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### Karen Choong

Professor  
Department of Pediatrics and  
the Department of Health  
Research Methods, Evidence,  
and Impact  
McMaster University  
Ontario, Canada

choongk@mcmaster.ca

twitter: karen\_choong

# Post-intensive Care Syndrome – The Paediatric Perspective

This article outlines the current understanding, prevalence, risk factors and management of the post-intensive care syndrome in paediatrics.

## Introduction

Persistent critical illness acquired morbidities have been well known to affect adults since our attention was drawn to this in the landmark publication by Herridge et al. in 2003. What was first labelled as intensive care unit-acquired weakness, was broadened as we began to understand the physical, neurocognitive and psychological sequelae that can affect not only patients, but their caregivers. The Post-Intensive Care Syndrome (PICS) was coined in a 2012 publication, to capture the three key affected domains of mental health, cognitive function and physical sequelae that adult survivors experience (Needham et al. 2012). This understanding of long-term impact of critical illness on patients has prompted clinicians and researchers to expand our focus beyond acute care and survival, to optimising survivorship and longer-term functional and health-related quality of life (HRQL) outcomes in our patients and families.

PICS has only recently been described in the paediatric population (Herrup et al. 2017; Watson et al. 2018). Challenges leading to a delayed recognition of PICS in children include the paucity of long-term follow-up research in critically ill paediatric survivors, the heterogeneity of outcome measures used to assess the key domains of PICS, challenges with respect to measuring functional disability or recovery trajectories in children, a dependency on surrogate reporting of these outcome measures, and evolving paediatric populations with increasing medical complexity and chronic illness being admitted to our

Paediatric Intensive Care Unit (PICUs) today. The application of the PICS framework to the PICU population was unclear until an international, interprofessional Pediatric Critical Care working group conceptualised a Post-Intensive Care Syndrome-Pediatric (PICS-p) framework (Manning et al. 2018). PICS-p recognises the following key nuances in children:

1. The paediatric population is heterogeneous; it encompasses infants to adolescents, spans across children with a wide range of physical, social, cognitive and developmental

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function, and includes a broad spectrum of acute to complex, chronic disorders.

2. A child's critical illness occurs at a time of significant growth and maturation that can impact their physical, cognitive and emotional development. The PICS-p model recognises that the child's unique baseline health status and the impact of critical illness on the stage of their development influences their trajectory of recovery, and that trajectory is varied (Choong et al. 2018).

3. The PICS-p framework recognises the interdependency between family and child, and therefore integrates family outcomes in the functional recovery of paediatric

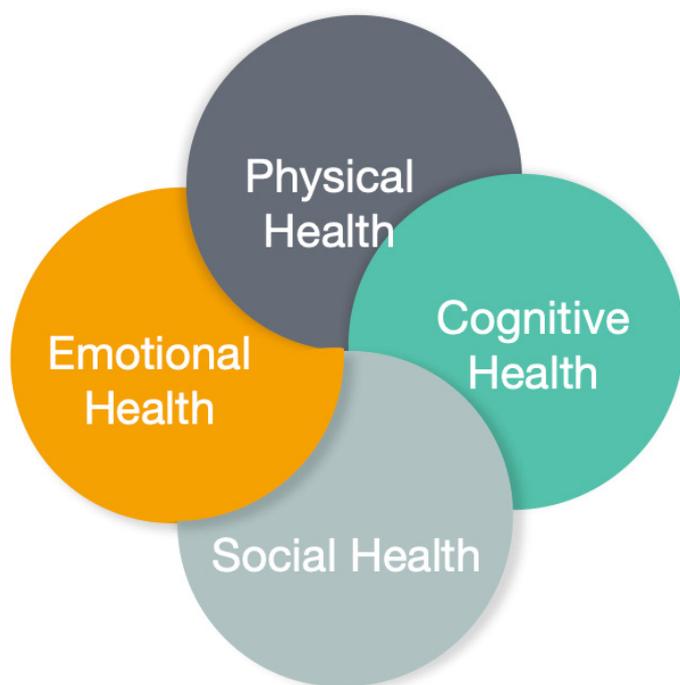
critical illness survivors. The child-family dyad are inseparable - the child's critical illness can have significant impact on family members' own physical and mental health (PICS-family); the family members' stress and coping in turn, are intricately related to and influence a child's functioning and quality-of-life (Jarvis et al. 2019b).

