

## Palliative care interventions for pediatric surgical patients: a systematic review

M. Longacre<sup>1</sup>, J. Hale<sup>1</sup>, E. Rickerson<sup>2</sup>, A. Bader<sup>1</sup>

<sup>1</sup>Department of Anesthesia and Critical Care Medicine, Brigham and Women's Hospital, Boston, MA, USA

<sup>2</sup>Assistant Professor of Anesthesia Department of Anesthesia and Critical Care Medicine, Brigham and Women's Hospital, Children's Hospital Boston. MA, USA

Corresponding author: M. Longacre, Department of Anesthesia and Critical Care Medicine, Brigham and Women's Hospital, Boston, MA, USA. Email: mmlongacre@mgh.harvard.edu

### Keypoints

Palliative care should be sensitively offered to all critically and terminally ill children early in their illness. It is likely that pediatric surgical patients are referred to palliative care with less frequency than their medical counterparts, due in part to a lack of education and exposure to pediatric palliative care during surgical training. Ways to increase access include increased provider, parent and patient education.

### Abstract

#### Introduction

There is a growing body of evidence that pediatric palliative care increases patient quality of life and parent satisfaction. Furthermore, the scope of palliative care continues to expand to include complex care and coordination for chronically ill children who are not necessarily approaching end of life. Many ill children with palliative needs interact with surgical providers and teams. Little is known about the utilization or efficacy of palliative care referrals for pediatric surgical patients.

#### Material and Methods

To better understand the potential need for palliative care as well as barriers to accessing care among this vulnerable population, we performed a systematic review of PubMed, EMBASE, and Cinhal for relevant literature published from January 1, 2008 to March 1, 2018.

#### Results

10 articles met inclusion criteria. No high-quality studies were identified.

#### Conclusion

The limited available evidence suggests an unmet need

for pediatric palliative care. Barriers to access were identified including lack of provider palliative care education, and reluctance of the primary team to refer patients to palliative care. Further study is warranted to better guide the use of palliative care for pediatric surgical patients.

#### Keywords

Palliative care, end of life, hospice.

#### Introduction

In a recent review of adult surgical patients, interventions aimed at improving perioperative decision making "improved quality of communication...decreased use of health care resources and decreased cost."<sup>(1)</sup> Pediatric patients and their families are likely to yield similar benefit from such interventions. "Approximately 400,000 children in the United States are living with a life-threatening disorder. Between 53,000 and 55,000 children die each year, with half dying of chronic, life-long disorders."<sup>(2)</sup> Furthermore, a significant proportion of these patients will require a surgical intervention at the end of life,<sup>(3)</sup> and for certain patient populations, rates of surgical involvement may be increasing.<sup>(4)</sup> In a study by Bauman et al of children (less than 18 years of age) who

were American Society of Anesthesiology (ASA) Class III or higher undergoing elective surgery, “only 36 (0.2%) patients had a signed DNR order before surgical procedure. Of severely ill ASA IV or higher patients, only 1% had DNR status...Notably, 17.1% of children who died within this period had multiple surgical procedures performed before expiring.”(5) A study by Brown et al found that of 23 pediatric patients with a documented DNR/DNI status pursuing surgery, no reconsideration of code status occurred for 41% of cases, despite the fact that 13% suffered life threatening events in association with their procedure.(6) This disparity may prove more common in children due to the inherent discomfort associated with planning for the end of life for children. Pediatric palliative care is a heterogenous and evolving field that aims in part to bridge this gap. The World Health Organization defines palliative care as an effort “to improve the quality of life of patients facing life-threatening illnesses, and their families, through the prevention and relief of suffering by early identification and treatment of pain and other problems, whether physical, psychosocial, or spiritual.”(7) For the purposes of this review, we defined palliative care as any interdisciplinary healthcare team with special training in the medical management of palliative care issues.

**Material and Methods**

We performed a systematic review of the utilization and efficacy of palliative care interventions for pediatric surgical patients. We hypothesized that 1) pediatric palliative care is underutilized for surgical patients, 2) when implemented for appropriate patients, pediatric palliative care improves patient morbidity, and 3) there are unique barriers that prevent access for surgical patients as compared to medical patients.

