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Promoting Functional Recovery in Critically Ill Children

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INTRODUCTION

The landscape of pediatric critical care has changed since the establishment of pediatric intensive care units (PICUs) in the 1950s. The number of children who become critically ill each year in the United States has been steadily increasing by approximately 3% each year.¹ More than two-thirds of children admitted to the PICU have a previously diagnosed condition, and half have impaired or abnormal functioning at their baseline.^{2,3} Although PICU mortalities have decreased drastically to 2% to 3% in high-resource countries, rates of new morbidity and readmission have increased.^{2,3} This evolution has driven a paradigm shift in pediatric critical care from a focus on surviving pediatric critical illness to examining trajectories of recovery and promoting child and family functioning in the longer term.⁴

POST-INTENSIVE CARE SYNDROME IN PEDIATRICS

The persistence of PICU-acquired impairments across physical, cognitive, or mental health domains experienced by survivors of pediatric critical illness has been termed *post-intensive care syndrome in pediatrics* (PICS-p).^{5,6} Manning and colleagues⁷ created a conceptual model of PICS-p to depict this phenomenon and describe the impact on components unique to pediatrics, such as the impact on their continued development and family. PICS-p impairments are reported across domains of physical health (health status, mobility, activities of daily living, fatigue, and pain), cognition (attention, memory, executive functioning), emotional/mental health (anxiety, depression, acute- and posttraumatic stress, behavior), and social and family functioning (reintegration in the home, community, and school/work, family communication and cohesion).^{8–10}

Fig. 1 is a version of the PICS-p framework, depicting the impact of critical illness on the child and their family, the types of impairments experienced, and modified with

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author consent to highlight the association between post-PICU impairments and hospital readmission, and how all these components are impacted by their social and political context.

Physical Functioning

The World Health Organization developed the International Classification of Functioning, Disability, and Health to provide a common framework to conceptualize functional health and disabilities.¹¹ This framework considers functioning in 3 different ways: functional status and physical structures (eg, muscle strength); activities (eg, ability to complete tasks such as brushing teeth or transferring from bed to chair); and participation (eg, engagement in sets and sequences of meaningful life events, such as school field trips or family celebrations). Rates of impaired physical functioning range from 10% to 82% at PICU discharge, depending on how functioning was conceptualized and measured.^{12–17} When using the Pediatric Evaluation of Disability Inventory, a proxy/patient-reported outcome measure of children's ability to perform activities across physical, social, and cognitive domains, to compare level of functioning pre-PICU, impairments were reported in 82% and 28% of children at PICU discharge and 6 months after, respectively. Using the Functional Status Scale, trajectories of recovery differ between survivors; for example, although approximately two-thirds of survivors report impairments persist for several months to years after discharge,^{16,18} in a prospective cohort study by Pinto and colleagues,⁶ morbidities and mortalities increased in the initial 3 years after discharge.

Cognitive Health

Cognitive dysfunction following critical illness in children includes difficulties with attention, memory, and executive function, increased cognitive fatigue, delayed neurodevelopment, and worsened academic performance.^{19,20} Reported prevalence of new cognitive dysfunction in children following critical illness ranges from 3% to 73%, depending on the specificity of the measure, timing of assessment, and cohort characteristics.²¹ Among children with sepsis and meningitis requiring critical care, up to 42% report cognitive impairment or neurodevelopmental delays following illness.²² After cardiac arrest, 47% of children requiring extracorporeal membrane oxygenation report persistent learning difficulties.²³ Furthermore, there is emerging evidence cognitive impairments may persist or worsen over the first year.²⁴

Emotional Health

Children receive a median of 11 stressful and painful procedures in a single PICU day.²⁵ Unsurprisingly, 64% of children demonstrate the symptoms for acute stress disorder during their PICU admission.²⁶ Emotional dysfunction after PICU admission can manifest as anxiety, depression, behavior difficulties, and posttraumatic stress disorder (PTSD).^{19,27–30} PTSD is the most common psychiatric diagnosis after PICU. Prevalence of PTSD among critically ill children varies from 13% to 32% within 12 months of discharge.^{31,32} Other post-PICU psychiatric comorbidities include hyperactivity, depression, sleep disturbance, cognitive fatigue, and conduct disorders.^{33–35}

