

Pediatric Critical Care Outcomes: State of the Science



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KEYWORDS

• Pediatric • Critical care • Outcomes • Postintensive care syndrome • Follow-up

KEY POINTS

- Survivors of pediatric critical care are at risk of developing post-intensive care syndrome in pediatrics (PICS-p).
- PICS-p includes physical, cognitive, emotional, and social health impairments that can affect the child and/or their family and that can last for years.
- Future PICS-p research should prioritize prospective studies, data harmonization, data sharing, and creation of large multisite data repositories.
- Reframing pediatric intensive care unit (PICU) care to focus on improving survivorship and promoting resiliency may help mitigate the negative effects of PICS-p in PICU survivors and their families.

INTRODUCTION

Advances in pediatric critical care have improved the survival of critically ill infants and children worldwide.¹ Although mortality rates have decreased, survival after pediatric critical illness is often accompanied by new morbidities, leading researchers and clinicians to shift attention from child survival to family survivorship.² As such, pediatric

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critical care clinicians focus on prevention of pediatric intensive care unit (PICU)-related factors that may increase an individual child's risk for new PICU morbidities after hospital discharge.

New PICU morbidities, including new or worsening problems in physical, cognitive, social, and/or emotional health that persist beyond PICU discharge, are collectively described as post-intensive care syndrome-pediatrics (PICS-p; [Fig. 1](#)).^{3,4} Symptoms in these domains can vary and vacillate over time. Unique from adult frameworks of PICS, the PICS-p framework embeds a developmental and family perspective. Baseline status is assessed within the context of the family, including parents and siblings. Factors contributing to PICS-p include child and family characteristics, premorbid health, developmental level, critical illness trajectory including severity of illness, PICU therapies, the PICU environment itself, and family socioeconomic factors both before and after PICU admission.⁵ Recovery trajectories may span days or decades—some children and families improve rapidly, others worsen, others experience peaks and valleys, whereas others remain unchanged.

Although PICU hospitalization places all children and families at risk for PICS-p, it is important to note that each child and family who develop PICS-p will have a unique experience. Early recognition and timely intervention are essential to prevent the acquisition of new morbidity in this already vulnerable pediatric population. This article will detail the current state of the science of PICS-p, outline strategies to improve recovery and make recommendations for future research priorities.

Post-Intensive Care Syndrome-Pediatrics Framework Domains

The PICS-p framework encompasses 4 distinct domains of child and family dynamics and outcomes after critical illness.³ The following will detail each domain, precipitating factors, and example symptomatology ([Table 1](#)).

Physical health

Overall physical health and associated functional status are central to a child's daily activities. They encompass a child's ability to perform daily activities of living to meet their most basic needs and developmental milestones. New functional impairments are common after critical illness, with a broad range of difficulties experienced—including pain, sensation changes, impairments in mobility, self-care, feeding, and respiratory functions.⁶ Precritical illness functional status varies, with an increasing effect on the PICU population due to the increase in medically complex children admitted to PICUs.⁷ As such, determining baseline functional status is critical to understanding the recovery trajectory after critical illness. Validated functional status scales in the PICU include the widely used pediatric overall performance category (POPC) and pediatric cerebral performance category,⁸ the Functional Status Scale,⁹ and the Stein Jessop Functional Status II-R for children with developmental disability.¹⁰

A scoping review of 25 studies including 72,780 critically ill children found that up to 36% of children experienced newly acquired functional status decline essential to their daily routines at PICU discharge, with 26% and 13% showing improvement at 6 months and 1 year, respectively.⁶ A recent study found that at 6 months after PICU discharge, approximately two-thirds of critically ill children who survived had signs of recovery of functional impairment.¹¹ A substantial population of children who survive critical illness experience new functional impairments and may benefit from increased efforts to support functional recovery. Recent studies using long-term follow-up after PICU discharge have found new functional impairments may persist in children who survive critical illness, with an improvement during 1 to 2 years.^{6,12,13} Studies beyond 2 years post-PICU discharge are limited but needed.^{6,14}

