

# Reconceptualizing post-intensive care syndrome: Do we need to unpick our PICS?

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## 1 | POST-INTENSIVE CARE SYNDROME – CHALLENGES AND OPPORTUNITIES

Clinical research and technological innovation have greatly improved survival after admission to intensive care units (ICU), such that around 90% of patients are discharged.<sup>1</sup> However, their recovery is often complicated and partial.<sup>2</sup> Longitudinal studies have demonstrated that physical, cognitive, and psychiatric morbidity are prevalent post-discharge, with impairment often persisting for years.<sup>3–6</sup> Concerned with promoting quality of survival, the Society of Critical Care Medicine (SCCM) convened a 2-day conference in 2012 to develop strategies for improving long-term outcomes of critical illness for patients and family members.<sup>2</sup> The term “post-intensive care syndrome” (PICS) was coined to represent impairment and disability arising after a critical illness and persisting beyond acute hospitalization.

Widespread adoption of the term has contributed to achieving the longer-term aims of the conference by improving awareness and education around post-ICU recovery and identifying the research gaps and practical barriers challenging quality care provision after discharge.<sup>2</sup> Moreover, the PICS label has focused clinical and research attention on survival quality and has drawn attention to the personal, social, and economic costs of ongoing impairments. The term also helped to raise awareness and garner support for those who do not make a full post-ICU recovery.<sup>7</sup> Clinicians and researchers have focused on identifying risk factors, developing interventions to reduce the risk and impact of PICS,<sup>8</sup> and various interventions used within and beyond the ICU environment.<sup>8</sup>

Within ICU, the PADIS guidelines (Pain, Agitation, Delirium, Immobility, and Sleep Disruption)<sup>9</sup> and ABCDEF (A - Assess, prevent

and manage pain, B - Both SAT and SBT, C - Choice of analgesia and sedation, D - Delirium: assess, prevent and manage, E - Early mobility and exercise, F - Family engagement and empowerment) bundle<sup>10</sup> have been developed, which recommend pharmacological, non-pharmacological, and environmental measures to reduce the incidence of PICS. Post-ICU, there are peer support groups and clinics, such as the THRIVE initiative,<sup>11</sup> as well as patient/family education initiatives.<sup>8</sup> Some interventions have improved outcomes, but a recent meta-analysis showed that observed short- and medium-term benefits do not persist,<sup>12</sup> and a recent Australian national survey demonstrated that only 2% of ICUs offer a post-ICU clinic to primarily screen for post-ICU complications and refer on as needed.<sup>13</sup>

## 2 | THE CHALLENGE IN RESPONDING TO POST-INTENSIVE CARE SYNDROME

One possible explanation for the poor response and uptake of PICS treatment is the way the term has been applied, both in selection of intervention candidates and as an outcome measure. Increasingly, the term is used as if describing a single condition, with characteristic symptoms.<sup>14</sup> With PICS used to encompass, separately or collectively, physical, psychological, and cognitive impairment, the utility of the syndrome in research and clinical practice is undermined. For example, if clinically distinct causes of dyspnoea, such as asthma, pneumonia, and pulmonary embolism, were similarly conflated, it would be impossible to demonstrate the clinical efficacy of the indicated treatments and inhibit clinicians from applying targeted therapies (such as corticosteroids,

antibiotics, or anticoagulants), instead being confined to treatments that provide some universal benefit (such as oxygen). Admissions to ICU may be planned or emergent, resulting from misfortune (such as sepsis or a perioperative complication), misadventure (such as reckless driving), or deliberate acts (such as suicide attempt). Combined with the patient's premorbid coping strategies, support network, comorbidities, and their cognitive and physical function, the events leading to ICU admission will have a profound impact on how the patient perceives his or her experiences in intensive care and his or her subsequent recovery.<sup>15</sup>

### 3 | HYPOTHETICAL CASE SCENARIOS

To illustrate this, two fictional patients requiring heart transplant are described below. Both of them could be described as having "PICS"; however, their experiences and needs before, during, and after intensive care differ considerably:

