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“I didn’t want my baby to pass, but I didn’t want him suffering either”: Comparing Bereaved Parents’ Narratives with Nursing End-of-Life Assessments in the PICU

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Abstract

Little is known about how nursing care at the end of a child's life impacts long-term parental bereavement. We aimed to explain, contextualize, and examine comparisons between quantitative trends in children's end-of-life care and parents' qualitative perceptions. We used a mixed methods design; combining quantitative data from the *RESTORE* clinical trial with qualitative interviews with bereaved parents. Patients who died during *RESTORE* were included in quantitative analyses. A subset of their parents was interviewed 7–11 years later. The quantitative analyses included 104 children. Eight parents were interviewed; 4 had a child die following cancer, 4 following a complex chronic illness. Quantitatively, patients' pain and sedation scores were generally comfortable. Children died with multiple invasive devices in place. Parents' descriptions of their child's comfort and critical care requirements differed by illness trajectory (cancer, complex chronic illness). Parents' memories of their child's suffering aligned with peaks in clinical scores, rather than averages. Invasive devices and equipment altered parents' ability to make meaningful final memories with the dying child. Pediatric intensive care clinicians may need to broaden how they attend to dying children's pain and corresponding parental distress, as parent's memories of their dying child's suffering persist for years.

Keywords

Bereavement; end-of-life care; pediatrics; intensive care; mixed methods research

Introduction

Dying children and their families reach the end-of-life (EOL) phase after accumulating a vast range of experiences shaped by the child's acute or chronic illness/injury trajectory. Though pediatric mortality rates are decreasing globally,^{1,2} many children die in pediatric intensive care units (PICUs) following a planned withdrawal or limitation of life-sustaining treatment (LST) regardless of cause of death.^{1,2} The rarity of pediatric death combined with a diverse PICU population makes planning a quality EOL experience a complicated task.

The circumstances of each child's death experience shape their parents' grief.^{3–7} Care in the PICU is characteristically distinct from other pediatric settings and is stressful for parents.^{8–10} The PICU environment can be unsettling, especially the child's appearance, technological dependence, and loss of their parental role.⁶ The clinical team's care of the dying child and family can thus have lasting impact on parental grief, but knowledge of how the PICU context persists in parents' memories is lacking.

Studies examining bereaved parents' shorter-term perspectives illustrate their desire to remain physically close to their child, maintain their parental role, and need for optimal pain/symptom management.^{11–13} Quantitative studies described broad trends in pediatric

EOL,^{1,14} but have not captured experience and context. Further, such quantitative studies historically haven't included frequent pain and sedation nursing assessments, which guide EOL symptom management. Qualitative research with bereaved parents is limited by selection bias,¹⁵ thus the characteristics and experiences of parents who do not participate are unknown. Further, purely qualitative studies of parents cannot examine how parents' perceptions compare with received care.

This study offers a mixed methods exploration of bereaved parents' experience of EOL care following withdrawal of LST in the PICU to fill these gaps in the field. The aims are (1) to explain and contextualize children's quantitative EOL trends using qualitative parent interview data and (2) compare parents' perceptions of their child's EOL care with clinical documentation (i.e., how parents' perceptions corresponded with or diverged from nurse assessments).

Methods

This exploratory study employed a sequential (QUAN→ qual) mixed methods design.¹⁶ Quantitative data were collected and analyzed prior to qualitative data. The Good Death in the PICU conceptual model¹⁷ served as a guiding framework for the study. The model illustrates how clinicians may partner with parents to provide a quality EOL experience by honoring the relationship between parent and child, optimizing clinical factors such as pain control and invasive devices, managing situational factors (i.e., unit policies, structures), and tending to emotional/spiritual dimensions.¹⁷ The model guided quantitative variable selection, qualitative interview question development, and supplied an analytic framework for data integration. Details of the quantitative and qualitative studies are published elsewhere.^{18,19}

Sampling strategy and data collection

The quantitative arm of this mixed methods study consisted of a secondary analysis of existing data from the *RESTORE* clinical trial,^{20,21} which took place from 2009–2013 and evaluated the impact of a nurse-implemented, goal-directed sedation protocol on duration of mechanical ventilation in children. The *RESTORE* clinical trial included 2449 children up to 17 years of age who were mechanically ventilated for acute respiratory failure in 31 United States PICUs. A total of 155 patients died during *RESTORE*. We examined the 5 days preceding death for each patient. *RESTORE* was approved by the Institutional Review Board of the University of Pennsylvania. Parents consented for follow-up initially during the *RESTORE* trial (IRB #808830). All parents provided verbal informed consent to participate in the present interview.

The quantitative component of this study identified associations between patient characteristics and daily outcomes over days preceding death.¹⁸ We examined patient characteristics including demographic information, age, illness trajectory, and length of stay (LOS). Illness trajectory was categorized as acute, complex chronic condition, or cancer. Daily variables included measures of pain, sedation, comfort medication use, and nursing critical care requirements. Nurses assessed pain every 4 hours using validated 0–10 scales.^{22–26} Nurses assessed sedation every 4 hours using the State Behavioral Scale

(SBS), which ranges from -3 (unresponsive) to +2 (agitated).²⁷ We analyzed daily modal and peak pain and SBS scores. Critical care requirements were calculated daily using the Nine Equivalents of Nursing Manpower Score (NEMS),^{28,29} which measures frequency of monitoring (vital signs, lab values, etc.) and interventions (mechanical ventilation, vasopressors, etc.). Critical care devices included endotracheal tube, venous access lines, nasogastric tube, etc. We used mixed effects models to explore differences in daily outcomes between patient-level factors and identify associations between daily outcomes and patient characteristics across days leading up to death. We used Fisher's exact test to compare pain/SBS on day of death between PICU LOS groups (< 7 days or > 7 days).

Parents retrospectively described EOL needs, for their child and themselves, during and following the withdrawal of LST.¹⁹ Parents of children who died following withdrawal of LST (n = 111) who consented for *RESTORE* follow-up were eligible to participate in a phone interview. Parents were not contacted if they did not speak English (n=13), the child was transferred from the PICU prior to death (n=2), they did not consent to follow-up (n=6), contact information was unavailable (n=21), or the *RESTORE* site was unable to help with recruitment (n=29). The local *RESTORE* site investigator sent a personalized invitation letter and an opt-out card to the remaining 40 eligible parents. Interview questions were derived from The Good Death in the PICU conceptual model¹⁷ and structured to correspond with quantitative variables (i.e. comfort scores, devices).