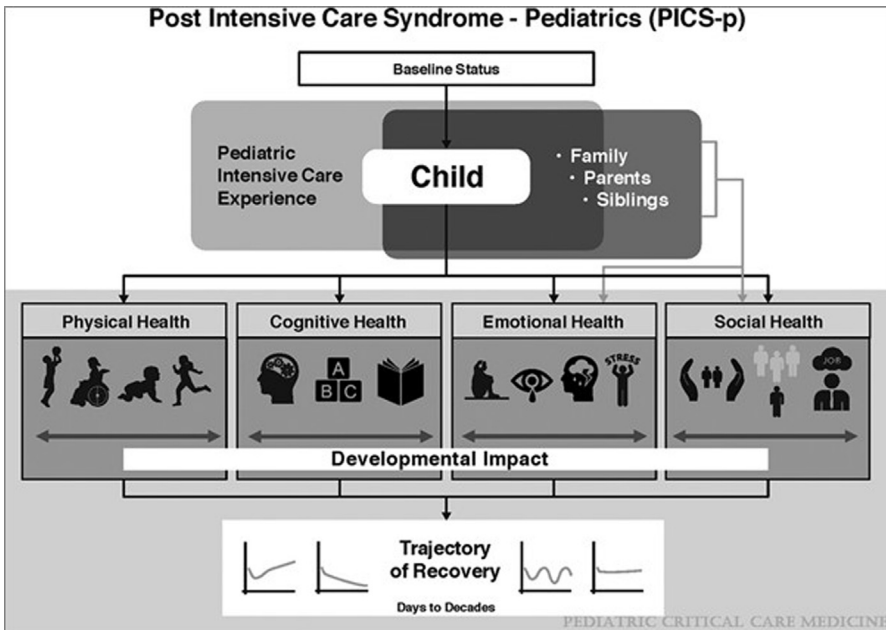


Fig. 1. Conceptualizing PICS-p in children. (From Manning, Joseph C.; Pinto, Neethi P.; Rennick, Janet E.; Colville, Gillian; Curley, Martha A. Q. Conceptualizing Post Intensive Care Syndrome In Children – The PICS-P Framework. PCCM. 19(4):298-300, April 2018. <https://doi.org/10.1097/PCC.0000000000001476>; with permission.)

In a scoping review by Ong and colleagues, of 25 PICU follow-up studies included, only 5 evaluated functional outcomes beyond 2 years after PICU discharge.^{15–19} These studies included not only POPC but also the PedsQL,²⁰ Modified Glasgow Outcome Scale,²¹ and the Health Utilization Index.²²

A recent scoping review synthesized the existing literature on post-PICU physical function. A total of 68 studies were identified with 23,967 children. Within these studies, up to 52% of children experienced impaired physical function after PICU hospitalization. Moderate-to-severe difficulty in physical function was associated with prolonged hospital stay and preexisting comorbidities.²³ Yet, there is a discrepancy in the evaluation of baseline preexisting comorbidities, especially regarding baseline physical function. In a recent scoping review of 102 studies evaluating post-PICU physical function, only 7% of studies included an assessment of baseline physical function.²⁴ Recognizing the association of moderate-to-severe difficulty in physical function after PICU with preexisting comorbidities is important. Especially given that the PICU population includes an increasing number of children with special health-care needs, medical complexity, and chronic critical illnesses.²⁵ Children in these special populations frequently experience prolonged admission, which may further increase their risk of post-PICU physical dysfunction. Although medical comorbidity is a significant risk factor for new physical dysfunction, children without preexisting conditions are not immune. Within the Life After Pediatric Sepsis Evaluation (LAPSE) Study cohort, many children without complex chronic conditions did not recover to their baseline health-related quality of life (HRQL).²⁶ Specifically, 56%, 41%, 32%, and 38% remained at least 1 mean clinically important difference (MCID) below their baseline HRQL as assessed by the PedsQL at 1-month, 3-month, 6-month,

Table 1 Postintensive care syndrome in pediatrics domain examples			
PICS-p Domain Examples			
Physical Health	Cognitive Health	Emotional Health	Social Health
<ul style="list-style-type: none"> • Decline in functional status • Pain (acute/chronic) • Fatigue • Feeding difficulties • Mobility issues • Delayed growth • Poor sleep hygiene 	<ul style="list-style-type: none"> • Poor school performance • Memory issues • Attention difficulties • Aphasia 	<ul style="list-style-type: none"> • Mood lability • PTSSs • Depressive symptoms • Anxiety • Regression (developmental) 	<ul style="list-style-type: none"> • Withdrawn from usual activities • School absenteeism • Social anxiety • Identity issues (dependency)

