Nursing Care at End of Life in Pediatric Intensive Care Unit Patients Requiring Mechanical Ventilation

By Elizabeth G. Broden, PhD, RN, Pamela S. Hinds, PhD, RN, Allison Werner-Lin, PhD, LCSW, Ryan Quinn, MS, Lisa A. Asaro, MS, and Martha A. Q. Curley, PhD, RN

Background Parents' perceptions of critical care during the final days of their child's life shape their grief for decades. Little is known about nursing care needs of children actively dying in the pediatric intensive care unit (PICU).
Objectives To examine associations between patient characteristics, circumstances of death, and nursing care requirements for children who died in the PICU.
Methods A secondary analysis of the data set from the Randomized Evaluation of Sedation Titration for Respiratory Failure trial was conducted.
Results This analysis included 104 children; 67 died after withdrawal of life-sustaining treatments; 21, after failed resuscitation; and 16, after brain death. Patients had a median age of 7.5 years, were cognitively appropriate, and were intubated for acute respiratory failure. Daily pain and sedation scores indicated patients' comfort was well managed (mean pain scores: modal, 0; peak, 2; mean sedation scores: modal, –2; peak, –1). Patients with longer PICU stays more often experienced pain and agitation on the day of death. Illness trajectory (acute, complex chronic condition, or cancer) was associated with pain scores ($P = .04$). Specifically, children with cancer had higher pain scores than children with acute illness trajectories ($P = .01$). Many patients (62%) had no change in critical care devices in their last days of life (median, 5 devices). Patterns of pain, sedation, comfort medications, and nursing care requirements did not differ by circumstances of death.
Conclusion Children with cancer and longer PICU stays may need comprehensive comfort management. Invasive devices left in place during withdrawal of life support may have inhibited parents' ability to connect with their child. Future research should incorporate parents' perspectives.
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Each death in the pediatric intensive care unit (PICU) is unique to the individual child and family.[1-3] Most often, critically ill and/or injured children die following a planned withdrawal of life-sustaining treatment (LST), whether the underlying problem is an acute or long-term process.[2,4,5] Nurses caring for a dying child in the critical care environment facilitate family connections and are therefore integral to shaping the end-of-life (EOL) experience.[6,7]

Throughout the rest of their lives, parents relive fine details of their child's death[8,9] such as their child's appearance and comfort and their connectedness as a parent.[10-14] Care in the PICU often encompasses an escalation of treatments, including invasive devices such as intravenous catheters and mechanical ventilators, that interfere with these parental priorities. Characteristics of clinical care during the shift from LST to comfort-focused care remain understudied, especially for nursing interventions that dying children receive in their last days of life.[15] Pediatric EOL care is often characterized by high symptom burden along with heavy sedation.[15-17] End-of-life care practices, particularly medication management, vary with patient-related factors such as age and length of stay (LOS).[4,16,17] Little is known about patterns of moment-to-moment PICU nursing care for dying children, including assessment of pain and sedation, administration of comfort medications, and titration of LSTs during the last days of a child's life.

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Because parents remember their child's death so vividly, it is profoundly important that pediatric critical care nurses are well equipped to support the best possible EOL experience. This study details the nursing care a cohort of PICU patients received in their last days of life. We describe the cohort's baseline and clinical characteristics, examine care patterns (such as daily pain scores) in the days before their death, and report associations between patient characteristics (eg, age and illness trajectory) and patterns of care. We hypothesized that patient characteristics would be associated with different care patterns across time.

Methods

This study is a secondary analysis of data from the Randomized Evaluation of Sedation Titration for Respiratory Failure (RESTORE) clinical trial.[18] The RESTORE study was a randomized controlled trial to evaluate the impact of a nurse-implemented, goal-directed sedation protocol on duration of mechanical ventilation in children intubated for respiratory failure. Thirty-one PICUs in the United States were randomized to the sedation protocol or usual care. From 2009 through 2013, baseline and daily clinical data were collected for up to 28 days from endotracheal intubation or from when the patient was admitted to the PICU. Institutional review board approval for the parent study was obtained at the University of Pennsylvania and at each site. Consent was obtained from the parent or legal guardian of each patient before study enrollment. This secondary analysis was deemed exempt by the University of Pennsylvania.

Patients in the RESTORE trial who died in the PICU by study day 28 were eligible for this study. We defined 3 mutually exclusive circumstances of death: withdrawal of life support (planned deescalation or limitation of LST or an active do-not-resuscitate order at time of death), failed resuscitation, and brain death. Some patients who transitioned to EOL care were withdrawn from the RESTORE study. These patients were excluded if more than 3 days passed between the end of RESTORE daily data collection and their death.