This systematic review was conducted per PRIMSA guidelines using Covidence Software. A systematic review of palliative care for adult patients conducted by Lilley et al was used as a conceptual model, with permission of the authors.(1) Searches of PubMed, EMBASE,

and CINAHL were constructed with appropriate MESH terms with the assistance a senior medical research librarian. Articles met inclusion criteria if they were: in English, published between January 1, 2008, and March 1, 2018, peer reviewed, included patients 21 years of age or younger, and at least half of the study population were surgical patients (defined as patients who had or were candidates for a surgical intervention applicable to their primary illness). Stem cell transplant patients were included given the overall complexity and frequent additional surgical involvement of this patient population. Other minor procedures, or procedures often performed by non-surgical teams were excluded (eg lumbar punctures and lymph node biopsies). Studies describing a single palliative surgical or pain procedure, or complementary and alternative medicine, were also excluded. Experimental, quasi-experimental, observational, meta-analyses, and review articles were included. Articles were excluded if they were: case reports, clinical conference notes, comments, editorials, letters, or lectures. All articles meeting inclusion criteria were screened by title and abstract for relevance. Articles meeting inclusion criteria were reviewed in their entirety. Articles of uncertain relevance were discussed with the senior authors prior to study inclusion. (Table 1).

Searches:
<p>PubMed:                      ("Palliative Care"[Mesh] OR "Palliative Medicine"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh] OR "Terminal Care"[Mesh] OR "Hospices"[Mesh] OR "Terminally Ill"[Mesh] OR hospic*[tiab] OR palliat*[tiab] OR supportive care[tiab])AND                      ("Surgical Procedures, Operative"[Mesh] OR "Anesthesia"[Mesh] OR surgery[subheading] OR surger*[tiab] OR surgical[tiab] OR operative[tiab] OR anaesthesia[tiab] OR anaesthesia[tiab])                      AND                      (Child[MeSH] OR "Infant"[Mesh] OR Adolescent[MeSH] OR Pediatrics[MeSH] OR child*[tiab] OR adolescen*[tiab] OR toddler*[tiab] OR teen*[tiab] OR boy[tiab] OR boys[tiab] OR girl*[tiab] OR pediatric[tiab] OR paediatric[tiab] OR infant*[tiab] OR baby[tiab] OR babies[tiab] OR neonate*[tiab] OR newborn*[tiab])</p>
<p>Embase                      (palliative therapy/de OR 'palliative nursing'/exp OR 'terminal care'/de OR 'hospice care'/exp OR 'terminally ill patient'/exp OR hospic*.ab.ti OR palliat*.ab.ti OR 'supportive care'.ab.ti)                      AND                      ('surgery'/exp OR 'anesthesia'/exp OR surger*.ab.ti OR surgical.ab.ti OR operative.ab.ti OR anaesthesia.ab.ti OR anaesthesia.ab.ti)                      AND                      (child/exp OR 'adolescent'/exp OR 'pediatrics'/exp OR child*.ab.ti OR adolescen*.ab.ti OR toddler*.ab.ti OR teen*.ab.ti OR boy.ab.ti OR boys.ab.ti OR girl*.ab.ti OR pediatric.ab.ti OR paediatric.ab.ti OR infant*.ab.ti OR baby.ab.ti OR babies.ab.ti OR neonate*.ab.ti OR newborn*.ab.ti)</p>
<p>CINAHL                      (MH ("Palliative Care" OR "Hospice and Palliative Nursing" OR "Terminal Care" OR "Hospice Care" OR "Hospices" OR "Terminally Ill Patients+") OR TI (hospic* OR palliat* OR 'supportive care') OR AB (hospic* OR palliat* OR 'supportive care'))                      AND                      (MH ("Surgery, Operative+" OR "Anesthesia+") OR TI (surger* OR surgical OR operative OR anaesthesia OR anaesthesia) OR AB (surger* OR surgical OR operative OR anaesthesia OR anaesthesia))                      AND                      (MH ("Adolescence+" OR "Child+" OR "Pediatrics") OR TI (child* OR adolescen* OR toddler* OR teen* OR boy OR boys OR girl* OR pediatric OR paediatric OR infant* OR baby OR babies OR neonate* OR newborn*) OR AB (child* OR adolescen* OR toddler* OR teen* OR boy OR boys OR girl* OR pediatric OR paediatric OR infant* OR baby OR babies OR neonate* OR newborn*))</p>

