

# Symposium

## Introduction

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## Patient and Family Post-Intensive Care Syndrome

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For years it has been known that many patients who survive critical illness do not return to their original state of health, resulting in long-term consequences of critical illness.<sup>1</sup> Weakness acquired in the intensive care unit (ICU) is a physical consequence occurring in 25% to 80% of patients who receive mechanical ventilation for more than 4 days and in 50% to 75% of patients with sepsis. Nearly all patients affected with ICU-acquired weakness have symptoms that persist years later.<sup>1,2</sup> Issues with cognitive function occur in 30% to 80% of ICU survivors and include memory, planning, problem-solving, visual-spatial, and processing problems.<sup>1,3</sup> Cognitive consequences may improve during the months after discharge. However, 25% of patients with adult respiratory distress syndrome (ARDS) have long-term persistent cognitive impairment 6 years after discharge.<sup>4</sup> In several studies,<sup>1-3</sup> survivors of severe sepsis who were more than 65 years of age still had cognitive impairment 8 years after hospital discharge. Anxiety, depression, and sleep disturbances can last from months to years.<sup>1,2</sup> Survivors also experience posttraumatic stress disorder (PTSD) long-term, with an incidence between 10% and 50% and persisting for up to 8 years.<sup>2,5,6</sup> Follow-up studies longer than 8 years have not been reported, and for some survivors, these consequences of critical illness may not resolve.

Together, these physical, cognitive, and mental changes may affect socioeconomic status and quality of life. Caregiving assistance is required by 50% of patients 1 year later, consisting of help with daily living activities and in some cases a need for full care. One year following discharge, 50% of ARDS survivors have not returned to work.<sup>4</sup> One year after discharge, less than 10% of patients who required more than 4 days of mechanical ventilation are alive and independent.<sup>1-3,5,7</sup>

Families of survivors and nonsurvivors can have difficulty coping with the ICU experience,<sup>8</sup> encountering psychological and social consequences of exposure to critical illness.<sup>2</sup> Anxiety is present in 10% to 75% of families, with symptoms of PTSD reported in 8% to 42% of families and in up to 50% of decedents or parents of critically ill children.<sup>8</sup> At discharge, one-third of families are taking medications for depression or anxiety. As in ICU survivors, these psychological consequences may remain for many years.<sup>8-11</sup> In families of decedents, complicated grief may occur.<sup>8,12</sup>

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## The Birth of Post-Intensive Care Syndrome and Post-Intensive Care Syndrome-Family

In 2010, the Society of Critical Care Medicine (SCCM) convened a task force to examine the long-term consequences of critical illness. This group of scientists and clinical experts gathered for a summit.<sup>2</sup> The state of the science was reviewed for outcomes associated with critical illness for both patients and patients' families. Participants agreed to refer to the new or worsening mental health, physical, and cognitive outcomes that linger past the ICU stay as post-intensive care syndrome or PICS. When those outcomes affect patients' family members, an "F" is added and the term becomes PICS-F.

### Raising Awareness

One of the major goals of the stakeholder conference was to identify and promote strategies to increase awareness of PICS and PICS-F outside the critical care health care community and among ICU survivors and their families. Attendees have given presentations to their peers, published in their journals, and begun initiatives toward this end. It became clear to us that a transfer out of the ICU should include a functional reconciliation to assess distance from baseline condition before hospitalization.<sup>7</sup> This checklist would follow the patient's progress through their postdischarge care and serve to inform caregivers of potential often-missed issues.

The SCCM THRIVE Initiative is a grant-funded project to test a program of peer-to-peer support to treat PICS and PICS-F. Demonstration projects are in progress.<sup>13</sup> SCCM's ICU Liberation Task Force is developing standard slide sets and work tools to inform clinicians about the efforts to reduce PICS through appropriate and minimal sedation, mobility programs, and delirium prevention and assessment.<sup>14</sup> During a second summit, the ABCDE bundle, which addresses the PICS risk factors of delirium, immobility, sedation, and duration of mechanical ventilation,<sup>14-16</sup> was endorsed as a method of minimizing PICS. The letters in ABCDE stand for airway (A), spontaneous breathing trials (B), care coordination and communication between disciplines (C), delirium assessment (D), and early mobility (E). An FGH was added to the ABCDE mnemonic to address issues with the family and transitions

of care: family follow-up referrals and functional reconciliation (F), good handoff communication (G), and handout educational materials on PICS and PICS-F (H).<sup>17,18</sup>

To promote awareness in patients and families, YouTube videos have been created by patients and their families to describe their experiences.<sup>19</sup> We established a definition of PICS on Wikipedia<sup>20</sup> and created a new PICS brochure for patients and their families that is available through the SCCM website ([www.sccm.org](http://www.sccm.org)).<sup>19</sup>

### This Issue: A PICS and PICS-F Primer

Even though the problem of PICS and PICS-F is clearly recognized, much more can be learned about effective interventions to minimize symptoms and conditions experienced by ICU survivors and their families. In this issue, we have invited authors to describe strategies they are exploring to improve outcomes. It should be recognized that the science supporting these strategies is young. However, in the absence of strong evidence, we have a duty to take action in the best interest of the health of our community given what is known today. To that end, this issue is designed as a primer to promote new ideas and programs targeted at improving care in and out of the ICU to prevent, recognize, and treat PICS and PICS-F.

We have asked each team of authors to provide replicable steps for starting new initiatives in care. They have also invited a survivor and/or family informant as coauthor to keep the focus on the real issues and values at the forefront of why practice needs to change. We learn most when we listen, and we hope that the guidance offered in these articles will provide a compelling impetus for change.

The details of implementing an early mobility program in the ICU are described by Ramona Hopkins and her team from Intermountain Medical Center in Utah. Mary McCarthy and her nursing colleagues from Madigan Army Base in Tacoma, Washington, describe their fledging diary program and the steps needed to implement diaries in the ICU. Diaries have been used in the Netherlands and Europe for more than 20 years with some promising results for both survivors and their families.<sup>21-25</sup> Use of diary programs in the United States has not been reported before. Moving outside of the ICU, Huggins and colleagues discuss how to establish a post-ICU clinic to

help patients and families who are dealing with PICS and PICS-F. Finally, Mark Mikelsen, a leader from the SCCM THRIVE Initiative, describes one of the demonstration projects in progress to establish peer-to-peer support programs to help survivors and families after an ICU stay.

In addition to the articles in the symposium series, 2 of the regular columns in this issue also address the topic of PICS and PICS-F. In the Drug Update column, Joanna Stollings and colleagues discuss medication management options to ameliorate PICS. The ethics of PICS and PICS-F are explored through a historical case study in the Ethics column. It was originally planned that Jessica, an ICU survivor whose story is publicly available on video and in print,<sup>17,26</sup> would coauthor that manuscript. However, with much regret, we report that she died this year, presumably of complications of her ICU stay many years ago. We dedicate this issue to Jessica and all those who share their ICU experiences with us so that we can learn from them.

These articles will provide practical guidance on how to start programs like these in your own organization, measures of success for quality monitoring, and a list of potential research questions related to addressing the gap in evidence.

In conclusion, it is our goal through this issue not only to raise awareness surrounding PICS and PICS-F, but to stimulate adoption of strategies to enhance family-centered care, to decrease the modifiable risk factors of PICS (immobility, oversedation, duration of mechanical ventilation, and delirium), and to study the effects of these strategies on outcomes. This is an important time for critical care nurses and nurse scientists. Interventions are being tested to address PICS and PICS-F, and further research is needed in all areas related to these potentially devastating syndromes.

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