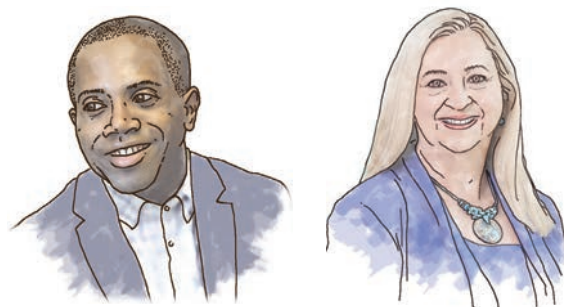


# Editorial

## UNDERSTANDING AND IMPROVING CRITICAL CARE SURVIVORSHIP

By Aluko A. Hope, MD, MSCE, and Cindy L. Munro, PhD, RN, ANP



In recent decades, the longevity revolution, coupled with improvements in our treatments for acute and chronic illnesses, has contributed to an unprecedented increase in the number of survivors of critical illness.<sup>1</sup> From multiple studies throughout the years, it has become clear that our intensive care unit (ICU) survivors experience high rates of new physical impairments and disabilities, new cognitive impairments akin to moderate traumatic brain injury, and psychological distress that can include depression or posttraumatic symptoms.<sup>2</sup> Their caregivers and loved ones suffer financial, social, emotional, and psychiatric impairments that can affect their quality of life. The terms *post-intensive care syndrome* (PICS) and *post-intensive care syndrome-family* (PICS-F) draw attention to these new and/or worsening impairments in ICU survivors and their families, respectively.<sup>3</sup> What factors are associated with PICS remains unclear, and developing and testing ICU aftercare models to address these survivorship issues is a pressing challenge for many health systems. We argue that the moral imperative to provide holistic care for ICU survivors is strong and that waiting for clinical research methods to inform the best care approaches would be foolhardy. We believe that health care systems need to design and evaluate care approaches that match their local contexts and that academic societies and other learning

communities in critical care can advance the field by incentivizing such innovation.

### Challenges in Understanding PICS Through Traditional Clinical Research

Despite the urgency to understand and improve the survivorship experience of ICU patients and their family members, there are many challenges to advancing the field through the traditional clinical research methods. First is the conceptual challenge of how to define both the exposure (critical illness) and the outcome (the morbidity of survivorship) of interest. For most adults, critical illness is not sudden.<sup>4</sup> More commonly, acute critical illness emerges as a complication of multiple chronic comorbidities or their treatments. The days in the ICU receiving life-support treatments are typically followed by more days on the hospital ward and often weeks to months in subacute rehabilitation facilities before the patient returns home. With such complex illness trajectories, how do we best define and catalogue the relevant exposures that place the patients at risk for PICS?

In describing the challenges of critical illness survivorship, critical care researchers are often imprecise in their terminology and would do well to ground their morbidity outcomes in terms of the World Health Organization's International Classification of Functioning, Disability and Health.<sup>5</sup> Treatments in the ICU cause impairments in organ function due to tissue damage; such damage can lead to transient or protracted limitations in functional activities when assessed in a standardized environment; functional limitations if prolonged

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can lead to disability, defined by the restriction in the participation of social roles; and how survivors value or perceive their level of disability is their health-related quality of life,<sup>5</sup> which is modulated by social and psychological factors. With so many potential domains for capturing morbidity, which ones are the most salient and how do researchers begin to capture the social, psychological, and societal/environmental modulators of patients' quality of life?

As more and more research studies in critical care attempt to explore outcomes relevant to PICS, the wide heterogeneity in the instruments being used to capture PICS and the lack of standardization of the timing of these outcome measures across studies make it difficult to compare results across studies. Recently, Needham et al<sup>6</sup> addressed this challenge in survivors of acute respiratory failure by using rigorous methods to achieve consensus among an international panel of researchers, clinicians, and survivors about a core set of outcome measures to be used in measuring PICS outcomes in acute respiratory failure. Such consensus-based recommendations facilitate comparisons across studies while still allowing researchers the flexibility of including additional outcome measures beyond the core outcome set.<sup>6</sup>

