Review Article

Pediatric palliative care in the intensive care unit and questions of quality: a review of the determinants and mechanisms of high-quality palliative care in the pediatric intensive care unit (PICU)

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Abstract: This article reviews the state and practice of pediatric palliative care (PC) within the pediatric intensive care unit (PICU) with specific consideration of quality issues. This includes defining PC and end of life (EOL) care. We will also describe PC as it pertains to alleviating children's suffering through the provision of "concurrent care" in the ICU environment. Modes of care, and attendant strengths, of both the consultant and integrated models will be presented. We will review salient issues related to the provision of PC in the PICU, barriers to optimal practice, parental, and staff perceptions. Opportunity areas for quality improvement and the role of initiatives and measures such as education, family-based initiatives, staff needs, symptom recognition, grief, and communication follow. To conclude, we will look to the literature for PC resources for pediatric intensivists and future directions of study.

Keywords: Pediatric palliative care; pediatric intensive care; quality; end of life (EOL); hospice

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Pediatric palliative and hospice care (HC)

Palliative care (PC)

The World Health Organization defines PC as "*that which improves patients' quality of life and that of their families facing consequences of life-threatening illness through the prevention and relief of suffering by early identification, impeccable assessment, and the treatment of pain and other problems, physical, psychosocial, and spiritual*" (1). The American Academy of Pediatrics (AAP) and American College of Critical Care Medicine (ACCCM) recommend that pediatric PC be offered at the time of diagnosis and continue throughout illness, regardless of outcome (2-4). They recommend that optimal PC models involve collaboration of palliative and non-palliative health care providers with patients and families to address needs across domains "concurrently". In this model, palliative efforts occur simultaneously with curative and life-prolonging care throughout disease course so long as life sustaining care remains in accordance with a family's goals. The AAP and the Institute of Medicine (IOM) support a similar paralleled approach (3,5,6), arguing that "effective management of pain and other distressing symptoms, along with psychosocial care, spiritual care, and decision-making guidance are critically important beginning at diagnosis and continuing throughout the course of a child's life and beyond" (7). For a portion of patients, PC includes end of life (EOL) care if or when disease-modifying efforts fail or become inappropriate. The Robert Wood Johnson EOL Peer Group has outlined seven care domains associated with complete physical, social, and spiritual support involved in PC (*Table 1*) (8).

Table 1 Domains of palliative care

- 7 domains of palliative care—Robert Wood Johnson End of Life (EOL) Peer Group
  - Patient and family centered decision making
  - Communication within the team and with patients and families
  - Continuity of care across physical locations in and out of hospital and continuum of illness
  - Emotional and practical support for patients and families
  - Emotional and organizational support for ICUs
  - Spiritual support for patients and families
  - Symptom management and comfort care

Table 2 Adult and pediatric palliative care (PC) and hospice care (HC)

- Palliative care
  - Adult
    - Care that improves quality of life for patients and their families facing consequences of life-threatening illness, through prevention and relief of suffering via early identification and aggressive treatment of pain and other problems, physical, psychosocial and spiritual (WHO)
    - Can occur independently or in consultation with the patient's primary care team (ICU, surgery, primary care doctor, or subspecialists)
  - Pediatric
    - Integrated care occurring across the spectrum of illness, ideally starting at diagnosis in collaboration with the patient's primary or active treatment team. Focus on alleviation of physical, psychosocial, and spiritual suffering and considering quality of life concurrently with disease-modifying or life-prolonging therapy (WHO, NHPCO).
    - Occurs in consultant or integrative models in collaboration with the patient's primary care team or primary care doctor
- Hospice care
  - Adult
    - EOL care based on prognosis. Patients must have physician certified life expectancy <6 months if the disease follows its expected course, and an agreement that hospice enrollment involves cessation or limitation of disease modifying therapy
    - Can occur at home or in dedicated or free-standing hospice agency with hospice team assuming primary responsibility
    - Covered under Medicaid, defined benefit under Social Security Act, Section 1861 (dd) [1]
  - Pediatric
    - Concurrent care model for children with life-limiting or threatening illness, typically, though not always near EOL, that permits ongoing disease modifying or curative therapy. HC can institute care limitations, advanced directives and DNR orders and exclusively focus on comfort care when appropriate based on family's wishes and child's disease state
    - Can occur at home, or through an adult or pediatric hospice agency with pediatric consultation
    - Primary care teams remain involved though medical responsibility can shift to the HC team if desired
    - Benefit described for Medicaid and CHIP under Patient Protection and Affordable Care Act [2010 (Pub L No. 111-148)]

WHO, World Health Organization; NHPCO, National Hospice and Palliative Care Organization; EOL, end of life; DNR, do not resuscitate; CHIP, Children's Healthcare Insurance Program.

Hospice care (HC)

HC is a form of PC for patients at EOL (3). Licensed hospice agencies provide medical, psychosocial, and spiritual services as well as medications, durable medical equipment, and a range of diagnostic and therapeutic services (3). Generally, and particularly for adults, prognosis of 6 months or less is required for insurance approval of the hospice benefit. Pediatric HC is often home-based and coordinated by adult hospice institutions unfamiliar, uncomfortable, or unable to bear the cost of complex pediatric treatment plans on per diem reimbursement strategies (3,8). National cohort data indicate that of the 78% of adult HC agencies provide pediatric care, with average annual pediatric census of fewer than 20 children (7,9). Most providers are familiar with Medicare's adult HC mandates (*Table 2*). Pediatric

Table 3 Epidemiological cause of death by age in children birth to 19 years old in children with and without a complex chronic condition (CCC)

Cause of death in infants without CCC
Congenital malformations
Prematurity/LBW
Maternal complications
SIDS
Accidental/unintentional injury
Complications of cord & placenta
Cause of death in infants with CCC
Cardiovascular disease
Congenital/genetic
Respiratory
Neuromuscular
Cause of death in children 1–19 years without CCC
Accidents
Suicide
Assault
Malignancy
Congenital/genetic
Cardiovascular disease
Infection
Cause of death in children 1–19 years with CCC
Malignancy
Neuromuscular
Cardiovascular

NHPCO 2015. NHPCO, National Hospice and Palliative Care Organization; LBW, low birth weight; SIDS, sudden infant death syndrome.