Variables and Measures

Baseline variables included patient demographic data, functional status, medical history, illness trajectory, and severity of illness at PICU admission. Pediatric Cerebral Performance Category and Pediatric Overall Performance Category scales were used to describe cognitive and functional status, respectively. These scales have established validity and reliability (interrater reliability, 0.88-0.96).[19] Scores range from 1 (typical) to 6 (brain death). A score of greater than 2 is considered developmentally atypical.[19] Illness trajectory was categorized as acute (sudden onset), complex chronic condition, or cancer on the basis of each child's medical history.[20,21] Medical history was determined by the presence or absence of prespecified conditions (eg, asthma, diabetes) as documented in the patient's electronic health record. We characterized medical history as respiratory dysfunction, immunocompromise, aspiration risk, or none in tables to simplify the reporting of diverse conditions. Severity of illness was measured using the Pediatric Risk of Mortality III-12 score, a mortality prediction model based on physiological variables collected in the first 12 hours of PICU admission with well-established validity (area under the curve, 0.941-0.947).[22]

We examined the last 5 days of pain and sedation, comfort medication use, and nursing critical care requirements among 104 children who died in the PICU.

We examined up to 5 days preceding death for each eligible patient. Daily data included measures of pain and sedation, comfort medication use, and nursing critical care requirements. All RESTORE sites used the same instruments to record these outcomes on a daily basis.[23]

Pain was assessed on a scale of 0 to 10 using the Face, Legs, Activity, Cry, and Consolability (FLACC) scale,[24] Individualized Numeric Rating Scale,[25,26] or Wong-Baker Faces scale[27] as appropriate for child age and development. Because patients were intubated and sedated, pain was most often assessed using the FLACC scale, which has acceptable validity (convergent validity, 0.80) and reliability (interrater reliability, 0.94).[24] The State Behavioral Scale (SBS), which ranges from −3 (unresponsive) to +2 (agitated), was used to assess sedation level and had interrater reliability greater than 90% across RESTORE sites.[23,28] Bedside nurses assessed each patient's pain and sedation every 4 hours. For patients who were receiving continuous neuromuscular blockade, pain and sedation were assessed hourly and deemed present when the patient's heart rate or blood pressure increased by at least 20% when stimulated (pain or agitation assumed to be present). In this analysis, patients for whom pain or agitation was assumed present at any point during each 24-hour data collection period were assigned a peak daily pain score of 4 and a peak daily SBS score of +1. To broadly capture clinical discomfort, we characterized daily peak pain and SBS scores of greater than 0 as episodic pain and agitation, respectively. We analyzed daily modal (most frequent) and peak comfort scores, and we assessed cumulative sums of 24-hour doses of comfort medications measured in morphine equivalents (milligrams per kilogram) for opioids and midazolam equivalents (milligrams per kilogram) for benzodiazepines.

Nursing critical care requirements were measured using the Nine Equivalents of Nursing Manpower Use Score (NEMS).[29] The NEMS measures monitoring frequency (vital signs, laboratory values, etc) and intervention use (mechanical ventilation, vasopressors, fluid replacement, etc). Scores range from 0 to 63. Higher scores indicate greater critical care requirements.[29] Critical care devices were classified as life-sustaining devices (mechanical ventilation, chest tube, vasoactive medications, dialysis, extracorporeal membrane oxygenation), monitoring/access devices (arterial catheter, central venous catheter, peripheral intravenous catheter, wound drain), or nutrition/continence devices (nasogastric tube, bladder catheter). We categorized changes in devices during the 5 days before death as escalation (increase), deescalation (decrease), titration (both increase and decrease), or no change.

Statistical Analysis

We described and compared the cohort's baseline characteristics by circumstances of death (withdrawal of LST, failed resuscitation, or brain death) using Kruskal-Wallis tests for continuous variables and Fisher exact tests for categorical variables. Stata software version 15 (StataCorp LLC) was used to summarize, describe, and visualize the data.[30]

We examined associations between patient characteristics and daily outcomes. We generated unadjusted mixed-effects models to explore associations between each patient-level factor (including age, race, ethnicity, illness trajectory, PICU LOS, and circumstances of death) and each daily outcome (including peak pain and sedation scores, comfort medication doses, and NEMS) across time. Adjusted multivariable models were generated for pain, sedation, and NEMS using a backward stepwise variable selection approach.

Predictors with significant effects with a *P* value of less than .05 in unadjusted models were considered for inclusion in the multivariable model for each outcome. Variables with the highest *P* values were removed until all independent variables in the adjusted multivariable model had a *P* value of less than .20.[31] We controlled for daily cumulative opioid dose and benzodiazepine dose in adjusted models of peak daily pain and sedation scores, respectively. We controlled for neurologic failure in models of sedation scores and for age and Pediatric Risk of Mortality III-12 scores in models of NEMS. We conducted sensitivity analyses including RESTORE treatment group and without recoding scores for assumed presence of pain and agitation.Sensitivity results are presented when they impacted the relationship between predictor of interest and outcome. Length of stay and circumstances of death were not included in adjusted modeling because of the temporal relationship between these factors and outcomes. For these variables, we used Fisher exact tests to compare scores on day of death between PICU LOS groups (≤7 days or >7 days) and between groups for circumstances of death. SAS software version 9.4 was used for all modeling (SAS Institute Inc).[32] Model results are presented as model-based means and SEs.

Results

Of the 155 patients in the RESTORE study who died, 45 were excluded because they died after study day 28 and 6 were excluded because more than 3 days passed between the end of daily data collection and their death, resulting in 104 patients for this analysis. There were no clinically meaningful differences between patients included and excluded in this analysis.

