# Improving Critical Care Survivorship

## A Guide to Prevention, Recovery, and Reintegration

Kimberley J. Haines
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*"We dedicate this book to the many lives lost during the COVID19 global pandemic – including the frontline healthcare workers and their families, thank you for your service.*

*We also dedicate this book to the survivors of critical illness – before the pandemic, and as a result of the pandemic. Our hope is that as a critical care community, we can continue to improve the way we care for survivors and their families into the future."*

# Foreword

> Ring the bells that can still ring
> Forget your perfect offering
> There is a crack, a crack in everything
> That's how the light gets in
> *Leonard Cohen, "Anthem"*

In the early days of critical care, we learned to keep dying people alive. We celebrated our "wins" when patients survived to leave the Intensive Care Unit. But it wasn't long before we began to follow our patients beyond the automatic doors of the ICU, down the dark, twisted path through hospital wards, care facilities, home if they were lucky, back to the hospital if they were not. We learned of our patients' suffering that often lasted for months, for years. The broken bodies, broken minds, and broken homes that we've come to know as the Post-intensive Care Syndrome. The crack in critical care.

Post-critical illness survivorship can be cruel—to patients, to their loved ones, even to those of us who have dedicated our professional lives to providing care and searching for elusive cures. It can be tempting to look back at what has been lost, to lose hope. However, as Leonard Cohen wistfully reminds us, we must ring the bells that can still ring.

The bells ring in a new era of improving survivorship after critical care, bringing a new community together, across professions and disciplines, across continents, across the divide that previously separated health care providers from patients and families. Our community has been moved to action—generating an evidence base for treatment and prevention of PICS where the evidence exists, moving forward with innovation where evidence is lacking. In many ways, the challenge of critical care survivorship has given us new hope and a new, fulfilling mission that has let the light back in.

This book shares that light with clinicians and researchers, sharing best practices, new ideas, and practical advice. The visionary editors and authors remind us how big the world of critical care survivorship is, spanning from the ICU to the community and around the globe. They share their vision of a future state where we work together to solve these challenges starting today. Armed with this book and united as a global, interprofessional community, we walk in the light.

Portland, OR, USA Catherine L. Hough

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# Part I
# Preventing Adverse Outcomes in the ICU

# Chapter 1
# Preventing PICS with the ABCDEF Bundle

**Kaele M. Leonard, Matthew F. Mart, and E. Wesley Ely**

## Introduction

Over the last several decades, advances in critical care medicine have led to significant treatment improvements in diseases with high mortality, and in return, an increasing number of patients survive their admission to an intensive care unit (ICU) [1]. With those successes, there is a down-side; increasingly, survivors are burdened with persistent impairments in their cognitive abilities, their physical function, and their mental health. These impairments are identified as part of the post-intensive care unit syndrome (PICS). [2] Most ICU survivors will be impacted by one or more of these impairments after their acute illness, with PICS affecting numerous areas of their lives, including their employment and performance of activities of daily

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living [3–5]. Additionally, a substantial burden is placed on family and caregivers as they help care for these survivors [6, 7]. Family members of critically ill patients and survivors are affected both physically and psychologically, which is described as post-intensive care unit syndrome—family (PICS-F) [8]. These manifestations of PICS, and the risk factors for its development, have transformed the care of the critically ill patient. Preventing PICS has been increasingly understood to begin at the onset of critical illness. Minimizing iatrogenesis, preventing and managing delirium, mobilising early to prevent acute muscle wasting, and engaging families are all evidence-based interventions shown to reduce the numerous complications of critical illness. These individual processes, combined into a synergistic bundle of care called the ABCDEF Bundle, represent the most significant advances in preventing PICS and the sequelae of critical illness in the last two decades.

In response to the growing number of impairments noted in survivors of critical illness, the American College of Critical Care Medicine originally created the Pain, Agitation, and Delirium (PAD) guidelines for the assessment, treatment, and prevention of these concerns in the ICU [9], which were updated in 2018 as the Prevention and Management of Pain, Agitation/Sedation, Delirium, Immobility, and Sleep Disruption in the Adult Patients in the ICU (PADIS) Guidelines [10]. A large-scale quality improvement programme, developed by the Society of Critical Care Medicine (SCCM), used these guidelines to create the ABCDEF Bundle, or ICU Liberation Bundle, to address pain, agitation, and delirium in the ICU (Fig. 1.1) [11]. The components of the bundle include the following: **A**ssess, prevent, and manage pain; **B**oth spontaneous awakening trials (SAT) and spontaneous breathing trials (SBT); **C**hoice of analgesia and sedation; **D**elirium— assess, prevent, and manage; **E**arly mobility and Exercise; and **F**amily engagement and empowerment. Each individual component of the bundle is evidence-based and validated in multiple clinical trials, and the bundle combines the individual impact of each intervention into a synergistic process of care that improves ICU outcomes and mitigates the burden of PICS in survivors.

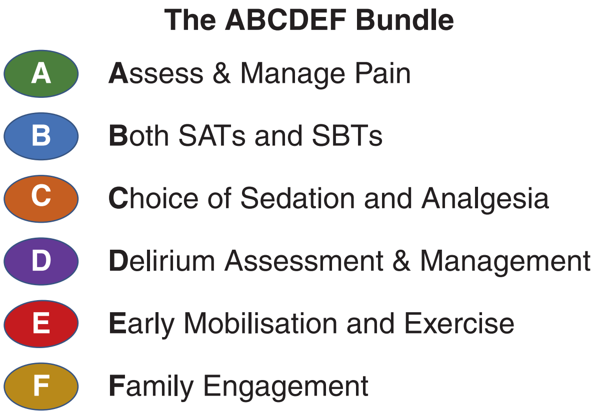


**Fig. 1.1** ABCDEF bundle (original graphic adapted with permission from icudelirium.org and Ely [11]); SAT spontaneous awakening trial, SBT spontaneous breathing trial

## Assess, Prevent, and Manage Pain

During critical illness, most patients experience pain, with one-half reporting significant pain, while only a minority of patients undergo any assessment and treatment for pain prior to interventions in the ICU [12, 13]. The gold standard for assessing pain in the hospital is self-reported pain using a 1 to 10 numerical rating scale [9]. However, in patients who are unable to provide self-reported pain due to their disease or mechanical ventilation, pain can be assessed using nonverbal pain scales. Two of the most common, validated tools are the Behavioral Pain Scale (BPS) and the Critical Care Pain Observation Tool (CPOT) [14]. For example, the BPS uses facial expression, movement of the upper limbs, and compliance with mechanical ventilation on a scale from zero to 12, with a score of five or higher reflecting uncontrolled pain [15]. Similarly, the CPOT uses components of facial expression, body movement, muscle tension, and compliance with ventilator or vocalization for extubated patients, on a scale from zero to eight, with a score of three or greater indicating uncontrolled pain [16].

The PADIS guidelines recommend frequent pain assessment and treatment, assessing pain using any of the previous tools at least four times per shift and as needed, such as before using sedative or prior to procedures [10]. The recommended pharmacologic treatment is parenteral opioids for non-neuropathic pain with the use of gabapentin or carbamazepine in cases of neuropathic pain. These should be used as a component of a multimodal approach with adjunctive nonopioid analgesics, such as acetaminophen or nonsteroidal anti-inflammatory drugs, and nonpharmacologic interventions, such as repositioning and use of heat/cold, to reduce opioid requirement. Other modalities, such as regional analgesia, can be used in special circumstances, such as post-operative populations and patients with traumatic rib fractures [9].

Poorly managed pain puts patients at risk for multiple complications. For example, undertreated pain and excessive use of opioids are risk factors for delirium [9]. Untreated pain also potentially limits the ability of patients to mobilise and participate in early exercise during critical illness. It can also limit inspiratory effort, further complicating weaning from mechanical ventilation. All of these circumstances, through a cascading series of events, can increase the risk of PICS for patients. It is vital to actively assess, prevent, and manage pain, not only for improving patient comfort and reducing suffering, but to also prevent and manage several risk factors for the development of PICS.

## Both Spontaneous Awakening Trials and Spontaneous Breathing Trials

Spontaneous awakening trials (SATs), or daily sedative interruptions, are a recommended approach to sedation management and minimization in the ICU. Practically, it is a nurse-driven protocol involving a safety checklist for sedation cessation.

Should patients pass the safety screen as administered by the bedside nurse, then all continuous sedative infusions are stopped and the patient is carefully monitored. If needed, such as for significant agitation or tachypnoea, sedation and analgesia are started at half the previous dose [17]. In a single-centre, randomized controlled trial of 128 mechanically ventilated patients, daily SATs reduced duration of mechanical ventilation by 2 days and ICU length of stay by 3.5 days, as well as reduced ventilator-associated pneumonia (VAP) and complications [18, 19]. Additionally, with regard to the safety and long-term outcomes, patients who underwent daily SATs reported fewer signs of PTSD with similar rates of anxiety and depression at follow-up after critical illness [20].

Once a patient passes an SAT, respiratory therapists or critical care physicians then perform a spontaneous breathing trial (SBT) following a safety screen [17]. Routine performance of daily SBTs has been shown to reduce the median of days of mechanical ventilation [21]. SBTs are performed either by placing the ventilator in a spontaneous breathing mode such as pressure support ventilation or by attachment of a T-piece. Once a patient has tolerated an SBT for at least 30 minutes without adverse response, such as hypoxia, tachycardia, or tachypnoea, they meet criteria for extubation [22, 23]. SBTs have been studied with varying time frames, from 30 minutes to 2 hours, with 30-minute trials showing similar efficacy and fewer adverse events than two-hour trials. Notably, Subira and colleagues demonstrated that patients that underwent 30-minute SBTs as compared to two-hour T-piece trials were more likely to remain successfully extubated [24].

While SATs and SBTs have improved outcomes as individual practices in mechanical ventilation, the daily, paired coordination of both SATs and SBTs has demonstrated even greater success in liberating patients from mechanical ventilation (Fig. 1.2). In the multicentre, randomized controlled Awake and Breathing Controlled (ABC) Trial, when pairing both SATs and SBTs compared to standard sedation and daily SBT, patients were extubated 3 days sooner, ICU and hospital length of stay were reduced by 4 days, and there was a 14% absolute reduction in mortality at 1 year with number needed to treat of 7 [25]. Pairing of both SATs and SBTs represents a significant advance in our approach to mechanical ventilation and represents the standard of care in liberating patients from the ventilator. Using best practices to facilitate prompt liberation from mechanical ventilation reduces the downstream complications of mechanical ventilation, including muscle weakness, delirium, and prolonged ventilation, limiting the physical deficits so often manifested in ICU survivors with PICS.

## Choice of Analgesia and Sedation

Frequent assessment of pain and sedation targets for goal-directed use of sedative agents is the current standard of care in critically ill patients needing such interventions [10]. It is recommended to use the validated sedation and level of arousal assessment tools, such as the Richmond Agitation-Sedation Scale (RASS) and the

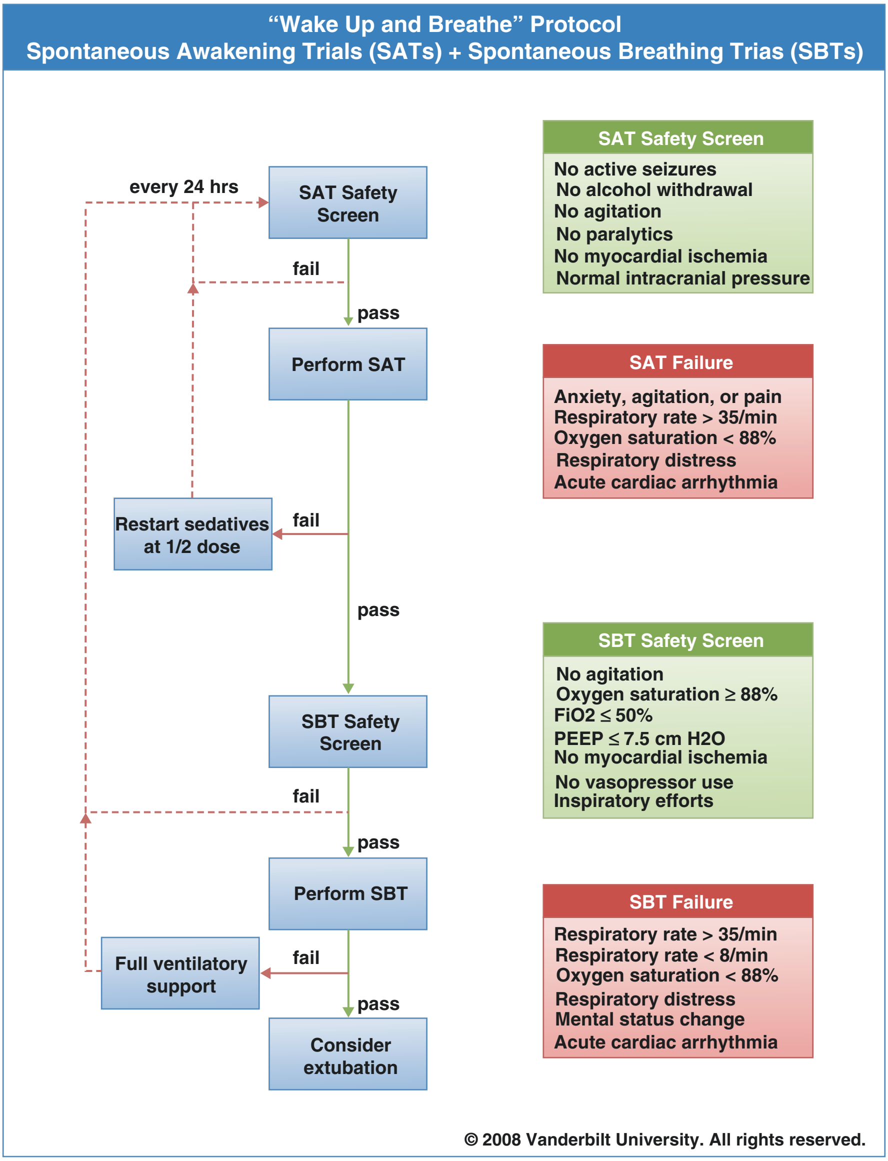


**Fig. 1.2** "Wake Up and Breathe Protocol"—paired SATs and SBTs. (Adapted with permission from ICU Delirium, Vanderbilt University Medical Center—icudelirium.org); FiO2 fraction of inspired oxygen, PEEP positive-end expiratory pressure

Riker Sedation-Agitation Scale (SAS). The RASS is a 10-point scale with four levels of agitation (+1 to +4), one level of calm and alert (0), and three levels of sedation (−1 to −3), and two levels of coma (−4 to −5). The SAS is a 7-point scale ranging from coma (1) to severe agitation (7) [26]. These scales perform well at the bedside and are convenient. For example, the RASS has been shown to be easily performed by nurses, taking less than 20 seconds to perform, with high inter-rater reliability [27].

Analgesics, predominantly parenteral opioids, should be used as first-line agents prior to use of sedative medications to target and achieve a RASS of −2 to 0 or SAS of 3 to 4 with a goal of patients purposely following commands without agitation. If patients are over-sedated, sedatives should be held until the level of consciousness is at target and then only restarted at half the previous dose [9]. Critical care practice has migrated away from deep sedation due to evidence that inappropriate deep sedation is associated with poor outcomes. Early deep sedation in the ICU is associated with longer ventilation times, increased length of stay, and higher rates of mortality [28]. Similarly, targeting lighter sedation is associated with more delirium-free days and less use of restraints with no difference in self-extubation rates [29].

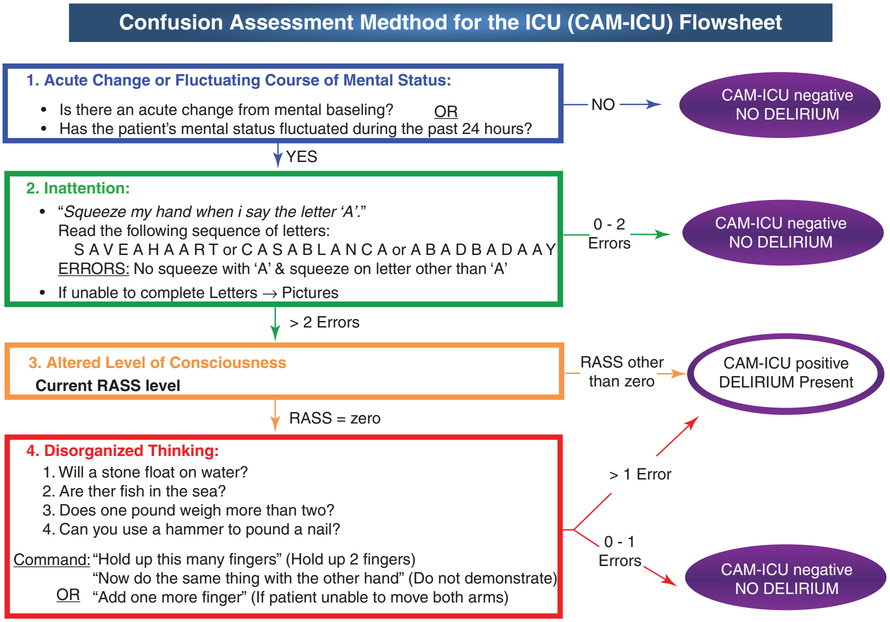
For sedation, the PADIS guidelines recommend using either propofol or dexmedetomidine (DEX) over benzodiazepines, which are associated with worse outcomes, specifically an increased risk of delirium in a dose-dependent fashion [30]. There has been increasing interest as well in central α-2 agonists as sedation agents in the critically ill. In the MIDEX and PRODEX trials, dexmedetomidine was noninferior to midazolam and propofol for time to target sedation and associated with decreased duration of mechanical ventilation compared to midazolam, though not propofol [31]. There have been two other trials evaluating the α-2 agonist dexmedetomidine to benzodiazepines. The MENDS study (Maximizing Efficacy of Targeted Sedation and Reducing Neurologic Dysfunction) compared dexmedetomidine to lorazepam, and patients receiving dexmedetomidine had 4 more days alive without delirium or coma and were more often at target-level sedation without differences in mortality or ventilator-free days [32]. However, the subgroup of patients with sepsis receiving dexmedetomidine had shorter durations of delirium and coma, lower probability of incident delirium, decreased time on the ventilator, and a 70% decrease in mortality [33]. In the SEDCOM trial (Safety and Efficacy of Dexmedetomidine Compared with Midazolam), there was a lower prevalence of delirium and two fewer days of mechanical ventilation with DEX compared to midazolam [34]. Regardless of sedative choice, targeting light sedation should be achieved through use of analgosedation with a focus on treating pain first and then adding sedation medication as needed. Focusing on light sedation is an important aspect of the ABCDEF bundle and its impact on PICS, as it limits immobilisation and helps reduce delirium. Future investigation is needed to determine the optimal sedative agent for improving outcomes.

## Delirium Assessment, Prevention, and Management

Delirium is a devastating and serious complication of critical illness. It is defined by an acute change in attention and awareness that develops over a short period of time with a waxing and waning course, which can be categorized into hypoactive delirium with reduced level of consciousness, hyperactive delirium with increased levels of agitation, or mixed delirium with elements of both [35]. It is vital to screen for the disease because it affects 60–80% of mechanically ventilated patients and is associated with long-term cognitive impairment and increased disability, both cardinal features of PICS [4, 36–38].

There are two validated tools used for assessing and screening for delirium: the Confusion Assessment Method for the Intensive Care Unit (CAM-ICU) and the Intensive Care Delirium Screening Checklist (ICDSC) [10]. The ICDSC is an eight-item screening tool, and a score of 4 or greater is positive for delirium with sensitivity and specificity of 74% and 82%, respectively, compared to the CAM-ICU that has sensitivity and specificity of 80% and 96%, respectively [39]. The CAM-ICU is composed of four features: (1) acute onset of mental status changes or fluctuating course, (2) inattention, (3) disorganized thinking, and (4) altered level of consciousness, and a patient is considered CAM positive for delirium if components 1 and 2 in addition to either 3 or 4 are present (Fig. 1.3) [40].

There are many risk factors for delirium, including sedating medications (most notably benzodiazepines), hypoxemia, sepsis, preexisting cognitive impairment, advanced age, mechanical ventilation, untreated pain, prolonged immobilisation, sleep deprivation, and multiple medical conditions [41]. When delirium is identified, the first step is to search for all reversible causes. These include unrecognized disease or infection and removing offending drugs. Additionally, performing


Confusion Assessment Medthod for the ICU (CAM-ICU) Flowsheet

1. Acute Change or Fluctuating Course of Mental Status:
- Is there an acute change from mental baseling? OR
- Has the patient's mental status fluctuated during the past 24 hours?

2. Inattention:
- "*Squeeze my hand when i say the letter 'A'.*"
  Read the following sequence of letters:
  SAVEAHAART or CASABLANCA or ABADBADAAY
  ERRORS: No squeeze with 'A' & squeeze on letter other than 'A'
- If unable to complete Letters → Pictures

3. Altered Level of Consciousness
Current RASS level

4. Disorganized Thinking:
1. Will a stone float on water?
2. Are ther fish in the sea?
3. Does one pound weigh more than two?
4. Can you use a hammer to pound a nail?

Command: "Hold up this many fingers" (Hold up 2 fingers)
"Now do the same thing with the other hand" (Do not demonstrate)
OR "Add one more finger" (If patient unable to move both arms)

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**Fig. 1.3** Confusion Assessment Method for the Intensive Care Unit (CAM-ICU). (Courtesy of E. Wesley Ely, MD, MPH and Vanderbilt University Medical Center, Nashville, TN) nonpharmacologic interventions, such as early mobilisation, frequent reorientation of the patient, and promoting appropriate sleep–wake cycles, are important management strategies as well.

Antipsychotics were previously used and recommended for the treatment of delirium; however, based on evidence from multiple RCTs, there is no definitive evidence supporting the treatment of delirium with antipsychotics [42, 43]. Girard and colleagues performed the MIND-USA trial (Modifying the Impact of ICU-Induced Neurologic Dysfunction-USA), a multicentre, randomized, placebo-controlled trial comparing haloperidol and ziprasidone versus placebo in treating delirium. The authors found no difference in duration of delirium or adverse outcomes, including mechanical ventilation, ICU length of stay, and mortality [44]. Based on this and similar trials showing no treatment benefit with antipsychotics [43, 45], the PADIS guidelines do not currently recommend the use of antipsychotics to treat delirium. There remains a role for these drugs in the management of agitation, which can be seen in hyperactive delirium, but the medication does not treat the underlying disease but instead manages the symptoms. There remains an unmet need for further investigation into pharmacological treatment options for delirium.

## Early Mobility and Exercise

Prolonged immobilisation is common during critical illness, most often due to due to disease severity and regular interventions in the ICU such as mechanical ventilation. It causes muscle wasting and weakness and can eventually lead to ICU-acquired weakness. It affects 25–60% of critically ill patients and is associated with worse outcomes, including prolonged mechanical ventilation, increased hospital length of stay, and greater mortality [46–49]. This weakness can last years and is associated with disability at one and 5 years in patients with acute respiratory distress syndrome [50, 51]. ICU-acquired weakness and its link to poor physical functioning contribute to the development of PICS in survivors of critical illness.

Early mobilisation refers to the initiation of rehabilitation and physical activity at the beginning of critical illness, even when patients are receiving invasive support. For example, early mobilisation has been shown to be safe in patients receiving advanced support, including mechanical ventilation and extracorporeal cardiopulmonary support with low risk of complications [52, 53]. It has also been shown to be one of the few interventions that reduces duration of delirium [54, 55]. Similarly, in a related prospective cohort study, patients receiving treatment with a dedicated mobility team compared to usual care were more likely to receive physical therapy in the ICU, were out of bed 6 days earlier, and were discharged from the ICU and hospital earlier [56]. When paired with SATs, early mobilisation within 3 days of mechanical ventilation reduced duration of delirium, increased days breathing without assistance, and improved return to independent functional status at discharge [55]. However, when mobilisation occurred four or more days after initiation of mechanical ventilation, there was no difference in long-term function [57], suggesting that the benefit to early rehabilitation may be seen predominantly in the early phases of critical illness. As such, mobility interventions need to be timed early during critical illness to optimize the impact on ICU recovery and be effective in reducing ICU-acquired weakness and PICS.

Given its impact on delirium and physical function, early mobilisation and exercise are foundational to the success of the ABCDEF bundle and synergistic in promoting the other components of the intervention. Needham and colleagues demonstrated that a focused quality improvement process to improve sedation practices and increase mobilisation resulted in decreased prescriptions of benzodiazepines, lower doses of narcotics, increased number of physical and occupational therapy treatments, doubled amount of days without delirium, and patients were awake and alert on twice as many ICU days [58]. These outcomes are integral to minimizing the iatrogenic causes of PICS with early mobility as the core preventative measure.

## Family Engagement and Empowerment

The ABCDE bundle, as it initially began, evolved to include the letter "F" to represent family engagement as a core pillar of the bundle in facilitating patient-centred care. Incorporation of family engagement at the bedside allowed for wishes, questions, and concerns to be addressed, which is especially important when the patients are unable to communicate due to their underlying illness and medical interventions. Without family engagement, these patient preferences and values would otherwise fail to respect patient dignity and be a missed opportunity for shared decision-making [59].

Family presence on rounds is one way to promote family engagement in their loved one's care. In pediatric ICUs, such presence did not interfere with education or communication and results in families having increased feelings of inclusion, respect, and increased understanding of the patient's care. It also increased nurse satisfaction with team communication [60]. In adult ICUs, family rounds were associated greater satisfaction with care [61]. Additionally, family satisfaction with medical care was higher when they felt included with their loved one's care, as well as with clinician facilitated family conferences [62, 63].

Critical illness impacts both the patient and their entire family and support system and can lead to psychological distress. Although a directed family-support intervention for surrogates, which included providing emotional support by trained nurses and ensuring frequent clinician-family communication, did not decrease this distress, it did increase perception of quality communication and patient and family-centred care, as well as a reduction in ICU length of stay [64]. Studies of patient and family ICU diaries suggest an association with reduced symptoms of post-traumatic stress disorder (PTSD) in both patients and families [65, 66]. However, a recent study of ICU diaries did not show a significant reduction in PTSD symptoms at

3 months, so more investigation is needed to find the most effective way to reduce patient and family suffering [67]. Additionally, family presence during CPR did not interfere with medical efforts and was associated with fewer symptoms of anxiety and depression amongst family members [68].

Ultimately, in patients who do not have survivable illness, increased focused communication with the family through routine ICU family conference and palliative care consultation can facilitate family decision to transition to comfort-focused care and forgo life-sustaining treatment [69, 70]. This is important to preserve patient's dignity and autonomy while also ensuring they have minimal discomfort. Ultimately, family engagement is fundamental to promoting the care of the whole patient as well as their family members, and this synergy is at the core of the ABCDEF bundle. Future investigations will be needed to clarify the best practices of family engagement and their impact on both PICS and other important patient-centred outcomes.

## The ABCDEF Bundle—Evidence and Implementation

Each of the previously mentioned interventions, from light sedation to delirium assessment to family engagement, has been validated in multiple critical care trials in improving both short- and long-term outcomes in critically ill patients. Combining these evidence-based interventions into a singular care philosophy, the ABCDEF bundle is a multidisciplinary, synergistic approach to improving ICU outcomes and preventing complications of ICU care.

In addition to the evidence for individual components, there have been multiple studies examining the impact of the bundle in totality [71–74]. For example, in a prospective single-centre cohort study including almost 300 patients, after implementation of the ABCDE bundle, patients spent three more days without mechanical ventilation and had almost half the odds of patients having delirium and increased odds of mobilising out of bed. Notably, there was no difference in self-extubation or reintubation rates [71]. A prospective multicentre cohort study including 6000 patients across seven community hospitals in California demonstrated the dose–response of the ABCDEF bundle in improving outcomes [72]. They found that with each 10% increase in bundle compliance, the odds of hospital survival increased by 7%, and for every 10% increase in partial bundle compliance, there was a 10% increase in hospital survival. Both findings were more pronounced when removing patients identified as receiving palliative care (12% and 23%, respectively) [72]. In addition, with both partial and total bundle compliance, patients had more days alive and free of delirium and coma. In a related prospective multicentre cohort study of 15,000 patients across 68 academic, community, and federal ICUs, compliance with the ABCDEF bundle was associated with a higher likelihood of ICU and hospital discharge and a lower likelihood of death, mechanical ventilation, coma, delirium, physical restraint, ICU readmission, and discharge to a destination other

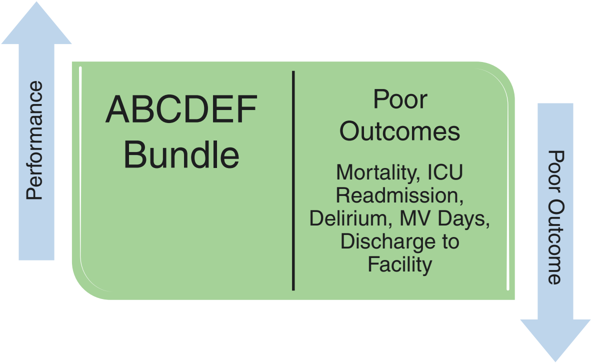

**Fig. 1.4** Association between proportional performance of the ABCDEF bundle and poor ICU outcomes. Based on data from Pun et al. and Barnes-Daly et al, there is a significant dose–response showing that increasing percentile performance of the bundle is associated with reduced mortality, delirium, days of mechanical ventilation, and decreased likelihood of discharge to a facility. Abbreviations: MV mechanical ventilation

than home when compared with patients who did not receive 100% of possible bundle elements [73]. (Fig. 1.4) In addition, there is a dose–response related to bundle performance with a greater percentage of eligible bundle components associated with similar findings of increased likelihood of ICU and hospital discharge and lower likelihood of death, mechanical ventilation, coma, delirium, and physical restraint [70]. However, the increased dose is also associated with more significant pain episodes, which was not seen in the complete bundle performance analysis, highlighting the complex and interconnected nature of the bundle.

The ABCDEF bundle has been developed to uniquely combine interventions that are complementary. In a survey across 51 Michigan ICUs, ICUs that completed both SATs and delirium assessments were 3.5 times more likely to exercise ventilated patients, whereas those who completed SATs but not delirium assessments were no more likely to achieve exercise outcomes compared to other incomplete implementers of the bundle [74]. The authors of this study note that their findings support the idea that “the whole truly is greater than the sum of its individual parts” [74]. The multifactorial nature of PICS necessitates a multifactorial treatment philosophy, which the ABCDEF bundle addresses.

The ABCDEF bundle has demonstrated significant improvements in outcomes in clinical trials. To reach its full impact, consistent implementation of the bundle across ICUs is needed to improve ICU outcomes and help prevent PICS. One recent attempt at improved implementation is the Society of Critical Care Medicine’s ICU Liberation ABCDEF Bundle Improvement Collaborative, which aims to improve bundle implementation [75]. Through research focused on identifying implementation difficulties, they noted that common barriers that were encountered included issues with electronic health records, inaccurate/unreliable assessments, staffing ratios and high turnover rates, challenging patient populations, communication and care coordination, data collection and documentation burden, no formal protocols, and lack of administrative buy-in. Various implementation approaches were used to identify these barriers and potential solutions. Possible solutions include forming interprofessional teams to engage and empower leaders, establishing quality improvement methods to implement the bundle elements, utilizing small tests of change, eliciting feedback through discussions or surveys, scheduling frequent coaching calls and meetings, providing multimodal educational offerings, sharing bundle-related protocols, sharing former family and patient stories and cases to highlight bundle-related successes, and using auditing and feedback [75]. Providing standardized assessment, documentation, and communication of each bundle component in the electronic health record and on ICU rounds is also essential to implementation [76]. This requires interdisciplinary teams to work together and engaging patients' families during mobility and on rounds [77]. When all stakeholders are committed, change can be made with one or two patients at time, building upon small quality improvement cycles that set the foundation for successful implementation of the ABCDEF bundle and culture change promoting ICU liberation. Read more about the SCCM ICU Liberation Campaign and find resources and implementation tools at http://www.iculiberation.org.

## Example Case

An instructive example of the implementation of the ABCDEF bundle is as follows: A 65-year-old man is admitted to the ICU for respiratory failure requiring mechanical ventilation due to streptococcal pneumonia. The nursing staff use the CPOT to frequently assess for pain and use as needed pain medications, target light sedation with dexmedetomidine for a RASS goal of −2 to 0, and monitor for delirium using the CAM-ICU, and the physical therapy team is engaged within the first 48 hours for early mobilisation. The patient's family is present on ICU rounds to participate in decision-making, as well as at the bedside with nursing and physical therapy to help comfort and orient the patient. Every morning, per the nursing protocol, sedation is stopped for a spontaneous awakening trial (SAT), and if passed, respiratory therapy performs a spontaneous breathing trial (SBT). After 3 days of mechanical ventilation, he passes his SAT and SBT and is liberated from the ventilator. Nursing continues to assess for pain and delirium, physical therapy mobilises and gets him out of bed and walking in the hallway, and his family is at the bedside to support him. He is transferred to the medical floor, and after a few more days in the hospital, he is discharged home with the ongoing assistance of home physical therapy and his family. Given his critical illness, he follows up in the ICU recovery clinic, where he undergoes a full assessment of his post-ICU recovery and any impairments, including physical, cognitive, and psychological symptoms. As his needs are identified, the ICU recovery clinic assists in coordinating further care, resources, and therapy the patient needs and provides the patient and family with educational resources and support groups [78].

## Conclusion

There continues to be significant urgency to elucidate targets for intervention to prevent PICS, including optimal strategies and agents for pain and sedation, effective pharmacological treatments for delirium, and the optimal methods to engage families and reduce suffering. In addition, with the assistance of ICU recovery clinics, further investigation is needed into the long-term outcomes of the ABCDEF bundle in a prospective manner, as well as the most effective strategy for improving post-ICU recovery. The role of post-ICU clinics and various interventions in the post-discharge arena require further study to optimize outcomes for patients.

We have seen a substantial shift in the culture of critical care medicine. No longer are we only treating only the pathology, but instead we are focusing on the outcomes for the entire person, from physical to cognitive. A substantial and integral part of this culture change is made manifest in the ABCDEF bundle. Moving forward, as we understand in increasing depth the mechanisms of PICS and the best practices that prevent those sequelae, the bundle will continue to evolve, and ICU clinics will be able to address improving ICU recovery. As these advances are made, the ABCDEF bundle will remain on the front line in cultivating a holistic philosophy of ICU care that directly addresses the causes and risks for PICS, ultimately leading to improved post-ICU outcomes.

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# Chapter 2
# Implementing Early Mobilisation in the Intensive Care Unit

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## What Is the Impact of Implementing Early Mobilisation in the Intensive Care Unit?

As critical care survivorship improves, research has increasingly focused on interventions which may prevent or manage critical illness-related morbidity [1]. Physically, intensive care impacts negatively on muscle and nerve structure and function with the literature supporting an incidence of intensive care unit-acquired weakness (ICU-AW) more than 50% in patients requiring prolonged mechanical ventilation [2, 3]. There is an association between ICU-AW and poorer outcomes including mortality, length of stay and physical function [3–5]. Early mobilisation

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(EM) has gained significant interest due to its potential to attenuate the negative effects of bed rest and thus improve service-centred and patient-centred outcomes. Whilst many studies report findings related to implementation of EM interventions, there remains no consistent definition of the term [6, 7]. Mobilisation "facilitates the movement of patients and expends energy with a goal of improving patient outcomes" [8]. Mobilisation can encompass a variety of interventions and forms one component of early rehabilitation which may also include treatments to address areas such as cognition, speech, swallowing and inspiratory muscle strength [8, 9]. In the intensive care unit (ICU), where traditionally patients have been managed with sedation and bed rest, the implementation of any mobilisation intervention during the critical illness period may have been considered early. However, it may be important to distinguish mobilisation delivered at different time points during critical illness. Mobilisation delivered early, within 48–72 hours of admission, may have the potential to stimulate muscle regeneration and consequently prevent or reduce the severity of sequelae of critical illness such as intensive care-acquired weakness (ICU-AW) and delirium [10–12]. It may also contribute to reduced mechanical ventilation (MV) time, length of stay (LOS) and improved long-term outcomes for critical illness survivors [8, 12]. Conversely, the rapid onset of muscle degeneration in critically ill patients means that physical rehabilitation applied later in or after an ICU admission aims to reverse impairments to improve outcomes. Selection of EM modalities for each individual patient depends upon medical stability and whether the patient can or cannot actively participate in mobilisation [13, 14].

For patients unable to actively participate in EM, neuromuscular electrical stimulation (NMES), cycling and passive movements are forms of rehabilitation that may be utilised in the ICU [14]. Reviews of clinical trials demonstrate that NMES may improve impairments such as muscle strength; however, there is no clear evidence for the impact of NMES on long-term outcomes [15, 16]. Two recent RCTs have investigated the effects of cycling in addition to early rehabilitation and have not demonstrated any significant changes in functional capacity, independence at hospital discharge, global muscle strength, ventilator-free days or health-related quality of life at 6 months [17, 18]. The feasibility of cycling has been demonstrated via pilot RCT, and ongoing trials are being completed in this area (NCT03471247) [19, 20]. As evidence emerges, systematic review which separately evaluates the effects of cycling and passive movement interventions may be warranted. To date, there is no available meta-analysis of the incidence of adverse events related to NMES or cycling in critically ill patients. Table 2.1 provides a summary of recent publications which have detailed the effects of passive cycling and EMS in critically ill patients.

For patients who are able to participate in active therapy, EM focuses on active exercises and functional retraining activities such as active exercises in bed or in the chair (aiming to improve muscle strength and joint mobilisation), sitting, balance, transfers, standing and walking. Multiple systematic reviews have been undertaken examining the short- and long-term effects of active participation in EM (Table 2.2). Results indicate that active participation in early rehabilitation may result in reduction in incidence of ICU-AW, hospital and ICU LOS whilst improving functional status at discharge and long-term quality of life. Three systematic reviews suggest

**Table 2.1** Publications evaluating the effect of early mobilisation interventions for intensive care patients which do not require active participation

| Author, year | Patient characteristics | Intervention characteristics | Quality of evidence | Outcomes |
|---|---|---|---|---|
| Parry et al. 2013 [15] Systematic Review | Adult patients admitted to the intensive care unit | Electrical muscle stimulation applied to peripheral muscles as an exercise intervention | Eight randomised controlled trials and one case–control study<br>Two studies of poor quality, four studies of fair to good quality as assessed on the PEDro scale | Early EMS application did not attenuate bicep or quadriceps muscle wasting<br>EMS may have a greater impact on muscle preservation in long-stay patients or those with lower illness acuity<br>Improvement in muscle strength related to the application of EMS |
| Zayed et al. 2019 [16] Systematic Review and Meta-Analysis | Adult patients admitted to the intensive care unit | *Intervention:* neuromuscular electrical stimulation in addition to usual care<br>*Comparator:* usual care including early functional rehabilitation | Six randomised controlled trials<br>Moderate to high risk of bias | No difference for global muscle strength at ICU discharge, ICU mortality, duration of mechanical ventilation or ICU length of stay. |
| Fossat et al. 2018 [17] Randomised Controlled Trial | Adult patients who were previously independent and expected to require an ICU length of stay >48 hours | *Intervention:* cycle ergometry and electrical muscle stimulation in addition to usual care<br>*Usual care:* standardised early rehabilitation programme | Single centre trial of 314 patients. | No difference in median MRC score at ICU discharge.<br>No difference in any outcome measures at ICU discharge or at 6 months. |

(continued)

**Table 2.1** (continued)

| Author, year | Patient characteristics | Intervention characteristics | Quality of evidence | Outcomes |
|---|---|---|---|---|
| Eggman et al. 2018 [18] Randomised Controlled Trial | Adult patients who were previously independent, requiring mechanical ventilation and expected to require an ICU length of stay >72 hours | *Intervention:* early progressive combined endurance and resistance training utilising a cycle ergometer and weights or therapist resistance in combination with usual care<br>*Usual care:* individually tailored physiotherapy including early mobilisation. | Single centre trial of 115 patients | No difference in functional capacity at hospital discharge.<br>No difference in incidence of ICU-AW at ICU discharge, length of stay in ICU or hospital or 6-month health-related quality of life |
| Wollersheim et al. 2019 [29] | Adult patients who were previously independent with a sepsis and multiorgan failure (SOFA score $\geq 9$) within 72 h after ICU admission | *Intervention:* protocolised early physical therapy (including PROM) + daily 20 Min NMES and/or whole-body vibration (WBV)<br>*Usual care:* protocolised early physical therapy (including PROM)<br>*Historic control:* physician initiated mobilisation only on weekdays without prespecified goals | Single centre trial of 50 patients | No difference in functional capacity at hospital discharge.<br>No difference in incidence of ICU-AW at first awakening, ICU discharge or 12 -month follow-up<br>Prevention of muscle atrophy (myocyte cross-sectional area) by intervention. |
| Grunow et al. 2019 [30] | Adult patients who were previously independent with a sepsis and multiorgan failure (SOFA score $\geq 9$) within 72 h after ICU admission | Post hoc analysis of Wollersheim et al. on contractile response to neuromuscular stimulation | Single centre trial of 50 patients | Patients show a differential contractile response to NMES, which appears to be dependent on the severity of illness and also relevant for potential outcome benefits. |

**Table 2.2** Systematic reviews of early mobilisation interventions which require active participation

| Author, Year | Patient Characteristics | Intervention Characteristics | Quality of Evidence | Outcomes |
|---|---|---|---|---|
| Tipping et al. 2017 [21] | Adult patients admitted to ICU >24 hours | *Included:* any of active exercises, functional mobility retraining, tilt table therapy, hoisting to a chair delivered during the ICU stay<br>*Excluded:* passive therapies only, cycle ergometry or FES as a sole therapy<br>*Comparator:* usual care | Fourteen randomised controlled or controlled clinical trials included<br>Five studies with low quality, four studies of moderate quality, five studies of high quality assessed using the Cochrane risk of bias tool<br>Overall meta-analysis limited by variation in selection and timing of outcome measures | No impact on mortality or discharge destination<br>Improved muscle strength at ICU discharge for patients receiving rehabilitation<br>Improved SF-36 at 6 months in studies implementing high dose rehabilitation.<br>Increased number of days alive and out of hospital to 6 months for intervention participants receiving early and low dose rehabilitation |
| Fuke et al. 2018 [31] | Adult patients admitted to ICU.<br>*Excluded:* Patients with TBI and stroke | Early rehabilitation which started earlier than usual care or was administered within 7 days of admission<br>*Comparator:* standard care or no early rehabilitation | Six randomised controlled trials<br>Quality of evidence considered low to very low due to risk of bias | Significant reduction in the incidence of ICU-AW associated with early rehabilitation.<br>Significant improvement in MRC and long-term role physical score associated with early rehabilitation<br>No significant difference in delirium free days, anxiety or depression. |

(continued)

**Table 2.2** (continued)

| Author, Year | Patient Characteristics | Intervention Characteristics | Quality of Evidence | Outcomes |
|---|---|---|---|---|
| Doiron et al. 2018 [32] | Adult patients admitted to ICU and requiring mechanical ventilation<br>*Excluded:* neuromuscular disease, spinal cord injury, cardiopulmonary arrest, raised ICP, advanced dementia or expected six-month mortality | Any of cycle ergometry, active exercises, functional mobility retraining or ADL practice during the ICU stay designed to commence earlier than the control group<br>*Comparator:* delayed intervention, usual care or inspiratory muscle training only | Four randomised or quasi-randomised controlled trials | Low-quality evidence for improved independent function at hospital discharge for early rehabilitation.<br>Insufficient evidence for the effect of intervention timing on physical function, performance, adverse events, muscle strength or health-related quality of life.<br>Low-quality evidence to support that adverse events are low for early rehabilitation |
| Zang et al. 2019 [22] | Adult patients admitted to intensive care | Early mobilisation and rehabilitation | 15 randomised controlled trials<br>1 trial at low risk of bias, 4 trials at unclear risk of bias, 10 trials at high risk of bias | No effect on mortality<br>Early mobilisation associated with a significant reduction in incidence of ICU-AW, ICU length of stay and hospital length of stay.<br>Favourable effect for muscle strength and Barthel Index at hospital discharge |

that interventions delivered earlier during the ICU stay may be more beneficial than those delivered later during admission [21–23]. Ding et al. [23] identified via network meta-analysis that ideal initiation of EM is within 48–72 hours of mechanical ventilation [21–23]. Additionally, a systematic review of 10 RCTs examining physical rehabilitation interventions delivered after ICU discharge, either in hospital or after hospital discharge, to patients who received mechanical ventilation has demonstrated moderate evidence that these programmes do not make a difference to quality of life [24]. Meta-analysis examining safety of active EM interventions in the ICU has demonstrated that potential safety events are low and events associated with consequences are rare [25]. Based on the currently available evidence of the risks and benefits of a variety of EM interventions, clinicians should focus on delivery of mobilisation activities delivered as early as possible during the ICU admission, with active participation wherever possible.

## Why Is Early Mobilisation Challenging to Implement into Clinical Practice in the Intensive Care Unit?

EM is a complex intervention and has been consistently difficult to implement in ICU in both clinical trials and clinical practice. Whilst there are concerns for patient's safety and physiological stability, the main reported barriers to EM, such as sedation and staff levels, may be managed with multidisciplinary team input and coordination [26].

In a multicentre observational study of EM in critically ill patients, during 1288 planned early mobilisation episodes in patients on mechanical ventilation, no mobilisation occurred in 1079 (84%) of these episodes despite the presence of dedicated physical therapy staff. The main reported barrier to EM in the first 7 days after enrolment was intubation and sedation [2]. At day 7, the reported barriers also included agitation and weakness. However, EM has been shown to be safe and feasible in intubated patients and can occur in conjunction with sedation minimisation or disruption, so why does this continue to be a barrier to implementation in the clinical setting?

First, EM is easier to implement in an ICU that has a culture that prioritises and values rehabilitation and functional recovery [2]. In this case, maximising the opportunities to safely implement EM occurs with discussion on the multidisciplinary round, accompanied by clear goal setting based on the patient's current status and with a plan to implement EM as a coordinated effort by the ICU team [12]. The type and timing of EM, as well as the specific staff and equipment required to achieve the planned activity, are all planned in advance with buy-in from the medical staff, nursing staff and physiotherapists, as well as any other staff specific to achieving that goal.

Patients have reported that during the early phase of critical illness, and particularly the first sessions of EM in ICU, they prefer a paternalistic approach to rehabilitation where the activities and the process of EM are directed by the staff delivering EM [27]. It is important to have one person leading and coordinating the EM to ensure the patient can focus clearly on instructions and to maximise safety [28].

## What Solutions Are Available to Support Implementation of Early Mobilisation in the Intensive Care Unit?

The translation of research evidence into clinical practice remains a challenging aspect of evidence-based care in the intensive care unit [33, 34]. Early mobilisation is no exception with multiple observational studies demonstrating that physical activity levels in the critically ill remain very low [2, 35–37]. However, a number of recent publications provide potential solutions to support evidence translation and implementation of EM into daily clinical practice.

The Society of Critical Care Medicine (SCCM), American Thoracic Society & American College of Chest Physicians (ATS), the German Society of Anesthesiology and Intensive Care Medicine (DGAI) and the New South Wales Agency for Clinical Innovation (ACI) have all recently published clinical practice guidelines (CPGs) which make recommendations related to EM in the ICU [8, 28, 38, 39]. All of these CPGs support implementation of EM based on reviews of the current evidence. The recommendations of these guidelines are summarised in Table 2.3.

Both the SCCM and ATS guidelines utilised the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) methodology for guideline development [40]. This methodology requires a detailed assessment of the quality and certainty of the research evidence underpinning the recommendations including the risk of bias, effect size and consistency between studies with meta-analysis of results undertaken where possible. This detailed analysis revealed that whilst there is a significant body of evidence supporting the potential of EM to improve outcomes such as decreased mechanical ventilation time, improved functional independence at hospital discharge and increased strength, there remain significant limitations to the evidence for EM. There is a lack of Phase 3 evidence from large randomised controlled trials (RCTs) with the evaluation of all relevant outcomes including adverse events. Importantly, a well-powered Phase 3 RCT is required to evaluate long-term safety outcomes including mortality. There is inadequate evidence available to guide recommendations related to dosage, intervention selection or the identification of responders and nonresponders. The contrast in strength of recommendation made by the ACI guideline is likely related to the evaluation of the evidence using the NHMRC levels of evidence which classifies studies based on design only without a detailed assessment of other factors which effect quality.

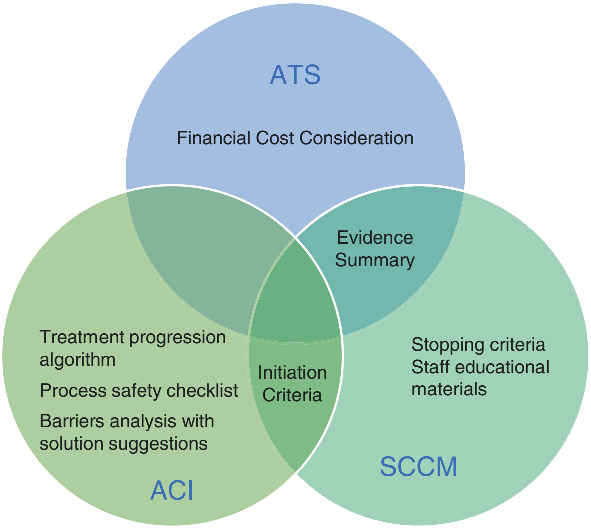
Whilst there are important limitations to the recommendations provided by existing CPGs, clinicians can utilise these documents to support changes to clinical practice. It is important to recognise that these recommendations are made via expert consensus based on careful evaluation of the risks and benefits in the context of healthcare values and therefore can represent best evidence-based practice despite a lack of high-quality research evidence [41]. Conditional recommendations are considered to apply to most patients, but significant consideration must be given to local healthcare system factors and individual patient conditions and values when implementing these recommendations. Clinicians should consider a range of factors when selecting CPG recommendations for implementation in the local context. Tools such as the Practice Guidelines Evaluation and Adaptation Cycle and the Appraisal of Guidelines Research and Evaluation II (AGREE II) Instrument can be used to identify and select recommendations of high quality and relevance to the local patient cohort and clinical practice environment [42, 43]. Preference may also be given to a CPG based on the needs of the guideline user, for example, the development of a business case compared to a local practice guideline or staff education programme. The resources provided by each guideline are summarised in Fig. 2.1.

In addition to the resources provided by recent clinical practice guidelines, a broad range of published resources are available to support delivery of early mobilisation. These include Hanekom and colleagues [44] algorithms for patient and

**Table 2.3** Summary of the recommendations for early mobilisation from recent clinical practice guidelines

| Publication | Recommendation | Strength | Evidence |
|---|---|---|---|
| SCCM 2018 [8] | "We suggest performing rehabilitation or mobilisation in critically ill adults"<br>Remark: "This recommendation suggests performing rehabilitation/mobilisation interventions over usual care or similar interventions with a reduced duration, reduced frequency or later onset" | Conditional | Low quality |
| ATS 2017 [38] | "For acutely hospitalized adults who have been mechanically ventilated for more than 24 hours, we suggest protocolized rehabilitation directed toward early mobilisation" | Conditional | Low certainty |
| ACI 2017 [28] | "A dedicated physical activity and movement program should be implemented to aid in the recovery of critically ill patients" | NHMRC Grade A | Not specified |
| | "Early physical activity and movement is feasible and safe for critically ill patients and should be incorporated into usual practice" | NHMRC Grade A | Not specified |
| | "All patients admitted to the ICU should be screened on a daily basis for inclusion in a physical activity and movement program … this screening should occur within 24 hours of admission" | NHMRC Grade C | Not specified |
| | "The program, based on the patient's current activity level, should be developed in consultation with a multidisciplinary team" | NHMRC Grade C | Not specified |
| DGAI 2014 [39] | "In principle, early mobilisation should be conducted in all patients treated in intensive care, for whom no exclusion criteria apply" | Recommendation grade A | Evidence level 2b |
| | "Treatment should begin no later than 72 h after admittance to intensive care and be conducted twice daily with a duration of at least 20 min for the length of stay in intensive care. A gradual approach should be aimed for starting with passive mobilisation. In this regard, the development of an algorithm specific to a unit or hospital is recommended" | Recommendation grade B | Evidence level 3 |
| | "A protocol-based approach is recommended for implementing early mobilisation. Active mobilisation should be conducted by at least two qualified staff members; a physiotherapist should be regularly integrated. Sufficient spatial requirements and resources should be kept"<br>"Early mobilisation should be incorporated into a set of measures, which includes the strategy for adapted symptom monitoring of pain, fear, agitation and delirium, as well as for the daily assessment of spontaneous breathing" | Recommendation level A | Evidence level 2b |

**Fig. 2.1** Implementation resources provided by existing clinical practice guidelines



intervention selection, Hodgson et al. [13] expert consensus on a safety screening traffic light system and the practical guide with mobility planning pneumonic and progression chart by Green et al. [45]. Additionally, many authors have provided early mobility protocols [12, 46, 47]. However, the key limitation to translation of these guidelines and resources into daily practice is the lack of consideration given to the development of strategies to maximise applicability and provision of processes which support staff to implement the recommendations and resources locally in a sustained manner.

Existing studies investigating EM interventions in daily practice via implementation science and quality improvement projects provide important insights into which knowledge translation approaches are effective. A recent review of quality improvement studies implementing early mobilisation of mechanically ventilated patients demonstrated four key themes which related to successful outcomes: managing the change process through strong leadership, designing strategies and interventions to overcome barriers to implementation, multidisciplinary team collaboration and data collection and feedback systems [48]. Other successful strategies identified in the literature include the implementation of early mobilisation interventions within a multifaceted approach such as care bundles to minimise other barriers such as sedation and delirium [49, 50]. Studies demonstrating programmes which can be effectively translated to other institutions and sustain improvements have been based on a structured quality improvement process known as the strategy for translating evidence to practice [51–54]. Key components of this approach include local barriers analysis, development of targeted strategies to overcome these including a variety of educational and executional methods and repeated performance measurement. The final overarching theme of implementation studies is the provision of adequate resourcing of the programme via staffing and equipment, the timing of introducing this resourcing was variable between projects with some introducing additional staffing to support initial implementation, whilst other utilised positive initial results to motivate redirection of resources for sustainability of the programme. The results of these multicomponent structured quality improvement projects are in contrast to studies investigating single component interventions to improve compliance with early mobilisation which have not shown a positive effect [55]. Figure 2.2 describes the key components clinicians should utilise when developing a local EM research translation approach.

Together with the resources described above, several tools are also available to support the development of these components including:

- Patient Mobilisation Attitudes & Beliefs Survey—Intensive Care Unit (PMABS) [56].
- Core Outcome Measures for Acute Respiratory Failure Survivors [57].
- *Under development*: Physical Rehabilitation Core Outcomes in Critical Illness (PRACTICE) [58].
- The Surgical Intensive Care Unit Optimal Mobility Score (SOMS) [59].
- The ICU Mobility Scale [60].
- The ICU Liberation Resources [61].

## How Will Early Mobilisation Be Delivered in the Future?

New ideas and concepts are being developed and discussed for intensive care, including living ICUs, where the historical technological focus of medicine will be complemented by a patient- and family-centred care approach. Focusing on the future of EM, three key domains are expected to play a major role: regulation, personnel resources and technology and biomedical development.