HC does not follow this model. Pediatric hospice patients represent a diverse cohort of diagnoses, many rare and with consequent prognostic uncertainty and unpredictable course of illness (10). Children live longer in hospice than adults and carry a diverse number of admission diagnoses and attendant morbidities (7,10,11). Recognizing that prognostics-driven HC may not be appropriate for children, the 2010 Patient Protection and Affordable Care Act [2010 (Pub L No.111-148)] specified that children can concurrently receive hospice services and curative or life-extending therapy.

Emphasis on tailored, concurrent, comfort-focused care alongside disease-modifying therapies led the AAP and Society of Critical Care Medicine (SCCM) to encourage universally available PC and HC teams whose role includes aiding providers and families navigating these systems (3,4,12). They highlight that successful PC and HC bridge the patient's physical location, coordinates care across subspecialties, and adapts services to phase and severity of illness. Though a handful of pediatric hospitals boast pediatric home-based hospice programs, most pediatric PC teams partner with local adult hospice organizations (13).

PC statistics and populations

PC is a growing specialty. In 2016, 90% of US hospitals with more than 300 beds had PC programs. Academic and non-profit hospitals in the North East, Pacific, and Mid-Atlantic regions have a significantly higher dissemination of PC compared to for-profit and Southern institutions (14). Most recent national data estimate that 70% of children's hospitals currently offer PC services (9,13,15).

In 2015, there were 53,000 pediatric deaths in the United States (US), reflecting a stable annual pediatric mortality (16). Congenital malformations, prematurity, cancer, and non-accidental death are the most common causes (7,9,16). The incidence of complex chronic conditions (CCCs) and associated mortality rates vary by age (*Table 3*). Genetic and congenital conditions rather than oncologic disorders constitute most of PC referrals and recipients of pediatric hospice (9,13). Many children receiving PC and HC remain technology-dependent with active use of medical resources including periodic in-unit care, tracheostomies with ventilators, augmented feeding, and complex medication regimens. Annual mortality of pediatric hospice patients national is 33% (*Table 3*) (7).

Complex chronic conditions (CCCs)

Children with CCCs are a population with significant overlap in both palliative and critical care populations. According to the US Department of Health and Human Services, the population of children with special health care needs is increasing. Fifteen percent of US children less than 18 years old (11.2 million children) and 23% of American households have at least one child with special health care needs (17); of this group, 27% have limited ability to participate in daily activities or have atypical bodily functions.

Data from 28 US hospitals demonstrate that children with CCCs account for 19% of patients and half of patient hospital days (49%) and charges (53.2%). Over the 5-year study period, the number of patients with a CCC increased by 35.6% (18). Others estimate that 24% of pediatric hospital days and 30% of hospital dollars are spent on this group (19). Further information about pediatric PC and HC cohorts was published by Feudtner and colleagues that assessed the PC census of five major children's hospitals (*Table 4*) (9). They saw a distribution of ages (<1 year 17.1%, 1–18 years 67.5%, ≥19 years 15.5%) and a higher frequency of patients with primary diagnosis of congenital and inherited conditions contributing to care referral (genetic/congenital disease 40.8%, neuromuscular disease 39.2%; malignancy 19.8%). Median time from consult to death was approximately 100 days in this cohort (9).

A review of over 50,000 PICU admissions showed an association between CCCs, length of stay (LOS), morbidity, and mortality (20). This study utilized Feudtner's definition of CCC: "*one expected to last more than 12 months and involve one or more organ systems sufficiently to require pediatric subspecialty care*" (21). Children with at least one CCC accounted for 53% of admissions and 77% of admissions >15 days. Cohort mortality was 2.7% and 75% of mortalities (1,078 of 1,448 deaths) were children with a CCC (20). The presence and number of CCCs increased odds ratio of mortality. UK patients with life-limiting or CCCs demonstrated higher in-unit mortality, significant decline in post-discharge functional scores, and increased mortality up to one year after PICU discharge (22).

PICU survivors have substantial medical burdens. Termed "post intensive care syndrome" or "chronically critically ill" these patients suffer significant symptom burden, poor cognitive outcomes, depression, mortality, financial, and social difficulties (23). Patients often remain dependent on intensive or near-intensive care due to continued organ failure, neuroendocrine disarray, developmental disorders, and recurrent infections (23-28). Caregivers frequently assume ongoing complex, technology-dependent homecare and continued interface with the health care system. Costs of this group are thought to exceed 20 billion dollars annually (29).

Sudden unexpected death

Sudden, unexpected death (SUD) from intentional injuries, acute illness, and unintentional trauma is a prevalent cause of death in the PICU (20,30). Traditionally, PC is targeted to deaths classified as not preventable, such as treatment failure of life-threatening or chronic conditions (13,18,23,31). Yet, PC teams can provide short-term services, decision-making support, as well as attend to complex emotion, grief, and bereavement for families affected by trauma or sudden illness. One PICU's experience showed that 22% of mortality was a result of SUD and only 4.2% of these families received PC services compared with 28.6% of patients who died from complications of CCCs (25). Families of children with SUD may represent a vulnerable population currently underserved by PC teams (32).

Pediatric locational death in the US

PICU mortality ranges from 1% to 5% with an average of 2.7% nationally. In the US, the most common location of pediatric death is the PICU (26,33-35) versus at home or other hospital locations. Thirty to sixty percent of PICU deaths involve withdrawal of one or more forms of life sustaining medical treatment (LSMT) including mechanical support (30,33,36). Of children at EOL in the PICU, less than 1% receive HC (37,38). Some tertiary centers offer critical care transport for home withdrawal of LSMT with hospice, but the frequency of this is unknown.

A nineteen-center study of tertiary PICUs showed that 50% of death occurs following withdrawal of LSMT compared to consequences of failed cardiopulmonary resuscitation (CPR) (20%) or after limitation of support (17%) (39). Thirty-seven percent of families were approached for organ donation (range, 17–88%); of those, 20% donated. Autopsy was requested in 37% of non-medical examiner cases (30). Seventy percent of families received PC consultations. Sixty-seven percent of consults involved discussions of care limitations; 92% of families subsequently decided to limit LSMT (30).

