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Post-Intensive Care Syndrome in Paediatrics: Setting our sights on survivorship

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You can't go back and change the beginning, but you can start where you are and change the ending – C.S. Lewis

Broader access to healthcare, preventive policies, and medical and technological advances have collectively contributed to very low rates of observed paediatric intensive care unit (PICU) mortality in high-income countries. However, increased survival has been paralleled by a proliferation of children who leave the PICU with newly acquired or worsening morbidity. Thus, the focus of clinicians and researchers is broadening beyond the PICU walls.¹

As the global burden on healthcare systems has heightened exponentially in the COVID-19 pandemic, a spotlight has been focused on the fundamental importance of high-quality, humanized ICU care for critically ill patients. Though most paediatric COVID-19 cases are not severe, some children, particularly those with pre-existing health conditions, require hospitalization, including critical care. Therefore, universal measures, such as restricting family visitation, have been implemented in PICUs to reduce COVID-19 spread. Furthermore, in response to the tremendous demand of COVID-19 on adult ICU resources, PICUs worldwide are now either supporting care of adults or redeploying their workforce to adult ICUs.² These collective changes have, in many cases, transformed the configuration, organisation, and delivery of PICU services, which may in turn impact care experience, quality, and outcome of all children admitted to the PICU.

Recovery from COVID-19, as with other critical illness, has already begun extending beyond the confines of both adult and paediatric ICUs. As we emerge from this pandemic, acute and post-ICU rehabilitation by multidisciplinary teams must support thousands of patients and families worldwide. Critically ill children and their

families need this same intense level of post-ICU support.

The constellation of physical, cognitive, and mental health morbidities that appear as a direct consequence of ICU admission in adults has been termed Post-Intensive Care Syndrome (PICS).³ The concept of PICS in paediatrics (PICS-p) further integrates the centrality and interdependence of the child in the family structure and the dynamic developmental trajectory of the child, a complex interplay that may influence the pathway to recovery.⁴ Recent evidence suggests that PICU survivors suffer from a range of deficits that affect their physical, neurocognitive, emotional, and social health, as well as that of their families, effects that may be exacerbated in the context of COVID-19.

Over one-third of PICU survivors experience functional impairment in the immediate recovery stage, and 10-20% remain medically vulnerable 2 to 3 years after discharge.^{3,5} The loss of physical function may be magnified downstream by limited participation in fundamental activities of daily living. Risk factors for worse post-PICU functional status include baseline impairments, lengthy mechanical ventilation, and multi-organ dysfunction syndrome,^{3,6} which are already observed in critically ill children with COVID-19.

PICU survivors demonstrate poorer academic results and neuropsychological test performance than do their healthy peers. Impaired neurocognitive function among children may be sustained, persisting even 1 year after PICU discharge. Difficulties in memory and attention are especially frequent in children who survive sepsis. These obstacles may affect the developing child during periods when essential life skills and foundational education concepts are typically acquired. COVID-19 may further compound these issues, as social distancing disrupts education systems globally and potentially delays the recognition and intervention for cognitive impairment.

Children are also at risk of psychological sequelae after a PICU stay and may experience residual distress and anxiety. Between 17% and 62% of PICU survivors experience post-traumatic stress disorder (PTSD).⁷ These sequelae may be magnified by COVID-19–related practice changes, including restricted visitation (e.g., no sibling access), heightened anxiety due to health concerns and personal protective equipment, and co-located care of critically ill adults on the PICU, many with poor outcomes.

Collectively, mental health issues, along with functional and neurocognitive sequelae, have detrimental short- and long-term effects on the quality of life of critically ill children,^{7,8} with multiple reports of lower HRQOL 2 to 3 years after discharge. Risk factors for poor HRQOL among PICU survivors include admission diagnosis (sepsis, meningoencephalitis, and trauma), chronic co-morbidities, duration of PICU stay, and requirement for certain ICU therapies (cardiopulmonary resuscitation or invasive technology).⁸

The psychological well-being of the family may also be impacted. Parents of PICU survivors may exhibit symptoms of PTSD, anxiety, and depression soon after discharge and during the recovery process. Siblings also endure considerable stress and anxiety from both their sibling’s illness and reduced availability or attention from parents/caregivers who have competing demands on their time.⁹ Additionally, PICU admission may financially burden families who must reduce or forgo employment outside of the home, seek home nursing care, or pay for therapeutic services. Without doubt, these adversities will be heightened during the COVID-19 pandemic. Existing concerns about their own health status and that of others, distancing from social support networks, and economic hardship may contribute to an already difficult period of readjustment post-PICU.

Our growing understanding of PICS-p emphasizes the importance of developing

interventions to mitigate the burdens facing critically ill children and their families. Furthermore, the outcomes from critical illness need to be explored in the context of a global pandemic, wherein wider determinants of child and family health may be affected. Therefore, preventive multidisciplinary strategies within the PICU and high-quality fundamental critical care have never been more important. Interventions such as early rehabilitation, minimal but effective sedation, delirium assessment and prevention, fostering a sleep-friendly PICU environment, and family-centred care with early engagement have already begun a global cultural change, but much more work is necessary.¹⁰ In critically ill adults, these multicomponent strategies have been shown to improve many patient-centred outcomes, including duration of mechanical ventilation and mortality. Thus, advocacy for humanized care, with attention to reducing both mortality and long-term morbidity in adult ICUs, should be a priority and standard of care for both children and adults.

Post-ICU clinics, diary programs, and peer-support groups may provide additional benefits for patients and families.¹¹ PICU follow-up clinics can support children in the recovery process by facilitating physical and emotional rehabilitation. Collaboration across multiprofessional stakeholders, including critical care, psychiatry, neurology, developmental and behavioural paediatrics, general paediatrics, therapy services (speech, physical, and occupational), social work, and education will be essential to improving the diverse outcomes of children and their families who survive critical illness. In the context of a global pandemic, we must continue to identify research priorities for families, investigators, and clinicians¹² that can help us to understand, prevent, and treat the effects and implications of PICS-p and ultimately improve the quality of life of PICU survivors so no one is left behind.

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