

Postintensive Care Syndrome: Right Care, Right Now...and Later

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Since critical care began over 50 years ago, there have been tremendous advances in the science and practice that allow more severely ill and injured patients to survive. Each year, millions of people are discharged back to the community. The recognition of long-term consequences for ICU survivors and their families is a growing concern. Critical care practitioners have always known that the patients have a long road to recovery after discharge from the ICU. In the 2 past decades, research has revealed how remarkably common and devastating long-term consequences of critical illness can be and how much some patients and their families suffer (1–9). These consequences in patients are referred to as postintensive care syndrome (PICS) and in families as postintensive care syndrome-family (PICS-F) (1).

The research findings are disturbing and a source of distress to critical care practitioners. In response, they are working hard to identify the risk factors for PICS and are rapidly implementing ways to mitigate their impact. Although the critical care community is becoming increasingly aware of PICS, patients, families, and the posthospital care community need more information. They are the ones who are dealt most directly PICS and PICS-F.

There are three key emerging concepts driving these initiatives: a focus on safe transitions and handoffs, an emphasis on family-centered care, and the acceptance that critical care is defined by the whole episode of care, not just the ICU stay. It is clear that those in the field of critical care have a responsibility to increase the awareness and to work with those who care for patients post-ICU to identify and treat the consequences of critical illness in patients and families.

Key Words: consequences of critical illness; family care; ICU survivors; long-term outcomes; postintensive care syndrome

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INCREASING AWARENESS OF PICS

One of the ways the Society of Critical Care Medicine (SCCM) chose to address PICS was to hold stakeholder conferences in 2010 (1) and 2012 (2). Stakeholders included SCCM and international experts, representatives from national noncritical care organizations such as the Joint Commission, National Institutes of Health, primary care, rehabilitation, physical therapy, occupational therapy, speech-language-hearing, long-term care, palliative care, case workers, and large healthcare systems, and patients, families, and patient advocacy groups. Representatives that attended these conferences have begun to increase the awareness of PICS in their peers via publications, presentations, and initiatives.

It is also important to increase the awareness of the possible long-term consequences of intensive care among ICU survivors and their families. Awareness can decrease their fear of the unknown, decrease feelings of being unique or of something else being terribly wrong with them, and alert them to the possible need for out-patient follow-up assessments and referrals. They need to know they are not alone or abandoned. Steps taken by SCCM toward improving awareness in patients and families include establishing a section in Wikipedia on PICS, creating several videos with patients and families describing their experiences for YouTube, and offering a pamphlet on PICS on SCCM's website (10). Johns Hopkins University Medical Center has created the Outcomes After Critical Illness and Surgery open-access webpage, which has very useful information on PICS as well (11).

SCCM has further demonstrated a commitment to addressing PICS by establishing a fund that will award grants of up to \$50,000 to members conducting research aimed at improving patient and family support and recovery after critical illness. This initiative is called "Thrive" (12).

PREVALENCE OF PICS AND PICS-F

PICS is defined as new or worsening impairment in physical, cognitive, or mental health status arising and persisting after hospitalization for critical illness (Fig. 1) (1). Study results on the prevalence of these findings in patients are summarized in Table 1 [(1–9)] and the prevalence in families in Table 2 (13–16). The wide range of occurrence rates found is due to the differences in each study's patient population, patient