Patient Characteristics

Most patients (64%) died following withdrawal of LST, 20% died after failed resuscitation, and 15% died after brain death. The median (SD) age at PICU admission was 7.5 (6.3) years, and most patients had age-appropriate cognition and functionality at baseline. On PICU admission, patients had high risk of mortality (median, 27.2%; IQR, 6.3%-57.9%). Children who died of brain death were more frequently developmentally typical with an acute illness trajectory. There were no differences in demographic characteristics or RESTORE intervention assignment between groups (Table 1).

Patients who died after withdrawal of LST had longer stays than did patients with other circumstances of death (*P*<.001). Most patients were supported with multiple LSTs, including a median of 5 medical devices, vasoactive medications (88% of patients), and renal replacement therapies (33% of patients). Most patients (93%) remained intubated until death. The primary cause of death for most patients (38%) was respiratory failure; for 27% of patients, the primary cause of death was multisystem organ failure. Table 2 shows hospital course details by circumstances of death.

Comfort Management

Figure 1 shows patients' daily pain and agitation scores during the 5 days preceding death. Daily modal pain scores were low (mean [SD], 0 [1]), as were daily peak pain scores (mean [SD], 2 [2.5]). Patients were well sedated, as shown by daily modal SBS scores (mean [SD], −2 [1]) and peak SBS scores (mean [SD], −1 [1.5]). Patients with stays of longer than 7 days were more likely to experience episodic pain and pain with agitation on their last day of life than were patients with stays of 7 days or less (Table 3).

Mean (SE) daily peak pain scores significantly decreased with time (*P*=.008) from 2.5 (0.3) to 1.0 (0.3). In unadjusted models, illness trajectory was significantly associated with differences in peak daily pain scores (*P*=.04). Across time, patients with a cancer illness trajectory had higher mean (SE) pain scores (2.5 [0.3]) than did patients with an acute illness trajectory (1.5 [0.3], *P*=.01) (Figure 2). Age, race, ethnicity, LOS, and circumstances of death were not significant in unadjusted modeling. When opioid dose was controlled for in the adjusted model, time (*P*=.003) and illness trajectory (*P*=.04) remained significantly related to peak daily pain score. When RESTORE treatment group was included in the model in a sensitivity analysis (*P*<.001), illness trajectory was no longer significant (*P*=.06).

> Although breakthrough episodes of pain and/or agitation occurred, pain and sedation scores indicated that the dying child's comfort was well managed.

Mean (SE) daily peak SBS scores decreased with time (*P*<.001) from −0.6 (0.2) to −1.3 (0.2). In unadjusted models, patients with shorter stays had lower (more sedated) mean (SE) SBS scores (−1.4 [0.2]) than did patients with longer stays (−0.6 [0.1], *P*=.001). Patterns of peak daily SBS scores did not differ according to age, race, ethnicity, illness trajectory, or circumstances of death.

Table 1
Patient demographics and baseline characteristics according to circumstances of death

	Total (N=104)	Withdrawal of LST (n=67)	Failed resuscitation (n=21)	Brain death (n=16)	P[a]
Age at PICU admission, median (IQR), y	7.5 (2.0-14.5)	7.4 (1.6-14.3)	7.0 (2.6-15.1)	9.4 (3.4-13.4)	.74
Age, y, No. (%)					.96
<2	26 (25)	19 (28)	4 (19)	3 (19)	
2 to <6	20 (19)	12 (18)	5 (24)	3 (19)	
6 to <10	13 (13)	9 (13)	2 (10)	2 (12)	
10 to <18	45 (43)	27 (40)	10 (48)	8 (50)	
Sex, No. (%)					.65
Female	52 (50)	31 (46)	12 (57)	9 (56)	
Male	52 (50)	36 (54)	9 (43)	7 (44)	
Race, No. (%)					.07
White	73 (70)	53 (79)	11 (52)	9 (56)	
Black	22 (21)	10 (15)	7 (33)	5 (31)	
Other/multiracial	9 (9)	4 (6)	3 (14)	2 (13)	
Ethnicity[b]					.22
Hispanic/Latino	25 (24)	15 (22)	4 (19)	6 (38)	
Non-Hispanic/Latino	78 (75)	52 (78)	16 (76)	10 (63)	
Baseline functional status, No. (%)					
Pediatric Cerebral Performance Category					.02
≤2	81 (78)	47 (70)	18 (86)	16 (100)	
>2	23 (22)	20 (30)	3 (14)	0 (0)	
Pediatric Overall Performance Category					.09
≤2	78 (75)	46 (69)	17 (81)	15 (94)	
>2	26 (25)	21 (31)	4 (19)	1 (6)	
Medical history,[c] No. (%)					
Respiratory dysfunction[d]	13 (12)	9 (13)	3 (14)	1 (6)	.83
Immunocompromise[e]	36 (35)	27 (40)	6 (29)	3 (19)	.23
Aspiration risk[f]	16 (15)	13 (19)	3 (14)	0 (0)	.15
None	46 (44)	24 (36)	10 (48)	12 (75)	.02
Illness trajectory, No. (%)					<.001
Acute[g]	47 (45)	22 (33)	10 (48)	15 (94)	
Complex chronic condition[h]	27 (26)	22 (33)	5 (24)	0 (0)	
Cancer[i]	30 (29)	23 (34)	6 (29)	1 (6)	
Primary diagnosis, No. (%)					.10
Pneumonia	34 (33)	22 (33)	7 (33)	5 (31)	
Sepsis	30 (29)	19 (28)	8 (38)	3 (19)	
Pulmonary edema	11 (11)	8 (12)	1 (5)	2 (12)	
Bronchiolitis	7 (7)	4 (6)	3 (14)	0 (0)	
Trauma	3 (3)	0 (0)	0 (0)	3 (19)	
Other[j]	19 (18)	14 (21)	2 (10)	3 (19)	
Severity of illness on admission, median (IQR)					
PRISM III-12 score	15 (8.5-22)	14.0 (8.0-21)	15.0 (9.0-22)	20.5 (10.5-27)	.26
ROM based on PRISM III-12 score, %	27.2 (6.3-57.9)	23.5 (6.3-58.7)	23.2 (6.3-53.5)	4.7 (7.6-58.3)	.89
RESTORE group, No. (%)					.88
Sedation protocol	44 (42)	28 (42)	10 (48)	6 (38)	
Usual care	60 (58)	39 (58)	11 (52)	10 (62)	

