


Pediatric Chronic Critical Illness, Prolonged ICU Admissions, and Clinician Distress

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Abstract

To gain an in-depth understanding of the experience of pediatric intensive care unit (PICU) clinicians caring for children with chronic critical illness (CCI), we conducted, audiotaped, and transcribed in-person interviews with PICU clinicians. We used purposive sampling to identify five PICU patients who died following long admissions, whose care generated substantial staff distress. We recruited four to six interdisciplinary clinicians per patient who had frequent clinical interactions with the patient/family for interviews. Conventional content analysis was applied to the transcripts resulting in the emergence of five themes: nonbeneficial treatment; who is driving care? Elusive goals of care, compromised personhood, and suffering. Interventions directed at increasing consensus, clarifying goals of care, developing systems allowing children with CCI to be cared for outside of the ICU, and improving communication may help to ameliorate this distress.

Keywords

- ▶ pediatric intensive care units
- ▶ chronic critical illness
- ▶ heath teams
- ▶ interdisciplinary
- ▶ palliative care
- ▶ communication

Introduction

“It’s hard to say exactly at what point that keeping her alive was unethical. But it certainly was.” (RT)

“It becomes part of your genes... You remember these cases for the rest of your life.” (MD)

A growing population of children have prolonged stays in pediatric intensive care units (PICUs) related to complex chronic conditions and dependence on medical technology. These children with “chronic critical illness” (CCI) tend to be concentrated in the PICUs of academic medical centers.^{1,2}

Designed for acute care, the PICU is not well equipped for patient stays of months or years. PICU clinicians struggle to balance the needs of patients with CCI with the more urgent needs of typical patients, noting that the time required to address chronic needs is often unsupported by ICU staff scheduling and unfunded by ICU reimbursement structures.³

PICU clinicians report ethical challenges during the care of children with CCI, for example, when considering decisions about long-term medical technology.^{1,3} It has been shown, however, that palliative care and ethics consultations are underutilized supports.⁴ These challenges can lead to staff stress and moral distress (distress specific to situations in which one recognizes a moral problem, feels responsible to

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Table 1 Interview participants

Discipline	Number of participants	Average number of years of PICU Experience
Nurses	10	9.2 y (range: 2.5–32 y)
Respiratory therapists	4	10 y (range: 5–20 y)
Nurse practitioners	3	19.6 y (range: 2–33 y)
Physicians	7	12 y (range: 2–30 y)
Total	24	

Abbreviation: PICU, pediatric intensive care unit.

address it, yet participates in perceived moral wrongdoing.⁵ This in turn contributes to decreased morale, burnout, and staff turnover.^{3,6–8}

A deeper understanding of the unique experience of caring for children with CCI in the PICU can help us anticipate the needs of CCI patients and families and provide targeted staff training and supports. Drawing from interviews with interdisciplinary PICU clinicians, we explore distinctive elements of CCI patient management which are distressing for PICU staff.

Methods

This study occurred in an academic pediatric medical center in the northeastern United States with 36 beds, a full range of medical and surgical consultants, extracorporeal membrane oxygenation, and dialysis. Interdisciplinary PICU clinicians (► **Table 1**) with 2 or more years of experience were eligible. The study was approved by the institutional review board; written consent was obtained.

We used purposive sampling to identify a cohort of PICU patients who died following long admissions, whose care had generated substantial staff distress as evidenced by repeated discussions in weekly clinical care meetings (► **Table 2**). We recruited (by unit-wide email) four to six clinicians per patient who had frequent clinical interactions with the patient/family. No compensation was provided. We excluded clinicians with less than 2-years' experience, presuming that differentiating distress related to working in the PICU from

distress specific to caring for CCI patients might require some ICU experience.

Interview questions were developed based on literature regarding ICU staff stress and moral distress. Semistructured, in-depth, in-person interviews were conducted in 2014, audiotaped, and transcribed. Conventional content analysis, a method which allows for themes to emerge from the data itself rather than from preconceived theories or categories, was applied to the transcripts. Two authors (AM, RB) independently assigned initial codes to participants' responses. These authors met with a third author (BW) to review individual codes and resolve any discrepancies through repeated discussion. Codes were grouped by topic into code families that summarized participant responses. Finally, code families were combined into themes that representing the overarching ideas that emerged from the interviews. Representative quotations illustrate key themes.