**Table 1.** Systematic Database Searches

## Results

Figure 1. Summary of Articles Reviewed

Source (Country of Origin)	Design and Setting	Intervention	Study Objective	Participants	Results	Study Quality
Al-Gharb 2015 (Lebanon)	Design: Convenience sample of 85 children and 85 parents. Setting: a tertiary pediatric cancer center in Lebanon	Survey	"To assess the quality of palliative care in terms of: access to care, patient-clinician relationship, and clinician communication"	"Patients 7 to 18 years of age who were diagnosed with cancer for more than one month, and were receiving cancer treatment."	"Adolescents reported excellent quality of medical care." Children expressed concern with respect to lack of participation in decision-making.	IV
Docherty 2007 (New Jersey, USA)	Design: Qualitative interviews with health care providers Setting: southeastern medical center	Semi structured interview	"Describe the experiences and views of health care providers of children who have undergone intensive therapies for life-threatening illnesses"	17 pediatric providers from NICU, PICU and bone marrow transplant service	Three challenges in employing palliative care to acutely ill infants and children were identified: "finding the true dying point, making the transition to palliative care, and turning care over to an outside palliative care team at a critical juncture of caring." Other challenges identified include: inadequate preparation and, crossing professional boundaries.	IV
Doorenbos 2013 (Seattle, WA, USA)	Design: Review of the electronic medical record for palliative care "of 59 children requiring extracorporeal life support for which a palliative care consult was automatically obtained." Setting: tertiary care hospital	Retrospective chart review	"To describe pediatric advanced care team involvement...in automatic consultations for extracorporeal life support patients, and their family members."	59 children "...receiving extracorporeal life support who received automatic palliative care consult." Mean age was 31.7 months.	Patients were stratified by degree of pediatric advanced care team involvement (low, moderate and high). "Characteristics associated with...high involvement included high prognostic uncertainty and complexity."	IV
Fowler 2015 (Newcastle, UK, Boston, MA, USA)	Design: Opinion piece	Opinion piece	n/a	n/a	"Transplant teams do not always make timely referrals to palliative care teams."  Barriers included: perceived incongruence between active care plans and palliative care. "Attention must be paid to clinician training and support" in order to dispel the perceived conflict between palliative care and active treatment.	V
Goudreau 2018 (Montreal, Quebec, Canada)	Design: Electronic medical review of "children who had a procedure under general anesthesia within 6 months of their death." Setting: tertiary children's hospital	Retrospective chart review	"Characterize the involvement of pediatric surgeons caring for children near end of life."	"83 patients who had a procedure under general anesthesia within 6 months of their death over a five-year period...(excluding traumas and neonatology cases). Mean age 8 years.	"The pediatric palliative care service was involved in 66 cases (80%)... The aim of the procedure was palliative in 48 cases, diagnostic in 16, and curative in 19."  "Surgeon involvement with children near end of life is not infrequent... Lack of formal palliative care training by surgeons highlights the need for increased collaboration with palliative care services to provide children optimal care when they need it most."	IV
Hancock 2018 (Ann Arbor, Michigan, USA)	Design: Survey of maternal emotional wellbeing "collected at a prenatal visit and neonatal discharge to assess the impact of these palliative care interventions." Setting: tertiary care hospital	Palliative care intervention	To determine whether early palliative care intervention may benefit mothers of infants born with single ventricle disease.	38 mothers of neonates were randomized: 18 received early palliative care and 20 standard care.	"Early palliative care resulted in decreased maternal anxiety, improved maternal positive reframing, and improved communication and family relationships"	III
Kopecky 1997 (Toronto, CANADA)	Design: Review of electronic medical record of 126 children who had been referred to a home based palliative care Setting: Tertiary care hospital	Retrospective chart review	"To describe the patient characteristics and utilization of the home-based palliative care program at the Hospital for Sick Kids, Toronto."	"126 terminally ill children referred for home-based palliative care between 1986 and 1994."	"Of the 93 patients who died in the program, 53% died at home, 18% died in a community hospital, and 29% died in a tertiary care facility."  Home base palliative care appeared to be an effective program for many children with terminal illnesses (after adequate patient and family supports had been established.)	IV
Shelton 2011 (Nashville, TN, USA)	Design: Palliative care primer for the pediatric surgeon.	Opinion piece	n/a	n/a	Describes the challenges of providing pediatric palliative surgical care and suggests "general guidelines for delivering palliative surgical interventions."	V
Ulrich 2016 (Boston, MA, USA)	Design: Retrospective review of the electronic medical record for palliative care intervention and location of death of children who underwent hematopoietic stem cell transplant (HSCT)	Retrospective review	"To evaluate whether pediatric palliative care (PPC) consultation is associated with differences in end of life care patterns for children who underwent HSCT and did not survive"	A total of 147 patients underwent HSCT between September 2004 and December 2012 and subsequently died.	"Children were likely to die in a medicalized setting, irrespective of PPC. However, PPC was associated with less intervention-focused care and greater opportunity for end of life communication and advance preparation."	IV
Westlandt 2014 (Canada)	Design: National survey of Canadian pediatric oncologists Setting: Canada	Quantitative and Qualitative survey	"Describe the attitudes and referral practices of pediatric oncologists [with respect to] palliative care, and to compare them with those of adult oncologists."	All Canadian physician members of applicable pediatric oncological societies were solicited.	"13% of pediatric oncologists reported deferring palliative care referral while patients are undergoing chemotherapy... 58% reported they would refer earlier if palliative care were renamed 'supportive care.'...17% reported palliative care adds too many providers... 60% reported that palliative care was perceived negatively by their patients."	IV