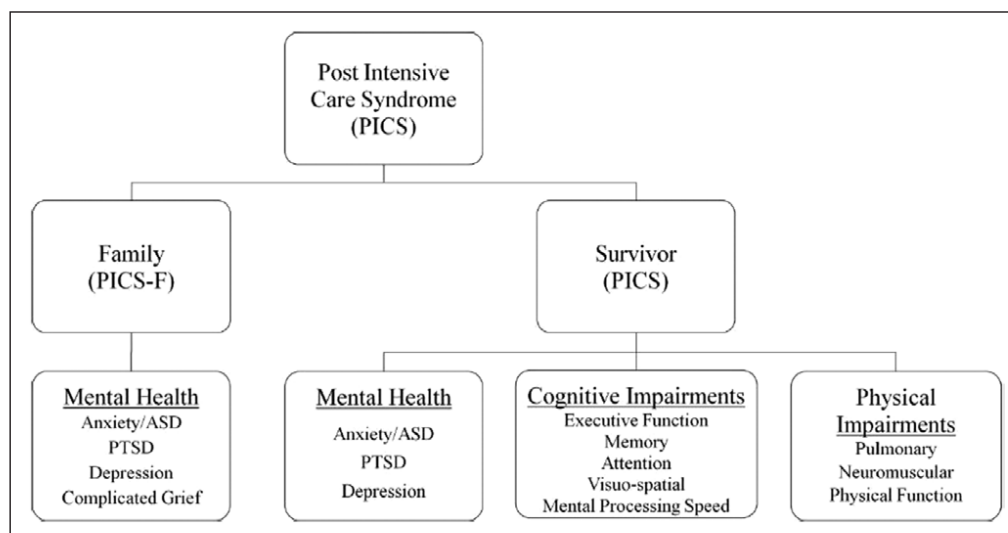


Figure 1. Postintensive care syndrome (PICS) conceptual diagram. ASD = acute stress disorder, PICS-F = postintensive care syndrome-family, PTSD = posttraumatic stress disorder. Reproduced with permission from Needham et al (1) (p. 505).

comorbidities, measurement tools, and the time frames that vary from 1 month to 8 years.

Physical consequences include ICU-acquired weakness that occurs in 25–80% of those on mechanical ventilation for more than 4 days and 50–75% of those with sepsis. Almost all of these patients still have weakness years later (1, 3). Cognitive impairment occurs in 30–80% of patients and includes problems with memory, processing, planning, problem solving, and visual-spatial awareness (1, 3, 5). These can improve over several months, but 25% of those with adult respiratory distress syndrome (ARDS) still have cognitive impairment 6 years later (9). In those over 65 years old with severe sepsis, impairment can still be present 8 years later (1, 3, 5). Psychologic consequences include symptoms of depression, anxiety, and sleep disturbances, which can last from months to years (1, 3). A total of 10–50% of patients have symptoms of posttraumatic stress disorder (PTSD), which can persist for 8 years (1, 4, 6).

These physical, cognitive, and mental changes may have an impact on the patient's socioeconomic status and quality of life. A total of 50% of patients require caregiver assistance 1 year later. This assistance can be anything from help with the activities of daily living to full care. Around 50% of patients who had ARDS have not returned to work 1 year after discharge (9). Less than 10% of patients on mechanical ventilation for over 4 days are alive and independent 1 year later (1–5).

PICS can only occur in ICU patients who survive, but PICS-F can occur in families of survivors and nonsurvivors. Long-term consequences in families consist of psychologic, physical, and social consequences (Fig. 1) (1). Around 10–75% of patients' families suffer from anxiety, and 8–42% patients have symptoms of PTSD and it occurs in up to 50% if the patient is a child or the patient died (13). One third of families are taking medications for anxiety or depression at patient discharge. These psychologic consequences can persist for years (13–16). When the patient does not survive, the family may suffer from feelings of loss and prolonged or complicated grief. Potential physical consequences

include weakness and exacerbation of previous physical and health problems. Because of these problems and the possible added role of being a caregiver, family dynamics are challenged. Family members may also need to take time off from work to care for the patients or for themselves. When accompanied by medical costs incurred, the family's financial security may be at risk.

STRATEGIES TO DECREASE PICS

One way to decrease the prevalence of PICS in patients and families is to prevent or minimize the risk factors. Patient risks

include immobility, number of days on mechanical ventilation, length of stay in the ICU, heavy sedation, delirium, sepsis, ARDS, hypoglycemia, and hypoxia (1–9). All of these have been the focus of quality improvement efforts for a long time for other reasons. Now that it is known that these risk factors have the potential for increasing the long-term consequences for ICU survivors, there is even more reason to address them. In addition to preventing risk factors, several strategies to mitigate PICS have been identified and their adoption is spreading (Table 3) (1–9, 13–41).

Early Mobility Programs

Studies have found that patients can safely tolerate mobility very early in their ICU stay even when on mechanical ventilation with invasive catheters and continuous IV infusions. Activities range from passive to active exercises in bed and neuromuscular electrical stimulation to cycle ergometers and ambulation. Early mobility programs have been shown to lower ICU and hospital lengths of stay and thus decrease the cost of care. They can increase strength, improve functional status, and decrease delirium, depression, and anxiety (17, 34).