Results

Twenty-four participants were interviewed. Five themes characterized respondents' experiences caring for patients with prolonged PICU hospitalizations: (1) nonbeneficial treatment; (2) who is driving care?; (3) elusive goals of care; (4) compromised personhood; and (5) suffering.

Nonbeneficial Treatment

The most common theme was the belief that patients had received nonbeneficial treatment. Treatment intensity seemed to escalate indefinitely despite little or no chance for meaningful improvement. Participants felt that nonbeneficial treatment sometimes occurred because clinicians lacked communication skills to recommend treatment limitations. A "do something" mentality of PICU clinicians and the different perspectives of rotating physicians were also perceived to fuel escalation. Most children received innovative therapies, leaving staff unsure how to gauge success especially when minor improvement could make clinicians and families reluctant to terminate therapy. Some participants were distressed by the costs of nonbeneficial treatment. A few were proud that "everything" was tried, believing that these children would have died much earlier without these interventions.

Table 2 Patient cohort

	Age (at death)	Approximate PICU LOS	Diagnoses	Major interventions
Patient 1	Teen	3 mo	Terminal cancer	Chemotherapy
Patient 2	Infant	2 mo	Complex CHD	Cardiac surgery, ECMO, dialysis
Patient 3	Toddler	2 y	Genetic syndrome, Hypoxic ischemic encephalopathy	Tracheostomy
Patient 4	Infant	1 y	Complex CHD	Cardiac surgeries, ECMO
Patient 5	Toddler	>1 y	Complex CHD	Cardiac surgeries, heart transplantation, dialysis

Abbreviations: CHD, congenital heart disease; ECMO, extracorporeal membrane oxygenation; LOS, length-of-stay; PICU, pediatric intensive care unit.

"We went through a lot of drugs that you would not normally either give a child on a regular basis or that you would [not] give long-term. We were doing things that we knew would sustain her in the short term but not in the long term." (NP)

"The whole last couple of months just seemed very unethical and very unfair to put somebody through treatment that was clearly not treating." (RN)

"This is not going to result in [the parents] ever being able to take her home, and I don't think that those things are said a lot of times. I think that causes us to continue to create these patients and these situations that make it difficult for all of us to take care of the patient." (NP)

Who Is Driving Care?

Participants felt that nonbeneficial treatment was often driven by families' desire to do anything possible to prolong their child's life. Most understood this motivation but believed they would not do the same for their own child. Participants commonly saw parent requests as unrealistic, in part because few parents were present 24/7 to witness their child's care; some rarely visited. They wondered why parent requests were allowed to drive care despite minimal benefit to the child, noting imbalances in power, (e.g., staff accommodating family behaviors because the child was seriously ill) that often began early in the hospitalization. Limitations were difficult to instate later, giving parents more control than participants thought appropriate.

"You'd have this mother that's pushing, pushing, pushing, and you're trying to get her to see that her daughter cries every time I touch her. That's not fair." (RN)

"At this point we've allowed that culture with that family to be adopted....and it started from day one, two years ago, that they never had to follow the rules. ... I feel like we did a poor job of being a team and taking a stance on what we were going to say is acceptable and not ..." (RT)

Participants noted that care for these children was often driven by one to two physicians whose belief in potential improvement was not shared by the rest of the team. This was most often heard from nonphysician participants. Subspecialty consultants, perceived as "organ-centric," could also drive care. The rotating schedules of individual physicians also contributed to inconsistencies.

"I think it's unethical to say one day that we are going to escalate care, and then we're not..., and then we are." (RT)

"One week you'd get an attending who was like, 'This is hopeless. What are we doing? This is cruel.' And the next week you'd get somebody who was like, 'We're going to press on. We're going to try this one other thing. I really do think this is somehow salvageable.' And so you'd get very mixed messages over time." (MD)

Finally, participants worried that "nobody" was driving care for these patients. Lack of a cohesive management plan was common when multiple subspecialists were involved.