Abbreviations: LST, life-sustaining treatments; PICU, pediatric intensive care unit; PRISM, Pediatric Risk of Mortality; ROM, risk of mortality.

[a] *P* values comparing circumstances of death groups were calculated using Kruskal-Wallis tests for continuous variables and Fisher exact tests for categorical variables.
[b] One patient did not report ethnicity or ethnicity was unknown.
[c] Medical history categories are not mutually exclusive and therefore do not total to the category total.
[d] Existing diagnosis of asthma, cystic fibrosis, or bronchopulmonary dysplasia.
[e] Existing diagnosis of immunocompromised status, or past history of bone marrow transplant/chemotherapy.
[f] Existing diagnosis of seizure disorder with Pediatric Cerebral Performance Category >2 or neurological disorder.
[g] No prespecified medical conditions.
[h] Pediatric Cerebral Performance Category >2 and/or diagnosis of neurological disorder with aspiration risk, seizure disorder, chronic tracheostomy, cystic fibrosis, sickle cell disease, bronchopulmonary dysplasia, or diabetes.
[i] Active chemotherapy or after a bone marrow transplant. Patients who fell into both chronic illness and cancer categories were placed into the cancer category. Illness categories are based on Feudtner et al[20] and Stein et al.[21]
[j] Other diagnoses include aspiration pneumonia, acute respiratory failure due to bone marrow transplant, asthma, pertussis, acute chest syndrome, and pulmonary hemorrhage.

Table 2
Overall hospital course according to circumstances of death

	Total (N=104)	Withdrawal of LST (n=67)	Failed resuscitation (n=21)	Brain death (n=16)	P[a]
Length of stay, median (IQR), d					
In PICU	10 (4-19)	14 (6-21)	4 (2-8)	6 (4-11)	<.001
In hospital	14 (6-35)	24 (10-53)	6 (2-14)	7 (4-11)	<.001
PICU interventions[b]					
No. of devices per day, median (IQR)	5 (4-5)	5 (4-5)	5 (4-5)	5 (4-6)	.33
Vasoactive medications, No. (%)	91 (88)	57 (85)	19 (90)	15 (94)	.75
Renal replacement therapies, No. (%)	34 (33)	26 (39)	4 (19)	4 (25)	.20
ECMO, No. (%)	12 (12)	9 (13)	0 (0)	3 (19)	.12
Procedures with transport out of the PICU, No. (%)	50 (48)	31 (46)	7 (33)	12 (75)	.04
Daily NEMS score, median (IQR)	34 (27-40)	34 (27-40)	39 (27-39)	39 (27-40)	.11
Inadequate comfort management, No. (%)					
Inadequate pain management[c]	12 (12)	10 (15)	2 (10)	0 (0)	.28
Inadequate sedation management[d]	14 (13)	11 (16)	2 (10)	1 (6)	.59
Extubated before death,[e] No. (%)	7 (7)	5 (7)	2 (10)	0 (0)	.63
Primary cause of death, No. (%)					.02
Respiratory failure	40 (38)	27 (40)	8 (38)	5 (31)	
Multisystem organ failure	28 (27)	18 (27)	6 (29)	4 (25)	
Sepsis/septic shock	14 (13)	7 (10)	6 (29)	1 (6)	
Cancer	11 (11)	10 (15)	1 (5)	0 (0)	
Trauma	2 (2)	0 (0)	0 (0)	2 (13)	
Other[f]	9 (9)	5 (7)	0 (0)	4 (25)	

Abbreviations: ECMO, extracorporeal membrane oxygenation; LST, life-sustaining treatments; NEMS, Nine Equivalents of Nursing Manpower Use Score; PICU, pediatric intensive care unit.