Although this table is not all-inclusive, these are some key examples of physical, cognitive, emotional, and social health examples of PICS-p, which may affect a child and its family after critical illness.

and 12-month, respectively, and 50%, 16% 15%, and 17% remained 4 MCIDs below their baseline HRQL.^{26,27} Notably, older children (aged >2 years) and those with abnormal neurologic examination and/or injury during their PICU admission had worse physical HRQL at 1-year after discharge.²⁶

Children also frequently experience pain and altered sleep after PICU discharge.²⁸ A recent study showed that severe pain episodes during PICU stays were independently associated with lower postdischarge HRQL after controlling for potential confounding factors such as age, baseline cognitive function, and illness severity.²⁹ Considering the number of painful procedures children experience in the PICU (averaging >10 per child per day),^{30–32} pain is a common, and potentially modifiable, risk factor for poor outcomes even if a single painful episode is experienced. Sleep is important to multiple aspects of health and is also often interrupted in the PICU. Studies have consistently demonstrated the importance of restorative sleep for healing during critical illness.^{14,33–35} Sleep interruption in PICU is multifaceted, with environmental, pharmacologic, and physical causes, and likely has short-term and long-term implications for the child including, but not limited to, cognitive decline, immune dysfunction, increased inflammation, respiratory compromise, catabolism, impaired glucose metabolism, and delayed healing,^{28,33,36} all of which are important in critically ill children. In adult intensive care unit (ICU) survivors, sleep impairments are one of the most frequently reported problems after discharge.³⁷ Unfortunately, studies evaluating sleep in children after PICU discharge are limited. One study conducted a median of 5 months after PICU discharge found that up to 80% of children who survived critical illness were at risk for sleep disturbance.³⁸

Cognitive health

The National Institutes of Health (NIH) National Institute on Aging defines cognitive health as, “the ability to clearly think, learn, and remember –[it] is an important component of performing everyday activities.”³⁹ In the context of critical illness, children who survive are at risk for deficits in attention, memory, communication, and/or processing speed.^{40,41} In a retrospective analysis of 29,352 admissions in the Virtual PICU System (VPS) Database, the overall prevalence of newly acquired cognitive disability was 3.4% from January 1, 2009 to December 31, 2010 in children aged 1 month to 18 years, who survived to discharge.⁴² Children with increased severity of illness,

receipt of invasive mechanical ventilation, longer PICU stay, cardiopulmonary resuscitation, renal replacement therapy, and extracorporeal membrane oxygenation were associated with greater risk of newly acquired cognitive disability.⁴² Additional risk factors for poor cognitive outcomes after pediatric critical illness include young age during illness, older age at follow-up, lower socioeconomic status, oxygen requirements during PICU admission, and the receipt of opioids while in the PICU.^{43,44} The notion that younger age during critical illness and older age at follow-up are independently associated with poor cognitive function is consistent with the developmental neurology concept of “growing into deficits.”⁴⁵ This phenomenon posits that early brain damage and/or injury during key stages of brain development are cumulative as a child matures, and an increasing number of deficits may surface as the child ages chronologically and executive functions are expected to mature.^{46,47}

Cognitive and neurodevelopmental outcomes have been specifically evaluated among critically ill children who require sedation to facilitate safe PICU care. Polypharmacy and administration of opioids and sedatives, particularly benzodiazepines, during critical illness are consistently associated with the likelihood of developing ICU delirium.^{48,49} Although ICU delirium is associated with decreased postdischarge cognitive function in adults, the impact of these medications and ICU delirium on long-term neurocognition in children is not well understood.^{50–52} A recent study by Watson and colleagues⁴¹ examined the role of critical illness—acute respiratory failure requiring mechanical ventilation—and its association with neurocognitive outcomes. Children without a prior history of cognitive dysfunction who survived critical illness without severe cognitive dysfunction at PICU discharge and matched biological siblings underwent neurocognitive evaluation of intelligence quotient (IQ) memory, visuospatial, skills, motor skills, language, and executive function 3 to 8 years after critical illness. The critical illness survivors had significantly lower estimated IQ scores compared with their otherwise healthy siblings, with the greatest difference among children hospitalized at the youngest ages. Although the differences were significant, the authors cautioned that the absolute differences were small, and their clinical significance requires further investigation.