"I think it played out the way it always plays out, a lot of confusion and mixed messages and the plan changing from week to week. And that's confusing to the nursing staff; it's confusing to the families; it's confusing to the residents and fellows taking care of her." (MD)

Elusive Goals of Care

Overarching care goals were believed to be essential, yet challenging to define for these children. Participants believed that parents lacked understanding of their child's prognosis due to inadequate provider communication skills and lack of personal investment in the patient's care. Difficulty helping parents separate their personal goals (e.g., to avoid their child's death) from child-centered goals (e.g., to avoid suffering) distressed many; participants wondered whether it was possible or ethical to discuss this with families. Participants were also uncomfortable when parents' goals required indefinite hospitalization, questioning whether this was a life worth living. Lack of early palliative care consultation was consistently noted as a barrier to establishing meaningful care goals.

"I don't believe that what we're doing is the best thing for her. I don't believe it's the best thing for the unit. I don't believe it's the best thing just for society, in general, when you think about the healthcare dollars. I think it probably is the best thing for her parents" (NP)

"Honestly I don't know what [X specialty] was thinking. I really cannot fathom what they were thinking." (MD)

Participants were distressed when the goal of care was to maintain the status quo, that is, not alter therapy despite no improvement. This was perceived to occur when clinicians spent less time managing chronic versus acutely ill patients. Subspecialists contributed to this status quo by not joining family or team meetings, or by focusing on organ-specific goals.

Compromised Personhood and Humanity

Participants lamented the compromised personhood and humanity of these children, their families and the PICU staff. They were distressed when treatment escalated well after the child lost the ability to interact. Several children were "hard to look at," due to their physical compromise; this led to avoidance by clinicians, and, it was perceived, by families.

"I think we were doing things to him constantly without considering him as a person or as a human being. It's more like doing things like you do in the lab." (MD)

"It was difficult for me to take care of her because I think that we created something that wasn't a person... It's almost like, when somebody dies you go to the wake and

you say well, that's not that person anymore. That person had a personality and character traits and that person laying in the casket is not that person anymore. I feel like, although she wasn't dead, I feel like that wasn't [Child's name].” (NP)

Conflicts between staff and families undermined staff appreciation for the humanity of the parents. Participants often understood little of families' lives, despite months of interactions. Parents were described as “difficult” or “angry” or “unrealistic.”

Finally, participants struggled with their own humanity while caring for these children. Many described how months of care created special relationships; clinicians thought of these children outside of work or brought gifts for them. When parents rarely visited, staff felt like the child's family. This reinforced the humanity of the child and clinician alike, but also frustrated clinicians who could not guide medical management. They describe feeling obligated to provide care that went against their values, threatening their professional integrity.

“...I feel like I'm caving on my judgment and on my expertise. The word that came to mind is I'm sort of prostituting myself to the system to be doing this when I feel it's, just to use the common word, it's futile.” (MD)

Suffering

The theme of suffering was ubiquitous. Physical pain occurred for all of these children and clinicians grieved that they could not help. Some participants noted that pain is justifiable when it permits improvement or more time to interact with loved ones; the suffering of this cohort was perceived as cruel because it did not achieve either outcome. Some staff perceived suffering resulting from an imbalance of benefit and burden—this was especially true of children who had limited or no ability to interact.

“She suffered for a long time and to a pretty big extent. You couldn't really even change her diaper or do oral care or just take care of her human basic needs, it was just really painful. She suffered through that. I think that was particularly terrible.” (RN)

“I have a definition of quality of life as just that you have some sort of meaningful interaction with the environment. I don't have a grandiose definition... but she does not have a meaningful interaction with the environment.” (NP)

Families clearly suffered. Some were hypervigilant, anxious about the next catastrophe, or any small oversight by staff. Families who rarely visited were also perceived as suffering, though staff felt that this did not justify not being present. Staff tried to protect parents by postponing painful interventions during their visits, while wondering if seeing the child's suffering would have helped parents adjust treatment goals.

“I don't think the parents got a picture of the fact that she was suffering. Because they weren't there long enough to see how difficult it was to change her diaper... We kind of shot ourselves in the foot by not showing them that she was miserable.” (RN)

Clinicians suffered in their inability to protect these children and families. Bedside caregivers knew they had repeatedly caused pain while providing routine care. They regretted that parent goals often trumped the child's interests but did not know how to resolve this or even if it should be resolved. Some felt like failures who did not help the child, the family, or their coworkers. Some were angry and described detaching themselves and joining the “status quo” goal of care.

