

Post intensive care syndrome across the life course: Looking to the future of paediatric and adult critical care survivorship

The COVID-19 global pandemic continues to place critical care services under significant pressures. Despite persistent challenges, optimizing the outcomes of those that survive the intensive care unit (ICU) remains of utmost importance. In this editorial, we take stock of post-ICU survivorship across the life course and propose future areas of focus for the field.

The study and clinical follow up of ICU survivors remains a young but growing field, catalysed by the shift in focus of critical care from saving lives to optimizing outcomes. This has culminated in physical, cognitive, and psychological sequelae being described as postintensive care syndrome (PICS).^{1,2} More recently, PICS has been conceptualized for the paediatric ICU populous, termed "PICS-p".³ This is differentiated from PICS by the interconnectedness of the critically ill child with their family unit, impact that can transcend physical, cognitive, emotional, and social health domains, and recognition that childhood is a period of significant maturation that can affect outcomes.^{3,4}

Across the lifecourse PICS and PICS-p are now recognized as a public health burden. In adults, the impact has been shown to persist for decades, with 30% of patients not returning to work, another 30% not returning to their pre-ICU income, and 25% needing increased assistance with daily activities.⁵ For the paediatric ICU population survivorship outcome trajectories are largely undefined across the four health domains, with inconsistencies in the measurement and reported prevalence evident. However, at 6 months post-ICU, 38% had fatigue and 72% experienced sleep disturbances,^{4,6} and at 1 year after their PICU stay, up to 75% can have impaired health related quality of life, over half have functional morbidities, including weakness and feeding problems,^{4,7} and greater than 25% have negative psychological and behavioural responses, including post-traumatic stress disorder PTSD, symptoms of depression, fears, and anxiety.^{8,9}

Consequently, current literature encourages identifying PICS/PICS-p risk factors in all ICU admissions and preventing iatrogenic harm associated with critical illness through targeted interventions.^{10,11} For adults, coordinated post-ICU follow-up is advised to provide education, identify where patients are not recovering well, and provide resources to promote their recovery, including referral to appropriate specialists.⁵ However, there remains a limited understanding of which patients should receive what care, combined with a

fragmentary approach may adversely impact patient outcomes.¹² For the paediatric ICU field there is a paucity of large epidemiological studies, which detail outcome trajectories for the heterogeneous population. This currently impairs understanding of who is most at risk of developing PICS-p, when it manifests, what are the modifiable factors, and what (if any) interventions would be most effective at minimizing or mitigating the morbidity.¹³

1 | RISK FACTORS

Across the life course, studies have explored risk factors for one or more of the PICS domains, however, this remains challenging due to the heterogeneity of PICS manifestations. In addition, family members can be impacted by critical illness, which is integrated into PICS-p³ or defined as the family subtype (PICS-F).¹⁴ Both need to be studied further in their own right, and in combination the child or adult critical illness survivor.

A recent meta-analysis found that older age, female sex, previous mental health problems, severe illness, a negative ICU experience, and delirium were predictive of various functional impairments post-ICU.¹⁵ Current understanding of risk factors associated with impaired physical, cognitive, and emotional health outcomes for paediatric ICU survivors include length of stay, illness severity, younger age, emergency admission, and length of sedation.^{4,7,9} However, for both paediatric and adult studies there are few studies that have explored all risk factors across the PICS/PICS-p domains, there is limited agreement on inclusion/exclusion criteria, or on potential risk factors to study.

There are likely other risk factors relevant to post-ICU recovery that will come to light when researchers better establish consistent inclusion/exclusion criteria, timeframes for outcomes, and risk factor definitions. The pandemic has certainly further illuminated the fundamental impact social determinants of health have on health outcomes and these need to be better understood and explored in relation to critical illness survivorship. Integrated models should explore how multiple risk factors may interact, and explore potential counter-predictors, or resilience factors that may reduce a patient's risk of developing PICS; especially where such factors can be nurtured or facilitated.

2 | MODIFIABLE FACTORS

Identifying risk factors that are modifiable in hospital, or upon returning home could further reduce the incidence, duration or severity of PICS. Future research can explore further the patient experience (be it the ICU environment, interactions with staff and co-patients, or visits from loved ones)¹⁶⁻¹⁸ and how this can be improved to reduce psychological complications. The ABCDEF bundle demonstrates how known modifiable risk factors can be targeted to ameliorate PICS/PICS-p, in this case by reducing delirium and immobility to prevent cognitive impairment and neuromuscular weakness.^{10,19}

Future research could build on this concept by applying a similar approach across the illness course, tailoring a care pathway to the modifiable risk factors specific to that patient. This would begin at presentation (or with prehabilitation for planned admissions), and follow through their time in ICU, other in-hospital care, and after they return home.

3 | SURVIVORSHIP GROWTH AND CAPACITY FOR CHANGE

PICS/PICS-p emerged conceptually as intensive care shifted its focus from surviving critical illness, to addressing post-survival morbidity after ICU.¹ Much academic input has since been invested into measuring, preventing, and treating the longstanding adverse effects of critical illness and iatrogenic harms of the ICU. While this will remain important, attention should also be invested into the positive effects of surviving a critical illness.

A recent qualitative study identified 12 core patient priorities that were framed in terms of maximizing wellbeing, contrasting starkly with the current clinical focus on minimizing morbidity.²⁰ Positive experiences, such as feeling appreciated, life having more meaning, and strengthened relationships have been reported both by critical illness survivors, and their care networks.²¹ Much like considering resilience factors, future research needs to measure positive as well as negative outcomes following critical illness. Similarly for paediatric ICU survivorship literature, positive aspects for the child relate to the social health domain and greater level of perceived resilience and prospective outlook on life.²² For their parents/carers positive outcomes relate to a greater degree of expressiveness and lower degree of conflict, with siblings reporting enhanced kinship with the critically ill brother/sister.²³

4 | HEALTH, EDUCATION, AND SOCIAL NETWORKS

The complexity of PICS goes beyond the patient, which is recognized in the integrated PICS-p framework. Family and the patient's network play an important role in post-ICU recovery. As identified by both PICS-p and PICS-F, family members (including parents, spouses, siblings, and others) can experience psychological and social effects, with

some reporting rates of anxiety, depression, and PTSD comparable to those experienced by the patients.²⁴ Among children's families, one third of parents reported having an acute stress disorder, half have anxiety, and 30% have depression. Social disruptions are also reported with significant changes to family roles and functioning, loss of friends and acquaintances, and economic hardship.²³


Recognizing that patient and family cannot be untangled, it has been suggested for clinical interventions to approach the patient and their family as a dyad that recovers together.²⁵ The exact shape of the survivor family will depend on the patient, and their care network. One may have a resilient care network, another may have carers who need considerable support themselves, third may have no community support at all. However, the impact of the network as part of wider social determinants of health and outcomes needs to be further explored and understood as part of PICS/PICS-p.


5 | CONCLUSION

As we firmly set our sights on the post COVID-19 pandemic era we need to, as a paediatric and adult critical care community, continue to optimize outcomes of those that survive critical illness. To do this we need to build understanding of: risk and modifiable factors; survivors' (and their families) capacity for change; and the function of care networks. Furthermore, we must remain cognizant of the dynamic context, varied case mix, and multiple demands on our often limited resources. However, with innovation, collaboration, and continual (re) evaluation, we can ensure the diverse needs of the ICU populous and their families are met.

CONFLICT OF INTEREST

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