We used content analysis to develop descriptive categories of parents' perceptions of EOL nursing care needs.^{30,31} The first author conducted interviews and analysis iteratively until saturation, when patterns of codes demonstrated repetition between participants with varying characteristics (parent/child age, illness trajectory, LOS).^{32,33} The research team compiled a codebook to illustrate and define each code and category. Discrepancies were discussed with the research team until consensus, and a final codebook was generated and reviewed by all authors. Qualitative codes that directly corresponded with quantitative nursing assessments were included in this mixed methods analysis to facilitate data integration.

Data analysis

We compared demographic and clinical information between eligible parents by recruitment outcome for the qualitative interview using Fisher's exact test for categorical variables and Kruskal-Wallis test for continuous variables. We integrated data across cases to explain/contextualize quantitative associations using qualitative data, and directly compared parent perceptions with clinical documentation within each case. The dataset was managed in Microsoft Excel, Microsoft Word, and NVivo 12 (QSR International, Pty Ltd 2018).

In across-case analyses, we explored differences in qualitative data between quantitative grouping variables to explain/contextualize significant and non-significant associations between patient characteristics and daily outcomes. We examined qualitative code frequency and content between patient illness trajectory and LOS groups.

We used within-case analysis to directly compare each child's quantitative clinical data to their parent's interview data. We compiled means, medians, and ranges of quantitative outcomes, as well as qualitative codes and illustrative quotes for each child case to compare

(similarities and differences) between parents' qualitative descriptions of their child's comfort and nursing care requirements at EOL with quantitative nursing evaluations of pain, sedation, comfort medication doses, and critical care requirements (i.e., NEMS, devices).

Results

Eight parents of 8 children aged from 1 to 17 years old completed a qualitative interview. Parents who participated in the interview were more likely to have a child die after cancer (n=4, 36%) or a complex chronic condition (n=4, 36%) than an acute illness or injury. All of the parents were female, and 7 (88%) were white (Table 1).

Summary of Quantitative and Qualitative Results

In the quantitative sample (n=104) that the qualitative sample (n=8) recruited from, the majority of children died following withdrawal of LST (65%).¹⁸ There were no differences in outcomes based on end-of-life circumstances (withdrawal of LST, failed resuscitation, brain death). Over the days preceding death, patients were generally comfortable, with low modal pain (median: 0, interquartile range [IQR]: 0:0) and SBS scores (median: -2, IQR: -2: -1), and low peak pain (median: 0, IQR: 0:4) and SBS scores (median: -1.5, IQR: -2: 1). Across the 5 days prior to death, patients with cancer experienced higher peak pain scores ($P=0.01$). On day of death, more children with LOS > 7 days experienced pain (46%; $P=0.02$) or pain with agitation (28%, $P=0.04$) compared to children with LOS ≤ 7 days (23% pain, 12% pain with agitation). Children died with a median of 5 invasive devices (e.g., endotracheal airway, intravenous access, etc.).

Qualitatively, parents retrospectively defined categories of needs for their child and themselves as they navigated the EOL and grief experience. Parents' primary need was "*To Be Together*" with their dying child,¹⁹ which often intersected with other competing needs, including the child's clinical care. The category "*To make sense of evolving clinical care*" involved parents' need to understand their child's clinical signs and symptoms throughout the clinical course leading up to EOL. Table 2 aligns quantitative and qualitative data.

Across-Case Analysis

Children with cancer had higher pain scores in the days prior to death than children with complex chronic conditions or acute illness trajectories. Their parents discussed "bearing witness to suffering" more frequently than parents of children who died following complex chronic conditions (69% vs 31%). While parents of children in both illness trajectory groups vividly described pain, there were key differences in how they situated their child's suffering. Parents of children with cancer used highly emotional language to describe their child's illness experience (Figure 1).

"I don't think he was comfortable at all. I think he was inside screaming unless he was on so many meds. (Mother of a 4-year-old who died from cancer)

The language that parents of children with complex chronic illnesses used reflected their understanding of how suffering fit into their child's overarching illness experience, such

as remembering not wanting their child to “struggle” any longer and knowing they had “fought” as much as they could.

Children who died following longer LOS experienced pain and agitation on the day of death more frequently than children with shorter LOS. Over 80% of parents whose child had a longer LOS described suffering, compared to less than 20% of parents of children with shorter LOS. However, the language parents used to describe suffering did not meaningfully differ by LOS group.

Parents’ recollections of their child’s many invasive devices differed between illness trajectories. Parents of children with chronic conditions described witnessing complex, chaotic clinical treatments less often than parents of children who died from cancer (71% vs 29%). Parents of children who died following a complex chronic condition also used more biomedical language that was less emotionally intense, to describe their child’s clinical care (i.e. “filling” [complex chronic condition] vs “pumping” [cancer]; Figure 1).

“We had to go to the hospital cause ... he couldn’t breathe...I knew him inside and out and know I always knew when it was more than I could do at home.” (Mother of a 17-year-old with a chronic condition)

These parents had developed experiential knowledge from caring for their child with a chronic illness. Parents of children with cancer, however, used words that corresponded with a more emotionally overwhelmed experience of illness (Figure 1).

“When he was in the oncology floor, I kept it straight and I was educated, but when we got up to the intensive care, it was, it was beyond ... what I could keep up with.” (Mother of 4-year-old who died from cancer)

Parents’ descriptions of critical care requirements varied with LOS as well. Parents whose child died following a shorter LOS talked more frequently about medical devices (73%) than parents of children with longer LOS (27%). The content of parents’ descriptions of critical care requirements did not follow a discernible pattern based on LOS.

Within-Case Analysis

Pain scores, sedation scores, and comfort medication administrations suggested that pain was well-managed with infrequent episodic discomfort. Parents’ qualitative descriptions of their child’s discomfort included memories of the child’s profound suffering, corresponding more closely with peaks (outliers) than averages in quantitative trends (Figure 2).