Currently, EM is recommended by some medical societies [8, 38, 39], is part of quality indicators for intensive care in some countries [62] and is one part of the ICU liberation strategy using the ABCDEF bundle [63]. The results of the TEAM RCT (https://www.teamtrial.org.au, NCT03133377), investigating early active mobilisation in ventilated patients using a published algorithm, will have a major impact on the future directions for EM. If the TEAM RCT provides evidence of a positive effect on mortality or days alive and out of hospital within 180 days, it is likely that in addition to patient advocacy groups, regulatory entities will step in and mandate a protocolised active EM regime. To provide such active and protocolised care, it will be necessary to provide far more resources than that are currently available for EM. Most developed countries already struggle with physical therapy and nursing staffing. A possible solution might be to reduce the number of healthcare providers necessary to mobilise a patient safely. Mobilisation typically needs at least two people; with technology, such as robotic assistance, this might be reduced. For example, tilt tables have been modified to be connected to a robotic mobilisation system [64] so that a critically ill patient stays in a (special) bed that can be attached to and used by a robotic mobilisation system. Since the patient is not

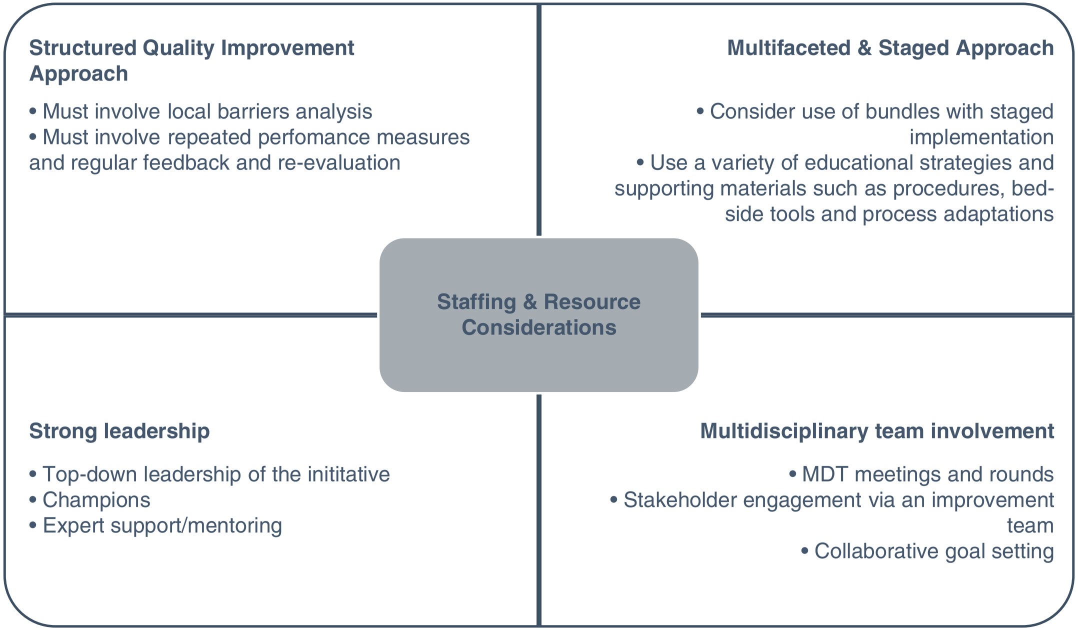


**Fig. 2.2** Key components to a successful EM implementation programme

transferred out of the bed, there is potential for the system to allow one person to complete mobilisation treatments alone. Even then, the system is still limited by the required personnel resources, such as time to set up the system, and the patients' low exercise capacity. Therefore, we should aim to develop systems which require only a single application and can be automatically and repeatedly activated. This could support the neuromuscular system of the patient whilst accounting for the individual training capacity and regeneration phases necessary without further staff supervision of the intervention. Imagine a futuristic advanced exoskeleton or just a suit in contact with the skin with sensors and stimulation capacities.

Besides such technological advances, in the patient- and family-centred ICU, patients would ideally be liberated from sedation to maximise their participation in care and decision-making [38]. They would have the opportunity to be surrounded by their regular social environment, such as family members, to support their psychological well-being and the (self-)healing process. The social construct could be a motivator and allow family to act as therapists by providing EM to the patient. This process already has started locally in some locations, where family members are encouraged to be part of mobilisation sessions, support therapy or provide passive mobilisation to their loved ones.

## How Will Early Mobilisation Be Prescribed in the Future?

Independent of the TEAM RCT results, more questions must be answered to guide clinicians prescribing EM interventions in the future to achieve the greatest impact on patient- and service-centred outcomes and to maximise the efficiency of resource use. Firstly, what is the optimal dose of EM? We have seen that the dose of EM may influence the outcome of our patients following a stroke and the resources needed are dose-dependent [65]. There is an ongoing international collaboration preparing a study to answer this question. Secondly, do patients who have been functionally dependent before the hospital admission benefit from EM in a similar way? Are the pathomechanisms in this cohort the same? Is the goal of EM for such patients to prevent further functional decline? If yes, is the prevention of a decline possible and what resources are necessary to achieve this? Emerging investigation into measures, such as frailty, which allow stratification of cohorts may assist in the identification of responders and nonresponders to interventions such as EM. Finally, what is the impact of staff expertise on the delivery and outcomes of EM interventions? To date, most EM trials have utilised highly experienced staff for delivery of EM treatments. As intervention uptake increases and spreads to centres with minimal exposure to this complex intervention, it will be important to consider the impact of confidence and training on outcomes.

In summary, the coming years will be exciting for EM of critically ill patients. Ideally, the future will hold a clearer perspective for clinicians with the availability of selection criteria for the most appropriate patient cohort. Algorithms need to be developed to identify dosage, monitoring and stopping criteria based on clear evidence from trials. Key areas for improvement include improved follow-up and an understanding of both the dose–response relationship to EM and the expertise needed to successfully deliver these programmes. This will benefit critically ill cohorts around the globe.

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# Chapter 3
# Engaging Families in the Intensive Care Unit to Support ICU Survivors

**Jonathan Ludmir and Giora Netzer**

## Introduction

The psychological morbidity incurred by families during their loved ones' ICU course can persist after discharge. This constellation of symptoms has been termed the Post-intensive Care Syndrome-Family (PICS-F) [1]. During the ICU stay itself, families experience high levels of stress, anxiety, depression, PTSD, and sleep deprivation [1–8]. This may also be considered as a Family Intensive Care Syndrome (FICUS) [8]. These psychological and emotional symptoms begin during admission and persist post-discharge, impacting the ability of family members to support their loved ones at home [9–11]. By supporting and engaging families in the ICU, high stress levels may be mitigated and families may utilize the tools acquired during admission to better care for their loved ones post-discharge [12–16]. Outside of our patients themselves, families are the key stakeholder in long-term trajectories after critical illness. Engaging our families, a previously underutilized resource, works to improve these outcomes [17].

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## Why Do We Need to Support Families in the ICU?

### *Functional Limitation Vs. Disability*

We know that a significant proportion of ICU survivors will leave the ICU with new physical and cognitive deficits. Our goal in the ICU is to minimize those deficits through conscientious care, including early mobilisation and implementing the Society of Critical Care Medicine's (SCCM) ABCDEF (*A*ssessment, Prevention, and Management of Pain, *B*oth Spontaneous Awakening Trials and Spontaneous Breathing Trials, *C*hoice of Analgesia and Sedation, *D*elirium Assessment, Prevention and Management, *E*arly Mobility and Exercise, *F*amily Engagement and Empowerment) bundle for ICU liberation [18]. Family Engagement and Empowerment can create a positive feedback loop with the other five components to maximize outcomes [19].

Similarly, families can help to define post-ICU trajectories. The World Health Organization's International Classification of Functioning, Disability and Health may help us consider this conceptually. Critical illness can incur physiologic *impairments*. These, then, can cause *activity (or functional) limitations*. A limitation is one that is measurable under controlled circumstances, e.g., six-minute walk test. This does not correlate directly to restriction in participation in social roles, i.e., *disability*. The perception of disability may then reduce the individual's *perception of quality of life*. As an example, the ability of an ICU survivor with ICU-acquired weakness to return home may be as or more dependent on the design of the home, being able to afford a stair climber, and the ability and strength of their caregivers as it is on their grip strength [4]. Families can assist not only with adaptation, but they may also help with neuroplasticity and recovery. For example, stroke survivors with strong family support regain higher levels of functional status over the 6 months following stroke [20]. Supporting families in order to maximize their well-being at the time of discharge is therefore beneficial for the ICU survivors, but also our patients themselves.

### *Challenges Families Face in the ICU*

Families of critically ill patients immersed in a high stress, often unfamiliar, environment are emotionally vulnerable and suffer from depression, PTSD, and anxiety [21]. In a large prospective cohort study involving 78 French ICUs, 73.4% of families had anxiety symptoms and 35.3% had depression symptoms prior to discharge [22]. Moreover, a systematic review of 40 studies of psychological sequalae among ICU families found the following prevalence: 4–94% for depression, 2–80% for anxiety, and 3–62% for PTSD [9]. While the prevalence of symptoms varies, psychological sequalae continue to evolve and progress over time in the ICU [23] and often persist post-discharge [24, 25]. For example, family members who had elevated depressive symptoms during the ICU stay continued to have high degree of symptoms at 2 months of post-discharge [24]. One study demonstrated depressive symptoms among 43% of family members 1-year post-discharge [10]. Risk factors associated with the development of psychological symptoms among family include younger caregiver age, lower socioeconomic status, spouses, and poor communication in the ICU [9]. Sleep deprivation is yet another component contributing to the development of psychological sequalae, stress, and cognitive blunting [3].

The combination of stress, high-intensity emotions, psychological symptoms, and grief comprises a constellation of symptoms coined by Netzer and Sullivan as Family Intensive Care Unit Syndrome (FICUS) [8]. Development of FICUS affects caregivers ability to make decisions, to effectively care for their loved ones, and to manage day-to-day stress of the ICU [8]. FICUS may persist post-discharge and the caregiver burden extends beyond psychological sequalae.

Caregivers often dedicate significant time, money, and other resources in the care of their family members, which can lead to economic hardship, loss of employment, and interference with prior lifestyle [26, 27]. A Baltimore-based study of families of surgical ICU survivors found that after 1 month, 44.9% of family members quit their jobs, 84.5% quit other activities to care for their family member, 24.6% had most of their savings lost, 14.5% delayed medical care for another family member, and 2.9% moved to a less expensive home [28]. After 1 year, 23.1% had quit their jobs, 36.7% had lost savings, 38.5% had major family plans changes, and 19.2% had delayed medical care for other family members [28]. In another UK-based study, 50% of family caregivers had changes in their employment [29]. Hence, ICU admissions have not only short-term but also long-term negative ramifications on families' psychological health and lifestyle (Fig. 3.1). Helping families to anticipate and prepare for these challenges is a task occurring infrequently; this is an area in which social work can be a vital stakeholder.

Because of the emotional and financial challenges families face throughout admission and post-discharge, we offer a framework to engage and support families in hopes of mitigating the stressful effects of an ICU admission. Our framework is based on evidence-based techniques that support families throughout the ICU journey – beginning with compassionate and respectful communication by a trained ICU team, family-centered rounds, family meetings, and provision of a family support zone and learning to be active participants in the care of their loved ones.

## What Strategies Will Help Families in the ICU?

### *Effective Communication*

Ensuring effective, compassionate, and respectful communication is integral for supporting and empowering families. Seaman and colleagues provide five goals for facilitating ICU communication with a family:

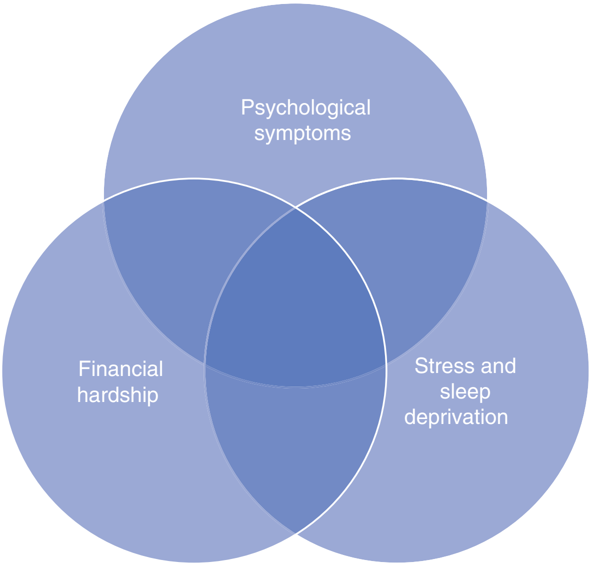

**Fig. 3.1** Impact of ICU stay on families

1. *Establishing a trusting relationship* – providing accurate and timely information to family.
2. *Providing emotional support to families* – allowing families to express feelings and displaying empathy.
3. *Helping families to understand diagnosis, prognosis, and treatment options* – providing consistent information, allowing for shared-decision making.
4. *Allowing clinicians to understand the patient as a person* – learning and valuing the patients' preferences.
5. *Creating conditions for careful deliberation about difficult decisions* – allow for adequate time and decision-making with family members [14].

Additionally, using communication toolboxes including mnemonics optimizes family-staff interactions. One well-utilized mnemonic is VALUE, which stands for the following: -.

- V – *value family statements*
- A – *acknowledge family emotions*
- L – *listen to the family*
- U – *Understand the patient as a person*
- E – *Elicit family questions* [13]

Utilizing *VALUE* as a guide for family communication may ensure that each key aspect of interaction is maintained. Moreover, the aforementioned goals may be achieved through the implementation of family-centered rounds, daily updates, electronic patient portals, and interdisciplinary family meetings [14]. ICU communication and end-of-life discussion are challenging; however, if done in an effective and well-planned structured manner, they lead to improvement in patient and family satisfaction [12–14, 30].

## *Facilitated Sensemaking*

Facilitated sensemaking is a mechanism that helps families build a reality-based narrative through providing support and helping them understand their ICU surroundings [31]. Facilitated sensemaking interventions are achieved through the following:

1. Developing trustworthy and respectful relationships
2. Establishing effective communication via decoding the ICU environment
3. Welcoming family presence and engagement
4. Participating in shared decision-making and on family-centered rounds [32]

One study in the cardiac surgery ICU provided a set of facilitated sensemaking card which included the following prompts and questions for staff to answer:

1. *Explain the environment that surrounds your loved one (tubes, sounds, etc.).*
2. *Explain your loved one's plan of care.*
3. *Interpret medical procedures/terminology.*
4. *Inform you about the current medical treatment, medical status, and potential outcome(s).*
5. *Teach and assist you in activities you can perform for your loved one.*
6. *Assist you in performing personal care activities.*
7. *Coach you on how to ask the health care providers' questions.*
8. *Inform you of what support services our hospital has available for you and your loved one (social worker, chaplain services, pastor, language translator, etc.).*[33]

These pieces of information may be basic and straightforward for healthcare workers but provide important explanations of the ICU care. By incorporating the facilitated sensemaking intervention, the mean levels of situational anxiety significantly decreased in the cardiothoracic ICU [33]. Through proactive communication and effective communication, family members may feel more supported [16, 34].

## *Family-Centered Rounds*

Family-centered rounds is an interdisciplinary approach to decision-making and task delegation with the active participation of family. Inclusion of family members decreases family anxiety, improves family and staff satisfaction, improves overall team communication, and enhances trainee education [2, 12, 35, 36]. In one neonatal ICU study, the implementation of family-centered rounds with family participation resulted in significant increase in communication satisfaction [37]. In another pediatric ICU-based prospective study, 98% of family members enjoyed being on rounds, and over 90% were satisfied with the process [38]. Similarly, an adult based medical-surgical ICU prospective study found that family inclusion on rounds improved family understanding of the clinical situation (96.3%) and reduced stress level (77%) [39]. Anxiety levels were also reduced in a cross-sectional neonatal ICU study, with 84% of parents reporting being less worried about their child [40]. Family-centered rounds may improve transitions of care, as families feel more comfortable with the next stage of the care journey. When one children's hospital implemented family-centered rounds, morning discharges increased significantly [41].

Establishing a structured and standardized rounding process is central to ensuring successful family-centered rounds. This process includes typically, but not limited to, a primary bedside nurse, advanced practice provider and/or resident physician, attending physician, respiratory therapist, pharmacist, along with the family.

One approach for operationalizing is as follows:

1. Member of rounding team welcomes and invites the family to rounds either at bedside or outside of room. Attending physician may preface rounds with a statement that medical lingo will be utilized; however, clarifications and questions will be welcomed at the end.
2. Bedside nurse presents overnight events.
3. Pharmacist lists all medications.
4. If part of team structure, resident or advanced practice provider discusses plan in a systematic manner.
5. Attending physician recaps, makes teaching point, and then welcomes questions.
6. Family participates in discussion and asks questions.

Standardizing the approach to family-centered rounds not only has a direct impact on family perception but also enhances overall staff communication and workflow [42].

## *Family Meetings*

Family meetings are predesignated set meetings to review clinical information in depth with members of the team. It is a fixed time outside of rounds to gather team members with consultants and provide information and discuss goals of care with the family. Utilizing the VALUE framework along with providing consistent communication and empathic support structure should guide family meetings [13]. A French multicenter randomized trial of standardized family meetings utilzing the mnemonic VALUE resulted in decreased stress and anxiety symptoms among family members [30]. Another multicenter ICU study demonstrated that the role of frequent family meetings by a designated ICU support team improved perception of family-centeredness and quality of communication while also decreasing ICU length of stay [15]. Standardizing family meetings is another important mechanism by which to support caregivers.

## *Family Support Zone*

Family support zones are important for addressing daily family member needs including food and sleep. The Society of Critical Care Medicine recommends that each ICU contain family support zones comprised of a family lounge, meditation space, nourishment area, and sleep rooms, and its most current guidelines specifically support a lay-flat surface for sleep [12, 43]. These features allow for caregivers to step away from the bedside, recuperate, and take care of basic needs, including sleeping. A Dutch study evaluating the role of a new ICU design with a family support zone found that mean family satisfaction scores were significantly increased after implementation [44]. Families should be apprised of the need for self-care. Social workers can play a key role in this [45].

## *Active Participants in Care*

Integrating and engaging caregivers into bedside patient care is a key part of supporting families during the ICU stay. Extending an explicit invitation to families and providing them menus for participation in care have been in use for over a decade [46]. In the neonatal ICU, decreased parental anxiety resulted when parents were incorporated into daily patient care routines. This accompanied the benefit to patients, with improved weight gain and higher likelihood of breast feeding [47]. Another qualitative study in the adult ICU study found families' perceived participation in care as important and motivating [48]. This approach consistently improves family well-being, with reduced stress levels and reductions in post-traumatic stress disorder [33, 49].

Participating in care benefits not only families but also their loved ones – our patients – and brings them into partnership with the care team. Families are highly effective in increasing early mobilisation [50, 51], which can reduce the length of stay. The benefit extends outside the ICU's walls. Families working alongside the clinical team are empowered to understand both their loved one's conditions and potential complications and also are more effective caregivers by virtue of this relationship facilitating a "teachback" approach to education. This can be seen in reduced readmission rates among patients whose families partner with the bedside team [52]. By engaging and supporting families during the ICU stay, caregivers may have more physical and emotional strength to be effective caregivers and thereby improve and enhance day-to-day life for the ICU survivor.

## *What Should Best Practice Look Like?*

Best practice solutions for engaging and supporting families should be based on the 2017 Society of Critical Care Medicine Family Centered-Care Guidelines [12]. These guidelines highlight five key recommendations:

1. Family presence in the ICU – *allowing patients to be present at the bedside at all times and participating on rounds.*
2. Family support – *educational programs, information brochures, diaries, decision support tools.*
3. Communication with family members – *routine family meetings, using the VALUE mnemonic.*
4. Use of specific consultations and ICU team members – *palliative care and ethics consultations as needed, family navigators, chaplain support.*
5. Operational and environmental issues – *protocols for sedation, hospital-wide policies in family-centered care, family support zones.*[12]

While achieving proficiency in all aspects of the guidelines is important, initially focusing on optimizing family-centered rounds, family meetings, empathic communication, and family support zones are strong first steps in establishing a culture of engaging and supporting family members (Fig. 3.2). This empowers families through the care journey to improve trajectories after the ICU.

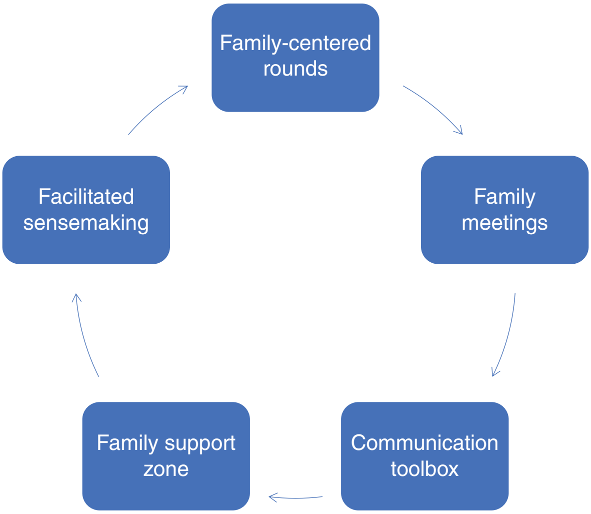

**Fig. 3.2** Framework for engaging and supporting families in the ICU

## Preparing Families for Life After the ICU

### *Teaching Family Members About PICS*

As discussed above, families are key stakeholders in the post-ICU trajectories of our patients. We know that a significant proportion of survivors will face new deficits after their critical illness. Yet, our approach to discussing these issues with patients is both scattershot and infrequent [53]. A frank discussion of the functional deficits potentially incurred, as well as the clinicians and adaptations available to address them may alter the relationship between limitation and disability markedly. If a family member is aware of a loved one's ICU-acquired weakness, they may anticipate these challenges as they occur. Difficult toileting can be addressed with a raised toilet seat, grab bars, a bath stool, and referral for aggressive physical therapy. This may be the difference between maintaining activities of daily living and skilled care needs. Resources to educate families include those created by SCCM's THRIVE initiative [54].

### *Teaching Family Members About PICS-F*

The constellation of symptoms comprising PICS-F has been recognized formally since 2012 [53]. Anxiety (35–49%), depression (20–39%), and PTSD (16–35%) occur commonly in family members after the discharge or death of their loved ones from the ICU [55]. In addition to these symptoms, many family members suffer sleep disturbances as well. In aggregate, up to half of family members suffer caregiver strain [56]. More than a third will have decreased quality of life as measured by the SF-36 Survey [10]. This points to the reality that many of the challenges facing family members of the ICU come not only from the sequelae of the ICU but also from caring for loved ones with new deficits. In this respect, these family members' experiences have striking similarities to those caring for loved ones with dementia or cancer.

Extrapolating from the experience of other caregivers, support to the families of ICU patients can take the form of psychosocial interventions, counseling, caregiver support groups, and respite [11]. Indeed, peer support appears to be a promising strategy in this population [57]. Successful post-ICU clinics utilize a multidisciplinary team providing these interventions and meet with both survivors and their families [58]. Family members report that the intentional support and interventions addressing feelings of guilt and helplessness are important mechanisms of benefit for these clinics [59]. Clinicians should be cognizant of families' access to clinics as a barrier [60]. As part of a program to support survivors and their families, peer support is a promising therapy [57]. In the absence of a formal post-ICU program, the care team can educate families prior to discharge about the interdisciplinary experts who can provide care, e.g., psychologists, psychiatrists, social workers, physical therapists, and physiatrists.

## Conclusion

Families play a vital role in the lives of our patients. This is true not only of their days before critical illness, but also those in the ICU and then after. Supporting families allows them to participate in care, improves their well-being, and may potentially improve clinical outcomes. For survivors, their families can help them maximize their post-ICU trajectory and minimize disability. Communicating clearly with families, both regarding care in the ICU and their lives afterwards is essential.

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# Chapter 4
# Humanising the ICU

**Sarah J. Beesley**

## The Problem of Dehumanisation in the ICU

When a patient enters the intensive care unit (ICU), they are often critically ill and needing advanced therapies to sustain life. The medical advances and ongoing research that occur in the field of ICU medicine have made it possible for the majority of ICU patients to survive their acute illness [1, 2]. As described in detail in other chapters in this book, survivors of critical illness, and their loved ones, may subsequently develop post-intensive care syndrome—a long-lasting constellation of cognitive, physical and psychological symptoms [3, 4]. Ongoing research into this syndrome is evaluating numerous interventions that could prevent or improve these outcomes.

Family member distress is not always correlated to the patient's degree of illness (such as that measured by the severity of illness scores), but more by other factors such as lack of privacy, respect, control, dignity or support [4–6]. Dignity is "the intrinsic, unconditional value of all human beings that makes them worthy of respect" [7], and "respect" describes actions that honour this dignity. All people are to be treated with respect and dignity, but a system where a power hierarchy could exist (such as between physician and patient) can create a situation where dehumanisation can occur. Dehumanisation can be manifest in many ways including:

- Lack of clear communication to patient and their family members, keeping them from being able to participate fully in informed decision-making.
- Archaic visitation policies that do not allow family members to be present at their loved one's bedside

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- Failing to address a patient by name and not honouring their personal identity
- Patients and family members may be given little or no control about when interventions occur or when team is available for updates
- Little effort is made to maintain the modesty of patient, including taking into account the cultural background or preferences of patient if possible
- Examining a patient without explanation or consent
- Not ensuring patients have access to aids such as their glasses, dentures, hearing aids or other similar items that allow them to participate in their environment

Some of these actions are not always avoidable, but many are related to the culture of an ICU and treatment team. For example, a provider may feel that when a patient is delirious or unconscious, there is no need to introduce oneself or ask for permission prior to examining the patient. This type of dehumanising behaviour can be disturbing to family members, and reports of ICU survivors indicate that some patients may have memories of this time despite their altered state and appreciate efforts to humanise their care [8]. These examples of dehumanisation illustrate "emotional harms", which are considered as preventable medical errors and are particularly distressing to patients and their loved ones [9, 10].

Emotional harms do not just affect patients; healthcare professionals are at high risk for burnout and particularly those who work in an ICU. Depersonalisation of patients by busy ICU clinicians contributes to a scenario where patients may be dehumanised inadvertently [11, 12]. This may also occur as ICU clinicians try to cope with the psychological demands of caring for the critically ill and experience "compassion fatigue" [13, 14]. While some have postulated that humanisation of patients may increase the risk of burnout, it appears more likely that the opposite is true. Burnout is associated with feeling moral distress or a lack of control [11]. Humanisation of the ICU may increase job satisfaction and longevity for critical care providers as it is likely that many interventions that improve family engagement and communication will also improve the experience of the clinical team [15–17].

## Humanising the ICU: Solutions

Humanisation as an explicit endpoint is rarely evaluated as part of clinical research, and research in this area is largely qualitative or observational studies [18–20]. Studies are limited by a lack of standard patient- and family-centred instruments that measure family experience in the ICU though endpoints that measure satisfaction with care, collaboration, communication, psychological symptoms and shared decision-making are frequently used [20–24]. Extrapolating from cultural norms regarding the treatment of other individuals combined with empathy and common sense lends to a guide of how to humanise the ICU. The fundamental intervention may be a simple as developing and supporting actions that treat patients and their loved ones more humanely [23–26].

An essential piece of humanising care is to recognise who the patient is and who is important in their world and then to include those loved ones in the care and support of the patient. Family includes all those who the patient wants to include, regardless of genetics or legal ties [23, 27]. The clinical team must be aware of personal biases that might lead to exclusion of a patient's loved one from the bedside or during important discussions [28, 29]. Encouraging patients to clearly identify these family members prior to an illness or in the early stages of an illness is a priority for all providers to ensure that the patient's wishes are honoured when they are not able to speak for themselves [30]. Of note, family relationships are often complicated; this chapter describes interventions for the inclusion of family members assuming that both they and the patient want them to be involved. Common sense and sensitivity are needed to address patients and family members with different relationships and coping styles [31–33]. Once family are identified, their involvement in the ICU is key to humanisation of the ICU as this promotes understanding and the treatment of the patient with dignity and respect [24].

Humanisation of the ICU includes simple but important personal actions such as addressing patients by name, making sure they have their glasses or hearing aids, asking for consent when examining them and maintaining their modesty when possible. Humanisiation may also include the following practices that require more intentional ICU culture and policy changes, such as:

- Open visiting. Whenever possible, patients must have the option to have family members be present at their bedside. Open visitation has been associated with less anxiety, less PTSD, less agitation, shorter length of ICU stay, higher patient/family satisfaction, and even improved patient safety [34–42]. In situations like the COVID-19 pandemic in 2020, families were removed from ICUs for infection control reasons. Creative solutions such as video conferencing may have some of the same benefits though little research has been done on this modality. Patients who are altered or impaired are not able to participate as well with care or to interact with their loved ones. Large trials now support interventions such as the ABCDEF bundle that aim to reduce sedation, mobilise patients, prevent delirium and engage families, all with the outcomes of improved outcomes [43–45]. Current guidelines recommend open visitation and flexible visiting policies that allow families to meet their and the patient's needs (without hindering patient care) [46].
- Learning about the patient's nonmedical history. As patients are not always able to communicate well, their family can be asked to share about who they are as a person. Some ICUs have put up "get to know me boards" that can be filled out by family to introduce the patient to their team. Knowing additional information about a patient may encourage the clinical team to see them as a person beyond their illness and understand them in the context of their life [47].
- Presence at rounds. Family member presence at rounds can improve the communication and relationship with the ICU team as well as family member satisfaction. Mutual understanding regarding the patient's clinical status and goals of care may be improved with family presence at rounds [18, 48, 49]. Family at

rounds also encourages the ICU team to think and speak about them as a person with sensitivity and respect at all times.

- Regular family meetings and shared decision-making. Whether family meetings are done in person or over a virtual format, family meetings allow the team to learn more about the patient's values and goals, and to incorporate them into care decisions [50, 51]. The ICU team can also use terminology that promotes shared decision-making and humanisation of the patient. For example, a recent guideline discussed the frequent misuse of the term "futile" when "potentially inappropriate" is what is really meant [52]. The use of "potentially inappropriate" in discussing goals of care allows the team to demonstrate respect for patient and family factors and values.
- Participation in patient care. Family members, when able, can assist in patient care activities such as ambulation, wound care and feeding [53, 54]. Beyond the potential benefit of humanising the care of the patient, family member involvement in this way may also decrease ICU length of stay and hospital readmission rates [55, 56].
- Presence at resuscitation and invasive procedures. Family members feel they have a right to be present during resuscitation and procedures if they would like to be, and honouring this is fundamental to humanising the ICU [57–62]. Family presence in these situations appears to improve outcomes psychologically, both short and long term, for family members and for patients who may be experiencing fear or pain [34, 63–66]. See Fig. 4.1 for an example of how family presence during a procedure can be performed. Family presence may decrease the stress that accompanies waiting in a waiting room to hear the outcome of a procedure as this information is communicated immediately. Like other practices that demonstrate transparency, family presence may also reduce concerns that their loved one was not always treated with respect or dignity. Family presence at resuscitation efforts is now considered standard of care, and family presence of procedures is gaining ground as such as well [61, 67].
- Patient and family advisory councils. After experience with critical illness, patients and their family members may have recommendations and insight into

**Fig. 4.1** Family presence at an invasive ICU procedure (placement of a central venous catheter)

the ICU experience that is invaluable [68]. These advisory councils can help improve and humanise ICU design and operations [26].
- Family physical support. This may include providing visitor sleep rooms and accessible showers as well as care packages such as toothbrushes for families.

There are likely additional examples of ways to humanise an ICU physically and psychologically for patients and their family members. Additional study of these interventions will be beneficial to ICU teams who are working to balance their time and efforts in the most effective avenue for humanisation.

## Conclusion

Patients in the ICU, as well as their family members and loved ones, are first and foremost people with intrinsic dignity who deserve to be treated with respect. Critical illness and the ICU environment can easily lead to situations that are dehumanising for patients and their family members. ICU teams—including administrators, nurses, physicians, therapists and social workers—must actively work with patients and families to design and implement ICU policies to personally and systemically support humanisation of the ICU.

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# Chapter 5
# Complementary Therapies in the ICU

**Sumeet Rai and Alex Psirides**

Priorities of treating and supporting organ failure in the intensive care unit (ICU) often lead to a lack of appreciation of the near-death and overwhelming experience for most patients and family members. The mechanistic, data-driven, mortality-focussed clinical environment of the ICU often creates a sedation-clouded atmosphere for the patient, devoid of individualistic choices. For most intensive care patients, a loss of control and lack of privacy with an inability to communicate defies the concept of being ‘human’. While conventional intensive care medicine aims to improve survival, complementary therapies may contribute to a more humanistic environment to sustain the individual and the family in their journey to recovery from critical illness.

The National Center for Complementary and Integrative Health defines complementary therapies as nonmainstream practices used in conjunction with conventional medicine [1]. It is thought that complementary health approaches could provide a holistic critical care environment with a focus on improving the psychological and physiological well-being of patients and helping with sleep and relaxation [2]. While a number of nonpharmacological interventions like music, mind–body interventions, e.g. body-based therapies (movement therapy, massage), energy therapies (healing touch, therapeutic touch, reiki, acupuncture, acupressure, reflexology), and animal-assisted interventions have been proposed, few have been

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vigorously tested in critical care [2–5]. Of these, a number of the mind–body therapies require education, training and practitioners may require to be credentialed, potentially limiting bedside use in the critical care settings [5]. In addition, a vast majority of these interventions have only focussed on short-term outcomes and physiological stress response in the ICU [6].

This chapter seeks to focus on music as a feasible complementary therapy with a reasonable evidence base and animal-assisted interventions as an upcoming therapy in reducing the barriers to a humanised ICU and involving patients in their own well-being.

## Music Intervention

> Music is the language of the spirit. It opens the secret of life bringing peace, abolishing strife.
>
> —Kahlil Gibran

Music is one of the oldest complementary therapies associated with medicine across cultures and time, with mention even in the Biblical times as a healing therapy. The advent of music in medicine could be attributed to the holistic approach to health as defined by the Hippocratic philosophy [7]. More recently, modern neuroscience studies have shown that music stimulates various emotional processes in the brain [8].

A majority of ICU patients display some type of distressing symptoms (anxiety, stress, fear, discomfort, immobility, thirst, inability to communicate), especially during the process of mechanical ventilation or liberation from it [9, 10]. Acute emotional or psychological distress and distress related to endotracheal suctioning, procedural pain are common in ICU patients [11, 12]. In order to treat these symptoms, patients are often offered sedatives and analgesics, with variable adverse effect profiles, prolonging duration of time on the mechanical ventilator. There is scant research on nonpharmacological approaches in reducing these distressing symptoms. Music can help patients move their focus from stressful events, reduce perception of pain and act as a relaxation technique [13–15]. Although music may help in blocking out ambient noises from the intensive care environment, the role of music probably goes beyond distraction therapy and rather acts as an emotional phenomenon.

**Effects of music intervention** The effect of music on intensive care patients has largely been studied in the subset of patients receiving mechanical ventilation, with a number of proven beneficial effects (Fig. 5.1). Music has been shown to induce a relaxation state, contributing to an overall improved well-being [16]. Music suppresses sympathetic nervous system activity and appears to act on the limbic system with the release of endorphins [17, 18]. In ICU patients, music listening has been associated with hormonal changes, viz. increased levels of growth hormone, decreased interleukin-6 levels [19], and decreased cortisol, increased ACTH/cortisol ratios and decreased prolactin levels [17]. Music interventions have been associ-

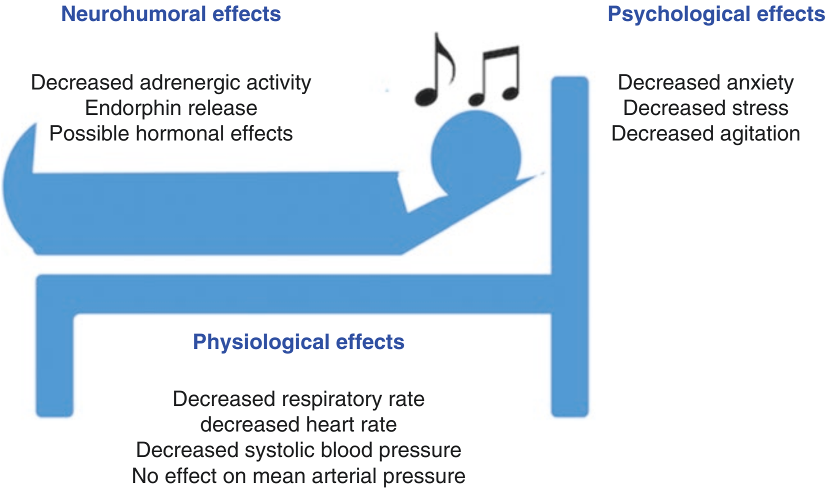

**Fig. 5.1** Potential beneficial effects of music as complementary therapy for critically ill patients. Based on the literature from Bradt, Dileo (2014) [18]

ated with improved physiological variables in ventilated patients, as a result of beneficial effects on state anxiety [20–22]. Due to a number of these effects, it has been proposed that music interventions can have beneficial effects on oxygen consumption, facilitating weaning from mechanical ventilation [16, 20]. In addition, relaxation music may have a role in improving sleep in intensive care patients.

**Types of music interventions** There is a clear distinction between the different types of music interventions (music medicine vs music therapy) that can be offered to intensive care patients.

The term ‘music medicine’ refers to the practice of passive listening to prerecorded music offered by healthcare professionals or self-administered by the patient [18]. Self-administration of music adds to the concept of humanisation of ICU, offering control back to the patient, in an environment where they may appear to have surrendered important decision-making to their healthcare providers. On the other hand, music medicine, when administered by healthcare professionals, is not without risks. Music evokes strong emotions, and it is possible that an inappropriate choice of music may lead to a negative experience for the patient, especially if they are unable to communicate.

The term ‘music therapy’ involves music interventions offered by trained music therapists and the use of personally tailored music experiences [18]. This is a complex intervention to deliver as it involves the assessment and delivery of a therapeutic process to address physical, emotional and cognitive needs of a patient. Music therapy may be receptive (listening to tailored music) or active (playing a musical instrument). While interactive and active music therapy may allow significant emotional expression, receptive relaxation music therapy is likely to be suited to the majority of intensive care patients. Patient-directed music (PDM) therapy, where intensive care patients self-initiate a tailored selection of music (after an initial consultation with a music therapist), may have an important role in empowering patients in self-management of their anxiety state.

**Type of music** The ideal kind of music largely depends on the patient preferences but should be grounded on research and preferably guided by music therapists, based on patients' physical and emotional state. Music with a slow tempo (60–80 beats per minute), low frequency and stable rhythm with relaxing tones assists in relaxation, reduces stress, anxiety and may reduce pain [23]. The use of live music by music therapists may allow alterations in tempo and pace, based on changes in patient's condition. Live music performance with stringed (harp/guitar/cello) and wind instruments (flute) offers the chance to engage the patient and family without being too obtrusive. Classical music has been thought to be beneficial in inducing a relaxation state, improving anxiety, depression, stress and pain [24]. Soothing and relaxation music may assist in improving sleep, while stimulating music may help energise patients. The literature recommends against the use of heavy metal or techno genre of music in intensive care settings, due to adverse cardiovascular effects and the possibility of aggravating aggressive behaviour [24].

**Evidence for effectiveness of music interventions** Music interventions in mechanically ventilated patients have been shown to improve important patient-centred outcomes. Music interventions reduce pain intensity with decrease in analgesic requirements [17, 25], reduce intake of sedatives and are associated with higher levels of sedation scores [19, 26]. Music interventions (predominantly studies on music listening) have demonstrated a significant beneficial effect on anxiety management in ventilated ICU patients [18]. PDM therapy was found to be superior to self-initiated use of noise-cancelling headphones or usual care in reducing anxiety and sedation exposure in mechanically ventilated ICU patients and has been likened to patient-controlled analgesia [26]. In addition, PDM was found to be a cost-effective strategy for the reduction of anxiety in ventilated intensive care patients with an approximate cost reduction of 2000 USD compared to standard care [27]. Despite the burgeoning evidence base on this topic in the last decade, there is weak evidence to associate music interventions with mortality, with virtually no studies that have evaluated effect of music interventions on post-discharge or long-term outcomes or quality of life. Of note, none of the studies have shown any harm with music interventions.

## Animal-Assisted Intervention

> "A small pet animal is often an excellent companion for the sick, for long chronic cases especially. A pet bird in a cage is sometimes the only pleasure of an invalid confined for years to the same room"
>
> Florence Nightingale. Notes on Nursing: What it is and What it is Not (1859)

Animal-assisted intervention (AAI) is the process of introducing animals to clinical areas to aid and improve the recovery of patients, or to provide comfort during end-of-life care. Although this may be relatively new for critical care, the formal introduction of animals as emotional support aids was first described in a US veteran hospital in 1919 [28].

Pet ownership is common, particularly in the Western world. A 2015 survey of over 27,000 people in 22 countries found that over half of those polled owned at least one pet [29]. For many patients, these pets are a part of their everyday life, and they may even be closer than some family members. Being separated from this support during what are often the most difficult times of their lives may contribute to stress, anxiety and exacerbate symptoms such as pain. Although there are clear contraindications to AAI (in immunocompromised patients or visiting by dangerous animals), the default position had often been that intensive care is an animal-free zone based largely on unproven fears of zoonoses and ignorance of the benefits to both patients and staff. A proposed mechanism of such benefits is outlined in Fig. 5.2.

The type of relationships between the animal and the patient can be divided into three categories.

Firstly, the animal may be part of an ‘animal-assisted activity’ (AAA) where the animal is previously unknown to the patient. Such animals (usually dogs) are brought into the clinical environment by trained volunteers or professionals as part of a ‘meet and greet’ programme. AAA is designed to increase patient interaction and engagement with their therapy and hasten recovery. Animals are prescreened, often specifically trained for visitation and may visit on a regular schedule. Several private companies and not-for-profit organisations exist that provide such services to healthcare facilities [30, 31].

The second category involves visitation by domestic pets with whom the patient has a previously established relationship. This will present different challenges. Although the patient and pet are more likely to share a biome and a stronger emotional connection that enhances the therapeutic benefit (not least of which is increasing the motivation to leave intensive care and hospital), such animals are not trained and may react badly to the stresses of a critical care environment. Specific limitations should be applied in advance—the pet must be accompanied by a family member they know who must remain with them at all times, they must remain leashed or caged, they must be toilet trained and toileted prior to entering the hospital, and their visit is restricted to the single patient with whom they have a relationship. Such visits are generally not routine and should only occur after prior discussion and planning including consideration on how to get the animal in and out of the critical care area and consent of adjacent patients if relevant. Although ideally the patient should be awake and interactive to maximise the benefit of such visits, in the authors’ ICUs, pets have visited patients with brain damage as well as being present (physically on the bed) at the family’s request during a terminal extubation.

The third category includes service animals. These are (almost exclusively) dogs that are specifically trained to do work or perform tasks for an individual with a disability that may be physical, sensory, psychiatric or intellectual. Such animals

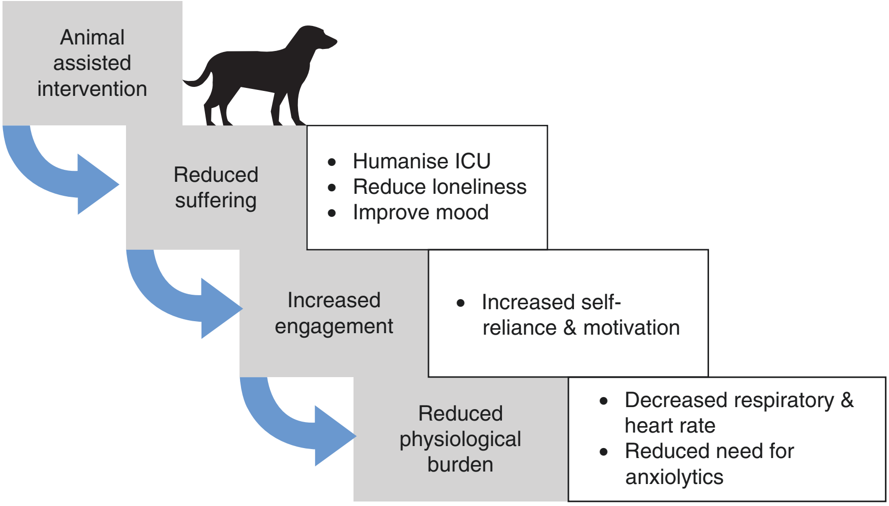

**Fig. 5.2** Animal-assisted intervention as an example of nonpharmacologic intervention to reduce suffering with potential downstream benefits. (Adapted with permission from Hosey et al. [37])

are highly trained in the specific needs of the individual and would normally accompany the patient during their everyday life, including hospital out-patient clinics. It is likely there is a significant emotional bond between animal and owner that may exceed that in the preceding category. The significant training such animals receive makes their anticipated behaviour in a critical care environment more predictable.

The evidence base describing the benefits and risks of AAI continues to accumulate. A 2016 systematic review of animal therapy in an in-patient setting, although not specific to the critical care environment, identified 36 articles of relevance [32]. The described benefits included a reduction in stress, pain and anxiety. Other outcomes described included changes in vital signs and nutritional intake. Most studies utilised dogs, but some also described the effects of birds, fish, rabbits, horses, ferrets and even dolphins. The described risks included allergies, infections and animal-related accidents. Simple hygiene protocols were effective at minimising risk. The review concluded that benefits significantly outweigh risk.

Such benefits may not just extend to patients. Pet ownership is likely to be just as prevalent amongst hospital staff. A 2018 US study described the effects of an animal therapy programme upon both patients and nurses in an inpatient surgical oncology unit and found similar benefits in both groups [33]. Quality-of-life indicators for patients improved while for staff compassion and satisfaction increased with a reduction in burnout. Staff reported the presence of dogs made ‘a stressful day better’, ‘give me something to look forward to’ and ‘bring a calm atmosphere to the nurses’ station’. In a critical care environment where stressors and burnout are prevalent, it is likely this effect is transferrable and may even be more important.

Examples of both AAI and domestic dog visitation are shown in Fig. 5.3.

**Fig. 5.3** (**a**) (left): 'Oxford', a black Labrador visits the staff and patients of Wellington ICU in New Zealand as part of an AAI programme. (**b**) (right): 'Zeb', a domestic pet visits their owner, a long-stay patient in Canberra ICU in Australia

Where barriers to the introduction of animals into clinical environments have been encountered, they have largely come from infection control clinicians. As the potential benefits of AAI have become clearer with little evidence to quantify risk, this position has softened. Several infection control professional bodies have published guidelines that would be considered 'best practice' approaches on how to address valid concerns. These include a position statement from the Australasian College for Infection Prevention and Control that recommends all healthcare facilities develop policies that allow animal visitation and resolves to support this process while making recommendations around reducing zoonotic infections [34].

In the USA, the American Journal of Infection Control has published a comprehensive guide to developing AAI which includes [35].

- Types of animals that are suitable to visit (excludes those with higher zoonotic potential such as reptiles, amphibians, nonhuman primates, hamsters and hedgehogs)
- Assessment of animal temperament, particularly under stress
- Details of animal health criteria with up-to-date vaccinations, flea/tick treatments and recent bathing (but including a recommendation that routine microbiological screening is *not* required)
- Training required for both the animal and handler
- Advice on consent processes
- Areas of the hospital that are off-limits

Although the risk of animal-to-human transmission can be mitigated with selection and appropriate hand hygiene, consideration must also be given to transmission of infection in the opposite direction. As such, visiting animals should avoid patients with transmissible diseases including tuberculosis, *Salmonella, Shigella, Giardia, Campylobacter, Streptococcus A*, tinea corporis, amoebiasis and methicillin-resistant *Staphylococcus aureus* [28]. This is particularly true if the animal is visiting as part of an AAI scheme where they may subsequently come into contact with other patients.

The presence of animals in critical care areas where they would never have previously been considered reflects the recent shift from ‘survival at all costs’ to improving the experience of patients. This is particularly relevant to those who may be resident in units for prolonged periods of time. Critical care, probably more so than other clinical areas, is prone to dehumanising the patients within its walls. Such unconscious strategies may be defensive on the part of the clinician. Increasingly, they are being challenged. Several international programmes, including those supported by major publications such as the New England Journal of Medicine, have proposed redesigning the way that sickest patients are cared for, by moving to a focus on a human being-centred care model [36]. AAI has a clear role to play in this context. With appropriate planning, supporting policy and engagement with infection control concerns, the introduction of animal visitation in the critical care setting is likely to improve the welfare of both patients and clinical staff.

## Summary

Both music therapy and animal-assisted intervention are effective, relatively inexpensive and safe nonpharmacological therapies in intensive care patients with multimodal effects on reducing pain, anxiety and their physiological sequelae. Although neither may currently be considered mainstream therapy, as their adoption spreads, there is increasing evidence supporting benefit with little evidence of harm. Centres that have adopted either have often relied on enthusiastic individuals to convince their colleagues of benefits and address perceived risks. As with all practice change, collegial consultation and supporting policy documentation are recommended; the references that follow may help begin this process.

We recommend that intensive care practitioners routinely consider the adjuvant role of both music and animal therapy in alleviating stress and anxiety in critically ill patients and facilitate the process for those who may wish to try them. The use of either may be self-directed by the patient with support from their family or supplied as part of an institutional initiative. Both help advance patient-centred care models and humanise the person in the bed in front of us. This process may convey benefits greater than either intervention alone.

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# Chapter 6
# ICU Diaries

**Ingrid Egerod and Peter Nydahl**

## Introduction

In this chapter, we illustrate the concept of intensive care unit (ICU) diaries by presenting theory accompanied by an authentic case. The case we have chosen describes 58-year-old Mrs. Miller (pseudonym) who was involved in a motor vehicle accident and suffered severe traumatic brain injury. She was rushed to the nearest hospital by ambulance and was immediately sedated, intubated, and mechanically ventilated. The patient was expected to stay in the ICU for a while, so the nurse started an ICU diary.

> **Mrs. Miller's Diary**
>
> Dear Mrs. Miller, you were admitted to the Intensive Care Unit at the University Hospital this morning after a serious car accident where you hurt your head badly. When you arrived by ambulance, we immediately examined you and started treatment. You will spend the next days here at the Intensive Care Unit. You are connected to monitors, infusion pumps and a ventilator that helps you breathe. This is all for your safety, but I can imagine that it might be frightening or disturbing for you. You receive medications to keep you comfortable and help you sleep. Some patients have told us that they dreamed a lot while they were here, and that the ICU might have influenced their dreams, which can lead to confusion. We are writing this diary to help you understand later what went on when you were here. We are taking good care of you. Carol Smith, RN, September 5th, 2019.

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## *Post-intensive Care Syndrome (PICS)*

Acute critical illness and intensive care put patients at risk for short- and long-term physical and psychological complications, described as post-intensive care syndrome (PICS) [1–3]. About 25–30% of ICU survivors show symptoms of anxiety, depression, or posttraumatic stress disorder (PTSD) during the first 6 months after ICU discharge. Common risk factors include younger age, benzodiazepines, frightening ICU experiences, and pre-existing psychiatric illness [4–6]. Close family, known as family caregivers, might experience similar symptoms. Depending on the circumstances, the prevalence of anxiety, depression, and PTSD in family caregivers have been recorded as 2–80%, 4–94% and 3–62%, respectively [7, 8]. Symptoms dissipate more rapidly in caregivers than survivors. Risk factors for caregivers include younger age, relationship to the patient, lower socioeconomic status, and female sex [8].

## *ICU Diaries*

ICU diaries were initiated by intensive care nurses to alleviate patients' psychological symptoms after critical illness and to help them come to terms with their illness during recovery [9]. The intervention was developed in Denmark, Norway, and Sweden in the early 1990s [10] and is now used in many countries worldwide [11]. No single purpose has been given for writing a diary [12], but diaries are assumed to:

- Help patients to come to terms with critical illness.
- Help patients and families to cope with their experiences.
- Fill memory gaps and help describe the critical illness trajectory.
- Explain physical and psychological symptoms.
- Understand hallucinations and unreal experiences.
- Support follow-up consultations.
- Improve patient-hospital communication and quality of care.
- Support bereaved after the patient has died.

ICU diaries were not based on a nursing theory but were influenced by theories of crisis, coping, and communication. They have been described as a therapeutic instrument, an act of caring, an expression of empathy, a vehicle for communication and orientation, a supplement to follow-up visits, and a humanizing factor in the technical ICU environment. The intervention emerged as a nurse-led bottom-up initiative that was later investigated, structured, and described in guidelines [13]. As a therapeutic instrument, some nurses believed that diaries could help resolve stages of crisis [10]. This was contested by other nurses who believed that a therapeutic perspective would sustain the "sick role" of the patient. An alternative perspective was using diaries as an act of care and compassion. In some cases, it was written from an existential perspective where the nurse vicariously described what the patient might be experiencing. In later years, there has been less debate on the underpinnings and more focus on evidence of the effect of the diary. Perhaps, as the body of knowledge on ICU diaries increases, a theory of ICU diaries will emerge from increasing research describing the phenomenon.

## *Practical Aspects of Writing a Diary*

ICU diaries can be described from a practical (clinical) aspect of how and what to write, or from a theoretical (academic) aspect of the mechanism and outcome of the intervention. The following concepts are important to ICU diaries:

- Authors: Person or persons writing the diary
- Recipient: Person receiving the diary
- Diary type: Handwritten or computerized diary
- Design and format: Cover layout, decorations, page setup, abbreviations
- Structure: Rules for first, middle, and last entry
- Content: Topics included in the diary, e.g., greetings, patient appearance, mood, etc.
- Writing style: How and what to write
- Photographs: How and when to photograph the patient or others
- Handover: Timing of diary handover and follow-up

### Authors

ICU diaries can be kept by hospital staff, family, or friends, depending on local practice or national guidelines. In Norway, the national guidelines state that ICU diaries should only be written by nurses or other hospital staff as the diary is regarded as part of the hospital chart [14]. ICU diaries in Norway are quality assured by peer assessment before they are handed over to the patient. Most other countries allow for a broader group of authors and consider the diary the property of the patient rather than the hospital. ICU diaries were initially considered as a “gift” from the nurses to the patient [15]. The diaries are written “to” or “for” the patient but will never convey the actual patient perspective. Each author narrates their own version of the story [15]. It is becoming more common for family caregivers to write a diary for the patient. This is a version of the caregiver perspective that can enable a shared story with the patient [16]. It is still uncommon for the patient to participate, but the diary holds the potential for the patient to continue the story during recovery.

**Mrs. Miller’s Diary**

Mr. Miller and their two daughters are at the bedside. One is writing in the diary.

“Dear Mum, we are so worried about you. I received a call from Dad and hurried to the hospital. Mary is also here, she cancelled her holidays. I’m crying, but the doctor told us to

> be patient. They don't know how you will wake up, we must wait. You know that I can do almost everything, except waiting. I love you so much, and I can't see you like this. You are my beloved MUM! We will spend all day at your bedside, we are always at your side!
>
> Love, Donna"

## Recipient

The ICU patient, and later the ICU survivor, is the recipient of the diary. After the handover, there might be many readers of the diary, most often close family and friends. It is up to the patient to decide who may read the diary and where to place the diary at home. In some cases, diaries have been used to document the patient's illness to obtain sickness benefits. More attention is being given to selecting the patients that will benefit most from receiving a diary. This is to control the workload of the nurses and target the effort.

## Diary Type

Diaries can be handwritten or computerized. If handwritten, different formats are used, such as small notebooks or A4/A5 size paper [17]. Some patients still prefer handwritten diaries for personal touch, whereas others prefer computerized diaries that are easier to read, store, and share. Diary examples and templates are available on www.icu-diary.org.

## Design and Format

Diaries can include standardized information such as how to contact the ICU, daily ICU routines, glossary of common terms, photographs of the ICU (often from the view of the patient), pictures of equipment, DVDs, or questions for evaluation of the diary. To avoid legal issues, some ICUs have a general disclaimer stating the non-legal status of the diary, e.g., "The following diary entries do not constitute a form of documentation of your treatment and are not created for this purpose. The entries are therefore not part of your medical record. The diary is offered to support your recovery by helping you to understand your experiences in ICU."