These findings concur with an earlier study evaluating intellectual function, memory, attention, and teacher assessment of children after critical illness in 88 children with meningoencephalitis, sepsis, or other critical illness (respiratory, surgical—elective and emergency, metabolic, cardiac failure).⁵³ Survivors performed worse on neuropsychological testing compared with healthy controls, and teachers perceived these children as emotionally labile and having difficulty with schoolwork, executive functioning, and attention. Dysfunction was more prevalent in younger children, those of lower socioeconomic status, and if the child experienced a seizure during the PICU admission. Finally, dysfunction was worse in children with severe infection, specifically sepsis and meningoencephalitis.⁵³

Similar associations have also been observed in a cohort of children diagnosed with bacterial meningitis specifically. In a meta-analysis of 39 studies including 2015 children with IQ data and 12 studies on developmental delay with 382 subjects, children with bacterial meningitis frequently experience significant decline in IQ of approximately 5 points less compared with healthy controls. Survivors are also 5 times more likely to have intellectual impairment.⁵⁴ As such, children who survive severe infections should be considered at particular risk and should be assessed and treated for cognitive deficits beyond the immediate PICU period. Although follow-up after PICU may not be feasible or beneficial in all children, special emphasis for those at greatest risk of neurocognitive decline after PICU, including those of younger age, of seizure history, and of lower socioeconomic status, should be considered.

Emotional health

A facet of mental health, emotional health refers to one's ability to cope with negative and positive stressors, adapt to change, and have overall awareness of one's own emotions.⁵⁵ A review by Nelson and Gold found that at least a quarter of children who survive critical illness developed posttraumatic stress disorder (PTSD), and up to 62% of children will demonstrate posttraumatic stress symptoms (PTSS).⁵⁶ Studies of illness-specific PICU cohorts have identified sepsis as an independent predictor of PTSS.^{38,57} In addition to PTSD and PTSS, other psychopathologies affecting one's health such as anxiety and depression after PICU discharge are prevalent in children who survive critical illness, although the reporting of their prevalence is variable. In a review of 17 studies examining psychiatric symptoms and disorders after PICU, the point prevalence of clinically significant depressive symptoms ranged from 7% to 13%, with a median point prevalence of 10% (2 studies, $n = 51$). Major depression diagnosed via diagnostic interview occurred in 0% to 6% of children, with a median prevalence of 3% (3 studies, $n = 128$).⁵⁸ Although prevalence is variable, pre-PICU psychosocial characteristics are risk factors for post-PICU distress in children who survived critical illness. In a small single-center study, 51% of survivors reported pre-PICU adverse childhood events and nearly all (96%) reported posttraumatic stress. There was a strong association with acute stress, PTSD, and impaired HRQL before the current PICU admission,⁵⁷ indicating baseline psychosocial factors are important indices and predictors for emotional health after discharge from the PICU, although the authors acknowledged that baseline HRQL may have been impacted by potential recall bias and should be considered in interpretations of the findings.

The emotional influence of pediatric critical illness spans beyond the child into the family unit. Parents, guardians, and caregivers are particularly susceptible to the emotional effects of their child's critical illness as well. These effects are variable, ranging from PTSS, depression-like symptoms, a sense of powerlessness, loss of work, and financial hardship.^{59,60} This is not a comprehensive list, and these effects are influenced by baseline factors such as social support and social determinants of health, which may impact many facets of post-PICU wellness, including quality of life and emotional health in both the child and their family.^{61–63} Parents of children who survive critical illness frequently experience PTSD and PTSS, up to 21% and 84%, respectively.⁵⁶ PTSD and PTSS experienced in parents of survivors may contribute to family dysfunction, which may substantially affect the child's overall well-being. A pilot randomized controlled trial of 31 parents of children who survived critical illness was conducted in the United Kingdom. Parents were randomized to usual treatment or a post-PICU psychoeducational tool administered by a telephone call. Those parents who received the intervention reported lower PTSS, as well as fewer emotional and behavioral health problems with their child.⁶³ Although underpowered, this study demonstrated feasibility. A larger trial is necessary to understand if such an intervention improves parent outcomes in a broader context.