One mother reflected, “I was almost relieved when he started to get cold because I knew he wasn’t suffering.” Parent’s recollections of physical pain suggest that this was a particularly poignant dimension of suffering. Other sources of suffering included technology-dependence (“the machine was breathing for him”), deep sedation (“waking on that paralytic”), or the child’s ability to interact (“she didn’t squeeze my finger anymore”; Figure 2). For some parents, attempting to balance the severity of suffering with ongoing medical treatments was how they recognized that the child was at EOL (i.e. “I didn’t want my baby to pass, but I didn’t want him suffering either”). Sometimes this recognition was difficult to cope with, knowing that their child was spending their last moments “in hell”.

The presence of multiple critical care requirements over the days prior to death impacted parents' longstanding memories of their child's EOL. Trends in NEMS scores indicated that children often required high levels of critical care therapies over the days preceding their death. Comparing the quantitative trends with the qualitative data (Figure 2) reveals that, at times, such devices constituted a barrier to parents' need to be physically close with their dying child.

“She was there for nine days and ... they kept adding ... the machines to put medicine in. Looked like totem poles on either side of her bed.” (Mother of a 13-year-old with a complex chronic condition)

This mother went on to recall closeness during the dying process, describing how her husband “sat in the rocking chair and the nurse put her in his arms and he held her and rocked her.” Sometimes, clinicians were able to arrange equipment to enable the parent to be physically close with their child with invasive devices in place. In some cases, the escalation of therapeutic devices and treatments assured parents that the clinical team did all they could to save the child. Parents' and clinicians' interpretation and ability to incorporate critical care requirements into relational and situational needs at EOL was more influential on parents' memories than the number of devices itself.

Discussion

Comparing quantitative and qualitative data about a cohort of children who died following withdrawal of LST revealed important insights about EOL experiences in the PICU. Parents identified and understood their child's needs differently based on the child's illness trajectory (complex chronic condition or cancer). Parent's memories demonstrated that their situated understanding of the extent that clinical interventions interfered with their needs (i.e., to be with the child) were more influential on their memories than the actual quantity of devices. Trends of clinician-measured comfort scores indicated that children were relatively pain-free, but parents readily recounted their child's suffering years later. This suggests that clinician evaluations alone may generate a limited view of EOL suffering. Incorporating parents' perspectives into caring processes, including symptom assessment and device management, may aid in easing parents' transition to their lifelong grief process.

Parents and children who are approaching EOL with characteristically distinct illness and PICU experiences likely have different priorities for EOL care. Consistent with the nursing pain scores and existing literature,^{34–36} suffering was especially memorable to parents of children with cancer. Parents of children with complex chronic conditions focused more closely on monitoring their child's symptoms.^{37,38} This finding is consistent with families lived experience: parents of children living with complex chronic conditions develop a constant vigilance, including assessing and monitoring their child's physiologic signs and symptoms, to maintain the tenuous balance between their child's unique health needs in tandem with family life.³⁹

Longer LOS also corresponded with an increased parental focus on pain and suffering. While all critically ill children can benefit from a primary/integrated palliative care approach,^{40–42} children with cancer and/or longer lengths of stay may especially benefit

from specialty pediatric palliative care for comprehensive pain management.^{43–45} Parents of children with complex chronic conditions may benefit from stronger involvement in caring activities during the EOL period, including tending to their child's needs in close partnership with the bedside nursing team.^{37–39} Stronger nurse-parent partnership may also present opportunities for improved communication, shared decision-making and psychosocial care.⁴⁶ Improved understanding of the underlying relationships between illness trajectory, LOS, and family/clinician perceptions of EOL care should inform development of interventions.

Persistent memories of suffering were a major component of parents' stories of their child's death in the PICU. Despite clinical documentation and medication doses that indicated well-controlled pain and agitation, parents recounted episodes of suffering with fine detail, including specific manifestations. This divergence between clinical documentation and parental evaluations may be attributed to cognitive processes of emotional memory-making, or differences in how parents and nurses identified pain.^{3,47,48} Parents' understanding of their dying child's suffering derives from an emotional and existential understanding.^{49,50} Nurses' documented assessments, which guide PICU workflows, are driven by physiologic parameters. The relationship between children's end-of-life suffering and contributing factors, including communication, remains underexplored in pediatric critical care. Research examining how nurses and parents identify and make meaning of suffering is necessary to better attend to the multidimensional nature of children's EOL suffering.

Parents' broad characterizations of their child's EOL suffering may require more expansive strategies than purely biomedical management of high pain/agitation scores.⁵⁰ Clinicians can attend to parental distress by providing time and space to validate emotional responses to suffering, possibly during routine comfort assessment.⁵¹ The fast-paced critical care environment has minimal infrastructure for PICU clinicians to help dying children and their parents navigate these stressors while balancing their moment-to-moment care at the bedside, suggesting a need to use interprofessional models, including primary palliative care.⁴¹ Incorporating innovative technology, such as staffing optimization software⁵² and documentation automation⁵³ could be a useful way to prioritize relational and emotional needs more effectively while balancing clinical tasks and documentation requirements.^{54,55} A firmer empirical and ethical understanding of how health technology and documentation help or hinder quality EOL care can help guide implementation of such innovations.