ICU providers miss opportunities to provide straightforward PC (32,40,41). One tertiary center's mortality review found that only half of patients with anticipated mortality received multidisciplinary supportive care (SW, chaplaincy, child life, care conferences) and symptom-directed care, including pain medication, during their terminal hospitalization. Only 26% received additional analgesia at time of withdrawal or during limitation of support. Less than 30% of SUD patients received comfort-based measures. No patients in either cohort were referred to hospice (40).

Demographics of home versus in-hospital death are changing as children with CCCs utilize more complicated and technologically-dependent home care (9,13,26,35).

Table 4 Demographic data of Pediatric Palliative and Hospice Care Censuses; 515 patients from six hospital-based pediatric palliative care teams in the US and Canada

Characteristics	Total, N (%)	Early mortality within 30 days, N (%)		P value
		Yes	No	
Total	515 (100.0)	60 (11.7)	455 (88.4)	
Site				
Akron	163 (31.7)	13 (21.7)	150 (33.0)	<0.01
Boston	70 (13.6)	16 (26.7)	54 (11.9)	
Minneapolis	102 (19.8)	8 (13.3)	94 (20.7)	
Philadelphia	38 (7.4)	10 (16.7)	28 (6.2)	
Seattle	67 (13.0)	7 (11.7)	60 (13.2)	
Vancouver	75 (14.6)	6 (10.0)	69 (15.2)	
Age				
<1 month (and fetal consultations)	24 (4.7)	11 (18.3)	13 (2.9)	<0.01
1–11 months	64 (12.4)	10 (16.7)	54 (11.9)	
1–9 years	193 (37.5)	16 (26.7)	177 (38.9)	
10–18 years	156 (30.0)	17 (28.3)	139 (30.6)	
19 years or older	78 (15.5)	6 (10.0)	72 (15.8)	
Gender				
Female	237 (46.0)	27 (45.0)	210 (46.2)	0.87
Male	278 (54.0)	33 (55.0)	245 (53.9)	
Race				
White	358 (69.5)	36 (60.0)	322 (70.8)	0.09
Black	46 (8.9)	8 (13.3)	38 (8.4)	
Asian	36 (7.0)	2 (3.3)	34 (7.5)	
Native population	9 (1.8)	1 (1.7)	8 (1.8)	
Mixed	24 (4.7)	5 (8.3)	19 (4.2)	
Other	24 (4.7)	3 (5.0)	21 (4.6)	
Not indicated	18 (3.5)	5 (8.3)	13 (2.9)	
Ethnicity				
Hispanic	38 (7.4)	4 (7.7)	34 (8.2)	0.91
Non-Hispanic	477 (92.6)	48 (92.3)	382 (91.8)	
Residence				
With both parents	311 (60.4)	39 (65.0)	272 (59.8)	0.38
Only/mostly with mother	113 (21.9)	9 (15.0)	104 (22.9)	
Other[a]	91 (17.7)	12 (20.0)	79 (17.4)	
Siblings				
No	122 (23.7)	12 (20.0)	110 (24.2)	0.49
Yes	374 (72.6)	47 (78.3)	327 (71.9)	
Unknown	19 (3.7)	1 (1.7)	18 (4.0)	
US insurance				
Government	218 (49.7)	23 (42.6)	195 (50.7)	0.03

Table 4 *(continued)*

Table 4 *(continued)*

Characteristics	Total, N (%)	Early mortality within 30 days, N (%)		P value
		Yes	No	
Private	107 (24.4)	18 (33.3)	89 (23.1)	
Both	103 (23.5)	9 (16.7)	94 (24.4)	
None	11 (2.5)	4 (7.4)	7 (1.8)	
Canadian insurance				
Government	75 (100)	6 (100)	69 (100)	
Diagnoses				
Genetic/congenital	210 (40.8)	17 (28.3)	193 (42.4)	0.04
Neuromuscular	201 (39.2)	22 (36.7)	179 (39.3)	0.69
All cancers	102 (19.8)	18 (30.0)	84 (18.5)	0.04
Hematologic	36 (7.0)	5 (8.3)	31 (6.8)	0.66
Solid tumor	36 (7.0)	6 (10.0)	30 (6.6)	0.33
Brain tumor	29 (5.6)	7 (11.7)	22 (4.8)	0.03
Hematologic and solid tumors	1 (0.1)	0	1 (0.2)	0.72
Respiratory	66 (12.8)	8 (13.3)	58 (12.8)	0.90
Other	55 (10.7)	7 (11.7)	48 (10.6)	0.79
Gastrointestinal	51 (9.9)	4 (6.7)	47 (10.3)	0.37
Cardiovascular	43 (8.3)	10 (16.7)	33 (7.3)	0.01
Metabolic	37 (7.2)	1 (1.7)	36 (7.9)	0.08
Renal	14 (2.7)	2 (3.3)	12 (2.6)	0.76
Immunology	12 (2.6)	0	12 (2.6)	0.20
Medications				
Acetaminophen	194 (38.0)	23 (38.3)	174 (38.2)	0.99
Albuterol	126 (24.7)	8 (13.3)	133 (29.2)	0.01
Lansoprazole	126 (24.7)	10 (16.7)	116 (25.5)	0.14
Lorazepam	119 (23.2)	17 (28.3)	104 (22.9)	0.35
Oral antibiotic	83 (16.2)	9 (15.0)	75 (16.5)	0.77
Morphine	78 (15.3)	21 (35.0)	57 (12.5)	<0.01
Ranitidine	78 (15.3)	10 (16.7)	68 (15.0)	0.73
Levetiracetam	78 (15.3)	7 (11.7)	71 (15.6)	0.42
Phenobarbital	74 (14.5)	10 (16.7)	64 (14.1)	0.60
Ibuprofen	65 (12.5)	5 (8.3)	60 (13.2)	0.29
Polyethylene glycol	57 (11.2)	5 (8.3)	53 (11.7)	0.45
Baclofen (oral)	56 (11.0)	1 (1.8)	55 (12.1)	0.02
Intravenous antibiotic	52 (10.2)	9 (15.0)	43 (9.5)	0.18
Medical technology				
None	105 (20.4)	8 (13.3)	97 (21.3)	0.15
Any feeding tubes	307 (59.6)	35 (58.3)	272 (59.8)	0.83
Gastrostomy tube	250 (48.5)	21 (35.0)	229 (50.3)	0.03