Critical illness and ICU admission are associated with PTSD and/or PTSS; however, positive aspects of survival and posttraumatic growth have also been reported.⁶⁴ Posttraumatic growth is well studied in survivors of traumatic events (eg, abuse, disaster)^{65,66} and adolescent cancer survivorship⁶⁷; it is less well studied in ICU populations. It is defined as positive psychological change and improvement that can result from processing trauma.⁶⁸ In the case of children who survive critical illness, and their families, the traumatic event is the critical illness and the PICU environment itself. Colville and Cream surveyed parents of critically ill children who survived 4 months after discharge, and found that a majority (88%) experienced posttraumatic

growth as a direct result of their experience in the PICU.⁶⁴ Parents of ventilated children and older children reported higher levels of posttraumatic growth after discharge. Interestingly, posttraumatic growth scores were positively correlated with PTSS scores, suggesting that these experiences do not happen in isolation. Another study of parents of children who survived critical illness also confirmed that posttraumatic growth is a common experience. More than a third of parents (37%) reported at least a medium level of posttraumatic growth 6 months after their child's PICU discharge.⁶⁹ These results suggest that parents/guardians of critically ill children demonstrate incredible resiliency in the face of adversity.

Social health

Social outcomes encompass a child's ability to participate in social activities, engage meaningfully with other people, and feel socially connected and supported by others.⁷⁰ Such social interactions are crucial to a child's development, and critical illness can deeply affect the social health of both children and their families. Children surviving critical illnesses still want to "fit in" with their friends, despite new physical changes and limitations. They can suffer from isolation and loneliness, partly related to difficulty talking about the experience,⁷¹ as well as from experienced or anticipated social stigma.⁷²

Similar to adults and work, a large proportion of life for many children is spent in school. Although not all children attend school, for many, school serves as the foundation not only for scholastic growth but also for social development, and relationship-building outside the family is crucial for overall development. In a prospective study of critically ill children in an urban PICU, 43% missed at least 7 days of school while admitted to the PICU.⁷³ After discharge, more than two-thirds (70%) of critically ill children who survived missed school, with a median absence of 16.9 days.⁷⁴ At 3 months after discharge from the PICU, up to 20% had not returned to school, and for those who did, a third of parents or caregivers thought that their child's school performance declined.⁷⁵ Moreover, 1 in 5 caregivers thought that their school did not do enough to support the child through services to catch up academically.⁷³ Even years following ICU discharge, children admitted to the PICU as infants remain at higher risk of academic impairment based on standardized testing compared with age-matched peers.⁷⁶ School absenteeism in the setting of critical illness and subsequent recovery may lead to poor scholastic performance, economic hardship, and poor health outcomes in adulthood.⁷⁴

Family social considerations. Family social effects are wide-ranging, including community, relationship, parenting, employment, and other economic effects. Namely, missed work is common among caregivers of critically ill children; with nearly half of primary caregivers having to miss work pre-PICU and post-PICU discharge to care for their critically ill child.⁷⁴ This may lead to job loss, financial and mental health strains on the caregiver and the family unit and may last for years beyond the PICU discharge.⁶⁰ The child's post-PICU disposition, their baseline functional and health status, increased length of PICU stay, and discharge functional status are all associated with the caregiver's need to miss work.⁷⁴ Caregivers and families of critically ill children must be assessed at individual levels to ensure that aside from the burden of the actual critical illness, they are not burdened by outside factors such as financial strain that may be associated with medical bills, lost wages, and hospital-associated costs such as meals, lodging, and transportation costs.⁷⁷⁻⁷⁹

In addition to economic hardship, parental relationships are often strained. In a qualitative study of 10 parents conducted 2 years after PICU admission, parents cited

persistent strain in their interpersonal relationships due to the theme of “losing manageability.”⁶⁰ Parents struggled with feelings of isolation, leading to loss of friendships, and difficulty with parental attachment to their critically ill child. Despite these difficulties, some parents described strengthened relationships because they were able to handle hardships together.⁶⁰ This is a unique finding because it has long been hypothesized that parents of seriously and/or chronically ill children experience disproportionately higher divorce rates yet evidence for this is not supported in the literature.⁸⁰