> **Mrs. Miller's Diary**
>
> Dear Mrs. Miller, I took care of you today. Your condition has stabilized, and we are trying to wake you up. This is a process that takes time because you were sedated. You are slowly waking up: you blink when I call your name, and you have some strength when we turn you. Your breathing is slower when your daughter has visited you. I wonder if you recognize her voice or her touch? Perhaps you are dreaming – I wonder what you are experiencing.
>
> Kelly Dawson, RN, November 7th, 2019

## Writing Style

Diaries are usually written "to" and "for" the patient and sometimes "for" and "by" the families [18]. The patient is addressed in a kind and direct manner (see diary examples). The authoring staff member signs each entry, including the date and year. In Scandinavia, the UK, and the Netherlands, it is common to use the first name of the patient and nurse. In more paternalistic societies, the patient is addressed as Mr./Mrs./Ms. using the last name. Nurses do not always use their last name in a diary, maintaining some degree of anonymity. Using last names for patient and physician and first name for nurses might indicate some degree of subordination.

Diary entries include description of the patient status in layman's terms [19]. The first, and usually longer, entry describes the conditions leading to ICU admission followed by daily interventions and events and finally the last entry summing up the ICU stay and patient condition. The stages identified in ICU diaries are crisis, turning point, and normalization [15]. Rehabilitation initiatives start as soon as possible, e.g., early mobilisation and continue throughout the stay. The golden rule is to write only what would be discussed in front of the patient. Due to issues of confidentiality, the diary should not contain diagnosis, prognosis, or treatment. Other things to avoid are abrasive language or information that could be misunderstood in a legal sense. In general, diaries should be written in plain language, avoiding clinical terms. The language can be individualized taking into consideration the personality and experience of the patient. Patients have expressed a need to know what they looked like, what they said, how the staff identified their needs, how they expressed their feelings, and how the staff communicated with them [20].

Some nurses like to write in a reflexive manner introducing a sense of wonder, e.g., "I wonder what you are dreaming/hearing/feeling?" This is to stimulate patients to recall and communicate their experiences and dreams that are often remarkably vivid [21]. Of course, the frequency of this type of questions should be appropriate. ICU diaries are sometimes authored by family caregivers with guidance from the nurses. Families can write more freely as they have fewer restrictions than nurses. Contributing to the diary might be a simple and effective coping strategy for the family. They can express their thoughts and feelings in the diary and share them at a later time [22], thus reducing the burden [23]. It is still debated whether the caregivers should unburden their emotions in the patient's diary, as evidence is lacking into the potentially harmful effects of ICU diaries [24].

**Mrs. Miller's Diary**

Dear Mum, now you have been here for five days. Only a few days – it seems like a month. It came so suddenly, so unexpected. Do you remember: Tuesday morning we were shopping in the city, laughing and everything was as usual, and now …? Your "vitals" are still stable, and they were able to reduce the sleep medications again. You are "flying" just above the ground, like an airplane – you know, that's what they said from Grandpa back then. We are patient and give you time – holding your hand a bit is all we can do for you. But at the same time, I am still really scared, and can't sleep and have bad dreams. We all worry. And all those who can't visit you here are in your thoughts with you. I love you so much, Marie

## Photographs

Photographs have always been an integral part of ICU diaries: photos of the patient at different stages of recovery in ICU, photos of family or staff surrounding the patient, or generic photos of patients and ICU equipment. The early ICU diaries were called photo diaries, and according to the patients, the photos were appreciated [25]. The photos helped them more than words to realize how seriously ill they had been [26]. For legal reasons, the patient should not be photographed while unable to give consent. This includes patients that are unconscious or deeply sedated. This issue is often resolved by keeping photographs in a safe place until the patient is able to decide whether to keep the pictures for the diary or discard them. At first, pictures were taken with polaroid cameras, but now pictures are taken with smartphones or electronic cameras, perhaps raising concerns about patient's privacy and data protection. National and local policies for data protection should be followed. Pictures can be used to record patient progress and as the basis for follow-up consultations [27]. Some patients regard pictures as the most important part of the diary.

> **Mrs. Miller's Diary**
>
> Dear Mrs. Miller. So, the last few days you have made great progress. I took care of you just after your admission, when you were seriously ill. That's why I'm so happy that I can experience the great success after so many days. You help when I get you up in a chair or brush your teeth. You are like a top athlete. I complement you - I know how exhausting it is, but despite the stress, you manage to smile. We took a picture of you, with the physiotherapist and me. You are looking good! Keep up the good work and you'll be out of here very quickly. Carol Smith, RN, November 20th, 2019.

## Diary Handover

There are many ways to hand over the diary. In Scandinavia and some other countries, diaries are usually handed over to the patient during a follow-up visit, where a nurse discusses the ICU stay with the patient and the patient has a chance to ask questions. The diary is read aloud by the nurse and the photographs are discussed. In other countries, there might be less time for follow-up, and the diary is instead given to the nurses at the general ward or to the family to continue writing.

The patient does not usually read the diary at handover from ICU. Most patients are not ready to confront their ICU stay before some time has passed, and patients with symptoms of PTSD and avoidance wait until they are ready after 6 months or a year, if ever [28]. Patient readiness to receive and read the diary is individual [29–31]. It is generally recommended to hand over the diary when:

- The patient is fully awake, conscious, and emotionally stable.
- The traumatic situation (critical illness) is resolved.
- The patient is interested in the process of recovery, asking questions such as "What happened to me?" "How long have I been in ICU?" or "Why am I so weak?" [11].

**Mrs. Miller's Diary**

Dear Mrs. Miller, you have almost recovered. You can care for yourself and enjoy your coffee. Only when getting up you need a little assistance. You are doing so well that you can transfer to the general ward soon and move on to rehabilitation. Everything is planned, and the other wards will be informed by us. Your daughter said that everyone at home is looking forward to seeing you again! We wish you all the best! Susan Sanchez, RN, November 26th, 2019.

Mrs. Miller's diary illustrates some of the different types of authorship and diary content, from practical to family-oriented issues. The diary is used as a tool for communication and as a receptacle for information that can be accessed by the patient at a later time. Ideally, the diary should contain an introduction explaining how and why the patient came to the ICU and a final entry summarizing events and providing a sense of closure. Mrs. Miller's diary shows the compassion of the family and the caring of the nurses. This offers the patient a sense of safety and not being abandoned while unconscious. This is a way of sustaining personhood during a time when the patient is unable to make her own choices or act at will.

## ICU Diary Research

Through the years, ICU diaries have been subject to research focusing on the qualitative and quantitative evidence of the intervention (Table 6.1). Studies on ICU diaries have described their extent and application [12]; history [32]; effect on patient PTSD [31]; effect on patient and family PTSD [33]; impact on patient and family well-being [34]; impact on teamwork and communication between patient, family, and staff [35]; impact on nurses' work satisfaction [36]; and effect on anxiety, depression, and quality of life of survivors and family [37].

Research has also covered issues on structure and content of nurse-authored diaries [15], structure and content of family-authored diaries [38], the meaning of

**Table 6.1** Potential benefits of ICU diaries

| | |
|---|---|
| Patients | Improved well-being [34]<br>Improved quality of life [37]<br>Better coping [14, 20, 22, 42, 46]<br>Better understanding [20]<br>Less anxiety and depression [37] |
| Family | Improved well-being [34]<br>Better coping [16]<br>Better communication [35]<br>Less PTSD [37]<br>Less anxiety and depression [37] |
| Staff | Improved humanization of care [32, 50, 51]<br>Improved quality of care [39]<br>Improved work satisfaction [36]<br>Improved reflection on critical care [12, 48] |

diaries for nurses [39], the meaning of diaries for patient and family [16], prediction of patients benefitting from diaries [40], the workload of writing a diary [41], the experience of reading a diary [20], and the patient and family use of diaries [42].

Evidence of the usefulness of ICU diaries is still weak and lacks discussion of potential harms of the intervention, such as stimulation of frightening memories, flashbacks, or emotional disturbances [9]. More qualitative evidence is emerging on patient satisfaction of ICU diaries and nurse-led follow-up [39, 43, 44], whereas quantitative research has been unable to demonstrate a strong correlation between diaries and psychological recovery [24, 45]. In some cases, the ICU diary is a good supplement to the hospital chart. When patients have access to both, they are enabled to distinguish between real and delusional memories and to cope with their experiences [14, 20, 22, 42, 46]. Recent meta-analyses have suggested that patients receiving ICU diaries, compared to no diaries or post hoc diaries, experience significantly less anxiety and depression [37, 47].

Family caregivers can express their thoughts and experiences in a diary that might help them to cope with the patient's illness, while hospital staff perceive the diary as a vehicle for the improvement of quality of care [48, 49]. The ICU diary tells a different story than conventional documentation and highlights the human aspect of critical illness [32, 50, 51]. Finally, pediatric ICU diaries show potential to help parents and siblings to cope with the critical illness of a child [52, 53].

### *Free Online Resources*

In 2011, an international group of diary experts founded a network with a website for ICU diaries: www.icu-diary.org. The website offers information on diaries, contact with experts worldwide, diary templates from different countries in several languages (e.g., English, Spanish, German), implementation assistance, risk calculation, discussion of legal aspects, consent forms, and other helpful information. Participation and use of the resources are free of charge. If new papers are published, updated references are appreciated. The diary network is informal, offering newsletters on diaries and psychosocial needs of ICU patients, families, and more.

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# Chapter 7
# Optimising Sleep

**Edward Litton and Mary Elizabeth Wilcox**

## Introduction

Sleep is essential for health and is a foundation for the success of many other strategies aimed at optimising recovery in survivors of critical illness. Sleep disruption impairs immunity and increases the risk of infection, potentiates metabolic dysfunction including insulin resistance, lowers mood and cognitive performance, increases inflammation and increases perceived exertion and exhaustion, reducing the capacity for early rehabilitation [1–5].

Both the quality and quantity of sleep are important. Deeper, stage three non-rapid eye movement (NREM) sleep, also known as slow-wave sleep (SWS), and rapid eye movement (REM) sleep activate restorative physiological processes. For example, SWS decreases sympathetic nervous activation and cerebral glucose utilisation and stimulates substantial growth hormone release, an essential hormone for muscle repair [6]. Optimising these restorative sleep phases requires efficient, uninterrupted, deep, nocturnal sleep of sufficient duration. Unfortunately, sleep in critically ill patients is typically fragmented and light and spreads over the entire 24-hour period (see Fig. 7.1) [7]. As a result, patients admitted to the ICU consistently report

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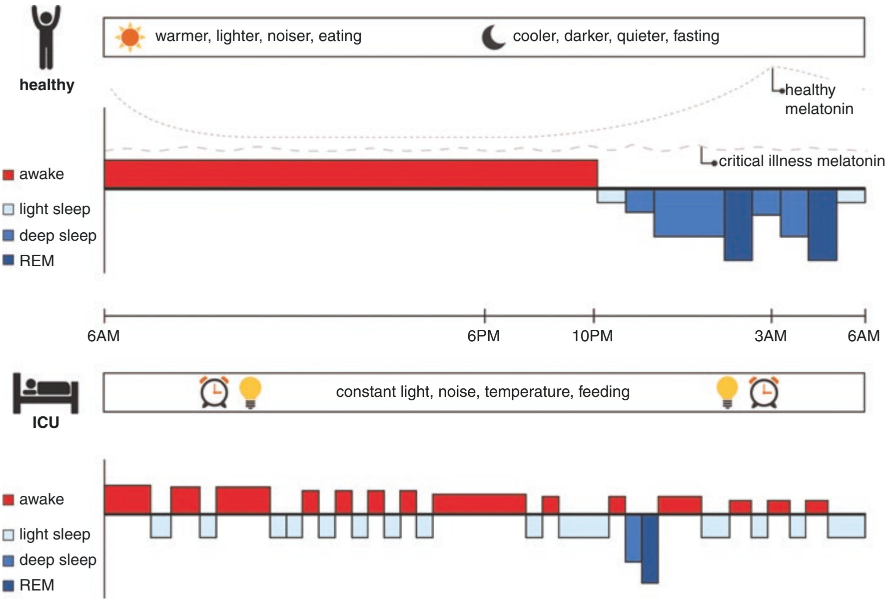

**Fig. 7.1** Sleep patterns in health and in critical illness

sleep disruption as a severely distressing experience [8, 9]. This disruption may persist and in turn may be associated with psychological distress and impaired survivorship, limiting recovery and quality of life after discharge [10–12].

Patients and clinicians rate sleep as a priority research area [13]. However, recent incorporation of sleep recommendations into practice guidelines was based on evidence of limited quality, preventing the recommendation of effective interventions [13, 14]. How can this unmet need be addressed? An effective approach to optimising sleep requires that critical care clinicians acknowledge sleep as an essential component of recovery from critical illness, an irrefutable conclusion once the physiology of sleep is understood. In clinical practice, sleep must be measured routinely, and this information considered and acted on, in much the same way as any other substantial abnormality in physiological parameter. Finally, at the level of the ICU, a dynamic approach is required to implement sleep-enhancing interventions, informed continually by the best available evidence.

## Measuring Sleep in the ICU

Accurate measurement is one of the biggest challenges of studying and improving sleep in the ICU. Sleep can be measured in terms of quantity (total sleep time [TST] and time spent in each stage of sleep), quality (fragmentation, sleep EEG patterns) and distribution over a period of 24 hours. Full polysomnography (PSG) is the only reliable tool for measuring sleep, including the identification of individual sleep stages following the Rechtschaffen & Kales [15] or the recently modified rules [16]. At least three EEG signals (preferentially F4-A1, C4-A1, O2-A1), two electro-oculography signals and a submental electromyography (EMG) signal are required for accurate scoring. The application of conventional classification criteria is challenging in the ICU as EEG patterns are attenuated by alterations in cerebral metabolism, electrolyte disorders, intoxications and commonly administered medications that influence sleep patterns. Alternative, or supplementary, criteria for PSG scoring in the ICU were proposed by Drouot et al. (2012), who scored EEG recordings by separating epochs into states of either pathological wakefulness or atypical sleep [17]. Bispectral index (BIS), an EEG-derived method for assessing the depth of sedation mainly used during general anaesthesia in the operating room, has been proposed as an alternate measure of sleep assessment. Unfortunately, BIS is sensitive to technique and its interpretation is difficult. Further, its use for sleep assessment is poorly documented. Spectral edge frequency (SEF) has been evaluated to assess sleep states as well as circadian rhythmicity [18] but suffers from inconsistency in selecting which epochs to include. Further studies are needed to determine its validity in an ICU population.

Actigraphy continuously measures an individual's movement using a wristwatch-like device on the wrist or ankle and is an alternative to PSG. The presence of movement indicates wakefulness, and its absence indicates sleep. This widely used method has been validated in several populations for its measurement of TST and sleep fragmentation [19]. Further, actigraphy has been validated against biochemical markers of circadian rhythmicity [20]. A recent systematic review of actigraphy in the ICU showed that actigraphy has been increasingly used as a measure of sleep. Several limitations exist for its general use in an ICU patient population including the difficulty in differentiating sleep from immobility due to critical illness or associated weakness, sedation or paralysis. Studies to date have been heterogeneous and lack data regarding actigraphy-based measures of sleep and patient outcomes (See Table 7.1). Actigraphy was used in a study by Solverson and colleagues after ICU discharge and found no relationship between patients' subjective and objective sleep quality by questionnaire and actigraphy at 3 months follow-up [21]. To date, this study is the only follow-up cohort assessing sleep by actigraphy as a long-term outcome.

The use of subjective measures of sleep assessment, such as patient or nurse questionnaires, is simple, easy and relatively inexpensive compared to other objective measures of sleep. Patients may keep daily sleep diaries or a sleep log. The Richards-Campbell Sleep Questionnaire (RCSQ), the Sleep in the Intensive Care Unit Questionnaire and the Verran and Snyder-Halpern (VSH) Sleep Scale have all been tested in ICU patient populations [22]. Incident delirium and the frequent use of sedatives limit the use of such instruments. Further, they typically report only nighttime sleep, whereas sleep in the ICU is distributed over a 24-hour period. Nursing assessment with the Echols Sleep Behaviour Observation Tool, Nurses' Observation Checklist and the RCSQ may be used to estimate sleep [22]. Nursing-derived assessments however tend to overestimate TST and sleep efficiency but

**Table 7.1** Methods for measuring sleep in the intensive care unit

| Method | Description | Advantages | Disadvantages |
|---|---|---|---|
| Polysomnography | Multi-parametric test that measures brain activity (electroencephalography), eye activity (electrooculography), skeletal muscle activity (electromyography) cardiac rhythm (electrocardiogram) and oxygen saturation (pulse oximetry) | Gold standard<br>Detect and determine duration of sleep stages | Impractical in the ICU<br>Requires skilled placement and interpretation<br>Electrical interference<br>Interpretation confounded by acute illness and medication |
| Bispectral index | Derived from a weighted sum of several electroencephalographic channels to provide a single dimensionless number between 0 and 100 | Easier to administer than PSG<br>Commonly available in the hospital setting | Correlation with sleep uncertain<br>Prone to artefacts<br>Multiple confounders in ICU including sedation and acute brain pathologies |
| Actigraphy | Comprises an accelerometer, clock, low-pass filter, memory and interface for accessing the stored information | Much easier and cheaper to administer than PSG<br>Validated measure of total sleep in healthy individuals<br>Able to be worn whilst ambulating and continuously for days or weeks | May overestimate sleep time in critical illness<br>Varying quality and accuracy of devices<br>Unable to accurately assess sleep stages |
| Survey | Multiple surveys exist for measuring sleep quality. The most widely cited is the five-item Richards-Campbell Sleep Questionnaire assessing sleep depth, latency, awakenings, return to sleep and sleep quality | Low tech<br>Direct measure of patient's subjective sleep experience<br>Can be completed by the patient or bedside clinician on behalf of the patient<br>Validated against PSG, including in the ICU setting | Patient must be awake and have capacity<br>Requires clinician input |
| Clinical observation | Bedside clinicians used to record the occurrence and duration of sleep as part of regular patient observations | Easy to administer<br>Provides a reasonable measure of sleep quantity | Lacks detail of sleep depth and quality<br>Inter-operator variability<br>Frequent awakenings may be missed<br>Tends to overestimate sleep duration |

*ICU* intensive care unit, *PSG* polysomnography underestimate awakenings when compared to PSG. Subjective assessments of sleep are variably reliable but provide no information on experienced sleep stages or circadian rhythmicity, limiting their utility in assessing sleep outcomes in the ICU.

## Circadian Rhythm and Melatonin in the ICU

The circadian system is a fundamental biologic system underpinning homeostasis.

The suprachiasmatic nucleus (SCN) is a primary modulator of this system, regulating multiple neurotransmitter systems including the hypothalamic-pituitary-adrenal (HPA) axis and melatonin secretion from the pineal gland [23]. These processes cycle with time, with the period between one peak and the next being roughly equal to 24 hours. For example, in healthy individuals, melatonin concentration is a robust marker of circadian rhythm, with levels rising in the evening and peaking at about 3 am (see Fig. 7.1.) [24]. Amongst many functions, normal circadian rhythmicity prepares the body for periods of increased energy demand or stress, enhancing the function of individual cells, organ systems or whole organisms.

Critically ill patients are particularly susceptible to circadian disruption (dysrhythmia) due to loss of environmental sensory cues (e.g. light required for photoentrainment) and/or pathological disruption at a cellular level (e.g. sepsis). The latter phenomenon is imperfectly understood but may relate to the inflammatory response [25]. Animal models suggest that the cellular effect on circadian rhythm disruption seems to persist for weeks after a septic insult [26]. Melatonin secretion can be influenced by numerous factors, such as age, benzodiazepines and other sedatives, adrenergic compounds, ß-blockers, opiates, light exposure, mechanical ventilation and sepsis [25, 27]. The relative contribution of each of these factors to disturbances in melatonin release in ICU patients remains unclear [28–33]. The pattern of circadian rhythm disturbance can vary, including loss of amplitude, a shift in timing of the acrophase and even degradation to erratic fluctuations or complete flattening [34]. Although targeted interventional studies are lacking, there is emerging evidence of the effect of patterns of circadian disruption in critically ill patients.

### *Optimising Circadian Cues in the ICU*

The clinical consequences of circadian dysrhythmia in critical illness are thought to be manifold but may have been neglected in the past due to more obvious and life-threatening features of physiological instability. In chronic critical illness, the loss of amplitude may impair the capacity for adaptation, whilst phase shifting may uncouple maximum function from peak demand. A high-risk subgroup most likely to benefit from such interventions might include those with higher severity of illness, shown to correlate with degree of circadian disruption [35]. Addressing modifiable risk factors associated with disruption of circadian rhythm in the ICU through the implementation of chronobiological strategies, targeting specific *zeitgebers* (rhythmically occurring cues), may facilitate recovery of post-critical illness.

1. Light
    (a) Bright light exposure during daytime hours (>1000 lux).
    (b) Minimise nocturnal light pollution (<2 lux).
2. Feeding
    (a) Intermittent daytime feeding aligned with mealtimes
    (b) Avoidance of continuous and overnight feeding
3. Temperature
    (a) Warmer environment during day
    (b) Cooler environment at night
4. Activity
    (a) Exercise (e.g. physical therapy) at a similar time each day taking into account patient's baseline habits prior to admission
5. Noise
    (a) Minimise noise during evening hours.
6. Medical and nursing interventions
    (a) Minimise and cohort night time interventions.
    (b) In non-sedated patients, allow and encourage sleep as per habits prior to admission.
7. Sedatives
    (a) Minimise use through regular review.
    (b) When possible, give prescribed medications at the time of day least disturbing to patients' circadian rhythm.

## Sleep vs. Sedation

Commonly administered ICU sedative agents including propofol, opioids and benzodiazepines can all impact sleep quality. In hospitalised patients, there is insufficient evidence that pharmacotherapy improves either the quality or the quantity of sleep [36]. Benzodiazepines shorten sleep latency, facilitate sleep continuity and increase total sleep time (TST). However, this comes as the expense of a greater proportion of light, stages one and two sleep and less, restorative slow-wave sleep

(SWS) and REM duration [36]. Short-acting oral benzodiazepines commonly prescribed for insomnia are also associated with daytime drowsiness and memory impairment [37].

There is some animal data suggesting that propofol may induce benefits that overlap with some functions of sleep. Tung and colleagues have shown propofol sedation during the habitual sleep period of rats did not lead to signs of sleep deprivation in the hours following anaesthesia [38]. In a second experiment, the restorative effect of natural sleep and 6 hours of propofol administration were compared in sleep-deprived rats where no difference was found in delta power, REM sleep or NREM sleep [39]. Although this suggests that propofol may mimic some NREM sleep function that may promote recovery from sleep deprivation, this does not extend to all sleep function as both propofol and benzodiazepines have been shown to suppress REM sleep in ICU patients [39] [40].

Dexmedetomidine, a centrally acting selective α2-receptor agonist, may also induce beneficial qualities associated with sleep. Nighttime infusion has been shown to induce sleep and increase stage two sleep [41, 42]. In contrast to benzodiazepines, this appears to occur without adversely impacting restorative SWS and REM [41–43]. Opioids, commonly administered in conjunction with sedatives in critically ill patients, bind the μ-receptors of the ponto-thalamic arousal pathway that plays a key role in REM generation. In a dose-dependent manner, opioids suppress both SWS and REM [44]. Antipsychotics induce various sleep changes. Although haloperidol has a tendency to increase sleep efficiency and possibly stage two sleep, olanzapine increases TST, SWS and REM sleep, and risperidone only decreases REM sleep [45]. Importantly, abrupt drug discontinuation may elicit withdrawal reactions such as insomnia after discontinuation of sedatives [46, 47]. In the most recent 2018 Pain, Agitation/Sedation, Delirium, Immobility, and Sleep Disruption (PADIS) Clinical Practice Guidelines for the Society of Critical Care Medicine recommendations regarding the use of medications to improve sleep could not be made from existing evidence [47]. Despite this, efforts should be made to minimise the use of agents known to disrupt sleep in critically ill patients.

## Mechanical Ventilation and Sleep

The relationships between sleep, mechanical ventilation and patient outcomes are important and complex. However, much of the current understanding is based on extrapolations from physiological descriptions of healthy subjects rather than patients with critical illness [48]. Observational and interventional studies of sleep in critically ill and mechanically ventilated patients are limited. Nevertheless, the evidence that exists suggests sleep can have profound effects on ventilation and mechanical ventilation affects sleep. Optimising this bidirectional relationship has the potential to reduce duration of mechanical ventilation and improve patient outcomes.

## *Sleep Affects Ventilation*

Patients receiving mechanical ventilation may be particularly vulnerable to the substantial physiological changes that occur with the respiratory system during sleep. Without appropriate consideration and action, these effects can exaggerate respiratory instability and impairment [49]. Sleep induces a progressive decrease in the central respiratory drive and hypoxic and hypercapnic ventilatory responses through NREM stages, resulting in a decrease in minute ventilation and an increase in PaCO2 of between 3 and 7 mmHg. REM sleep results in further decrease in tidal volume and more erratic ventilation. Both NREM and REM sleep are associated with suppression of the cough reflex, potentially reducing sputum clearance and increasing micro-aspiration. Post-extubation, patients may also suffer from the consequences of upper airway hypotonia and delayed and decreased response to negative airway pressure that occur in sleep. These may potentiate the effects of acute lung pathology, sedating medication and chronic conditions, inducing or worsening sleep apnoea.

In addition to the expected physiological consequences of sleep, patients receiving mechanical ventilation may be at increased risk of some of the pathological consequences of sleep deprivation. Sleep impairment reduces skeletal muscle efficiency, impairing inspiratory muscle function in as few as 30 hours [50]. By inducing the release of inflammatory mediators causing immune suppression, sleep impairment may also contribute to the risk of ventilator-associated pneumonia and lung injury.

## *Ventilation Affects Sleep*

In patients receiving spontaneous mechanical ventilation, both inadequate and excessive assistance can impair sleep. Inadequate support disrupts sleep by causing anxiety, dyspnoea and excessive work of breaking. Excessive support leads to central apnoea as the PaCO2 decreases below the raised, sleep-induced apnoea threshold. Although definitive evidence is lacking, interventional studies suggest that mandatory mechanical ventilation, rather than a fixed level of spontaneous mode, tends to improve sleep quality, including less sleep fragmentation and greater sleep efficiency [51]. However, the benefit of mandatory ventilation may be mitigated by clinically adjusted spontaneous ventilation to minimise hypo- or hyperventilation [52].

Patient-ventilator dyssynchrony is associated with reduced sleep quality [53]. Newer modes of ventilation such as proportional assist ventilation (delivering pressure adjusted dynamically to derived respiratory mechanics) and neutrally adjusted ventilatory assist (delivering pressure adjusted dynamically to diaphragmatic electrical activity) have been proposed to reduce dyssynchrony. However, effects on sleep and other patient-centred outcomes remain uncertain [53, 54].

### *Optimising Sleep During Mechanical Ventilation*

The modifiable factors to consider in optimising sleep during mechanical ventilation can be divided into patient, ventilator and environment:

1. Patient Factors
    - (a) Minimise exposure to sedation medication, in particular benzodiazepines.
    - (b) Bundle care and avoid unnecessary nighttime interventions.
2. Ventilator
    - (a) Explicitly review the settings. Make a plan for the night.
    - (b) For those receiving a spontaneous mode of ventilation, consider whether a nocturnal mandatory setting, or adjustment of the level of pressure support, may be appropriate.
    - (c) Consider nocturnal inflation of tracheostomy tube cuff to reduce the risk of micro-aspiration.
    - (d) Consider the use of high-flow nasal oxygen or continuous positive airway pressure (CPAP) post-extubation in at-risk patients, particularly at night, to counteract the effects of sleep-induced upper airway hypotonia.
3. Environment
    - (a) Maintain a day/night rhythm (see Fig. 7.1).
    - (b) At night, dampen alarms where possible; provide a cool, dark room; and limit bed space conversations, noise and cluster interventions.

## Reducing Noise

### *Adverse Effects of Noise*

Noise is any unwanted sound. It can have substantial adverse consequences for critically ill patients. Noise at a level of normal conversation, approximately 60 decibels (dB), can activate the hypothalamic-pituitary-adrenal axis and increase catecholamine levels for up to 90 minutes after the removal of the signal and also subjectively disrupts sleep [55–57]. Noise can also have a direct impact on memory processing and higher intellectual functions [58, 59]. Indirectly, the adverse psychological effects of noise may adversely affect patients by reducing caregiver performance. Of greatest concern to recovery after critical illness is the effect of noise on sleep. Both absolute noise levels and change in noise levels cause sleep fragmentation, contributing to a decrease in total sleep duration, increased latency and less deep, restorative sleep. This fragmentation also contributes to phase shifting of circadian rhythms and disruption of the day/night cycle. Current World Health

Organization (WHO) recommendations suggest maximum nocturnal hospital noise levels should not exceed 40 dB [60]. Noise levels of 48 dB, similar to normal conversation, cause awakenings, and levels as low as 33 dB, little more than a whisper, are associated with appreciable physiological changes including cortical arousals [61, 62].

## *ICU Noise*

Excessive ICU noise is ubiquitous, exceeding WHO hospital recommendations, and at levels likely to contribute to sleep disruption, in all ICUs, day and night, in open areas and single rooms and across the spectrum of patient illness severity and bed census [63–65]. Although alarms and equipment contribute, staff conversation appears to be a major source of noise [66]. ICU noise results in polysomnographic evidence of sleep impairment and is also cited as a major cause of sleep disruption by patients themselves [67, 68]. Studies examining the causes of sleep disruption in patients admitted to the ICU suggest that between 11% and 21% of arousals are attributable to noise [67, 69]. However, subjectively, patients report noise to be a major cause of awakenings [8, 70].

## *Noise Abatement*

More than one third of ICU noise may be avoidable, but attempting to reduce noise through behavioural modification interventions alone may not be sufficient [71]. The results of studies evaluating interventions, including quiet-time protocols, decreasing alarm volumes, minimising non-clinical bedside discussions and keeping doors closed, have been variable, demonstrating no benefit or at best associated with modest noise reduction and sleep improvement [71–74].

Alternatively, or in addition, patients can be protected from noise with earplugs or noise-cancelling headphones. Small studies suggest that this can result in a 7–10 dB reduction in noise, the equivalent effect of halving the volume of a typical alarm clock, the peak noise levels commonly reported in the ICU [63, 75, 76]. Ear plugs are cheap, well-tolerated and feasible to place in ventilated and non-ventilated ICU patients [75]. However, evidence from RCTs is limited. Demoule et al. reported a significant reduction in prolonged awakening and increased duration of stage three sleep in the subgroup of patients randomised to receiving earplugs and an eye mask in the ICU and in whom the earplugs remained in situ for the entire night [77]. The available evidence suggesting that earplugs may reduce delirium requires confirmation in adequately powered RCTs [78].

## Reducing Light

### *Patterns of Light Exposure in the ICU*

In the outside environment, the variation between light and darkness ranges from 0.0001 lux on a moonless night to 1000 lux on the most overcast day and 130,000 lux in bright sunshine. There is substantial evidence that a disrupted 24-hour light-dark cycle is associated with increased morbidity and mortality for a variety of conditions including cancer [32, 79–82]. The ICU obliterates the usual schedule of zeitgebers, including light. Patients in the ICU are exposed to a disrupted day/night pattern of light exposure with unnaturally low levels of light during the day and constant light interruptions through the night [83]. Nocturnal light intensities vary across ICUs but can exceed 1000 lux [84, 85]. Importantly, exposure to only 100 lux is sufficient to affect melatonin secretion and modify circadian rhythms.

### *Improving Light Exposure Patterns*

It is relatively straightforward to restore a more normal pattern of light exposure to patients in the ICU. Through the evening and into the night, eye masks can be worn to shield subjects from the lighting required to safely navigate the unit and to undertake clinical examinations. Similarly, upgrading room or bed lighting, orienting patients towards the window and changing how task lighting is employed could be used to reproduce a more normal daytime level of light exposure. A longitudinal study in critical care implementing nonpharmacological environmental changes designed to reduce disturbing patients during the night (noise and light reduction by the use of blackout masks) demonstrated a reduction in delirium and an improvement in sleep [86]. However, a recent clinical trial of continuous bright light therapy during the daytime in the ICU concluded that there was no improvement in clinical outcome [87]. In this study, the maximal light intensity achieved was 700 lux, a level substantially below daylight levels that may not have been sufficient to stimulate the desired circadian rhythm entrainment. Effective bright light therapy does not need to be continuous. Exposure to three consecutive bright light ‘pulses’ for just 15 min can be more effective than continuous bright light [88]. This strategy may also be more practical for use in the ICU.

Even though many ICU patients have their eyes closed (e.g. due to sedation), bright light can entrain circadian rhythm through non-visual pathways via the retina [89, 90]. If high-intensity light interruptions are unavoidable, wearing a blackout mask overnight might minimise this potential disruption to circadian rhythm [89]. Despite light therapy interventions being successful in shifting the phase of circadian rhythms, evidence of an impact on any outcome other than subjective patient experience is lacking. As an example, delirium is associated with disturbances of circadian rhythm and sleep; however, bright light therapy as a single intervention in the ICU was unsuccessful in reducing the cumulative incidence or duration of delirium in a mixed medical-surgical patient population [90]. Further, no differences were seen in ICU or hospital length of stay and mortality [90]. This absence of a difference may have been argued to be secondary to illness severity or sedation exposure; however, similar results were recently found by Pustjens and colleagues in a coronary care unit. No significant differences were seen in any outcome measured with dynamic light therapy as compared to standard environmental conditions [91]. Although existing evidence does not support routine light therapy in isolation, the optimal dose, timing and patient population require further investigation, and it may be that light therapy is best deployed as part of a multicomponent strategy [92–95].

## Emerging Therapies for Improving Sleep

The science of sleep is advancing rapidly. In addition to a greater understanding of the causes and consequences of sleep disruption, an increasing number of pharmacological and nonpharmacological candidate solutions to promote sleep are being investigated.

### *Pharmacological Solutions*

Several established pharmacological agents may have beneficial effects on sleep in critically ill patients that are yet to be fully elucidated. Ketamine, a N-methyl D-aspartate (NMDA) receptor antagonist, increases sleep consolidation and slow-wave activity, producing rapid antidepressant effects in patients with major depression [96]. Although research is still in its infancy, and long-term use is known to be harmful, short-term use of cannabidiol may have beneficial effects on sleep including deceased latency and increases SWS [97]. Intriguingly, recent evidence from a fruit fly model has identified a sleep-inducing, antimicrobial peptide encoded by the *nemuri* gene. The molecule is secreted by brain cells in order to drive deep and prolonged sleep post-infection and is the first direct evidence linking sleep to recovery from infection [98]. Although nemuri is not known to be present in humans, investigating the role of other antimicrobial peptides in sleep is of substantial interest.

### *Nonpharmacological Solutions*

A variety of nonpharmacological sleep improvement interventions are at various stages of development. For ICUs under construction or undergoing redesign, attention should be paid to all the environmental factors necessary to optimise sleep. The layout and materials used in the design of ICU spaces may have a substantial impact on important contributors to sleep such as noise [99]. For established ICUs, simple environmental changes, such as reducing nocturnal temperature to an optimal range for sleep (16–18 degrees Celsius) and introducing policies for nocturnal light levels, are relatively easy to implement.

Although not suitable for all patients admitted to the ICU, there is some evidence that massage in critically illness improves sleep [100]. Similarly, music interventions may improve subjective measures of sleep as well as reduce anxiety [101]. A separate but related subset of music interventions, known as binaural beats, may also improve sleep. A binaural beat occurs when the presentation of two pure tones with slightly different frequencies to each ear (so must be heard with headphones) leads to the perception by the brain of a merged virtual beat at the midpoint of the two frequencies. The binaural beat then entrains neural activities, inducing behavioural states related to that activity. Although not yet studied in patients admitted to the ICU, this intervention is relatively easy to administer and shown to improve sleep quality in healthy individuals, as well as to reduce pain and anxiety [102, 103]. For patients receiving enteral nutrition, it is plausible that intermittent, daytime feeding may have a role in maintaining or re-establishing circadian rhythmicity and requires further investigation [104]. Finally, mindfulness interventions that train participants in the practice of attending to moment-by-moment experiences from a non-judgemental perspective have been shown to improve sleep quality in older, sleep-disturbed adults, but have not been studied extensively in ICU survivors [105].

### *Improving Sleep After ICU*

Amongst ICU survivors, persistent impairment of sleep architecture is common. Modest improvement in sleep quality at 6 months compared to shortly after discharge suggests that whilst sleep disruption may be prolonged, some degree of reversibility is possible and worthy of further study [106]. However, the extent to which longer-term, post-ICU sleep disturbance is causally related to the episode of critical illness is uncertain, with chronic underlying disease identified as a dominant contributor [10]. Given the strong association between anxiety and depression symptoms and sleep disturbance and the high prevalence of both after an episode of critical illness, it is plausible that the treatment of one improves the symptoms of the other, though this has yet to be rigorously evaluated [107].

## Conclusions

Sleep disruption is ubiquitous in patients admitted to the ICU. For survivors of critical illness, sleep disruption is often persistent and associated with an increased risk of functional impairment and reduced quality of life. Optimising sleep should be considered as a high priority in its own right and as a foundation for the success of other strategies aimed at improving recovery in survivors of critical illness. Routine measurement is a key first step in order to implement timely and appropriately targeted interventions. For survivors of critical illness with sleep disruption, optimising patient, environmental and staffing factors whilst hospitalised is essential. In addition, acknowledging that sleep issues may persist for some time and providing information on sleep hygiene (for which there is substantial, high-quality, web-based resources) and advice on when to seek further help may be highly beneficial.

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# Chapter 8
# Flexible ICU Visiting Policies

**Regis Goulart Rosa and Cassiano Teixeira**

## ICU Visiting Hours Around the World

Although intensive care unit (ICU) visitation policies vary worldwide, evidence suggests that most adult ICUs impose restrictions to the presence of family members at the bedside of critically ill patients [1–9]. In a recent survey conducted by the World Federation of Societies of Intensive and Critical Care Medicine (WFSICCM), only 39% of WFSICCM country members reported that open visiting hours were fully adopted [10].

Restrictive visitation policies have been justified by the theoretical risks associated with an increased presence of visitors in the critical care setting (mainly infectious complications, disorganization of care, and ICU staff burnout) [11, 12]. Controversially, these risks have not been consistently confirmed by the literature on the subject [13–15], and flexible ICU visiting hours have been endorsed by societies' guidelines as an important strategy to improve patient- and family-centered care [16, 17]. However, the proportion of adult ICUs with unrestricted visiting hours is still very low (Table 8.1). Data from literature shows that a considerable portion of hospitals in the USA [9] and the UK [8] has restrictions regarding visiting hours. Among ICUs with restrictive visiting policies, published studies show that the daily visiting time ranges from a median of 1 hour in Italy [4] and a mean of 1.1 hours in Belgium [1] to a mean of 4.7 hours in France [3]. In Iran, nearly 40% of ICUs do not allow visitors [5]. In Brazil, most adult ICUs follow a restrictive visitation policy in which family members are allowed to visit the critically ill patient from 30 minutes to 1 hour, one to two times per day [2].

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**Table 8.1** Published studies about practices regarding adult ICU visiting hours

| Country | Year of publication | Number of ICUs | Proportion of ICUs with unrestricted visiting hours |
|---|---|---|---|
| Belgium [1] | 2010 | 57 | 0% |
| Brazil [2] | 2014 | 162 | 2.6% |
| France [3] | 2016 | 188 | 23.9% |
| Italy [4] | 2008 | 257 | <1% |
| Iran [5] | 2011 | 71 | 0% |
| Netherlands [6] | 2013 | 55 | 2.4% |
| Spain [7] | 2015 | 135 | 3.8% |
| UK [8] | 2010 | 206 | 19.9% |
| USA[9] | 2013 | 695 hospitals | 19.6% |

**Table 8.2** Effects of flexible ICU visiting hours on patients, family members, and ICU clinicians

| Patients | Family members | ICU clinicians |
|---|---|---|
| Less anxiety<br>Less cardiocirculatory complications[a] | Higher satisfaction<br>Less anxiety symptoms | Perception of disorganization of care?[b]<br>Staff burnout?[b] |
| Less delirium | Less depression symptoms | |

[a] Cardiac arrhythmias, pulmonary edema, or cardiocirculatory shock

[b] Flexible ICU visiting models with education support for family/visitors are not associated with perception of disorganization of care or staff burnout

## Effects of Flexible Visiting Hours

Studies assessing the impact of distinct visiting policies on patients, family members, and clinicians are scarce [15]. Most evidence on the effects of flexible visiting models comes from observational and before-and-after studies. To date, only two randomized clinical trials have been conducted to evaluate the effects of different visiting policies on clinically relevant outcomes [13, 14], and this evidence gap may constitute a barrier to the implementation of patient- and family-centered interventions at the ICU. A summary of the effects of flexible visiting policies on patients, family members, and ICU clinicians is shown in Table 8.2.

### *Effects on Patients*

Beyond the justification of patient preference, flexible ICU visiting models are proposed as a means to improve patient outcomes. Small single-center before-and-after studies have shown an association between flexible ICU visiting hours and reduced incidence of delirium – a form of acute brain dysfunction associated with worse outcomes, such as long-term cognitive impairment. In the study of Rosa et al., a change of visitation policy from a restricted model (4.5 hours/day) to an extended model (12 hours/day) resulted in a reduction of 50% in the cumulative incidence of delirium (9.6% vs. 20.5%; risk ratio [RR], 0.50; 95% confidence interval [95%CI], 0.26–0.95) [18]. Interestingly, in comparison with a restricted visitation model, an extended visitation model demonstrated a shorter length of delirium/coma (1.5 days vs. 3.0 days; $p = 0.03$) and ICU stay (3.0 days vs. 4.0 days; $p = 0.04$) for patients. Similarly, Westphal et al. showed that the incidence of delirium decreased from 12.1% to 6.7% with the implementation of a 24-hour open visiting policy (odds ratio [OR], 0.52; 95%CI, 0.28–0.96) [19]. Although the precise mechanism for delirium prevention remains unknown, multiple factors are thought to mediate the relationship between flexible ICU visiting policies and reduced incidence of delirium [20]. First, flexible ICU visiting hours may increase the opportunities for improvement in patient-centered care. In this context, the higher interaction between family members and ICU professionals may allow a better sharing of the decision-making process, minimizing the patient exposure to modifiable risk factors for delirium, such as unnecessary sedation and benzodiazepines. Second, it is plausible to assume that flexible visiting policies may promote family engagement in non-pharmacologic interventions for delirium prevention, such as pain control, reorientation activities, establishment of a familiar environment, prevention of sensory deprivation, cognitive stimulation, early mobilisation, and sleep hygiene. Interestingly, these actions have been described as part of multicomponent non-pharmacologic interventions that demonstrated to be associated with reduced incidence of delirium in several studies [21]. Nevertheless, a recent pragmatic cluster-randomized clinical trial with more than 1600 patients from 36 ICUs with restricted visiting hours (median 90 minutes/day) showed a nonsignificant reduction in the incidence of delirium by changing the standard restricted visitation to a flexible visitation supported by visitor education in which close family members were allowed to visit patients for up to 12 hours/day (18.9% vs. 20.1%; RR, 0.91; 95%CI, 0.73–1.15) [13]. The authors hypothesized that the relatively short duration of implementation (mean 3.2 months) may have mitigated the potential benefits of flexible visits, since a longer implementation period might have improved the ability of clinicians to engage family members in multicomponent prevention strategies for delirium. Additionally, the trial excluded a large portion of patients with increased risk for delirium (e.g., patients with prolonged coma) who could have benefited from the intervention.

Flexible visiting hours are also associated with lower severity of stress symptoms among patients. A systematic review and meta-analysis by Nassar et al. showed lower severity of anxiety symptoms among patients during ICU stay with flexible visiting policies [15]. Additionally, a pilot randomized trial showed a reduction in cardiocirculatory complications among ICU patients admitted during periods of unrestricted visiting hours, possibly due to reduction of anxiety and establishment of a more favorable hormonal profile [14].

Regarding possible risks associated with flexible ICU visiting policies, a systematic review and meta-analysis showed no evidence of significant differences between flexible and restricted models in the frequency of ICU-acquired infections or ICU mortality [15].

## Effects on Family Members

Flexible visiting hours are often preferred by family members. Results of observational and before-and-after studies show that flexible visitation models are associated with higher family satisfaction [15]. A recent cluster-randomized clinical trial with more than 1200 close family members of critically ill patients showed that the implementation of a flexible visiting policy which included flexible visiting hours and educational support for family members was associated with better satisfaction scores in the following domains of care: proximity (family's access to the patient), information (the way in which information is shared, how regularly information is given, and the extent to which the process of communication is interactive), reassurance (level of reassurance offered by clinicians), support (support provided by clinicians and the abilities of staff to recognize and allow the family to make use of their own social support structures), and comfort (the emotional and physical comfort offered by clinicians and hospital facilities) [13]. Additionally, the trial showed lower severity of anxiety and depression symptoms with flexible visitation during ICU stay – flexible visitation resulted in significantly lower prevalence of probable clinical anxiety (13.4% vs. 28.2%; prevalence ratio [PR], 0.48; 95%CI, 0.35–0.66) and depression (8.1% vs. 17.7%; PR, 0.46; 95%CI, 0.28–0.76) during ICU stay compared to the standard restricted visitation. Lastly, flexible visitation was associated with greater family self-perception of involvement in activities of patient care (e.g., reorientation, emotional support, helping ICU staff understand patient needs, pain control, and mobilisation). Congruent with these findings, the greater involvement of family in critical care may constitute a valuable strategy to improve patient- and family-centered care. In a recent systematic review, Goldfarb et al. found that patient- and family-centered care interventions such as education, communication, emotional support, and respect for the patient's values, preferences, and needs were associated with patient and family satisfaction, improved mental health status, and decreased resource utilization in ICUs, including decreased length of ICU stay [22].

## Effects on ICU Clinicians

Observational studies show that ICU clinicians sometimes perceive visits as a source of increased workload and disorganization of care [23, 24]. In a single-center study, 59% of ICU staff members stated that the open visitation policy impaired the organization of patient care, and 72% believed that their work suffered more interruptions due to the extended presence of families in the ICU [23]. Consistent with these data, a before-and-after study of nine ICUs showed a significant increase in burnout levels among ICU professionals after partial liberalization of visiting hours (42.6% vs. 34.5%; $p = 0.001$) [25]. However, in a cluster-randomized clinical trial with more than 800 ICU clinicians (physicians, nurses, nurse technicians, and physiotherapists) from 36 ICUs, the implementation of flexible visiting hours did not result in significant impact on staff perception of disorganization of care, occurrence of conflicts with visitors, or burnout [13]. Notably, in this trial, the use of an educational strategy targeting visitors may have improved visitor understanding of the ICU environment and perhaps lessened any negative effect of increased duration of visits on ICU routines and staff workload. Altogether, these study findings call attention to the importance of clinician-centered strategies (reduction of workload, training in communication skills, and both clinician and family education) while implementing flexible visiting hours, since increased workload and burnout may be associated with reduced patient safety [26, 27].

### *Long-Term Outcomes*

So far, no study has assessed the impact of different visitation models on long-term outcomes among patients, family members, and ICU clinicians. Nevertheless, it is plausible to expect better long-term mental health outcomes for patients and their families with flexible visiting policies, since symptoms of acute stress during ICU stay – major risk factors for long-term anxiety, depression, and posttraumatic stress disorder – can be lessened with the implementation of flexible visiting policies.

## Implementation

The literature on strategies of implementation of flexible visiting hours is scarce. So far, only one randomized clinical trial assessed the efficacy of a large-scale implementation of flexible visitation policy [13]. In this study, the implementation of a flexible visitation model (up to 12 hours for close family members) in 36 ICUs of public and private nonprofit hospitals in Brazil was feasible, as reflected by the high adherence of ICUs to the implementation process (mean implementation 90%; 95%CI, 87–92) which included increasing visiting hours, staff training, dissemination of flexible visiting policies, and visitor education. Moreover, the daily mean duration of visits was significantly increased with the flexible visitation model (4.8 hours vs. 1.4 hours; adjusted absolute difference, 3.4 hours [95%CI, 2.8–3.9]). Notably, in this study, visitor education was used as a means to promote a safe flexible visiting policy for patients, family members, and ICU professionals. Family members participating in the flexible visitation model had to attend a structured face-to-face education meeting in which they received guidance about the ICU environment, common procedures, multidisciplinary work, infection control, patient privacy, palliative care, and delirium prevention [28]. Additional educational strategies, such as website access and brochures, were also used. Future studies may provide additional insights regarding cost-effective strategies of implementation of flexible visiting policies.

## Conclusion

Beyond being safe and associated with better patient and family outcomes, a flexible visiting policy is important to respect and to preserve the patient's ties with family during the course of critical illness. Although the implementation of flexible visiting policies may be considered a complex intervention, with a large number of interacting components, it is an achievable aim with many potential benefits for patients and family members. In this context, well-designed studies may help to understand the best way to implement flexible visiting policies and improve their effects on both short- and long-term outcomes among patients and family members.

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# Part II

# Enhancing Recovery Post-ICU

# Chapter 9
# Physical Rehabilitation Programmes Following ICU Discharge

**Elizabeth H. Skinner, Jennifer Jones, and Sue C. Berney**

## What Is the Problem?

Earlier chapters in this book, as well as a significant body of literature, have clearly outlined the cognitive, physical and mental health implications of post-intensive care syndrome and the associated disability and societal consequences for patients, their carers and families and the broader community.

An argument can be made that there is significant face validity in providing physical rehabilitation to optimize recovery for survivors of critical illness. It is untenable for patients to remain indefinitely bed-ridden, without the provision of services to assist them in their recovery of an ability to sit unsupported, stand and walk to a level sufficient for them to provide self-care and achieve their activities required for daily living in an independent manner (or at least to return to their baseline activities). In much the same way basic nursing care (i.e. assistance with turning in bed, feeding, toileting and medication administration) is not up for debate as to whether it is beneficial or not – like a parachute – it is simply required [1].

Following ICU discharge, management is frequently multidisciplinary with the aim of achieving functional independence to enable discharge into the community.

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Following discharge, rehabilitation can be home- or centre-based or via telehealth and generally aims to improve muscle strength, functional independence and cardiovascular endurance [2].

However, the question follows: what level of service provision of physical rehabilitation following ICU discharge is sufficient to achieve patient goals? And what are these goals? To extend life span regardless of quality? To return to a baseline level of functional independence sufficient to return home? Or to return to the patient baseline function, whatever that may have been? Or perhaps to return the patient to an even higher functional level than that before their ICU admission – not an unlikely occurrence or unreasonable goal in the event of chronic declining health that culminates in an event or intervention that reverses such health decline (e.g. insertion of a cardiac stent, organ transplant or other successful surgical procedures). Any health service intervention such as physical rehabilitation, most frequently provided by physiotherapists in the hospital and community settings [3], must be subject to rigorous evaluation in order to optimise the spending of health dollars to maximise outcome for as many as possible.

Moreover, it must be asked: how can such services be best provided to optimise equity in access, treatment and outcomes? Disadvantaged populations (i.e. non-white, poor educational level) do even worse following critical illness [4–6]; therefore, incumbent upon our health service delivery is an ethical obligation to ensure we optimise the outcomes of all.

## Proven Solutions: Review of Evidence Base

### *Why Post-ICU Rehabilitation Programmes?*

While an earlier chapter in this book focuses on early mobilisation commencing in the ICU, the largest proportion of physical rehabilitation following critical illness takes place in the acute wards, in other inpatient facilities (as appropriate) and in the community following discharge home.

These programmes are therefore critical to evaluate, especially since once sufficient functional restoration has been achieved to enable such discharge back into the community, there is a relative stable state from which changes in outcomes are potentially more easily quantified.

However, despite the perception of benefit in physical rehabilitation programmes following ICU discharge, the studies conducted in the area to date (Table 9.1) deliver two important conclusions:

1. Post-ICU physical rehabilitation programmes (as studied to date) do not work.
2. More targeted research is required to define where such services should be delivered.

**Table 9.1** Selected studies investigating post-ICU physical rehabilitation programmes, in order of design (SR/MA) and then sample size, chronologically

| Author | Design | Sample size[a] | Intervention | Control | Primary outcome measures | Summary |
|---|---|---|---|---|---|---|
| Taito et al., 2019 [37] | SR<br>MA | 10 trials (1110 participants) | Commenced earlier/more intensive physical rehabilitation than control | Control | HR-QOL (PCS, MCS), mortality | Intervention-level physical rehabilitation following ICU discharge does not affect HR-QOL or mortality in MV patients |
| Connolly et al., 2015 [2] | SR | 6 trials (483 participants) | Intervention commenced after ICU discharge | Any other intervention/ control or usual care | Functional exercise capacity<br>HR-QOL | Unable to determine an overall effect on functional exercise capacity or health-related quality of life of interventions initiated after ICU discharge for survivors of critical illness |
| Morris et al., 2016 [8] | RCT | 300 participants | Daily physical therapy until hospital discharge | Weekday physical therapy if ordered by clinical team | Hospital LOS | No difference in primary outcome |
| Cuthbertson et al., 2009 [11] | RCT | 286 participants | Rehabilitation package/ manual, for 3 months after discharge | No intervention | Mortality, HR-QOL<br>Cost-effectiveness | No difference in primary or secondary outcomes at 12 month follow-up; follow-up programmes more costly so unlikely to be cost-effective |
| Walsh et al., 2015 [38] | RCT | 240 participants | Mobilisation in hospital from ICU discharge until hospital discharge (max 3 months) | Usual care | RMI, HR-QOL | Post-ICU hospital-based rehabilitation did not improve physical recovery or HR-QOL but improved patient satisfaction |
| Elliott et al., 2011 [39] | RCT | 195 participants | Home-based physical rehabilitation programme for 8 weeks, five times weekly | Usual care | 6MWT<br>Physical function | Intervention did not change physical function recovery (similar in both groups) |
| Denehy et al., 2013 [7] | RCT | 150 participants | Physical rehabilitation in ICU, in acute wards (daily) and post-hospital discharge for 8 weeks (x3 weekly) | Usual care | 6MWT, HR-QOL | No differences in primary outcome, rate of change over time/mean between group differences in 6MWT greater in intervention group |

(continued)

**Table 9.1** (continued)

| Author | Design | Sample size[a] | Intervention | Control | Primary outcome measures | Summary |
|---|---|---|---|---|---|---|
| Jones et al., 2003 [12] | RCT | 126 participants | Rehabilitation package/ manual for 6 weeks, daily | No intervention | Mortality, HR-QOL, depression, anxiety, phobic symptoms, PTSD | Intervention group reported an improvement in physical function (as measured by SF-36 HR-QOL scores) at 8 weeks and 6 months |
| Moss et al., 2016 [40] | RCT | 120 participants | ICU, hospital floor/ward, home-based/outpatient Physical therapy programme: breathing, exercises, functional mobility, range of motion Provided for 28 days, daily in hospital and 3 days/ week when discharged home (outpatient or home-based) | For 28 days or until hospital discharge participated in a physical therapy programme (exercises, functional mobility) | Physical function performance (CS-PFP-10) | An intensive physical therapy program did not improve physical function performance at 1, 3 or 6 months |
| McDowell et al., 2017 [41] | RCT | 60 participants | Personalised exercise programme for 6 weeks, three times weekly | No intervention | Self-reported physical function (SF-36 PF domain) | No statistically significant difference in the primary outcome measure of self-reported physical function |
| McWilliams et al., 2016 [42] | RCT | 63 participants | Outpatient exercise and education programme for 7 weeks, three times weekly | No intervention | Mortality, HR-QOL Exercise capacity | Outpatient rehabilitation improved health-related quality of life but not exercise capacity |
| Batterham et al., 2014 [43] | RCT | 59 participants | Physiotherapist-led, hospital-based exercise for 8 weeks, two times weekly | No intervention | HR-QOL, anaerobic threshold | Small benefit in intervention group compared to control for the anaerobic threshold of 1.8 (95% confidence interval, 0.4–3.2) ml O2/kg/min, not sustained by week 26. No significant differences in HR-QOL |

[a] Studies had to include a minimum of 50 participants for inclusion in the table. *RCT* randomised controlled trial, *ICU* intensive care unit, *HR-QOL* health-related quality of life, *MV* mechanical ventilation, *PCS* physical (health) component summary score (of the Short Form-36), *MCS* mental (health) component summary score (of the Short Form-36), *PF* physical function, *LOS* length of stay, *RMI* Rivermead Mobility Index, *6MWT* 6-minute walk test, *PTSD* post-traumatic stress disorder, *SF-36* Short Form-36, *CS-PFP-10* Continuous Scale Physical Functional Performance 10

### *Why Don't These Programmes Work?*

Many hypotheses have been advanced as to the lack of benefit quantified to date in the randomized trials conducted, including heterogeneity in study groups, if not in diagnoses, in clinical trajectory (as outlined below in the tiered framework) and arbitrary definition of inclusion terms for studies rather than inclusion based on need; high mortality & attrition from programs/loss to follow up; provision of rehabilitation to patients who would not benefit (either too well, or too sick); sub-optimal outcome measure selection and insufficient dosing of rehabilitation and lack of separation between groups. In several of the bigger studies, the differences between intervention and control were i) minimal and ii) at doses likely insufficient to achieve cardiovascular or musculoskeletal training benefit based on exercise physiology principles. For example, Morris and colleagues, the intervention group received a median 5 days of physical therapy and 3 days of resisted exercise compared with a median 1 day in the control group; while Wright and colleagues reported the delivery of a median (IQR) of 23 (16–28) minutes for 10 (4–19) days in the intervention group and 13 (10–17) minutes for 6 (2–12) days in the usual care group (7–10). It is also possible that these programmes are just not beneficial in this population when applied to the whole population and that individualised rehabilitation solutions are required, depending on need, access and response.