[a] *P* values comparing circumstances of death groups were calculated using Kruskal-Wallis tests for continuous variables and Fisher exact tests for categorical variables.
[b] Receipt of any of the listed PICU interventions; reported across all study days (0-28).
[c] Inadequate pain management was defined as a pain score >4 (or pain assumed present if receiving neuromuscular blockade) for 2 consecutive hours not related to a planned extubation attempt.
[d] Inadequate sedation management was defined as agitation (State Behavioral Scale score >0 or agitation assumed present if receiving neuromuscular blockade) for 2 consecutive hours not related to a planned extubation attempt.
[e] Duration of mechanical ventilation is not reported because most patients (93%) were intubated until death.
[f] Other causes of death: terminal neurological event (n=7), myocarditis, liver failure.

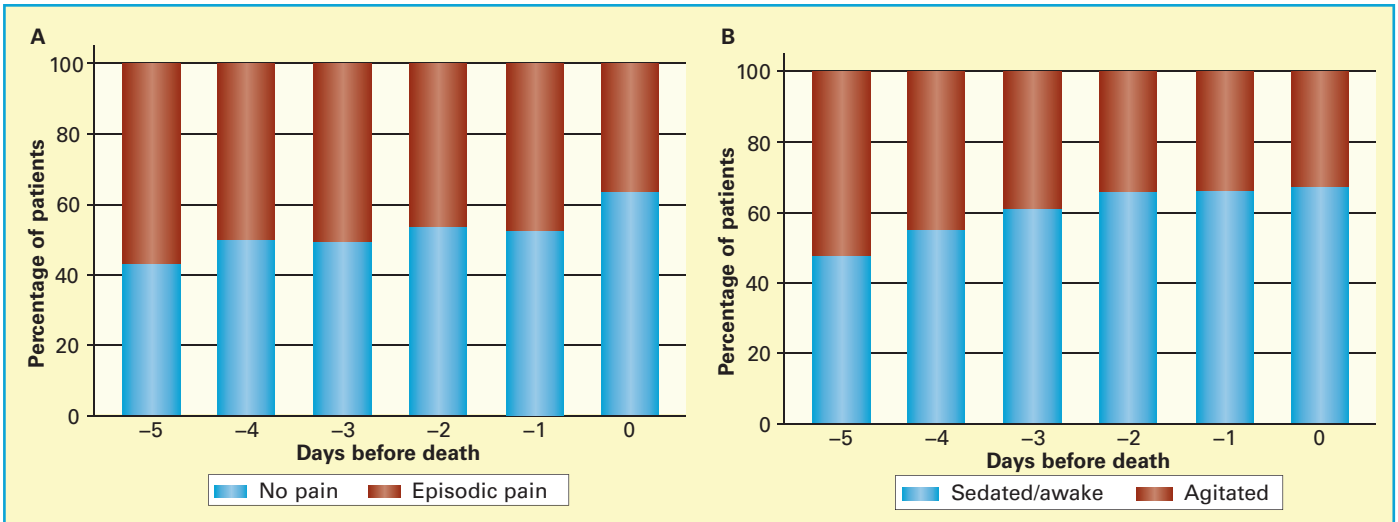

Figure 1 Patients' level of comfort on the 5 days leading up to death. A, Percentage of patients with daily peak pain score of 0 (no pain) vs greater than 0 (episodic pain), as rated by nurses. B, Percentage of patients with daily peak score of 0 or less (sedated/awake) vs greater than 0 (agitated) as rated by nurses using the State Behavioral Scale. For both pain and sedation/agitation, the sample size ranges from 67 patients 5 days before death to 104 patients on the day of death.

Table 3
Episodic pain and agitation on last day of life

	No. (%) of patients			
	Total (N = 104)	PICU LOS ≤7 days (n = 43)	PICU LOS >7 days (n = 61)	*P*[a]
Episodic pain	38 (37)	10 (23)	28 (46)	.02
Episodic agitation	34 (33)	11 (26)	23 (38)	.21
Episodic pain and agitation	22 (21)	5 (12)	17 (28)	.04

Abbreviations: LOS, length of stay; PICU, pediatric intensive care unit.

[a] From Fisher exact tests.

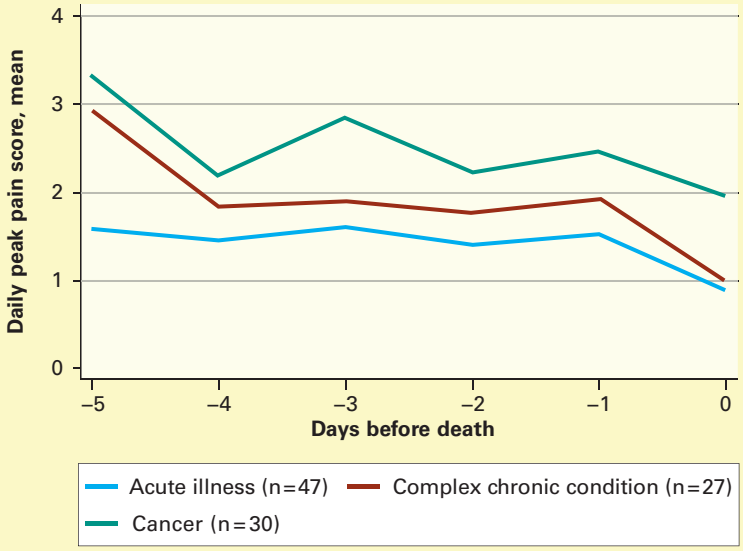

Figure 2 Differences in daily peak pain scores (mean per group) between illness trajectory groups (acute illness, complex chronic condition, cancer).

