The pediatric surgeon and palliative care

Chris Feudtner, MD, PhD, MPH,a,*, Thane A. Blinman, MDb

a Department of Pediatrics, The Children's Hospital of Philadelphia, CHOP North, Room 1523, 34th and Civic Center Blvd, Philadelphia, Pennsylvania 19104
b Department of Surgery, The Children's Hospital of Philadelphia, 34th and Civic Center Blvd, Philadelphia, Pennsylvania 19104

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ABSTRACT

Palliative care is now a core component of pediatric care for children and families who are confronting serious illness with a low likelihood of survival. Pediatric surgeons, in partnership with pediatric palliative care teams, can play a pivotal role in assuring that these patients receive the highest possible quality of care. This article outlines a variety of definitions and conceptual frameworks, describes decision-making strategies and communication techniques, addresses issues of interdisciplinary collaboration and personal self-awareness, and illustrates these points through a series of case vignettes, all of which can help the pediatric surgeon perform the core tasks of pediatric palliative care.

In this chapter, we provide an overview of central concepts in the field of PPC, describe some useful communication techniques, outline core surgical palliative care tasks, and then describe six specific patient scenarios that will demonstrate these concepts and methods in clinical practice. We base our recommendations on a combination of our clinical experiences, the published literature, and the research we have conducted regarding pediatric palliative care and decision-making in pediatric serious illness. And in order to be clear and concrete, we address ourselves directly to you, the reader, as the surgeon in charge of the care of these patients.

Central concepts of pediatric palliative care

PPC aims to help patients and families confront serious illness. By “serious illness,” we mean illnesses or conditions that pose a tangible probability that the patient will not survive. This aspect of survivability distinguishes PPC from other forms of surgical palliation where the intervention trades a substantial morbidity for a lesser one, such as substituting living with ulcerative colitis for living with a total colectomy, or hyperinsulinism for pancreatectomy. These forms of definitive surgical palliative interventions, although not truly cures for the original conditions, certainly can provide great and lasting benefit. PPC, in contrast, is more circumstantial, concerned with the interventions that can and ought to be performed for children with low probability of survival. This probability does not need to be 0. In fact, when determining who might benefit from PPC services, prognosticating accurately is not as important as acknowledging that a patient is suffering, or noticing the patient and family are worried about the gravity of the illness and the prospect of mortality. If palliative care is only considered when death is certain or imminent, it has been considered too late.
Palliative care is more than just end-of-life care

PPC should not be thought of as being principally about a very specific set of end-of-life interventions and practices that are called on in the last hours and minutes prior to death. This is not to deny the crucial importance of knowing how to do a compassionate extubation, provide effective pain management and sedation at the end of life, or help a family with bereavement; rather, the point is to emphasize that these are only part of what excellent PPC can offer patients and families.

The PPC model of care of patients with serious illness views care as being composed of multiple modes of complementary interventions that can be provided concurrently (Figure 1). This underlying model of care does not view palliative care as being essentially incompatible with curative care, nor does it view curative care and palliative care as mutually exclusive or having to be traded-off, one for the other. Instead, in the complementary multi-modal model of care, PPC can be delivered concurrently with cure-seeking care, such as might be done for patients undergoing bone marrow transplantation for high-risk conditions. Similarly, PPC can be provided to children for whom cure is no longer possible, or perhaps never was (such as those who have severe impairments from birth injury or genetic syndromes), but for whom medical and surgical care can effectively extend life by years or even decades. The core elements of PPC—which can be combined with either cure-seeking or life-extending care—focus on improving the quality of life and maximizing comfort, providing the family with supportive care and attending to grief and other emotions, doing likewise for the healthcare staff who have likely become attached to the child and family. Both of these latter components of care can continue after the death of the child.