It could also be hypothesised that rehabilitation programmes reported in the literature to date have predominantly concentrated on the physical aspects of recovery [2] and have not incorporated cognitive and psychological interventions nor addressed remedial issues of social disadvantage that potentially have a greater impact on outcomes such as health-related quality of life. Where this has been attempted [11, 12], interventions have been in a passive format (i.e. rehabilitation manuals) where measuring adherence to intervention is more difficult.

## Speculative Solutions: What Does Best Practice Look Like?

The extent to which these post-ICU deficits are reversible remains arguable – are survivors destined to be left with loss of physical function? Can this loss be mitigated with physical rehabilitation? Are fat mass gains reversible? Can this loss be fully reversed with physical rehabilitation? To what extent should adaptation be a focus of rehabilitation programmes rather than futile attempts at restoration of muscle mass/strength and function?

Characteristics identified from observational and trials of rehabilitation such as comorbidity [13, 14] and APACHE 2 scores [15], age [16, 17] and sex [16] have been identified as important in recovery and can potentially be used to identify cohorts of patients who may benefit from rehabilitation. Comorbidity and premorbid health-related quality of life have long been associated with outcomes following critical illness [18–22]. Alternatively, it is appealing to consider how rehabilitation is delivered and stratify this by clinical phenotypes, and an early paper by Elliott and colleagues [23] described a three-tiered framework which aimed to assist in this process from the beginning of an ICU admission as follows:

- Tier 1 patients: defined as a brief, uncomplicated ICU care trajectory with low risk of physical impairment, likely ventilated for <48 hours
- Tier 2 patients: ventilated for 48 h but less than 7 days, with a steady improvement trajectory in ICU over 3–4 days and a moderate risk of physical impairment
- Tier 3 patients: complex ± long-stay trajectory in ICU, with prolonged ventilation and a high risk of significant physical impairment and disability

Combined with stratifying phenotypes according to physical function (i.e. patients able to stand, vs. non-standing patients) as a clinically meaningful way of tailoring rehabilitation and outcome measurement efforts [23], this framework identified groups broadly similar to Herridge and colleagues [17] and aims to consider the varying needs of presenting patients following critical illness, regardless of diagnosis, which can lead to significant heterogeneity in study groups.

While there have been additional efforts to describe trajectories of recovery, the earliest attempts at this were conceptual, largely not based on empirical data, and also did not include conceptualisation of trajectories where patients returned to their baseline level or even superseded it [24]. Recent work, based on empirical data, must be given more emphasis and demonstrates clear differences in trajectories, such as patients who either fully recovery completely or not (resulting still in a third unclassifiable group) [25] or who suffer disability and either (i) do not improve by 6 months, (ii) have minimal initial improvement and residual disability at 6 months, (iii) have initial low function who improve by 6 months or (iv) have intermediate function and rapid improvement by 6 months [16, 26]. Unfortunately, such work is limited by a lack of comparison with baseline physical function, and while studies have attempted to address this post hoc [27], urgent work is required to facilitate clear and accurate measurement of baseline physical function in ICU patients (proxy-validated) to establish trajectories across the arc of care following admission, especially since factors such as disadvantage and chronic comorbidity (associated with health status) predict poor outcomes [4, 5].

A further limitation in evaluating such ‘recovery trajectories’ is that most studies interrogating such trajectories are limited to the sickest patient populations (i.e. ARDS, septic shock), which do not always represent the majority of cases journeying through an ICU in any given time period. Excluding less sick cases from evaluation skews the data such that it looks like ICU survivors have poor recovery outcomes, whereas studies with more generalisable inclusion criteria (i.e. LOS in ICU > 48 hours) have found different results that may suggest many patients admitted to the ICU return to their baseline level of function/quality of life without additional rehabilitation [27].

Perhaps it is only cost-effective to return patients to a level of independence fit for return to their home-living situation rather than return to usual level of function. These outcomes, or the stated goals once defined, should be distinguished; the former is certainly used as a criterion for discharge from acute care and rehabilitation facilities all over the world – once a patient can walk and perform their usual ADLs, they can return home, but is this the same as their baseline level of function? In many cases, no. Few post-ICU rehabilitation programmes have aimed to define the clear end-goal and whether it was achieved – variously reporting the quality of life or walking distance 'improvements'; however, these lack meaning in a clinical context. Does it matter to Bill Smith if he can walk on average 50 m more in 6 minutes following rehabilitation, or if his $VO_2$ peak improves by 1 mL/kg/min, if he can walk to the post office like he did before, or he can't run marathons like he did before? These studies and results, along with previously described outcome measures [23], are devoid of context and urgently need rethinking if they are to be patient-centred in their conduct, application and ability to inform clinical care delivery.

It is clear from the current evidence base that these questions remain to be answered, and work is in progress which will continue to progress and inform our understanding of these issues [28]. Most follow-up ICU studies, including those of post-ICU rehabilitation programmes, are significantly limited by attrition and loss to follow-up, including high mortality rates (at least 50% of ICU admissions in one Australian long-term follow-up study were dead by 5 years) [29]. It is clear that old models of physical attendance to a centre for outpatient rehabilitation, especially in the era of COVID19 [30], do not work, are not financially viable and are no longer sustainable. Tele-rehabilitation [31, 32], remote models of care and independent exercise programmes [33] leveraging portable wearable/fitness technology [34] and the most disadvantaged groups [6] must be the way of the future. Stratification of inclusion also needs to target those most likely to benefit, as there is clear evidence that not all ICU survivors are equal [14, 16, 25–27] and, indeed, may not need additional rehabilitation. Moreover, in terms of improving access and reducing costs of service delivery, rehabilitation of critical care patients must begin to be streamlined into existing services to leverage current infrastructure. There are many existing outpatient disease-specific rehabilitation programmes for patients with chronic diseases, into which the majority of ICU survivors fall, and there have been efforts to combine such programmes into multimorbidity rehabilitation programmes providing exercise training for any patient with clinical need rather than providing care in siloes [35, 36]. This streamlined model of offering individualised exercise prescription (where exercise training principles are the same, regardless of diagnosis(es)) in group or virtual training settings mitigates the need to run costly siloed disease- or setting-specific programmes in parallel and would markedly improve cost-effectiveness as well as access across the healthcare system.

There is an urgent need to design studies tailored to the considerations outlined above and investigate their outcomes in the context of patient-centred, clinically meaningful goals, as well as their feasibility, success in behavioural adherence and cost-effectiveness. We recommend that funds that would be channelled into delivering standalone post-ICU rehabilitation services with little evidence of benefit would be better invested into conducting empirical research to inform future health service delivery.

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# Chapter 10
# Neurocognitive Rehabilitation

**James C. Jackson and Ramona O. Hopkins**

## Cognitive Impairment in ICU Survivors

Since the late 1990s, research has explored the effects of critical illness on cognitive functioning, initially with survivors of acute respiratory distress syndrome (ARDS) and later with individuals suffering from sepsis and more general forms of critical illness [1–3]. Then and now, findings from studies – large and small, often methodologically rigorous – have been remarkably consistent in documenting the prevalence and severity of the cognitive impairments [3–6]. Namely, studies have demonstrated that between approximately 30% and 40% of individuals display significant neurocognitive deficits months to years after discharge from the ICU [5–7]. Cognitive impairments also range in severity from mild to severe impairments and the impairments that are similar to the cognitive impairments that occur following traumatic brain injury and dementia [6].

A recent systematic review of the natural history of post-ICU cognitive impairments identified 46 studies that measured cognitive outcomes [8]. The prevalence of cognitive impairment occurred in 35% (95% CI 25–41%) to 81% (95% confidence interval 71–91%) of survivors of critical illness. The prevalence of cognitive impairment differed by how cognitive function was assessed. In studies that used cognitive screening tests, the prevalence of cognitive impairment was lower than studies that

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used comprehensive neuropsychological test batteries: 36% vs 61% at hospital discharge and 43% vs 78% at 12-month follow-up, respectively. The prevalence of cognitive impairments also varies by etiology of the critical illness with 82% [78–66%] of ARDS survivors developing cognitive impairments compared to 42% [44–52%] in a mixed ICU population [8]. Thus, there are a number of factors that can influence the prevalence of cognitive impairments in ICU survivors including etiology of the critical illness, time cognitive impairments were assessed after critical illness, and instruments used to assess cognitive impairments.

The mechanisms contributing to problems such as cognitive impairments are heterogeneous, and some are yet to be elucidated but may include the direct effects of delirium on the brain [9]. Other mechanisms of brain injury include hypoxia [4, 10], inflammation, and glucose dysregulation including hypoglycemia and hyperglycemia [11, 12]. In addition, neuroinflammation can occur and allow increased levels of circulating proinflammatory cytokines such as interleukin-10 and tumor necrosis factor and anti-inflammatory cytokines to enter the central nervous system due to blood-brain barrier damage from peripheral cytokines [13]. The information regarding pathophysiology of brain injury and critical illness is rapidly increasing (see several recent review papers for additional information) [13, 14].

The cognitive deficits often reflect the presence of cognitive impairment which, variously defined, typifies the presence of significant problems, sometimes in a single domain, but more typically, impairments occur in a range of different domains including attention, executive functioning, memory, processing speed, and visuospatial ability [6, 7, 15]. While time is limited in some individuals, for a significant portion of survivors of critical illness, impairment persists and, at times, can transition into a pattern of persistent and/or worsening decline, as is seen in conditions such as vascular dementia or even Alzheimer's disease (AD) [6]. Unfortunately, the cognitive problems so often endemic after critical illness are not an esoteric problem – rather it has practical and functional implications. Cognitively impaired individuals struggle in key areas of functioning – they may have problems driving, balancing a checkbook or managing money, taking medication [16] and generally "staying on top" of healthcare demands, using technology efficiently, or understanding social cues, among others. In addition, many survivors are not able to return to work [17–20] and experience financial toxicity [21] largely caused by large medical bills, change in insurance coverage, and loss of employment.

Wide-ranging efforts have been made and continue to be made to prevent the development of cognitive impairment. These have predominantly focused on the development of interventions that seek to eliminate or reduce delirium – both a "modifiable" risk factor and, in dozens of studies, ostensibly the primary risk factor cognitive decline [22]. Initiatives to reduce delirium and, indeed, the emergence of entire clinical paradigms focused on delirium reduction have been very successful, but, of course, delirium persists. Many other risk factors are considerably more difficult to modify and, in some instances, include immutable characteristics such as baseline cognitive function or the degree of cognitive reserve possessed by an individual patient at the time of the onset of critical illness. As such, it seems likely that cognitive impairment will always be an adverse by-product of critical illness – even as the prevalence of this condition decreases in the future. This highlights the vital importance of interventions such as cognitive rehabilitation, which must increasingly become a standard feature and even a fixture of post-ICU care.

## What Is Cognitive Rehabilitation?

Cognitive rehabilitation is a "systematic, functionally oriented service of therapeutic activities that is based on assessment and understanding of patient's brain-behavioral deficits" [23]. Cognitive rehabilitation seeks to achieve functional improvements by (1) reinforcing or reestablishing previously learned behavior patterns or (2) establishing new cognitive activity patterns or compensatory mechanisms for impaired neurological systems [24]. Modern cognitive rehabilitation likely began during World War I in an effort to treat soldiers surviving increasingly severe head injuries [25]. Current concepts in cognitive rehabilitation emerged during World War II and led to the creation of specialized brain rehabilitation centers. Cognitive rehabilitation is an active field of research, primarily due to its use for over two million individuals suffering TBI each year. Within the VA healthcare system, rehabilitation for TBI is a key element for large numbers of veterans returning from combat theaters [23]. It seems appropriate, then, for the VA to be the leader through which to advance the science of cognitive rehabilitation for the battlefield of ICU medicine.

## Efficacy of Cognitive Rehabilitation in Traditional Populations

A large and growing body of data support the use of cognitive rehabilitation in the treatment of traditionally defined acquired brain injuries (any non-congenital brain injury, e.g., TBI and stroke) [23, 26, 27]. Three systematic reviews of the cognitive rehabilitation literature (nearly 400 studies with 65 graded Class I evidence) found that cognitive rehabilitation was effective in remediating impairments in attention, memory, language and communication, and executive dysfunction in patients with an acquired brain injury due to TBI or stroke [23, 26, 27]. These studies used strategies including therapist-based, group-based, and computer-based interventions. Acquired cognitive impairment occurs extensively in ICU survivors, and data supporting the efficacy of cognitive rehabilitation with traditionally defined brain-injured populations likely applies to patients with cognitive impairment including executive dysfunction and impaired memory, due to the effects of critical illness on the brain. Indeed, this logic has been the impetus for the use of cognitive rehabilitation with other brain-injured medical populations (described below).

## Efficacy of Cognitive Rehabilitation in Medical Conditions

Cognitive rehabilitation is increasingly being applied to patients with medical or psychiatric conditions resulting in acquired brain injuries such as human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), epilepsy, Parkinson's disease, multiple sclerosis, "chemo fog," and schizophrenia [28–32]. A recent review included 34 studies of cognitive rehabilitation in patients with 11 medical illnesses [29]. The majority of the studies cited in this review were case series or uncontrolled studies (pointing to the need for rigorously designed studies such as Returning to Everyday Tasks Utilizing Rehabilitation Networks-III (RETURN-III VA: NCT04353804) clinical trial. Nevertheless, qualitatively, 30 of 34 studies demonstrated positive findings [29]. Additionally, cognitive rehabilitation has also been successfully used to improve cognitive impairment in randomized trials of over 500 patients with "chemo fog" [28, 33] and HIV-associated neurocognitive disorders (HAND) [34, 35].

## Cognitive Rehabilitation in Survivors of Critical Illness

Given the long-term adverse effects of cognitive impairments after critical illness, there is a growing need to develop interventions and delivery care to improve long-term outcomes [36]. Patients may benefit from cognitive rehabilitation studies, but few studies exist, and interventions are often not available due to lack of awareness of cognitive impairments after critical illness. Studies of cognitive rehabilitation in survivors of medically related critical illness are very recent, and few studies exist.

In one of the first studies of its kind, the Returning to Everyday Tasks Utilizing Rehabilitation Networks-I (RETURN-I) pilot study, researchers randomized 22 patients with executive dysfunction at the time of hospital discharge either to 12 weeks of in-person cognitive rehabilitation (using a method known as Goal Management Training) and physical rehabilitation via telehealth visits or to a "usual care" condition typically characterized by no formal rehabilitation [37]. Over 87% of patients participated in at least one cognitive rehabilitation session (80% completed all sessions). Despite equivalent executive functioning scores at baseline on the Tower Test, patients receiving the in-home rehabilitation intervention demonstrated significantly improved cognitive function (higher test scores) at 3-month follow-up (Adjusted $p < 0.01$). Fewer patients in the cognitive rehabilitation group were evaluated at 3 months than at discharge. The small number of dropouts in the cognitive rehabilitation group had high pre-intervention Tower Test scores, indicating relatively more intact executive functioning, and withdrew from the trial primarily because they were functioning well. Patients in the intervention group also reported significantly better daily functioning as measured by the Functional Activities Questionnaire ($p = 0.04$) [37].

Other cognitive rehabilitation studies have utilized different cognitive rehabilitation techniques. Zhao and colleagues (2017) developed a novel cognitive intervention including playing an electronic keyboard, learning simple Spanish, memory for the time, and talking to a psychiatrist 4 days a week for 3 months [38]. The study found improved memory, attention, and language in the intervention group [38]. Another study developed an individual management plan to improve cognitive impairments, and survivors in the intervention group improved cognitive function compared to controls [39]. A study that used virtual reality for cognitive rehabilitation found the virtual reality intervention was safe and feasible, and patients were able to tolerate the intervention [40]. Finally, computerized cognitive rehabilitation that focused on improving memory, attention, executive control, and response time improved cognitive function across cognitive domains when comparing baseline performance to post-intervention scores [41]. While the number of cognitive rehabilitation studies is limited, and the sample sizes are generally small, cognitive rehabilitation in survivors of critical illness appears promising in improving cognitive function.

## Support Groups for ICU Survivors

One of the most exciting developments in the care of ICU survivors in recent years is the development of support groups as a means to improve patients' functioning. Support groups have a long and storied history in the pantheon of psychologically oriented treatment approaches. They have much to commend them – they are typically relatively inexpensive to organize, they can easily be "scaled," they can be delivered by people with relatively little specialized training (whether psychologists or healthcare professionals from other non-mental health disciplines), and, in general, they have proven to be quite effective. Although precise estimates are hard to achieve, since the advent of an initiative called "Thrive" sponsored by the Society of Critical Care Medicine (SCCM), approximately 20 support group programs have been initiated in North Americans, with perhaps an equal number of programs operating around the world [42].

These groups to date have been marked by a panoply of diverse approaches, with regard to everything from the populations being treated to the context of treatment to the timing of delivery [42]. In general, they have targeted patients shortly after their discharge from the ICU, believing, perhaps correctly, that patients are most likely to benefit from treatment in the early post-discharge period. Of course, this may be correct – as far as it goes – although it may be the case that individuals may be well positioned to benefit from support groups months and years after discharge from the ICU (this has been the experience at Vanderbilt), as their acute symptoms have stabilized a bit and they may have better insights into what their actual challenges are. Also, a majority of groups have followed a prescribed, time-limited curriculum – those they vary in content. In general, they have been educational in nature and have addressed a circumscribed range of topics, using a model that begins with certain assumptions about issues of interest to ICU survivors. While the groups are largely attended by ICU survivors, in some cases, they also integrate family members as well – typically spouses or significant others but also possibly children.

Many support groups rely on what might be called a "bottom-up" approach, in which topics are largely dictated by group members in the context of an open group that does not have a fixed "expiration date." Although we have largely attempted to lead a group without any fixed agenda (recognizing that doing this "perfectly" is impossible), we have observed that a small number of central themes emerge consistently across groups. In general, these themes relate to the following issues:

1. Identity – notably "who am I" following critical illness in light of physical debility, diminished capacity, psychological symptoms, bodily changes, etc.
2. Calibration of expectations – specifically, what changes and improvements are realistic to expect and what is the natural history of cognitive impairment, PTSD, etc. after critical illness
3. Grief and loss – processing and "working thru" feelings of sadness and loss related to unwanted changes including and prominently changes in cognition and mood
4. Acceptance – "coming to grips" with the persistence and reality of changes after discharge and working to find ways to accept and gradually even embrace them
5. Empowerment – finding ways to reshape a patient's narrative from one of victimhood to one of overcoming obstacles and barriers

Few of any support groups for ICU survivors have employed outcome measures to demonstrate efficacy, although the positive impact of support groups on a range of outcomes in patients with diverse medical conditions is well known. While anecdotal information supports the idea that support groups facilitate change in the context of PICS, perhaps the most significant benefit we have observed relates to the development of rich community and support, both things that are often sorely lacking in individuals after critical illness. As many have described, networks for survivors of conditions such as sepsis and ARDS are few and far between, and though they are members of a fraternity that is numerically very large, they frequently feel intensely isolated and lonely. In our experience, the benefits that individuals with PICS experience when they realize they are part of a supportive, understanding "tribe" are palpable and one of the key benefits that lead our patients to return to the group week after week.

## Practical Considerations

Apart from what might be called "scientific" considerations, issues in cognitive rehabilitation may be guided by a variety of "practical" concerns. We will briefly address and elucidate these in the paragraph that follows:

- *Timing:* Questions persist regarding when to deliver cognitive rehabilitation, and little empirical evidence exists to guide these decisions. It may be that "early" implementation is preferable, although there are clear barriers that may prevent meaningful engagement with patients in ICU or hospital settings (e.g., the presence of delirium, frequent interruptions from allied health providers, etc.). Alternatively, it may be that patients are better able to engage in treatment without the distractions of hospitalization and, moreover, that they may have better insights into their deficits (and, by extension, more motivation) after leaving an acute care environment.
- *Modes of Delivery:* As with issues of timing, little data exists to guide informed decisions about how cognitive rehabilitation is delivered. Historically, it occurs in an intensive face-to-face context or, in the case of Goal Management Training (GMT), in a group.

## Outcomes of Interest in Rehabilitation Trials

A key issue of importance in research has to do with how to determine if cognitive rehabilitation is indeed effective, highlighting the relevance of outcome instruments. A quick review of the clinical trials described on the website www.clintrials.gov lists literally dozens of outcome tools – ranging from tests of quality of life to tests of daily functioning (e.g., instrumental activities of daily living or IADLS) and to tests of attention, executive functioning, memory, and processing speed, reflecting an obvious lack of consensus related to issues of measurement. Although a thorough discussion of these issues is beyond the scope of this chapter, several points are salient:

1. *Outcomes of interest must matter to patients:* The last decade has witnessed a virtual explosion in what is broadly known as patient-centered outcome research, and critical to those movements is the idea that patients, themselves, should have a prominent voice in determining, for instance, what "matters" and how to improve it. In the development of our own research (we are not alone in this), we have frequently exposed patients to a variety of cognitive tests and have literally asked them whether, for example, the Tower Test (a traditional neuropsychological measure of planning) or the Hotel Task (a novel measure of planning which incorporates a range of "real-life" tasks that mimic what a hotel manager would do) evaluates more effectively the kinds of difficulties they experience daily. We have also queried them about the feasibility of completing these tasks and about whether they could tolerate the time demands of either. Information obtained this way allows researchers to push past their (often) inaccurate assumptions and get to the truth about patient priorities and perspectives.
2. *Outcomes of interest should correspond to the interventions being employed:* Outcome tools should engage areas of functioning that should – theoretically and actually – correspond to the types of therapy being delivered. Put another way,

cognitive rehabilitation interventions like Goal Management Training (GMT) that seek to improve abilities such as planning and strategy should not be measured with tests of memory but rather with tests of executive functioning. Tests should match interventions. (3) *Outcomes of interest should reflect ecological validity:* Ecological validity is a term unknown to many critical care researchers and practitioners as it originated in the field of perceptual studies [43]. Yet, this term points to a vitally important concept and one that undergirds so much of modern neuropsychology. Stated simply, ecological validity refers to the correspondence between performance on a measure of cognition (or quality of life or functioning) and performance in the arena of "real-world" challenges. In other words, performing well on a test of attention should suggest the presence of intact attention in diverse actual circumstances – shopping at the grocery store, doing homework, operating a table saw in the workshop, etc.

## Future Directions

Cognitive rehabilitation is increasingly employed with medical populations of different kinds, many of whom experience significant and prolonged cognitive impairment. While individuals with brain injuries or dementias secondary to medical illness are, perhaps, not a conventional population as far as rehabilitation is concerned, they are nevertheless a population for whom the need is great and a population for whom interventions may be effective. This is particularly the case for survivors of critical illness – patients who have neuropsychological deficits that are frequently quite severe and who, in early research, appear to respond well to innovative therapies. Still, relatively little is known about how to optimally address their many needs, about whether interventions should primarily help compensate for deficits, or whether, more fundamentally, they should be designed to actually improve cognition through, for example, by harnessing and extending natural processes of neuroplasticity. Future emphasis – both clinical and research related – should engage these issues and many more and ideally will do so in a comprehensive and programmatic manner that integrates areas of focus such as basic science and the development of animal models, the rigorous testing of novel treatments via rigorous clinical trials, and the use of biomarkers such as EEGs and neuroimaging to develop treatment targets and to monitor improvement.

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# Chapter 11
# Peer Support to Improve Recovery—Concepts and Considerations

**Elizabeth Hibbert, Helen Devine, and Kimberley J. Haines**

## Introduction

### *Post-intensive Care Impairments*

Impairments resulting from post-intensive care syndrome (PICS) can impact the quality of survival following an intensive care admission [1–5]. Return to employment, dependence on their relatives to provide care, and other socio-economic issues are common for those that survive ICU [2]. These problems can also directly impact family members who often adopt the role of informal caregivers [6–8]. This is known as PICS-Family (PICS-F) and can result in patients' relatives and carers experiencing psychological disorders and emotional burden [9, 10]. Peer support has been suggested as a possible aid in recovery following critical care and may mitigate PICS impairments for both patients and their informal caregivers [11].

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### *What Is Peer Support?*

Peer support can be delivered using a variety of different models. Commonly, it can take the form of 1:1 peer-to-peer support for those with a similar condition working in partnership, or support groups focused on behavioural changes and education, or in the form of former patients facilitating advice and support [12]. Patients sharing similar experiences and challenges with their peers may create a safe environment where their journey is 'normalised' and they do not 'feel alone'. This commonality of experience may also create a nonhierarchical reciprocal relationship leading to its success [13]. This in turn could possibly mean that patients will be more inclined to accept new behaviours and knowledge more effectively from another peer who has 'been there and done that' rather than a professional who may not share this same lived experience. Another way it can assist is with providing hope for those affected by PICS. Through these shared experiences, patients are able to see how those further along in their recovery are coping and managing, despite starting at a similar baseline [14].

### *Peer Support in Varied Patient Cohorts*

Peer support has been shown to promote recovery amongst a variety of different patient populations [15]. In a systematic review of peer support programs for cancer patients, one-on-one face-to-face and group Internet peer support programs were highlighted as the favoured methods used [16]. Diabetic patients were found to have improved blood sugar control in a randomised control trial of peer support comparing a reciprocal peer support programs to nursing care management [17]. A pilot study looking at telephone-based peer support for those with heart failure showed encouraging findings on patients' depressive symptoms, self-management, and health outcomes [18]. Patients and family members of those with a traumatic brain injury were found to have improved coping skills from a community-based peer support programs [19]. Patients with chronic obstructive pulmonary disease (COPD) have reported feelings of social isolation similar to ICU survivors. Attending peer-supported pulmonary rehabilitation groups have helped establish social support networks that were lost through their condition [20]. Their caregivers have also reported improved social interactions within this peer-support group [21]. These benefits could possibly be mirrored through the use of peer support within critical care survivors.

### *Peer Support in Critical Care Cohorts*

When delivered in a critical care cohort, peer support involves bringing ICU survivors together who share similar lived experiences, usually after their ICU admission. Survivors provide each other with reciprocal pragmatic and social support which may support enhanced self-management and aid recovery. More specifically, peer support is the '*process of providing empathy, offering advice, and sharing stories between ICU survivors. It is founded on the principles that both taking and giving support can be healing, if done with mutual respect*' [22]. The burden of PICS impairments can potentially be mitigated through the use of peer support, by promoting a culture of resilience and enhanced recovery [22].

In a secondary analysis of an existing data set of patient interviews recruited through the Society of Critical Care Medicine's THRIVE collaboratives, key mechanisms of peer support were identified [23]. Shared expectations, care de-briefing, and opportunities for altruism may be the key mechanisms of peer support interventions during patients' ICU recovery (Fig. 11.1) [14]. Peer support groups differ to post-ICU clinics, by 'providing a sense of purpose' that may not be accessible in the typical biomedical model of clinics [23]. Peer support may also reduce social isolation and loneliness, which may be an important factor in assessing patient mortality. Further research needs to be undertaken to assess if there is an association.

Peer support can also be utilised as an intervention for families as informal caregivers of ICU patients. Some institutions solely deliver their peer support programs to the informal caregivers during their loved ones' ICU admission [11]. This may provide informal caregivers with the chance to connect with others who are going through a similar experience, at the same time. Peer support may offer informal caregivers the opportunity to connect with others who share the same lived experience, unique to providing care to ICU patients. For example, caregivers may be able to offer each other emotional support with the challenges of adopting a new role as advocate and decision-maker, while trying to manage competing demands and usual responsibilities such as work and caring for others. In

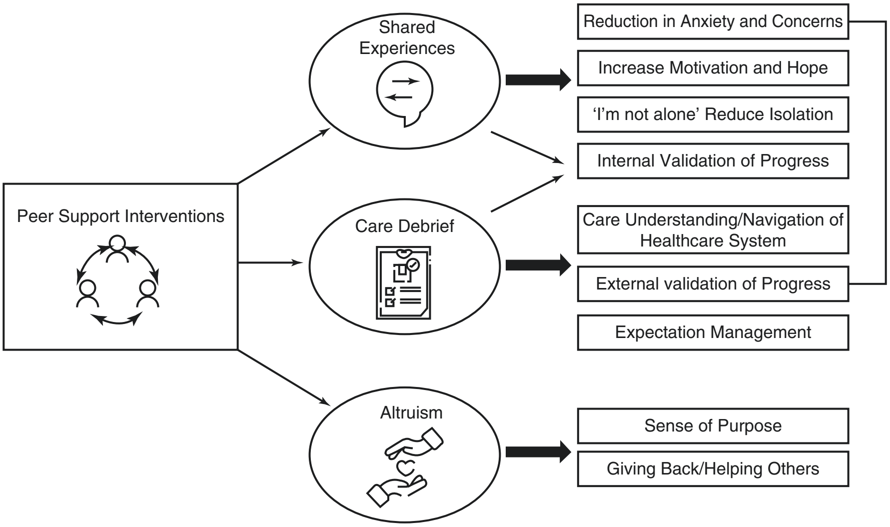


**Fig. 11.1** Key mechanisms of peer support. (From McPeake et al. [14])

unpublished data from the SCCM-funded, international, Collaborative Assessment of ICU Recovery Needs (CAIRN) Study, caregivers described how they accessed support during and following the ICU admission. They appeared to access support via three key avenues (where they existed): (1) formal support (e.g. ICU nurses, psychologists); (2) informal support (e.g. existing support networks of family and friends). Peer support offered a third crucial element of hybrid support, where caregivers accessed both formal and informal support networks (Fig. 11.2).

Peer support may also have other underreported benefits such as for those in the 'helper' role. Older adults that volunteer have shown to have higher levels of well-being representing the possible positive impact of being in the supporting 'helper' role [24]. Former ICU patients who return as volunteers and have given support or advice to another patient, may themselves feel better psychologically. Potentially, this volunteering role could result in their improved self-esteem and a return to formal employment ameliorating their journey of recovery post-ICU.

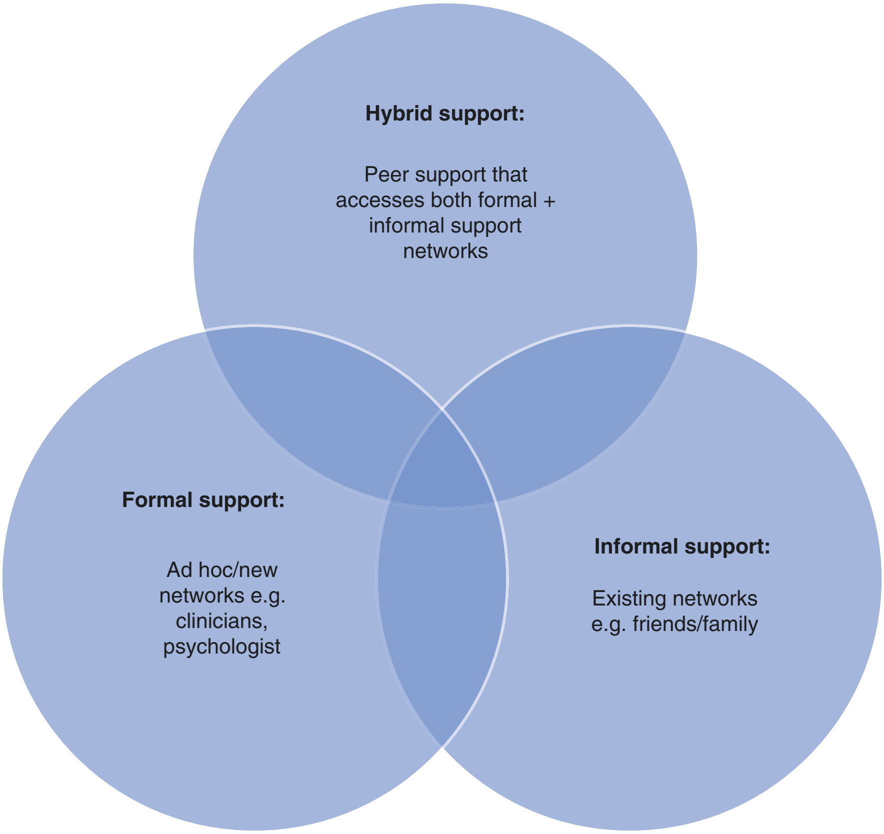


**Fig. 11.2** Mechanisms of caregiver support accessed during and following ICU admission

## *Potential Risks Associated with Peer Support*

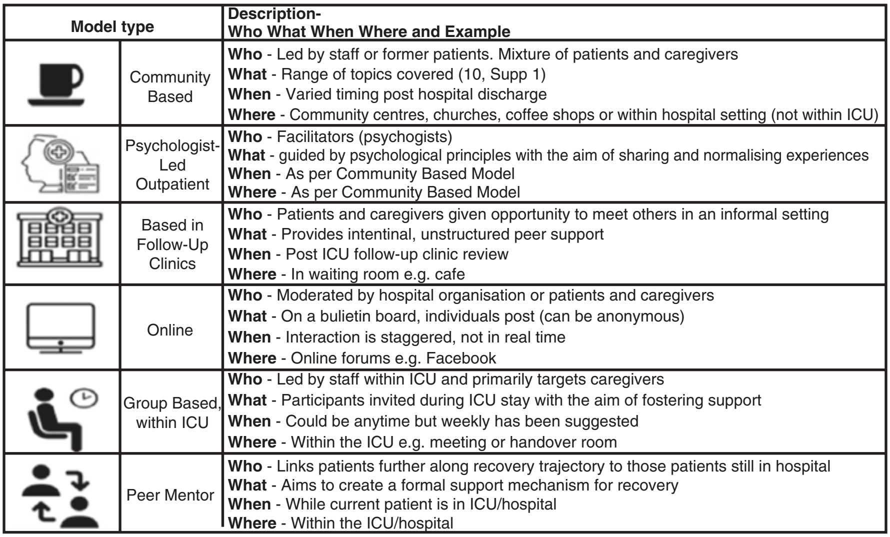
There are some potential risks, however, that should be considered when planning facilitation of peer support amongst patients and relatives/caregivers. Some patients may not feel comfortable in a group environment and therefore should be offered 1:1 sessions or written information on any educational sessions provided in a group setting. There should also always be ‘quiet’ spaces available if patients/caregivers may find sessions too intense or traumatic. Therefore, extra staff should always be available to support individuals who may struggle with group sessions. Staff need to be mindful of this and ‘check-in’ with patients and caregivers as appropriate. Skilled expert facilitators, e.g. psychologists or social workers, are ideally placed to manage these group sessions or provide training to staff as an alternative. ‘Group rules’ should be covered at the start of any group session so that all attendees are aware that everyone should be allowed to contribute, but if someone is keen to specifically speak about their own experience in depth, then they can avail of a 1:1 with a staff member for support and guidance. These staff also need to be appropriately trained to understand how to support these patients and to signpost to appropriate specialist services if required.

## *Evidence for Peer Support Within Critical Care Cohorts*

Currently, there is limited research into the use of peer support within critical care survivors. Eight full-text articles were included in a recent systematic review [15]. The studies included were heterogeneous and included only one randomised control trial (RCT). Three of the five quantitative studies included, used standardised outcome measures, the most common being State-Trait Anxiety Inventory to measure anxiety amongst participants of the support groups. The other two studies used investigator-developed questionnaires for their outcome measures. The three qualitative studies included, identified two key themes: 1. universality of experiences; and 2. shared thinking. All of the qualitative papers concluded that coming together and sharing a mutual experience in a safe space allowed participants to validate their own experiences and identify coping strategies that have been used by others in similar situations.

The authors concluded there was a lack of rigorous, high-quality evidence to support the implementation of peer support universally within intensive care units. However, the studies that were included indicated a favourable signal for peer support to assist with psychological morbidity and increased social support beyond what might be accessed via usual support networks, or that provided by the hospital.

For the purposes of this chapter, we reran the same search strategy from this systematic review (see [15], Fig. 11.3—search strategy) to identify any new studies published since the review was published. We identified one additional study that



| Model type | | Description-<br>Who What When Where and Example |
|---|---|---|
| | Community Based | **Who** - Led by staff or former patients. Mixture of patients and caregivers<br>**What** - Range of topics covered (10, Supp 1)<br>**When** - Varied timing post hospital discharge<br>**Where** - Community centres, churches, coffee shops or within hospital setting (not within ICU) |
| | Psychologist-Led Outpatient | **Who** - Facilitators (psychogists)<br>**What** - guided by psychological principles with the aim of sharing and normalising experiences<br>**When** - As per Community Based Model<br>**Where** - As per Community Based Model |
| | Based in Follow-Up Clinics | **Who** - Patients and caregivers given opportunity to meet others in an informal setting<br>**What** - Provides intentinal, unstructured peer support<br>**When** - Post ICU follow-up clinic review<br>**Where** - In waiting room e.g. cafe |
| | Online | **Who** - Moderated by hospital organisation or patients and caregivers<br>**What** - On a bulietin board, individuals post (can be anonymous)<br>**When** - Interaction is staggered, not in real time<br>**Where** - Online forums e.g. Facebook |
| | Group Based, within ICU | **Who** - Led by staff within ICU and primarily targets caregivers<br>**What** - Participants invited during ICU stay with the aim of fostering support<br>**When** - Could be anytime but weekly has been suggested<br>**Where** - Within the ICU e.g. meeting or handover room |
| | Peer Mentor | **Who** - Links patients further along recovery trajectory to those patients still in hospital<br>**What** - Aims to create a formal support mechanism for recovery<br>**When** - While current patient is in ICU/hospital<br>**Where** - Within the ICU/hospital |

**Fig. 11.3** Models of peer support. (Adapted from McPeake et al. [11])

developed an ICU support group in Israel [25]. The group ran weekly in the family room of the ICU that was targeted toward family members of admitted ICU patients. The group was facilitated by the nurse manager and a social worker. The group was based upon the conceptual framework of focus group research [26]. The authors used qualitative analysis to distil themes and categories from the family perspective. The following four themes were identified:

1. *Behavioural*—this related to ICU norms that were different to other social norms.
2. *Perceptual or sensory*—family members needed to reorganise their own sensory systems as well as orientation and navigation of unfamiliar, new, and challenging environments.
3. *Emotional*—there were a multitude and rollercoaster of emotions that families endured with a loved one critically unwell in the ICU.
4. *Support*—families drew upon support and strength and developed coping strategies to deal with the daily challenges they faced in the ICU.

The family participants in this study reported the peer support group offered them an avenue and safe space to openly express their fears, emotions, and thoughts. The groups were also perceived to be a useful tool to help families navigate one of the most stressful times in their lives. Of note in this study, the nurses involved in the group also reported benefits. They reported they were better equipped to answer questions and concerns from families that the bedside nurses could not (due to lack of preparation and training to interact with relatives), or simply because the bedside nurses lacked time to answer family queries, as they were dealing almost exclusively with patient care.

In addition to providing potential benefit to patients and their families, peer support programs may also provide benefit to ICU clinicians. A recent study [27] found that post-ICU programs drive improvements back into the ICU. Some of the key mechanisms this may occur via, include:

1. Inviting critical care clinicians to the post-ICU programs (e.g. peer support group) as a way to educate about post-ICU issues and motivate them to participate.
2. Altering the clinician's own understanding of the patient experience from working in the post-ICU programs, which helped them to preempt future issues post-discharge, when caring for patients in the ICU.
3. Mitigating known workforce issues such as burnout by improving morale and meaningfulness of ICU work. Post-ICU programs offer an opportunity to close the feedback loop to ICU clinicians about patient and family outcomes.

## *Global Collaboration to Innovate and Implement Peer Support in Critical Care*

Internationally, there has been growing interest in peer support groups as a strategy to improve recovery following critical illness. This international interest has emerged via the Society of Critical Care Medicine's Thrive Peer Support Collaborative that was set up in 2015. This initiative aimed to support hospitals to locally innovate and discover start-up strategies to develop peer support groups globally. In a report conducted for the collaborative, six models of peer support were identified (Fig. 11.3) [11].

## *Implementation of Peer Support—Enablers and Barriers*

Haines et al. undertook a large, international qualitative study using focus groups conducted with the SCCM Peer Support Collaborative to evaluate the enablers and barriers to establishing post-ICU programs including peer support and follow-up clinics [28]. They used the Consolidated Framework for Implementation Research (CFIR) [29] for the organisation and allocation of coded data. Nine enablers were identified specific to the implementation and maintenance of peer support programs globally at various hospitals [28]. These included:

1. Building social cohesion—to help the survivors connect with each other;
2. Defining operational processes—captured in a standard operating procedure, given the complexity of the intervention;
3. Accessing skilled group facilitators—such as social workers and psychologists who have requisite expertise;

4. Value of debriefing for the group facilitators—to support the well-being of those running the groups;
5. Membership to the SCCM THRIVE Peer Support Collaborative—which provided a forum for sharing ideas and troubleshooting challenges;
6. Engaging participants into the group—working out who is best to attend and how to get them to attend;
7. Motivated interprofessional clinicians—who persist to overcome barriers as they arise;
8. Patients and family volunteers and advocates—who can support the running of the group; and
9. Leveraging ICU follow-up clinics—as a means of cross-referral from clinic to peer support group.

From these enablers, the most crucial elements for a peer support programs to function effectively appeared to be:

- A team of dedicated interprofessional clinicians (this could also include patient and family volunteers);
- Access to external support, e.g. the THRIVE Peer Support Collaborative;
- A clearly, defined operational procedure for the peer support group to be delivered according to and that other clinicians could follow if needed.

Barriers to implementation of peer support were also identified and included these five common barriers:

1. Patient and family nonattendance;
2. Access to a skilled facilitator;
3. Bureaucratic limitations of health services;
4. Building therapeutic trust and rapport; and
5. Challenges in managing expectations of former patients as volunteers.

From this study, the major barrier identified was related to the 'intervention characteristics' domain of the CFIR, where nonattendance was the most common theme for perceived lack of success of the various peer support groups globally.

## *Additional Barriers to Peer Support—Our Clinical and Research Experiences*

Despite the myriad of studies detailing PICS impairments [1–4], patients may not necessarily associate the disability experienced post-hospital, with their ICU stay [11]. Unlike most medical conditions where a clear diagnosis can be given to the illness or disease, PICS impairments are multifactorial and are usually underrecognised by health professionals (including ICU staff, ward staff, and community professionals) in the continuum of care [30]. Given this potential lack of recognition of the problems associated with PICS impairment by patients, their caregivers, and clinicians, it is challenging to explain why participating in peer support may benefit their recovery. This can mean that patients and their caregivers may not necessarily appreciate the potential benefit of peer support that is anchored to their ICU admission, and potential post-ICU impairments. Additionally, patients and their families often report needing to attend numerous medical and allied health appointments following discharge from hospital [28]. This can make attendance at a peer support group, run in the post-hospital phase, challenging to attend, and may seem irrelevant or less important than other appointments [28]. These may be some of the contributing factors to help explain why there is generally low uptake and participation in peer groups globally by patients and caregivers, as a commonly reported barrier to implementation.

A related challenge to the limited awareness of PICS, outside of the critical care community, is that it may be particularly challenging to articulate the problem and need for a peer support group to hospital administrators and executives in order to secure funding or in-kind support to deliver a peer support group. Access to skilled facilitators and acquiring funding and organisational in-kind support to run peer support programs for post-ICU patients and their caregivers are significant barriers to implementing successful peer support programs [28]. A lack of rigorous evidence to maintain the use of peer support (as well as different ideas about who, what, when, and where) means there is difficulty in both starting these programs, and sustaining them.

## *The Future State of Peer Support*

Peer support remains a novel and scientifically underexplored intervention to potentially aid recovery for critical care survivors and their family members. However, there remain significant challenges to the uptake of peer support programs, where this intervention is delivered to a small subset of ICU patients who may or may not choose to participate. It may be that those, who are willing and able to attend a peer support programs, are those who have existing high levels of self-efficacy and robust health behaviours that they would seek such a programs out and commit to attending. Conversely, in patients where peer support may benefit their recovery, these patients may have lower levels of self-efficacy and may not have the emotional, social, and physical capital to allow them to attend a peer support programs. Investigating the characteristics of those who do, and do not, attend these programs, and reasons why, could help refine the delivery of this intervention.

While the SCCM Peer Support Collaborative has made progress in supporting various sites to establish different models, ongoing testing is required to better understand the feasibility and efficacy of these programs. It will be important to establish whether peer support is a clinically and cost-effective intervention to invest in, given these programs are labour-intensive to design, implement, and sustain. Such data is important to gather from the perspectives of patients, caregivers, and the clinicians and health services delivering these programs.

To date, a limited number of studies have used a qualitative design to evaluate the use of peer support in critical care cohorts. As peer support is a complex intervention to deliver, it may be that a qualitative study design could be a useful approach to elicit the benefits and disadvantages of peer support, as well as the nuances of delivery and implementation. Further, given the mechanisms of peer support in the critically ill are not yet well understood, qualitative methods could help build the evidence base from an exploratory perspective. Simultaneously, testing of various models of peer support is required via randomised controlled trial to evaluate the efficacy of peer support on patient and family-centred outcomes. We know of one randomised controlled trial of peer support currently in progress (Australian New Zealand Clinical Trial Registry ACTRN12618000615280), although there may be others in progress. Additional quantitative evaluation of outcomes important to health services, such as cost-effectiveness, and healthcare utilisation would also be beneficial to the field. There is a need for well-designed and rigorously reported research into this complex intervention whether that be qualitative or quantitative design, to help advance the science of peer support. In an effort to move the field forward, and given the complex nature of this intervention, the use of recommended standardised reporting checklists such as the template for intervention description and replication (TIDieR) [31] is important to use when reporting studies of peer support. Doing so may help us to continue to advance the science and clinical applicability of peer support as a viable intervention to aid recovery following critical illness.

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# Chapter 12
# ICU Follow-up Clinics

**Carla M. Sevin**

## Introduction

As the challenges facing survivors of critical illness come into focus, patients, families, and clinicians are seeking ways to address the needs of this unique population. One model of post- ICU care is the ICU follow-up clinic, also known as a post-ICU clinic or ICU recovery clinic. These clinics, with their root in early nurse led clinics in the United Kingdom and Scandinavia, commonly take a multidisciplinary team approach to addressing unmet needs after critical illness. Posthospital conditions contributing to needs being unmet include vague or incomplete discharge instructions, insufficient medication reconciliation, missing durable medical equipment, inadequate follow-up, delayed or absent rehabilitation and/or home services, fragmented care systems, and caregiver misinformation. Late recovery may be hampered by lingering symptoms of Post-intensive Care Syndrome (PICS), including physical and cognitive impairment, inability to return to work, socioeconomic barriers to care, insufficient family support, and polypharmacy. Further study of unmet needs in the post-ICU population is ongoing [1]. Insufficient evidence exists thus far to dictate which structure of intervention is most beneficial to patients and families recovering from critical illness [2–4]. However, patients and families have highlighted, in qualitative studies, case studies, and the lay press, a number of key components of needed post-ICU care, including anticipatory guidance, care coordination, targeted support for physical, emotional, and cognitive recovery, financial counseling, peer support, and interventions specific to caregivers [5]. Where ICU follow-up

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programs have been established, they are often multidisciplinary in nature, reflecting the complexity of critical illness recovery and PICS. An overview of the current state of ICU follow-up clinics is presented here.

## Rationale

While a clinic is a concrete concept, the principles behind ICU follow-up clinics are more abstract:

1. Critical illness is complex.
2. Critical illness requires specific knowledge to be successfully resolved.
3. Critical illness is life changing.
4. Critical illness is followed by a long recovery requiring serial assessments to address changing needs.
5. Critical illness impacts the physical function, psychology, and socioeconomic standing of patients and families.

As described elsewhere in this book, critical illness impacts every organ system, resulting in the often long-lasting effects on physical, mental, and cognitive health known as post-intensive care syndrome (PICS). There is no single specialty trained and experienced in identifying and treating PICS. Most patients will have no specific follow-up after a complex critical illness, and may struggle to identify the clinician best suited to help them when they encounter problems. Primary care physicians are commonly tasked with dealing with PICS, but receive little training or support to optimize this aspect of care [6]; communication about the details of the ICU stay and experience with specific sequelae of critical illness are frequently lacking (see also *Transitions to Primary Care*).

The specialist best equipped to apply their expertise to PICS may be the intensivist. As in the ICU, the intensivist is accustomed to treating a wide array of problems, performing frequent reassessments, identifying complications of critical care, and working closely with families [7, 8]. Of the clinicians a patient may encounter during an episode of critical illness, the intensivist has the most comprehensive overview of the clinical problems at hand, their treatment, and the outcomes of both illness and treatment. And yet, intensivist led ICU follow-up is uncommon in most parts of the world [9, 10].

## Multidisciplinary Team Clinics

The earliest descriptions of intentional, outpatient, multidisciplinary follow-up of survivors of critical illness were published in the United Kingdom (UK) and Scandinavia [11–13]. The concept of a post-ICU clinic has been most widely adopted in the UK, where national guidelines recommend that all patients surviving an ICU stay have dedicated post-ICU follow-up after critical illness [https://www.nice.org.uk/guidance/cg83]. Even in the UK, however, the road to post-ICU follow-up as standard of care has been rocky, and such services remain endangered due to funding, space, and staffing limitations. In 2006, about 30% of ICUs had a follow-up clinic program in the UK, according to a national survey [14]. Over half of those clinics were led by nurses, 59% were funded by their affiliated hospital, and almost 90% of ICUs studied reported financial constraints. A 2009 study of ICU follow-up clinics in the UK was unable to show a benefit in health-related quality of life (HRQoL) at 1 year among almost 300 patients participating in an ICU follow-up program [11]. Mortality also did not differ between the groups, but a third required medical specialist referral and another third needed referral for psychological services. By 2014, implementation of the NICE guidelines had been successful in profiling the importance of rehabilitation for survivors of critical illness. However, 4 years after publication only 48 of 182 responding organizations (27.3%) offered aftercare following hospital discharge, the majority ($n = 39$, 84.8%) in clinic format [15]. Nonetheless, post-ICU follow-up clinics are gaining traction in response to perceived need [16], with many spurred into existence by a renewed focus on issues of ICU survivorship due to the COVID-19 pandemic. Indeed, many new “post ICU clinics” are called “post COVID clinics” but are structured similarly and serve the same purpose and in many cases the same population.

## Key Components of Post-ICU Clinics

Although no standard model of post-ICU clinic has been evaluated or validated in rigorous trials; patients, families, and clinicians have outlined a number of important elements of ICU follow-up care [5]. These include attention to physical, cognitive, and emotional recovery, with longitudinal assessments and goal setting by a multidisciplinary team, information on adapting to new impairments, peer support, interventions specifically tailored to caregivers, and guidance regarding welfare support and employment. Setting expectations for recovery may include acknowledging uncertainty, giving a range of things to expect, and confirming that the care team will not abandon the patient or family, regardless of what their outcome looks like [17].

## Identifying Patients for ICU Follow-Up

Millions of patients are discharged from an ICU each year, but not every patient needs or will benefit from post-ICU follow-up. Identifying which patients will benefit most from an ICU follow-up clinic is unclear. Patients who are already receiving comprehensive care from a multidisciplinary team, such as those who have had a transplant or are undergoing cancer therapy, may receive little additional benefit from a post-ICU clinic. Those who are discharged to another facility for long-term care or hospice are unlikely to return for outpatient services [18, 19]. In a recent systematic review of attempts to predict impairments after critical illness, only three studies had developed a prediction model of any post-ICU impairment, suggesting an area of opportunity: the ability to predict post-ICU impairments would enable not only clinical care and prognostication for patients and families, but targeted enrollment in research trials and the development of standardized post-ICU outcomes [20]. In the absence of validated prediction models, expert consensus has converged on the following risk factors as predictive of post-ICU impairments: pre-existing cognitive impairment, physical impairment, or mental health problems, delirium, sepsis, hypoxia, shock, the use of benzodiazepines, memories of frightening experiences in ICU, and early symptoms of post-traumatic stress [21]. Clinical characteristics of the ICU stay have been used to select patients for ICU follow-up clinics, including shock, delirium, length of ICU stay, the use of mechanical ventilation or extra corporeal membrane oxygenation (ECMO), and new [22–26].

## Timing of ICU Follow-Up

The ideal timing of an ICU follow-up clinic intervention has not been definitively established. Early post-ICU clinics in the UK and Scandinavia saw patients around 3 months after discharge to home and were unable to demonstrate an improvement in health-related quality of life at that time point. More recent studies describe high health care need early after hospitalization; thus many current ICU follow-up clinics seek to reach patients at an earlier time point. The trajectory of recovery from critical illness starts in the ICU but may continue for months or years after discharge from the hospital, necessitating serial assessments and perhaps different types of interventions as patients move from one stage of recovery to the next. Interventions to improve recovery from critical illness and their potential timing are depicted in Fig. 12.1; see also the Timing It Right Framework by Cameron and Gignac [27].