Mean (SE) opioid doses decreased over time (*P* = .004) from 4.2 (0.6) to 3.4 (0.6) mg/kg/24 h. In unadjusted models, patients older than 10 years received lower mean [SE] cumulative daily opioid doses (2.3 [0.8] mg/kg/24 h) than did patients aged 0 to 1.99 years (5.3 [1.1] mg/kg/24 h, *P* = .03) and patients aged 2 to 5.99 years (7.0 [1.3] mg/kg/24 h, *P* = .002). Across days prior to death, patients with stays of 7 days or less received a mean [SE] of 3.6 [1.1] mg/kg/24 h less cumulative daily opioid dose than did patients with stays of longer than 7 days (*P* = .002) (Supplemental Figures 1 and 2, available online only at ajcconline.org).

Mean (SE) benzodiazepine doses decreased over time (*P* = .002) from 3.0 (0.6) to 2.8 (0.6) mg/kg/24 h. Patients older than 10 years had lower mean (SE) benzodiazepine doses (1.6 [0.9] mg/kg/24 h) than did patients aged 0 to 1.99 years (4.9 [1.1] mg/kg/24 h, *P* = .02) and patients aged 2 to 5.99 years (6.3 [1.3] mg/kg/24 h, *P* = .003). Patients aged 6 to 9.99 years received benzodiazepine doses lower by a mean (SE) of 4.4 (2.0) mg/kg/24 h than did patients aged 2 to 5.99 years (*P* = .03). Patients with shorter stays had benzodiazepine doses lower by a mean (SE) of 3.7 (1.1) mg/kg/24 h than did patients with longer stays during the days preceding death (*P* = .002) (Supplemental Figures 3 and 4, available online only). Race, ethnicity, illness trajectory, and circumstances of death were not significantly associated with patterns in medication doses.

Nursing Care Requirements

Patterns in NEMS were not associated with time and did not significantly differ by any patient-level factors. Patients had a median (IQR) of 5 (4-5) total devices across all days. More than half of patients (62%) experienced no change in total number of devices in the 5 days preceding death. Across all groups according to circumstances of death, 30% of patients experienced an escalation in life-sustaining devices (mechanical ventilation, chest tube, vasoactive medications, dialysis, extracorporeal membrane oxygenation) within 5 days before death. More than half (58%) of patients who died following withdrawal of LST experienced an escalation (27%), deescalation (9%), or titration (22%) in life-sustaining devices in the 5 days preceding death (Figure 3).

Discussion

In this analysis of nursing care at EOL, patients in the PICU were generally comfortable, exhibiting patterns of low daily modal pain and sedation scores, with moments of discomfort. Patients with cancer and longer PICU stays had more episodic pain and agitation and may require increased attention to comfort management. Patterns in outcomes did not vary by circumstances of death, indicating that withdrawal of LST, failed resuscitation, and brain death may not be mutually exclusive categories with divergent nursing care needs but instead may be overlapping domains reflective of rapid medical changes and decision-making. These findings support the need to tailor nursing care on the basis of patients' clinical characteristics throughout evolving goals of care.

We built upon previous research that examined the presence or absence of discomfort[15,33,34] by examining modal and peak measures of pain and sedation to understand fluctuations in patients' comfort during their last days of life. Patterns of daily modal and peak scores indicated that patients experienced episodic discomfort in the days before death. In this analysis, patients with cancer had higher peak daily pain scores

than did patients in other illness trajectory groups, corroborating existing literature that suggests that for children dying from cancer, pain is an especially common EOL symptom that requires comprehensive management.[35] Clinician and parent perceptions of child comfort may diverge,[36-38] warranting research and assessment strategies that incorporate parents' perspectives in addition to clinicians' reports.

Consistent with previous work,[16,17,39] our findings demonstrated variability in EOL medication doses that was associated with both age and LOS. This variation may represent comfort medication titration to meet evolving comfort and symptom needs of a diverse patient population because our pain and sedation scores demonstrated that patients' pain and sedation needs were met. Pediatric pain management practices have diversified and become more comprehensive,[40,41] but additional information is needed as to how such advances are integrated into EOL care in the PICU specifically.[42] An approach that strengthens partnerships between pediatric intensive and palliative care teams may alleviate critically ill children's discomfort[43,44] more effectively than standardizing dosing recommendations amidst this variability.[39] Parental perspectives and emotions may also influence medication administration, but this remains an underexplored dimension of EOL care for children.