Table 4 *(continued)*

Table 4 *(continued)*

Characteristics	Total, N (%)	Early mortality within 30 days, N (%)		P value
		Yes	No	
Nasogastric tube	51 (9.9)	15 (25.0)	36 (7.9)	<0.01
Jejunostomy tube	50 (9.7)	3 (5.0)	47 (10.3)	0.19
Central venous catheter	115 (22.3)	24 (40.0)	91 (20.0)	<0.01
Tracheostomy	52 (10.1)	4 (6.7)	48 (10.6)	0.35
Noninvasive ventilation	49 (9.5)	6 (10.0)	43 (9.5)	0.89
Ventilator-dependent	44 (8.5)	14 (23.3)	30 (6.6)	<0.01
Wheelchair	21 (4.1)	0	21 (4.6)	0.09
VP/VJ shunt	15 (2.9)	2 (3.3)	13 (2.9)	0.84

Includes institutional facility, foster care, only father, other relatives, alone or with spouse, in hospital since birth, and not yet born. Reprinted with permission of the American Academy of Pediatrics. Copyright © 2018 AAP. *Pediatrics* is an official journal of the American Academy of Pediatrics. [a], includes institutional facility, foster care, only father, other relatives, alone or with spouse, in hospital since birth, and not yet born. VP/VJ, ventriculoperitoneal/ventriculojugular.

Ireland and Canada have experienced a decline in PICU deaths, with 95% incidence in 1998 versus 67% in 2012. PC involvement increased from 10% to 74% over this period (26). One factor is early advanced care planning (ACP), though one US study demonstrates that only 56% of children with terminal illness had evidence of any ACP on chart review and 64% had current do-not-resuscitate (DNR) orders at time of death according (34).

Methods of providing PC in the PICU

Fifty to seventy percent of children's hospitals offer formal PC programs (13,15). Staffing varies and can include multidisciplinary providers such as nurses, nurse practitioners, social workers, child life, chaplains, bereavement coordinators, and physicians. Not all PC programs are staffed to 24/7 availability, thus resulting in institution-specific methods for providing PC within the PICU (15).

Basic tenets of PC, such as attention to symptom burden and considerations of quality of life are within the skill set of practicing intensivists and constitutes "primary PC". This is PC within a subspecialist's practice scope, not requiring specific pediatric palliative expertise. However, for complex decision-making, complicated grief, care transitions, and high symptom burden, intensivists might seek PC expertise. In 2012, the SCCM recommended consideration of PC for children living with CCCs, those with high risk of mortality, significant morbidity, cases complicated by conflict around goals of care, difficult symptom control, anticipated long hospitalization, frequent readmission, and staff moral distress (37). PC also serves ICU families needing extra psychosocial support and those requiring hospice referral (37).

PC involvement commonly occurs in "consultation" where interdisciplinary PC certified specialists serve the "primary" ICU team. Other institutions "integrate" PC-trained providers into the PICU team to address prevalent PC needs and weave palliation into daily practice (23,42,43). Advantages exist for both models. Successful implementation likely relates to institutional-specific factors such as dedicated PC resources, census, and continuity in and out of the ICU (*Table 5*).

Optimal referral populations and timing continues to be studied and represents an important quality metric for PICU and PC teams. Methods for referral include "physician order" consults, parental or nurse prompted consultations, or "automatic/triggered referral" when certain criteria such as transplant, mechanical support, or LOS are met (23,32,42,44). One institution's tool prompted consideration of PC for ICU LOS more than 2 weeks, 3 or more PICU admissions within 6 months, persistent mechanical support, organ failure, and/or disease severity criteria (32). They saw a 500% increase in PC referrals across all intensivists, illustrating that "triggers" may overcome individual provider oversight or reticence to consult PC. Populations with high morbidity and mortality such as severe neurologic injury, continuous renal replacement therapy (CRRT), and extracorporeal membrane oxygenation (ECMO) still experienced low referral (32). Seventy percent of all eligible patients based on the trigger tool were referred; 66% were

Table 5 Comparison of consultative and integrative approach to providing PC in the PICU

Consultative model		
	Advantages	
		Expert, established interdisciplinary team without need of further training
		Continuity of care outside the unit including hospital and home environments
		Ability to consult and integrate care prior to ICU admission
		Demonstrated empiric evidence of benefit to patients and families
	Disadvantages	
		Adequately staffed team needed
		Lack specific ICU expertise
		ICU "outsider" team without therapeutic relationship
		Potential duplication or overlap of role/efforts with risk of miscommunication or conflict
		Reduces incentive of ICU team to improve PC knowledge or skill
		Patients' needs must be recognized and appropriate referral placed to initiate care
Integrative approach		
	Advantages	
		PC is available to all PICU patients and families
		No need for additional providers or teams
		Acknowledge PC as core part of ICU care
		Systemic ICU work process and seamless presentation of PC to ICU families as standard of care
		Improved PICU staff PC knowledge and skill
		Reduced lapse in recognition of need and institution of PC
	Disadvantages	
		Additional education of ICU team (physician, nurse, social work, chaplain, case management)
		Continued commitment of PC within PICU requiring an appropriate institutional culture
		Resource intensive for ICU
		Requires care hand off following ICU discharge to a hospice, ward, home care, consultant palliative team, or patient's primary medical team

PC, palliative care; PICU, pediatric intensive care unit.

new consults. Of patients who went on to die at home, 75% did so with hospice, indicating that PC consult made ICU death less likely without an increase in overall mortality rate (32). Other adults criteria trigger tools exist and are outlined in the supplemental materials (*Table S1*) (45).

This study and others noted delay between PC eligibility and new referral, reinforcing that PC integration at diagnosis, rather than at decline, improves timeliness to care (25,31,46). ICU days to PC consult was reduced by over a week (12 days) in one adult ICU study of integrated versus consultant models (47). They also found higher rates of PC involvement, completed ACP, hospice referrals, and lower use of medical resources at the integrated campus despite equal mortality across the two groups (47).

