been involved with the patient, their input could provide the perioperative team with a baseline understanding of the family's perspective.

Surgical or interventional procedures that might be necessary in a critically ill and unstable child who may be approaching end of life might include central line placement for intravenous administration of medications, ventriculoperitoneal shunt placement for relief of increased intracranial pressure, drain placement for management of ascites or pleural effusions, debulking of tumors for pain management, or nephrostomy placement for an obstructed urinary tract. Any procedure performed in this setting requires a thorough and unhurried discussion among the parents, anesthesiologist, and the surgeon, with the goal of ascertaining the family's understanding of the goals, the risks, and the benefits of the planned procedure. During this discussion, it would also be important to review the family's wishes regarding resuscitation status, if the patient's condition should deteriorate during the procedure. In years past, DNR (do not resuscitate) orders were routinely suspended during surgery, but that is no longer the case. In most cases, it is possible to distinguish between a change in patient status related to surgery or anesthesia, and a change in status related to the underlying condition. Each encounter requires a frank discussion of options and recommendations, and the parents' choices should be recorded in the medical record. It has been suggested that the code status be included in the morning huddle for the operating room and incorporated into the time-out [25]. For example: "If she arrests, we will give one round of medications and continue ventilation, but we will not perform chest compressions, as reflected in today's note." One important point is that, if the existing DNR order is partially or completely suspended while the child is anesthetized, the time or stage of recovery (e.g., discharge from the recovery room) at which it will be re-instated should also be discussed and recorded [26•].

Obviously, the anesthesiologist assigned to anesthetize the child should participate in the preoperative discussion with the surgeon and family, and should review the chart for additional input about goals of care from other caregivers. Discussion with the parents should include the practitioner's specific anesthetic goals, plans, and recommendations, along with a review of potential complications and remedies, including complications in the postoperative period, such as inability to

extubate. Occasionally, this interview will expose that parents' incomplete understanding of the risks associated with the procedure necessitates further discussion [27•]. Only when all members of the team are "on the same page" should the procedure commence.

Conclusions

The early introduction of palliative care after the diagnosis of life-threatening or life-limiting disease supports families as they navigate pain and symptom control for their child, changes in condition, communication with multiple specialists, and complex decision-making. Contrary to the fears of many caregivers, introducing palliative care does not increase family distress and may actually "decrease the use of aggressive interventions at the end of life." [18•] Further growth in the number of trained palliative care practitioners will facilitate programmatic expansion to serve additional groups of patients who could benefit from palliative care interventions, encourage the growth of community-based care, and enable rigorous outcomes research. The author encourages her anesthesiology colleagues to learn more about palliative care principles and skills applicable to the perioperative period.

Compliance with Ethical Standards

Conflict of Interest Nancy L. Glass declares that she has no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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