## Discussion

There is a paucity of high-quality data pertaining to the overall utilization and efficacy of palliative care for surgical pediatric patients. Our search revealed a heterogeneous patient population, with an emphasis on severe congenital heart diseases (44% of the prescreen articles, [1467/3302]). Results included 10 studies: 1 pilot palliative care intervention, 2 opinion pieces, 2 qualitative interviews, 5 retrospective chart reviews and one early palliative care pilot study; there were no high quality randomized controlled trials revealed by our search. However, within the available data, several key themes palliative care education 3) A need for systems level data and support of palliative care.

### *A Need for Broad and Timely Palliative Care Consultation*

There is little data regarding when and for whom palliative services should be offered. However it is likely that palliative care resources are underutilized. Wang et al observed that "[Palliative care] consultation occurred for 19% (n=114) of HSCT patients... and few were enrolled emerged with respect to 1) A need for broad and timely palliative care consultation, 2) A need for increased in hospice (15%, n=17)." (8) This was despite the fact that "most patients (85%, n=99) died in the hospital." (8) In a study by Doorenbos et al, patients with "high prognostic uncertainty, medical complexity, and high need for coordination of care were more likely to receive a palliative

care consultation.”(9) It is likely that there are significantly more children who would benefit from palliative services than are currently receiving care.

Among patients that received palliative care consultation, preliminary evidence suggested a greater likelihood of having code status documented. In a retrospective review by Ullrich et al comparing pediatric SCT recipients that received palliative care consultation (PPC) versus those who did not, “The PPC group was...more likely to have resuscitation status documented (PPC, 97%; non-PPC, 68%;  $P = .002$ ).”(10) One small study of infants with hypoplastic left heart syndrome also found improved outcomes for mothers who received palliative care consultations. In a randomized control trial by Hancock et al for this specific patient population, “palliative care was found to reduce postnatal depression.”(11) “The early palliative care group had a decrease in prenatal to postnatal State-Trait Anxiety Index scores (-7.6 versus 0.3 in standard care,  $p=0.02$ ), higher postnatal Brief Cope Inventory positive reframing scores ( $p=0.03$ ), and a positive change in PedsQL Family Impact Module communication and family relationships scores (effect size 0.46 and 0.41, respectively).”(11) Further research is needed to understand the applicability of these preliminary findings to other pediatric surgical populations.