Children in this study died with multiple invasive devices in place. The degree to which critical care instrumentation intruded on parent-child togetherness influenced parents' long-term grief, consistent with previous research.^{11–13} Parents of children with complex chronic conditions described their child's critical care requirements using their experiential clinical knowledge while parents of children with cancer used more emotional language. These parents' recollections of EOL care illustrate the long-term deleterious impact of language, such as battle narratives commonly used in oncological care, as well as a need for supportive care strategies tailored to individual families' experiences. Straightforward communication, shared decision-making, and interdisciplinary supportive care while critical care requirements increase leading up to the EOL period could mitigate future distress while promoting an adaptive grief response.^{46,56–58} Communication strategies that incorporate

parents' experiential knowledge from their child's illness experience may help meet family's individualized needs. Development of best practices for in-the-moment EOL communication to help foster shared decision-making with parents is warranted.⁵⁹

The quantitative component of this study used a secondary analysis of existing data, which presents limitations. The parent study did not aim to study EOL care, thus contextual variables, such as palliative care consultation and family conferences, were not available. The design limited the scope of the data integration to clinical domains, which led to specific implications for PICU practice. The qualitative sample in this study was small and lacked gender and racial diversity, and the perspectives of parents of children who died acutely were notably missing. These voices are commonly missing from the extant pediatric palliative and EOL literature. Future research should aim to rectify this gap by centering the perspectives of males, socioeconomically diverse, and minoritized parents,¹⁵ as well as parents whose child died acutely in larger samples. Though recall bias within our sample is possible; in this study, retrospection provided important insight into which memories of PICU EOL care influenced parents' long-term grief. Though bereaved parents' long-term perspective is important to understand, it is likely that EOL practices in the PICU have evolved in the time since the children in this study died. However, our findings echo those from more recent studies,^{12,13} suggesting that similar strengths, weaknesses, and barriers exist that influence children and families' EOL experiences in the PICU.

Using clinical documentation to examine EOL care was feasible, but presents only a sliver of the therapeutic caring that clinicians engage in. Additional studies including interdisciplinary perspectives are necessary to improving EOL care. Future research of pediatric EOL care could utilize innovative, participatory strategies, incorporating frontline clinicians, parents, and terminally ill children when possible, to advance the science of caring for children who are dying.

Conclusion

This comprehensive exploration integrated quantitative data and retrospective qualitative data, generating novel insights about how to best care for children and their families during EOL in the PICU and illuminating future paths for inquiry. Considering broader metrics of pain and suffering to match parents' priorities for their child's dying process more closely may be an especially important way to alleviate adverse parental grief outcomes. Helping parents to navigate escalations in critical care requirements in a way that assures them their dying child is thoroughly and thoughtfully cared for while facilitating opportunities for physical closeness and humanity is among the most meaningful of PICU clinicians' tasks. These findings present opportunities to strengthen clinical practice, direct future research, and improve family outcomes when a child dies in the PICU.

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References

1. Trowbridge A, Walter JK, McConathey E, Morrison W, Feudtner C. Modes of Death Within a Children's Hospital. *Pediatrics*. 2018;142(4):e20174182. doi:10.1542/peds.2017-4182 [PubMed: 30232217]
2. Moynihan KM, Lelkes E, Kumar RK, DeCoursey DD. Is this as good as it gets? Implications of an asymptotic mortality decline and approaching the nadir in pediatric intensive care. *Eur J Pediatr*. 2022;181(2):479–487. doi:10.1007/s00431-021-04277-8 [PubMed: 34599379]
3. Clark OE, Fortney CA, Dunnells ZDO, Gerhardt CA, Baughcum AE. Parent Perceptions of Infant Symptoms and Suffering and Associations With Distress Among Bereaved Parents in the NICU. *Journal of Pain and Symptom Management*. 2021;62(3):e20–e27. doi:10.1016/j.jpainsymman.2021.02.015 [PubMed: 33631329]
4. Snaman JM, Kaye E, Cunningham MJ, et al. Going straight to the source: A pilot study of bereaved parent facilitated communication training for pediatric subspecialty fellows. *Pediatrics*. 2018;141(1). doi:10.1542/peds.141.1-MeetingAbstract.381
5. Snaman J, Morris SE, Rosenberg AR, Holder R, Baker J, Wolfe J. Reconsidering early parental grief following the death of a child from cancer: a new framework for future research and bereavement support. *Support Care Cancer*. 2020;28(9):4131–4139. doi:10.1007/s00520-019-05249-3 [PubMed: 31872296]
6. Butler AE, Hall H, Copnell B. The changing nature of relationships between parents and healthcare providers when a child dies in the paediatric intensive care unit. *J Adv Nurs*. 2018;74(1):89–99. doi:10.1111/jan.13401 [PubMed: 28746800]
7. Suttle M, Hall MW, Pollack MM, et al. Post-Traumatic Growth in Parents following Their Child's Death in a Pediatric Intensive Care Unit. *Journal of Palliative Medicine*. Published online February 3, 2022. doi:10.1089/jpm.2021.0290
8. O'Meara A, Akande M, Yagiela L, et al. Family Outcomes After the Pediatric Intensive Care Unit: A Scoping Review. *J Intensive Care Med*. Published online December 17, 2021:08850666211056603. doi:10.1177/08850666211056603
9. Alzawad Z, Lewis FM, Kantrowitz-Gordon I, Howells AJ. A Qualitative Study of Parents' Experiences in the Pediatric Intensive Care Unit: Riding a Roller Coaster. *Journal of pediatric nursing*. 2020;51:8–14. doi:10.1016/j.pedn.2019.11.015 [PubMed: 31835065]
10. Alzawad Z, Marcus Lewis F, Ngo L, Thomas K. Exploratory model of parental stress during children's hospitalisation in a paediatric intensive care unit. *Intensive & critical care nursing*. 2021;67:103109–103109. doi:10.1016/j.iccn.2021.103109 [PubMed: 34247940]
11. Falkenburg JL, Tibboel D, Ganzevoort RR, Gischler S, Hagoort J, van Dijk M. Parental Physical Proximity in End-of-Life Care in the PICU. *Pediatric Critical Care Medicine*. 2016;17(5):e212–e217. doi:10.1097/PCC.0000000000000682 [PubMed: 26890197]
12. Falkenburg JL, Tibboel D, Ganzevoort RR, Gischler SJ, van Dijk M. The Importance of Parental Connectedness and Relationships With Healthcare Professionals in End-of-Life Care in the PICU*. *Pediatric Critical Care Medicine*. 2018;19(3):e157–e163. doi:10.1097/PCC.0000000000001440 [PubMed: 29329163]
13. Butler AE, Copnell B, Hall H. The impact of the social and physical environments on parent-healthcare provider relationships when a child dies in PICU: Findings from a grounded theory study. *Intensive Crit Care Nurs*. 2019;50:28–35. doi:10.1016/j.iccn.2017.12.008 [PubMed: 29295759]
14. Suttle M, Hall MW, Pollack MM, et al. Post-Traumatic Growth in Parents following Their Child's Death in a Pediatric Intensive Care Unit. *J Palliat Med*. 2022;25(2):265–273. doi:10.1089/jpm.2021.0290 [PubMed: 34612728]