Another unique consideration is the role the siblings may play in the critically ill child’s life and vice versa.⁸¹ Similar to parents, siblings of critically ill children are not shielded from the negative effects of critical illness.⁸² Unlike parents, they are often excluded from the PICU environment for various reasons including concerns of increased risk of infection, perceived psychological trauma, and effects on the child.⁸³ Although literature exploring sibling response to chronic illnesses such as cancer are abundant,^{84,85} there are limited studies in pediatric critical care.⁸⁶ In a recent qualitative study of siblings of critically ill children, several themes were found to be experienced by siblings: pre-illness stressors, the PICU environment, their sibling’s appearance, uncertainty, and their parent’s stress.⁸¹ None of these stressors occurred in isolation. Presence in the PICU for some siblings was quite therapeutic, whereas it was distressing and anxiety-inducing for others. Much of this variation was age-dependent and varied by pre-illness factors such as social support, sibling-patient interactions, and sibling relationship. Sibling wellness (physical, social, emotional, and spiritual) is likely affected by the experience of having a critically ill sibling, and changes to the sibling relationship may also affect the critically ill child once discharged.

Future Directions

Within the last decade, research evaluating pediatric critical care and postdischarge outcomes have dramatically increased.^{24,40} There is an increasing need to understand the rapidly evolving population of children who survive critical illness, including their own unique needs and priorities. The following section will outline the process of creating the PICU Core Outcome Set (COS) and Core Outcome Measurement Set (COMS), to support more systematic assessment of long-term function and morbidity in children who survive critical illness. Both efforts may be useful from a data harmonization perspective in order to better answer clinical questions regarding post-PICU care. Additionally, we will discuss the emergence of PICU follow-up clinics to support the child and family’s recovery after PICU discharge and discuss mitigation strategies to reduce PICS-p and optimize recovery in the post-PICU period.

PICU core outcome set

Reliably assessing PICS-p across studies has been challenging due to the sheer breadth of measurement tools used in PICU outcomes studies. Each measurement tool assesses unique domains of PICS-p, and not all tools are equally robust. The Pediatric Outcomes STudies after PICU Investigators of the Pediatric Acute Lung Injury and Sepsis Investigators (PALISI) Network and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)-funded Collaborative Pediatric Critical Care Research Network (CPCCRN) recently put forth recommendations for a COS for pediatric critical care. As defined by the Core Outcomes Measurements in Effectiveness Trials initiative, a COS is an “agreed upon standardized set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or healthcare.”^{87,88} Using an in-depth multinational modified Delphi consensus process, 333 key stakeholders were surveyed, including

researchers, clinicians, and family/advocates. After 2 rounds, stakeholders agreed on the inclusion of 4 global domains (physical, cognitive, emotional, and overall health) and 4 specific outcome domains (survival, child HRQL, pain, and communication). In addition to the COS, an extended COS (PICU COS-Extended) was generated because 21 additional domains were identified as important by families but were not included in the COS. Identifying a PICU-specific COS for pediatric critical care research may enhance research harmonization across studies. In addition, future studies with similar outcome metrics, will be available for data-sharing across studies, which may help to better understand and answer clinical questions related to PICU survivorship.

Following the development of the COS is the development of a PICU COMS.⁸⁹ Using a similar standardized approach of key stakeholders, the COMS is a robust recommendation of instruments and measurement tools for clinicians and researchers to assess pediatric critical care outcomes. Development of the PICU COMS is an important step in harmonizing data across pediatric critical care outcomes research.

Surveillance, large research networks, and data sharing

With the use of electronic medical records and the generation of data repositories, the potential for data sharing is greatly increasing. The VPS is the largest collaborative database for quality improvement based on severity of illness-adjusted comparisons specifically in pediatric critical research.^{90,91} VPS has more than 200 enrolled PICUs who opt to share data, with more than 1.5 million patient admission records. Variables for analysis include severity of illness scores, basic laboratories, and vital signs. Although VPS is a robust research tool, it is a voluntary registry limited to the acute inpatient PICU stay and the data include very little information on social determinants of health. Although quite different, other pediatric-specific databases may capture some of this data, such as the Kids' Inpatient Database (KID), a large population-based administrative database provided by the US government-funded Agency for Healthcare Research and Quality.⁹² The KID database includes all pediatric inpatient admissions, including those to the PICU but many pediatric critical care-specific variables are not collected (eg, PICU-specific severity of illness scores) because it is compiled from billing records. However, some patient-level socioeconomic variables are recorded, as well as discharge location and readmissions to units other than the PICU. This makes the KID database a useful tool to explore social determinants of health because the data may pertain to the entire hospital course and discharge, although there are no outcomes after discharge. A noteworthy model worth mentioning for its robust nature is the Paediatric Intensive Care Audit Network (PICANet) for the UK Network.⁹³ Established in 2002, PICANet is a United Kingdom-funded audit database that records all National Health Service-funded PICU patient encounters and now includes 2 Dublin PICUs as well. This data is available in aggregate and de-identified patient-level on a by-request basis to researchers with the proper ethics approvals.