Palliative care is compatible with long-term survival

As hospital-based PPC teams have developed and matured over the past decade, they have increasingly cared for a wide variety of patients, many of whom live for years. In a multi-center study of six established PPC teams in the United States and Canada, a cohort of 515 patients who received services in 2008 were followed up for a year (Figure 2).16 The overall 1-year survival in the cohort was 74%, far greater than expected survival in adult patients receiving palliative care services. Even in the members of the cohort who had cancer diagnoses and were receiving PPC, the 1-year survival was nearly 50%. “Palliative care” cannot be defined simply by actuarial expectations.

Palliative care is not hospice care

PPC is distinct from, but closely related to, pediatric hospice care. Both modes of care largely embrace the same philosophy, goals, and interventions; they diverge in legal definition, regulation, and venue. Hospice care is provided by specially licensed and regulated organizations and, in the United States, is most often provided to the child in the home setting. PPC, by contrast, is provided mostly by hospital-based clinicians and often in the hospital setting. But the difference is more than location: some outstanding examples of community-based PPC programs exist, while a major focus of hospital-based PPC is to enable children and their families to spend as much quality time at home, away from the hospital, as is possible.

Until recently, a major impediment to conceiving palliative care as more than just end-of-life care was the requirement, under the federal regulations governing hospice benefits within the Medicare program, that patients who elected to receive hospice care had to decline other modes of care. This regulation inadvertently delayed or diverted patients and families from initiating hospice or even learning how hospice service could help them. Fortunately, the 2010 Affordable Care Act removed this restriction. Now, the simultaneous provision of hospice care with ongoing care oriented toward seeking cure or life prolongation is explicitly part of the benefit that state-run Medicaid programs are charged with providing to all pediatric patients who fulfill hospice eligibility criteria. This so-called concurrent care model is now being implemented across the US.17

Palliative care does carefully consider the ways that patients die

While the death of a child is never a good outcome, some ways of dying are far worse than others. Once the disease or condition has progressed to the point where death is inevitable, surgeons and physicians need to consider the ways in which the patient might die. Admittedly a grim task, but necessary if clinicians are to take care to avoid interventions that may increase the likelihood of a “worse” dying process. For example, the quiet coma of uremia may be preferred to septic shock after an aspiration event. Be mindful that a procedure that may prevent one medical problem from worsening might ultimately result in the patient having to die due to another more distressing or uncomfortable problem.

Surgical palliative care core tasks

Pediatric surgeons may need to confront any of several tasks when caring for patients with serious illness. Surgeons are well prepared to apply the mechanical solutions offered by surgical intervention, but feel less prepared for other tasks. But just as with surgical interventions, there are working methods, empirical heuristics, and avoidable pitfalls for these other tasks (Table 1).
Conducting challenging conversations

Discussions about serious illness with patients and parents are often fraught with strong emotions. A few communication techniques can help clinicians navigate these conversations more skillfully.18

Making promises

When patients and families present themselves for care, they may have done so on the basis of a recommendation and knowledge about who we are as surgeons and physicians, or simply by the luck of the draw. Either way, they are unlikely to know how we will attempt to communicate with them, or what standards we will hold ourselves to. Discussing this briefly when first getting to know a patient and family can subsequently prove to be very useful. One might say, “Before we move on, there are a few things I want you to know about me and how I want to communicate with you. First, I promise to be as clear and straightforward as I possibly can be. Second, I promise that I will tell you what I think I can do that will help, and I will tell you when I am worried. Third, I promise that I will work hard to make sure that you have been provided with good information and that all of your questions have been fully answered.” These promises may seem unnecessary, but stating them explicitly allows patients and families to essentially agree to enter into a relationship where these promises will be honored even when the going gets rough.19

Asking permission

Before broaching a difficult topic for discussion, seek and obtain permission to do so. One might say, “There’s something that I think is important and that we need to talk about. Is it okay if we

Table 1
Surgical palliative care core tasks.

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do so?” Again, this may seem contrived or forced, but allowing patients and families some control over what will be discussed and when, in a situation that otherwise may feel totally out of their control, can promote feelings of trust and respect.