Another challenge in understanding PICS is how best to maximize the retention of research participants after discharge from the index hospitalization. The patients who are functioning well may have little time or interest in looking back at their negative illness experience, whereas the patients who are most impaired may be least able to interact over the phone or appear in person for an assessment. In addition, survivors of critical illness remain at high risk of death in the months after discharge from the hospital, and many of these PICS-related outcomes are more likely to occur in those patients who are at the highest risk of dying after hospitalization. Both loss to follow-up and the competing risk of death potentially introduce bias into estimates of outcomes from research studies and are important threats to the validity of research findings about PICS. More

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rigorous epidemiologic approaches to maximize retention of participants and statistical methods to account for the potential bias from loss to follow-up and from the competing risk of death will undoubtedly improve our ability to understand PICS.<sup>7</sup>

## Recent Research Advances in ICU Survivorship and Post-ICU Care

In this issue of the journal, we present several articles relevant to ICU survivorship and ICU aftercare. Biason et al,<sup>8</sup> in a prospective cohort study conducted in Brazil, compared morbidity and mortality 2 years after ICU discharge in patients with versus without sepsis. The researchers did telephone follow-up in a large cohort of ICU survivors to assess for survival, hospital readmissions, pain, and functional status. They found higher mortality, pain, and numbers of hospital readmissions and lower performance status in the survivors with sepsis than in the survivors without sepsis. Bouvet et al<sup>9</sup> present a brief report showing that stroke patients who required mechanical ventilation had about a 50% hospital mortality and that only 32% had a favorable neurological outcome at 1 year.

In patients who undergo coronary artery bypass surgery (CABG), postoperative delirium (POD) is common and has been associated with prolonged hospital stays and long-term cognitive impairment in survivors.<sup>10</sup> Wu et al<sup>10</sup> investigated the trends in levels of serum interleukin 6 (IL-6), a proinflammatory cytokine associated with the development of POD, in CABG patients with and without POD. In a sample of 266 CABG patients (85 with POD and 181 without POD), patients with POD had higher levels of IL-6 at the 6th, 12th, and the 18th postoperative hours, although at the 18th postoperative hour the associations were robust to adjustment for other confounders. These findings are consistent with the emerging role of plasma biomarkers measured early in the course of critical illness in predicting the risk of acute brain dysfunction and may also suggest that inflammation plays a key role in the development of delirium and cognitive impairment in postoperative patients.

As critical care rises to the moral challenge of developing approaches to improve the recovery process of our survivors and their families, the challenge will be to design and test innovative interventions and care models for a health care system better equipped for the heroism of rescue than for the incremental art of survivorship care.<sup>11</sup> Cairns et al<sup>12</sup> report on the feasibility of a brief innovative, nonpharmacological

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stress-management intervention called Sensation Awareness Focused Training that elicits a rapid calming response in individuals and may be useful in alleviating the stress of being a caregiver. The sample size is small, but the results are encouraging enough to warrant a larger, more rigorous clinical trial.

Although many health systems are designing post-ICU recovery clinics and/or peer support programs to address PICS, the evidence base for effectiveness of these interventions is slim. In the Clinical Evidence Review, Halm<sup>13</sup> reviews the role of ICU diaries and/or follow-up consultation in reducing anxiety, depression, posttraumatic stress disorder, or physical/cognitive impairments in critical illness survivors. Eaton et al<sup>14</sup> review the current emerging practices in ICU aftercare with a focus on the role of the nurse leader. Solis et al<sup>15</sup> describe their experience starting a peer support group for survivors of critical illness and how they struggled to get patients to attend this group despite many months of careful planning.

In order to advance the innovation in care models for survivors, we think it is important that health systems find ways to accumulate and share the knowledge they have gained from their successes and failures in trying to improve PICS. For example, in 2015, the Society of Critical Care Medicine (SCCM) established a THRIVE task force aimed at providing resources and education for ICU survivors and their families related to PICS.<sup>16</sup> As part of this THRIVE task force, SCCM sponsored a Peer Support Collaborative and a Post-ICU Clinic Collaborative, 2 international networks of clinicians interested in testing and innovating models of providing ICU aftercare. These networks and the SCCM-sponsored Collaborative Assessment of ICU Recovery Needs (CAIRN) study have been the source of multiple recent high-impact publications that have produced generalizable insights regarding the barriers, facilitators, and strategies for implementing ICU aftercare processes and insights into the key mechanisms by which post-ICU activities can drive improvements in ICU care.<sup>17,18</sup> We think that international, interdisciplinary collaboration across health systems will be the crucial means through which we can accelerate the pace of innovation in post-ICU care, and we hope that other academic and learning societies join SCCM in facilitating innovation and collaboration to address ICU survivorship.