Most patients experienced no change in critical care devices, meaning that they had the same number of invasive devices during the 5 days preceding death. Patients across age, illness trajectory, LOS, and circumstance-of-death groups often remained highly device laden until their death. Devices might have remained in place while their therapeutic effect was discontinued, but even without a therapeutic effect, devices drastically alter the ways parents are able to connect with their child.[8,11,45] Educational and clinical support is necessary for nurses to partner with parents to facilitate meaningful final memories with children on various EOL trajectories with multiple medical devices.

The outcomes we examined did not differ significantly according to circumstances of death, but the proportions of escalation and deescalation of critical care requirements between these groups are worth noting. Patients who died following withdrawal of LST experienced escalation or titration of life-sustaining requirements more frequently than deescalation. This pattern reveals that decisions to withdraw LST may occur in the context of quickly evolving clinical scenarios, with all options pursued until the very final moments preceding a child's death.

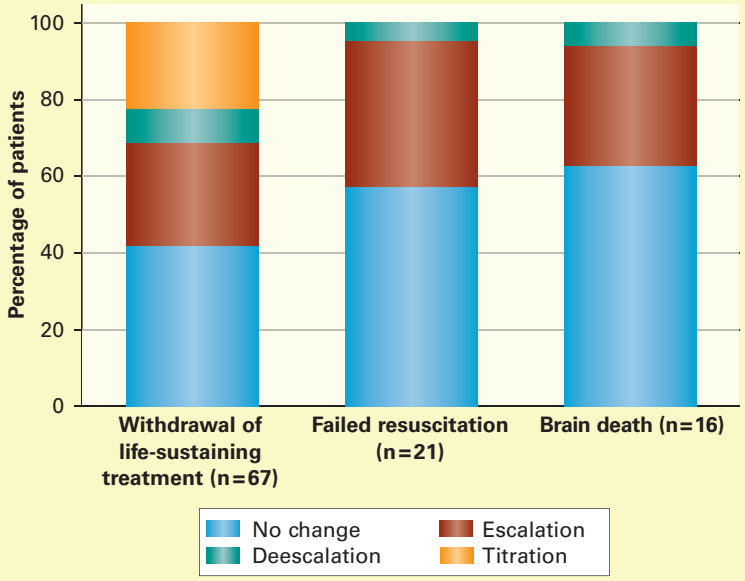

Figure 3 Percentage of patients experiencing changes in life-sustaining requirements (mechanical ventilation, chest tube, vasoactive medications, dialysis, extracorporeal membrane oxygenation) in the 5 days preceding death by circumstances of death. Changes were categorized as an escalation if the number of devices increased during the 5 days, a deescalation if the number of devices decreased, a titration if the number of devices both increased and decreased, or no change. The last observation carried forward was used to compare across days in cases with fewer than 5 days of data.

Formal family meetings may not be fully possible in such situations.[46,47] Flexible communication frameworks are necessary to strengthen support for parents navigating these fast-paced, difficult decisions. Nurses must remain central to such models because frontline bedside clinicians are the ones who attend to arising patient and family questions, concerns, and emotions during these moments of need.[48]

This study presents a deep yet limited level of detail about nursing care at EOL in the PICU. This secondary analysis is subject to the restrictions of the parent study, which may limit the generalizability of our findings. The RESTORE study protocolized pain and sedation management, which could have accounted for differences in pain and sedation scores to a greater degree than the hypothesized factors. Our sensitivity analyses attempted to account for the effects of the study protocol by examining the effect of treatment group, but more variability may be observed in other populations. The generalizability of our findings may be

> Nurse-led communication frameworks may help support families making fast-paced decisions about pursuing or limiting life-sustaining treatment.

limited by the composition of the study population, which was 73% White. Examining the EOL experiences of minoritized populations would lend important insights into their specific experiences and needs. The RESTORE data set is composed of medical record information and presents one perspective about EOL in the PICU. Including parents' perceptions will provide greater contextual depth about a child's death.

Conclusions

When a child is admitted to the PICU, death is seldom anticipated. Equipped with the knowledge that patients' presenting characteristics influence their EOL needs, bedside nurses can identify priorities in their care for dying children. Children with cancer and longer stays likely require comprehensive comfort management and palliative care consultation. Parents may need help to connect with their dying child in the presence of multiple invasive devices. This study represents a sliver of the nursing care that unfolds when a child is dying in the PICU; relational and supportive care surround the important tasks of symptom and device management. Evidence to develop nursing care strategies to support parents as they navigate anticipatory grief amidst fast-paced clinical changes and evolving goals of care is necessary. Nurses in the PICU can integrate these findings within their practice to provide the most thorough and thoughtful care to children and families during the end of a child's life.