In addition to these large databases of pediatric inpatient clinical data, an additional potential source is the NIH, which commits to data sharing from NIH-funded studies. The NIH does not fund or support other databases. Funded Principal Investigators are required to upload their relevant data to NIH repositories such as the NICHD Data and Specimen Hub (DASH—<https://dash.nichd.nih.gov/>) and the National Heart, Lung, and Blood Institute Biological Specimen and Data Repository Information Coordinating Center (BioLINCC—<https://biolincc.nhlbi.nih.gov/home/>). Although there are several other NIH-funded data and biospecimen repositories, an exemplar study submitted and available through the DASH biorepository is the aforementioned, *LAPSE*

observational Study. *LAPSE* includes the clinical data of 389 critically ill children with severe sepsis and/or septic shock, including biospecimens and robust follow-up data. In addition to clinical data, biological specimens may be requested by qualified researchers. Such datasets need to be used to draw conclusions on large populations of children who survive critical illness.

Although large repositories such as DASH and BioLINCC are useful in making data readily available to pediatric critical researchers who may not otherwise have the resources, these datasets are limited to the primary research questions. In the example of *LAPSE*, collected clinical variables are related to sepsis, and all included children had sepsis or septic shock. To answer questions outside of a specific population, more representative datasets are required. The integration of electronic health records (EHRs) and data sharing has made data accessible to researchers and clinicians alike. An example of an NIH repository integrating EHR is the National Coronavirus disease (COVID) Cohort Collaborative (N3C) Enclave an initiative by the National Center for Accelerating Translational Sciences (NCATS) and the Center for Data to Health (CD2H). N3C is unique because it incorporates more than 50 health systems, including pediatric inpatient units/hospitals, collecting COVID-specific clinical and outcomes data. Any scientist interested in asking COVID-specific questions is invited to request data from the Enclave to answer specific questions. Although the N3C is population-specific (COVID-19–positive children and adults), the creation of similar collaboratives to share EHR data could provide a powerful tool for critical care research. Members of the PALISI subgroup Pediatric Data Science and Analytics are in the process of creating a PICU Data Collaborative (<http://vpicu.net/>). The PICU Data Collaborative will allow members to contribute and share anonymized EHR data. This, along with improving outcome standardization across new research studies by using the COMS, may help support data aggregation, and algorithm development to improve long-term post-PICU outcomes.

Strategies to Optimize Recovery After Pediatric Intensive Care Unit Discharge

Post-PICU follow-up clinics

Increased survival, awareness of PICS-p, and increased interest in long-term outcomes after PICU have spurred an exploration into the utility of PICU follow-up clinics worldwide. Post-ICU follow-up clinics have become potentially feasible solutions for adult ICU survivors to improve outcomes,⁹⁴ especially in the time of the COVID-19 pandemic.^{95,96} However, their overall feasibility for general ICU patients remains questionable. The optimal patient eligibility, timing, method of delivery, and cost-effectiveness of Post-ICU follow-up clinics are not well understood.^{94,97} Initiatives such as the Society of Critical Care Medicine's THRIVE collaborative aim to establish a multinational effort of multidisciplinary post-ICU follow-up clinics and peer support to facilitate post-ICU growth and recovery.^{98,99} However, such clinics and their feasibility and utility in critically ill children and their families have been minimally evaluated. A cross-sectional web-based study conducted in the entire United Kingdom and the Republic of Ireland assessed the prevalence of post-PICU follow-up. Data collection included responses from 22/28 PICUs. Of the 22 PICUs providing data, only 4 PICUs provided postdischarge PICU follow-up, using telephone ($n = 2$), follow-up clinic consultation ($n = 1$), or home visit ($n = 1$) methods.¹⁰⁰