15. Cleveland RW, Snaman JM, DeCoursey DD. Factors Affecting Recruitment and Participation of Bereaved Parents in Research: A Brief Report. *Journal of pain and symptom management*. 2021;62(3):E213–E217. doi:10.1016/j.painsymman.2021.03.026 [PubMed: 33845118]
16. Creswell JW. *Designing and Conducting Mixed Methods Research*. Third edition. SAGE; 2018.
17. Broden EG, Deatrick J, Ulrich C, Curley MAQ. Defining a “Good Death” in the Pediatric Intensive Care Unit. *Am J Crit Care*. 2020;29(2):111–121. doi:10.4037/ajcc2020466 [PubMed: 32114610]
18. Broden EG, Hinds PS, Werner-Lin A, Quinn R, Asaro LA, Curley MAQ. Nursing Care at End of Life in Pediatric Intensive Care Unit Patients Requiring Mechanical Ventilation. *Am J Crit Care*. 2022;31(3).
19. Broden EG, Werner-Lin A, Curley MAQ, Hinds PS. Shifting and intersecting needs: Parents’ experiences during and following the withdrawal of life sustaining treatments in the paediatric intensive care unit. *Intensive and Critical Care Nursing*. Published online February 24, 2022:103216. doi:10.1016/j.iccn.2022.103216 [PubMed: 35219558]
20. Watson RS, Asaro LA, Hertzog JH, et al. Long-Term Outcomes after Protocolized Sedation versus Usual Care in Ventilated Pediatric Patients. *American journal of respiratory and critical care medicine*. 2018;197(11):1457–1467. doi:10.1164/rccm.201708-1768OC [PubMed: 29313710]
21. Curley MAQ, Wypij D, Watson RS, et al. Protocolized Sedation vs Usual Care in Pediatric Patients Mechanically Ventilated for Acute Respiratory Failure: A Randomized Clinical Trial. *JAMA : the journal of the American Medical Association*. 2015;313(4):379–389. doi:10.1001/jama.2014.18399 [PubMed: 25602358]
22. Malviya S, Voepel-Lewis T, Burke C, Merkel S, Tait AR. The revised FLACC observational pain tool: improved reliability and validity for pain assessment in children with cognitive impairment. *Pediatric Anesthesia*. 2006;16(3):258–265. doi:10.1111/j.1460-9592.2005.01773.x [PubMed: 16490089]
23. Merkel SI, Voepel-Lewis T, Shayevitz JR, Malviya S. The FLACC: a behavioral scale for scoring postoperative pain in young children. *Pediatric nursing*. 1997;23(3):293–297. [PubMed: 9220806]
24. Home. Wong-Baker FACES Foundation. Accessed April 8, 2022. <https://wongbakerfaces.org/>
25. Solodiuk J, Curley MAQ. Pain assessment in nonverbal children with severe cognitive impairments: the individualized numeric rating scale (INRS). *Journal of Pediatric Nursing*. 2003;18(4):295–299. doi:10.1016/S0882-5963(03)00090-3 [PubMed: 12923744]
26. Lares E, LaFond C, Hanrahan K, Pierce N, Min H, McCarthy AM. Pain Assessment Practices in the Pediatric Intensive Care Unit. *Journal of Pediatric Nursing*. 2019;48:55–62. doi:10.1016/j.pedn.2019.07.005 [PubMed: 31325800]
27. Curley MAQ, Harris SK, Fraser KA, Johnson RA, Arnold JH. State Behavioral Scale: A sedation assessment instrument for infants and young children supported on mechanical ventilation. *Pediatric critical care medicine*. 2006;7(2):107–114. doi:10.1097/01.PCC.0000200955.40962.38 [PubMed: 16446601]
28. Giuliani E, Lionte G, Ferri P, Barbieri A. The burden of not-weighted factors – Nursing workload in a medical Intensive Care Unit. *Intensive & critical care nursing*. 2018;47:98–101. doi:10.1016/j.iccn.2018.02.009 [PubMed: 29622474]
29. Miranda DR, Moreno R, Iapichino G. Nine equivalents of nursing manpower use score (NEMS). *Intensive Care Medicine*. 1997;23(7):760–765. doi:10.1007/s001340050406 [PubMed: 9290990]
30. Hsieh HF, Shannon SE. Three Approaches to Qualitative Content Analysis. *Qualitative health research*. 2005;15(9):1277–1288. doi:10.1177/1049732305276687 [PubMed: 16204405]
31. Selvi AF. Qualitative content analysis. In: *The Routledge Handbook of Research Methods in Applied Linguistics*. Routledge; 2019.
32. Morse JM. “Data Were Saturated . . .” *Qual Health Res*. 2015;25(5):587–588. doi:10.1177/1049732315576699 [PubMed: 25829508]
33. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine*. 2022;292:114523. doi:10.1016/j.socscimed.2021.114523 [PubMed: 34785096]
34. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med*. 2000;342(5):326–333. doi:10.1056/NEJM200002033420506 [PubMed: 10655532]