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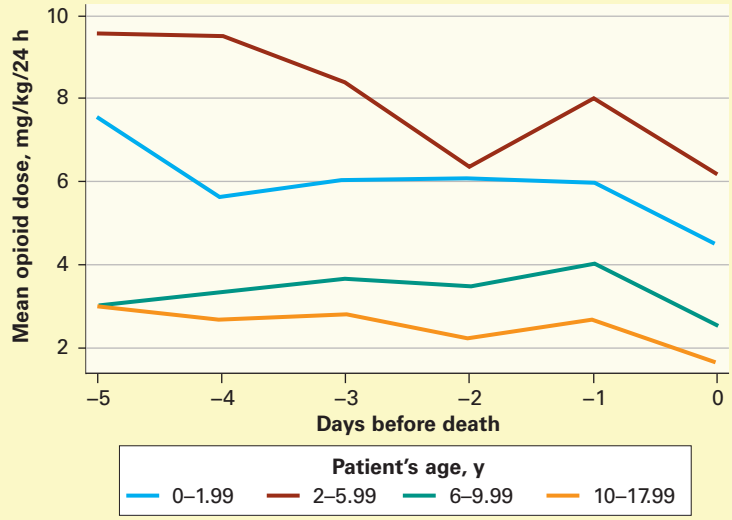
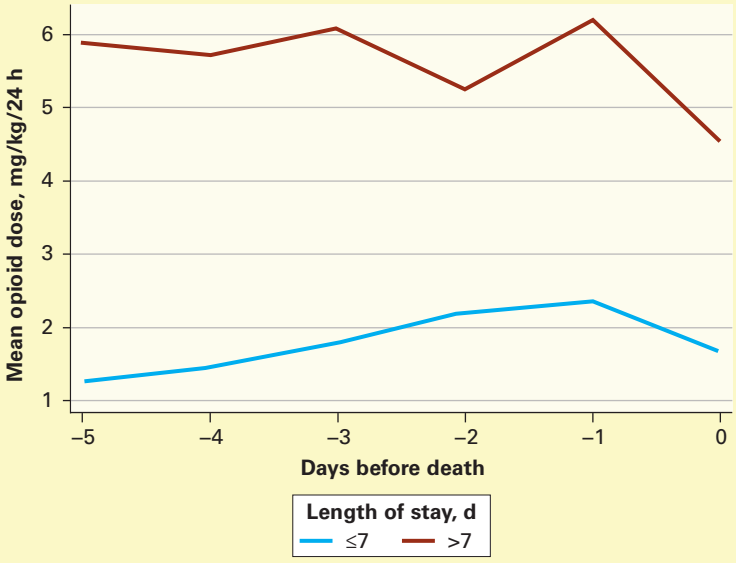
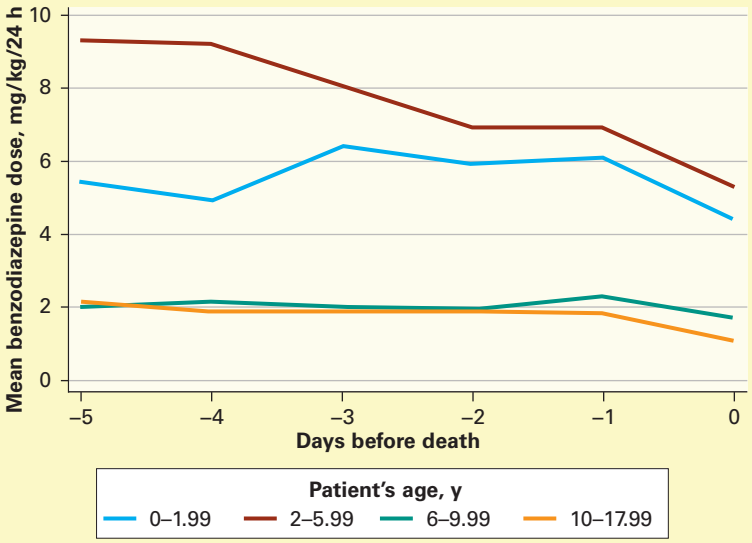


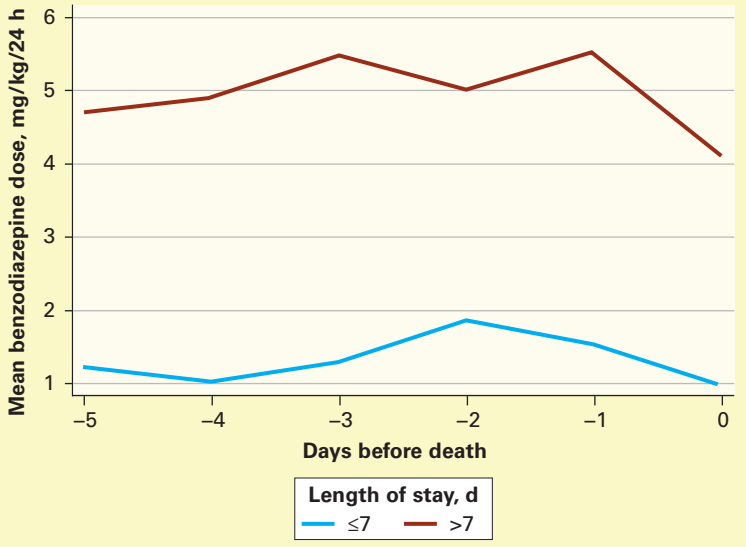
Supplemental Figure 1 Differences in daily opioid dose between age groups.



Supplemental Figure 2 Differences in daily opioid dose according to length of stay.



Supplemental Figure 3 Differences in daily benzodiazepine dose between age groups.



Supplemental Figure 4 Differences in daily benzodiazepine dose according to length of stay.