4. "Social health" is added as a fourth core domain in the PICS-p model, recognising the important role of the social environment around the child, and impact of critical illness on the child and family's social functioning (Figure 1).

## Prevalence of PICS-p

Previous studies report a variable prevalence of PICS-p in large part due to challenges in study methods, the identification of and measurement of the domains of PICS-p (Ong et al. 2016). The majority of earlier studies focused on assessing single domains, rather than a multi-system phenomenon (Watson et al. 2018). Recent evidence demonstrates that PICS-p is much more common than previously understood, and suggests that over 80% of paediatric survivors develop newly acquired functional deterioration as a direct result of their critical illness admission (Choong et al. 2018). The current literature reveals that each of the key domains of physical mobility, social and cognitive functioning as well as HRQL are collectively and significantly affected in children (Choong et al. 2018; Watson et al. 2018). Recovery trajectories from PICS-p are variable.

Prospective studies reveal that 67% experience some improvement in functioning 6-months post discharge, however, up to 20%



**Figure 1.** The four key domains of PICS-p model

of survivors experience persistent morbidities 1-2 years post PICU discharge (Ong et al. 2016; Pinto et al. 2017). The pattern of recovery from PICS-p is also varied. Evidence from the prospective longitudinal “Weecover” study suggest that physical functioning lags behind the recovery of other domains at six months, and that social well-being appears to lag behind the recovery of psychological well-being in HRQL assessments (Choong et al. 2018). Parents describe negative behavioural changes, and decreases in their child’s self-esteem and emotional function (Als et al. 2015); children report anxiety, medical fears, changes in friendships and their sense of self (Rennick et al. 2009). Disruptions in cognitive function after critical illness are particularly important in the developing brain. The reported prevalence of acquired cognitive impairments ranges widely from 3% to 73% amongst PICU survivors, depending on the nature of the study (Watson et al. 2018). Cognitive deficits vary in severity, from lower IQ to severe deficits in attention and memory (Als 2013). These deficits may persist for years, and in some cases, worsen

over time (Mesotten et al. 2012). Psychological functioning has been challenging to evaluate in the heterogenous paediatric population, however, the evidence reveals that a significant proportion of critically ill children are affected long after PICU discharge - 35-62% experience post-traumatic stress symptoms, 7-12% experience symptoms of depression, 33% recall delusional experiences, and 20% of paediatric survivors are at risk of a general psychiatric disorder (i.e. emotional, hyperactivity, or conduct disorders) (Nelson et al. 2012). These data highlight the importance of growth, development and the social environment when considering how PICS affects children; critical illness significantly impacts a child’s functioning, their HRQL, and their ability to re-integrate into their home, school and community long after PICU discharge (Kastner 2019; Khetani et al. 2018).

### Risk Factors for PICS-p

The risk factors for the development of PICS-p are multifactorial, and may be categorised into 1) pre-morbid, 2) critical illness and PICU care, and 3) post-discharge related factors.

### Pre-morbid factors

Baseline patient characteristics such as functional status, older age at presentation, chronic complex disease, malignancy and immunodeficiency have been identified as risk factors for poor functional and HRQL outcomes in critically ill children (Choong et al. 2018; Killien et al. 2019; Watson et al. 2019). Pre-existing comorbidities influence a child’s self-care and dependency on caregiver support. Maternal mental health, family functioning and lower socioeconomic status have also been shown to have important influence on a child’s adaptive behaviour and emotional health, predisposing them to poor recovery from PICS-p symptoms (Small et al. 2006; Yagiela et al. 2019).