Revisiting

Sometimes a single conversation can result in a definitive, even irrevocable, decision. More often, though, big decisions require several conversations to sort through, and decisions made yesterday need to be evaluated in the light of today regarding whether they should be continued tomorrow. Some of the pressure that patients and families feel when discussing palliative care topics can be relieved by knowing that there is a plan to “revisit” the topic in the future. One might say, “So today we’ve talked about whether or not we should consider a tracheostomy. We don’t need to make this decision right now, we have several days. Let’s plan to think about what we’ve discussed and revisit the topic again when I see you tomorrow.”

Delivering bad news forthrightly yet empathetically

Delivering bad news is difficult. But stating the facts in clear, non-euphemistic language makes the task more straightforward. Even better, if you have already made a commitment (see above, “Making promises”) to speak about the facts and your worries in a forthright manner, and the patient or family have agreed that this is what they want you to do, then the task is part way done. Furthermore, delivering bad news about the patient’s prognosis, if done empathetically, builds trust and does not destroy hope. One might say, “I promised you that I would be straightforward and tell you when I’m worried. I wish that the news from the biopsy was different. The results show that the cancer has spread.”

At this point, pause for several seconds to gauge the emotional response of the recipients and to acknowledge with one’s silence the gravity of the situation. One can then resume “This certainly is not the result I’d hoped for. I believe we are going to have to think carefully, given this news, about how we can best take care of your child.”

Notice in this script the phrase “I wish the news was different.” This is called a “warning shot,” a brief phrase that interrupts the flow of the news to provide the patient or family members with a warning that the next thing you will say is going to be hard for them to hear. Adult patients receiving bad news report that they appreciate being provided with a warning shot so that they can brace themselves for the news that follows and leaves them with the sense that the clinician providing the news is truly empathetic. Bad news usually takes time to be absorbed and integrated by the recipient. We therefore recommend that the conversation in which bad news is delivered be separated by some period of time from the conversation focused on planning the next steps of care. For some patients or families, this period of time may literally be minutes or hours; for others, days or even longer might be required. Without this time, what you say may not be what they hear.

Clarifying patient and family perceptions and hopes

The importance of clarifying patients’ and families’ perceptions of the predicament, and the range of things they may be hoping for in light of the predicament, cannot be overstated. Quite often, disagreements about what course of medical and surgical care to pursue are rooted in fundamentally differing perspectives or premises regarding the clinical situation. A little time spent discussing this situation until consensus emerges can save a lot of time and confusion later.

Once there is agreement about the basic predicament, one might say, “It will help me to take better care of your child if you can tell me, given the tough situation we’ve been discussing, what you are hoping for.” Expect that the first hope that parents are likely to voice will be for “a cure,” “a miracle,” or “to wake up from a bad dream.” These are common expressions of both longing and a sense of parental duty, and care should be taken to acknowledge that you have heard this wish, and to neither debate nor argue about it. Instead, one might say, “I wish we could do that. What else are you hoping for?” Be patient: This is a hard question and it may take several moments for parents to formulate or be able to articulate their answer. Commonly, these hopes may focus on a desire to go home, be free of pain, be able to see loved ones, and other results that palliative interventions and care may be able to facilitate.

Once this range of hopes has been put in front of both the clinical team and the family, they can be translated into feasible objectives in light of inevitable constraints. One might say, “Thank you for telling me all of this. Several of the things you said really caught my attention, because I think we can potentially help make those hopes come true. While I don’t want to make promises that I can’t be sure to deliver on, and I know we are going to face some challenges ahead, let me suggest that we think about what would help your child to be able to go home in the next few days, to be more comfortable, and to have some quality time with family and friends.”

Pursuing benefits and saying “Yes”

The conversation about what the patient and family are hoping for, and the translation of these hopes into tangible objectives, provides a very useful framework for considering possible surgical options. For example, if a patient with a neurodegenerative disorder and gastroparesis requiring long-term enteral tube feedings hopes to stay at home as much as possible, but is thwarted in achieving this objective by repeated mechanical failure of a gastrojejunal tube, then the pros and cons of placing a direct jejunal tube should be evaluated. Palliative care and surgery are completely compatible if the surgical intervention has a reasonable chance of improving patient well-being or comfort.