Barriers to PC in the PICU

PICU-related PC barriers have been reported spanning parental concerns, provider issues, knowledge gaps, and systems issues (31,48-51).

Provider barriers, staff concerns, and provider availability

Surveyed intensivists indicate avoidance of "consulting out" EOL care, worry that parents perceive PC as "giving up", and report concerns that PC teams will provide conflicting recommendations, and at times perceive poor availability of PC providers (31,38,48,49). The most frequently cited reason is that intensivist have strong general confidence in addressing PC needs personally (38,48).

PICUs perceive poor availability of PC related to poor visibility within the ICU as well as an insufficiently staffed PC workforce outside of larger centers (14,33). Within consultative models, successful interventions include "trigger" consults for high risk patients with consequent "ripple effects" of further consults due to a reminding presence of the consultant team and observed benefits of PC for patients (33,42,44).

Emotional concerns, moral distress, and burnout represent barriers to providing and involving PC. Nurses particularly bear burdens of alleviating suffering, accommodating families' wishes, and providing peace in an ICU environment (52). Nurses are at high risk of moral distress as they are often disenfranchised from decision-making but called upon to enact bedside care plans (53-55). PICU staff report the most common cause of moral distress is prolonged, aggressive treatment unlikely to result in a positive outcome. This frequently results from systems issues, poor communication, and lapses in unit or institutional policy and leadership (27,53,56). Moral distress is associated with feelings of frustration, guilt, self-blame and powerlessness; these feelings often persist, contributing to dissatisfaction and burn out (54,57). PC specialists may mitigate moral distress by providing additional staff and family support, advocating for staff, exploring and clarifying goals, and coordinating communication amongst the medical team and family.

Impactful builders of resilience and mitigators of burnout include one-on-one or small group discussions with colleagues and informal social interactions out of the hospital (54). Other resources such as scheduled breaks from stressful patients, relief from duty after a patient's death, PC support for staff, Schwartz Center Rounds, and structured social interactions were helpful but underused (54,57). "Fully"-staffed PICUs with highly effective teamwork zones by the Safety Attitudes Questionnaire were associated with improved resiliency scores (55).

Symptom recognition and management

Despite reported confidence, providers demonstrate poor PC-related symptom management and under-recognition of delirium, dyspnea, nausea, secretions, agitation, and psychological symptoms (27,41,56,58). As many as 60% of bereaved parents rate ICU management of EOL symptoms, including pain, poorly (41). Intensivists' knowledge of PC principles and perception of their role in symptom management and decision-making in the ICU has been demonstrated to be variable and at times inadequate (31). Common knowledge gaps surround legal and ethical issues of pediatric EOL care (27,55). One study found that 7% of surveyed intensivists equate a "DNR" order with "comfort care", and 33% felt that DNR orders implied general limitation of LSMT (38). Providers also under treat EOL symptoms, citing concerns that narcotics administered during withdrawal of LSMT risks euthanasia (27,56). Most subspecialist pediatricians, including intensivists, rate themselves as knowledgeable about EOL care, though half were unfamiliar with the principle of double effect or questioned its legality (27).

PICUs poorly anticipate complicated grief, a phenomenon occurring in up to 60% of bereaved PICU parents (59-61). Routine follow-up with bereaved parents is uncommonly offered by PICUs (59,62,63). These meetings, ideally 3–6 months after death, allow parents to revisit events surrounding death and gain assurance around decision-making, especially reassurance that everything possible was done for their child. Providing feedback to the ICU team gives a degree of closure and positive feeling for bereaved parents (61,63). It is additionally possible that follow-up meetings may be used to screen for complicated grief or other morbidities. Related to appraised risk or levels of bereavement, institutions may facilitate contact with trained bereavement providers to addresses the unique needs of families grieving loss of a child (62,63).

Systems issues, the ICU environment, and PC's "Branding"

Physicians as well as parents conflate PC with EOL (18,31,41,50,51,55,56). This impression is further solidified when referral occurs proximate to bad news or late in illness, when few or no medical interventions remain. This branding issue led some institutions to rename their PC team as "Comprehensive Care", "Supportive Care", "Quality of Life" or "Advanced Care" teams (23,31,64). Others use information packets explaining the role of PC (42,65), or favor the integrative model so that PC is perceived as part of "routine" intensive care (23,31).

The time-intensive nature of PC, competing demands on intensivists' time, and poor reimbursement models represent pressures that impact PC practice (31,51,66). Weekly service changes and numerous subspecialists impair therapeutic relationships and cogent communication (29). This phenomenon multiplies across hundreds of providers and consultants over prolonged or multiple hospital stays. Short service periods skew decision-making to emphasize short-term over "big picture" goals and hinder integration of short-term choices into illness trajectory (48,49). The continuous and vigilant ICU environment negatively impacts parents' coping (56,67). Parents often feel disenfranchised from decision-making and perceive loss of parental role particularly when experiencing language barriers, uncertain LOS, or when hospitalizations included several invasive procedures or significant changes in children's physical appearance (29,67,68). Coping was significantly improved in parents who felt actively involved in care and well-informed (60).

Families differing needs surrounding complex decision-making are difficult to anticipate though are perhaps less time-intensive than perceived (69). Most parents forgoing LSMT made this decision after 1 or 2 meetings (70). Successful meetings involve repetition of key information within and across meetings, open parental inquiry regarding all aspects of care, consideration of spirituality and religiosity, and emotional expression (60,71). Nearly all parents desire to share fully in decision-making despite significant emotional burdens. Most parents ultimately assent to physician recommendations limiting interventions (59,61,63,70,71). Important factors in deciding to forgo LSMT included medical team recommendations, expected neurologic recovery, diagnosis, and degree of pain and suffering (60).