Social/Familial Health

Pediatric critical illness is a highly stressful experience for caregivers and siblings of the patient and can negatively impact their mental health and family cohesion.^{36–38} A third of caregivers report moderate to severe anxiety or moderate to severe depression after PICU.³⁰ One study reported 10% of caregivers receive a new mental health diagnosis within 6 months of their child's critical illness, 110% higher than projected.³⁹ Critical illness also impacts child and family social networks, relationship functioning, and work or school attendance. One prospective cohort study reported 43% of children had missed 7 or more days of school and 14% had missed 30 or more days of school 3 months after PICU.⁴⁰

Risk Factors and Social Determinants of Health

Individual risk factors for PICS-p are outlined in Table 1. Although an in-depth review of the PICU care equity and related health disparities is out of the scope of this review, it is necessary to briefly discuss the impact of the social and political factors that influence health and health care when discussing trajectories of functional recovery.^{41–43} Access to care is the opportunity to have health needs fulfilled through timely and appropriate care.⁴⁴ Access to care opportunities results from the interaction between an individual's abilities/resources (eg, mobility, transportation) and the health care system characteristics (eg, geographic location, physical layout), both of which are influenced by social and political policies and norms. Unfortunately, there is an abundance of literature demonstrating access to care is inequitable, that is, access differences that are unjust, for children with disabilities, children of color, and children with lower-socioeconomic status in both the hospital and the community.^{45–47} The *Conceptual Model of Disability and Disparities* demonstrates the impact of disability on access to care and how access to care experiences influence the abling/disabling process.⁴⁸ Thus, given the complexity and vulnerability of the PICU population, the authors posit that it is crucial to include examination of and support for access to care for all services developed and implemented to assure equitable care and recovery for all children.

MANAGEMENT OF POST-INTENSIVE CARE SYNDROME IN PEDIATRICS

Given the breadth of the impact of PICS-p, there are several approaches emerging to optimize the functioning of PICU survivors. These approaches include prevention, identification, and intervention during and after the PICU and may be targeted at the level of the individual/family or health care system. Fig. 2 illustrates the existing approaches across the care continuum, and components are summarized in later discussion.

Prognostication and Screening

Identifying those at risk for PICS-p presents several challenges. First, functional impairments can be difficult to detect in very young children until they are older or after resuming home and family life, emphasizing the need for repeated screening, including after hospital discharge.¹⁴ Second, there is currently no validated measure to assess PICS-p. Existing measures of functional outcomes tend to be validated only for a specific diagnosis or narrow age group and may not detect all of the deficiencies associated with PICS-p.^{27,49} Given the importance of early identification to guide resource distribution and care

coordination, multimodal approaches to screening and prognostication may be necessary, such as using both caregiver/patient-reported outcome measures and clinical data, including serum, physiologic, and imaging biomarker data. For example, serum-derived vascular endothelial growth factor 1 day after PICU admission was associated with decreased functional status at hospital discharge for 44 children with acquired brain injury; heart rate variability metrics within the first 24 hours of admission predicted organ dysfunction and mortality in a cohort of more than 7000 critically ill children, and decreased connectivity strength in paralimbic tracks identified via resting state functional MRI and diffusion tensor imaging was associated with neurocognitive impairment among 12 children with cardiac arrest.^{50–52}

Pediatric Intensive Care Unit–Based Care

System level—Environmental modifications, such as limiting noise from alarms and shift change, keeping the child on a familiar routine, and decorating the room with familiar items, are suggested to prevent some of the psychological sequelae of critical care.^{53–57} Interventions to optimize PICU culture include approaches to care delivery, such as providing family-centered care, the equity in care allocation and care quality, availability of translators, and educational materials and resources in non-English languages.^{57–63} Policies and training to promote family-centered care include protocols to improve communication (Table 2), incorporating caregivers in goal setting and care planning, provision of resources that support caregiver presence, for example, a place to sleep and nutritious food, and remote/telehealth options to engage caregivers in care planning when they cannot be at the PICU bedside.^{58,64–66} Implementation of multidisciplinary rounds within the PICU facilitates referral of necessary services and care coordination (Fig. 3). Last, adherence to pediatric critical care guidelines for pain and sedation management, mechanical ventilation, and delirium prevention may prevent development of PICS-p.^{63,67–70}