One challenge to optimal palliative care utilization may be delayed consultation. A survey by Durall et al noted that, even when palliative care consultation occurs, it is often too late in the disease course to be of maximal benefit to patients and families. In a survey of 266 physicians and nurses “71% of those surveyed felt advance care discussions occur too late.”(12) They reported that “60% of the time, discussions are initiated when death is impending.”(12) The limited available evidence suggests a correlation between “late integration of palliative care and poor standards of end of life care.”(13, 14)

One proposed solution in the adult literature is a system of automatic consultation in which patients with certain high-risk factors are offered palliative care interventions

early in their presentation. (15, 16) In a small study of 25 patients with high risk malignancies, Mahmood et al. demonstrated that early consultation (within the first 30 days of diagnosis) for patients with certain high risk pediatric oncological diagnoses was feasible.(17) Although a small, specific study population, this preliminary evidence suggests early consultation for certain illnesses may provide families with additional time to explore values and goals at a less emergent phase of illness, as well as to connect families to other potential longitudinal outpatient services.

Early palliative care consultation also increases the ability to help patients and families receive care in their desired location, particularly for families who prefer to avoid the hospital setting at the end of life Van de Wetering et al argue “children in palliative care for progressive cancer should be at home as much as possible, even in the terminal phase.”(18) A study by Cantwell-Bartl et al reviewed “outcomes of hypoplastic left heart syndrome at a pediatric hospital 1983-2004...Of 134 surgically treated... only 1% died at home.” (19) In the study by Wang et al, palliative care consultation significantly decreased the likelihood of dying in the ICU (PPC, 20%; non-PPC, 42%;  $P = .03$ ).”(8) Interestingly, however, palliative care did not decrease the overall likelihood of dying in a medicalized setting.(8) This may be due in part to late consultation; Liben et al suggest that this persists because, although DNR orders are often present at time of death, they are often instated too late in the disease course, and perhaps for this reason are less likely to be actionable.(20) Other barriers may include inadequate out of hospital complex care resources. To this end, Kopecky et al explored the efficacy of home-based palliative care as an alternative and found it to be an “effective program for many children with a variety of terminal illnesses after adequate supports for the child and family had been established.”(21) Exploring and expanding our ability to offer home-base palliative care may provide significant benefit to patients and their families. Further

studies are needed to understand the efficacy and cost-effectiveness of such programs.

### ***A Need for Increased Education***

Barriers to palliative care consultation are multifactorial and include: family, provider and system factors. On a patient level, there is often a reluctance by providers to invite age-appropriate end of life conversations with ill children. (22) The child's own perspective "has been especially neglected, despite evidence that when asked in a sensitive manner, children as young as 10 years are able and willing to talk about their experiences and end-of-life decisions." (20) This finding was echoed in a survey by Al-Gharib et al of children undergoing in-patient oncological care, in which children desired greater participation in decision making. (23) With respect to parents and families, Durall et al identified "insufficient understanding of the prognosis, unrealistic parental expectations, or lack of readiness to discuss end-of-life care" as significant barriers to accessing palliative care. (12)

Lack of palliative education and training of care providers likely further contributes to provider discomfort with initiating palliative discussions. (24) Durall et al found that compared to nurses, physicians were more likely to report "not knowing what to say." (12) Interestingly the most significant barriers perceived by nurses were "perceived as lesser importance by physicians." (12) Additionally, providers—and surgeons in particular—may be reluctant to "switch the curative concept into a palliative ambition." (25) Fowler et al report, "transplant teams do not always make timely referrals to palliative care teams due to various clinician and perceived family barriers, an important one being the simultaneous, active care plan each patient would have alongside an end-of-life plan." (26) This sentiment was also reported by Robinson et al, who report that the increased pursuit of lung transplantation for cystic fibrosis has changed the nature of end-of-life discussions for such children and their families, and further awareness by transplant providers for the role of palliative care is needed. (4) Reluctance to engage

palliative services has also been observed among pediatric oncologists. In a National Canadian study by Wentlandt et al "13% of pediatric oncologists reported deferring palliative care referral while patients are undergoing chemotherapy." (27) In survey data collected by Docherty et al palliative care was perceived as, "care that is instituted once it is known that a child is dying." (12)