Parents whose children die in the PICU require and value assistance in achieving an appropriately "sacred" death that is peaceful and dignified. Parents require sufficient time and privacy with their child and calm, sensitive care that honors personhood (72). Particularly valuable persons are nurses, holistic health, music therapy, religious or spiritual providers, and other family members (63,71). Appropriate alterations to the ICU environment are imperative. Loud noises, laughing, or insensitive remarks proximate to the child's room are vividly recalled and regretted by parents. Maintaining parental identity throughout this process is achieved through proximity to their children, staff's respect of their decision-making, engaging in caregiving, and using cultural and religious symbols including mementos (71). At the time of death, the opportunity to say goodbye is critical, and if missed or not utilized, was a source of parental distress and deep regret, often maintained for years (50,61).

Having a staff member assist in paperwork, contact the funeral home, and guide them through the next steps are important to families (61). The complex and myriad needs of parents at EOL led some institutions to create "End of Life" checklists or packets with items completed by designated family liaisons to ensure appropriate care (4,36,38,73). Additionally, USCF Benioff Children's Hospital Oakland offers a "Reflection Room", a private home-like suite for families to stay with their child during EOL and up to 24 hours after death (74). This has decreased PICU locational death and most surveyed staff ascribe value to this resource as promoting patient-and family-centered care.

Hospital memorial services are attended by up to 60% of bereaved parents despite emotionally difficult returns to the hospital (68). Services are particularly supportive when familiar staff are present. Lack of familiar staff is noted and regretted, as parents nearly universally wish that their child not be forgotten (68,71).

Parental barriers

Providers perceive parents' "unrealistic expectations" as significant barriers to PC (48,51). However, bereaved parents frequently cite unmet needs in symptom management and emotional support, and often regret that PC was not involved earlier (35,41,61,75-77). Providers can misinterpret parents' hope as hinderance to considerations of comfort or quality. Parents of dying children often indicate a simultaneous and seemingly contradictory recognition of their child's ultimate prognosis and a persistent hope that their child will live a long life (15,51).

Other parents cite concerns that they want "*everything done for their child*", against which PC represents no impediment. PC teams advocate for each family's unique wishes and goals providing support through continuums of care with sensitivity to suffering. Literature also indicates that poor preparation for significant morbidity and mortality impacts receptiveness to PC (63). This can be mitigated by better communication about a child's condition or orientation to PC's role. Adult initiatives surrounding

ACP use brochures to this end. ACP brochures decreased discordance amongst surrogate decision makers and the medical team, decreased depression and posttraumatic stress disorder (PTSD) in bereaved families, and improved satisfaction with care provided in the ICU (78). Other decision support tools such as videos discussing DNR orders and consequences of prolonged mechanical ventilation have been associated with improved family-physician concordance, perceived quality of communication, and lower hospital costs (79,80).

October and colleagues used the "Good Parent" tool to explore goals of care within the PICU. Themes of "focusing on quality of life", "advocating for their child with the medical team", and "putting the child's needs above their own" emerged in all surveyed parents. These themes spanned race, socioeconomic status, and illness severity. When asked strategies that could fulfill these goals, the most common answer was "keeping parents well informed" (81).

Communication

High quality communication is perhaps the most important driver of high-quality PC in the PICU (51). PICU provider communication predicts parental perceptions of care quality regardless of illness severity or quantity of care received. It impacts decision-making, particularly surrounding technology use, care limitations, trust in the medical team, and bereavement outcomes (60,61). Parents who rated their ICU communication poorly were significantly more likely to regret their EOL decision-making or to feel misled by the medical team (60,71). Parents desire to receive all, including difficult, information promptly and honestly from a familiar person (50,71,78). News from unfamiliar sources resulted in disbelief and questioning, which staff can perceive negatively. Insensitive, abrupt, and cold remarks such as judgment of parents' requests or decisions and statements of hopelessness are vividly recalled (71,78). Parents' perceptions of compassion or insensitivity in communication was a theme of either comfort or distress throughout their grief (59-61).

Difficulties in communication center thematically around communication issues within teams, lack of consensus, prognostic uncertainty, insufficient communication training or confidence, and disagreement as to which team should provide news (82,83). Incidence of poor communication within an ICU admission is as high as 70% and highly predictive of conflict (55,71,84,85). PICU admissions greater than 8 days experienced a 50% incidence of conflict with consultants, parents, or within the medical team as seen in one tertiary institution's prospective study; poor communication was causative in 48% of cases (84). Proper timing of autopsy, organ donation, and DNR requests are vital and particularly sensitive. Poorly worded or timed requests cause distress and negatively affect perceptions of care quality (63). Communication techniques more often associated with family satisfaction are those that address emotion and express empathy assuring support of the family no matter the outcome or decision (35,69,81).

Qualitative studies exploring PICU communication show differences between PC and ICU provider speech (75,85). PICU physicians speak 50% more than PC providers on average. Pediatric intensivists often poorly balance speech dedicated to benefits versus risks of interventions, offer prognostication, mention hopelessness, or speak insensitively (85). Fifty four percent of PC's speech provides emotional support, gives plain-language summary, discusses quality of life, elicits the family's input, embraces uncertainty, provides praise, and normalizes emotions (75,85). Average number of attendees to family meetings numbered 19, pointing to the frequently overwhelming environment and content of PICU communications (85).

Pediatric PC quality measures in the PICU

In the PICU, PC remains an effective but underutilized quality-based intervention for children to achieve higher quality care (15). Some studies find decreased costs when PC is involved, particularly early in the illness trajectory. The UCLA Center for Health Policy showed an 11% ($1,677) reduction in monthly cost per patient, a 32% reduction in average LOS, reduced stress, sleep disturbance, and increased confidence amongst primary caregivers compared to patients who did not receive PC services (86).

A single-center study evaluated the top decile of pediatric patients by cost and divided the cohort into mortalities versus survivors and PC exposure or none. Within this cohort, only 10% were referred to PC. PC patients who died had significantly lower inpatient costs. Amongst survivors receiving PC, their costs were more, but significant difference disappeared when cost was adjusted for medical complexity. This phenomenon perhaps represents the population of "chronically critically ill", patients whom are life-long high utilizers (87). Survivors receiving PC, though cost-equivalent to non-PC survivors, were half as likely to be readmitted to the hospital in the study period (87). Adult administrative data has compared approximately

9,000 live versus deceased "usual care" and "PC" discharges across eight hospitals. Live PC discharges had net savings of $1,696 per admission and $279 per diem savings, mostly laboratory and ICU costs. Deceased PC patients had net cost savings of $4,908 in direct cost and $374 per diem. These cost savings were statistically significant compared to live and deceased patients not receiving PC (88).