#### 3.1 | Patient A

This case is of a 21-year-old fashion design student who engages in musical theatre part time to fund her studies. She maintains a healthy diet and exercises regularly, often hiking long distances on weekends. She contracts a viral illness while taking a year out of her studies to travel and returns home early. She presents to the hospital with lower limb oedema and a poor exercise tolerance. She is found to have a rapidly deteriorating ejection fraction and is placed on the transplant waiting list. A suitable organ quickly becomes available, and within a few weeks of returning from her trip, she is admitted in the middle of the night for a transplant. Her surgery is uncomplicated, followed by a planned ICU admission. During her stay, she develops delirium. She hears her boyfriend stuck in the air conditioning vents and sees cockroaches crawling through her bedsheets. For a period, she believes she is still overseas and has been kidnapped. She is restrained by staff when she tries to get out of bed, requiring sedation and comfort from her family to settle. A year after leaving hospital, she has been unable to return to acting or hiking and has been missing classes at university. She is wondering whether to continue with her studies at all as her previous interests all seem small in the face of her own mortality. Her cardiologist advises her that, while her new heart is performing well, over time, its function will slowly deteriorate, and she is likely to require a second transplant eventually. She no longer likes her reflection and hates her sternotomy scar. Previously described as "easy-going", she is now anxious and irritable generally and has lost some of her friends because of this. Ambulance sirens or her morning alarm cause flashbacks to her ICU stay and panic attacks. She still has nightmares in which she is trapped in a confined space.

#### 3.2 | Patient B

This is a case of a 66-year-old retired plumber. He was diagnosed with cardiomyopathy following his second myocardial infarction several

years ago. His ejection fraction has been slowly deteriorating over the past few years, and he has been on the waiting list for a transplant for some time. It has been challenging finding a matching organ, and a friend had remarked that organ donations often come from young people in vehicular accidents. Shortly after this conversation, he is advised that a donor organ has become available and is admitted to hospital. He experiences a prolonged episode of hypotension peri-procedurally and takes longer than expected to wake up postoperatively. He finds his ICU stay mostly boring, spending several days studying the ceiling and finding it painful to breathe deeply. He has no family to visit him, having lost his wife to cancer a few years ago and having chosen not to have children. As he starts to mobilize, he has a warm conversation with the patient in the bay next to his. That evening, he does not sleep because of the noise of the unsuccessful attempts to resuscitate that patient for a sudden cardiac arrest. B is discharged shortly afterwards into a large and empty house, which he struggles to keep clean because of ongoing pain. He is also finding it more difficult to remember where he placed things and struggles to concentrate on his favourite television shows. He moves his bed into the living room and no longer goes upstairs. He finds it even harder to get out of the house to socialize or attend appointments. He forgets to take his medications or do his exercise programme. He feels he is "wasting" his new heart and ruminates on who the donor was and what happened to them.

### 4 | A WAY FORWARD

These cases have been designed to demonstrate the complex biopsychosocial interactions that can occur before, during, and after ICU and highlight the need for a more nuanced approach to both research and treatment. Patients A and B are unlikely to respond to the same intervention. Their experiences before, during, and after their ICU stay differ substantially. Their challenges and needs are equally disparate. It is likely that an interventional study incognizant to these nuances would not find a positive result. An effective intervention for patient A would fail to meet the needs for patient B, whose poor response may obscure the efficacy of that treatment and vice versa. Improving ICU outcomes is a social and economic imperative and depends on recognizing PICS as an umbrella term, encompassing a myriad of pathophysiological, psychological, and social processes. The challenge to the researcher is now to develop a detailed understanding not of "what works in treating PICS" but rather "what works, for whom, and in which circumstances, to deliver their desired outcomes". The challenge to the clinician is then to identify what underlies his or her individual patient's complicated recovery and which interventions are best suited to help, and when.<sup>12</sup> When a patient has a complicated recovery following ICU stay, the first goal should be to identify the modifiable problems impeding his or her recovery, which will then lead to individualized care. The patient with primarily psychological sequelae is unlikely to benefit from an intervention focused on physical rehabilitation and vice versa. Furthermore, the experiences before and within ICU, as well the situation into which they will be

discharged, must be considered for both patients and their family during recovery. Implementing individualized care is essential to improving the quality of life in those with PICS. The recognition of this syndrome has been important in ensuring that the clinical needs of patients following discharge from ICU are recognized. The challenge now is to implement appropriate care for those with PICS, so their opportunity to recover is maximized.

## 5 | IMPACTS

The term “post-intensive care syndrome” (PICS) was coined in 2012 to focus attention on the quality of survival post-ICU. This has supported investment in understanding risk factors and developing diverse interventions to reduce the impact of impairments post-discharge from the ICU. However, “PICS” is often used as a unitary term to encompass diverse manifestations. This reification of PICS as a uniform entity fundamentally challenges ongoing improvement in outcomes. The population described are heterogeneous and experience a wide range of problems. They are thus unlikely to respond uniformly to interventions provided either during ICU admission or following discharge. We contend that, to optimize outcomes, research and clinical efforts could focus on how patient-specific factors interact with the broader processes that complicate recovery. Improving clinical outcomes will almost certainly require a combination of universal multi-disciplinary interventions, which address common factors, combined with targeted approaches tailored to individual patient factors.

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