## Potential Disciplines Involved in ICU Follow-up Clinics

Preliminary studies have not clearly delineated the optimal structure of an interdisciplinary post-ICU team, but the wide array of functional domains affected by critical illness has led many centers to develop a team-based approach to diagnosing and treating PICS. As in the intensive care unit, collaboration between clinical pharmacists, physical and occupational therapists, psychologists, intensivists, and other clinical consultants can address the variety of problems encountered by patients and families after they leave the hospital. Descriptions of multidisciplinary team care after stroke, cancer, and traumatic brain injury have been suggested as models to

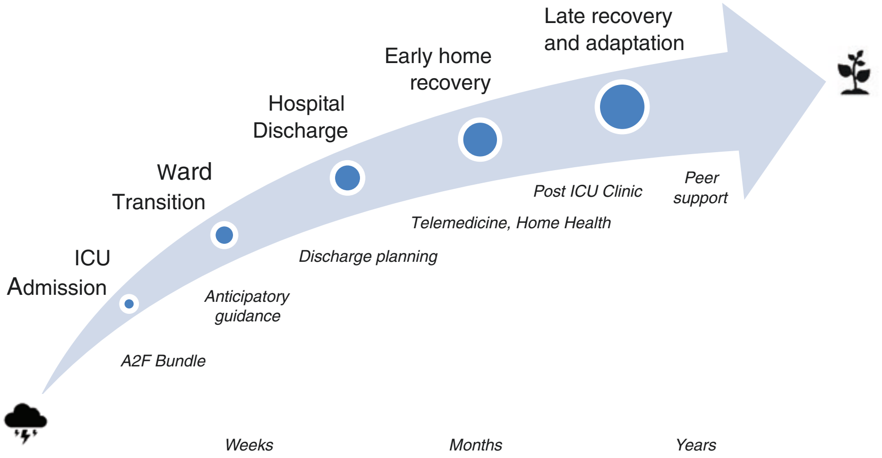

**Fig. 12.1** Repeated Assessments and Proposed Timing of Post-ICU Interventions

emulate when caring for patients recovering from critical illnesses such as acute respiratory distress syndrome and sepsis [28].

Given the prevalence of critical illness myopathy, cognitive dysfunction, and swallowing disorders in this population, many post-ICU clinics employ physical therapists, occupational therapists, and speech therapists to evaluate patients in the clinic, or refer out for more comprehensive evaluations by these specialists. Targeted screening in an ICU follow-up can identify sometimes subtle post-ICU impairments; the patient can then be referred for appropriate tertiary follow-up. For example, laryngeal injury is common in survivors of critical illness, impacting more than half of patients who received mechanical ventilation [29]. A respiratory therapist may perform screening spirometry that reveals flattening of the expiratory flow loop, raising concern for intrathoracic airway obstruction and prompting referral to otolaryngology for further evaluation and treatment of subglottic tracheal stenosis.

Deficits in physical function can be missed without expert evaluation, e.g., by a physiatrist or physical therapist; pain or fatigue with certain movements, for example, must be elicited with focused assessment and testing [30].

Cognitive dysfunction is particularly prone to going undiagnosed without specific assessment; early post-ICU symptoms are associated with persistent symptoms, which may not resolve without specific intervention [31, 32]. A psychologist or psychiatrist can address precritical illness psychiatric morbidity, noting that medications or therapies that may have previously stabilized such conditions are often disrupted during the critical illness or the many transitions of care thereafter. Post-traumatic stress disorder (PTSD), depression, and anxiety are common and clinically significant in up to a third of survivors of critical illness; they tend to co-occur [33]. New therapies or adjustments in treatment, including psychotherapy and antidepressant medication, may be needed. Cognitive behavioral therapy for post-ICU PTSD is being explored [34]. See also *Neurocognitive Rehabilitation*.

Given the high morbidity and mortality of the population seen in post-ICU clinics, the presence of a palliative care specialist, intervention, or assessment is likely to have some impact. Palliative care specialists focus on improving quality of life for patients and families experiencing critical or chronic illness and can be an integral part of the care team, providing therapies aimed at easing pain, dyspnea, and other symptoms, whether or not patients are pursuing treatments intended to prolong life. In our center, patients and families were less receptive to palliative care discussions and end of life planning in an ICU follow-up clinic than anticipated; this may reflect a self-selected population focused on aggressive therapies with the goal of returning to their preillness baseline [23]. In contrast, discussion of goals in another post-ICU clinic led 23% of previously intubated patients to change their code status to "do not intubate" (DNI); out of 95 patients who had a goals of care discussion, 10 formally changed their code status to "do not resuscitate" (DNR) during the post-ICU clinic visit [35]. For more discussion of palliative care after critical illness, see also *Palliative Care and End of Life Planning*.

The socioeconomic consequences of critical illness are increasingly well described, including loss of income and employment for both patients and their caregivers [36–43]. Thus, a structured case management or welfare intervention is a highly beneficial part of a multidisciplinary ICU follow-up program. Intensive case management approaches to ICU follow-up in the United States have demonstrated decreased mortality and even cost savings following a hospitalization for critical illness [26, 44].

The possible contributions of discrete specialties to an ICU follow-up clinic are only beginning to be described, by nurses [45]; airway specialists [29]; clinical pharmacists [46–48]; physical therapists and physiatrists [30]; occupational therapists [49, 50]; speech therapists [51, 52]; psychiatrists [33]; and psychologists [34, 53, 54]. Many of the assessments and tools used to screen for impairments in the three domains of PICS may be deployed by overlapping specialties [21]. For example, either an occupational therapist or a speech therapist can assess cognition. Likewise a psychologist or a social worker may assess affective disorders and provide short-term psychotherapy. See Table 12.1 for a sampling of the types of clinicians and assessments that may be deployed in an ICU follow-up clinic.

## Peer Support

An important aspect of post-ICU care involves peer mentors. These are often volunteers, themselves survivors of critical illness, who partner with patients and family members to ease and facilitate the recovery process [55]. Peer support in various forms may be integrated into or be structured adjacent to post-ICU clinics [56, 57]. For more detail about models of peer support for survivors of critical illness, see *Peer Support.*

**Table 12.1** Sample Post-ICU Clinic Assessments and Interventions by Specialty

| Specialty | Sample Assessments | Sample Tools | Sample Interventions |
|---|---|---|---|
| Respiratory therapy | Pulmonary function | Spirometry, ambulatory oximetry | Treat obstruction, refer to ENT |
| Pharmacy | Medication review | Drug interaction check, lab monitoring | Deprescribe inappropriate medications, provide pill box, vaccinate |
| Nursing | Clinical course review, quality of life | ICU diary debrief, EQ5D | Enable peer support, educate patient, and family |
| Physical Therapy | Mobility, frailty | Six-minute walk, timed up and go, sit to stand | Prescribe mobility aids, additional physical therapy, home exercises |
| Occupational Therapy | Activities of daily living | ADLs (Katz), IADLs (Lawton) | Energy conservation techniques, home safety equipment, return to work plan |
| Speech therapy | Communication, voice, swallowing | Dysphagia screen, VFSS, FEES, MoCA | Education of patients, families and clinicians, speech therapy |
| Nutrition | Nutrition, weight loss | Malnutrition Universal Screening Tool (MUST) | Protein supplementation plan |
| Psychology | Affective disorders, cognitive screen, PTSD | Affective: HADS, PHQ9, GAD7,<br>Cognitive: MMSE, MoCA, RBANS<br>PTSD: PCL5, IES-R, civilian PTSD inventory | Psychotherapy, referral to community resources, peer support |
| Palliative Care | Goals of care | PEACE tool | Code status discussion, end of life care wishes, and plan |
| Social Work | Caregiver assessment, socioeconomic status | Zarit burden interview, MSPSS | Respite care, short-term psychotherapy, welfare advice |

Abbreviations: *ENT* Ear Nose and Throat specialist, *EQ5D* EuroQoL-5D, *ADLs* Activities of Daily Living, *IADLs* Instrumental Activities of Daily Living, *VFSS* Video Fluoroscopic Swallow Study, *FEES* Fiberoptic Endoscopic Evaluation of Swallowing, *MoCA* Montreal Cognitive Assessment, *PTSD* Post-Traumatic Stress Disorder, *HADS* Hospital Anxiety and Depression Score, *PHQ9* Patient Health Questionnaire 9, *GAD7* General Anxiety Disorder 7, *MMSE* MiniMental State Exam, *RBANS* Repeatable Battery for the Assessment of Neuropsychological Status, *PCL5* PTSD check list 5, *IES-R* Impact of Events Score – revised, *PEACE* Physical, Emotive, Autonomy, Communication, Economic, and Transcendent domains, *MSPSS* Multidimensional Scale of Perceived Social Support

## Telemedicine for Post-ICU Care

Just as telemedicine has been used to stretch limited intensivist workforces in hospitals, the use of telemedicine may extend ICU expertise to patients recovering from critical illness, and their families. Telemedicine has been used to reach other high risk, high need populations requiring subspecialty care, including patients with stroke, Parkinson’s disease, cancer, COVID-19, and chronic illnesses managed by primary care. Preliminary data from a study of telemedicine for ICU follow-up (ClinicalTrials.gov NCT03926533) suggest that patients recovering from critical illness found multidisciplinary ICU follow-up by telemedicine comprehensive, easy to navigate, and potentially preferable to an in-person intervention in the early post-hospital period [58]. In addition to serving as a mechanism for delivering a post-ICU clinic intervention, telemedicine can enable remote patient monitoring both in and after the ICU [59, 60].

## Addressing Disparities in Risk, Access, and Critical Illness Survivorship

Minority populations are at higher risk for critical illness, have insufficient access to critical care, are more likely to die as a result of critical illness, and are less likely to have the resources needed to ensure optimal recovery after critical illness. Socioeconomic and clinical risk factors, such as race, education, hospital type, and delirium duration, have been linked to worse PICS and long-term cognitive impairment after critical illness [61]. The financial burden of post-ICU care is likely even heavier for socioeconomically disadvantaged patients and their families; access to postacute care facilities is limited by insurance coverage, which in the United States is more likely to be lacking or insufficient for nonwhite patients [62]. Likewise, outpatient programs including rehabilitation, counseling, cognitive therapy, and subspecialty clinics are, unlike emergency and inpatient medical services, out of reach or inaccessible for rural or underinsured populations. In many health systems, interpreter services are needed in order to provide appropriate post-ICU follow-up to survivors of critical illness. The lack of adequate interpreter services is a potential barrier to providing equitable care to survivors of critical illness, as those populations who do not speak the primary language of their country of residence are even less able to advocate for post-ICU follow-up services. Given these stark realities, it is perhaps unsurprising that societal disparities extend into critical illness survivorship: in the United States, underserved populations including those with Black, Hispanic, and Native American heritage are less likely to be enrolled in critical care studies including long-term outcome measures, and less able to access post-ICU recovery programs. Future efforts should focus on improved identification of and access for these higher-risk groups to promote survivorship [63].

## Assessing the Impact of ICU Follow-up Clinics

As complex and usually pragmatic clinical interventions serving a heterogeneous population of patients, ICU follow-up clinics are difficult to study. However, measuring their impact is an important means to improving care for patients both in and after the ICU. A number of outcomes important to patients, families, clinicians, and healthcare systems have emerged as potentially useful metrics when implementing ICU recovery programs:

- *Readmission.* Early and late unplanned readmissions are common after critical illness: nearly a third of critically ill patients will be rehospitalized at least once in the 6 months following an ICU stay [64]. Attempts to reduce unplanned readmissions by targeting PICS with an ICU recovery bundle have shown a possible impact on readmissions after critical illness, especially those that occur in the early posthospital period [65]. In a study of an ICU recovery program at Geisinger, annual cost savings approached $1.1million after expenses, due in large part to decreased readmission in the intervention group [26].
- *Healthcare utilization.* In the absence of timely access to appropriate outpatient attention, patients recovering from critical illness often have no choice but to seek costly emergency and inpatient services to address post-ICU problems [66–68]. Unsurprisingly, healthcare utilization is high following a critical illness. Given that approximately 40% of hospital readmissions occurring in the 90 days after an episode of severe sepsis are thought to be potentially avoidable with timely and appropriate outpatient care, ICU follow-up clinics may be a way to decrease healthcare utilization as patients recover from critical illness [69].
- *Morbidity.* ICU survivors are much more likely than the general population to be diagnosed with a new chronic illness in the year after their critical illness, including diabetes, heart disease, and chronic obstructive pulmonary disease; ICU survivors without pre-existing chronic conditions were five-fold more likely to develop a new chronic condition [70]. Where chronic conditions emerge, early screening, diagnosis, and treatment may improve outcomes.
- *Mortality.* Taylor et al. showed a reduction in morbidity and mortality among patients who received recommended postsepsis care; although implementation of all recommended care was uncommon, the more elements of a postsepsis bundle received, the better the patient outcome [71]. In comparison to less at risk populations, assessing the impact of a post-ICU intervention on mortality is a reasonable goal: more than one in five ICU survivors die within a year of their critical illness, and most of these deaths occur within 90 days of ICU discharge [72].
- *Patient satisfaction*. Many health centers depend on patient satisfaction to ensure loyalty to a health care system, and patient satisfaction has been used to rate hospitals, gauge quality, and compensate clinicians. In the Collaborative Assessment of ICU Recovery Needs (CAIRN) study, patients and families highlighted attention to follow-up and the ability to stay connected to their inpatient teams as key components of recovering from critical illness [5]. Interventions designed to improve care transitions after hospitalization have been shown to increase patient satisfaction as well as patient and caregiver empowerment; bolstering these metrics may also result in decreased health care utilization [73].
- *Medical training.* If critical care succeeds in saving the life of a critically ill patient, ICU survivorship is a certain consequence. And yet, issues surrounding

ICU survivorship are little represented, if at all, in critical care training. A survey of ward clinicians in Australia found that fewer than half were familiar with the term PICS [74]. But, a majority of those surveyed – including physicians, nurses, and allied health professionals – reported that they would value education on the health concerns of ICU survivors in order to provide better patient care.

- *Quality improvement.* The potentially positive effects of following critically ill patients on quality improvement feedback back to ICU are understudied. As Walsh and Endacott noted in their commentary "Learning from aftercare to improve acute care," it makes economic sense to find interventions to improve recovery after the expensive investment in an ICU stay [75]. Haines et al. described five key mechanisms through which post-ICU activities can improve in-ICU care: identifying otherwise unseen targets for quality improvement or education, allowing clinicians to understand the patient experience, creating a new role for survivors, educating colleagues by inviting them to visit post-ICU programs, and improving morale [76]. With the onset of a respiratory pandemic creating many more ICU survivors, ICU follow-up clinics may be leveraged to expand knowledge of new diseases, as well as to refine and improve ICU care [77].
- *Burnout*. Clinician burnout is a significant problem in the critical care workforce. There is growing evidence linking clinician well-being and patient experience; recent data demonstrate that burnout is associated with lower quality care and patient satisfaction [78]. In a small study evaluating a nonclinical forum that brought together patients, caregivers, and staff after an ICU stay, clinicians reported that such engagement after the ICU allowed them to understand the patient journey better, and led them to feel valued and appreciated, "like I made a difference"[79]. Participants in the CAIRN study reported that ICU follow-up programs such as clinics offered the opportunity to close the feedback loop to ICU staff; communicating positive outcomes of challenging cases, for example, appeared to mitigate the risk of burnout for some clinicians [76]. A recurrent theme in that study was that work in the post-ICU setting addressed contemporary workforce issues such clinician burnout and compassion fatigue both directly (for those staffing the clinic) and indirectly (by providing feedback to others).

## Challenges and Opportunities

Despite interest in and enthusiasm for ICU follow-up clinics, barriers to wide dissemination and implementation of this care model remain. In the study evaluating implementation of the NICE guidelines discussed above, lack of funding was reported as the most frequent ($n$ = 149/164, 90%) and main barrier ($n$ = 99/156, 63.5%) to providing such post-ICU services. Insufficient resources ($n$ = 71/164, 43.3%) and lack of priority by the clinical management team ($n$ = 66/164, 40.2%) were also highly cited barriers to service delivery [15]. The CAIRN study further identified lack of collective identity of ICU survivorship, practice variation between clinicians, space issues, limited ability of clinicians to dedicate unfunded time, difficulty identifying appropriate patients, poor patient and family attendance, and hospital billing infrastructures as barriers to sustained operation of ICU follow-up clinics [16]. However, ten major themes were noted to facilitate ICU follow-up clinics, including working in interprofessional teams, humanizing ICU survivorship, aligning ICU follow-up clinics to organizational priorities, and participating in a learning collaborative with other clinics.

One major limitation to building care systems designed to manage long-term outcomes after critical illness is the paucity of data regarding these patients, their problems, and best way to treat them. In contrast to clinical trials conducted entirely in the hospital setting, long-term follow-up studies of critical illness survivors are hampered by high study attrition (because of death or loss to follow-up), data missingness, and a lack of standardized outcome [80]. And yet, this too, is an opportunity [81] and a mandate [82] as the critical care community develops and resources research priorities.

In conclusion, the ICU follow-up clinic is a potential model of care to support recovery for survivors of critical illness and their families. The benefits and impacts of ICU follow-up clinics deserve further study.

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# Chapter 13
# Transitioning towards the Mobile ICU

**Yameena T. Jawed, Sophia Wang, and Babar A. Khan**

## Introduction

In 2004, it was estimated that there were 13–20 million mechanically ventilated patients, 1.2–5.5 million patients with ARDS and 15–19 million patients with sepsis worldwide [1]. More than 5.7 million patients are admitted to the intensive care unit (ICU) annually in the United States [2]. With the recent advances in critical care, the number of ICU survivors has increased over the past two decades and is expected to continue to grow in coming years. Nevertheless, the mortality rate for ICU survivors at 1 year is still 20% [3]. Various factors such as clinical factors (such as age and comorbidities) and systemic factors (such as early discharge due to ICU bed shortage) may contribute to the increased long-term mortality of ICU survivors [4]. Evaluation of these factors at the time of ICU discharge may identify patients who are at higher risk for poorer clinical outcomes, and may benefit from closer

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follow-up after discharge. Common issues which affect ICU survivors include neuromyopathy, depression, anxiety, functional impairment, sleep disturbance, and post-traumatic stress disorder (PTSD), collectively described as post-intensive care syndrome (PICS). The prevalence of depression and anxiety ranges from 17% to 48% [5, 6]. The prevalence of PTSD is 19–22% ten years after ICU hospitalization, and can be as high as 44% in patients with Acute Respiratory Distress Syndrome (ARDS) [7, 8]. Cognitive impairment can affect up to 79% of ICU survivors at 1 months and 71% at 1 year [9]. Functional disability in PICS is also common and persistent as well. At a median time of 6 years after ICU discharge, 23.9% of the survivors of acute respiratory distress syndrome (ARDS) show cognitive impairments in various tasks assessing attention skills. Disability is found in 41.3% of the patients [10]. These symptoms make it difficult for ICU survivors to resume their prehospitalization lives and result in significant long-term health and financial burden.

The term post-intensive care syndrome-family (PICS-F) was coined by the task force of SCCM in 2010 to address the cluster of complications experienced by family members of ICU survivors. It describes the psychological impact of ICU hospitalization and post-ICU recovery on family members and other caregivers. Prevalence rates of psychiatric symptoms in family members range from 15–24% for anxiety, 36% for depression, and 35–57% for PTSD 6 months after hospitalization [11]. These caregivers often find themselves with a long-term burden of psychological symptoms. This leads to high acute care utilization and preventable rehospitalizations. Furthermore, ICU survivors and their families find it challenging to keep up with the multitude of follow-up appointments after discharge [12]. There is a need to address these long-term complications and implement an accessible multidisciplinary model of care for ICU survivors and for their family members to improve their function and reduce acute health care utilization, most notably emergency room visits and rehospitalizations.

## Post-ICU Clinics and Services

Follow-up services for ICU survivors specifically address their various health needs in order to reduce the long-term physical, psychological, and social problems [13]. The National Institute for Health and Care Excellence (NICE) guidelines recommend starting preventative measures in the ICU and performing a multidisciplinary assessment 2–3 months after ICU discharge [14]. These services are a relatively recent development in healthcare, and practice guidelines for these services have yet to be developed. Possible forms include informal meetings or organized clinic appointments which are led by a physician or nurse, performed face to face or remotely, standardized assessments, or a customized approach based on patient's profile. Since 1993, 80 ICU survivor clinics have been created in the U.K [15]. Universally, different countries have focused on different programs, including physical rehabilitation and nurse-led ICU clinics in United Kingdom, patient-led initiatives like diaries in Scandinavian countries, and home-based rehabilitation [16]. There are reportedly close to 16 ICU survivor clinics in the United States [17]. We will give an overview of the working model of two of these clinics.

The first ICU survivor clinic in the US, the Critical Care Recovery Center (CCRC) affiliated with Indiana University, was created in 2011 [18]. CCRC was established with the primary aim to maximize cognitive, physical, and psychological recovery following hospitalization for a critical illness. Other goals of the CCRC include addressing caregiver stress, improving the quality of transitional and rehabilitation care, and reducing inappropriate rehospitalizations and emergency room visits. The CCRC utilizes a collaborative care model for ICU survivors, which has been shown to be successful in older patients with dementia and late-life depression (Fig. 13.1). This model is based on the principles of the complex adaptive system, which is a network of semiautonomous, competing, and collaborating individuals who interact and coevolve with their surrounding environment in nonlinear ways. The social worker and clinic nurse act as recovery care coordinators and perform clinical assessment including a pre-CCRC visit (through phone or in person) to assess the needs of ICU survivors, followed by an initial visit, and four follow-up visits. The Healthy Aging Brain Center Monitor is the primary tool utilized at the CCRC to assess the cognitive, functional, and psychological symptoms occurring over the last 2 weeks and also to guide the recovery process [19]. It can be used to

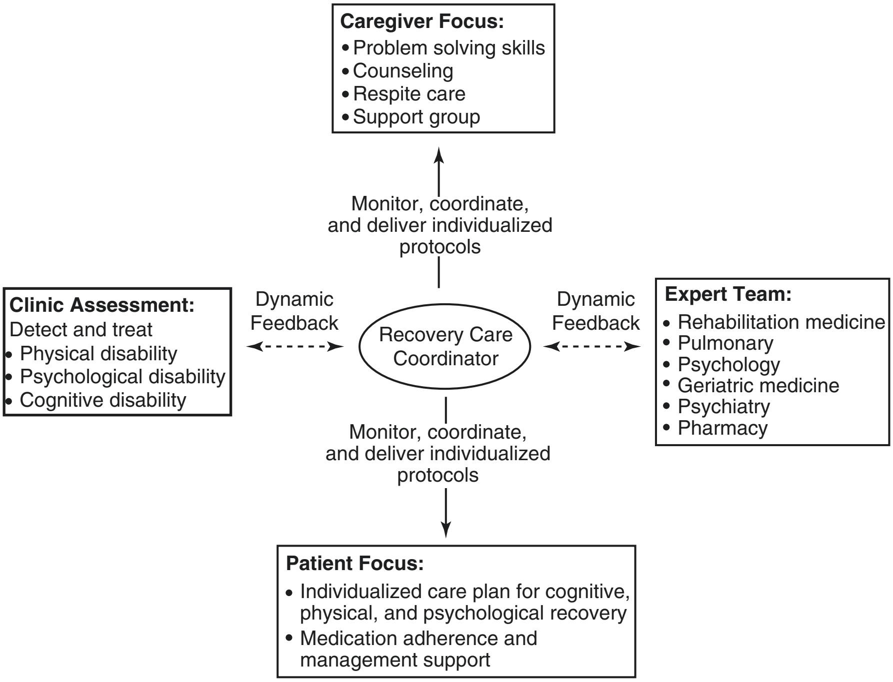

**Fig. 13.1** Collaborative Care Model of CCRC. (Reprinted Khan et al. [18], with permission from Author)

monitor symptoms of ICU survivors and their caregivers. A dynamic care plan incorporating patient and caregiver feedback at regular intervals informs the recovery process at the CCRC.

The ICU Recovery Center affiliated with Vanderbilt University Medical Center utilizes a similar interprofessional approach to evaluate and manage PICS and PICS-F. Their team consists of an intensive care physician, nurse practitioner (NP), a neuropsychologist, an intensive care pharmacist, and a case manager. They also offer support groups for ICU survivors and their families. A randomized controlled trial testing this intervention showed that the patients in the ICU recovery program appeared to experience a lower frequency of death or hospital readmission within 30 days and longer time to readmission [20]. The ten component intervention includes an introductory inpatient visit by ICU NP, distribution of educational brochures, and medication reconciliation by ICU pharmacist. After discharge, the ICU survivors are provided a phone number for direct access to ICU recovery clinic. In the recovery center, the ICU NP performs an evaluation; the ICU pharmacist reconciles medications; the psychologist performs a neuropsychological evaluation; the case manager screens the patient's living situation and addresses financial concerns; the intensive care physician reviews the multidisciplinary plan and performs 6-minute walk tests, spirometry, and smoking cessation, and makes appropriate referrals to the primary care physician (PCP) and subspecialty providers.

## Mobile ICU Recovery

Initial evidence suggests that well-designed transitional care services, such as those being offered by these post-ICU clinics, may reduce mortality and use of acute care resources. These transitional care services include active follow-up for at least 6 months after discharge, close monitoring through telephone calls, and multidisciplinary care coordination. This coordination includes medication reconciliation with a pharmacist, patient education, and promoting patient and family participation in care. However, limited access to these recovery clinics can be a major barrier to implementation of these follow-up clinics [21]. Often times, the caregiver finds it too challenging to bring the sick family member to an in-person clinic and may be faced with time constraints and financial burden. Consolidating these transitional services through a delivery system such as home health services may provide continuity of care, improve patient's quality of life, and reduce mortality [22].

This model is being tested in a randomized controlled trial of a mobile multidisciplinary intervention (m-CCRP) led by a nurse care coordinator.The goal of the program is to utilize a mobile care coordinator to improve the quality of life of patients who survived an episode of acute respiratory failure requiring mechanical ventilation by maximizing their cognitive, physical, and psychological recovery (Fig. 13.2). The care coordinator brings the intervention to the patient, irrespective of the patient's physical location and is supported by an interdisciplinary team of a

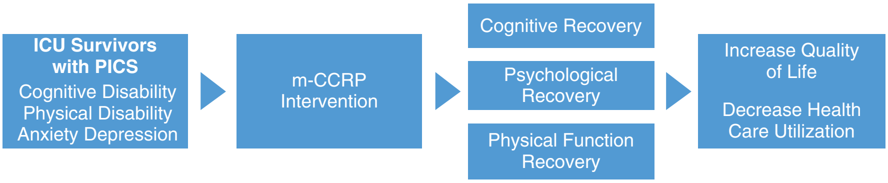

**Fig. 13.2** Conceptual model of mCCRP. (Reprinted from Wang et al. [15], with permission from author)

critical care physician, a geriatrician, an ICU nurse, and a psychologist, with input from other consultants as needed. The intervention consists of a visit from the care coordinator at 1 week postdischarge, followed by bimonthly visits for the 6 months and then monthly visits for 12 months. During these visits, a needs assessment of the patient and the caregiver is conducted, the medication list is reviewed, and individualized care plans set up, which includes referrals to specialists as needed. These care plans address cognition, physical function, personal care, mobility, sleep disturbance, depression, anxiety, agitation or aggression, delusions or hallucinations, caregiver stress/physical health, driving safety, nutrition, and medication adherence. The control group, on the other hand receives printed educational materials, telephone inquiries about mobility and chronic conditions, and has access to a provided ICU survival guide to connect to resources if needed. A collaborative critical care recovery program like m-CCRP offers comprehensive personalized care based on the unique needs of ICU survivors [23].

Another form of support mechanism for ICU survivors is peer support models, which are being investigated by a group of investigators across United States, United Kingdom, and Australia. Peer support is the "process of providing empathy, offering advice, and sharing stories between ICU survivors. It is founded on the principles that both taking and giving support can be healing, if done with mutual respect"[24]. In 2016, the SCCM sponsored the creation of a national collaborative network of ICU survivor clinics, known as the Thrive Post-ICU Clinic Peer Collaborative. This network included 17 sites from the three countries. The six generic models of support are community-based, psychologist-led outpatient, models-based within ICU follow-up clinics, online, groups-based within ICU, and peer mentor models. These models have not been formally evaluated, so their efficacy is not yet known. Common barriers to implementation include recruitment to groups, personnel input and training, sustainability and funding, risk management, and outcome measurements of success. The investigators concluded that future research around peer support in critical care should focus on three key areas: optimization of recruitment for programs, the development of effective and appropriate outcome measures for both patients and healthcare providers, and finally, the efficacy of each particular model.

Mobile ICU recovery programs can also be designed to focus on certain clinical problems in order to deliver a more personalized care to the high-risk population. Cognitive impairment is a major concern of caregivers [25]. A trial was designed to improve ICU-acquired cognitive impairment among the elderly population by combining cognition and physical exercise [26]. The intervention includes the use of computers and broadband Internet to deliver the physical exercise and cognitive training to older ICU survivors in their homes using trained coaches via video conference. This approach removes the burden of keeping multiple appointments from the caregiver and patient. Patients 50 years and older who screen positive on the CAM-ICU and survive the ICU stay are recruited within 48 hours of their anticipated hospital discharge. A baseline assessment is performed within 2 weeks of hospital discharge using various tools before patients are randomized to four groups of various combinations of cognitive training and physical exercise. Secondary outcomes include assessing the effect of cognitive and physical exercise on physical function, anxiety, depression, quality of life, and biomarkers. Outcome assessments are performed at 3 and 6 months. The approach to deliver these trainings through the internet has the potential for widespread dissemination of this modality.

## Post-intensive Care Syndrome-Family (PICS-F)

Critical illness can have long-term consequences for the family members and caregivers of ICU survivors. PICS-F has been associated with certain risk factors such as female gender, younger age of patient, lower education level, spouse of patient, previous history of mental health disorder, and family history of mental health disorder. ICU-related risk factors are near death experiences, unexpected or sudden patient illness, anxiety and depression about the ICU hospitalization, and poor communication between family members and ICU physicians [27]. Prevention strategies include optimization of communication and screening family members with mentioned risk factors for timely intervention. Family members accompanying the ICU survivors can be screened in post-ICU clinics and support provided to alleviate caregiver burden.

ICU diaries and educational materials can help in addressing adverse psychological outcomes among family members [28]. A pilot study was performed to prevent PICS and PICS-F in patients who had been intubated for more than 24 hours with or without delirium. The investigators implemented a program which included an 18 page ICU diary with entries from the nurse, physician and family, an educational brochure, and video and polaroid camera for pictures for diary. Patients took the diaries with them when they were transferred to a hospital floor or discharged from the hospital. This intervention was very well received by the staff and patients and their family. Furthermore, it served as a source of inspiration for ICU survivors and their family. Post-ICU clinic visits are an opportunity to revisit these ICU diaries and educate the ICU survivors and their family members about the biopsychosocial consequences that follow critical illness. ICU diaries can be used to develop a personalized plan to address the long-term consequences of critical illness. Postdischarge clinic visits and support groups can assist in unique short-term and long-term needs assessment for professional referrals.

It is clear that our current healthcare system lacks the support structure to improve family health and adaptation to caregiving roles. Aging ICU survivors, who have increased rates of cognitive and physical impairment, can have "high needs" for care giving. Geriatric psychiatrists may be able to play a key role in creating guidelines for clinical care of PICS-F and in helping provide a special emphasis on the needs of older caregivers with PICS-F. Four major recommendations shown to improve both patient and family outcomes include the creation of "open" ICUs, family witnessing of resuscitation efforts, ICU diaries, and proactive engagement of family members in patients' care [12]. The SCCM/American College of Critical Care Medicine guidelines recommend that the ICU staff be educated on assessing the families' need, update the families frequently through different means, and actively involve them in medical decision making.The ICU diaries represent one possible promising intervention, but more work is needed to address this challenge in critical care medicine.

Enhancing the recovery of ICU survivors requires a multidimensional and multidisciplinary approach which is sustainable, widely applicable in different settings, accessible, and mobile. The implementation processes can be tailored based on the culture of the specific health care system. The first step is to increase awareness about PICS and PICS-F amongst inpatient and outpatient providers, the ICU survivors, and their families. Prevention of PICS begins from early stages of an ICU admission, with the providers employing delirium preventive strategies including medication and environmental changes, practicing psychotropic stewardship in older ICU survivors, open communication with families, distributing ICU diaries, and educational material. Educational component should also include information about chronic disease designed to enhance knowledge and self-management skills. This can be informal, patient led, through ICU diaries and dialogue or can be more organized with involvement of NP, RN, and MD. There should be involvement of a pharmacist to improve treatment adherence and adjust medications. ICU nurses taking care of patients and families at high risk of developing PICS should be prompted to place a referral to the recovery clinic (where they exist).

## Integrating Primary Care Physicians in ICU Recovery

Despite the increase in the number of ICU survivor clinics, the majority of this population follows up with their primary care provider postdischarge. If this followup is in a community setting, there should be an accurate and adequate patient hand off inorder to prevent potential information loss. This is often done in the form of a discharge summary, although direct communication may be more appropriate in certain conditions given the complex nature of critical illness. The inpatient care to primary care transition poses a number of challenges, as this transition is frequently indirect, with the patient spending some time in rehab before transitioning home. Many critical illnesses also require input from consulting providers which may further complicate the role of primary care providers, who are expected to assess the patient's follow-up needs from the discharge summary and coordinate care across a range of providers [29]. Referral to a specialized post-ICU clinic, when available, may facilitate this process. A validated screening tool for PICS is needed for appropriate diagnosis and referral to the recovery clinics, such as the quick, easy to use Healthy Aging Brain Care Monitor Self-Report (HABC-M SR) in patients with normal cognition or mild cognitive impairment [30]. This is a 27-item questionnaire used to evaluate symptoms from the cognitive, functional, and psychological domains during the last 2 weeks. This screening tool can be administered by a wide range of providers in a short time and can also be used to longitudinally following the patients. Screening caregivers for symptoms of PICS-F may include the administration of standardized screens for depression (such as the Patient Health Questionnaire-2), anxiety (such as the Generalized Anxiety Scale-7), and caregiver stress screens (such as the short version of the Zagit Caregiver Burden Scale). These screens can be performed over the phone or as part of the face to face visit at a post-ICU clinic to integrate care for patients and informal caregivers. Potential areas of study for PICS-F include differences in caregiver stress for older versus younger ICU survivors, algorithms to identify caregivers at high risk for PICS-F to deliver depression-focused psychotherapies, and family-based interventions to provide emotional support while in the hospital and after discharge. Some strategies which could be considered include standardized caregiver education during the ICU stay to help raise awareness of PICS and PICS-F in order to connect patients and caregivers to resources earlier and family debriefing visits during ICU rounds and upon ICU discharge. Others include education with providers to ensure timely referrals to post-ICU recovery services and standardized screening of PICS and PICS-F during posthospital visits.

## Conclusion

Given the multifaceted nature of PICS, post-ICU recovery clinics should be equipped to detect and manage the wide range of physical, cognitive, and psychological problems among ICU survivors and also provide psychoeducation and support to their families. This requires a comprehensive interdisciplinary team consisting of a critical care physician, an ICU nurse, pharmacist, physical therapist, case manager, and a psychologist. Counseling services and support groups should be available for caregivers. The multidisciplinary recovery plan should be personalized and frequently modified depending on the ICU survivor's needs. This requires close monitoring of patients through a combination of telephone and in-person follow-up. Innovative delivery systems such as telemedicine interventions, smartphone applications, and mobile ICU recovery teams should also be integrated into traditional clinic follow-up models for post-ICU care. These approaches may be able to help overcome barriers, such as frailty, inability for caregivers to take additional time off of work to accompany patients for appointments, and residence in rural areas, which have resulted in the relatively low attendance of ICU survivors in the traditional outpatient clinic care model.

The generalizability of critical care programs is also limited based on various factors, including local healthcare systems and provider availability. Potential pitfalls of these models of care include unnecessary utilization of services by ICU survivors and potential exacerbation of PTSD symptoms in certain vulnerable individuals. We should be aware of these concerns as models for post-ICU recovery are being developed.

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# Chapter 14
# Medication Management to Prevent and Mitigate Post-intensive Care Syndrome

**Antoinette B. Coe, Pamela MacTavish, and Joanna L. Stollings**

Post-intensive care syndrome (PICS) describes new or worsening impairments in physical, cognitive, or mental health status following critical illness and persisting beyond acute care hospitalization often resulting in recurrent hospitalizations. Physical impairments include both pulmonary dysfunction and neuromuscular weakness. Impairments in memory and executive functioning are examples of cognitive dysfunction. Mental health impairments include depression, post-traumatic stress disorder, and anxiety [1]. This chapter will discuss medications commonly used in the ICU that contribute to the development of PICS, medication problems in the post-ICU period, and best practices for medication management to mitigate medication problems in ICU survivors.

## Medication Management Strategies Used in the ICU that Contribute to PICS

The problem is that intensive care unit (ICU) medication strategies may impact long-term outcomes and clinical pharmacists are ideally placed within the health

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care team to help minimize the impact of these strategies, prevent, and treat PICS [2]. Of particular concern is the use of medications that contribute to delirium placing patients at higher risk of poor outcomes.

One medication management strategy linked to cognitive and physical impairment is intensive insulin therapy. However, studies are conflicting on the benefit of intensive insulin therapy and the potential negative effects of hypoglycemia. A retrospective study of 74 patients with acute respiratory distress syndrome (ARDS) found that a blood glucose value of 153.5 mg/dL or greater resulted in a 2.9 greater chance of developing cognitive impairment [3]. In contrast, a second retrospective case-control study of 37 surgical ICU patients with at least one episode of hypoglycemia found that cognitive impairment was higher in patients that had hypoglycemia compared to those without ($p < 0.01$) [4]. Intensive insulin therapy, defined as maintaining blood glucose levels between 80 and 100 mg/dl, in surgical ICU patients decreased neuropathy from 51.9% to 28.7%, and the prevalence of critical illness polyneuropathy (CIP) and critical illness myopathy (CIM) from 49% to 25% in surgical ICU patients ($p < 0.0001$) [5]. In medical ICU patients who had an ICU stay of at least 1 week, intensive insulin therapy also decreased CIP and CIM from 51% to 39% ($p = 0.02$) [6].

Increased mortality in the intensive insulin group (81–108 mg/dL) (27.5%) versus conventional glucose control (less than 180 mg/dL) (24.5%) was found in the NICE SUGAR study ($p = 0.02$) [7]. The Society for Critical Care Medicine (SCCM) guidelines for the use of an insulin infusion for the management of hyperglycemia in critically ill patients recommend that once a patient reaches a blood glucose of 150 mg/dL or greater, interventions should be initiated to maintain blood glucose less than 180 mg/dL [8].

Use of opiates for treatment of pain in critically ill patients has been associated with an increased risk of delirium in some studies [9–13] and a lower risk of delirium in others [9, 14]. The pain, agitation, and delirium (PAD) guidelines [15] state that all adult critically ill patients be routinely assessed for pain using numeric pain scale in verbal patients and either the Critical Care Pain Observation Tool or the Behavioral Pain Scale in nonverbal patients. Pain assessment in critically ill patients and appropriate medication management are imperative due to the risk for the development of delirium secondary to untreated pain. Delirium is a preventable adverse event associated with an increased risk of morbidity and mortality.

Sedatives and neuromuscular blockade are two other medication classes that can be optimized to prevent PICS. The Pain, Agitation/Sedation, Delirium, Immobility, and Sleep Disruption in adult patients in the ICU (PADIS) guidelines suggest using either propofol or dexmedetomidine over benzodiazepines for sedation in critically ill, mechanically ventilated adults [16]. Numerous studies have shown an association between benzodiazepines and the development of delirium [9, 14, 17–20]. Prolonged use of neuromuscular blockers should be minimized to avoid severe myopathy and ICU-acquired weakness [21, 22].

Corticosteroid use has been associated with delirium and physical impairment. A prospective cohort study of 520 mechanically ventilated adult patients with acute lung injury evaluated factors associated with the transition from a nondelirious, comatose state to delirium. Age 40–60 years old and age greater than 60 years were both independently associated with the transition to delirium as compared to patients younger than 40 years of age. Administration of any systemic corticosteroids in the prior 24 hours was also independently associated with the transition to delirium [23]. A prospective cohort study of 3 MICUs and 2 SICUs found steroids as a predictor of ICU-acquired weakness (OR, 14.9, 95% CI: 3.2–69.8) [24]. A second prospective cohort study of patients with acute respiratory distress syndrome (ARDS) found that the absence of steroids was associated with better functional status at 1-year follow-up [25].

A further drug class which has an association with delirium is anticholinergics or medications with anticholinergic side effects. A prospective cohort study of 1112 patients without a neurological disorder or another condition that would alter delirium assessments admitted to the ICU for at least 24 hours was conducted to determine the effects of anticholinergic exposure on development of delirium. The Anticholinergic Drug Scale was calculated for each medication based on anticholinergic activity and dose administered. A one-unit increase in the Anticholinergic Drug Scale resulted in a nonsignificant increase in the probability of delirium occurring the next day (OR, 1.05, 95% CI: 0.99–1.10). Neither age (OR, 1.02, 95% CI: (1.01–1.02)) nor the presence of acute systemic inflammation (OR, 1.37, 95% CI: 1.13–1.65) modified this relationship [26].

Antimicrobials, in particular 4th generation cephalosporins, are thought to be associated with delirium. A prospective cohort study of 418 ICU patients was conducted to determine the association between antimicrobials and the transition to delirium. Delirium occurred in 308 (74%) patients exposed to antimicrobials. In this study, only 1st-3rd generation cephalosporins were associated with the transition to delirium (GEE OR = 1.96, 95% CI: 1.04–3.69, $p = 0.036$) [27].

Constipation is another risk factor for delirium. A prospective observational cohort study of 1052 ICU patients was conducted to evaluate the effects of constipation on delirium. Delay in passage of stool was associated with delirium (HR = 1.14, 95% CI: 1.06–1.12) [28]. Clinical pharmacists can play a role on the ICU team to suggest appropriate medications for constipation.

The Society of Critical Care Medicine recommends implementing the ABCDEF bundle (A, assess, prevent, and manage pain; B, both spontaneous awakening and spontaneous breathing trials; C, choice of analgesic and sedation; D, delirium: assess, prevent, and manage; E, early mobility and exercise; and F, family engagement) to align and coordinate care using an interprofessional approach. A prospective, multicenter, cohort study from 68 ICUs during a 20-month collection period indicated that performance of the complete ABCDEF bundle was associated with a lower likelihood of death within 7 days (HR 0.32; 95% CI: 0.17–0.62), next-day mechanical ventilation (OR 0.28; 95% CI:0.22–0.36), coma (OR 0.35; 95% CI: 0.22–0.56), delirium (OR 0.60; 95% CI: 0.49–0.72), physical restraint use (OR 0.37; 95% CI: 0.30–0.46), ICU readmission (OR 0.54; 95% CI:0.37–0.79), and discharge to a facility other than home (OR 0.64; 95% CI: 0.51–0.80). There was a dose response in between higher proportional bundle performance and improvement in each clinical outcome ($p < 0.002$). As bundle performance increased, pain was more commonly reported ($p = 0.0001$). This was most likely observed since patients were more awake [29] and indicates a role for medication management that addresses pain management and assessment of medications associated with delirium.

The 2018 PADIS guidelines suggest not using an atypical antipsychotic, haloperidol, or a statin to treat subsyndromal delirium or delirium [16]. The Modifying the Impact of the ICU-Associated Neurological Dysfunction-USA (MIND USA) study is a multicenter, randomized, placebo-controlled study of 566 patients that showed that haloperidol and ziprasidone did not reduce delirium, time on the ventilator, ICU or hospital length of stay, or death compared with placebo [30]. However, numerous surveys have shown that prescribers use haloperidol or atypical antipsychotics for the treatment of delirium in the ICU [31].

## Medication Problems in the Post-ICU Period

Medications problems are common in the post-ICU period. Often chronic medications temporarily discontinued during critical illness are not restarted and acute medications specific to the ICU are inappropriately continued after discharge [32, 33]. In addition, ICU survivors experience care transitions during their hospital stay and recovery, for example from the ICU to a medical ward, or from the hospital to the patient's primary care provider. Adverse Drug Events (ADEs) are at greater risk of occurring at these transitions of care if communication of medication changes is suboptimal [32]. ADEs have been associated with an increase in hospital length of stay, mortality, and increased healthcare costs [33, 34]. In a recent qualitative study of ICU survivors who had experienced an early unplanned hospital readmission, polypharmacy and medication-related problems were considered by some patients and their caregivers to have contributed to their readmission [35].

Antipsychotics are of particular concern for potentially inappropriate continuation in ICU survivors. A single-center, prospective cohort study of 172 ICU survivors found that 42 (24%) patients were prescribed an antipsychotic at discharge [34]. Multiple studies have shown the continuation of antipsychotics at hospital discharge following an ICU admission [35–39]. Ventricular arrhythmias, excess sedation, akathisia, and hypotension are all risk factors associated with the use of antipsychotics [40]. Additionally, the use of atypical antipsychotics was associated with an increased risk of death compared with nonuse in elderly patients with dementia in a population-based, retrospective cohort study [41]. Mismanagement of patient's home psychiatric and pain medications may also an impact on patient outcomes. A multicenter prospective study of 183 ICU survivors followed up 4–12 weeks after hospital discharge found that 32.8% of the medication-related problems identified were related to neurological medicines with almost half of these problems related to medicines patients were prescribed before admission to ICU [42].

Following an ICU admission, stress ulcer prophylaxis using proton pump inhibitors or histamine-2 receptor blockers is commonly continued. Quality improvement initiatives have been developed to decrease this practice. Numerous studies have documented the inappropriate continuation of acid suppressive therapy at hospital discharge following ICU stay [43–46]. The following complications associated with proton pump inhibitor use, hospital-acquired *Clostridium difficile* infection, pneumonia, hip fracture, and dementia, emphasize the importance of appropriate stewardship of these agents [47–51].

Patients are frequently exposed to opiods in the ICU and along with the high incidence of pain experienced by ICU survivors, it is likely that patients may continue to be prescribed opioids. There are limited studies examining the chronic use of opioids in ICU survivors. A multicentre study examining medication-related problems in 183 ICU survivors 4–12 weeks following hospital discharge found the number of patients prescribed a regular opioid increased from 22.4% to 38.7%, an absolute increase of 16.3% (95% CI, 9.8–22.8%; $p < 0.001$) [42]. Another study investigated opioid use in ICU survivors with surgical and nonsurgical diagnoses. They identified opioid use in 12.2% of patients at hospital discharge and this proportion fell to 4.4% at 48 months. No difference was found regarding chronic opioid use between medical and surgical patients; however, chronic opioid use prior to ICU admission and length of hospital stay were associated with postdischarge chronic opioid use [52].

## Solutions to Medication Problems in the Post-ICU Period

Several processes of care can help to mitigate medication errors and problems in the post-ICU period, including during care transitions. A key process shown to reduce medication errors at transitions of care is Medicine Reconciliation. Medicine Reconciliation has been defined by the Institute for Healthcare Improvement (IHI) as “the process of identifying the most accurate list of a patient’s current medicines—including the name, dosage, frequency, and route—and comparing them to the current list, recognizing discrepancies, and documenting any changes, thus resulting in a complete list of medications, accurately communicated.” Medicine Reconciliation has been shown to reduce medication errors in patients discharged from the ICU [36].

Many ICU survivors would benefit from a medication review at each transition of care to ensure appropriate and optimal medication therapy. A single-center study of 120 older adult ICU survivors evaluated the frequency of prescribed potentially inappropriate medications (PIMs) and actually inappropriate medications (AIMs). Medications were identified at five points during the hospital stay: admission, ward admission, ICU admission, ICU discharge, and hospital discharge. Opioids, anticholinergic medications, antidepressants, and drugs causing orthostasis were the most common categories of PIMs identified at hospital discharge. Thirty-six percent

**Table 14.1** Five Steps to Deprescribing

| |
|---|
| 1. Determine that each medication has an appropriate indication |
| 2. When determining the number of medications that should be discontinued, the overall potential harm of each of the medications should be considered |
| 3. Determine if each individual drug should be discontinued |
| 4. Prioritize which medications should be discontinued first |
| 5. Start and monitor a drug discontinuation plan |

of these PIMs were considered AIMs. Anticholinergics (55%), nonbenzodiazepine hypnotics (67%), benzodiazepines (67%), atypical antipsychotics (71%), and muscle relaxants (100%) were the PIM categories at hospital discharge with the highest positive predictive values for being AIMs. The number of discharge PIMs was independently predicted by the number of preadmission PIMs ($p < 0.001$), discharge to somewhere other than home ($p = 0.03$), and discharge from a surgical service ($p < 0.001$). Approximately, two-thirds of AIMs were initiated in the ICU [53].

Another medication management solution to mitigate potentially inappropriate medication use is deprescribing. Deprescribing is defined as tapering or stopping medications to reduce polypharmacy [50]. The following 5 step protocol for deprescribing has been recommended (Table 14.1). In the ICU, deprescribing can be futher enhanced by determining if the medication has a current indication, such as stress ulcer prophylaxis, which is no longer needed in a nonintubated patient without other risk factors [54]. After the ICU, deprescribing can be included as part of a comprehensive medication review.

A comprehensive medication review after discharge, often conducted by a pharmacist, is another medication management strategy to decrease polypharmacy and optimize medication use in ICU survivors. An outpatient comprehensive medication review includes medication reconciliation, a complete medication review for appropriateness, drug-drug and drug-disease interactions, risk versus benefit, cost concerns, and adherence problems. The comprehensive medication review includes development of a plan to resolve medication problems and patient concerns with the healthcare team, provision of patient education, and referral for other services if needed [52]. To mitigate medication problems after ICU survivors' transition home, a medication review is clearly indicated [2, 55] including a review for inappropriate continuation of acute medications at discharge [33].

Additionally, medication reviews in ICU survivors should include an assessment of chronic medications withheld during the patient's hospital stay with a plan to restart medications to avoid inapproproate discontinuation. One large population-based Canadian cohort study of 396,380 patients evaluated hospital and outpatient medication records with prescriptions from at least one of five of the following groups: (1) statins, (2) antiplatelet/anticoagulant agents, (3) levothyroxine, (4) respiratory inhalers, and (5) gastric acid-suppressing drugs. Those admitted to a hospital with or without an ICU stay were more likely to have medications discontinued compared with control patients [32]. There was a higher risk of medication discontinuation in all medication groups in patients hospitalized with an ICU

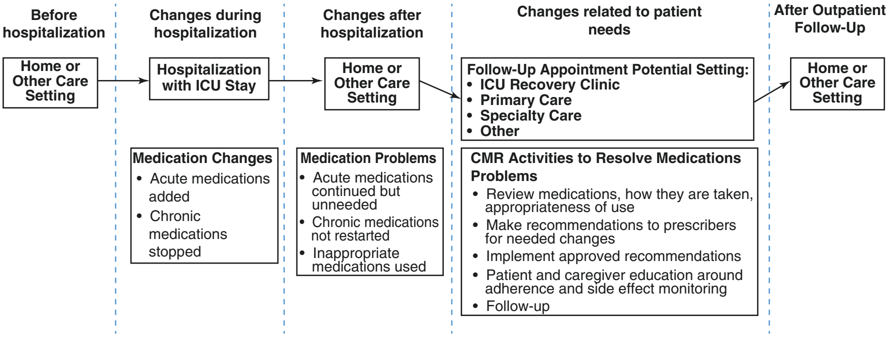

**Fig. 14.1** Conceptual model of care transition medication changes and problems that occur in critical illness survivors: a need for comprehensive medication reviews (CMR)

admission than in patients hospitalized without an ICU admission with the exception of respiratory inhalers. These medication discontinuations can have significant impact on patient outcomes and subsequent healthcare utilization. The composite outcome of death, hospitalization, and emergency department visit up to 1 year after hospital discharge in all study patients was higher in patients in whom a statin or antiplatelet or anticoagulant was stopped [32].

A proposed conceptual model for medication problems during transitions of care and the role of comprehensive medication reviews in ICU survivors are provided in Fig. 14.1. Several settings exist to address medication problems and polypharmacy in patients that remain after discharge from a hospitalization with an ICU stay.

One potential setting to improve medication management in ICU survivors is ICU recovery clinic. ICU recovery clinics are an increasingly available outpatient, interprofessional innovation designed to help ICU survivors and their caregivers with lasting complications, including medication-related problems that remain after the transition to home [2, 55–57]. ICU recovery clinics are often supported by a team of interdisciplinary experts, such as physicians, pharmacists, nurses, social workers, physical, respiratory, and occupational therapists, to address all of the lasting complications and PICS that an ICU survivor and their caregivers may experience [56]. The addition of a clinical pharmacist to address medication problems in ICU recovery clinics can support the care team.

For example, in a prospective, observational cohort study of all outpatient appointments (n = 62) in one tertiary care's ICU recovery center, pharmacist-provided comprehensive medication reviews led to a median of 4 interventions per ICU survivor (interquartile range 2–5), with one-third of patients having a medication stopped or started [55]. Additionally, the pharmacist identified adverse drug events in almost 1 in 5 patients and provided both influenza (23% of patients) and pneumococcal (4% of patients) vaccines for preventative health measures.

Another study from an integrated health system's post-ICU follow-up clinic included patients who were evaluated by a pharmacist (*n* = 47). The pharmacist provided a full medication review including medication reconciliation, assessment of medication appropriateness and adherence, and identification of medication-related problems. The post-ICU clinic pharmacist identified at least one medication problem in over 80% of patients and in almost 19% of medications reviewed [57]. In addition, a survey of an international expert panel of ICU recovery clinic pharmacists identified that the pharmacists perceived a need for medication education, the presence of medication adherence problems, medication side-effects, subtherapeutic medication dosages, medication use without an indication, failure to receive medications after discharge, and need for preventative health measures (e.g., influenza or pneumococcal vaccine) in the ICU survivors from their clinics [56].

Although ICU recovery clinics may be the ideal interdisciplinary setting to optimize medication management in ICU survivors, they may not be available in all areas. Other settings, such as primary care and specialty care (e.g., geriatrics), see ICU survivors and their caregivers for follow-up after hospitalizations and will need to fill this gap. For example, in the United States, older adults with Medicare government insurance are eligible for Transitional Care Management visits provided by a physician supported by team members to coordinate care within 7 or 14 days after an inpatient discharge. Transitional Care Management visits include medication reconciliation but may not include a comprehensive medication review. Transitional Care Management visits have reduced readmissions, costs, and mortality; however, completion rates remain low [58, 59].

An additional benefit for older adults in the United Sates with Medicare prescription drug (Part D) insurance is Medicare Part D Medication Therapy Management programs. These programs include an annual comprehensive medication review and targeted medication reviews if the beneficiary meets certain eligibility requirements. Current eligibility criteria are having multiple chronic diseases, taking multiple covered medications, and meeting an annual drug cost threshold [60]. Comprehensive medication reviews are effective in reducing medication problems and improving medication appropriateness in older adults [61–64], but have not been studied in ICU survivors nor are they required after a transition of care. Policy changes may be warranted to cover comprehensive medication reviews and other services in ICU survivors, similar to the National Institute for Health and Care Excellence (NICE) guidelines. The NICE guidelines recommend that adults who have stayed in an ICU for greater than 4 days have a medical review within 2–3 months following ICU discharge [65].

In summary, increased awareness and education of providers around the intricacies of medication problems in ICU survivors, such as medication discontinuation, inappropriate medication continuation, and use of medications that impair cognition, are suggested. Specific medication classes with increased use in an ICU population, such as intensive insulin therapy, neuromuscular blockers, anticholinergics, antimicrobials, opiates, benzodiazepines, antipsychotics, and corticosteroids impact physical and cognitive function along with mental health and can play a role in the development of PICS and lasting complications. The inclusion of a clinical pharmacist to address medication problems and support an interdisciplinary care team both within the ICU and in the outpatient setting (i.e., ICU recovery clinics) is warranted to ensure safe and effective medication use in critical illness survivors.

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# Chapter 15
# Palliative Care and End-of-Life Care Planning after Critical Illness

**Erin K. Kross**

## What Is Palliative Care?

Palliative care is both an interprofessional specialty and an approach to care by all clinicians that focuses on improving the quality of life of patients and their families who are facing problems associated with serious illness [1]. Palliative care is not limited only to the provision of end-of-life care, but rather aims to provide relief from pain and other distressing symptoms at all stages of disease. As such, palliative care can be provided alongside life-prolonging, restorative, or curative treatments in all stages of an illness with a philosophy that focuses on supporting the best possible quality of life for patients – and their families – as they face serious or life-threatening illness. In fact, palliative care is often optimally provided together with life-prolonging care in a coordinated approach that has been supported by major critical care professional societies [2–5].