High value PC in the PICU is not completely encompassed by cost savings or measures. Hospital and PICU LOS, hospital readmission rates, and Emergency Department (ED) visits are frequently considered and easily measured sources of data and are comparable across cohorts (19). Often cited process measures are PC and HC referral rates. This infers intrinsic value to PC and HC and thus is threatened by circular logic, though exploring reasons for non-referral within this measure may be enlightening for systems or provider-related barriers to PC.

Other quality measures include discussions and documentation of ACPs. Only 20% of children with life-limiting conditions have a documented form of ACP, often related to poor recognition of patient trajectory (58,89). In a cross-sectional study of bereaved parents of childhood cancer, advanced planning for location of death increased home-based death and decreased hospital admissions in the last month of life. This is also important because the ability to plan the location of death, and to see that plan through, predicts better parental bereavement outcomes (90). Parents with ACPs had increased comfort with the setting and manner of their child's death, and were less likely to have preferred a different location (34,58). Instances of early ACP reduced negative consequences for staff and families in terms of perceived suffering, moral and emotional distress, and poor family satisfaction (58). Certain locational death, specifically, out-of-PICU death, has been proposed to imply less resource-intensive care and instances where parental advocacy and decision-making have resulted in effective choice and medical stewardship.

Other tools assess parental PC needs such as the Parent and Children Palliative Care Needs Assessment, a 22-item survey measuring quality of life and care concerns to inform clinical practice (91). Surveyed parents of children with malignancy report unmet needs around sibling impact, symptom management, financial issues, and family cohesion. Measures evaluating coping indicate effects of critical illness on the family. Coping Resources and the Texas Revised Inventory of Grief were used to assess a group of bereaved parents. Those whose children died of acute illness had greater intensity of acute grief by inventory than those succumbing to CCCs (61,71). Parents' physical coping resources and the perceived empathy of PICU staff were the most significant predictors of acute grief severity. Cognitive coping resources, emotional attitudes of staff, and adequacy of information predicted the intensity of long-term grief (59). Grief screening and in-unit mechanisms to provide anticipatory bereavement care may be appropriate for these high-risk groups. ICU mortality follow-up visits is another mechanism through which such tools could evaluate the coping reserves and grief of families.

Like care processes for the prevention of serious harm, such as central line associated blood stream infections (CLABSI) and catheter associated urinary tract infections (CAUTI), multiple researchers have assessed "Palliative Care-ICU Care" bundles (42,65,92). One adult effort involved a PC quality bundle with nine domains to improve the quality and quantity of PC communications (42). Domains included identification of medical decision makers, addressing advanced directive and resuscitation status, provision of an informational leaflet, systematic pain assessments and management, social work and spiritual support, and routine interdisciplinary family meeting. When applied to patients with ICU LOS greater than 5 days, compliance with the entire 9-domain bundle was 38–87% across 19 ICUs (44). The authors recognized the limitation in using process measures for compliance rather than outcome measures, but cited empiric data and society consensus statements supporting positive effects of these PC processes on outcomes (44). Other adult PC bundles utilized in high risk morbidity and mortality patients with predicted admissions of more than five days found that bundle compliance reduced LOS by one day and significantly reduced time to care plan consensus (92,93). These efforts showed variable and rather poor adherence to individual process measures at often less than 20%, particularly for care conferences (65,92,93).

Other measures considered in the literature include parental perceptions of decision-making, quality of life scores, parental stress, depression, utilization of bereavement and support groups, as well as medical decision-making support tools prior to family conferences (Question Prompt Lists), staff burn out, and resilience scores (29).

In considering measures of PC quality in the PICU, one must consider what constitutes high-quality PC. Adult ICU survivors, bereaved families, ICU, and PC providers in association with the Robert Wood Johnson Foundation's

Table 6 2008 ACCCM quality domains of quality PC in the PICU (Initiative for Pediatric Palliative Care supported by American College of Critical Care Physicians)

Quality domain	Definition	Example interventions
Support of the family unit	providing parents ready access to their children or opportunities for meaningful participation in their care and decision-making are valued	Nursing Mutual Participation of Care Model including participation in daily cares, e.g., clothing and bathing Family-centered rounds
Communication with the child and family about treatment goals	Families rate consistent and compassionate communication as the number one determinant of care satisfaction and quality, interventions should increase and improve ICU communications	Family conference triggered for clinical conditions, e.g., LOS, mechanical support, anticipated home care Primary nursing Communication and self-awareness education for staff; peer debriefing Family decision support tools, meeting planning, tools, brochures, videos
Ethics and shared decision making	Knowledge of ethical principles of EOL; interventions that promote, validate, and support parents as primary decision-makers improve trust and parents' feelings of "correct decision-making"	Curricula on ethics of EOL care including, the principle of double effect, DNR *vs.* ACP Initiation and documentation of ACP discussions early in patient's course
Relief of pain and other symptoms	Pain and other EOL symptoms require vigilant monitoring and aggressive treatment	EOL or withdrawal bundle Bedside discussion with RN, RT prior to withdrawal of care to discuss plan Regular use of symptom recognition tools
Continuity of care	Consider the PMD and other consultants in care and communication around EOL Recognition that family supports often include PICU staff and some grieve losing their "PICU family"	Follow-up phone calls after ICU discharge to bereaved parents by attendings are greatly appreciated Regular update to subspecialists and primary pediatricians Attendance of funerals, hospital memorial services, consider cards, phone calls, and follow-up meetings
Grief and bereavement support	Understanding risks of complicated grief, and its prevalence in the PICU including the role of anticipatory grief during ICU admission	Create an appropriate EOL environment that is private, quiet and facilitates memory making; use unit ques to EOL, e.g., wreaths or lighting Screen for complicated grief before death and at routine PICU follow-up with bereaved parents

LOS, length of stay; PICU, pediatric intensive care unit; EOL, end of life; ACP, advanced care planning; DNR, do not resuscitate; PMD, primary medical doctor; RN, registered nurse; RT, respiratory therapist.