Individual level—Early mobility has been a primary focus of rehabilitation therapies of PICU-based interventions to prevent impairment and promote recovery.^{71,72} Although feasibility, acceptability, and safety of early mobilization and rehabilitation therapies in the PICU has been demonstrated, there is a lack of evidence on efficacy.^{73–77} However, among adults, early mobility resulted in improved outcomes, such as increased strength and shorter durations of mechanical ventilation and lengths of intensive care unit (ICU) stay.⁷⁸ Furthermore, caregivers report less stress 6 months after discharge if their child received PICU-based rehabilitation therapies, compared with those who did not.⁷⁹ Thus, the 2022 Society of Critical Care Medicine Clinical Practice Guidelines for critically ill pediatric patients recommend incorporation of a standardized early mobility protocol outlining criteria to participate in early mobility, the contraindications, and mobility activities and goals.⁷⁰

Nonpharmacologic approaches to supporting children’s comfort and mental health, such as providing music or music therapy, virtual reality, and comfort-care holding, are emerging as potentially effective alternatives to decreasing stress and pain without the potentially deleterious effects associated with analgesics and sedatives.^{80–86} These studies primarily demonstrate feasibility, acceptability, and safety. However, there is promising results among

critically ill adults to encourage continued exploration of these approaches. For example, listening to music during mechanical ventilation resulted in decreased self-reported anxiety and less medication use, compared with usual care in a randomized control trial of 373 patients across 12 different ICUs.⁸⁷ Additional interventions to support both child and caregiver include caregivers reading to their child and PICU diaries.^{88,89} The latter involves working with families to create a written record detailing daily events about their child's condition and care during the PICU hospitalization in their own words. These diaries may address gaps in a child's memory regarding their critical illness hospitalization and provide clarity and context about their experience. Among adults, ICU diaries have been associated with a reduction in the incidence of PTSD, anxiety, and depression, as well as improve health-related quality of life.⁹⁰ Last, but possibly most importantly for addressing PICS-p, are approaches of bundled care. The *ABCDEF Bundle* (Fig. 4), also known as "A2F Care" and "PICU Liberation," aims to minimize pain and sedation, decrease unnecessarily prolonged mechanical ventilation, prevent immobility, and facilitate family engagement.⁹¹

Post-Pediatric Intensive Care Unit Follow-Up

The creation of post-PICU follow-up clinics is a postacute approach to optimize recovery through recognition of PICs-p, provision of referrals for health care and school accommodations requests, care coordination, and connection with psychosocial support. There is significant variability in the design of post-ICU clinics; however, families report high satisfaction and value from attending.⁹²⁻⁹⁴ Common components of these clinics are multidisciplinary engagement (eg, therapists, social workers, intensivists, psychiatrists, neuropsychologists) and screening for child and family functional outcomes.^{8,27} Developing such clinics can be complicated and time consuming, given the heterogeneity of the PICU population diagnoses, conditions, and ages coupled with the resources necessary to support multidisciplinary care.

To guide the successful development of post-PICU follow-up clinics, Butcher and colleagues⁹⁵ provide the following "5 S's" to consider when implementing a post-ICU clinic:

- *Space*: Affordability; availability; accessibility; maximum occupancy
- *Staff*: Disciplines; scheduling; compensation
- *Stuff*: Funding; technology; equipment
- *Screening*: Eligibility criteria; outcomes to assess; process to identify; timing of follow-up
- *Selling it*: Awareness; advocacy; assuring attendance