In a single, large academic PICU, Fitzgerald and colleagues¹⁰¹ implemented a nurse-led follow-up system for pediatric sepsis survivors embedded within an existing health-care system. A multidisciplinary approach was taken, including therapists (occupational, physical, speech), teachers, neuropsychology, and coordinators from existing survivorship programs—neonatology, stroke, and oncology. The program

included predischarge education and referrals, with postdischarge follow-up at 2 to 3 months to screen for new physical and/or psychosocial morbidity for referral purposes. This method of care coordination was found to be cost-effective and feasible to screen for potential new morbidity while making formal diagnoses and referrals within an existing system. A survey of active PICU follow-up clinics was conducted by Williams and colleagues. Results yielded responses from 17 active clinics, with significant variation among each regarding services provided. Of the respondents, more than 80% agreed that post-PICU follow-up clinics were beneficial to children and supported knowledge advancement. However, clinics are limited by “lack of support,” citing funding constraints, including reimbursement, and lack of clinical space to lead successful follow-up programs.¹⁰²

ICU liberation bundles

Adult ICUs have focused on attempts to reduce ICU-associated morbidity through implementing ABCDEF care bundle elements, including Assess, prevent, and manage pain; Both spontaneous awakening and breathing trials; Choice of analgesia and sedation; Delirium—assess, prevent, and manage; Early mobility; and Family engagement.¹⁰³ Implementation of this care bundle improves post-ICU outcomes, including reducing the development of PICS by reducing deep sedation and prolonged immobilization.¹⁰⁴

Although PICUs globally are implementing some of these bundle elements, they are implemented inconsistently. In the Prevalence of Acute Rehabilitation for Kids in PICU study (PARK-PICU), less than 10% of the 161 international PICUs (18 countries) incorporated all 6 components of the ABCDEF bundle into routine clinical practice.¹⁰⁵ The most common component was standardized pain assessment (91%), followed by family engagement (88%) and routine sedation assessment (84%).¹⁰⁵ Within PARK-PICU, early mobility was the least commonly implemented component (26%). Despite poor adoption of early mobilization in PICUs, quality improvement initiatives, such as PICU Up!,¹⁰⁶ demonstrate early mobilization programs in critically ill children are generally feasible and safe.¹⁰⁶ The Society of Critical Care Medicine is committed to increasing access and knowledge of the ABCDEF bundles in PICUs to promote ICU liberation and limit ICU morbidity.¹⁰⁷

SUMMARY

Advances in pediatric critical care have led to increased survival for critically ill children. Shifting attention from an exclusive focus on saving lives to PICU survivorship in children who survive critical illness, with emphasis on PICS-p, has increased in the past decade. Using the PICS-p Framework as a guide to clinical practice and research is necessary to optimize recovery for critically ill children and their families. Understanding the ever-changing epidemiologic landscape of children who survive critical illness is vital. Standardized post-PICU assessment, data harmonization, and data sharing to create large datasets may help optimize research efforts in this area. Additionally, strategies such as effective post-PICU clinics, ICU Liberation bundle implementation, and resiliency interventions to promote posttraumatic growth may help offset the negative effects of critical illness and PICU-related therapies, promoting recovery among children who survive critical illness.

CLINICS CARE POINTS

- Post-Intensive Care Syndrome in pediatrics (PICS-p) is now acknowledged as a phenomenon commonly experienced by children who survive critical illness and their families.

- Symptoms of PICS-p should be assessed in survivors of pediatric critical illness. Though uncertainties exist in which PICU patients may benefit most, when assessments should occur, and what interventions should be considered for support.
- Assessments should consider both a biopsychosocial and developmental approaches as described within the PICS-p framework, including elements of physical, cognitive, emotional and social well-being of the child and family, parents, and siblings.
- Core outcomes, evaluated systematically following PICU discharge, may allow for early detection and intervention in high-risk patients. However, the selection and implementation of specific instruments evaluating these outcomes will depend on access, resources, and context.
- Interventions within the PICU, including incorporation of ICU liberation and chronotherapeutic bundles, may aid in promoting resilience and recovery in children who survive critical illness.

DISCLOSURE

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