35. Feudtner C, Nye R, Hill DL, et al. Polysymptomatology in Pediatric Patients Receiving Palliative Care Based on Parent-Reported Data. *JAMA Netw Open*. 2021;4(8):e2119730. doi:10.1001/jamanetworkopen.2021.19730 [PubMed: 34351400]
36. Kaye EC, Weaver MS, DeWitt LH, et al. The Impact of Specialty Palliative Care in Pediatric Oncology: A Systematic Review. *J Pain Symptom Manage*. 2021;61(5):1060–1079.e2. doi:10.1016/j.jpainsymman.2020.12.003 [PubMed: 33348034]
37. Marcus KL, Kao PC, Ma C, Wolfe J, DeCoursey DD. Symptoms and Suffering at End of Life for Children With Complex Chronic Conditions. *Journal of Pain and Symptom Management*. 2021;63(1). doi:10.1016/j.jpainsymman.2021.07.010
38. Feinstein JA, Feudtner C, Valuck RJ, et al. Identifying Important Clinical Symptoms in Children With Severe Neurological Impairment Using Parent-Reported Outcomes of Symptoms. *JAMA Pediatrics*. 2020;174(11):1114–1117. doi:10.1001/jamapediatrics.2020.2987 [PubMed: 33044500]
39. Mooney-Doyle K, Deatrick JA, Ulrich CM, Meghani SH, Feudtner C. Parenting in Childhood Life-Threatening Illness: A Mixed-Methods Study. *Journal of palliative medicine*. 2018;21(2):28–215. doi:10.1089/jpm.2017.0054 [PubMed: 28772092]
40. Levine DR, Baker JN, Wolfe J, Lehmann LE, Ullrich C. Strange Bedfellows No More: How Integrated Stem-Cell Transplantation and Palliative Care Programs Can Together Improve End-of-Life Care. *JOP*. 2017;13(9):569–577. doi:10.1200/JOP.2017.021451 [PubMed: 28898603]
41. Moynihan KM, Snaman JM, Kaye EC, et al. Integration of Pediatric Palliative Care Into Cardiac Intensive Care: A Champion-Based Model. *Pediatrics*. 2019;144(2). doi:10.1542/peds.2019-0160
42. Grunauer M, Mikesell C, Callejas GB. Primary palliative care integrated model in paediatric ICU: an international cross-sectional study. *BMJ Supportive & Palliative Care*. Published online October 5, 2021. doi:10.1136/bmjspcare-2020-002627
43. Kaye EC, Weaver MS, DeWitt LH, et al. The Impact of Specialty Palliative Care in Pediatric Oncology: A Systematic Review. *Journal of pain and symptom management*. 2021;61(5):1060–1079.e2. doi:10.1016/j.jpainsymman.2020.12.003 [PubMed: 33348034]
44. Snaman J, McCarthy S, Wiener L, Wolfe J. Pediatric Palliative Care in Oncology. *J Clin Oncol*. 2020;38(9):954–962. doi:10.1200/JCO.18.02331 [PubMed: 32023163]
45. Ebelhar J, Allen K, DeGroot N, Wasilewski-Masker K, Brock KE. Defining palliative opportunities in pediatric patients with bone and soft tissue sarcomas. *Pediatric Blood and Cancer*. 2020;67(10). doi:10.1002/pbc.28363
46. Hendricks-Ferguson V, Newman AR, Brock KE, et al. COMPLETE (Communication Plan Early Through End of Life): Development of a research program to diminish suffering for children at end of life. *Journal of pediatric nursing*. 2021;61. doi:10.1016/j.pedn.2021.08.010
47. Cheng L, Wang L, He M, Feng S, Zhu Y, Rodgers C. Perspectives of children, family caregivers, and health professionals about pediatric oncology symptoms: a systematic review. *Supportive care in cancer*. 2018;26(9):2957–2971. doi:10.1007/s00520-018-4257-3 [PubMed: 29774474]
48. Pohlkamp L, Kreicbergs U, Sveen J. Factors During a Child's Illness Are Associated With Levels of Prolonged Grief Symptoms in Bereaved Mothers and Fathers. *J Clin Oncol*. 2020;38(2):137–144. doi:10.1200/JCO.19.01493 [PubMed: 31725342]
49. Davidoff K, Ullrich C. Eternal suffering: Addressing parental distress in children with advanced illness. *Pediatrics*. 2021;147(3):530. doi:10.1542/peds.147.3-MeetingAbstract.530
50. October TW. Is All Suffering Equal or Is It Time to Address Existential Suffering? *Pediatr Crit Care Med*. 2018;19(3):275–276. doi:10.1097/PCC.0000000000001447 [PubMed: 29499028]
51. October TW, Dizon ZB, Arnold RM, Rosenberg AR. Characteristics of Physician Empathetic Statements During Pediatric Intensive Care Conferences With Family Members: A Qualitative Study. *JAMA Network Open*. 2018;1(3):e180351. doi:10.1001/jamanetworkopen.2018.0351 [PubMed: 30646015]
52. Technology | Nightingale. Accessed March 28, 2022. <https://nightingalecaringsolutions.com/technology/>
53. Lin SY, Shanafelt TD, Asch SM. Reimagining Clinical Documentation With Artificial Intelligence. *Mayo Clinic Proceedings*. 2018;93(5):563–565. doi:10.1016/j.mayocp.2018.02.016 [PubMed: 29631808]

54. Bergey MR, Goldsack JC, Robinson EJ. Invisible work and changing roles: Health information technology implementation and reorganization of work practices for the inpatient nursing team. *Social science & medicine* (1982). 2019;235:112387–112387. doi:10.1016/j.socscimed.2019.112387 [PubMed: 31272078]

55. Dillard-Wright J Electronic health record as a panopticon: A disciplinary apparatus in nursing practice. *Nursing philosophy*. 2019;20(2):e12239-n/a. doi:10.1111/nup.12239 [PubMed: 30821896]

56. Butler AE, Copnell B, Hall H. When a Child Dies in the PICU: Practice Recommendations From a Qualitative Study of Bereaved Parents. *Pediatr Crit Care Med*. 2019;20(9):e447–e451. doi:10.1097/PCC.0000000000002040 [PubMed: 31206499]

57. Walter JK, Arnold RM, Curley MA, Feudtner C. Teamwork When Conducting Family Meetings: Concepts, Terminology, and the Importance of Team-Team Practices. *Journal of pain and symptom management*. 2019;58(2):336–343. doi:10.1016/j.jpainsymman.2019.04.030 [PubMed: 31051202]

58. Bogetz JF, Revette A, Rosenberg AR, DeCoursey D. “I Could Never Prepare for Something Like the Death of My Own Child”: Parental Perspectives on Preparedness at End of Life for Children With Complex Chronic Conditions. *J Pain Symptom Manage*. 2020;60(6):1154–1162.e1. doi:10.1016/j.jpainsymman.2020.06.035 [PubMed: 32629083]

59. Tarbi EC, Blanch-Hartigan D, van Vliet LM, Gramling R, Tulsy JA, Sanders JJ. Toward a basic science of communication in serious illness. *Patient Education and Counseling*. Published online April 8, 2022. doi:10.1016/j.pec.2022.03.019