It is important to distinguish palliative care as a broader principle that does, at times, include provision of high-quality end-of-life care. End-of-life care is a subset of palliative care that occurs during the last part of a patient's life, often at a time when life-prolonging therapy may no longer be effective or indicated. End-of-life care is typically reserved for the final days, weeks, or months of a patient's life. Palliative care includes end-of-life care, but also much more. This distinction is particularly important because palliative care is often misperceived by patients, family members, and clinicians alike as only being relevant for those who have made a decision to limit medical treatments or in the final days of life [6, 7].

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## Goals and Benefits of Palliative Care

Palliative care can address many domains of symptoms and needs that are important to those living with serious illness, including physical symptoms, psychological symptoms, spiritual needs, and social needs. Key domains that have been identified as important by patients and families of critically ill patients, and further described through expert consensus, include: (1) effective assessment and management of distressing symptoms including physical, psychological, and spiritual symptoms; (2) timely and sensitive communication to establish goals of care that are in line with a patient's values and preferences, taking into account a patient's condition and prognosis; (3) alignment of treatment with patient preferences; (4) attention to families' needs and concerns with provision of psychosocial, spiritual, and practical support; and (5) planning for care transitions and providing coordination of care across sites of care and through the trajectory of illness [8–11] (see Fig. 15.1).

**Fig. 15.1** Key domains of palliative care those are relevant and important to patients with critical illness and their families

Multiple studies across a range of serious illnesses have shown that palliative care services can improve patient symptoms and quality of life and lead to better patient and family satisfaction with care [12–15]. Palliative care also can lower costs by delivering care matched to patient and family preferences and needs, therefore potentially avoiding unnecessary or unwanted hospitalizations and interventions [16, 17]. There is even some evidence that in certain populations, including those with advanced lung cancer, palliative care may improve survival, though overall the data regarding survival benefit have been mixed [18–22].

Palliative care is becoming more commonly incorporated into the ICU setting, in both consultative and integrated models [23]. In this setting, palliative care services, and in particular promotion of key principles to improve communication in the ICU, have been shown to improve family emotional outcomes, improve family comprehension of diagnosis, prognosis and treatment, and reduce ICU length of stay and treatment intensity. Family satisfaction with decision-making in the ICU is improved with high quality communication, support for shared decision-making, and discussions of spiritual needs [24, 25], all of which are goals of palliative care services in the ICU. While evidence is building in support of the benefit of palliative care services during critical illness, less is known about palliative care needs and opportunities during recovery from critical illness. It is likely that many of the same needs and principles carry forward to post-ICU recovery.

## Primary Versus Specialty Palliative Care

While palliative care may be delivered by palliative care specialists who work alongside a patient's clinicians, palliative care may also be provided by clinicians who are not palliative care specialists. All clinicians who care for seriously ill patients, including those in the intensive care unit or in the critical care recovery space, may provide "basic" or "primary" palliative care [26]. This distinction between "primary" and "specialty" palliative care highlights that many aspects of palliative care should be within the skill set of all clinicians who care for seriously ill patients. These skills should include basic symptom management, routine discussions about goals of care, and managing transitions across the continuum of serious illness care. Primary palliative care is important because it can promote stronger primary clinician-patient relationships and reduce fragmentation of care [26]. Primary palliative care is also critical because across the globe, most patients with serious illness lack timely access to palliative care specialists. Even with overall expansion of palliative care services around the world, access remains variable and often quite limited [27].

While primary palliative care is important to extend the reach of palliative care principles to a larger population, there are other aspects of palliative care that may require the involvement of a palliative care specialist. These aspects often involve complex symptom management, difficult discussions about care goals, or transitions in care that involve conflict. Specialty palliative care is frequently delivered by an interprofessional team that can include physicians with specialty training in palliative care, nurses, social workers, pharmacists, nutritionists, spiritual care providers, and others.

## Relevance to Critical Care Survivors

While less is known about the role for palliative care services in recovery after critical illness, much is known about outcomes after critical illness that can lead to decreased health-related quality of life [28], frequent need for rehospitalization and ongoing medical care [29–32], and reduced long-term survival [33–35]. Many ICU survivors experience new or worsened impairments in cognition, mental health, and physical health, known as the post-intensive care syndrome (PICS) [36]. Family members may also experience adverse mental health outcomes after a loved one's critical illness, referred to as the post-intensive care syndrome for families (PICS-F) [37]. Given that the goals of palliative care include treatment of distressing symptoms, communication about goals of care, preparing for transitions in care, and supporting families, it seems clear that palliative care principles and services could provide benefit not only to patients who are critically ill but also those who survive their critical illness (Table 15.1).

**Table 15.1** Domains of palliative care related to symptoms and needs after critical illness

| Palliative care domain [10] | Post-intensive care opportunities |
|---|---|
| Assessment and management of distressing symptoms: Physical, psychological, spiritual | Comprehensive assessment of symptoms and treatment with multimodal therapies |
| Timely and sensitive communication to establish goals of care in line with a patient's values and preferences, taking into account condition and prognosis | Assess patient perspectives of illness, formally assess patient's values and preferences for future medical care; provide information on condition and prognosis, especially in vulnerable populations |
| Alignment of treatment with patient preferences | Help align treatment plans with patient values and preferences; complete advance directives if appropriate |
| Attention to families' needs and concerns including psychosocial, spiritual, and practical support | Comprehensive assessment of family needs and concerns; provide referrals or directed supportive care services |
| Planning for care transitions and providing coordination of care across sites of care and through trajectory of illness | Provide continuity of care across sites of care and help plan for transitions in care; shift to end-of-life care as appropriate |

## Palliative Care Needs in Specific Populations

While there are a number of challenges in the identification and definition of risk factors for the development of post-intensive care syndrome, risk factors are often categorized into pre-existing factors and intensive care unit (ICU) specific factors. Pre-existing factors that have been associated with PICS include those with pre-existing cognitive impairment, psychiatric illness, and comorbid conditions, while ICU specific factors are often related to acuity of illness, use and duration of mechanical ventilation, presence of acute delirium, and specific diagnoses including sepsis and acute respiratory distress syndrome. It is plausible that many of these same risk factors would lead to specific palliative care needs after critical illness; however, there have been few investigations into the specific palliative care needs of survivors of critical illness. To date, this has been assessed primarily in older adults including those with frailty, and in those with chronic critical illness [38–42].

Older adults (age ≥ 65 years) comprise almost half of all ICU admissions in the United States, have been receiving more intensive treatment over time, and are now more often surviving what previously were considered to be fatal critical illnesses [43, 44]. Generally, outcomes tend to be poor in this population, with about one-third of older adult survivors being discharged to postacute care facilities, nearly half requiring rehospitalization, and many dying within 6 months after critical illness [35, 45]. In one study which specifically examined the palliative care needs in a cohort of adults age ≥ 65 years who had their first ICU admission to a medical intensive care unit and survived to discharge to a postacute care facility, 88% were identified to have at least one palliative care need [38]. Factors that were identified and thought to indicate a potential need for palliative care services varied in frequency, and included: delirium or dementia (39%), supplemental oxygen use at discharge (37%), a preference to not be resuscitated (23%), chronic wounds (22%), and chaplain consultation as a marker for spiritual distress (17%). Less common factors suggestive of palliative care needs included use of noninvasive ventilation, prescription of specific medications including opioids and antipsychotics, and other characteristics suggesting an anticipated poor prognosis. Despite the high degree of needs identified in this cohort upon discharge from the hospital, only a small minority (3%) had received a palliative care consultation during hospitalization [38]. Similar to other studies, the 6-month mortality in this cohort was 40%, and 37% of participants were readmitted to the hospital at least once during the 1-year follow-up period. These findings support the notion that palliative care needs are likely present, especially in high-risk populations, and that older ICU survivors of critical illness might benefit from palliative care interventions not only in the ICU but also during the postcritical illness period.

Other populations that may be at particularly high risk for palliative care needs after critical illness are those with frailty. Frailty is a syndrome characterized by generalized vulnerability to stressors resulting from accumulation of physiologic deficits in multiple interrelated systems [46]. In a prospective cohort of patients aged 65 and older admitted to the medical ICU for acute respiratory failure, adverse symptoms were common in the week before hospital discharge, including fatigue, dyspnea, drowsiness, poor appetite, and nausea. Participants with frailty had higher emotional, physical, and total symptom distress scores than those who were not frail [39]. Further, this study found that these needs persist or worsen for a majority of patients during the month after hospital discharge. These findings add to the evidence that older adults have a high burden of unmet palliative care needs just before hospital discharge and that these needs persist over time. This raises the notion that, in addition to the more commonly reported and studied domains of PICS, there may be additional symptoms and signs that reflect unmet palliative care needs in these particularly high risk populations, and it is possible that these symptoms could interfere with overall functional recovery.

## Opportunities for Integration of Palliative Care into Post-ICU Recovery

### *Post-ICU Clinics*

Post-intensive care clinics have been introduced as a way to identify and support the specific needs of patients and families who survive critical illness. These clinics vary in structure and organization, but generally offer interdisciplinary care in the time after discharge following a critical illness in an effort to improve quality of life and functional recovery. Successful post-ICU recovery programs also provide continuity of care, help normalize and provide expectation management, provide internal and external validation of progress, and help reduce feelings of guilt or helplessness [47]. These clinics often have an interdisciplinary approach that mirrors the interdisciplinary approach of a palliative care team [10]. Many of the domains of a comprehensive palliative care assessment would likely be included in most post-ICU clinic assessments, including assessment of pain and physical symptoms, psychological symptoms, and cognitive symptoms [48]. Palliative care can also focus on domains may be less commonly addressed in post-ICU care, including illness understanding and care preferences (i.e., personal goals, expectations, understanding of illness trajectory), social and economic resources and needs of patients and caregivers, existential and spiritual concerns, and continuity and coordination of care across settings. There are many interdisciplinary professionals who make important contributions to post-ICU recovery work, and there may be value in adding palliative care specialists to the team. In settings where that are not possible, there are opportunities for other members of the team to embrace principles of primary palliative care to further meet the needs of patients and families.

## ***Community-Based Palliative Care Programs***

Outside of post-ICU clinics, there may be other opportunities for provision of specialty palliative care services in the community. Community-based palliative care programs can provide palliative care services within the home, within a nursing home, within a palliative care outpatient practice, or by embedding or integrating a palliative care team within an existing outpatient clinic. Community-based programs are most often run by hospitals or hospices, but are sometimes run by home health agencies, long-term care facilities, and office practices or clinics [49]. Clinic-based palliative care for patients with advanced illness is gaining in popularity as it has shown great promise for improving patient outcomes [50]. Outpatient palliative care clinics have been shown to lead to improvements in quality of life, reduction in health services utilization, and even potentially improved survival [18, 51, 52]. While many clinic-based palliative care programs are affiliated with oncology practices, there are many lessons that can be learned from the existing, successful programs who have built co-management services with palliative care and specialty care in the outpatient setting [53, 54].

## ***Communication Focused on Establishing Goals of Care and Aligning Treatment Plans***

Given the high morbidity and mortality of ICU survivors [29–34], the ICU recovery period provides an opportune time to have patients reflect on the care they have received, assess patient perspectives of their illness, formally assess patient values and preferences for future medical care, and provide information on their condition and prognosis in order to establish future goals of care. Little is known about the perspectives of ICU survivors on whether they would want to go through the process again, though in one cohort study of ICU survivors who were being weaned from prolonged mechanical ventilation at a long-term acute care hospital, when asked 6 months after discharged whether they would go through the process of mechanical ventilation again, the vast majority (85%) answered yes, while 8% said no, and 7% were unsure [55]. Compared with patients who would be willing to undergo mechanical ventilation again, those not willing had lower physical and mental summary scores on the SF-36 quality of life measure [55, 56]. Interestingly, in this cohort, only one-third of patients had unpleasant memories of their time on the ventilator, which may help explain why such a large proportion would be willing to undergo a further episode of prolonged ventilation. It is also important to note that this is a unique, and in some ways biased, sample given that the majority of the initial cohort had died by 6 months, and therefore the group of survivors asked this particular question likely do not reflect the broad experiences of survivors on the whole, including those who are earlier in their recovery course or more likely to die.

In any case, patients living with serious illness, including those recovering from critical illness, often face challenging treatment choices. High-quality discussions about what is important to patients can help promote good decision-making and patient-centered care. Understanding the patient's goals allows the clinician to align medical care plans with what is most important to the patient. There are many factors that affect decision-making about medical treatments, including disease extent and prognosis, but also an individual's values and preferences. While sometimes goals of care discussions have to happen urgently, as is the case in hospitalization or critical illness, these discussions tend to be most fruitful when they can occur earlier in the course of illness and continue over time. When this is the case, discussions often are more productive because they can focus on more than just goals for end-of-life care, but also about how the patient wants to live their life.

Goals of care discussions need to be approached with sensitivity and care. One recommended systematic approach is use of a talking map called REMAP [57]. REMAP describes a stepwise approach to discussing goals of care and includes five steps which reflect the key elements of goals of care conversation.

- Reframe – Place the current decision in the context of the clinical scenario. Start by assessing the patient's own perception of the clinical status and prognosis, and reframe as necessary.
- Expect emotion – Watch for emotional cues and attend to patients' emotional needs. It is important to name and acknowledge emotion, and use silence when appropriate.
- Map out the future – Start by identifying the patient's goals *prior* to recommending treatments. Ask what is most important to a patient, and if there are things that would be unacceptable.
- Align with values – Reflect back what the patient has said about their values. This demonstrates that the patient has been heard.
- Plan treatment that match values – It is often helpful to give a recommendation if one is clear after reflecting on the patient's goals.

## *Advance Care Planning*

The goal of advance care planning is to ensure that people receive medical care that is consistent with their values, goals, and preferences [58]. The process of advance care planning can help patients and their families think through particular approaches to follow if the patient's health declines. One goal is to help prepare the patient and their family to make the best possible "in the moment" decisions, recognizing that it is difficult to anticipate all possible scenarios in advance [59]. Documentation of advance care planning discussions is extremely important, especially when these discussions result in a specific, actionable medical treatment plan. At times, advance care planning can include completion of an advance directive where patients document their preferences for medical care and appoint a surrogate decision-maker. There are a number of types of advance directives, including living wills [60], durable powers of attorney for health care [61], physician orders for life-sustaining treatments [62], and other instruments. Each of these types of advance directives has advantages and limitations; appropriate use should be determined based on an individual patient's preferences and needs.

Advance care planning is important during post-ICU recovery, not only to ensure that future healthcare treatments are aligned with a patient's specific goals and values, but also because there may be potential benefit to family members. Family members of critically ill patients also can experience the post-intensive care syndrome [37] with adverse psychological symptoms including anxiety, acute stress, post-traumatic stress, depression, and complicated grief. In addition to opportunities to better support families during a critical illness – with frequent and effective communication – there are opportunities to better support surrogates in the post-ICU period. These including helping to better prepare them for future decision-making roles. Surrogate decision-makers often feel a high degree of burden and stress, and acting in the role of surrogate decision-maker has been shown to be associated with a substantial emotional burden that can last for months to years after the decision-making process [63, 64]. Nearly half of surrogates for critically ill patients have moderate or high levels of decisional conflict, and importantly, prior advance care planning has been shown to be associated with less decisional conflict among surrogates for critically ill patients [65]. In this way, advance care planning can be important not only to ensure that patient's get the medical care that they want, but also to relieve some of the responsibilities and potential conflicts for surrogate decision-makers.

## Summary

Palliative care is an approach to care that focuses on reducing symptoms and improving the quality of life of patients and their families when experiencing serious illness. While palliative care has become more integrated into critical care settings, there is opportunity to extend these services into the ICU recovery period as many patients and families have palliative care needs that extend for months or years after critical illness. In particular, palliative care principles around communication to establish goals-of-care, aligning treatments with patient preferences for future medical care, supporting families and helping plan, and coordinating care transitions are key principles that should be integrated into post-ICU care.

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# Chapter 16
# Home-Based Care for Survivors of Critical Illness

**Cassiano Teixeira and Regis Goulart Rosa**

## Home-Based Care

Home-based care is defined as any type of health service provided to patients directly at home with support from trained health care professionals [1].Home-based care aims to provide guidance, assistance, and social support for individuals with important health care needs to empower them to live as independently as possible in their own home environment [2].One important goal of home-based care interventions is to address the needs, values, and preferences of patients affected by multiple comorbidities, frailty, and disabilities, who usually require intensive medical management and rehabilitation or have difficulty accessing traditional facility-based care services. This model of care is feasible as a health policy, because it ensures cost-effectiveness while respecting the preferences of an increasing number of people to remain in their own homes rather than move to residential care facilities [3]. Nevertheless, home-based care interventions are not limited to the care of bedridden patients. Both patients and family caregivers are provided with guidance and psychological and social support aimed at improving treatment adherence, engagement in rehabilitation, prevention of complications, and quality of life.

Home-based care requires highly qualified professionals, since specific competencies, especially those related to interpersonal relationships, are necessary in order to effectively coordinate with patients, family members and caregivers, and multiprofessional teams [4]. It also demands autonomy, responsibility, and

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technical and scientific knowledge. Home-based care involves specific complex tasks that demand professional experience and home practice qualification.

A recent systematic review and meta-analysis of 20 randomized clinical trials assessing the effectiveness of hospital-initiated postdischarge interventions showed that home-based interventions, such as home visits and follow-up phone calls, were associated with lower rehospitalization rates [5]. Among postdischarge patients, two or more home visits were associated with a lower risk of hospital readmission compared with none (24% vs. 36%; odds ratio [OR], 0.6; 95% confidence interval [95% CI], 0.4–0.7). Similarly, two or more follow-up phone calls were associated with a lower risk of hospital readmission compared with none (OR, 0.7; 95% CI, 0.6–0.8). After controlling for follow-up duration, patient diagnosis, and exposure to discharge education, patients with the lowest risk of readmission were those exposed to multiple home visits and multiple follow-up phone calls (OR, 0.5; 95% CI, 0.4–0.7). Studies have also demonstrated the benefits of home-based interventions in specific contexts [6–8]. A randomized clinical trial of a home-based behavioral intervention involving patients with dementia and family caregivers showed less functional dependence, less dependence in instrumental activities of daily living, greater patient engagement, and greater caregiver well-being and confidence compared with controls at 4 months [6]. The home-based intervention included up to 12 home visits or phone contacts over 4 months by health professionals who assessed patient capabilities and deficits and trained families in home safety, task simplification, and stress reduction. Caregivers in the control group received phone calls and educational materials. Likewise, in a randomized clinical trial, a 10-session, home-based, multidisciplinary program in which occupational therapists, registered nurses, and home modifiers addressed self-identified functional goals by enhancing individual capacity and the home environment during home visits resulted in a substantial decrease in disability scores at 5 months among low-income community-dwelling older adults [7]. A systematic review and meta-analysis of 17 randomized clinical trials comparing the efficacy of home-based nonpharmacological interventions with usual care of patients with depression found that a combined, home-based, psychological, and exercise intervention was associated with improved depression scores and higher disease remission rates [8]. These results emphasize the effectiveness of home-based care for preventing unwanted outcomes in complex populations. Although evidence of effectiveness for home-based interventions in survivors of critical illness is scarce, it is plausible that this benefit may extend to patients recovering from critical illness as well.

## Why May Survivors of Critical Illness Require Home-Based Care?

The long-term morbidity and mortality of patients who survive acute critical illness is a reason for concern for critical care clinicians and policy makers [9, 10].The traditional focus of critical care on reducing short-term mortality has been challenged by the poor long-term outcomes of post-ICU patients. Current evidence shows reduced long-term survival in ICU survivors compared with the general population [11, 12]. Moreover, post-ICU patients often experience physical, cognitive, and psychological disabilities that may impair their quality of life and contribute to frequent hospital readmissions and increased use of health care resources [13–15].

About 15–20% of hospitalized Medicare patients are readmitted to the hospital within 30 days of discharge [16, 17], and these rates can reach up to 25–30% among patients recovering from sepsis [18]. Some authors have referred to this group as hospital-dependent [19]. Many contributing factors have been proposed, including the high burden of physical, cognitive, and psychological disabilities and comorbidities in this population, poor transition from hospital to outpatient care, lack of adequate medication reconciliation, and poor access to health services after discharge, such as timely postdischarge appointments with primary care physicians and specialists and specific rehabilitation programs for ICU survivors [20–24]. These factors may contribute to an increased risk of serious complications requiring in-hospital management, such as infections, exacerbation of chronic diseases, new organ dysfunctions, drug toxicities, and cardiovascular events [21]. Moreover, the pressure for shorter hospital stays and cost reductions has condensed the time and resources available for ICU clinicians and other hospital personnel to properly prepare patients and their caregivers for the transition from hospital to home. In this context, many survivors of critical illness encounter difficulties in self-management, resulting from either the impairment of their functional status or the lack of awareness of what to do and how to get help if their health worsens after discharge [23]. Caregivers are likewise infrequently prepared to manage the patient's prescribed treatments, lifestyle modifications and rehabilitation, or to recognize subtle changes in the patient's health status before the onset of overt symptomatology.

Post-ICU follow-up has been implemented in some settings to improve the long-term outcomes of critical illness survivors. Evidence suggests that post-ICU follow-up is a promising strategy to this end, but its proven benefits are still small and thus far mainly related to mental health outcomes (the most commonly studied outcomes to date) [25]. Interestingly, although the severity of patients' disabilities after critical illness is a plausible impediment to attending appointments, most studied post-ICU care models are mainly focused on facility-based follow-up, in which patients have to attend health facilities to benefit from rehabilitation programs. In one recent systematic review and meta-analysis of studies assessing the effects of post-ICU follow-up, only 11% of included studies implemented home-based care interventions [25]. Moreover, a study conducted in a middle-income setting showed that the burden of disability after critical illness was associated with the inability to attend clinic-based follow-up visits [26]. This finding suggests that the facility-based model may deprive the most disabled patients of appropriate care, thereby contributing to health inequalities in the post-ICU care setting. Alternative models,including home-based care, may be of great value to address the needs of this population. Close contact between clinicians and patients and their families and/or caregivers plays an important role in optimizing patient rehabilitation after critical illness and avoiding preventable complications by providing: (a) patient and caregiver education and guidance; (b) screening for post-ICU disabilities; (c) medication reconciliation; (d) development of personalized treatment and rehabilitation plans; (e) specialized care and social support; and (f) prevention of complications. Contact with the patient's home environment (via telehealth or face-to-face) will provide the clinician with opportunities to assess and address barriers to postdischarge rehabilitation that would otherwise remain undetected. Furthermore, for many patients, home visits help them develop a stronger connection with the clinician, which may promote a greater sense of trust between patients and providers and increase the likelihood of continued communication after discharge. A list of suitable home-care interventions for survivors of critical illness can be found in Table 16.1.

**Table 16.1** Suggested home-based care interventions for survivors of critical illness

| Intervention | Components |
|---|---|
| Goals of care discussion | Defining and establishing goals of care with patients and/or their surrogate decision makers to match home-based interventions with patient values and preferences. |
| Screening for disabilities | Physical disabilities: reduced physical functional status and/or ability to perform activities of daily living, muscle weakness, joint contracture, dysphagia, malnutrition, and compromised lung function.<br>Cognitive disabilities: deficits in memory, attention, mental processing speed, and problem solving.<br>Mental health disabilities (for both patient and family member): symptoms of anxiety, depression, and post-traumatic stress disorder. |
| Review and adjustment of long-term medications | Assessment of long-term medications to (1) discontinue treatments without ongoing indication or (2) adjust doses as needed based on body mass, renal, hepatic or cardiac function changes after critical illness. |
| Specialty referrals | Early referral to subspecialist follow-up based on screened disabilities (i.e., referral of a patient with dysphagia for speech therapy evaluation). |
| Individualized rehabilitation plan | Creation, maintenance or modification of a rehabilitation plan based on screened disabilities and patient and family needs. |
| Environment assessment and modification | Adapt or modify the home environment to facilitate physical rehabilitation and prevent falls. |
| Anticipatory guidance: "red flags" | Educate patients and family members regarding signs and symptoms that may indicate worsening condition and need for additional evaluation. |
| Education and engagement | Educate and engage patients and family members regarding post-ICU recovery, addressing concerns and values. |
| Preventative care | Prevention of infections (i.e., vaccination, family and patient education on risk factors), prevention of decompensation of chronic diseases (i.e., heart failure, renal failure or chronic obstructive pulmonary disease). |
| Palliative care | Introduce and offer palliative care (alone or combined with curative and/or rehabilitation interventions) to improve symptoms and quality of life. |

## The Brazilian Model of Home-Based Care

From a global perspective, home health care programs around the world share some similarities [27]. Except in the United States, these programs are typically publicly funded, comprehensive (offering postacute, supportive, and end-of-life home care in one program), and use need-based rather than income-based or risk-based eligibility criteria.

In Brazil, the "Better at Home Program" is a public home-based care program provided through the Brazilian Unified Health Care System that aims to: (1) promote the dehospitalization of stable patients, who may have their health care continued at home and whose level of care complexity is greater than that primary care is able to offer; (2) avoid hospitalization of patients referred from primary or emergency care settings; and (3) avoid hospital readmissions [28]. The program serves patients classified as levels AD2 and AD3 of care, according to the Home Care Ordinance of the Brazilian Ministry of Health (Table 16.2).

The "Better at Home Program" is suitable for people who have temporary or permanent difficulty leaving home in order to reach a health care facility, and for people who are in situations where home care is the most appropriate form of care for their needs. Home care aims to provide patients with care while keeping them close to their families, thus avoiding unnecessary hospitalizations and reducing the risk of infections while maintaining patients in contact with their loved ones in the comfort of their homes. Patients who need weekly or more frequent visits may be followed up by specific home care teams. Services are provided by multidisciplinary

**Table 16.2** Eligibility criteria for the Better at Home Program based on the Brazilian home care classification criteria

| AD2 criteria | AD3 criteria |
|---|---|
| Demand for more complex procedures that can be performed at home, such as:<br>Complex dressing and abscess drainage, among others;<br>Dependence on frequent monitoring of vital signs / unstable conditions;<br>Frequent and systematic need for less complex laboratory tests;<br>Patient and/or caregiver adaptation to the use of the tracheostomy device;<br>Patient adaptation to the use of orthoses/prostheses;<br>Patient adaptation to the use of probes and ostomy bags;<br>Postoperative home follow-up, as indicated by the surgical team;<br>Rehabilitation of people with permanent or transient disabilities who need frequent care until they are able to attend rehabilitation services;<br>Use of airway aspirator for bronchial hygiene;<br>Need for permanent or transient nutritional attention;<br>Frequent care in terminally ill patients/pain relief measures;<br>Need for intravenous or subcutaneous medication. | Existence of at least one of the situations accepted as inclusion criteria for care in AD2 modality and the need to use at least one of the following devices / procedures:<br>Invasive or noninvasive ventilatory support (continuous positive airway pressure [CPAP] or bilevel positive airway pressure [BIPAP]);<br>Peritoneal dialysis;<br>Paracentesis;<br>Use of total parenteral nutrition. |

teams consisting primarily of physicians, nurses, nurse technicians, physical therapists, and social workers. Other support personnel may also be included in the teams as necessary, such as speech therapists, dietitians, dentists, psychologists, occupational therapists, and pharmacists. Each team can follow, on average, 60 patients simultaneously. Home care teams are hired by state or city governments. The Unified Health Care System organizes the services for care delivery from Monday through Friday, with teams working 12 (twelve) hours per day, and ensures health care delivery on weekends and holidays by on-call teams.

## Conclusion

Survivors of critical illness may benefit from home-based care interventions, since the post-ICU period is often marked by disabilities that are long-lasting and associated with poor quality of life. Home-based interventions may improve the outcomes of critical illness survivors by improving their access to support and rehabilitation services. Additionally, home-based care interventions may improve patient and family caregiver outcomes by improving engagement, social and psychological support, and education.

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# Part III
# Community Reintegration

# Chapter 17
# Transitions to Primary Care

**Konrad Schmidt and Sabine Gehrke-Beck**

## Introduction

With an ageing population in developed countries and advances in critical care, more patients survive critical illness and are discharged from the Intensive Care Unit (ICU). Many of them do not go back to their previous health status and remain with long-term sequelae, both mental and physical, related to the critical illness and intensive care treatment [1, 2]. In the United Kingdom, a leader in postICU care, national guidelines dictate that patients with Post-intensive Care Syndrome (PICS) should have ongoing, long-term monitoring and therapy, even if evidence-based guidance for ICU follow-up interventions is limited [3].

After their ICU stay and hospital-based rehabilitation, most ICU survivors will be followed up by their primary care physician (PCP), as will the majority of chronically ill patients. PCPs have many competencies around the comprehensive care of ICU survivors. They often have a long-lasting relationship with their patients, know their psychosocial background and medical history, and are confident in the coordination of care [4]. PCPs, therefore, play a key role in the provision of critical illness aftercare.

However, although millions of patients survive critical illness every year in the U.S. alone [2], surveys suggest that typical PCPs on average only meet one to two patients per year [5]. (This may change with increasing numbers of COVID-19 survivors being discharged from ICU. [6])

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PCPs, therefore, may not always be prepared to identify complications and needs in these complex patients. With the exception of very young PCPs, family physicians usually have worked in primary care settings for many years; their residencies in hospitals and encounters with intensive care date some time back. PostICU complications have only in the past decade begun to be widely recognized and discussed, so it is likely that many practicing PCPs were not trained on these issues during their residencies. Continuing medical education is mandatory for PCPs in many countries but predominantly encompasses common diagnoses in primary care, such as cardiovascular and musculoskeletal diseases or common infections. A typical PCP, therefore, is not likely to follow recent developments in PICS management. Qualitative studies report that PCPs do not always feel confident recognizing and treating postICU complications [7, 8]. It has been suggested that PCPs need training and support to care for ICU survivors; however, there are no established concepts around how to provide this [9].

## Information Flow

PCPs have a profound and long-term knowledge of complex patients and can appreciate subtle impairments and residual symptoms on an individual level [8]. However, optimal follow-up of ICU survivors in primary care seems to be limited by a lack of specific knowledge about critical illness complications and how to manage them. Information transfer is of key importance, as many symptoms of PICS are similar to those caused by frequent chronic conditions: polyneuropathy symptoms, for example, do not differ much, whether being induced by diabetic polyneuropathy or by Critical Illness Polyneuropathy (CIP). Thus, many symptoms of PICS may go undetected or misdiagnosed in primary care. To enable PCPs to manage critical illness sequelae, adequate provision of information is mandatory.

Discharge letters comprise a major source of information about the hospitalization for outpatient care. Timeliness, comprehensiveness, and quality are essential to ensure patient safety after discharge; an insufficiency in any of these aspects increases the risk of readmission and complications [10]. Inadequate interdisciplinary and trans-sectoral information flow is a widespread problem and may be particularly difficult with transitions from intensive care to primary care. PCPs report that they are often not informed about their patients´ admission to ICU or the planned discharge date. They miss follow-up recommendations and would prefer to be involved in treatment decisions, for example, in the decision to limit treatment [11, 12].

Discharge letters from ICU often are addressed to a regular ward, meaning that the immediate recipient is not the PCP, resulting in further loss of information. In some ICUs, comprehensive discharge letters may not be written at all, as the writing of a discharge summary is delegated to the doctors of the regular ward from whence the patient continues to rehabilitation or outpatient care [13].

Training, checklists, software solutions, and positive peer pressure have all been shown to improve the quality and/or timeliness of discharge letters [10, 13]. The minimum requirements for a discharge letter include the patient's hospital course, length of stay, diagnostic findings, procedures undertaken, therapy recommendations, medication plans, and anticipatory guidance [14]. For patients with PICS, more detailed information may be needed to ensure adequate follow-up, outlining respiration, mobility, cognitive functioning, mental well-being, and nutrition, as well as recommendations for nonpharmaceutical therapy (physiotherapy, occupational therapy, speech therapy, or psychotherapy) and specialist referral. To ensure high quality aftercare, inpatient caregivers should perform a functional assessment before hospital discharge, including physical and mental domains, impact on activities of daily living, and future treatment goals [2]. Table 17.1 summarizes some key points for discharge notes as recommended by the guideline "Rehabilitation after critical illness in adults," from the British "National Institute for Health and Care Excellence" (NICE) [15].

Patient-directed discharge letters are another way to improve the transition from inpatient to outpatient care. In the UK, all hospital correspondence sent to PCPs is routinely copied to the patient [16]. In a German pilot project, discharge letters were "translated" to nontechnical language [17]. Patients' understanding of their hospital stay and recommendations for aftercare may thus be improved by discharge letters, and patients' autonomy and self-management strengthened [18]. Many patients do not have a clear recall of their illness and ICU treatment. Additional explanations for changes to the body, such as markings on the skin, or body functions, such as taste or fine motor skills, are helpful for disease processing and adaptation [19]. PCPs can answer questions and aid in sorting out memories (see 3.2). In this vein, the concept of the "ABCDEF bundle" for symptom management during critical illness [20] has been extended by some authors with "G" ("Good handoff

**Table 17.1** Recommendations for discharge notes, adapted from NICE's guideline on rehabilitation after critical illness in adults [15]

| Discharge information provided to primary care |
|---|
| Information about physical and cognitive recovery and rate of recovery, based on the rehabilitation goals set during ward-based care, if applicable. |
| Information about psychological and emotional recovery, including symptoms that frequently occur in the months after critical illness (for example, low mood, anxiety, flashbacks, nightmares, and changes or conflict in relationships). |
| If applicable, information about diet and any other continuing treatments. |
| Information about how to manage activities of daily living, including self-care and reengaging with everyday life. |
| If applicable, information about driving, returning to work, housing, and benefits. |
| Information about local statutory and nonstatutory support services, such as support groups. |
| General guidance, especially for the family or caregivers, on what to expect and how to support the patient at home. This should take into account both the patient's needs and the family's or caregivers' needs. |
| The patient should be given their own copy of the critical care discharge summary. |

communication") and "H" ("Hand the patient and family written information about possible components of PICS and PICS-F") [21].

In summary, information flow should continue from ICU to the patient and include the PCP.

## Follow-Up in Primary Care

A multiprofessional review 2–3 months after critical illness is recommended by NICE guidelines [15]. In the UK, about 30% of ICUs have follow-up clinics [22]; few other countries or regions provide similar structures. Even in the UK, sustainability is reported to be at risk due to lack of funds [23]. Most ICU survivors, therefore, will receive long-term aftercare from their PCPs. In addition to comprehensive discharge notes, there is a need for practical guidance that will ensure effective ICU follow-up in a busy primary care practice. Unfortunately, the complexity and diversity of critical care courses impede implementation of simple universal checklists. In addition, evidence from postICU follow-up trials is still inconsistent [24]. Several reassessment concepts are suggested by expert panels, such as the framework for reevaluation of sepsis survivors within 90 days after hospitalization (shown in Table 17.2). As sepsis sequelae are considered a key example of postICU problems [25], these recommendations may help PCPs, among others, to structure their postICU follow-up for a range of diagnoses. Medication use and objectives deserve special emphasis, as these often differ between in- and outpatient care. PCPs should make assessments of all their postICU patients to confirm whether any newly prescribed medication could be discontinued during the recovery process [26], to minimize interactions and side effects. Prescott et al. noted that doses of antihypertensive, diuretic, and renally cleared medications should be reassessed at each visit until patients have stabilized [24]. Figure 17.1 summarizes key aspects of early posthospital care for survivors of critical illness.

PostICU sequelae are heterogeneous and often complex, and thus, close collaboration between subspecialists and ancillary services is necessary. Since excessive treatment is also a burden to patients and families and may decrease adherence, Prescott and Angus recommend starting with one or two referrals, addressing the most significant symptoms, and then placing additional referrals over time [24]. Indeed, serial assessments of need have been championed by ICU survivors and expert consensus [27]. PCPs are well suited to estimating a patient's preferences and abilities in the management of different treatment options.

Due to heterogeneity in patients' underlying diseases, recovery pathways, timescales, and structure of reassessment must be adapted individually. Three key dimensions of PICS assessment are suggested, inspired by the definition of PICS itself [3]:

- Physical health and motor function
- Mental health/cognitive impairment
- Family health

**Table 17.2** Framework for evaluating and treating patients in the 90 days after hospitalization for Sepsis

| **Screen for common, treatable impairments** | **Anticipate and mitigate risk for common and preventable causes of Health Deterioration** |
|---|---|
| ***Functional Disability***<br>For patients with newly reduced exercise capacity, consider enrollment in a clinical trial of rehabilitation. If a trial is not available, consider referral to physical therapy and referral to pulmonary or cardiac rehabilitation, or prescribe a structured exercise program, depending on the severity of impairments and motivation of the patients.<br>For patients with new limitations of activities or instrumental activities of daily living, consider referral to occupational therapy.<br>If critical illness has occurred in the setting of long-standing comorbidity and declining health, discuss whether transition to palliative focus is appropriate.<br>**Swallowing Impairment**<br>For patients with evidence of swallowing impairment (dysphagia, weak voice, or cough), consider referral to speech therapy for further evaluation (e.g., fluoroscopic swallow evaluation) and treatment (e.g., swallow strengthening exercises and modified diet).<br>**Mental Health Impairments**<br>Review the details of the hospital course with interested patients, as ICU diaries are associated with decreased PTSD.<br>Consider screening for depression and anxiety with validated surveys.<br>Consider referring patients and caregivers to peer support programs or mental health services.<br>***Review and adjust long-term medications***<br>Confirm that long-term medications should remain on list.<br>Discontinue hospital medications without ongoing indication (e.g., inhalers, atypical antipsychotics, and gastric acid suppressants).<br>Assess whether any doses should be adjusted based on changes in body mass, renal, or cardiac function, focusing on diuretics, antihypertensives, and renally cleared medications. | ***Infection***<br>Counsel patients about their risk of infection and recurrent sepsis.<br>Ensure receipt of vaccines appropriate for the patient.<br>Encourage patients to seek medical care for infectious signs and symptoms.<br>Counsel patients on signs and symptoms that infection has progressed to sepsis (e.g., decreased urine output, confusion, cyanosis, and mottled skin), indicating that immediate evaluation is needed.<br>For patients presenting with signs or symptoms of infection, consider chest x-ray, complete blood cell count, urinalysis, or cultures to confirm or rule out suspected infection.<br>Schedule in-person or telephone follow-up to monitor for symptomatic improvement in patients with suspected infection.<br>**Heart Failure Exacerbation**<br>Reassess need and dosage for diuretics, β-blockers, and ACE-inhibitors, as dosage requirements may change after critical illness due to changes in bodyweight, renal function, or cardiac function.<br>Monitor volume status and weight at each visit, recognizing that dry weight may have declined due to lost muscle mass.<br>**Acute Renal Failure**<br>For patients with acute renal injury during critical illness, consider surveillance laboratory testing to ensure that renal function improves or stabilizes (e.g., check chemistry panel once a week for 3 weeks and then monitor less frequently once blood work is stable).<br>Reassess need and dosages for renally cleared and nephrotoxic agents (e.g., ACE inhibitors, NSAIDS, statins, ranitidine, opiates, and benzodiazepines)<br>**COPD Exacerbation**<br>Confirm and initiate appropriate controller inhalers.<br>Ensure receipt of vaccines appropriate for the patient.<br>Review and consider stopping or reducing dosages of medications that may suppress respiration, such as benzodiazepines and opiates. |

Modified from [24] with permission from Hallie C. Prescott MD

*Abbreviations*: *ACE* angiotensin-converting enzyme inhibitor, *COPD* chronic obstructive pulmonary disease, *NSAIDS* nonsteroidal anti-inflammatory drugs, *PTSD* post-traumatic stress disorder

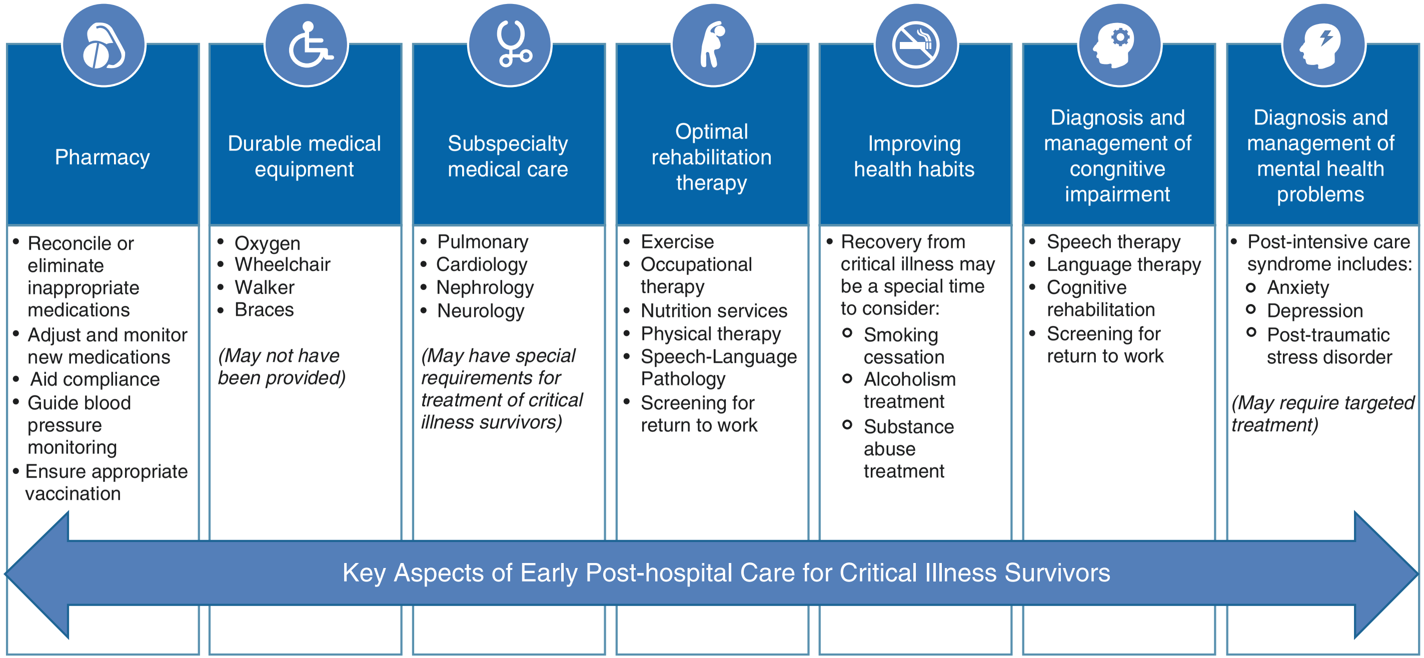

**Fig. 17.1** Key aspects from of early posthospital care [26]. (Reprinted with permission of the American Thoracic Society. Copyright © 2020 American Thoracic Society. All rights reserved)

## Physical Health

ICU-Acquired Weakness (ICUAW), caused by Critical Illness Polyneuropathy (CIP), Myopathy (CIM), and/or muscle atrophy, [28] [26] is considered to be the “single greatest determinant of outcome” after critical illness [19]. The true extent of muscle wasting can be difficult to determine and is not excluded by a normal Body Mass Index (BMI): a formerly obese patient may have lost weight due to muscle wasting during immobilisation in ICU, resulting in a normal BMI at discharge. The Malnutrition Universal Screening Tool (MUST) [29] includes weight changes over time, resulting in a more accurate assessment. Functional testing of muscle weakness may be helpful, for example, by testing handgrip strength [30]. Functional assessment should include evaluation of activities of daily living, such as rising from a bed and a chair or the ability to stand and walk unassisted. Prescription of medical aids, such as walking aids, could be of use. For additional screening tools that are useful and feasible in a primary care setting, please see Table 17.3.

Even if the current evidence regarding physical outpatient rehabilitation is limited, according to a Cochrane review [31], physiotherapy in postICU care is considered the “mainstay of fostering recovery” [19]. It affects several specific and overarching dimensions of postICU sequelae, such as pain, cachexia, polyneuropathy, quality of life, activities of daily living, aerobic capacity, and mental health [32]. Some physiotherapeutic interventions were identified by a three-step Delphi consensus process to be useful and may be initiated and continued in primary care. These interventions include interval or endurance cardio training, circuit training, functional exercises, balance training, strengthening exercises, High Intensity Interval Training, or Integrative Manual Therapy [29]. Besides professional interventions, an overall increase in physical activity in patients´ daily life should be for the goal. With a close doctor-patient relationship, PCPs may be in the best position to motivate their patients [4]. To support muscle reconditioning during physiotherapy, nutritional advice for adequate protein intake is recommended [33].

Physical impairment, other than neuromuscular, following critical care varies greatly and may include, among others, airway issues, chronic renal insufficiency, dysgeusia, dysosmia, hearing disorders, secondary sclerosing cholangitis, hormonal imbalance, hair loss, or low heart rate variability due to autonomic neuropathy [34, appendix], see also Table 17.2. Patients may not come forward with potentially personally embarrassing complaints, such as erectile dysfunction or small bladder syndrome, so these should actively addressed by the PCP in a trustworthy manner.

Special attention should be paid to dysphagia, a well-known but underestimated complication, which occurs in around 80% of patients after long-term mechanical ventilation. Dysphagia carries an increased risk for aspiration and pneumonia, as well as reduced quality of life. The 50 ml water test can assess aspiration risk, with swallowing observed by the PCP [35]. However, screening by a speech language pathologist (SLP) is preferred, including instrumental assessment of swallowing and ongoing follow-up, if needed [36].

**Table 17.3** Major post-intensive care complications adapted for primary care, including selected key symptoms, risk factors, screening instruments, and treatment options

| Sequelae | Description | Key symptoms | Example risk factors | Screening | Diagnosis | Treatment | Prognosis |
|---|---|---|---|---|---|---|---|
| Neuromuscular function | • Joint contractures<br>• Muscle weakness including<br>CIP<br>CIM<br>Disuse atrophy | • Reduced joint range of motion<br>• Symmetric, distal, and flaccid limb weakness<br>• Reduced or absent deep tendon reflexes<br>• Loss of peripheral sensation<br>• Relative preservation of cranial nerve function | • Sepsis<br>• Mechanical ventilation<br>• Hyperglycemia<br>• Use of glucocorticoids or neuromuscular blocking agents<br>• Immobility/bed rest | Hand grip and/or Manual Muscle Test [70] using MRC scale [71] | • Nerve conduction study<br>• Electromyography<br>• Muscle ultrasound<br>• Creatine kinase level (in ICU) | • Tailored rehabilitation across healthcare continuum, including PT and OT [19, 72]<br>Home exercise [73]<br>• Nutritional advice in the case of malnutrition [19]<br>• Assistive devices [26] | • CIP may recover more slowly than CIM<br>• Abnormalities extend beyond 5 years<br>• May not return to preICU baseline status [72] |
| Physical function | Impairment in activities of daily living and walking distance | | • Older age<br>• Preexisting impairment | 6MWT [74] and 4 meter gait speed [75]<br>ADL/IADL [76, 77] | | | |
| Dysphagia | Swallowing impairment | | • Prolonged intubation<br>• Gastrointestinal comorbidity<br>ICUAW | Early consultation to a SLP [36] | | Swallowing exercises with SLP [36] | Recoveries typically take more than 6 months [78] |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Mental Health | Depression | • Depressed mood<br>• Loss of interest and fatigue | • Sedation<br>• Traumatic/delusional memories of ICU<br>• PreICU psychiatric history<br>• Female gender<br>• Not associated with severity of illness | **HADS [79]**[a]<br>PHQ-2/9 [80] | DSM-5 diagnostic criteria, [81] semistructured interview | • Psychotherapy<br>• Antidepressants | May persist over first year [82] |
| | Anxiety | Excessive worry, difficult to control | | **HADS [79]**[a]<br>OASIS [83]<br>GAD2/7 [84] | | • CBT [72]<br>• Anxiolytics | May have little improvement over first year [78] |
| | PTSD | • Intrusive memories<br>• Avoidance of stimuli associated with the ICU<br>• Dissociative reactions<br>• Irritable behavior | | **IES-6 [85]**[a]<br>PTSS-10 [86] | | • Talking about ICU experiences [44, 87]<br>• Psychotherapy<br>• Avoid benzodiazepines | Onset may be delayed [41]<br>Little improvement in first year [88] |
| Cognition | Impairments in | | • Prior cognitive deficit<br>• Duration of ICU delirium<br>• Older Age<br>• Cerebral Hypoxia<br>• Hypotension<br>• Hypoglycemia | MoCA (Blind) [89][a] | Exclusion of reversible causes for dementia as:<br>• Normal pressure hydrocephalus (NPH)<br>• Hypothyroidism | • Cognitive rehabilitation [26]<br>• Assistance in organizing daily life | May improve during first year<br>Residual deficits up to 6 years later |
| | • Memory | • Attention | | | | | |
| | • Executive function | • Mental processing | | | | | |
| | • Visuospatial ability | • Speed | | | | | |

(continued)

**Table 17.3** (continued)

| Sequelae | Description | Key symptoms | Example risk factors | Screening | Diagnosis | Treatment | Prognosis |
|---|---|---|---|---|---|---|---|
| Family | ICS-F includes<br>- Anxiety<br>- Depression<br>- PTSD<br>- Complicated grief | see “Mental Health” | - Female gender<br>- Younger age<br>- Less education<br>- PreICU psychiatric history<br>- Distance to hospital<br>- Dissatisfaction with ICU communication | see “Mental Health” | | - See “Mental Health”<br>- Inclusion of family member into decision-making<br>- Involvement of trained nurse or social worker | PTSD and complicated grief may persist longer (over years) than depression and anxiety |

Modified from Desai et al. [90]/Mikkelsen et al. [62, 91], without claim to completeness

*Abbreviations*: *6MWT* 6 minute walk test [74], *ADL/IADL* (Instrumental) Activities of daily living [76, 77], *ARDS* Acute Respiratory Distress Syndrome, *CBT* Cognitive-behavioral therapy, *CIM* Critical illness myopathy, *CIP* Critical illness polyneuropathy, *GAD-2/7* Generalized Anxiety Disorder 2/7-item [84], *HADS* Hospital Anxiety and Depression Scale [79], *ICU* Intensive care unit, *ICUAW* ICU-Acquired Weakness, *IES-6* Impact of Event Scale-6 item version [85], *MMST* Mini-Mental State Examination [27], *MoCa Blind* Montreal Cognitive Assessment-Blind [89], *MRC* Medical Research Council [71], *OASIS* Overall Anxiety and Impairment Scale [83], *OT* Occupational Therapy, *PHQ-2/9* Patient Health Questionnaire-2/9 [80], *PICS-F* Post-intensive care syndrome-family, *PT* Physiotherapy, *PTSD* Post-traumatic stress disorder, *PTSS-10* Post-traumatic stress syndrome 10-questions inventory [86], *SIRS* Systemic inflammatory response syndrome, *SLP* Speech language pathologist

[a] Internationally agreed for acute respiratory failure survivors, see www.improveLTO.com [58]

Finally, some ICU survivors may be asplenic, for example, after traumatic spleen rupture or through miscellaneous hematological diseases. Any infection, especially one caused by encapsulated bacteria such as pneumococci, can be life-threatening for these patients. This complication is called 'Overwhelming Postsplenectomy Infection (OPSI)' [37]. PCPs should ensure that the recommended vaccinations are complete, in particular against pneumococci, meningococci and Haemophilus influenzae type b (Hib). An emergency passport or notification card should be handed out to patients to ensure that the patient and all providers are informed.

## *Mental Health and Cognitive Function*

Critical illness and ICU treatment are life-threatening events often accompanied by feelings of helplessness and anxiety. Medical procedures can be painful and frightening, especially when patients are not completely aware of what is happening to them. Of 464 patients from 10 Portuguese ICUs, 38% had no recall of any of their ICU stays at 6 months and 51% experienced nightmares [38]. Thus, it is not surprising that a considerable number of patients suffer from psychological distress, resulting in impaired quality of life and possibly low adherence to medical treatment advice [39].

Not all symptoms after a traumatic event fulfill the diagnosis of Post-Traumatic Stress Disorder (PTSD). Symptoms lasting less than a month may, rather, present an adjustment disorder or acute stress reaction and may resolve without treatment [40]. On the other hand, PTSD symptoms may occur in delayed fashion after a symptom-free interval up to 1 year [41].

Avoidance is one of the chief symptoms of PTSD; many affected patients will not elaborate on their complaints and will quickly change the subject when stress symptoms are broached. Thus, PTSD is likely underestimated after critical illness. Hallucinations, delusions, nightmares, excessive worry, or suspiciousness must be actively explored by the PCP. Empathic and accepting exploration of symptoms helps to make a PTSD diagnosis and can be supported by screening questionnaires (see Table 17.3).

Evidence-based and effective PTSD treatment includes trauma-focused psychotherapy to integrate traumatic memories. This is not easy to achieve in the early postICU period as physical problems often dominate, and mobility may be impaired. In addition, the availability of trauma-experienced psychotherapists is often limited.

In primary care, patients already benefit from a stable physician-patient relationship and a psychoeducative explanation of the symptoms ("normal reaction to an abnormal event") may alleviate suffering in the early recovery period [42]. Motivation for and organization of trauma-focused therapy may be demanding. If specialist psychotherapy is not available or accepted, short-term appointments may be offered with resource-oriented counseling for everyday functioning [42]. Even if treatment options are limited, it is important to offer possible choices clearly.

To date, the best available evidence for PTSD prevention suggests the use of ICU diaries [43]. Clinicians and/or relatives fill out a patient diary on the clinical course and other events during their ICU stay. After discharge, the diary is handed over to the patient. Reading their diaries helps patients to reintegrate fragmented traumatic memories. Many patients allow others to read the diary [44], and thus, PCPs may offer a review with the patient to contextualize what happened and normalize incompletely understood events [45].

Even if no ICU diary is available and no delusional memories are apparent, PCPs should consider inviting patients for an appointment after their ICU stay to discuss this stressful part of their illness. Most will benefit from being listened to and from a narrative of the ICU course in understandable language [44]; this will not happen by chance.

Patients who return home after a critical illness may have good reasons to be sad or in a low mood, especially if they cannot return to the life they led before or must depend on help from others. According to a recent review, around 40% of critical illness survivors are jobless at 12 months after discharge from hospital [46]. Unemployment may be associated with adverse mental health outcomes and a worsening of the patient's socioeconomic situation. Even if a return to some employment is achieved, patients may suffer from adverse changes to occupation and/or employment status. The emerging evidence in this field suggests that patients benefit from a multidisciplinary approach where the PCP, the employer, and occupational medicine specialists work together during the rehabilitation period [46].

Grieving, sadness, and adjustment may be appropriate reactions and should be distinguished from a depressive episode. As patients may avoid talking about mental suffering and consultations often are dominated by physical health issues, the use of established screening scales may be helpful in detecting and diagnosing depression: the PHQ-2 is a quick and practicable screening tool to exclude depression, if negative, or to prompt further evaluation if positive [47] (see Table 17.3). As depression is common in primary care, most PCPs will be confident in making the diagnosis and offering treatment. Treatment of a depressive episode after critical illness includes psychotherapy and pharmacotherapy (according to the Stepped Care approach) and does not differ from treatment in other primary care patients. However, it may be even more important in the postICU population for achieving adherence to the treatment of other conditions [48].

Cognitive impairment after ICU treatment, potentially related to delirium, hypoxia, or cerebral hypoperfusion, may markedly impact activities of daily living, for example, with self-care such as driving, shopping, or medication management [49]. Patients report these impairments to be among the most stressful complications postICU. Being present in up to half of critical illness survivors at ICU discharge [49], the clinical course of postICU cognitive impairment is variable and fluctuating. In the short term, mild encephalopathy may resolve, whereas deficits in attention, concentration or memory, and resilience will remain in severe cases.

