What are the long-term outcomes for New Zealand survivors of critical illness?

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ABSTRACT

The COVID-19 pandemic has drawn considerable attention to the survival journey and recovery of patients post critical illness. A decade ago, the Society of Critical Care Medicine described the prolonged adverse health effects after a critical illness as the “post intensive care syndrome” (PICS). Evidence is emerging from Australia around the impact critical illness has on disability, mental health, cognitive function and health-related quality of life for patients this side of the world. For example, one study has shown that disability was highly prevalent in survivor’s six-month post hospital discharge, with 50% having mild disability and 25% with moderate to severe disability. Currently it is unknown what the survival journey is like for patients in New Zealand; how we should best measure outcomes for our population; and how we should support Māori and Pasifika patients post critical illness. Research is needed in every aspect of PICS in New Zealand. In 2022, the much-anticipated Survivorship of Patients Post Long Intensive Care Stay, Exploration/Experience in a New Zealand Cohort (SPLIT ENZ) study will explore important aspects of recovery and long-term outcomes for New Zealand survivors of critical illness.

The advent of the worldwide COVID-19 pandemic has highlighted two important considerations: firstly, that a high proportion of those with COVID-19 require intensive care, and secondly that COVID-19 is associated with long-term health consequences, so-called “long COVID.” Now, more attention has been given to the recovery journey of patients after a critical illness. Modelling from over a decade ago had already estimated that 50% more beds were needed by 2020, partly to accommodate an increasing proportion of those aged over 80 years of age needing ICU treatment. Despite admitting and treating an increasingly complex group of patients, mortality (an indicator of success of ICU treatment) is the lowest it has ever been in Australia. More than 90% of critically ill patients receiving ICU treatment survive to hospital discharge. Although these increasingly complex patient cohorts are surviving ICU, they also endure the persistent burden of survivorship: poorer outcomes and lingering health issues. Attention is appropriately cast on the capacity of ICUs to accommodate an increasing proportion of complex patients, but it is critical that resourcing and ongoing management of critical illness does not just stop at the ICU doors.

Survival is clearly an important primary aim of intensive care. However, there is a growing emphasis on long-term outcomes for ICU survivors. Poor mental health and functional disability are common and persistent in up to a quarter of patients in the year following ICU treatment. Marra et al, for example, showed that cognitive dysfunction, depression, anxiety or physical impairments are common after discharge, with 64% of ICU survivors experiencing poor outcomes at three months. Even at 12 months post discharge, these poor outcomes persisted for 56% of ICU survivors. This collection of adverse health effects is labelled “post intensive care syndrome” (PICS). Caregivers of patients also experience their own poor health, known as “PICS-family” (PICS-f): complicated grief responses, post-traumatic stress disorder (PTSD), depression, sleep disturbances and fatigue are components of this.

This viewpoint aims to explore the existing literature on PICS, with particular attention
on the New Zealand perspective. We identify under-researched areas of the post-ICU survivorship journey and important avenues for future research to address gaps in the literature.

Long-term outcomes following ICU: international perspective

Since PICS was first conceptualised nearly a decade ago by the Society of Critical Care Medicine, a growing body of evidence and knowledge has developed. Early studies highlighted that patients with respiratory failure and the acute respiratory distress syndrome (ARDS) have significant persistent morbidity, with poor quality of life, functional, cognitive and mental health issues for up to five years after discharge from an ICU. This likely reflects these patients having the highest acuity, which requires long durations of mechanical ventilation and time spent in ICU (over three weeks for half of patients).

Two important international studies report health outcomes in patients after discharge from ICU treatment in a broader range of conditions. Jackson and colleagues explored the prevalence of depression, PTSD and functional disability in around 800 ICU survivors. This cohort was comprised of patients who received more than 72 hours of mechanical ventilation or who were in ICU for five or more days and received treatment for respiratory failure or shock. The group was followed up three and 12 months after discharge. After three months, 37% of the cohort reported depressive symptoms, which were still present in 33% of the cohort after 12 months. The authors reported that depression was predominantly driven by physical rather than cognitive symptoms. After three months, 32% of patients reported deficits in activities of daily living, and after 12 months, 27% reported these deficits. Mental health and functional problems were associated with older age, but the authors were unable to identify an association between mental health and functional disabilities and delirium while in ICU. The ANZICS TEAM trial, a multi-centre, randomised controlled phase III study of early activity and mobilisation in patients expected to require prolonged mechanical ventilation, aims to improve these outcomes.

The study by Marra and colleagues reported a multi-centre cohort of 406 patients treated in an ICU. This study has been crucial in our understanding of the impact of critical illness on new impairments, as, unlike Jackson’s study, Marra and colleagues actively excluded a large proportion of patients with known pre-ICU baseline impairments in Activities of daily living (ADLs) or cognitive dysfunction. Although there are inherent difficulties in quantifying pre-existing conditions, such as cognitive dysfunction and mental health issues, before a critical illness, the authors were able to exclude a third of the patients. The major impetus was to highlight how critical illness contributes to the development of new disability and new PICS issues. Three months after discharge, between 25% and 33% of patients had new cognitive impairments, functional disabilities or depression, and for many these problems persisted after 12 months. Although most patients were assessed as having problems in one PICS domain (39% and 35% after three and 12 months respectively), a substantial proportion of patients had problems in two domains (19% and 16% after three and 12 months respectively), and problems in all three domains were reported in 6% and 4% after three and 12 months. Development of PICS was associated with older age, higher pre-illness clinical frailty scores, a longer duration of mechanical ventilation, ICU delirium and more comorbidities.