### Critical illness and PICU-care related factors

Admission diagnosis, in particular a neurological insult and septic shock, and severity of illness are risk factors for poor functional outcomes and HRQL (Choong et al. 2018; Killien et al. 2019). Not only are the diagnoses and critical illness severity important, but the way in which we provide critical care is an under-appreciated, important modifiable risk factor for the development of PICS-p. Sedation management regimens, inadequate analgesia, and the number of invasive procedures are associated with adverse physical and psychological sequelae in children (Herrup et al. 2017). Prolonged immobilisation and excessive sedation are inter-related, and have repeatedly been associated with adverse downstream effects of prolonged mechanical ventilator requirement, delirium, iatrogenic withdrawal and ICU-acquired weakness (Choong 2019). We now understand that the development of one or more of these specific PICU-acquired complications predicts a greater decline in long-term physical, social and neurocognitive function (Choong et al. 2018). The development of these PICU-acquired complications also increases parental stress, and predisposes patients

to increased PICU mortality and longer lengths of stay (Choong et al. 2018; Kukreti et al. 2014; Traube et al. 2017). Long-stay patients have similar mortality rates, but are at greatest risk of prolonged PICS-p symptoms and poor recovery, compared to those with shorter stays (Matsumoto et al. 2019).

### Post-discharge related factors

Family functioning and well-being, the environment, community and peer support around the patient, caregiver strategies and access to resources for rehabilitation, financial support, and knowledge of healthcare provider and preparedness of family caregivers are all important factors demonstrated to influence the trajectory and nature of recovery of PICS-p symptoms following hospital discharge (Fayed et al. 2020; Hartman et al. 2020; Jarvis et al. 2019b).

### Management of PICS-p, From Within to Beyond the PICU

Recognising and educating clinicians on the magnitude and impact of PICS-p on our patients and families is the crucial first step in reframing our priorities in critical care to focus not only on survival, but survivorship. Within the PICU, this begins with early recognition, resuscitation, and stabilisation in accordance with recommended best practices and supportive evidence in order to reverse and prevent new or progressive multi-organ dysfunction. Potentially modifiable targets should focus on the key factors shown to adversely affect short and long-term patient outcomes, specifically, excessive or prolonged sedation, immobility, delirium, and disrupted sleep. This requires a paradigm shift and the integration of evidence-based harm-reduction and rehabilitation strategies as soon as possible after a patient is resuscitated and stabilised, rather than deferring these practices to the later stages of care, when PICU-acquired morbidities have already occurred (Choong 2019).

Specific objective screening for pain, delirium, pressure ulcer risk, readiness to mobilise and spontaneous breathing trials, are evidence-based, recommended standards that should be implemented in PICUs as it is in adult ICUs (Devlin et al. 2018; Harris et al. 2016). Early recognition therefore applies not only to resuscitation, but also to recognising the risk factors for PICS-p. Consultation of physiotherapy, occupational therapy, speech and language therapy, and psychiatry where available, are important in the acute rehabilitation and longitudinal planning of a child's recovery.

Beyond the PICU, the transition of care to the ward can be an extremely anxious and insecure time for patient families, and requires accurate and detailed transfer of information, and smooth continuation of appropriate clinical care, rehabilitation, and monitoring for PICS-p symptoms.

**critical illness significantly impacts a child's functioning, their health-related quality of life, and their ability to re-integrate into their home, school and community long after PICU discharge**

The recognition and management of PICS-p outside of the PICU and following discharge often falls on primary care providers, non-critical care subspecialists, rehabilitation clinicians and indeed patients and families themselves who may not be aware of nor appreciate the impact of PICS-p. Many if not the majority of PICS-p symptoms such as somatic complaints (pain, weakness, sleep disturbance), emotional, psychological