In primary care, cognitive dysfunction is not routinely recognized as a complication of critical illness and may be attributed to Alzheimer's dementia in older patients. For assessment of severity, instruments from dementia diagnostics, such as the Montreal Cognitive Assessment (-Blind) (MoCA-Blind) [50], can be helpful (see also Table 17.3). Cognitive impairment following critical illness is often a diagnosis of exclusion. It is important to consider detailed somatic tests in order to rule out reversible causes such as hypothyroidism or normal pressure hydrocephalus (e.g., cranial computed tomography, blood count, glucose, thyroid function, vitamin B12, electrolytes, creatinine, folic acid, and liver function tests). Specific treatment of ICU-related neurocognitive impairment is not yet available. Primary therapeutic approaches include attention and concentration training, physiotherapy and occupational therapy, and practical help for everyday life that includes family members and other psychosocial environments [34, appendix], see also Table 17.3.

## *Family Health*

Families and other informal caregivers provide valuable support for recovery following ICU. In addition to providing practical support in everyday life and facilitating physical functioning, relatives are essential for mental recovery, which is known to improve with stable relationships. For some patients, family members are the only people capable of placing the ICU hospitalization within a broader context [51].

While concerned about the survival and subsequent well-being of their loved ones, family members are not always equipped to assess a patient's mental health. Around 30% of family members themselves experience mental complications such as depression, adaptation or anxiety disorders, or high levels of post-traumatic symptoms after a loved one's critical illness [52]; this has been referred to as the Post-intensive Care Syndrome Family (PICS-F) [1].

Family members also need help coping – both for their own and for the patient's benefit – and should be part of a comprehensive aftercare plan. The mental health of patients' relatives should be screened repeatedly and actively; the scales shown in Table 17.3 can be used also. Since PCPs often care for all members of a family, they are in an ideal position to offer counseling and to encourage relatives to look after their own health issues. Counseling, peer support for caregivers, and information about support (such as around care services and funding resources) may be helpful.

Patients often lack both true memories of their time on the ICU and realistic perspectives on illness and recovery. In contrast, their families have been confronted with life-threatening conditions and their own inability to help, possibly resulting in an overprotective fear. This 'conflict of care', induced by differing perspectives of patients and their families and described by RD Griffith, [53] may be defused by frequent and easily understandable updates from the PCP about the patient's condition and prognosis.

Furthermore, family members must often make decisions for patients, if they are not capable of deciding themselves. Asking for and incorporating the family's description of the patient's values and wishes may support the process of shared decision-making (see 3.5).

In summary, family communication and family health should be considered a cornerstone of postICU rehabilitation.

## *Palliative Care*

Although mortality rates remain high in the year after discharge from intensive care [54], palliative care in noncancer illnesses is less well established than in patients with cancer, and there are barriers to patients and doctors discussing poor prognosis and end-of-life issues. The trajectories of illnesses involving organ failure, such as COPD and heart failure, are characterized by acute, life-threatening exacerbations and recovery to a level of quality of life slightly lower than previous [55]. Prognosis is difficult to estimate. The 'surprise question' is one that PCPs can ask themselves as a simple tool to identify patients who may be in need of palliative care: "Would you be surprised if the patient were to die in the next year/months/weeks/days?" [56].

The Supportive & Palliative Care Indicators Tool (SPICT) [57] is another instrument used in primary care for the early identification of patients with palliative care needs and offers more detailed guidance. Review of current treatments and medications is advised in order to ensure good symptom relief while minimizing polypharmacy. Referrals to specialists may be needed when symptoms are difficult to manage and impair quality of life. Specialized palliative care for noncancer patients is not always readily available, so coordination of and decisions about ongoing care are most likely to fall within the PCP's remit. Having experienced intensive care, including invasive life support measures such as mechanical ventilation or dialysis, ICU survivors may be in a better position to make decisions about future maximum care. In many cases, exacerbations or complications may be previewed and planned for. In the case of loss of decision-making capacity, an advance directive statement on the patient's choices can help PCPs provide the preferred care. Some patients may well choose to use all treatment options that previously helped them to survive, while some may prefer symptom relief and limited noninvasive treatment.

## *Resources*

In addition to detailed discharge notes, there are several resources and techniques, which may help PCPs when caring for critical illness survivors:

- Clinical assessment and documentation, as well as tracking of the clinical course, may be facilitated by the use of standardized scores. However, the appropriate assessment tools are not always known in primary care [5]. As previously mentioned, Table 17.3 provides an overview of the major postICU complications adapted for primary care at a glance, including selected key symptoms, risk factors, treatment options, and validated screening instruments. The selected instruments, characterized by a small number of items and simple analyzability, are feasible for primary care, with some of these scales already internationally agreed upon for acute respiratory failure survivors by a 3-step Delphi consensus process [58]; see also www.improveLTO.com.

(This compilation does not claim completeness, and most scales are not validated for the population of ICU survivors).

- Behavioral change and adherence to an exercise regime can be supported using directive, client-centered counseling styles: motivational counseling aims to build up intrinsic motivation for behavioral changes by exploring and dissolving ambivalences [59]. Initially, this concept was developed for counseling people with addiction problems. The underlying principle is to expose the conflict between the patient's current behavior and the life changes and goals that the patient desires, without urging or confronting the patient. Patients should come to their own understanding of this conflict and its inherent dissonance.
- Shared Decision-Making (SDM) describes a form of doctor-patient communication that aims to fulfill patients' desire to be involved in decisions about their health. Physician and patient discuss objective and subjective aspects of decisions as equal partners: the decision can have two or more options, including 'watchful waiting'. Three aspects differentiate the SDM approach from the old paternalistic and informative model of doctor-patient communication: providing information, weighing options, and deciding together [60].
- The concept of 'functional reconciliation' is recommended by the second stakeholder consensus meeting on PICS [61]. It means a formal comparison of a patient's physical, cognitive, and mental status before and after hospitalization, to facilitate communication between in- and outpatient resources. Screening tools as suggested in Table 17.3 may be applied. Progress in a patient's status can be tracked using a 'functional reconciliation checklist', which may prove useful to both parties, although its impact has not been evaluated [22].
- A growing supply of web resources on postICU care is available. PCPs can find detailed resources online, such as www.uptodate.com [62] and the afore-mentioned NICE guidelines website, [3] which includes 91 pages and 25 recommendations and is free to use [3].
- Patients and their relatives can be referred to an intensive care support group and/or follow-up clinic, where available: www.sccm.org/MyICUCare/Home. The charity "ICUsteps" [http://www.icusteps.org] provides a 24-page booklet in a range of languages, together with a list of peer-to-peer support groups. A self-help rehabilitation manual recommended by the NICE guideline comprises a six-week structured program, including physical exercises and psychological advice, and has been shown by a randomized clinical trial at three UK hospitals to improve physical recovery and reduce depression [63]. This pioneering work empowers patients and their families to take an active role in patients' recovery.

## Perspectives

The importance of a care coordinator is emphasized by the British Society for Rehabilitation Medicine and others [16]. ICU survivors would benefit from being assigned a single point of contact who knows their history and surveys all rehabilitation domains and facilities. Different persons have been suggested as candidates for this coordinating role of ‘Generic Rehabilitation Assistant’ (GRA) by the Scottish RECOVER trial collaboration [5]. A patient’s PCP will play this role, if anyone does. Consequently, support for PCPs is needed in order to improve ICU follow-up knowledge and skill in primary care.

Thus far, only a few studies have focused on postICU follow-up in primary care. Starting with the core components of the chronic care model [64], the German SMOOTH Study evaluated a multifaceted support intervention for PCPs caring for sepsis survivors. Two new roles were introduced: the care manager, a trained nurse with ICU experience who supported PCPs with proactive monitoring of patient’s symptoms, and the consulting ‘liaison physician’, who trained more than 150 PCPs in evidence-based sepsis aftercare in an individual education outreach program. Decision support based on monitoring results was provided by the liaison physician [34]. Figure 17.2 shows the resulting ‘therapeutic triangle’ around the patient.

The subsequent and ongoing PICTURE study concentrates on PTSD treatment postICU. Acknowledging limited access to specialist care in many (especially rural) regions, PCPs may need to extend their therapeutic portfolio to offer entry-level therapeutic options to treat post-traumatic symptoms. Within the trial, PCPs across Germany are trained in evidence-based talk therapy, an adapted version of Narrative Exposure Therapy (NET), in order to deal with post-traumatic symptoms following ICU discharge [65].

Other authors have proposed ideas to enhance the liaison between primary and secondary care. Guys’ and St Thomas’ NHS Foundation Trust aims for the integration of PCPs in their postICU clinic model [15]. Taylor et al. encourage PCPs to “help their patients to contact ICUs, requesting a visit and a meeting with an ICU

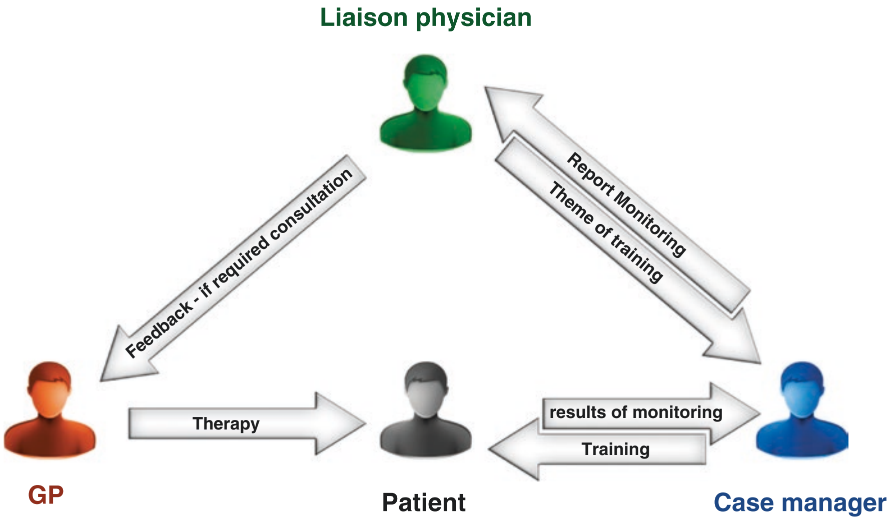

**Fig. 17.2** Key figures in the SMOOTH intervention [34]

consultant in order to gain information about what happened during their admission" [45].

Mobile phone technology may help future PCPs to monitor rehabilitation outcomes, especially in rural and remote populations, and to share this information with other specialists, as suggested by Elliot and Deneh [48].

Daly et al. [66] and Douglas et al. [67] have shown that Disease Management Programs (DMPs) for ICU survivors result in fewer rehospitalizations. These structured treatment plans are proven to be effective in managing many chronic conditions and could potentially provide a future framework for postICU follow-up coordination in primary care.

However, as evidence for the effectiveness of ICU follow-up is still insufficient (as confirmed by a recent Cochrane review [68]), more research needs to be undertaken before diagnostic and therapeutic standards can be established. Considering the clinical heterogeneity of ICU survivors, the requirements of particular subgroups may need to be addressed. In order to adequately reflect the priorities of patients and their families, such as symptom relief or preservation of social functioning, Patient-Centered Outcome Measures (PROM) should be a focus [69].

## Conclusion

Due to the complexity and heterogeneity of clinical courses, ICU follow-up should be a multidisciplinary and multiprofessional process. Within this framework, the PCP provides treatments, coordinates care, and functions as the patient's advocate on the rehabilitation pathway. Integrating the critical illness into the patient's own life context, identifying preferences, priorities, and motivation for treatment, as well as empowering the participation of patients and families all fall within the core competencies of PCPs.

To provide and coordinate comprehensive, continuing, and high-quality care, PCPs need effective information transfer and networks, encompassing in- and outpatient care providers. Structured discharge notes, the inclusion of PCPs in ICU follow-up programs, and the establishment of training modules should be applied. In addition, standardized scales and guidelines will help PCPs to perform effective ICU follow-up.

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# Chapter 18

# Socio-Economic Reintegration After Critical Illness

**Philip Henderson, Carly Robinson, and Tara Quasim**

## Introduction

Returning to work is often seen as the epitome of socio-economic reintegration. While some critical illness survivors quickly resume their previous life, this is generally the exception. For many, it results in altered dynamics in their existing roles and relationships, being economically inactive but with the burden of ongoing financial commitments. Further, for some, early return to work can be detrimental to both physical and mental well-being.

Irrespective of employment status prior to the critical illness, or return to work after it, there is a spectrum of social and financial strain after hospital discharge, including:

- Financial strain from existing debt
- Financial losses during hospital admission
- Ongoing shortfalls
- Strain on relationships
- Caregiver burden including caregiver social and financial strain

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- Loss of hobbies or interests
- Social isolation.

Ultimately, the possibility of significant changes to both social and financial circumstances can lead to a loss of identity, self-esteem, and reduced quality of life.

## *Definition of Socio-Economic Reintegration After Critical Illness*

There is no published definition of socio-economic reintegration after critical illness. We would suggest defining it as:

> The resumption of relationships, roles, and financial income after a period of critical illness. This should include family, friends, nurturing and supportive roles, reclaiming interests, as well as returning to work (if of employment age).

# The Financial Burden

## *While in Hospital*

### Direct Healthcare Costs

Hospitalisation can impact domestic finances, and for ICU survivors, the associated financial impact can be devastating resulting in "financial toxicity" [1]. This has been defined as the "objective financial burdens and subjective financial distress" associated with medical treatment. It is most often studied in advanced cancer [1].

Understanding the causes of financial toxicity is crucial. In countries with largely private healthcare systems, many patients pay directly for their treatment through health insurance or personal funds. Emerging evidence suggests healthcare costs are driving families into poverty in the US [2], where medical bills contributed to over 17% of all reported bankruptcies in 2007 [3]. ICU care can form a significant proportion of direct expenses with mean ICU admission costs (involving mechanical ventilation) of $40,000+ in the US [4]. The burden of direct costs is significantly reduced in socially funded healthcare; however, indirect expenses can be significant, e.g. travel or parking costs. Even within this system, many post-acute medical costs may be paid for by the survivor and their caregivers.

### Working Time Lost while in Hospital (Including Bills Not Paid)

Loss of earnings whilst unwell can be a significant contributor to overall financial hardship. Depending on job and location, employers may provide sick pay via an occupational scheme; however, worldwide, many employers do not.

Government-based schemes are unlikely to match the patient's previous earnings. Those with temporary contracts, casual work, or self-employed will not receive any sick pay. Ultimately, some patients may lose their job if unable to work for prolonged periods.

Loss of income can have serious impacts on caregivers and dependents of an ICU patient [5]. During the acute stage of the illness, many caregivers reduce hours or take time off work. With vastly reduced income, mounting household bills, and unaccounted for costs (e.g. travel/parking/child care), many households rely on using savings, credit cards, or loans, resulting in severe debt. The resulting "financial disability" for patients and families after critical care discharge is defined by Li et al. as unable to afford to pay at least three living expenses out of six: groceries, general bills, medications, medical bills, a small emergency, and a major emergency [6]. With low income generally leading to higher rates of functional decline and death in the community, dealing with financial strain and employment after critical care is vitally important to improving health-related quality of life after critical illness [7, 8].

## *After Hospital Discharge*

### Patient

For many, returning home after a period of critical illness involves significant changes to their lifestyle. Resultant frailty may necessitate home adaptations, e.g. relocation of beds and bathrooms, or alterations to access points including stairs and handrails [9, 10]. These may be funded by the patient and family rather than the healthcare or social care system. Not undertaking adaptations due to financial constraints can contribute to increasing social isolation if the patient is unable to move around the home unaided or is unable to leave home safely, or other physical barriers such as being unable to drive exist.

### Caregivers

Increased care needs after hospital discharge often result in caregivers giving up work or paying for professional carers, both of which add to the financial burden. Covinsky et al. (1994) demonstrated that 34% of critically ill patients needed considerable care from a relative in the 12 months following hospital discharge. In 20% of cases, a relative needed to leave employment and overall 33% of families reported losing their major source of income [5]. Similarly, Griffiths et al. (2013) found 22% of patients requiring care assistance at 12 months with 78% delivered by a family member [11]. Swoboda et al. (2002) described nearly 60% of responding families were providing a moderate or large amount of care between 1 and 9 months after discharge home, almost 50% had to give up employment after 1 month, and over 36% of families had lost savings at 1 year [12]. Other effects included moving to a less-expensive home, delayed educational plans, or delayed medical care for another family member.

### Returning to Work

Only 56% of ICU follow-up patients resume employment one-year post-ICU discharge [13], which supports the premise that return to work (RTW) after critical illness can be problematic. Post-intensive care syndrome (PICS) comprises physical, cognitive, and emotional symptoms post-ICU, all of which present barriers to resuming employment.

The physical impairments associated with PICS, including fatigue, weakness, and reduced mobility, can all contribute to being unable to work, particularly in a strenuous role. This has been demonstrated when estimating costs incurred after major trauma. It was found that blue collar workers lost more work days compared to white collar workers, and despite a lower overall salary, blue collar workers incurred greater lost earnings [14]. It is likely that the impact of physical impairments combined with the higher physical capabilities needed before returning to work contributes to this.

The cognitive effects of PICS including reduced concentration and memory problems alongside the psychological effects of low mood, disturbed sleep, post-traumatic stress, and hallucinations can hinder or even preclude resumption of employment [15].

Being unable to return to work can have a significant negative impact on quality of life. It can contribute to feelings of low self-esteem and self-worth, loss of identity, feelings of hopelessness, depression, and social isolation [16, 17].

For those survivors who do return to work, it may not be possible to return to the same career or number of hours worked before their critical illness. One study found that 22% of participants were working fewer hours between 6 and 12 months after ICU discharge [18].

## Social Readjustment: After Intensive Care

### Changing Relationships: Caregiver and Survivor

The "end-goal" for ICU survivors is often being discharged from hospital. However, many patients are unprepared for the reality of life at home. A serious challenge that ICU survivors face post-discharge is the transformation of their close personal relationships. Patients may change from fit, healthy, independent adults to having variable degrees of dependency, chronic symptoms, and ill health post-ICU. This, understandably, can be a difficult transition where family members, spouses, and children/parents are suddenly assuming the role of a "carer" without any formal training and potentially little support [19, 20]. The effective loss of a peer results in increasing social isolation contributing to a narrowed social network for both survivor and caregiver.

Caregiver burden can be extremely significant in these instances. They can suffer from a wide range of negative emotions in relation to their family member's illness and recovery including anger/resentment for the changes the illness has brought about, guilt for not being the one to have suffered, and anxiety that the survivor may fall ill again.

The significant differences between in-patient experiences of survivor and caregiver can lead to avoiding discussion. Patients often report long periods of memory loss, particularly during delirious phases, and report having very distorted memories and hallucinations. Caregivers have often been through their own significant trauma, fearing the loss of a loved one together with their life being on hold. The frustration can be that the caregiver remembers every traumatic event with the patient unable to empathise, lacking recollection.

## *Interests*

Reintegrating back into previous social circles can also be very difficult for ICU survivors. Wider groups of friends may not understand the severity of illness, nor the recovery time required, making survivors feel isolated and under pressure to resume previous activities. Some hobbies or activities may be detrimental to recovery, for example, those with addictions may need to avoid situations which place them at risk of relapse. There may also be new physical limitations that preclude participation in certain sports or fitness activities, which may further limit social interaction.

## *Social Isolation and Loneliness*

Social isolation is defined as the absence of contact from other people [21], whereas loneliness describes the negative feelings resulting from a mismatch between desired and achieved social interaction [22]. Both can be a barrier to recovery, while a poor recovery can increase social isolation and loneliness. How these factors relate to relationships and social networks are important for survivors and caregivers. Social isolation has significantly negative effects on health and quality of life, [21, 23–25] which can lead to loss of identity if patients are unable to maintain friendships and social activities [26].

### How Critical Illness Causes Social Isolation

Survival from critical illness and the radical alterations to a patient's circumstances can lead to high levels of social isolation. Drivers of social isolation include: being unable to work, spending long periods of time at home, mobility or mental health problems resulting in patients not socialising outside of the home, a change in relationships or family dynamics, and a lack of shared experience. Previously held ambitions or goals may no longer be achievable, and survivors may have a new perspective on life. Social isolation leads to higher healthcare utilisation often to satisfy a need for social interaction [27]. Healthcare utilisation is above average in the first year post-ICU discharge [28], and poor social support can be one cause of unnecessary re-engagement with acute services.

#### The Health Costs of Social Isolation

Social isolation has been linked to increasing mortality and morbidity [29] from cardiovascular disease [30], depression [31], and dementia [32]. Furthermore, it could be as damaging to health as smoking 15 cigarettes per day [33]. The societal cost of social isolation is huge, not only to the health, social, and welfare services but also to the wider economy. The mechanisms through which social relationships affect health remain to be explored [34].

## How to Improve Socio-Economic Reintegration After Critical Illness

### *Key Elements of Socio-Economic Reintegration*

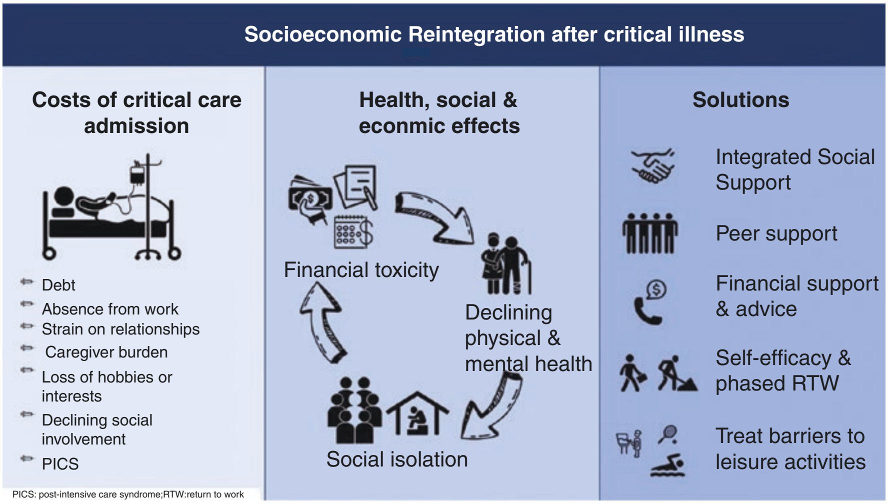
#### Goals of Socio-Economic Reintegration After Critical Illness

It may not be possible to return to the same life as before the acute illness. The aim should be to return to the most valued aspects, modifying others based on the extent of new physical or psychological limitations or a change in overall perspective.

Rather than enforcing a return to their previous life, optimising social reintegration should be directed by the patient with encouragement and support from those around them. This will include family, friends, colleagues, as well as the critical care follow-up team and the wider multidisciplinary team. The process of reintegration after critical illness is summarised in Fig. 18.1.

#### Integrated Social Support

Traditionally, social care and healthcare were separate entities dealing with their own problems in silos. This attitude belies the health consequences of social isolation and loneliness and vice versa. With the significant vulnerability of the critical care population to social isolation, any effort to improve survivorship after critical illness would be remiss if lacking an integrated focus.



PICS: post-intensive care syndrome;RTW:return to work

**Fig. 18.1** Process of socio-economic reintegration after critical illness

The paucity of interventional studies focussing on the efficacy of social support for the critical care patient after discharge results in a pragmatic approach when setting up new services [10]. Interventions beginning early at hospital admission should include gathering background information on social circumstances, pre-hospital social support (including family), and occupation. Information should be offered to the patient and family on available services and likely support required through the critical care course [35]. More details on in-patient care are beyond the scope of this chapter and will largely be determined by the geographical area and existing local systems. The importance of groundwork in early communication and information gathering cannot, however, be overstated and will improve delivery of care after discharge.

## Outpatient Financial Support

To improve quality of life after critical illness, financial burdens need to be addressed. The components and timing of this service will have to be determined locally depending primarily on the country or region involved. This will determine the likely level of financial deficit and existing support, e.g. private healthcare vs publicly funded, paid sick leave, or social security arrangements. Once the correct support structures are embedded in a service, advice can then be tailored to the individual patient needs. Common issues that need addressed include [36]:

- Welfare benefit advice
- Employment
- Adaptations and access to parking/mobility

- Debt/financial issues
- Housing
- Legal.

There are significant benefits in having a specialist who can deal with each issue on site or physically attending the clinic environment. This may not be possible, and the patient may need to be signposted to relevant community services.

It is likely that any illness associated with a critical care admission will have a longer convalescence period and longer time before RTW. The financial help available for patients with PICS is limited as it is not a recognised illness. In many countries, there may be more financial support available if PICS had this recognition.

## Returning to Work

Proven interventions to improve RTW rates after intensive care are lacking, [13] but the barriers should be addressed. The patient and family should be offered advice on the benefits, timeframe, likely challenges, and possible negative impacts of early RTW.

Non-modifiable factors associated with higher RTW rates for the general population after illness or injury include higher education levels and socio-economic status. Those associated with reduced RTW rates include higher severity of illness or injury, older age, being female, previous sick leave, and unemployment [37].

Modifiable factors showing a positive effect on RTW rates include:

- Higher self-efficacy
- Optimistic expectations for recovery and RTW
- RTW conditions
- Multidisciplinary interventions that include the workplace.

Modifiable factors associated with a negative impact on RTW:

- Higher pain or disability
- Depression
- Higher physical work demands
- Activity limitations.

Thus, improving self-efficacy [38] and engaging with employers should be key aims. A multidisciplinary approach will also need to address mental health. Interventions shown to improve RTW rates for common mental health disorders (e.g. stress or depression) include maintaining contact with the workplace and the use of multicomponent interventions alongside graded return to work. Further, interventions targeting stress are particularly effective [39]. With a high level of mental health problems after critical illness [40, 41], an improvement in RTW rates is unlikely without targeting this.

Cognitive dysfunction associated with critical care can be a significant barrier to employment. Cognitive impairment at 12 months post-critical illness is associated with reduced RTW rates; however, delirium and cognitive function at 3 months is not [42, 43]. Psychological support alongside a phased RTW process is likely to have the best results.

## Returning to Leisure Activities

A common goal for patients is returning to their leisure pursuits, including individual past times, group activities, physical endeavours, and social activities [44]. The ICU recovery clinic offers an opportunity to address the barriers to successful re-engagement in these activities. With limited evidence guiding which interventions allow resumption of previous interests, the course is best dictated by the patient using goal setting. The role of the professional at the clinic is to facilitate this discussion, guide which goals are achievable, identify modifiable barriers, and propose solutions to these. Framing the patient-family discussion in the context of the key domains of PICS can give the process structure [45–47]. Common issues and examples include:

- *Mental health* issues leading to reduced confidence in social situations, reduced motivation to engage in activities, and poor concentration. Strategies to ameliorate this may include medical and psychological management of the underlying condition alongside tapered goals allowing a gradual increase in social and leisure activities. Pre-existing anxiety and depression in relatives can compound their caregiver strain when looking after the ICU survivor post hospital discharge. This new role as carer may limit the time available for leisure activities but also their ongoing anxiety about the near loss of a loved one may lead to separation anxiety. In these instances, peer support may offer reassurance and the opportunity for the patient and caregiver to spend time apart in a safe environment [48].
- *Cognitive impairment* leading to significant barriers to social interaction or participating in hobbies. After medical assessment for modifiable causes (e.g. high dose opiates), management returns to appropriate goal setting as guided by the patient's ambitions. Cognitive function can improve but is not guaranteed [49]. This should be considered when goal setting and aiming to return to previous activities.
- *Physical impairment* can be variable after intensive care [50]. It can affect the patient's ability to return to hobbies and leisure activities from a generalised limitation (e.g. fatigue, muscle weakness, and shortness of breath) or be isolated to a single limb. A scalable approach to physical activity should be used focussing on the important goals directed by the patient.

## *Strength in Sharing: Peer Support*

Peer support is a growing area of survivorship after critical illness, while this is discussed in much more detail elsewhere its potential benefits for socio-economic reintegration after ICU merit discussion. Peer support has been described as [51]:

> The process of providing empathy, offering advice, and sharing stories between ICU survivors. Peer support is founded on the principles that both taking and giving support can be healing if done with mutual respect.

Although robust evidence demonstrating benefit on quality of life is lacking [52], this support offers the potential benefits of engaging with peers and thus resuming lost social interaction, in whatever form it may take [48]. This should improve confidence in skills lost while away from usual roles. This platform may also allow the patient to replace lost nurturing roles, e.g. for the patient with a previous caring role that they are no longer able to provide.

Perceived benefits are equally applicable to caregivers. Time lost from usual social roles combined with the new burden of caring responsibilities for the ICU survivor can limit social interaction. Peer support can offer the chance of social interaction, without the caregiver burden, to an empathetic compeer. In this context, caregiver models of peer support conducted away from the patient may offer the greatest improvement in social reintegration.

Peer support can also act as a sounding board for both patient and caregiver. The process of reintegration should acknowledge what the survivor and family have been through and accept this may have an impact on the future. Peer support may offer a place to discuss ongoing issues and increase confidence in discussing the existence and extent of limitations.

Ultimately, peer support offers a safe environment to get back to social roles. This stepping stone may increase confidence to participate in other activities and may be one step towards employment.

## *Experience in Other Specific Areas*

Many specialties have been through a process of improving survivorship, and while critical illness may have its own specific needs, linking with these organisations offers many advantages. We can learn from the development and design processes of these programmes. There may be local issues that can be anticipated especially with financial aid. Some patients and caregivers will have needs that can be directly met by other services, limiting the number of appointments and giving the patients more time to engage in socio-economic activities. Finally, critical care should learn from the survivorship experience of other specialties in order to raise the profile of PICS and generate more attention (including financial support) for this group of patients.

### Stroke

The cornerstone of stroke rehabilitation is physical therapy [53]. Higher functional status and improving overall stroke recovery can predict better social integration. Likewise, depression predicts reduced social reintegration rates [54]. The concept of improving physical function to improve social reintegration after stroke was confirmed in a recent systematic review [55].

### Cardiac Rehabilitation

Most research on cardiac rehabilitation has focussed on reductions in mortality and morbidity with some reporting quality of life and far fewer examining socio-economic reintegration [56]. The key difference to stroke rehab is, rather than focal loss of function, cardiac disease results in generalised reduced function. This probably explains why a complex cardiac rehabilitation programme was able to demonstrate increased RTW rates [57]. Given the prevalence of acute coronary syndrome in those of working age, RTW is an appropriate measure of success [58]. The key focus here is that the strategies should be a ‘complex cardiovascular rehabilitation’ rather than a simple exercise programme.

### Cancer

The large numbers of working age people surviving cancer combined with an unemployment rate in cancer survivors of 1.4 times the healthy population make RTW a key target for this population [59]. Some factors that affect RTW rates in cancer survivors include [60]:

- Sociodemographic factors: Increasing age is the strongest predictor of reduced RTW rates. Other factors include female sex, lower educational level, and reduced income.
- Work-related factors: Physically demanding work negatively affects RTW, similar to the effect seen when comparing RTW rates after trauma [14]; a supportive working environment was associated with a positive effect on RTW.
- Disease-related factors: Reduced RTW rates are seen with more aggressive cancer types and less favourable prognoses; however, more intense and longer treatments may not demonstrate any difference in RTW rates.
- Other factors: Changes in attitudes to work can affect RTW after cancer survivorship and more time after cancer increases RTW rates.

Focussed interventions have consistently shown no improvements in RTW rates or quality of life; however, more complex interventions involving the wider multidisciplinary team have [59]. In this sense, cancer survivorship and socio-economic reintegration more closely resemble the experience seen in cardiac patients rather than stroke patients. Part of this may be the breadth of effects and presentations seen in the cancer population. The variety of types of cancer makes this heterogeneous group's needs more complex and diverse. The ideal solutions will need to mimic this diversity. This mirrors survival after critical illness, and the solutions in this population will need to be as varied and comprehensive.

## Conclusion

Poor socio-economic reintegration after critical illness is a significant problem that needs to be acknowledged and addressed. ICU survivors are at high risk of financial toxicity, social isolation, and increased healthcare utilisation in the year after hospital discharge.

Evidence-based solutions are lacking, but a pragmatic approach, tailored to the needs of the patient and their caregivers, should be implemented using local community resources. Financial solutions should start at hospital admission with support continuing into the community. Peer support may offer a stepping stone to full reintegration, while we can learn from other specialist programmes already in existence. Ultimately, to move forward, PICS needs champions to raise the awareness of the condition. Governments, financial institutions, and employers can then recognise the enormity of the challenge that is socio-economic reintegration after critical illness.

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# Chapter 19
# The Role of the Volunteer Across the Critical Care Recovery Arc

**Tammy L. Eaton, Joanne McPeake, and Leanne M. Boehm**

## The Evolution of the Volunteering Role in Health Care

The American and European Governments, as well as the United Nations, have advocated volunteering as a method of improving well-being and decreasing health inequalities [1]. Motivations for volunteerism include giving back, improving employment opportunities, widening social circles, and giving purpose to one's life [1]. As such, many different types of individuals are likely to engage in volunteer roles. For example, older, retired adults may be more likely to volunteer in an effort to widen their social circle and give purpose and structure to their lives. However, individuals who have been through their own ICU experience *(peer volunteers)* may be more likely to have altruistic motives for taking part in volunteering activities. Whatever the motivation for taking part in these opportunities, research has found

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that volunteering can enhance physical and mental health, happiness, satisfaction in life, and self-esteem [1–6].

In the healthcare setting, the role of volunteers is well studied within populations such as people with cancer, burns, and dementia [7–9]. These survivors and their caregivers report volunteering as a meaningful experience. They also appreciate being able to help themselves and others and describe feelings of increased self-worth through these roles. Peer volunteers, as well as current patients and caregivers alike, have reported the resulting realization that they were *"not alone"* in their experiences and emotions, an increased ability to talk freely about difficult experiences, and learning how others cope [10]. In general, volunteers find their roles rewarding; describing satisfaction from putting their own experiences to good use; and acquiring a sense of belongingness, meaning, and hope [7, 11].

In addition to the direct impact on volunteers and the people in receipt of the care they offer, volunteering also benefits hospitals and healthcare systems. For example, in one Canadian study, across 31 hospital sites, volunteers offered a return on investment to the service of around 700% [12]. Volunteers are also likely to contribute to the quality of care delivered within organizations. In a recent review, volunteers were found to add perceived quality by contributing to the happiness and comfort of patients, their families, and visitors [13]. Further, one American study across 50 hospitals demonstrated that hospitals with larger volunteering programs and greater investment in these roles returned higher patient satisfaction scores than those with less investment and infrastructure [14]. Thus, the benefits of investing in volunteer roles appear to be multifaceted.

## Volunteering: The Critical Care Landscape

Similar to other chronic illnesses, survivors of critical illness face sequelae that threaten their physical, psychological, and social well-being [15]. This group of signs and symptoms are commonly referred to as Post-intensive Care Syndrome (PICS) [16]. As these survivors attempt to derive meaning from their intensive care unit (ICU) experience, many search for experiences that allow them to enhance their well-being, support their new self-identity, and give back to the healthcare team that cared for them [17, 18]. Recent data also suggest that many patients wish to reconnect with the ICU, as a means of understanding what can be a life-altering experience [18]. This mechanism of self-healing has encouraged some ICU survivors to begin volunteering roles.

Volunteerism after critical illness may help to combat negative experiences for both the ICU survivor volunteer and those influenced by their efforts (i.e., current patients). This desire to volunteer may emerge from an altruistic motivation to give back to something larger than themselves or the wish to make a difference to the people around them [19]. Individuals may also look to volunteering as an avenue to self-preservation, self-belief, personal empowerment, or simply to find meaning in a "new normal" way of life [17]. ICU survivor volunteer opportunities hold great promise in helping to strengthen overall ICU experiences and ICU survivorship clinical care. Peer volunteers can give back while enhancing and actively engaging in their personal survivor journey. They can offer healthcare providers perspective into the ICU patient journey by sharing their ICU experience and assist in normalizing survivor trajectory for patients currently in ICU or receiving treatment in postICU settings, through peer support [17]. Additionally, peer volunteers know and understand the healthcare team and can assist in providing patient psychosocial and educational support activities as a peer support mentor.

Evidence guiding the use of volunteerism to improve critical care survivorship is minimal. Yet, opportunities exist for ICU survivors and their caregivers to volunteer in roles that support other patients and caregivers recovering from critical illness, while also improving their own recovery experience. The growing numbers of ICU aftercare programs (i.e., ICU diaries, postICU clinics, and peer support groups) may also benefit from ICU survivor and caregiver volunteers' knowledge of reintegration to life after ICU [20, 21].

## What Role Could Volunteers Undertake Across the Critical Care Patient Journey?

Figure 19.1 details the typical critical illness patient pathway. Critically ill patients often have a number of transitions of care throughout their critical illness, and volunteers have the potential to interact across this entire journey.

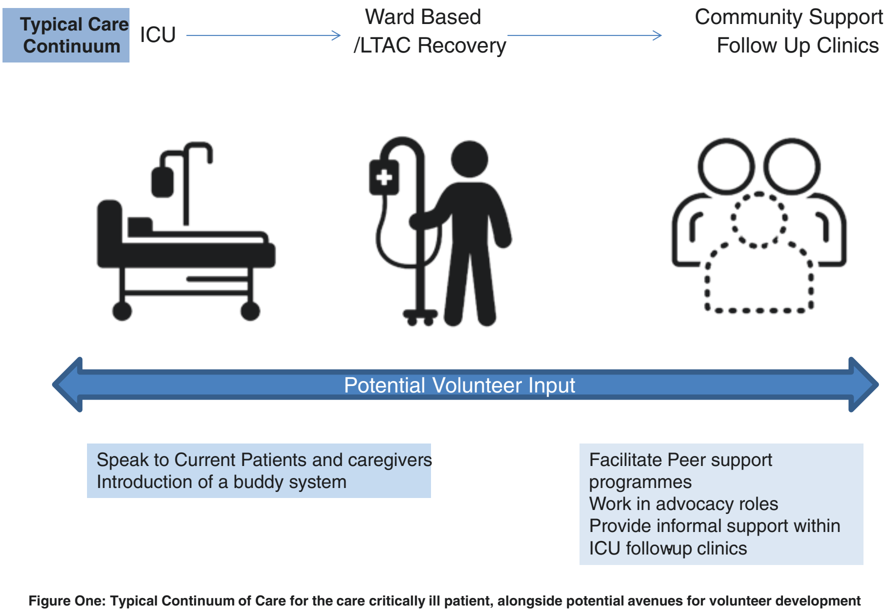

**Fig. 19.1** Typical continuum of care for the care critically ill patient, alongside potential avenues for volunteer development

## The ICU Environment

Former ICU patients and caregivers could adopt a number of volunteer roles within the ICU environment. One example is to have previous patients further along the recovery trajectory (e.g., 6–12 months) speak to current patients during their critical care stay. These volunteers could act as a symbol of hope, especially when current patients are in the ICU environment for extended periods. With an increasing number of persistently critically ill patients in our ICUs internationally, this role could support a large number of people [22]. Another method of integrating volunteer roles into the ICU environment is with a peer mentor or a peer 'buddy'. This model, which is a form of peer support tested in patient populations such as diabetes, has led to higher levels of positive action and coping [23]. In the critical care context, we can link individuals who are further along the recovery trajectory with patients still within the hospital environment. This peer mentor could work with patients and caregivers across the recovery arc, with the aim of providing guidance on aspects of care such as navigating the healthcare system and providing emotional support [24].

## Peer Support Groups

After hospitalization, attending a peer support group may be the first time a survivor encounters and socializes with others who have experienced a critical illness. With ICU survivor peer support programs gaining momentum internationally, this care delivery model provides the ICU survivor volunteer an opportunity to lead, participate, and shape these evolving programs [23]. One example is the ICU Survivor and Family Peer Support Program at UPMC Mercy Hospital in Pittsburgh, PA. After hospital volunteer training, this monthly program allows ICU survivor and family member volunteers to:

(a) contact other ICU survivors by phone or through mailings to share details of the monthly peer support groups,
(b) serve as a peer support group leaders during monthly group sessions,
(c) function as stakeholders for peer support group programming.

As a peer support group leader, the volunteer incorporates emotional assistance and mentoring through safety and comfort that can only be provided by someone having a similar experience. Through their ongoing input as stakeholders, the volunteer provides feedback for previous sessions as well as ideas for future meeting topics.

## Post-ICU Clinics/Recovery Programs

One area where the volunteer role is being developed internationally is in their involvement with postICU clinics and recovery programs [25, 26]. For example, the Intensive Care Syndrome: Promoting Independence and Return to Employment

(InS:PIRE) programme is a multidisciplinary service, run in almost a third of hospitals in Scotland, where patients and caregivers further along the recovery trajectory (6 months to 1 year post hospital discharge) support patients and caregivers during the initial phases of recovery. The main function of the volunteer in this setting is offering refreshments and 'chatting' with patients and caregivers in waiting areas where they may offer informal advice about recovery, as well as acting as a figure of hope. This model of supplying peer support through volunteering appears to provide benefit for current patients and caregivers, as well as to volunteers. In fact, volunteers have cited they felt that this role helped to improve their own recovery, in addition to serving as a mechanism to support reintegration into previous ICU activities (e.g., employment) [17].

## Important Considerations for ICU Clinicians and Providers

As we continue to develop ICU survivor volunteer opportunities, it is important to recognize there is a potential vulnerability to ICU survivor volunteers. Peer volunteers should be monitored for potentially negative psychosocial effects and triggers, which may be prompted by their support of those in distress [27, 28]. Clinicians working with volunteers should observe for signs of perceived burden, which could evolve in this role.

When attempting to implement these roles, ICU clinicians and providers must also ensure they are being inclusive and not exacerbating other inequalities. Although there is widespread adoption of peer volunteer roles internationally, evidence suggests there are social and health inequalities in those who undertake them. Individuals from more socially deprived backgrounds, and those with long-term chronic health problems, are less likely to volunteer than wealthier, healthier counterparts [29, 30]. Therefore, we must be cautious that we encourage and include individuals across the socioeconomic arc in these opportunities, that is, volunteers should mirror the patient group.

## Future Directions

As ICU recovery programs continue to develop and evolve to meet the needs of ICU patients, caregivers, and survivors, the role of the volunteer will also evolve. Research into the efficacy and sustainable implementation of ICU recovery programs is ongoing. Peer volunteers report benefits and describe finding value in their roles as volunteers within these programs. Likewise, the volunteer role has helped ICU survivors to support their reintegration into social circles and transition back to prehospital function and role [17]. Thus, inclusion of volunteer roles into ongoing and developing research programs will enhance the understanding of how to best use peer volunteers for the benefit of themselves and others during the ICU recovery process. As interests in peer volunteer roles increase in the ICU survivor population, practical concerns for the implementation should include navigating hospital and system-wide policies and procedures for onboarding and volunteer training and formalizing the structure of the role to avoid burnout and manage expectations of volunteer opportunity. Considerations for future research include the appropriate timing for an individual to take on the peer volunteer role (e.g., should this be at a specific time point in recovery), debriefing and self-care, attention to outcomes appropriate to determine efficacy of the volunteer role for both volunteers and recipients, and the potential influence of including peer volunteers in ICU recovery services.

## Conclusion

We have described opportunities for including peer volunteers into the arc of ICU recovery through a variety of methods both inside and outside of the ICU. Implementation of the peer volunteer role requires thoughtful consideration of peer equity and psychological burden of participants. Ultimately, peer volunteers can add immense value to ICU recovery programs while also receiving support for their personal transition back to "normal" life.

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# Part IV
# The Future State

# Chapter 20
# Issues of Survivorship in Lower Resource Settings

**Federico Carini and Dario Villalba**

## A Glimpse at the Problem – Two Cases

"Peter" is a 20-year-old man. He lives in Chivilcoy, a small town in Buenos Aires province, Argentina. One day, what started as an innocent cough proved to be a severe case of ARDS, which left him in the ICU (Intensive Care Unit) and deeply sedated for 10 days. When he eventually improved and woke up, his first thought was "where am I?" As the days went by, the medical team managed to wean him from the respirator, he was improving. But Peter started to get more and more anxious about his brother; he was the only family his small brother had. Who would look after the child while Peter was in the hospital? One month after he was discharged from the hospital, Peter came back for his first consult at the newly instituted post-ICU clinic. Several tests were performed, and everything seemed to be normal. But, he seemed anxious and depressed. We wondered if his mood had to do with the delirium he experienced during the ICU stay, the isolation, and the pain? Further inquiry revealed that it was a much more mundane and pressing issue that weighed on him: the electrical power at his house had been cut off because he had not paid it during his ICU stay, and he had not been able to solve the issue until that day.

Image 20.1: "El Recreo" – Grocer's shop ("pulperia") in Chivilcoy [1].

"Jules" lives alone and was in the ICU for 56 days after suffering a heart attack. Weaning from mechanical ventilation was particularly difficult because of severe delirium. After discharge, he had a striking improvement in his ICU acquired

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**Image 20.1** A traditional grocer's shop "El Recreo" in Chivilcoy, Province of Buenos Aires

weakness at home. When he attended post-ICU clinic 1 month after discharge, one of his main complaints was that he had not been able to collect his retirement pension during the 70 days he was admitted because he had not activated his electronic banking system. Thus, he was left without the financial means to survive at home after discharge.

## Background

Being admitted to the ICU for a severe disease represents a crisis for both the patient and his family. Whether the patient is a child, adult, or elderly person, the vital trajectory of that family suffers a sudden and inevitable change of direction. The manner in which each person copes with this type of crisis depends on several factors: the resilience of the patient and their family, preexisting chronic disease and frailty of the patient, and financial and social supports. During the last 50 years, we have seen an astonishing improvement in survival rates after ICU, with most series reporting that more than 80% of the patients admitted to the ICU will survive [2]. This has raised concerns about the long-term outcomes for these patients. What quality of life will the patient and family have once they are discharged, and can we do something different to improve that outcome? Moreover, what can be done to ameliorate the stress that being in the ICU represents for both the patient and the family? It is important to bear in mind that fear of the ICU, known as a place for very sick people at risk of dying, is high. On the other hand, reliable information about critical illness and ICU survivorship is lacking. These issues are prevalent worldwide, but low- and middle-income countries (LMICs) may have specific challenges to improving ICU survivorship. A recent newspaper headline in Argentina (Fig. 20.1) stated "More than 70% of the patients admitted to the ICU eventually recover." And yet, they fail to explain what recovery means in this context. This leaves both the patient and family wondering what to expect after an ICU stay.

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Se recupera del 70 al 90% de los pacientes en terapia intensiva

La mortalidad más baja se registra en las unidades destinadas a enfermos cardíacos

**Fig. 20.1** A newspaper title on critical care in Argentina "Between 70 to 90% of the patients survive ICU" [30]

We know that more than two thirds of the patients discharged from the ICU will experience some kind of limitation in their daily life and difficulties in returning to their previous activities [3]. Not only quality of life is reduced, but also mortality rates are higher among ICU survivors. Almost one third of patients surviving the ICU die during the first year after discharge; their mortality rate is five times higher than that of the general population [4] [5]. Moreover, resource utilization is also much higher after being discharged from the ICU [6]. In 2010, the Society of Critical Care Medicine (SCCM) named this collection of mental, cognitive, and physical problems in ICU survivors "post-intensive care syndrome" (PICS) [7]. As this topic has been reviewed extensively elsewhere in this book, we focus here on the importance of this new understanding for both patients and families in low- and medium-income countries (LMICs).

Most of the literature dealing with PICS comes from high- or middle-income (HIC) countries, where the availability of resources is higher – both during the acute phase of the illness and afterward when the patient goes home – than in low- and medium-income countries (LMICs). The World Bank defines countries by gross national income (GNI) per capita: for the 2020 fiscal year, low-income economies are defined as those with a GNI per capita, calculated using the World Bank Atlas method, of $1025 or less in 2018; lower middle-income economies are those with a GNI per capita between $1026 and $3995; upper middle-income economies are those with a GNI per capita between $3996 and $12,375; high-income economies are those with a GNI per capita of $12,376 or more [8]. Therefore, countries such as Bolivia, for example, would qualify as a LIC, while most of the rest of the countries in South America are LMIC, as are many countries in Africa, Asia, and Central America. But much of the literature about PICS comes from high-income countries (USA, Europe, and Australia), raising the question of whether the information they provide applies to the different contexts faced in LIC. These disparities exist in every part of the health system, from access to basic health-related services to availability of ICU beds, and with the added limitation, that information regarding health utilization is often unreliable in LMIC [9]. In this chapter, we examine PICS and its sequelae in the context of these lower resource settings.

## What We Know So Far – Issues for Patients

Several strategies for preventing or ameliorating PICS have been proposed, both during the ICU stay and after the patient has been discharged [10]. During the ICU stay, protocols should be established for the management of analgesia, sedation, and delirium, prioritizing the selection of drugs that have the lowest adverse effect profile and always including the whole interdisciplinary ICU team in the care of each patient. The important role that the family can play in the recovery of the patient, from the moment he or she enters the unit, should be emphasized and fostered. Once the patient has been discharged, anticipatory guidance and aftercare are needed to address the problems that they may face once they get home. For that purpose, both post-ICU clinics and group meetings for survivors and their families have been proposed.

In a recent study done by Geense, after a thorough review of the available evidence, they found only two strategies with evidence to support improved long-term outcome after the ICU: both ICU diaries and exercise programs appear to have a positive effect on mental outcomes [11]. One limitation to these strategies in LMIC is the lack of resources to implement them. It is important to detect such limitations when trying to implement new strategies across resource settings. Such limitations are not limited to LMIC, as outlined by Haines et al.: they found that the main barriers to post-ICU clinic implementation are lack of funding, a designated place to actually carry out the consult, difficulty identifying which patients to follow, and loss to follow-up after initial inclusion in the program [12].

Survivors of ICU also face several psychological challenges, which may vary depending on the country and culture studied. Hatchett [13] evaluated post-ICU psychological well-being in South Africa, specifically looking for anxiety, depression, and PTSD, and found a similar prevalence of these issues as in other studies. They found that 48% of the survivors had anxiety according to HADS (Hospital Anxiety and Depression Scale) (standard error (SE) 0.05; CI 0.38–0.58), and 28% of the sample showed symptoms of depression using the cutoff score of 8 on the HADS (SE 0.45; CI 0.185–0.365). Finally, a total of 32% (SE 0.05; CI 0.22–0.41) of the sample showed symptoms of PTSD using a cut off value of 8 or higher on the ETIC-7 (Experience After Treatment in Intensive Care 7), a scale specifically designed to detect PTSD in ICU survivors. Notably, younger patients seemed to be more compromised than older ones.

Another interesting study done in a LMIC regarding post-ICU follow-up was done by Pieris et al. [14]. They performed a multicenter follow-up study in over 400 ICU survivors, who were evaluated over the phone 1 month after ICU discharge. They found that almost 78% did remember the moment they were admitted to the hospital, but only 43% remembered when they were admitted to the ICU; 90% did not fear remembering their ICU stay, more than half of the patients evaluated their sleep during the ICU stay as enough and restoring, and only 12% remembered having nightmares. A few patients made suggestions for improvement: having more ICU beds, reducing noise, being kinder to patients, separate cubicles for patients, and allowing more visitors to reduce stress. They reported high levels of satisfaction with ICU care. Finally, stressful experiences were most frequently related to uncertainty about the future, dependency, family, and economic concerns.

Regarding ICU clinics in particular, it has not been clearly established if and how their use actually improves any of the domains included in PICS, or whether a post-ICU clinic improves the poor health-related quality of life (HRQoL) commonly experienced after critical illness. One possible factor involved in that lack of demonstrated effect is that clinicians usually fail to address important social and financial aspects that patients and families struggle with after being discharged. In the Intensive Care Syndrome: Promoting Independence and/or Return to Employment (InS:PIRE) study [15], a social welfare consultation was made available to participants; 31% of patients (33 of 108 patients who attended) and two caregivers requested a consultation, demonstrating that addressing this issue is feasible in post-ICU clinics and also that the socioeconomic needs of this group are prevalent and diverse.

Finally, clinicians are trying to better understand what patients feel and think after being discharged from the ICU. In a qualitative study looking into this issue in South Korea, Kang and Jeong found that ICU survivors are often “embracing the new vulnerable self.” They felt vulnerable in many aspects (physical, psychological, and social) after their ICU stay. They struggled for recovery; many faced new crises, and some were devastated. However, some develop a new sense of “normality” that allows them to push forward in life [16]. How this psychological trajectory plays out in LMIC has been less explored to date.

## Strategies to Improve – Issues for Health Systems

There has been a lot of debate around strategies to improve post-ICU outcomes, but at this point, it is unclear how those discussions apply in LMIC. LMIC need to generate their own evidence and experiences regarding PICS, starting with current prevalence and then moving to strategies to ameliorate its impact.

According to Murthy et al., [9] LMIC usually do not have enough ICU beds and also lack a clear definition of what an ICU bed is (it may depend on the nurse to patient ratio, the availability of mechanical ventilation for each bed, or the resources to support certain organ failures). It is not clear based on this systematic review if ICU bed scarcity impacts PICS, but it would be important to bear in mind that PICS prevalence would be lower if fewer patients were admitted to the ICU due to lack of beds or fewer patients survived the ICU due to a higher mortality. However, as critical care improves, more patients survive to hospital discharge and are thus at risk for PICS and in need of post-ICU recovery services.

Expansion of critical care capacity is needed in nearly every country, in particular considering that approximately 84% of the global population lives in LMICs, where critical care capacity is often insufficient. Having better care for the critically ill patient in that context can help to lower both mortality and morbidity and probably improve post-ICU outcomes [17–19]. Of note, several key factors in public health affect critical care in these countries, including those regarding basic needs such as clean water, waste management, and environmental pollution. Early detection of sepsis, trauma prevention, and primary health care for patients with chronic respiratory disease may also improve dramatically the need for critical care in these populations.

Funding is another key factor to bear in mind when it comes to understanding some of the challenges faced in LMIC. Not only is financing often scarce, but also in many LMICs, it is also fragmented and unevenly distributed. For example, in Argentina, there is a public system (derived from national funds), a private sector (resourced with private funds), and health insurance (associated with each profession or work activity). Furthermore, the biggest and most comprehensive health systems are concentrated in large cities, but without any effective networks for referral of patients from smaller cities. If patients are successfully transferred from a smaller health system to a larger one, they and their families may be isolated from loved ones and familiar places, with loved ones being forced to travel many thousands of kilometers to visit their relatives.

Of the strategies proposed to reduce or improve PICS, implementation of the ABCDEF bundle is perhaps the most readily adaptable to LMIC. However, there is scarce information regarding its implementation in LMIC. The ABCDEF bundle has proven to be effective in improving several key outcomes in critically ill patients in HIC, including duration of mechanical ventilation, delirium and coma-free days, mobility, pain management, and mortality [20, 21]. Adherence to this protocol is still heterogenous, though, especially in some of the strategies such as early mobilisation. In a recent survey done in Argentina, many of the respondents claimed to apply the bundle, but only 15% had started to broaden ICU visiting hours, a low cost intervention that has been shown to decrease the incidence of delirium in critically ill patients [22] (Fig. 20.2). Delirium, artfully interpreted by ICU survivor and artist Nancy Andrews (Fig. 20.3), is also a problem that has not been fully addressed, and many report not using adequate tools to detect it regularly. Another survey done in Africa by Baelani et al. [23] found that many centers did not have enough resources to fully apply the sepsis management bundle, in spite of having available ICUs, due to a lack of infrastructure, equipment, drugs, and disposable supplies.