Long-term outcomes following ICU: Australian perspective

There are some important studies emerging from Australia that are starting to generate a greater understanding of the survival journey for patients in the Southern hemisphere. Haines et al reported five-year outcomes for 150 Australian patients recovering from critical illness. The mortality
after five years was 44%, with about half of the deaths within one year of discharge. This estimated mortality is consistent with international literature. For survivors, most of the recovery occurred in the first year after discharge. However, there was a substantial burden of PICS associated with reduced quality of life and poor mental health function. Hodgson et al's report on disability used the World Health Organization's (WHO's) Disability Assessment Schedule 2.0 (WHODAS) to map PICS to the WHO International Classification of Functioning, Disability and Health (ICF). The study evaluated disability after six months in 262 Australian survivors of ICU treatment. Disability was highly prevalent in survivors after six months: 50% had mild disability and 25% had moderate to severe disability. Those with moderate to severe disability had a longer duration of mechanical ventilation and were more likely to have a history of depression and anxiety. The authors suggested that WHODAS could be an important comprehensive tool by which to measure PICS in future studies. WHODAS may also provide an efficient and effective tool for measuring and quantifying PICS, which would be useful to both clinicians and researchers. There are currently only single domain tools to quantify PICS (over 250 tools exist), with wide variations in outcome measures reported in PICS research.

Heydon et al reported on the health-related quality of life, activities and needs of 50 survivors and their families. The study participants were assessed for PICS using the EQ-5D-5L, the Functional Activities Questionnaire and a novel “needs” questionnaire regarding healthcare service usage and socioeconomic status. The authors reported that participants had a decline in their health outcomes and a modest improvement after three months. There was also an increase in healthcare-service usage in the three-month period after discharge. The most frequent self-reported unmet need among these patients was for mental health support.

Return to work, return to study, and reintegration into social aspects of life are severely affected after discharge from ICU. Return to work is of major concern for patients and their families, and it has societal and community effects. Two of the studies discussed reported that between 30% and 61% of patients were still unable to return to work three and six months after ICU discharge.

Long-term outcomes following ICU: New Zealand perspective

Although Australia and New Zealand share some cultural and health-system similarities, there is little research more specific to New Zealand. The small number of studies regarding New Zealand patients focus more narrowly on long-term mortality or the ICU experience of patients, families and staff. There is no published research addressing the needs, or the best ways of supporting, Māori or Pasifika patients, either during ICU or once home recovering from a critical illness. It is also uncertain as to the most appropriate and useful specific outcomes for Māori or Pasifika patients and their whānau/fono; although instruments such as the EuroQol may be suitable, it would be useful to explore more specific relevant outcomes, as has been done in the context of stroke research in New Zealand.

Research about PICS in New Zealand could quantify survival and disability in order to ensure follow-up resources equitably, but also provide important local information about the expectations and needs for patients, clinicians and their family and whānau. Generating future research into specific resources and strategies to improve health outcomes for patients after critical illness would be vital. This could include post-discharge ICU follow-up clinics or peer-support groups for those who are experiencing PICS in New Zealand.

A research project beginning in 2022 (SPLIT ENZ: Survivorship of Patients Post Long Intensive Care Stay, Exploration/Experience in a New Zealand Cohort (ETHICS Id no:21/NTA/107)) will explore the New Zealand survivorship journey and the extent of disability and PICS, with a view to highlighting the needs of critically ill patients treated in New Zealand.
Major points

• International evidence highlights the profound effect that critical illness has on recovery, quality of life and disability for ICU survivors.
• Risk factors for worse outcomes include older age, frailty, number of comorbidities, prolonged mechanical ventilation and a history of mental health disorder.
• Australian research also identifies low return-to-work rates after ICU discharge.
• Mental health support is likely an unmet need after ICU discharge.
• High-quality studies evaluating the recovery journey of New Zealand survivors of ICU treatment are needed.

Conclusion

The COVID-19 pandemic and an increasing number of complex critically ill patients has brought greater attention to the capacity of our ICUs to admit and manage our sickest citizens. For those lucky enough to be discharged from the ICU, the journey is not over. Attention is urgently needed on the under-researched areas of the survivorship journey, the extent of disability and PICS. In 2022, the SPLIT ENZ study will explore exactly this—long term outcomes, level of disability and the recovery journey of New Zealanders—and highlight the specific needs for these patients during their journey. This will hopefully contribute to, and stimulate further research into, specific resources and strategies that will improve health outcomes in the future for New Zealand critically ill patients.
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Nil.

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