Addressing these considerations inevitably depends on the resources and expertise available at individual institutions. Partnering *between* PICU physicians and established follow-up clinics provides a potentially universal solution to space and equipment. Particularly multidisciplinary, specialty clinics, such as Complex Care or Pediatric Rehabilitation Medicine clinics, can provide access to many of the support services patients require after ICU admission. Determining which patients will be offered follow-up visits may also depend on the number of staff available to participate in post-ICU clinics. Who should

be involved and mode of follow-up (eg, in-person, virtual, asynchronous) require careful consideration. Beginning with a focused patient population and expanding gradually as additional funding and resources are identified may facilitate the feasibility of starting and sustaining this care. Incorporating a diverse set of stakeholders, both end users and providers, in clinic design and optimizations can optimize care, facilitate efforts to promote awareness of PICS-p, advocate for clinic attendance, and promote retention across longitudinal care.^{92,96,97}

THE ROLE OF PEDIATRIC REHABILITATION MEDICINE

Pediatric physiatrists are well poised to champion this space of optimizing recovery for survivors of pediatric critical illness, given their unique focus on child functioning versus a specific organ system. Pediatric rehabilitation medicine spans the health care continuum from the PICU to postacute and ambulatory care, while consistently focusing on optimizing function through effective collaboration and communication with other health care professionals. Pediatric physiatrists are ideally equipped to identify and manage weakness and functional limitations in the PICU and can also help educate families about PICS-p and assist in coordination of care for patients who are able to transition home. For those pediatric patients who have more significant functional deficits, they can identify those who would benefit from transfer to a pediatric acute inpatient rehabilitation unit before discharge home.

FUTURE DIRECTIONS

There has been a rapid evolution of research aimed at characterizing and facilitating functional recovery for children and families after pediatric critical illness; however, significant hurdles still lay ahead. Resources and tools for PICS-p education and identification will be necessary to maintain momentum for improving functional recovery of survivors of pediatric critical illness.⁹⁶ In addition, evidence on PICS-p intervention efficacy and guidelines for equitable implementation are necessary to drive development of health policies for clinical implementation. Last, children and families admitted into the PICU reported a higher prevalence of adverse social determinants of health and prior adverse childhood experiences compared with the general population.^{94,95,97} Taken together with the high proportion of children from historically marginalized communities within the PICU population, additional research on best practices to screen for and intervene on adverse social determinants of health and assure equitable opportunity to access care is crucial to assure every child has the opportunity to achieve their optimal health.

SUMMARY

Pediatric critical illness can have a long-lasting, negative impact on children and families across a variety of different functional domains. Preventing, identifying, and treating PICS-p requires coordinated care among a multidisciplinary team of health care professions and intentional development of guidelines and policies that assure equitable implementation of evidence-based care during and after the PICU admission. Clinicians and researchers should evaluate their local needs, barriers, and facilitators for addressing PICS-p and collaborate

with lived experience experts to design the longitudinal support necessary for recovery in the longer term.

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KEY POINTS

- Post-intensive care syndrome in pediatrics (PICS-p) is composed of new or worsening impairments in physical, cognitive, social, and mental health for the child and their family.
- Addressing PICS-p requires a multilevel and longitudinal approach.
- An interdisciplinary team, including intensivists, rehabilitation specialists, and social workers, is essential for the prevention and management of PICS-p.
- Monitoring outcomes via validated measures of core outcomes and starting with focused patient populations can facilitate the implementation and evaluation of approaches to address PICS-p.

CLINICS CARE POINTS

- Children, their caregivers, and their siblings may experience new or worsening impairments after pediatric intensive care unit discharge, known as post-intensive care syndrome in pediatrics. Post-intensive care syndrome in pediatrics education and awareness for families, health care providers (eg, primary care physicians), and educators are necessary to improve identification and treatment.
- Within the pediatric intensive care unit, there are several promising interventions addressing post-intensive care syndrome in pediatrics at an individual and a system level. Protocolizing a bundled approach may be best, given the wide range of potential impairments.
- Follow-up assessment and care are necessary, but resource intensive. There is need for careful consideration of who should be a part of follow-up care, mode of delivery, and the level of specificity desired for outcome data (eg, general vs specific) to drive measure selection, although outcomes should always align with family priorities.
- Efforts to promote survivorship should incorporate addressing social determinants of health and equitable access.