“When you go in and you examine her, I think most pediatric providers hurt a little bit when they walk in the door.” (MD)

“I feel that we're inflicting all this stuff on this child with no hope that any of it is going to have any beneficial effect, apart from keeping this heart beating and these lungs working and this mother somehow getting some gratification from having a child that's alive.” (MD)

Clinician teams also suffered. They felt split by parents who spoke negatively about some clinicians and identified others as “fighting” for the child. Team members had differing values related to care of these patients which led to mistrust, sometimes generalized to particular disciplines, for example, “we can't trust [X specialists].” Some regretted being unaware until late in the child's course that some teammates were distressed about the treatment plan.

“The mom would only talk to one person. And that was the only opinion, the only thing that she was going to entertain... It made us feel—nursing—well, kind of us against them.” (RN)

“I am more distressed by the fact that we as a team didn't realize how distressing it was for other people. I don't like that feeling at all.” (MD)

Discussion

The growing population of children with CCI who require long ICU stays and significant medical technology challenges the current medical system. These children use a disproportionate amount of ICU resources and have a higher mortality than other ICU patients.^{9–12} ICUs are not adapted to best serve chronic patients, but these patients' significant illness renders them ICU-dependent. An important and sometimes overlooked consequence of this systematic mismatch is distress in ICU staff caring for these children, some of which is moral distress. Moral distress is defined as “the anguish in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action; yet, as a result of real or perceived constraints, participates in perceived moral wrongdoing.”⁵

We examined PICU staff perceptions of patient care and team dynamics in specific clinical situations involving substantial staff distress. Much distress was related to the suffering of the children—their pain, unconsciousness, disrupted physical integrity, indefinite hospitalizations. Clinicians struggled to justify these burdens. Distress also stemmed from difficult relationships with families, sometimes because families were barely involved in the child's care, and sometimes because they were driving the care. Clinicians were also distressed when team members had limited communication skills, inconsistent or incoherent care goals, and disregard for team consensus.

Staff distress was linked to feelings of helplessness, a known consequence of caring for very sick patients and a contributor to the development of both moral distress and burnout.¹³ Moral distress is associated with perceptions of undue patient suffering, aggressive care that is not in the patient's best interest, and feelings of conflict between ICU team members and is linked to burnout and job turnover for nurses.^{14–16} Frameworks for understanding and modifying moral distress in healthcare providers identify empathic distress, in response to another's suffering, as a factor that can lead to a cascade of responses.^{17,18} Data from this study reveal common responses to their distress including anger, distancing, numbing out, and moral outrage.

Our data suggests that nonbeneficial treatment is a major contributor to moral distress in PICU clinicians caring for children with CCI. Nonbeneficial treatment, (e.g., using a medication for weeks that appears to have no effect), led to multiple challenges for staff: it confused parents about achievable goals, prolonged a critically ill "status quo," and its pursuit sometimes prolonged the child's suffering. Participants reflected upon the ethical challenges of participating in such treatment, noting negative effects on their perception of their role and duty to their patients. Some felt that the care was detrimental to their patient's well-being and reflected a lack of regard for the patient as a person. Data supports a link between nonbeneficial treatment and burnout/decision to leave the job in both ICU nurses and physicians.¹⁹ Our participants also noted poor communication by PICU providers as a contributing factor to the initiation or continuation of nonbeneficial treatment. Similarly, a study of interdisciplinary adult ICU staff demonstrated a link between moral distress and lack of full disclosure regarding medical interventions.¹⁴

Nonbeneficial treatment, a subjective and value-based judgement, is difficult to define and often identified retrospectively.^{20,21} A recent study suggested that invasive treatments and cardiopulmonary resuscitation are offered despite clinician opinion that these therapies were unlikely to benefit the patient in 20 to 35% of cases.²² Decisions to limit therapies in children are emotionally fraught and complex, especially for parents who may reasonably perceive prolonging their child's life as fulfilling their parental duty.^{23,24} Predicting mortality is challenging in children with CCI given heterogeneous diagnoses and lack of long-term prognosis data. Given this, children with CCI may be at high risk of receiving nonbeneficial therapies resulting in prolonged ICU stays at end of life, increased patient suffering, and staff distress.