The specific challenges identified to initiating care were "finding the true dying point, making the transition to palliative care, and turning care over to an outside palliative care team at a critical juncture of caring." (28) Additional education is likely needed as part of surgical training to promote the concept that palliative care and curative interventions can and should be provided simultaneously.

Formal palliative training may have the additional benefit of helping surgical trainees "tolerate the degree of intimacy and personal engagement that other aspects of medical training may subvert or undermine." (20) Although some efforts have been made to integrate palliative care training into the milestone of physician trainees, this remains a significant and consequential training gap. (29)

### ***A Need for Systems-Level Data and Support of Palliative Care***

Nationally, there are 234 pediatricians certified by the American Board of Pediatrics (ABP) in palliative care. (30) This does not include non-physician providers, adult providers who provide palliative services to children, or physicians from other specialties who provide palliation, such as acute and chronic pain physicians. Even so, pediatric palliative resources in the US likely underrepresent the total need, and are likely unevenly distributed, with more resources near large, urban academic centers.

Evidence is needed to better understand barriers to entering the field (exposure, burnout, compensation, market, lifestyle, etc.) as well as strategies to overcome these barriers. One potential avenue to expand the field may be eliciting collaboration and integration from non-

pediatricians with allied skillsets, such as anesthesiologists with special training in acute and chronic pain.(31) In order to best support growth of the field, a comprehensive assessment is needed to quantify the cost and value of palliative care services; palliative care has in fact been associated with better patient care and decreased overall healthcare costs among certain adult populations.(1) Furthermore, although there is an emerging trend towards evidenced-based palliative care in adults (supported by high quality data including a Cochrane review by Wiffen et al in 2011), our review uncovered no evidence-based attempt to standardize core components of the pediatric palliative intervention.(32) Although palliative care should be individualized to the complex needs of the child and their family, there are likely certain key services that should be available to all critically ill children. “In considering [pediatric palliative care] as a philosophy of caring for children who are seriously ill, one obvious conclusion is that it should be the standard of care for all children.”(20) The current level of ambiguity may pose a barrier to additional hospitals launching needed palliative programs. Moreover, lack of standardization curbs our ability to ensure that all sick children receive the standard of care with respect to this important component of critical care.(20)

### **Limitations**

Although preliminary evidence suggests that there is an unmet need for palliative care for pediatric surgical patients, there is a paucity of high-quality literature available addressing the utilization and efficacy of such interventions. Of the available data, studies are largely retrospective, observational, and based on small, dissimilar sample populations. Additional research is needed to assess the need for and efficacy of interventions for special populations such as fetal surgical candidates.(33) Additional high quality research is needed to define the need and efficacy of palliative care for pediatric surgical patients.

### **Conclusion**

It is not surprising that there is a lack of high-quality data regarding the palliation of pediatric surgical patients given the vulnerability of this population. However, what we know of palliative care suggests it should be sensitively offered to all critically and terminally ill children early in their illness. It is likely that pediatric surgical patients are referred to palliative care with less frequency than their medical counterparts, due in part to a lack of education and exposure to pediatric palliative care during surgical training. Ways to increase access include increased provider, parent and patient education. Furthermore, promoting a culture in which palliative care is part of the standard of care will improve equitable access. More data is needed with respect to the current utilization and efficacy of interventions to better define and ultimately monitor high value intervention. On a systems level, studies are needed to understand the cost (and potential savings) associated with these interventions. Ultimately, there is clearly an ongoing need for protection of this population, as well as both education and support for those involved in this important and demanding field.

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**Abbreviations**

*HSCT: hemopoietic stem cell transplant*

*NICU: neonatal intensive care unit*

*PPC: pediatric palliative care*

*PICU: pediatric intensive care unit*

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