and behavioural symptoms are only identified well after hospital discharge during outpatient visits. This requires education and training on the screening and management of PICS-p. Unfortunately in paediatrics, there is currently a knowledge gap and there is at present no recommended standard for how to or when to screen for PICS-p. While early screening may be used to risk stratify adults and intervene in patients with PICS (Wang et al. 2019), this has not been well studied in children to date. Educating and providing anticipatory guidance to patient families around PICS-p improves their understanding, symptom identification, enables them to identify coping strategies, organise supports and access resources for rehabilitation, prepare the home, community and school environment where necessary (Esses et al. 2019). These in turn may improve the child's behaviours, reduce stress and anxiety, and optimise physical, emotional and neurocognitive outcomes (Jarvis et al. 2019a; Jarvis et al. 2019b). Not only have some institutions developed excellent family resources ([www.afterpicu.com](http://www.afterpicu.com)), families have also taken the initiative to create peer-support groups ([m.facebook.com/makinglemonade.pfcc](https://www.facebook.com/makinglemonade.pfcc)).

There is evidence that the current supports for families to address the many needs of their child recovering from a critical illness is limited. Clinicians do not routinely assess for long-term functional outcomes of PICU patients (Treble-Barna et al. 2019). 67% parents reported that their healthcare provider did not discuss child's return to school (Kastner 2019). Supports from community and education are also suboptimal - 20% parents reported that schools did not adequately address school reintegration (Kastner 2019). Diary programmes are emerging in PICUs and to date, the evidence is strongest for prospective use of diaries to prevent and manage psychological symptoms following

critical illness (Lasiter et al. 2016). Post-PICU clinics are emerging in paediatrics to address a growing need. The role of post-ICU follow-up clinics for the general PICU population has been evaluated in a small number of studies (Colville et al. 2010; Gledhill et al. 2014). The evidence to date suggests that while those who utilised these clinics found the follow-up and interventions helpful, the uptake is suboptimal (25-33% of eligible families attended). This is in part attributable to the potential burden and perception of yet another follow-up clinic, in a population where many have medically complex needs and require multiple appointments with numerous sub-specialty services. Nevertheless, there is a need for post-PICU clinics to address PICS-p which is currently under-recognised amongst healthcare providers, patients and families. While feasible, important logistical challenges include the infrastructure considerations for post-PICU clinics, which require the support of multi-professional clinicians trained to recognise, manage and counsel the multitude of physical, emotional and neurocognitive sequelae of PICS-p in both the patient and families.

### Future Directions

As PICU mortality continues to fall, this outcome is no longer the most appropriate indicator of the quality and effectiveness of our care. We now have a good understanding that survivorship, as defined by functioning and HRQL, are the outcomes deemed most important by patients and families (Fayed et al. 2020). Much of the attention in paediatric critical care has now turned to how we may best identify, quantify, prognosticate and ultimately intervene in the multidimensional, complex PICS-p that far outlasts critical illness. Research priorities have been identified (Watson et al. 2018), which has been accompanied by significant research progress in

this field (Choong 2019; Manning et al. 2020). Moreover, current clinical trials are increasingly including measures of longer term functional and HRQL outcomes in their study design.

### Conclusion

Mortality is very low amongst critically ill children. Increased survival is unfortunately accompanied by an increasing proportion of children who leave the PICU with newly acquired morbidities. This phenomenon known as the PICS-p is a constellation of physical, emotional, neurocognitive, and social sequelae that persists well beyond the resolution of acute critical illness. The paediatric framework recognises the important role of the social environment around the child, and the interdependency between family members on both the child and family's functioning and recovery from critical illness. PICS-p is not benign, and has important, long-lasting sequelae in critically ill children and families. The care of the critically ill child is no longer restricted to an acute life-threatening event, but extends well beyond the PICU. We have a responsibility to not only save lives, but to care for the lives that we have saved. This responsibility rests not only on critical care clinicians, but relies on a team of multiple healthcare professionals, family and community. Future research will help us determine how best to identify and manage the needs of these patients in-order to optimise recovery from within, to beyond the PICU.

### Conflict of Interest

Karen Choong has received the Academic Health Sciences Alternate Funding Plan Innovation Grant to conduct the Early Rehabilitation in Critically ill Children – the PICU Liber8 Study (Reference no. HAH-18-04) ■

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