Goals of care requiring indefinite hospitalization were a major concern for study participants. The issue of indefinite hospitalization is unique to the CCI population as seen in other pediatric studies. The ICU is often the "default" place for these patients given their complex and fragile medical state though the ICU care model is not best suited to CCI.³ Delivering care that is so outside the scope of one's experience and expertise can be stressful for providers and can negatively impact the patient.^{7,8} Sung and Herbst explore the ethics of caring for adult "hospital-dependent patients," noting that while providers may question the quality of life that comes with indefinite hospitalization, patients may view this as providing security and an acceptable quality of life.²⁵ More work is needed to explore the practical and ethical impact of hospital-dependence on children, families, clinicians, health systems, and society.

While moral distress was frequently noted by participants, our data suggests that a more general state of distress exists in PICU staff caring for children with CCI. Lack of consensus was one contributor. When participants perceived that there was a lack of shared decision-making leading to care driven solely by patients' parents, by a small cohort of physicians, or by no one, distress increased. This raises interesting questions. Should consensus be sought among ICU staff? What are the boundaries of parental autonomy? In a survey of U.S. PICU and NICU attendings, most reported that while they would seek team consensus when approaching serious decisions in CCI patients, fewer than half thought this was a professional responsibility and 15% would defer completely to family.²⁶ Kaempf et al described their process for reaching consensus about counseling and care of pregnant women at risk to deliver extremely premature infants. They demonstrated that guidelines could be developed and followed by interdisciplinary providers, improving communication and support for decision-making while being well-received by their patients.²⁷ This strategy may be useful to explore in the CCI population.

The staffing model in PICUs is not matched to the needs of the CCI population. Continuity of providers is often absent in the current system, making continuity of goals and plans difficult to achieve. The complexity of these children combined with a long ICU stay nearly ensures that important details get lost. Relationships between staff and family members may erode over time, creating conflict.⁸ Palliative care team involvement, specialized teams for children with CCI and/or continuity attendings could be helpful strategies to ameliorate some of these difficulties.

It is notable how participants perceived and experienced suffering. Some focused on the child's appearance, becoming distressed when it became apparent that the child was experiencing pain. Others perceived suffering when death was likely and the child was receiving aggressive life-sustaining care. Suffering was perceived in children who had little-no interaction with their surroundings but continued to receive critical care interventions. Staff suffered not only when their actions resulted in patient discomfort, but when they believed the care provided was not in the child's best interest, when they questioned whether the family understood the ramifications of

continuing elements of care, when the family was not present, and when staff did not understand why care plans were being made or changed. While many believed that short-term suffering can be justified if it achieves desired outcomes for a child, they struggled with how to reassess this benefit: burden ratio as the child's prognosis evolved. A clear opportunity exists for partnership with ethics consultants to assist in the ongoing calculus of treatment risks and benefits for children with CCI. Also essential is a focus on building moral resilience (the capacity of an individual to restore or sustain integrity in response to moral adversity) that can help staff manage suffering in ways that are not detrimental.²⁸

There are several limitations in this study. It occurred at a single center and it is unclear how many of the issues identified stem primarily from this unit's culture rather than from the nature of PICUs more generally. As participants self-selected, it is possible that staff with high levels of distress volunteered; their perspectives may not be representative of the staff as a whole. Finally, purposive sampling is subject to the bias of the research team and results may not be generalizable. Overall, our work is meant to be hypothesis-generating for multicenter investigations.

Conclusions

Several types of distress exist in PICU clinicians caring for children with CCI. Frameworks for understanding and modifying moral distress in healthcare providers exist and should be considered when developing interventions. Additionally, while moral distress is significant, other types of distress can impact the experience of caring for these children. Recognizing the difference between moral and other types of distress may be helpful in steering communication and creating interventions for PICU providers caring for children with CCI. Interventions directed at increasing team consensus, clarifying goals of care, developing systems that would allow children with CCI to be cared for outside of the ICU, and improving communication amongst providers as well as between providers and families may all be indicated to mitigate this distress.

Conflict of Interest

None declared.

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