The statements and opinions contained in this editorial are solely those of the coeditors in chief.

## FINANCIAL DISCLOSURES

None reported.

## REFERENCES

1. Zimmerman JE, Kramer AA, Knaus WA. Changes in hospital mortality in United States intensive care unit admissions from 1988 to 2012. *Crit Care*. 2013;17:R81.
2. Desai SV, Law TJ, Needham DM. Long-term complications of critical care. *Crit Care Med*. 2011;39(2):371-379.
3. Inoue S, Hatakeyama J, Kondo Y, et al. Post-intensive care syndrome: its pathophysiology, prevention, and future directions. *Acute Med Surg*. 2019;25(6):233-246.
4. Weissman GE, Halpern SD. Kairotrop: discovering critical illness trajectories using clinical phenotypes with big data. In: Vincent JL, ed. *Annual Update in Intensive Care and Emergency Medicine 2016*. Basel, Switzerland: Springer; 2016.
5. Iwashyna TJ, Netzer G. The burdens of survivorship: an approach to thinking about long-term outcomes after critical illness. *Semin Respir Crit Care Med*. 2012;33:327-338.
6. Needham DM, Sepulveda K, Dinglas VD, et al. Core outcome measures for clinical research in acute respiratory failure survivors: an international modified Delphi consensus study. *Am J Respir Crit Care Med*. 2017;196(9):1122-1130.
7. Murphy TE, Gill TM, Leo-Summers LS, Gahbauer EA, Pisani MA, Ferrante LE. The competing risk of death in longitudinal geriatric outcomes. *J Am Geriatr Soc*. 2019;67:357-362.
8. Biason L, Teixeira C, Haas JS, da Rocha Cabral C, Friedman G. Effects of sepsis on morbidity and mortality in critically ill patients 2 years after intensive care unit discharge. *Am J Crit Care*. 2019;28(6):424-432.
9. Bouvet P, Murgier M, Pons B, Darmon M. Long-term outcomes of critically ill patients with stroke requiring mechanical ventilation. *Am J Crit Care*. 2019;28(6):477-480.
10. Chen Y, Lu S, Wu Y, et al. Change in serum level of interleukin 6 and delirium after coronary artery bypass graft. *Am J Crit Care*. 2019;28(6):462-470.
11. Gawande A. Tell me where it hurts. *The New Yorker*. 2017; January 23:36-45.
12. Cairns PL, Buck HG, Kip KE, Rodriguez CS, Liang Z, Munro CL. Stress management intervention to prevent post-intensive care syndrome—family in patients' spouses. *Am J Crit Care*. 2019;28(6):471-476.
13. Halm M. Intensive care unit diaries, part 2: impact of diaries and follow-up consultation on post-intensive care syndrome. *Am J Crit Care*. 2019;28(6):488-492.
14. Eaton TL, McPeake J, Rogan J, JoÚson A, Boehm LM. Caring for survivors of critical illness: current practices and the role of the nurse in intensive care unit aftercare. *Am J Crit Care*. 2019;28(6):481-485.
15. Solis S, Bernot S, Kover N. A lesson in failure: when innovation in post-intensive care unit management yields negative results. *Am J Crit Care*. 2019;28(6):486-487.
16. Society of Critical Care Medicine: THRIVE Peer Support Collaborative and Post ICU Clinic Collaborative. 2019. <https://www.sccm.org/Research/Quality/THRIVE>. Accessed August 28, 2019.
17. Haines KJ, Sevin CM, Hibbert E, et al. Key mechanisms by which post-ICU activities can improve in-ICU care: results of the international THRIVE collaboratives. *Intensive Care Med*. 2019;45(7):939-947.
18. Haines KJ, McPeake J, Hibbert E, et al. Enablers and barriers to implementing ICU follow-up clinics and peer support groups following critical illness. *Crit Care Med*. 2019;47(9):1194-1200.

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