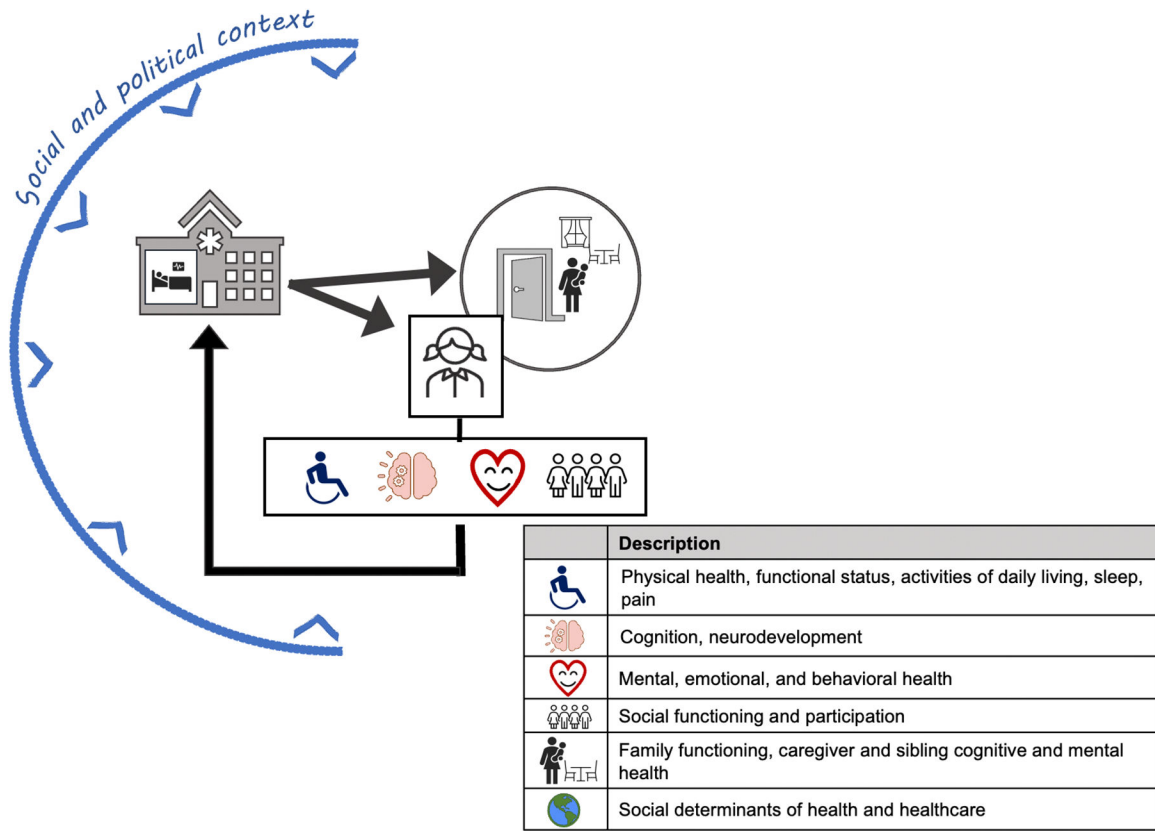


Fig. 1.
PICS-p.