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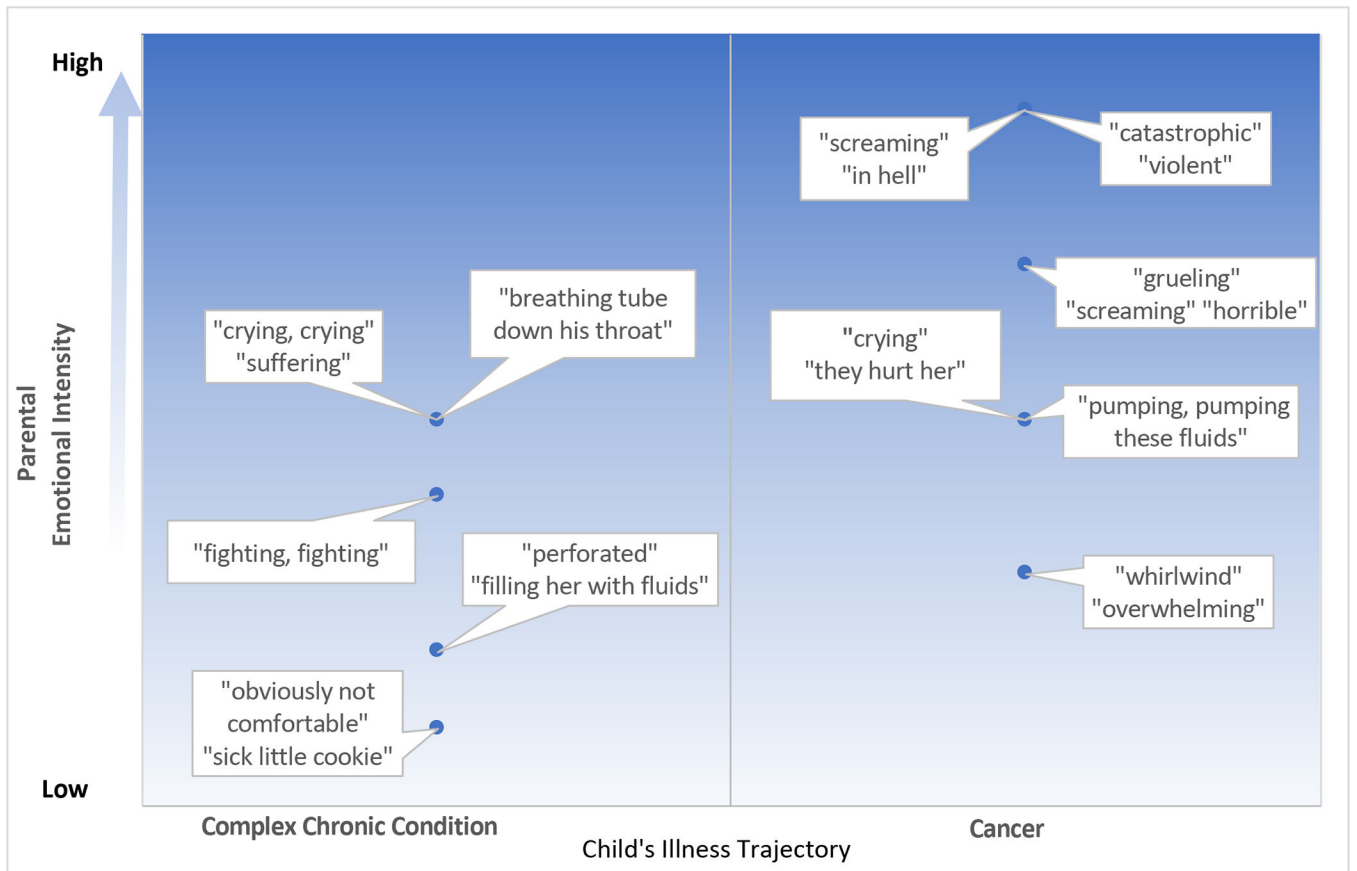


Figure 1: Parents descriptions of their child’s EOL experience compared by disease type