"Promoting Excellence in EOL Care Project" elucidated several domains of quality PC for adults in the ICU (42). In a parallel effort, Pediatric Intensivists, PC experts, and parents in conjunction with the Initiative for Pediatric Palliative Care put forth 6 domains of high-quality PC that were adopted by the ACCCM in 2008 (4). *Table 6* lists those domains, provides examples, and possible process measures (*Table 6*).

PC resources for PICUs

Palliative and intensive care experts call for still more data surrounding EOL and PC in children to further understand issues in this population (4,94) Without thorough understanding of root problems, interventional studies will be premature and not attuned to real population needs. Further, many issues are likely institution-dependent, based on population demographics, resources, and relative frequencies of conditions requiring ICU and PC. Overall, PC research is not well funded, limiting advances, and prompting concerns of early publication of insignificant findings. PC research comprises 0.2% of all NIH-funded research and from 2006–2010 only 20% of published adult or pediatric PC literature was supported by federal funding (31). Additionally, the majority of PC research funding is focused on adult and geriatric care rather than pediatrics. Potentially low cost, institution-responsive, and rapid cycle quality improvement efforts may allow teams to more efficiently address the unique issues facing PC in the PICU.

Lack of systematic PC education for trainees and providers plays a role in quality PC. Curricula within the subspecialty fellowship structure that includes PC and EOL expertise is advisable; indeed, the American College of Graduate Medical Education (ACGME) deems one of the major educational endpoints of PICU fellowship as "Care for children at EOL" (95). Perhaps, clinical exposure to home-based and ambulatory PC, including management of home ventilation, symptom management skills, and communication skills training, should be considered (29).

Training opportunities for other staff include communication skills training initiatives, such as, IntensiveTalk of the Vital Talk group, and the initiative for Pediatric Palliative Care's Critical Care Communications skills program "C3". Cellular phone applications such as Vital Tips has free family meeting planning and debriefing tools. For nurses, the End of Life Nursing Consortium (ELNEC) is widespread, and local hospices may offer outreach and education for nurses or other staff. Online educational modules for physicians are available from Education in Palliative and End of Life care (EPEC-Peds), and OPEN pediatrics (see *Table S2*)

Other resources for inpatient units include a concurrent care implementation toolkit from the NHPCO as a resource for hospice organizations and individuals caring for children who would benefit from PC and HC services. The IPAL-ICU project funded by the NIH, National Institutes of Aging, and the Center to Advance Palliative Care has several resources to use in the unit and a library of growing research on PC quality in the ICU. For patients exploring PC and EOL care, the Five Wishes document supported by the Association for Children's Palliative Care serves to alleviate difficulty "raising the issue" of the dying process. It is a conversational guide for discussions around hopes for the present, plans for when the disease progresses, goals of care during life threating events, and wishes for remembrance after death (89).

PC in the PICU is further guided by consensus statements and guidelines published by the AAP, ACCCM, the IOM, and American Heart Association (3,4,6). Additionally, clinical practice guidelines for quality PC and consensus guidelines on hospital PC programs from the Center to Advance Palliative Care supply guidance on team construct, role, and availability for PC teams.

Conclusions

Children in the PICU require both primary and subspecialty forms of PC often. Both forms are part of complete and high-quality care in the PICU. PC affects traditional quality measures such as hospital resource expenditures, LOS, and return to the hospital. It augments staff and parental experience of ICU care because the support, symptom management, communication, and advocacy associated with excellent PC augments these endpoints. Further research is needed to elucidate effective means to achieve quality PC surrounding accepted and known quality metrics and further address barriers to PC in the PICU. Quality improvement research will play a part as problem-focused, institutionally-responsive measures are more likely to align the resources, culture, issue, and needs of individual units.

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Footnote

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Supplementary

Table S1 Adult medical and surgical ICU PC consultation—clinical trigger criteria

Primary triggers
ICU admission after hospital stay ≥10 days
Age >80 years old with two or more life-threatening comorbidities
Diagnosis of active stage IV malignancy (metastatic disease)
Status after cardiac arrest
Diagnosis of intracerebral hemorrhage requiring mechanical ventilation
Alternative triggers
Family request
Futility considered/declared by medical team
Presence of advanced directive, intra-familial disagreement/conflict, or family disagreement with medical team >7 days
Death expected during the same ICU stay
ICU stay >1 month
Diagnosis with median survival <6 months
>3 ICU admissions during same hospitalization
GCS ≤8 for >1 week in patient >75 years; patients with GCS =3
Multiorgan system failure of ≥3 systems, e.g., Pa_{O2}/Fi_{O2} <300, platelet count <100,000/mm^3, acute increase in creatinine >2 mg/dL, acute increase in total bilirubin >2 mg/dL, use of vasopressors, GCS <13
Advanced stage dementia; global cerebral ischemia

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Table S2 Palliative care resources for the pediatric intensive care unit

Resource	URL
Vital Talk Communication Training	IntensiveTalk (ICU training for Intensivists); Vital Tips (Cellular Application) http://vitaltalk.org
Initiative for Pediatric Palliative Care	www.ippcweb.org
Critical Care Communications skills "C3" program: UCLA Health	www.uclahealth.org/palliative-care
Education in Palliative and End of Life care (EPEC-Peds) Northwestern Feinberg School of Medicine	bioethics.northwestern.edu/programs/epec
OPEN Pediatrics—free online education for general and subspecialty pediatricians	www.openpediatrics.org
National Hospice and Palliative Care Organization (NHPCO); End of Life Nursing Consortium (ELNEC)	nhpco.org/tools-and-resources
Center for the Advancement of Palliative Care (CAPC); Improving Palliative Care in the ICU (IPAL-ICU)	www.capc.org/ipal; Beyond Mortality: Assessing Pediatric Palliative Care Needs from the CAPC
Association for Children's Palliative Care (ACPC); Wishes Document	palliativedoctors.org/start/legal
End of life Care Practice Bundle	pedccm.wustl.edu
International Children Palliative Care; Network (ICPCN)	www.icpcn.org