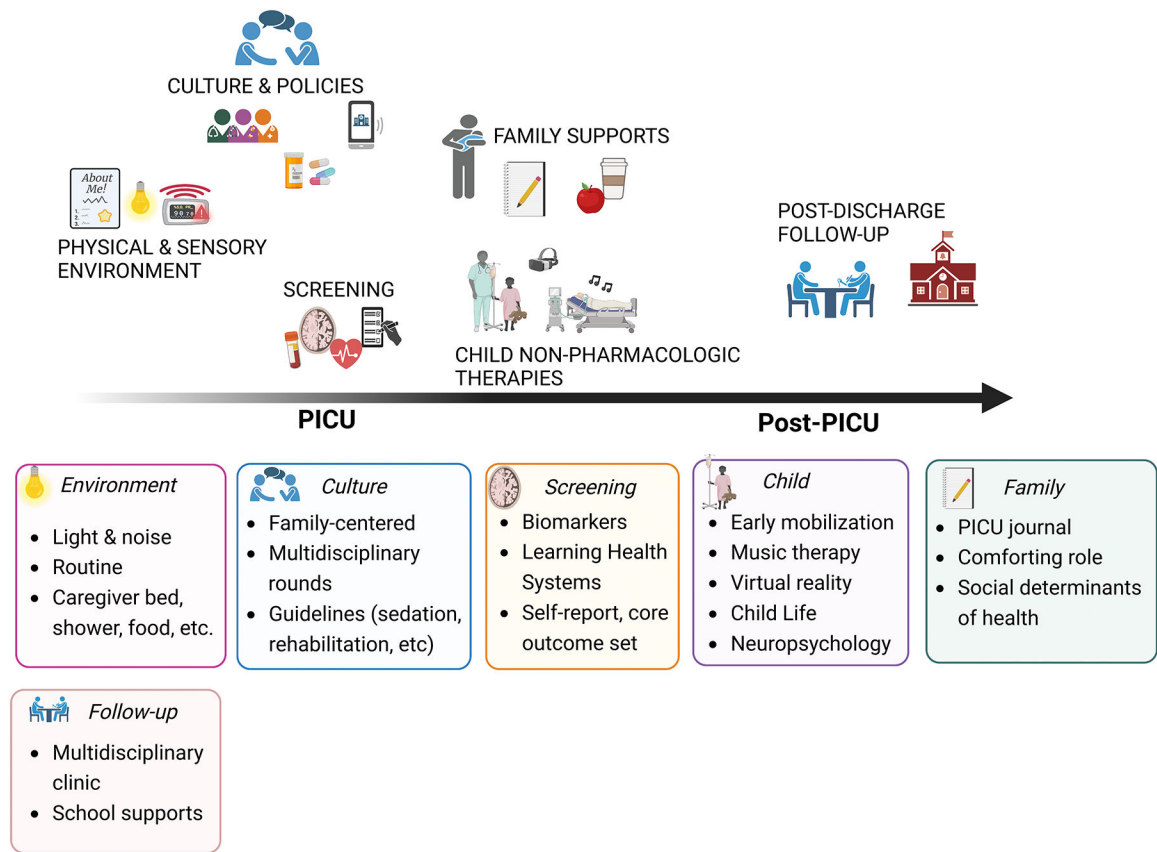


Fig. 2. Overview of system- and individual-level approaches to remediate PICS-p.



Fig. 3. Disciplines involved in multidisciplinary PICU care. OT, occupational therapy; PM&R, physical medicine and rehabilitation; PT, physical therapy.

- A.** Assessing, preventing, and managing pain
- B.** Both spontaneous breathing and awakening trials
- C.** Choice of analgesia and sedation
- D.** Delirium assessment, prevention, and management
- E.** Early mobility and exercise
- F.** Family engagement and empowerment

Fig. 4.
Components of the *ABCDEF Bundle* for addressing PICS-p.

Table 1

Risk factors for post-intensive care syndrome in pediatrics

Risk Factor	Description	Reference
Caregiver language and ethnicity	Non-English speaking is associated with worse outcomes, for example, increased mortality	59,98
Socioeconomic status	Lower income, education, and geographic location increase risk for PICU admission and poor PICU outcome	41
Child's baseline status	Prior chronic condition	23,47
Admitting diagnosis	Neurologic conditions, sepsis, multiorgan dysfunction	48
Invasive procedures	Invasive mechanical ventilation, receipt of extracorporeal membrane oxygenation	49
Sedation requirements	Length of deep sedation	27,58

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Table 2

Improving communication during pediatric critical care through the acronym HICCC

Component	Description
<i>Honest</i>	Straightforward, upfront, and candid
<i>Inclusive</i>	Listening to and implementing caregiver feedback and concerns
<i>Compassionate</i>	Caring about the patient and family
<i>Comprehensive & Clear</i>	Concise descriptions and rationales
<i>Coordinated</i>	Care team roles are defined and expectations listed

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