Reducing risk and saying “No”

Equally important as pursuing potential benefits is actively assessing and minimizing risk. Surgeons should always seek to find the least invasive intervention that will achieve the objective. Consideration should also be given to whether a given surgical intervention is reversible or not, seeking to prevent being stuck with a worse clinical predicament having burned bridges. For example, pyloroplasty is easier to construct than to reverse; a loop ostomy is easier to reverse than widely separated ostomy and mucus fistula; thoracoscopic diaphragmatic plication may be less risky than tracheostomy.

In certain dire clinical situations, there may simply be no surgical intervention where the potential for benefit outweighs the risk of harm. Nevertheless, there still may be the pressure to “please, just do something.” In such instances, one might say, “I hear you, that you want me to attempt another operation. Know that I would do so if I thought it could help. At this point, though, I am very worried that all we would achieve is to put your child at great risk of being harmed, and I cannot in good conscience do this.” Observe that even in cases where the surgeon declines to
take any further action, this denial still benefits both the patient and the parents. First, the surgeon serves the patient by standing for the lower risk option, a rational (rather than emotional) choice. Second, because the surgeon’s opinion carries weight of authority, this declaration that everything that should be done has been done lifts an enormous burden from the parents. They may be able put aside the doubt that there was something else they “should” have done.

Broaching the topic of palliative care and partnering with PPC teams

Pediatric surgeons have long provided various forms of palliative care to their patients. With the advent of dedicated PPC teams within children’s hospitals, surgeons have an ally in this realm. When introducing the patient and family to the PPC team, one might say, “I have colleagues here in the hospital who are experts at helping us to achieve some of the hopes that we’ve talked about. I’m going to ask them to come by and introduce themselves. They will speak with you and figure out how they can be of most help to your child and to your family.” This need not be a task faced alone.

Suspension of DNAR orders and clarifying post-operative care plans

If a patient with an active Do Not Attempt Resuscitation (DNAR) order is to undergo an operation, the surgeon and patient or family should discuss in detail the patient’s DNAR status both during the operation and during the period of time when the patient is recovering from the surgery. If the existing DNAR order is to be honored during the operation, or modified to some degree but not fully suspended, then the anesthesiologist and other members of the operating room team need to be well aware of this agreement (if not involved in the discussions from the outset) and have a chance to voice any questions or concerns. If this discussion happens both in the morning huddle before start of day and in the time out at the beginning of the case, then it is simple to have all the OR team on the same page: “If the patient arrests, we will...”. If the discussion waits until the code, it will be too late for this simple clarity. Equally important, if the DNAR order is suspended, the timing of when it will be reenstituted needs to be discussed and clarified, since certain surgical procedures (such as tonsillectomy) have a high likelihood of time-limited complications (such as difficult airway management) for particular patients (such as children with severe neurological impairment). Anticipation of the need for post-operative life-supportive interventions, and discussions about the limits of these interventions in terms of intensity and duration, is important.

De-complexifying patient care

Pediatric patients with serious disease often acquire, over the course of years of being ill or during a prolonged hospitalization, remarkably complicated care. Polypharmacy, ongoing use of several medical technologies, nutritional support, respiratory support, and numerous nursing care or other therapeutic interventions every day may all be beneficial—or a point of diminishing returns may have been reached, and simplification of care can benefit the patient (and the family, if the patient is at home). Simpler care, with fewer tasks and potential unforeseen interactions, can be safer and delivered more effectively. Even a regimen that protects sleep (for instance, by eliminating a late night feeding, shifting or reducing a medication dosing regimen, or altering a dressing change) can improve the sense of well-being in patients and parents. Simplifying care, though, takes thought, discussion, and the judgment to be able to find where less really is more.

Remaining committed

When patients and families learn that there is no longer the prospect of a beneficial surgical intervention, many fear that the pediatric surgeon and the surgical team will withdraw from their care. Words of reassurance that you are still committed to the patient and will still be involved in overseeing their medical care can be priceless, and even more so if the pediatric surgeon continues to visit the patient on rounds, even if briefly and intermittently, to stay connected to the patient and the family.