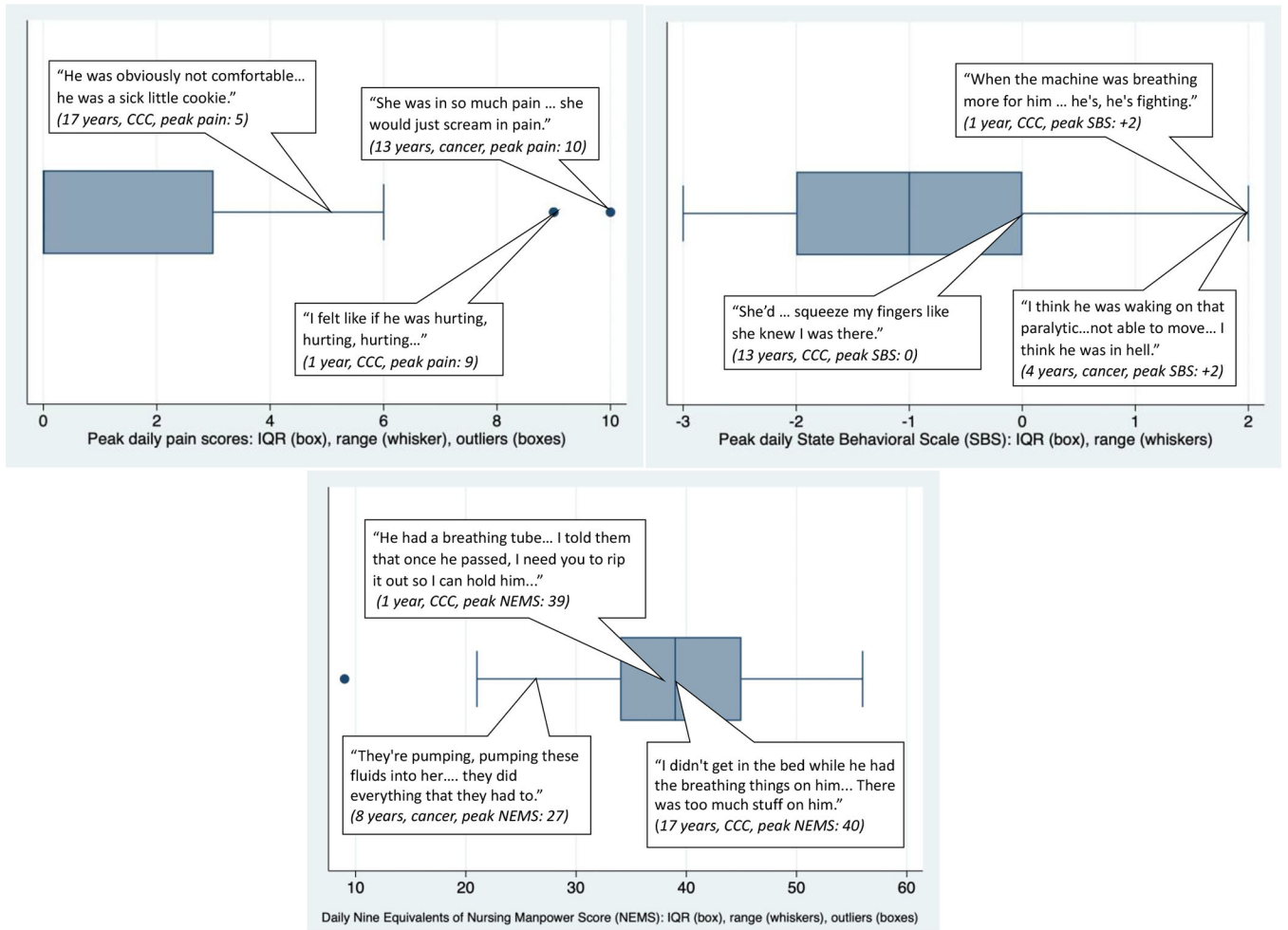


Figure 2: Ranges of pain, sedation, and critical care requirements over 5 days preceding death compared with parental quotes

Table 1.

Patient Demographic and Clinical Characteristics by Parent Recruitment Status

Patient Characteristics	Completed Interview (n = 8)	Declined/Opted-Out (n = 11)	Lost to Follow-Up (n=21)	P-value
<i>Demographic and Baseline Variables; n (%)</i>				
<i>Race</i>				
White	7 (88)	9 (82)	13 (62)	.71
Black	1 (12)	2 (18)	6 (29)	
Other	0	0	2 (9)	
<i>Ethnicity</i>				
Hispanic	0	1 (9)	3 (14)	.89
Non-Hispanic	8 (100)	10 (91)	17 (81)	
Female	3 (38)	7 (64)	12 (57)	.58
Age in years; median (IQR)	11 (2.6–14)	11.9 (4.4–14.3)	7.4 (3 –14.3)	.75
<i>Illness Trajectory</i>				
Acute	0	4 (36)	11 (52)	.06
Complex Chronic Illness	4 (50)	4 (36)	3 (14)	
Malignancy	4 (50)	3 (27)	7 (33)	
<i>Clinical Course Variables; median (IQR)</i>				
PICU LOS; days	18.5 (15.5–24.5)	16 (3–32)	22 (10–35)	.75
Pain score (peak)	6 (4.5–9)	4 (0–6)	5 (4–7)	.31
SBS score (peak)	1 (0–1.5)	1 (–1–2)	1 (0–2)	.22
NEMS score (peak)	47.5 (39.5–51)	45 (34–50)	44 (39–45)	.47
Number of devices	5 (4.5–6)	5 (5–5)	6 (5–6)	.06
Cumulative opioid dose	2.3 (1.7–9.1)	5.1 (3.1–7)	4.8 (3.1–13.3)	.35
Cumulative benzo. dose	2.8 (1–13.8)	3.2 (2–6)	5.1 (1.9–19.2)	.66

Note: Clinical course variables, except length of stay, are maximums across all days. Fisher’s exact was used for categorical variables, Kruskal-Wallis test was used for continuous variables. Medication doses are mg/kg/24 hrs.

Abbreviations: IQR (interquartile range), PICU (pediatric intensive care unit), LOS (length of stay), SBS (State Behavioral Scale), NEMS (Nine Equivalents of Nursing Manpower Score), benzo. (benzodiazepine)

Table 2.

Quantitative and Qualitative Variable Matching

Construct	Quantitative Variable(s)	Qualitative Code: definition ^a
Comfort	Daily Modal Pain score	Monitoring symptoms: Descriptions of the impact of illness on the child's body and mind
	Daily Peak Pain score	
	Daily Modal SBS ^b Score	Comfort and suffering: Specific descriptions of how much or little discomfort the child experienced, or what interventions were being implemented and how effective they were
	Daily Peak SBS Score	
	Daily Cumulative Opioid Dose ^c	Bearing witness to suffering: Parents' implicit or explicit descriptions of how challenging it was watching their child experience pain, distressing symptoms, and/or getting sicker without chance of recovery.
	Daily Cumulative Benzodiazepine Dose ^d	
Critical Care Requirements	Daily NEMS Score ^e	Witnessing complex and chaotic clinical treatments: Descriptions of the act of watching frequent, often escalating, biomedical interventions that provoked stress for parents
		Knowing they tried everything: Notions that parents trusted that every possible treatment option was exhausted
	Daily number of devices	Medical devices: References to specific clinical equipment on/in the child's body
		Medical procedures: Descriptions of specific clinical treatments (intubation, dialysis, dressing changes) that the child endured

Abbreviations: SBS (State Behavioral Scale), NEMS (Nine Equivalents of Nursing Manpower Use Score)

^a: Qualitative first-level codes defined during the qualitative analysis are presented. These are sub-codes that were grouped into the overarching category *To make sense of evolving clinical care*

^b: The SBS (State Behavioral Scale) ranges from -3 (unresponsive) to +2 (agitated)

^c: Daily cumulative opioid doses are morphine equivalents in mg/kg/24 hrs.

^d: Daily cumulative benzodiazepine doses are midazolam equivalents in mg/kg/24 hrs.

^e: Nursing care requirements were measured using the Nine Equivalents of Nursing Manpower Score (NEMS); which ranges from 0 to 63, with higher scores indicating greater critical care requirements.