Regarding long-term outcome after ICU, Das Neves et al. [24] performed a multicenter follow-up study in Argentina, with over 200 critically ill patients being evaluated. They reported a worse health-related quality of life (HRQoL), especially related to limitations in mobility, activities of daily living, and self-care. They also found a high prevalence of chronic pain, anxiety, and depression both before and after the ICU admission (almost 40% of the patients). Duration of mechanical ventilation was the only factor within the ICU stay that consistently impacted HRQoL (more time on mechanical ventilation was associated with worse HRQoL). Other independent factors for worse HRQoL were morbidities the patient had before coming to the ICU and the severity of illness at admission; after the ICU, ICU-acquired weakness (ICU-AW) also proved to be a determinant of lower quality of life scores. Busico [25] and Das Neves [26] also found that ICU-AW was an important factor for worse HRQoL. Therefore, reducing ICU-AW can be key in reducing PICS, but we need to better understand the challenges faced when trying to implement specific strategies to do so in differently resourced settings. Das Neves [26] also reported that patients who could return to their previous work or activities had better HRQoL. Perhaps, another important issue to address would be to include support programs for patients who struggle with work limitations after ICU, especially in LMIC.

**Fig. 20.2** Open visitation in ICU. Buenos Aires, Argentina

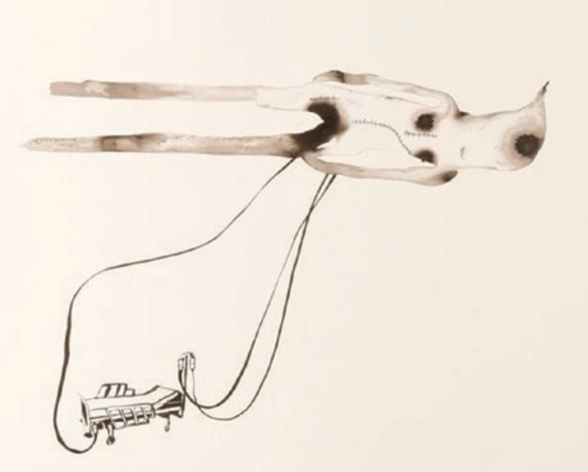

**Fig. 20.3** “Delirious” by Nancy Andrews (with permission) http://www.nancyandrews.net/drawings.html

Post-ICU clinics represent another strategy for dealing with some aspects of PICS and have been applied in several countries so far with different results. Schofield-Robinson et al. [27] performed a systematic review of post-ICU clinics and concluded that there is not enough evidence to determine if follow-up clinics are effective for detecting and managing the need of ICU survivors and their families. One limitation reported is the paucity of evidence on this topic. Due to this lack of evidence, they could not discriminate whether there is one preferred clinic format or if certain populations would benefit from such programs; they propose that future research should also focus on these points. The Argentine Society of Critical Care has published a guide to conducting post-ICU clinics, including some of the core outcome measures that may be useful to include. In that work, [28] they propose that only patients with the higher risk of suffering PICS should be included in the post-ICU clinics, using validated tools for assessing for PICS characteristics and in the native language of the country. Most of these tools are free to use, but some require a fee or previous training, both potential barriers in LMIC. In Fig. 20.4, we show a 6 minute walk test (6MWT) being performed in a post-ICU clinic in Buenos Aires, Argentina. In Fig. 20.5, we show a patient performing one of the tools included in the guideline, the Montreal Cognitive Assessment test (MoCA). One potential caveat of this specific tool is that it is only designed to screen for cognitive

**Fig. 20.4** 6MWT in a Post-ICU Clinic in Buenos Aires, Argentina

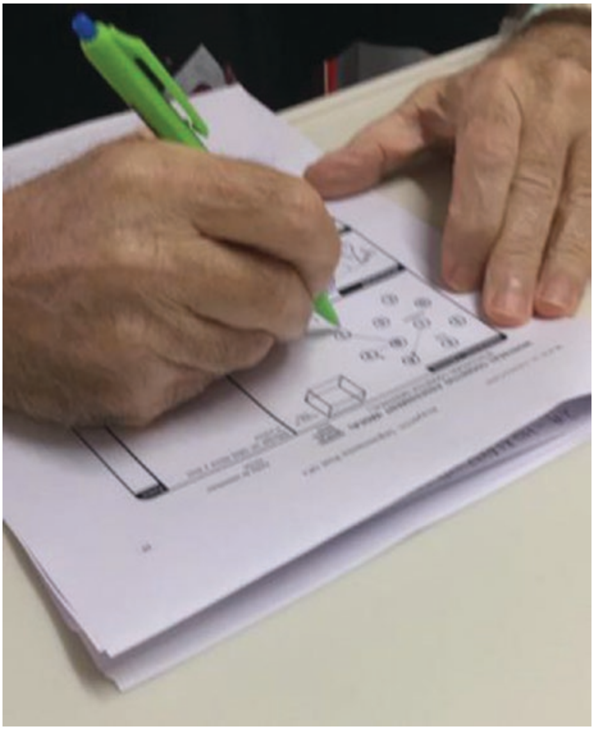

**Fig. 20.5** Performing a MoCA in a Post-ICU Clinic in Buenos Aires, Argentina

deficits; it doesn't include any treatment strategies, but rather recommends proper referral to a specialist. The ideal scenario would probably include an integrated multidisciplinary team, but that would not be feasible in many cases due to the aforementioned resource restraints in LMIC. Post-ICU clinics are a relatively recent development in the care of ICU survivors, and while evidence is still sparse that such an approach improves long-term outcomes, there is developing evidence that both patients and families are more satisfied with this type of approach.

In Fig. 20.6, we show a consult in a Post-ICU Clinic in Chivilcoy, Buenos Aires, Argentina. The experiences of this post-ICU clinic illustrate many of the challenges faced by clinicians caring for ICU survivors in LMIC and the barriers that must be overcome to establish and sustain post-ICU care in LMIC. There were no previous experiences with post-ICU clinics in the country and thus no model to emulate. When the clinic was established, PICS was a novelty almost unknown to most of the practitioners of critical care in the country, as well as the general population. Many of the reports about ICU survivorship were coming from the United States and Europe; the Latin American experience was relatively unknown. Most of the knowledge about ICU survivorship in Argentina, for example, started in the context of research studies; clinical services remained mainly because of individual efforts of some leaders in the field. Patients and relatives also face challenges when dealing with post-ICU consequences, with most post-ICU consults made in more informal environments with the general practitioner of each town or village.

**Fig. 20.6** A post-ICU Clinic in Chivilcoy, Buenos Aires, Argentina

Another challenge for post-ICU clinics in LMIC is funding and billing: as previously mentioned, funding is scarce and fragmented. Many motivated clinicians end up organizing and working in post-ICU clinics as voluntary work in their free time, making sustainability in an ongoing barrier to providing the best care for ICU survivors and their families.

In summary, responsiveness to PICS is relevant to both HIC and LMIC. But many questions remain. Should we follow every patient discharged from the ICU? How should we select the patients who would benefit the most from this type of program? Once we detect a problem during follow-up, how should we address it? From the personal perspective of the authors, it seems that we also need to adapt to every patient and their family. PICS is not a “one-size-fits-all” scenario: the values and expectations of both the patient and the family must be taken into account before deciding how and when to do post-ICU follow-up. As illustrated by the cases of Peter and Jules, it will be necessary to take into account the financial and social consequences of critical illness, and not just the physical, psychological, and cognitive deficits of PICS, when designing and implementing post-ICU programs in lower resource settings.

Pragmatic evaluation of post-ICU care (what is useful, for whom, in what context, and at what timepoint in the illness or recovery) is urgently needed in LMIC. In the words of Theodore J. Iwashyna, "survivorship will be the defining challenge of critical care in the 21st Century," and we dare to add "both in HIC and LMIC" [29].

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# Chapter 21
# The First Step in a Critical Journey: Selecting Patients for Intensive Care

**Thomas S. Valley**

## A Case Example

Picture two patients. Both are 70-year-old females in the emergency department of your hospital with pneumonia. You have been asked to consider whether either patient should be admitted to the intensive care unit (ICU).

The first patient is endotracheally intubated and on mechanical ventilation. She is hypotensive and on escalating doses of vasopressors.

The second patient is awake and alert but slightly confused. She is breathing 24 times per minute and is requiring 8 liters per minute of supplemental oxygen to maintain an oxygen saturation of 92%. Her blood pressure is 94/56 mm Hg. Her vital signs are otherwise normal.

These cases highlight that the complexity of ICU admission decision-making lies on a spectrum. Sometimes, triage is straightforward. Other times, determining whether a patient should receive intensive care is more difficult.

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## What Is Intensive Care?

In order to determine “who” should receive intensive care, it is critically important to understand “what” intensive care actually is. The term “intensive care” commonly reflects two related concepts [1]. First, intensive care often represents the highest level and most aggressive care available at a hospital. In this traditional context, critically ill patients receive care that is thought to be synonymous with an ICU—mechanical ventilatory support for respiratory failure and/or circulatory support (i.e., vasopressors) for shock.

Second, intensive care is typically provided in a geographically isolated location where the sickest patients in a hospital are brought to receive specialized care, often from physicians, nurses, respiratory therapists, and other healthcare staff with specific training or expertise in critical care. In this context, critically ill patients receive care from clinical staff with proficiency in the management of ventilators, vasopressors, and other forms of life support. However, it is less certain whether patients without traditional ICU needs (i.e., patients not receiving ventilatory or circulatory support) might also benefit from this specialized level of care.

Conventional wisdom has held that the aggressive life support and close monitoring in an ICU save lives. Overuse of ICU care may, in part, be due to the fact that, for individual patients, negative consequences associated with ICU use have not been definitively established. However, increasingly, harms of ICU admission are being considered.

At an individual level, patients admitted to ICUs often receive invasive procedures, regardless of their actual need for it [2–4]. These procedures can be painful and may place patients at risk of unnecessary procedural complications. Geographically isolating the sickest patients in the hospital may place patients within an ICU at increased risk of healthcare-associated infections [5, 6]. Furthermore, a French randomized trial evaluating increased ICU access for elderly patients suggested an increased risk of death at 6 months among patients admitted to an ICU [7]. Finally, survivors of critical illness are at increased risk of depression, anxiety, and post-traumatic stress [8]. Whether these symptoms are related broadly to critical illness or directly to ICU admission has yet to be disentangled.

At a societal level, the cost of intensive care is enormous [9]. In the USA, approximately one-quarter of all hospital stays included time in an intensive care unit [10]. These hospitalizations accounted for nearly half of the charges from all hospital stays [10]. In other countries, costs play an important role in the reduced number of ICU beds compared to the USA [11]. Having fewer ICU beds acts as some level of cost control but may also reduce access to patients who might benefit from ICU services [9]. These risks highlight that, like any medical treatment, clinicians must carefully identify patients who should receive intensive care. Both overuse and underuse of intensive care can be harmful to individuals and to the society at large.

## Who Should Select Patients for ICU Care?

Typically, there are two main parties involved in an ICU admission decision—a referring clinician and an ICU team [12]. Admission to ICU care is typically left to the discretion of a single physician, though no evidence exists that has tested this practice. The expertise of this physician may vary depending on the hospital and its staffing model. In hospitals with "open" ICUs (hospitals where ICU patients may be cared for by physicians who also care for patients outside of an ICU), referring clinicians may continue caring for their patients upon transfer to an ICU. In hospitals with "closed" ICUs (hospitals where ICU patients are cared for by ICU physicians), referring clinicians must request access to ICU care and then must transfer care of their patient to an ICU team. There is no available evidence as to how an "open" or "closed" staffing model might affect ICU admission decisions.

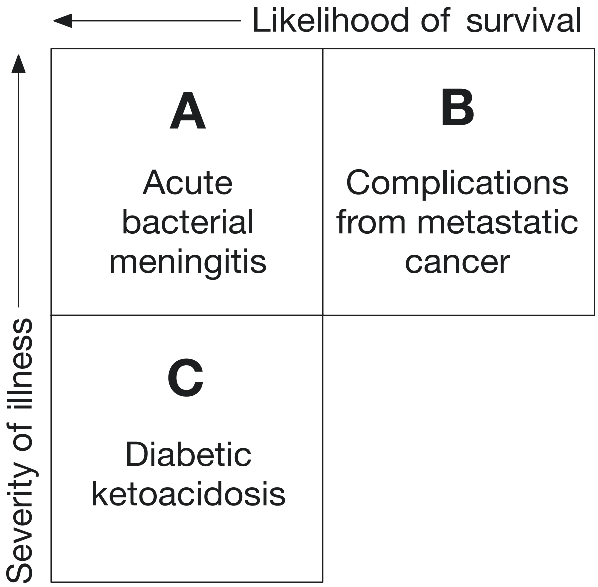
While ICU admission is typically left to a physician's judgment, it is also clear that other ICU clinicians, such as nurses or respiratory therapists, may offer important insights to the triage process. For example, many patients receive ICU care due to (perceived or actual) limitations of care on a general ward. Nurses and respiratory therapists may have key knowledge about the types of patients best suited for a general ward at a particular hospital. However, there are currently no data evaluating the effectiveness of multidisciplinary approaches to triage [13].

Rapid response teams (i.e., clinical teams available to provide care for unstable patients outside of an ICU) are now commonplace across hospitals [14]. These teams tend to be nurse-led with availability based on nursing concerns. Despite their broad appeal, studies evaluating the effectiveness of rapid response teams have been equivocal [15]. Some hospitals have also created critical care consult teams for patients outside of an ICU, who were either declined ICU admission or who are deteriorating on a general ward [16]. These teams tend to be led by intensivists and may be able to provide some level of critical care outside of a traditional ICU. Critical care consult teams appear to be less widely implemented than rapid response teams, and their effect has not been investigated as thoroughly.

## How Are Patients Selected for ICU Admission?

Various guidelines have aimed at assisting clinicians in the selection of medical ICU patients [13, 17–19]. These guidelines all highlight the need to target patients with the potential to benefit from ICU care [20]. Figure 21.1 presents three case examples with how severity of illness and prognosis might affect the concept of "potential to benefit from ICU care" and, in turn, affect ICU admission decision-making. *Panel A* depicts the ideal cohort of ICU patients—those with severe and reversible illness. *Panels B* and *C* depict two groups for whom ICU admission is generally not recommended—those with severe but terminal illness and those with reversible but mild illness.

**Fig. 21.1** A theoretical model for how severity of illness and prognosis interact with ICU triage



There is no proven method to identify patients who would benefit from ICU care and ensure that these patients (and not others) receive ICU care. Furthermore, there is little consensus about the ideal features for such a tool [21]. Unlike trauma [22] or mass casualty/epidemic scenarios [23, 24], there are very few established standards for the triage of medical ICU patients [25, 26]. This gap is reflected in clinical practice where variation in ICU use is staggering. Some US hospitals admit as few as 3% of their patients to ICU care, while other hospitals use ICU care for more than half of similar patients [27].

Three broad types of triage tools or algorithms exist: (1) subgroup-specific, (2) physiology-based, and (3) priority scores [19, 28]. Subgroup-specific algorithms exist for various conditions or diagnoses, though wide-scale implementation has yet to be demonstrated. Two prominent examples can be found for older patients and for patients with cancer.

Older patients have been noted to be less likely to receive ICU care, particularly in Europe [29]. As a result, a number of studies have focused on documenting these differences, evaluating causes, and considering next steps [30, 31]. The Eldicus 1 study created a triage score to identify elderly patients either too sick or too healthy to benefit from ICU care [29]. Factors within the score included age, diagnosis, creatinine, white blood cells, platelets, albumin, use of vasopressors, Glasgow Coma Scale score, Karnofsky Scale, operative status, and chronic comorbidities. Whether this score has been implemented in clinical practice outside of this study is unclear.

The ICE-CUB 2 study examined the effect of increased ICU access for elderly patients [7]. In a cluster randomized trial, all critically ill patients aged 75 or older were randomized to usual care or an intervention aimed at increasing ICU use. The intervention was successful—patients in the intervention arm had a 27-percentage point increase in ICU admission rate compared to the control arm. However, there was increased mortality demonstrated after adjustment, suggesting indiscriminate increases in ICU access may be harmful. The authors of this study subsequently published an ICU triage algorithm for critically ill patients over the age of 80 [32].

While not a true triage tool, the ICU Trial sought to increase ICU access for cancer patients requiring mechanical ventilation, for whom ICU care is frequently considered non-beneficial [33]. In this prospective cohort study, two in five cancer patients with respiratory failure who survived to the fifth hospital day survived to hospital discharge, suggesting cancer patients might experience systematic under-triage. Therefore, time-limited trials of ICU care may be of utility for these patients [34–36].

More commonly, objective values, such as vital signs or laboratory results, have been used to identify patients at risk for decompensation, either from the emergency department or general ward. Commonly used models include the Modified or National Early Warning Scores (MEWS or NEWS), the Sequential Organ Failure Assessment (SOFA), and the Electronic Cardiac Arrest Risk Triage (eCART) score [37]. For instance, the MEWS score uses systolic blood pressure, heart rate, respiratory rate, temperature, and level of alertness—assigning each category a score [38]. These models have often been used in tandem with other forms of clinical assessment (e.g., rapid response teams) to increase early identification of at-risk patients [39]. Both MEWS and NEWS have been used broadly and implemented into clinical practice to various degrees.

The 2016 Society for Critical Care Medicine guidelines for ICU admission suggested the use of a priority score for ICU admission, ranging from one (critically ill, likely to benefit from aggressive life support, no life-limiting preferences) to five (unlikely to benefit from aggressive life support) (Table 21.1) [19]. These guidelines are helpful for patients with a priority score of 1, but ambiguity related to priority scores of 2 through 5 has made wide-scale implementation difficult. Perhaps, as a result, one American study demonstrated that 65% of patients within an ICU were admitted with a priority score between 2 and 5 [40].

**Table 21.1** Society for Critical Care Medicine's priority score for ICU admission

| Priority score | Recommended care | Patient example |
|---|---|---|
| 1 | ICU | Requires life support |
| 2 | ICU | Same as 1 but may have poor prognosis or do not want cardiopulmonary resuscitation |
| 3 | Intermediate care | No current need for invasive life support but may need it in the future |
| 4 | Intermediate care | Same as 3 but may have poor prognosis or do not want intubation/resuscitation |
| 5 | Palliative care | Terminal patient with no chance of recovery |

## Why Is ICU Triage Difficult?

Traditionally, ICU triage has focused on identifying patients at the highest risk of mortality [41]. Certainly, identification of patients at increased risk for death is important. However, there may be a mismatch between tools seeking to identify patients at high risk of death and guidelines aiming to select patients with the most potential to benefit from ICU care. In particular, physiology-based tools and priority scores may not be tuned to identifying patients with more subtle risk of death who may still benefit from ICU care.

Some studies have suggested that patients at more modest risk of death may still benefit greatly from ICU care. For example, two studies, one among elderly patients with pneumonia and another in ST-elevation myocardial infarction, found that ICU admission reduced 30-day mortality by 6-percentage points [42, 43]. Patients who received this benefit in these studies did not have traditional ICU needs (i.e., require mechanical or circulatory support) and presumably received ICU admission based solely on their proximity to a hospital that used ICU care frequently.

## Factors Affecting the Selection of ICU Patients

A number of clinical and non-clinical factors have been associated with ICU admission (Fig. 21.2) [44–46]. Among clinical (or patient-related) factors, clinicians most frequently use age, admission diagnosis, and severity of illness to guide triage [44]. However, there is poor agreement between intensivists on how much these characteristics should guide ICU admission decision-making [47]. Race or ethnicity has frequently been found to influence decision-making in healthcare, with these implicit (and sometimes explicit) biases often resulting in unwarranted variation in care and differences in outcomes [48]. While some differences in ICU admission, particularly at the end of life, have been attributed to preferences for aggressive care

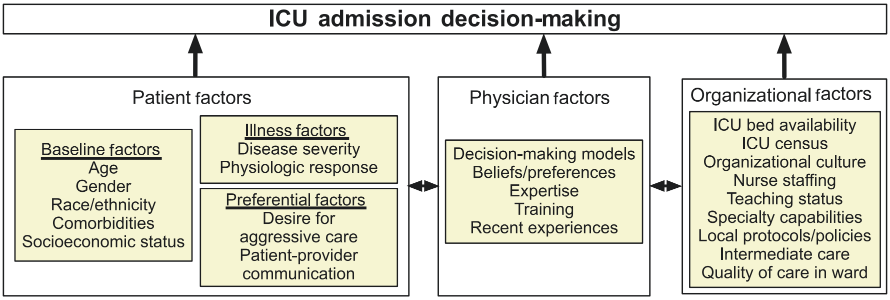


**Fig. 21.2** Patient, physician, and organizational factors influencing ICU admission decision-making

or other unmeasured factors [49–51], race or ethnicity had no effect on ICU triage, at least in two *in silico* randomized experiments [47, 52].

Patients with certain clinical conditions have been historically linked with critical care. For example, the vast majority of patients with ST-elevation myocardial infarction receive critical care, either in intensive or coronary care units [53]. Yet, most of these patients have no clinical needs consistent with the use of modern critical care [54]. To what extent these patients truly need intensive care and what strategies can be used to change entrenched triage practices remains unclear.

Patients experiencing chronic critical illness represent a unique population for whom the need for traditional ICU care is unclear [55]. These patients may have long-term requirements for mechanical ventilation and, thus, are often treated in intensive care units as most hospital units outside of an ICU do not typically care for patients on ventilators. Yet, patients with chronic critical illness are different in many ways from patients with acute critical illness, and whether outcomes are better or worse with ICU care remains unanswered.

More frequently, variations in ICU admission practices across hospitals have been attributed to non-clinical (or non-patient-related) factors [2, 27, 56]. These factors can be generally placed into one of two categories: organizational/hospital or physician. A number of organizational factors have been associated with ICU use. ICU bed availability is the most commonly cited non-clinical factor linked to ICU use [44, 57, 58]. On average, the more ICU beds available, the more likely a patient is to receive ICU care [20, 59]. One study of three academic hospitals in the USA found that ICU use increases linearly with ICU bed availability until approximately five ICU beds are available, at which point the likelihood for ICU admission plateaus [60].

Other less established organizational factors associated with ICU admission include hospital protocols or practice culture and the presence of an intermediate care unit. For certain conditions that typically have low rates of mortality, such as diabetic ketoacidosis or pulmonary embolism, wide variation in ICU admission has been attributed to either hospital protocols (e.g., many hospitals require intravenous insulin for diabetic ketoacidosis to be given in an ICU) or practice culture (e.g., there may be a mismatch between perceived risk of mortality and actual risk of mortality due to pulmonary embolism) [2, 3].

Intermediate care is increasingly utilized in US hospitals, despite fairly opaque definitions as to what intermediate care actually means [61]. At its most basic form, intermediate care represents a level of care between an ICU and a general ward. Triage to intermediate care presents an alternate care strategy for patients who may be too ill for a general ward but may not fit traditional definitions of a critically ill patient. Yet, like with intensive care, little is known about optimal patient types or triage strategies for intermediate care—placing intermediate care at risk for overuse, much like ICU care.

The factors intrinsic to clinicians that affect ICU admission decision-making are less established. As demonstrated in randomized vignette studies of both American and Swiss physicians, physicians have strongly held beliefs about the types of patients who should receive intensive care [47, 62]. Physicians may have certain patterns in their ICU admission decision-making—systematically either over- or under-weighing specific patient characteristics [63]. Opportunities may exist to retrain these decision-making models to more optimally standardize ICU triage practices.

## Long-Term Outcomes After ICU Admission

The direct impact of ICU admission on long-term outcomes, independent of the cause of admission or of severity of illness, is not entirely clear. Mortality estimates between observational studies vary, partly due to differences in inclusion criteria. A population-based Canadian study found that 11% of ICU survivors had died by 1 year and 29% by 5 years [64]. A prospective study from France and Belgium demonstrated that 21% of ICU survivors died in the following year [65]. Quality-of-life studies have mostly been performed among the very old ICU population, generally demonstrating decreased quality of life and functional status at 1 year [66, 67]. Yet, the results from the only available randomized trial of ICU admission (which included a highly selected group of patients over the age of 75) contrasted with these observational studies. The baseline 6-month mortality in the control arm of the ICE-CUB 2 study was 39%. Systematic ICU admission for patients over the age of 75 resulted in a 6-percentage point increase in unadjusted mortality at 6 months but, after adjustment for baseline characteristics, revealed no differences in mortality, functional status, or quality of life at 6 months [7]. There is a clear need to understand the long-term implications of ICU care.

## Toward Optimal Patient Selection for ICU Admission

The term “triage” strongly connotes the need of the accepting ICU clinician to sort patients in the order of greatest potential benefit, as ICU care is often a limited resource. Further complicating matters, it is impossible for ICU clinicians to know what (or who) lies around the corner. In other words, intensivists must accept or decline patients for ICU care without knowing whether the next patient referred for ICU care will be more or less ill than the current one or at what point additional ICU beds may become available.

What current strategies, then, are available for a clinician seeking to optimize their ICU selection? As detailed above, no evidence-based guideline exists to support decisions made regarding ICU triage. Current guidelines recommend maximizing potential to benefit [19].

The term “benefit,” within the context of triage, is difficult to conceptualize, as it may differ from patient to patient and clinician to clinician. In many ways, mortality is easier to grasp, as clinicians can more easily correlate severe illness with higher risk of mortality. Benefit, on the other hand, depends on a counterfactual. Benefit requires clinicians to estimate the difference between two immediately unmeasurable outcomes: (1) what will happen to a patient if they receive ICU care and (2) what will happen to a patient if they do not receive ICU care. Perhaps as a result of this difficulty, clinicians often disagree about which patients might benefit from ICU care [47]. Subsequently, attempts to triage patients based on potential to benefit, while well-meaning, lead to poor reliability in ICU use between clinicians and hospitals.

Ideally, just as mortality or severity of illness calculators are commonplace, benefit calculators would also be available to guide clinician's decision-making. These calculators would be most helpful for patients without straightforward indications for ICU care, as this patient population is particularly at risk for variation in care and this variation in care may result in differences in outcomes [42, 43, 68].

Without such empirical benefit calculators, the focus on one individual's "potential to benefit" may be problematic. It requires a clinician to estimate the following equation:

$$\text{Potential to benefit} = \left(P_{\text{ICU beneficial}} - P_{\text{ICU harmful}}\right) - \left(P_{\text{Ward beneficial}} - P_{\text{Ward harmful}}\right)$$

where $P$ is the probability of ICU/ward benefit or harm. If this equation is positive, then a patient conceivably benefits from ICU care. Yet, it is often difficult to visualize situations where a patient might have worse outcomes in an ICU than in a general ward, despite increasing awareness of possible harms associated with ICU admission. Subsequently, clinicians may systematically overestimate potential to benefit from ICU care.

What might clinicians consider instead of potential to benefit? There are several questions a clinician might ask themselves when contemplating ICU care for a patient. First, what specific clinical treatments does this patient require? In this context, "treatments" are not limited to tangible interventions (e.g., mechanical ventilation) but may also include care treatments, like close monitoring for respiratory deterioration. Second, to what extent could these treatments be reasonably provided outside of an ICU? This question should be considered in the context of the specific resources available within one's general ward or hospital. Finally, if treatments can only be reasonably provided in an ICU, then would these treatments be consistent with the patient's preferences? Some triage guidelines use preferences against cardiopulmonary resuscitation or endotracheal intubation as a reason to withhold ICU care [19]. However, extending these preferences beyond their stated intent may perpetuate implicit biases and create ethical quandaries [69].

At the same time, the above questions do not consider the organizational constraints that often influence ICU use. It may also be helpful for an ICU or a hospital to develop their own vision for their average ICU patient. This vision should ideally be informed by key stakeholders (patients, clinicians, administrators, from both within and outside of an ICU). This vision may be developed based on the resources available to the hospital as well as the practice culture of local patients and clinicians. This shared vision may then be used as a mental model for clinicians while understanding that there may be some patients who do not fulfill this vision who may still benefit from ICU care.

For instance, some hospitals may have the resources necessary to consider benefit under a short-term lens (e.g., could ICU care allow a patient to survive this hospitalization?). However, other hospitals may have more limited resources and may need to consider benefit on a longer term (e.g., could ICU care allow a patient to survive this hospitalization with a meaningful long-term prognosis?). In this latter context, "potential to benefit" is used as a hospital-level term (i.e., intended to maximize patients with the potential to benefit at a population level) rather than as a patient-level term (i.e., where clinicians must make individual decisions without a concrete sense of the larger organizational vision). At the same time, the ethical implications of differing resources across hospitals and the resultant variation in care and outcomes are complex and should be a consideration of broader health policy.

Ultimately, the selection of ICU patients is a nuanced endeavor. Clinicians must estimate the short- and long-term trajectories of critically ill patients early in the time course of a severe, acute illness, often on their first encounter with a patient and their family. Optimal triage requires not only an assessment of the patient's prognosis but also an understanding of the patient's preferences for life-sustaining treatment. Yet, despite these complexities, the importance of ICU selection cannot be overstated [70], and ongoing efforts to improve ICU triage may one day reduce overuse, prevent underuse, and ensure appropriate use of ICU care.

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# Chapter 22
# A PICS-Free Future: What We Need to Address Now

**Jason H. Maley and Mark E. Mikkelsen**

## Introduction

Through advances in care delivery, most patients survive critical illness to leave the hospital. The challenges of supporting the recovery of this growing population are evident and compounded by the rising costs of healthcare. However, the changing healthcare landscape provides opportunities to face these challenges head-on. Among these opportunities are value-based reimbursement and alternative payment models and an increasing focus on quality and safety, models, and principles which can be leveraged to optimize care coordination and health outcomes. In this chapter, we will describe the steps that we must now take, in pursuit of a post-intensive care syndrome (PICS)-free future.

## Post-intensive Care Syndrome Epidemiology

We must first acknowledge the current state of ICU survivorship, in order to move toward a PICS-free future. PICS is strikingly common, often severe and enduring, and negatively impacts health-related quality of life. In fact, the majority of ICU survivors experience new or worse impairment in at least one PICS domain:

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cognition, mental health, or physical function. Additionally, an estimated 25–50% experience impairment in multiple domains [1, 2]. These impairments may begin at the time of ICU discharge and often continue months to years after critical illness.

Despite the toll that critical illness inflicts on the mind and body, it is also true that 36% and 44% of survivors are PICS-free at 3 and 12 months, respectively [2], revealing that impairment is not a given and recovery is possible. Related, 72% of survivors are resilient or highly resilient, and post-traumatic growth can result from critical illness. In fact, 21% and 23% of survivors self-reported their physical function or mental health were "better" after critical illness [1]. As resilience was inversely correlated with cognitive dysfunction, anxiety, depression, PTSD, difficulty with self-care, and pain [1], a PICS-free future is dependent on promoting a culture of resilience among survivors.

Beyond physical health trajectory (i.e., frailty), which predicts PICS [2], social determinants of health appear to loom large in PICS. Specifically, more years of education predict being PICS-free at 3 and 12 months [2]. Conversely, loss of employment, common after critical illness, negatively impacts mental health and health-related quality of life [3]. Therefore, addressing PICS requires an understanding of the longitudinal journey of ICU survivors, including an appraisal of social determinants of health and addressing the financial shock that follows that could undermine recovery.

## *PICS Prevention: The Longitudinal Perspective*

Neither critical illness nor PICS are pre-destined fates. From that perspective, PICS elimination requires that we focus on three, interrelated goals: (1) prevent critical illness, (2) deliver high-quality critical care, and (3) optimize care coordination in the post-acute care setting to facilitate recovery and mitigate health setbacks after critical illness (e.g., hospital readmissions [4, 5]). Achieving these three goals will require both improved care coordination and care improvements in multiple care environments, including the ambulatory care setting, pre-hospital environment, and emergency department (Fig. 22.1).

## *Avoiding Critical Illness*

Emerging evidence suggests the opportunity to prevent a portion of critical illness episodes with timely and appropriate management in the outpatient setting. For example, as many as 250,000 ICU admissions could be prevented each year in the United States, as 16% of ICU admissions are preceded by potentially preventable, ambulatory care-sensitive conditions [6]. International sepsis awareness campaigns, with their focus on vaccination and timely recognition and treatment to "Stop Sepsis, Save Lives [7]," could dramatically decrease the global burden of PICS,

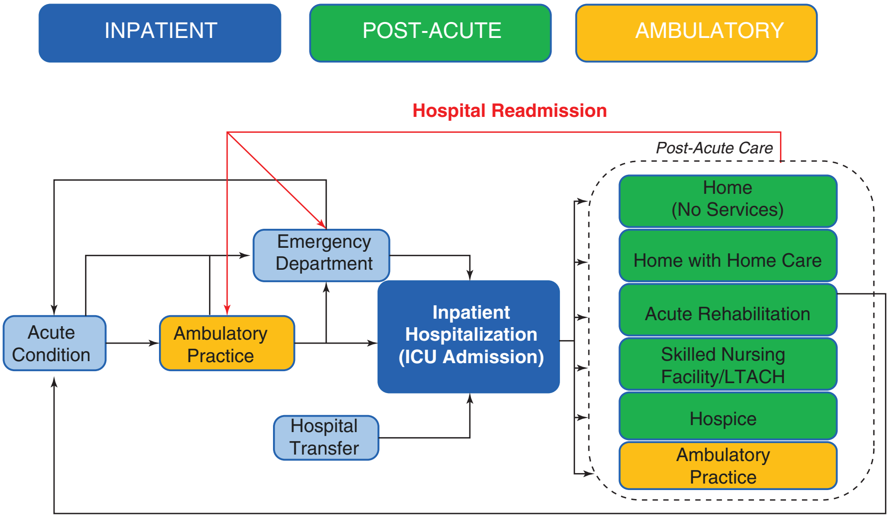

**Fig. 22.1** An episode of critical care includes the inpatient hospitalization, post-acute care, and ambulatory practice setting. Abbreviations: ICU intensive care unit, LTACH long-term acute care hospital

given the relationship between sepsis and PICS [8, 9]. Last, timely advanced care planning and early and appropriate palliative care engagement for patients with serious illness can avert undesired ICU admissions to ensure that care delivery aligns with preferences [10].

## *Optimize ICU Care Delivery*

A quality gap exists between evidence-based and actual practice [11], resulting in substantial excesses in morbidity and mortality. In critical care, the potential to improve long-term outcomes by bridging the quality gap is best exemplified by the success of the Society of Critical Care Medicine's ICU Liberation campaign, which focused on implementation of the ABCDEF bundle. The ABCDEF bundle – discussed earlier in the textbook – serves as a daily prompt for providers to follow evidence-based practices and more effectively engage family and caregivers for the better of our patients. ABCDEF bundle implementation, when successful, has been shown to improve survival; reduce the duration of mechanical ventilation, coma, delirium, and ICU readmissions; and increase the likelihood of maintaining functional independence [12–15].

A PICS-free future requires a commitment to ensure that best practices are delivered to every patient, every day, in the spirit of the ICU Liberation campaign. From this perspective, imagine a world where all patients received the recommended components of the ABCDEF bundle. Imagine a world where all patients with sepsis received evidence-based protocolized sepsis care [16] and all patients with acute hypoxemic respiratory failure receive high-flow nasal cannula [17]; as a result, many avoid the harms that accompany ICU admission and mechanical ventilation, in particular. Imagine a world where less patients develop ARDS, and among those who do, all receive lung protective ventilation targeted to normoxemia to avoid the risks of hypoxemia and hyperoxemia [18–21].

For a PICS-free future, we must measure the use of evidence-based practices and hold ourselves accountable as clinicians. As we invest in science designed to eliminate PICS, we must also invest in innovative, implementation science that ensures that evidence-based care is applied and wasteful care is avoided [22, 23]. A PICS-free future will require accountability of organizations to achieve standards that we believe will reduce the risk of PICS. This progress will also require that we understand the implications of all ICU interventions on PICS. Thus, long-term outcomes must be measured and reported in all future clinical trials of ICU interventions.

## *Post-Discharge Recovery*

At the time of ICU discharge, survivors of critical illness follow several paths toward recovery. On one such path, patients are commonly transferred to a hospital ward from the ICU, followed by discharge to a post-acute care setting. Despite the frequency of physical impairment after critical illness, its association with hospital readmission [24], and evidence that long-term survival is optimized by the receipt of acute rehabilitation [25], few survivors receive acute rehabilitation. Moreover, despite the opportunity to receive physical therapy in the home care or skilled care facility setting, in select cases, survivors are discharged directly home without services [26]. These examples highlight the opportunity to more effectively align the needs of patients with post-acute care services at hospital discharge.

Despite these early opportunities for intervention, issues of survivorship are rarely addressed during an ICU stay [27]. Moreover, survivorship is rarely addressed preemptively at any point after the critical illness. Patients and families may remain unaware of these impairments until the detrimental effects become apparent after hospital discharge.

The missed opportunity for early intervention is compounded by the fact that post-discharge care is often fragmented, involving transitions between many healthcare settings. These settings may not share a common medical record or healthcare providers. Thus, critical information about the patient's illness may be lost at each step, making the critical illness "invisible" to the outpatient provider [28]. Additionally, in the absence of formalized post-ICU follow-up centers, no single provider is responsible for helping patients navigate care post-ICU. For example, when transferring from the ICU to the hospital ward, key clinical details were often missing in the communication between ICU physicians and nurses and their hospital ward counterparts [29]. To optimize communication during these transitions of care, investigators recommended that organizations design and implement standardized processes (e.g., use of a documented patient care plan, handoff) with awareness of clinical operations (e.g., avoid transfers at change of shift) and accountability to the patient and family (e.g., have the care plan travel with the patient in addition to in the electronic health record and communicate pending transfers to the patient/family) [29].

Unfortunately, in this fragmented model of care delivery, outpatient care coordination is underutilized and ineffective, with as many as one in four hospital readmissions attributed to an ambulatory care-sensitive condition [5]. Further, care discontinuity (i.e., one-third of patients are rehospitalized at a different hospital) is common and is associated with increased mortality [30].

## The Future: How Policy Can Help Achieve a PICS-Free Future

Given the challenges we have outlined, how otherwise might we move toward a PICS-free future? Interventions discussed throughout this book – including post-ICU follow-up clinics and peer support groups – have had great success, albeit in limited settings. This success has come through the extraordinary efforts of dedicated clinicians and staff, often against significant odds.

Thus, these interventions have not yet been adopted on a large scale. Barriers to adoption include lack of funding, failure to align with hospital billing infrastructure, limited staff availability, lack of access to clinics, lack of awareness regarding clinics among patients and families, and lack of space for clinics [31].

To overcome these barriers, we must align this work with health policy and the evolving models of value-based healthcare delivery. Value-based healthcare aims to maximize health outcomes and minimize cost – thereby centering care on the patient's needs and outcomes. This is in contrast to the traditional focus of healthcare on the delivery of physician services (e.g., fee-for-service), centered on volume and profitability [32].

Many of the barriers to post-ICU care coordination appear to arise from this conflict between patient-centered care and traditional reimbursement models within healthcare. Fortunately, reimbursement models are shifting as health systems and payers (e.g., private insurance, Medicare) seek to curtail ever-rising costs. These new models focus on achieving quality standards, eliminating harms and waste (i.e., healthcare spending that does not improve health outcomes), and optimizing the care of common, high-risk conditions [33]. Importantly, the models provide a timely opportunity for higher-quality care of ICU survivors.

One model that aims to increase health system accountability, thus improving quality and reducing costs, is the Centers for Medicare and Medicaid Services (CMS) Bundled Payments for Care Improvement Initiative [34]. Broadly, bundled payments refer to an agreement between a healthcare provider and a payer, wherein payments are "bundled" together to cover a full episode of care (such as all care received from hospital admission to 90 days after admission). The health system is therefore incentivized to provide care that is less costly than the bundled payment received – however they must also meet specific quality standards. Given that the payment does not increase when a complication, readmission, or other costly event occurs, health systems are motivated to develop innovative approaches to improve quality of care.

Post-sepsis care provides an example of this opportunity for value-based healthcare delivery through bundled payments. Sepsis survivors commonly require inpatient rehabilitation at a post-acute care facility after hospital discharge. Additionally, they commonly experience readmission to the hospital within 30 days of discharge, most often for new or recurrent infection [35]. The use of post-acute care services, ED visits, and 30-day readmissions has been estimated to be nearly as costly as an initial admission [36]. Therefore, efforts to coordinate the longitudinal care of sepsis survivors (e.g., post-ICU follow up clinics) may offer substantial financial benefit to health systems and simultaneously improve short- and long-term outcomes for patients.

These longitudinal coordination efforts should span from the ICU through to a post-ICU follow-up clinic. The aim would be to mitigate the harmful consequences of critical illness and reduce the risk of preventable new or recurrent illness. For example, following discharge after sepsis, new impairments may be overlooked and rehabilitation delayed; likewise, new infections may be overlooked and treatment delayed. Patients and families are not typically educated on issues of survivorship or the warning signs of new sepsis. Further, post-discharge care is disjointed, and post-acute care providers and primary care physicians may not be aware of these challenges. These factors represent a substantial opportunity for post-ICU care to improve patient's lives and align with a health system's priorities.

Whether the post-ICU clinic is the optimal means to achieve a PICS-free state remains to be seen. What is certain is that (1) international collaboratives, such as the Critical and Acute Illness Recovery Organization (CAIRO), are necessary to accelerate and disseminate innovative recovery science, and (2) survivors' needs are many; their impairments and disabilities, once realized, require attention and rehabilitation; and loss of employment is a legitimate threat to them. As a result, a PICS-free future will require multidisciplinary post-discharge expertise, including clinicians, pharmacists, social workers, case managers, and therapists, to assess, treat, rehabilitate, and support survivors through the physical, mental, and financial challenges of recovery.

A beacon, in terms of prioritizing health and social support toward a PICS-free future, is the United Kingdom's Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE) program. InS:PIRE is a 5-week, peer-supported, self-management recovery program for survivors and their caregivers. As its participants realized improvements in quality-of-life, self-efficacy scores, and 88% returned to employment or secured volunteering roles [37], the program is being scaled up across Scotland with national support.

## Conclusion

Evolving health policy presents a timely opportunity to advance post-ICU care. This opportunity arises from the convergence of a growing population of ICU survivors with a continued shift of reimbursement toward value-based approaches. We must start with the systematic implementation of best practices in the ICU. These should be measured and reported and should inform reimbursement policies. After the ICU, post-acute care and rehabilitation must be a longitudinal, coordinated effort. And engagement with ambulatory practice partners is needed to both avoid preventable ICU admissions and facilitate recovery after the ICU. Again, health policy can drive these efforts if an institution providing ICU care is also accountable for shepherding patients through the post-acute care period. Overall, we believe a PICS-free future can be achieved through averting critical illness, mitigating harm in the ICU, rehabilitating impairments in the days and weeks after, and aligning implementation science with healthcare policy and reimbursement.

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# Chapter 23
# Institutionalizing Bold Humility via Collaboratives

**Theodore J. Iwashyna**

We do not know the best way to insure every patient has a full recovery from acute critical illness. The chapters in this book have made it clear that there is a lot we do know, and many best practices urgently need to be implemented more broadly. Yet critical illness remains common, mortal, and morbid. We cannot reverse all acute pathology; discoveries remain to be made.

Uncertainty remains everywhere along the translational spectrum: defining most urgent and tractable problems; understanding their biological, psychological, behavioral, and social roots; developing potential solutions; deciding on the metrics by which those solutions will be evaluated; rigorously testing those solutions; developing implementation strategies to integrate proven solutions into care; disseminating implementation; and maintaining quality in the face of challenges.

In the face of uncertainty, it may be that we ought to turn to a handful of visionary leaders, somehow gifted with unusual perspicuity and able to prophecy what should be done. Such leaders do exist, and I have had the privilege to work with some. Unfortunately, most of us are not such prophets; therefore, we need to develop processes of collaboration to allow us to gradually move toward less uncertainty and greater truth. The scientific process is one such process—cumulative incremental collective review of data, hypothesizing, testing, and re-interpretation. The optimal social organization of the scientific process remains unclear, and its implementation has sometimes developed narrow and rigid straightjackets as to what constitutes "testing" and "data." In particular, laboratory-based experimentation is not optimal as the sole mode of scientific progress in improving recovery of critical illness.

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What is needed, I propose, is a commitment to learning together in an organized way. Doing so requires institutionalizing bold humility. This chapter offers my tentative thinking on how to institutionalize bold humility via interdisciplinary collaboratives, beginning by articulating the rationale for such a focus.

## Committing to Institutionalized Bold Humility

The commitment to *humility* is the belief that no individual actually always knows the best thing to do, nor alone has the best judgment. It is a belief that saying "I was right all along" or "I knew that before the data came out" is counterproductive arrogance rather than laudatory vision. A commitment to humility recognizes that data change, and so provisional conclusions should change. And it recognizes that there are more ways to be wrong than to be right, and so all conclusions must be considered provisional. Especially in critical care, it also means recognizing that traditional hierarchies of expertise are often counterproductive—both across disciplines/professions and the equally false assumption of clinicians over patients and families.

*Boldness* is the commitment that despite individual fallibility, collectively, we can make progress on big, hard problems that are of central importance to helping patients and their loved ones heal from critical illness. We must boldly believe that no given failure is a sign that all of our ideas are bunk, but rather a celebration that we have rigorously evaluated an idea and can learn from that new data. Boldness is also being to act in the fog of uncertainty, doing the best one can even though it is imperfect—because our patients and their families deserve someone to help them.

*Institutionalization* provides robustness for this important work to the vagaries of life. Institutionalization involves making explicit choices about how work will be organized, what roles people will play, and how responsibility and credit will be allocated. It provides a way for the work to continue when someone gets sick or gets a promotion—especially in the days when participation in the collaborative is uncompensated and voluntary. While institutionalization is not synonymous with incorporation or some legal charter, it involves making explicit decisions about how the group will function that is bigger than any one individual. Institutionalization can promote boldness, by giving the group a way to keep moving forward in the face of challenges and to build on past success. Institutionalization should also promote humility, at the level of both the group (by embedding a culture of trial and error) and the individual participant (by mitigating against the medical world's tendency for cults of personality to develop).

There are several other resources that discuss general approaches to leadership of change organization, emphasizing the needs of early wins and the like [16]. The remainder of this chapter focuses instead on certain institutional design decisions in making a collaborative effective. In particular, I consider the barrier to collaboration that is the fact that physicians are overwhelmingly socialized to value decisive, singular leadership. The core contention of this chapter is that this socialization can be effectively counterbalanced by intentional partnership and collaboration—and should be when both evidence and outcomes are unclear.

## What Collaboratives Do

The defining technology of a collaborative, in the sense used here, is the open sharing of experience and judgment to improve practices of care in an area about which there is uncertainty. This is done by providing an institutional social structure to bring forward these voices.

The Peer Support and Post-ICU Clinic Collaboratives within the Critical and Acute Illness Recovery Organization (CAIRO) provide illustrative examples to help define strengths and weaknesses of this model of collaboratives (see http://CAIROrecovery.org or twitter @CAIROrg). More hierarchical models have been used with good success in other areas, particularly those for which a specific "best way" is known and the goal is to use peer pressure to insure implementation of that best way in the face of internal barriers to change. Here, I focus instead on areas where there is substantial uncertainty, and so the central task of the collaborative is to *discover* together.

(To be clear about my positionality: I was one of a group of individuals who helped the Society of Critical Care Medicine found the so-called "Thrive" initiative and who helped transition the collaboratives to independence in 2019 with the founding of CAIRO. I've been somewhat involved in the collaboratives but have never been the designated organizer; these are my observations and opinions as a partial insider, partial outsider, of work largely done (brilliantly) by others.)

The collaboratives are first and foremost coalitions of groups that are in some sense operational—either actively caring for patients or planning to in the near term. They are grounded in that specific activity and the challenges of it.

On an ongoing basis, the work of the collaboratives is regular sharing. This involves two parts: data-sharing and conversation. Data-sharing is the structured, routine submission of structured data around what it is they are doing at regular intervals. Such sharing provides an empirical foundation for the collaborative. It forms a lived track record of what has been done. It overcomes the frailty of memory.

In order to make data-sharing work, the group needs a process to decide to what it will attend at a given moment. That process—"this year we are going to focus on 'X'"—has value in itself. It often requires rigorous and careful prioritization, especially given the frequent limitations in resources for data extraction and the barriers of inter-institutional sharing of individual-level data. This process may be most effective when the data collection is used to drive questions about process of collaborative institutions and their care rather than attempting to replicate a large-scale cohort construction. That is, the data-sharing is a process by which the collaborative itself understands what it does. This process can also form the basis for publications, important for securing ongoing academic credit for those doing the work.

The lived center of the collaborative's sharing is conversation, usually monthly. These conversations are often structured around three components, which require an active facilitator. The first is cohering the group and finding ways to disseminate innovations that are being tried within the group. The second is working through specific common problems and brainstorming and sharing solutions. This is where the lived experience and expert judgment of the clinicians involved become especially useful—a vibrant collaborative call should be highly interactive and not merely a passive teleconference. This allows rapid evaluation of potential innovations and speeds their refinement and implementation. And finally, it is often useful to have short-term proximal specific products that are being written or produced—both CAIRO collaboratives have found it useful to focus on "state-of-the-art" or "how-we-do-it" documents as ways to rigorously understand the commonalities and heterogeneity in the ways in which the work is being done [11, 12]. Such documents are of great benefit to others seeking to begin programs but also provide concrete specificity to discussions to help collaborative members learn from each other.

In order to engage in such ongoing, longitudinal sharing of expertise and judgment, some sense of boundaries are needed. Many collaboratives do this by cohorting members [8]. There is fixed time when new organizations join the collaborative, and they must apply. Full membership is obtained only by routine participation in both data-sharing and conversation. This allows some active sense of how the "we" in the collaborative is.

## Hierarchical Decision-Making

Many in critical care, when they think of leadership, think of running a resuscitation team. Standing at the foot of the bed, they calmly orchestrate perhaps a dozen other highly expert professionals as they rapidly save the life of a dying patient. The team leader, we are taught, is open to input from all but makes the final call on how we move forward. It is a seductive vision.

Often attending rounds in the ICU are structured similarly, if with more distractions. Nurses, respiratory therapists, and dieticians report and provide input. Medical students eagerly rattle off carefully prepared presentations. The attending believes that he or she sits at the center of it, listening to all, dispensing a teaching pearl here and support and encouragement there, and encouraging learners to offer suggestions and "put their nickel down." But even (and especially) when the attending delegates decision-making authority, it is still the attending physician's team and their decision. From the perspective of this attending physician, it operates as if the attending physician has the last word.

(I write from my perspective as a physician. I have not worked as a nurse, but from my observation, it appears that strong hierarchies are also familiar modes of organization in departments and schools of nursing.)

The last several decades of work in high-reliability organizations have attempted to temper such hierarchy, aware that it often risks becoming a narcissistic autocracy.

The oft-repeated fifth principle of high reliability organizing is "deference to expertise," which argues that often final decision-making authority should be given to those "low" in the organization, "frontline" workers who have the best information [2, 17]. Yet its application in ICU far more often means "listen to frontline workers" than "give them budgetary authority without need for prior approvals" or even, in the United States, "let ICU nurses titrate drips on their own."

Such models are quite useful where hierarchy of rank is visible and well-correlated with hierarchy of judgment. They are similarly quite useful in either of two extreme situations: (1) there is a single best choice, and that choice is clearly identifiable by well-accepted criteria (e.g., "what is the evidence-based therapy here, RCT-proven, and guideline-recommended?") or (2) there are a wide variety of possible choices, all essentially equivalent, and coordinated action toward any one of them (but only one of them) is essential (e.g., "should we put in the central line or go to CT scan first?"). Such situations are common in medical practice.

Hierarchical decision-making fails in other situations. It fails when the central goal is to surface diverse perspectives and is less effective at information seeking. It fails when inclusivity and commitment are essential. It fails when it exceeds the cognitive processing limits of the centralized decision-maker, or when there is so much uncertainty that the decision-maker's biases are not adequately balanced.

## Alternative Models

When collective decision-making is needed, physicians often function quite poorly. A need for coordinated aggregation of input often degenerates into long-winded monologues, obstreperous refusal to abide by decisions, and not uncommonly shouting and recriminations if allocation of important resources is at stake. I offer as evidence of this a typical faculty meeting at every academic medical center of which I am aware.

This is in part because of willful clinician ignorance and refusal to abide by any of several other decision-making models. Humans have needed to make group decisions for as long as we have been human. The entire fields of political science and public choice exist to explore trade-offs.

Perhaps the best known alternative decision-making procedures are formal parliamentary procedure. In the United States, the canonical reference here is *Robert's Rules of Order*, which is well-known in both the world of nonprofits and sororities [14]. These offer highly structured ways to insure decisions can be made but tend to emphasize zero-sum allocation and promote the development of factional coalitions in the context of finite time to make a decision.

At the other end of the spectrum are pure consensus decision-making procedures, rooted in Quaker, anti-war, and feminist organizing traditions [1, 7, 15]. Consensus emphasizes respect for the perspective of small subgroups and finding innovative solutions that help everybody win—at the cost of potentially intractable inability to make a decision.

Somewhere between *Robert's Rules of Order* and full consensus lies the tradition of small group democracy [4]. Various degrees of formality may be used, as needed for the situation, but the key is a commitment to actively bring in all the relevant voices and work to reasonable compromise—where possible, a generative compromise that works through new problems that have surfaced. In general in smaller meetings, this philosophical commitment is more important than specific process, but the process may be quite useful to have been pre-established before contentious conflict develops. There are multiple antecedents, but the two I have found most generative are Ella Baker's work with the Student Nonviolent Coordinating Committee [13] and the Internet Engineering Task Force's (IETF) formulation of decision-making through "rough consensus and running code"—giving a bias toward trying things and doing things that are already working [3].

## What a Collaborative Is Not, and Keeping It That Way

The above comments provide some intuition about how collaboratives might work well. But collaboratives can also be killed off. Writing this in the second half of 2020, I am painfully aware of fragility of collective institutions, so I end with a few comments on threats to be avoided.

From my perspective, the single biggest threat to a collaborative is that it may become too dependent on any particular member as the charismatic leader and thereby degenerate into a cult of personality where that leader is too often turned to for all the answers. Yet collaboratives will not function if totally without leadership—somebody needs to plan an agenda and tend the relationships, recruit, and do the extra work. It becomes critical that individuals who step into such roles are appreciated but also rotated.

A second threat to a high functioning collaborative is that it will be colonized and farmed. It may be farmed for money, where an organization seeks progressively greater "dues" in exchange for providing a degree of professional staff organizing. (Such staff organizing talent can be invaluable; it must be clearly acknowledged.) Such professional staff may move from being highly valued facilitators to instead being a deferred to leader, losing the decentralizing value of the collaborative.

Equally risky, the collaborative may also be farmed for ideas and research subjects. In the highly competitive world of academia, and especially in the United States with funding typically being concentrated in single principal investigators, it can be very tempting to view a collaborative as a thing to be studied rather than a group who study themselves. A commitment to decentralized leadership is essential here and insuring group governance of projects. The Thrive collaboratives instituted the norm that any papers emerging from the group would be group authored by those individuals who submitted their data—all projects would be self-study, recognizing the ideas and questions framing the research were generated by the group even though, as in all projects, some specific individual was driving the data collection and writing. For individuals for whom that was not acceptable, the group declined to participate in the work. For those for whom it was, a remarkable series of publications led by the editors of this volume resulted [5, 6, 9, 10].

## Personal Conclusion

Over the last decade, a highly international, multi-professional group of clinicians, scientists, and increasingly patients have come together to transform the way we think about recover from critical illness [11, 12]. The organizational structure of that has included superb individual clinical work, classically funded and organized research, group consensus conferences, and, increasingly, a group of collaboratives. For many of us who have participated in the collaboratives, they have been a transformational experience, dramatically changing the way we think about the problems of our patients and our hospitals and changing the way we practice and research. The decentralized structures have allowed the development of rich relationships and some of the most profound friendships and intellectual partnerships of my life.

**Disclaimer** This work does not necessarily represent the views of the US Government, the Department of Veterans Affairs, or any of the coalitions and organizations discussed within.

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