Preventing burnout regarding specific patients

Some patients, for a variety of reasons, are more difficult to care for than others. While assuring that all patients and families receive high-quality care, clinicians have to marshal their own time and energy. Collaborating with a pediatric palliative care team to share the labor and responsibility of providing care to a patient with a serious or progressive illness allows the clinician to provide valuable guidance and skill throughout the duration of the illness. “Professionalism” is a composite concept, combining the ability to perform with proficiency with the will to exercise that ability. But willpower is an exhaustible human capacity, degraded by sustained mental effort. The clinician experiencing “willpower fatigue” may not have the patience to speak with pauses, or explain the circumstances with clarity, or imagine a less-is-more option. On the other hand, working with a team offers some protection from burnout, making it easier to “do the right thing” and to do so expertly.

Specific patient scenarios

Every patient is different, and customizing one’s approach to the management of a given patient, and the process of working with that patient’s family, is an invaluable aspect of the art of good surgical and medical practice. In discussing the brief scenarios that follow, we aim to highlight some common issues that arise in the care of pediatric patients with serious illness and integrate some of the ideas that we have described above.

Fetal consultation

The mother and father of a 26-week estimated gestational age infant have come in for an evaluation of what appears to be a congenital diaphragmatic hernia in their baby. Imaging confirms the diagnosis and reveals substantial pulmonary hypoplasia on the affected right side. The couple asks the pediatric surgeon, “What would you do if this were your child?”

- When parents ask point-blank questions, acknowledge that you’ve heard the question: “That is an important question, and I promise to answer it in a minute or two.”
- Early in the discussion, provide some promises regarding how you will conduct yourself: “Let me start by saying a few things about how I want to talk with both of you.” Then state that you promise to be straightforward, telling them what you are thinking and how worried you are, in an effort to be clear and provide the best care possible.
- Answer, or at least address, all questions. Some providers would feel comfortable telling the parents what they would do if the patient was their child, and others would not. Either way, the question can be addressed by saying, “When you ask
what I would do, I hear you trying to figure out what you should do. Let’s talk about that.”

Neonate with massive necrotizing enterocolitis

Jane was born at 32 weeks estimated gestational age and appeared to have been doing well for the first five days of life when she suddenly developed vomiting and abdominal distension. An abdominal radiograph showed extensive pneumatosis. Taken emergently to the operating room, she was found to have extensive necrosis of the small bowel from mid-duodenum through to the transverse colon. No resection was attempted; instead two drains were placed and the abdominal incision was closed. Now it is time to go talk to the parents.

- When delivering bad news, a brief recap of the clinical situation is helpful: “You know that about 2 hours ago, Jane suddenly got quite ill, and we took her to the operating room to see whether some of her bowel had died and if so what we could do about this problem.”
- Provide a warning shot: “I wish the news was different.”
- Deliver the news in plain language: “I found that almost all of her bowel had died, and I could not repair any of it. She is in recovery right now, but I am very, very worried about her.”
- Be quite and allow silence, even if for only 10 or 15 s.
- Provide a sense of what the next steps will be: “The coming hours will be critical. We are going to give her antibiotics, let the drains that I put in place help as much as they can, and make sure that she is comfortable. I will talk with you again in a few hours.”
- This discussion aims to deliver the news; subsequent discussions can address decisions about goals of care.

Infants with life-threatening syndromes or conditions

Jonah was diagnosed within the first weeks of life with spinal muscular atrophy type I. He is now 4 months of age and consequently has spastic tetraplegia along with severe cognitive deficits. Two weeks ago, she underwent Harrington rod placement for progressive scoliosis, which was thought to be causing respiratory compromise due to restrictive lung disease from thoracic deformity. Post-operatively she has had intolerance of feeding via gastrostomy tube with non-bilious vomiting. The pediatric surgeon is consulted regarding consideration of placement of a primary jejunostomy tube.

- Palliative care requires diagnostic acumen, since the best palliation is to identify the underlying cause of a symptom and either cure or ameliorate the pathologic process. In this case, superior mesenteric artery syndrome may be the cause, and a short period of transpyloric feeding may resolve the vomiting and prevent the need for surgery.
- Even though this is not an “end-of-life” situation, establishing a framework for working through difficult decisions may be very helpful down the road. Discussing hopes and fears and establishing a sense of true north to guide decisions are all worthwhile expenditures of time.
- With this framework of key considerations, both good (hopes) and bad (fears), and the overall direction (true north), consider the range of possible treatment options, and what might happen if they do not work as planned (such as when a short-term trial of total parenteral nutrition does not reverse the intestinal failure). Even if such future possibilities are only flagged as possible problems, they can prepare the way for future difficult decisions: “I am not sure if we will run into any of these problems, and hope that we do not. If we do, though, I promise to tell you when I get worried that the plan is not working, and we will have to talk again about what is the best way to take care of your daughter.”

Children with cancer

John is a 14-year-old boy with a 3-year history of a desmoplastic small-blue-cell tumor in his abdomen. Previously he had several debulking operations in addition to chemotherapy and radiation therapy. He presented 3 days ago with a small-bowel obstruction and, on imaging, was found to have complete occlusion of a portion of the small intestine due to tumor infiltration as well as marked progression of the disease. The parents have requested that an attempt be made to excise the portion of the bowel with the tumor infiltration so that John is able to eat again.

- This vignette illustrates situations where surgical interventions pose a high chance of making a bad situation worse, due to either a protracted or incomplete process of post-operative healing, or an operative complication.
- A surgical intervention might be warranted in a similar case if there was a reasonable likelihood of pain reduction, improved comfort, and enhancement of quality of life of a sufficient degree and for a sufficient span of time to offset the post-operative recovery.
- A key question is to figure out who wants John to eat and why. If speaking with the parents, one might say, “May I ask a question, so that I understand better? Does John want to eat again? Or are you advocating for him?” The parents may need assurance that they are being outstanding advocates for their son: “I see how much you are devoted to John, and deeply respect that. You are being great and loving parents in a terribly difficult situation.”
- Adolescent patients also deserve to have clinicians talk directly with them, and you can inform parents that this is your steadfast practice. Ideally with the parents present, ask the patient, “John, tell me how you are doing—what is bothering you?”
Long-term palliative care survivors

Jessica, now 19 years of age, had a massive hemorrhagic cerebral vascular infarct due to an arterial-venous malformation when she was 5 years old, leaving her with severe cognitive and motor deficits, such that she requires near-total care, but still smiles and vocalizes her pleasure when surrounded by her parents and younger siblings. She had a ventriculo-peritoneal shunt placed 3 days after the stroke, and since then has had the VP shunt revised 23 times, due to highly viscous cerebrospinal fluid that clogs the shunt tubing. Once, when she was critically ill with an aspiration pneumonia, her parents agreed with a Do Not Attempt Resuscitation order, but when she recovered, that order was rescinded. Jessica was just brought by her parents to the Emergency Department, having become somnolent and unresponsive. Her parents were concerned that she seemed to lie, while the surgeon’s experience, candor, and judgment can help parents to choose a course that supports their values, hopes, and objectives beyond a sole focus on survival.

References


Conclusion

Pediatric palliative care stands with other important pediatric surgical interests like critical care, nutrition support, or infections as a core component of complete surgical care for children and families confronting serious illness with a low likelihood of survival. Like other surgical arts, the art of good palliative care is not an inexplicable ability gifted to a few, but consists of particular techniques and strategies that any surgeon can deploy. These methods can improve communication, align expectations, and manage emotions, facilitating better application of surgical interventions that can reduce pain and minimize the risk of harm even when the prognosis is bleak. But pediatric palliative care is more than just “fostering communication.” The surgeon’s capacity for mechanical intervention, in partnership with pediatric palliative care teams, may enable the creation of options where none seemed to lie, while the surgeon’s experience, candor, and judgment can help parents to choose a course that supports their values, hopes, and objectives beyond a sole focus on survival.