Postdischarge Follow-Up Programs

Although it seems as though postdischarge rehabilitation and follow-up clinics would be a logical way to address the potential consequences of critical illness, research on such programs has been disappointing (18–24). Although studies are ongoing, 30% of ICUs in the United Kingdom have follow-up clinics and efforts are being made in various countries to design programs that work in their country's healthcare delivery system. Strategies and programs must be devised and investigated to help coordinate and facilitate access to more effective out-patient care.

Early Psychologic Intervention

When psychologists are included in the critical care team, they can offer both patients and families support, counseling, and education on stress management and coping skills. Their

TABLE 1. Prevalence of Elements of Postintensive Care Syndrome in Patients (1–9)

Less than 10% of patients on mechanical ventilation for > 4 d are alive and fully independent 1 yr later
Caregiver assistance ranging from assistance with activities of daily living to full care is required by patients 1 yr later
Half of patients with adult respiratory distress syndrome have not returned to work 1 yr later
ICU-acquired weakness that can persist for years can develop in 25–80% of those with sepsis or on mechanical ventilation for > 4 d
Cognitive impairment that can persist for years develops in 30–80% of patients
Symptoms of depression occur in 8–57% of patients and may improve over months
Symptoms of anxiety occur in 23–48% have symptoms of anxiety
Symptoms of posttraumatic distress syndrome occur in 10–50% of patients and may persist for years

TABLE 2. Prevalence of Elements of Postintensive Care Syndrome in Families (13–16)

Anxiety is present in 10–75% of family
Symptoms of posttraumatic distress syndrome occur in 8–42% of family
Medication for anxiety or depression are required by 33% of family
The above can persist for years
Family members may develop prolonged or complicated grief
Family members may have exacerbation of chronic health conditions
Family dynamics may be challenged
Family financial security may be at risk

involvement has been shown to cut the prevalence of anxiety, depression, and PTSD in half (25–27).

ICU Diaries

Creating ICU diaries is a common practice throughout Europe. Diaries are kept by families and staff to describe the patient's experiences during the ICU stay. Pictures are sometimes included. When read by the patient after their discharge, diaries can fill in memories gaps, replace false memories and delusions, and help them understand what happened to them. ICU diaries address PICS by decreasing anxiety, depression, and PTSD symptoms (27, 29). They have also been shown to decrease PTSD symptoms in families (30).

Healing Environments of Care

Measures to provide a more healing and compassionate environment can decrease anxiety and delirium, promote sleep, and demonstrate an understanding and respect for the needs of both patients and their families. It is important to attend to room temperature and lighting, to decrease noise and false alarms, to make sure the patient uses their sensory aids such as glasses and hearing aids, and to promote family presence and participation in care. Decreasing anxiety and delirium has been shown to decrease the risk of cognitive impairment and PTSD postdischarge (31, 32).

TABLE 3. Strategies to Decrease the Prevalence of Postintensive Care Syndrome in Patients and Families

In patients (1–9, 17–34)
Reduction of risk factors for PICS
Early mobility programs
Postdischarge follow-up programs
Early psychologic intervention
ICU diaries
Healing environments of care
Functional reconciliation checklist
ABCDEFGH bundle
In families (13–16, 35–41)
Family-centered care programs
Frequent and understandable communication about the patients care and condition
Shared decision making
Early psychologic intervention and support
Family presence and participation in care programs
Case worker and social worker involvement in care and planning
Training of family for skills needed to care for patient at home
ICU diaries and education on how to use them
Functional reconciliation checklist
Information on PICS and list of resources
Coaching of family on the importance of caring for themselves

PICS = postintensive care syndrome.

Functional Reconciliation Checklist

A functional reconciliation checklist can be used to describe and keep track of progress in the patient's physical, cognitive, and mental status and to facilitate communication across the continuum of care. This process begins with an assessment

of the patient's status prior to admission and follows them through their recovery to monitor for continued improvement in status and to help coordinate care (2). Although it could be a very useful tool, its impact not been studied to date.

ABCDEFGH Bundle

Professional critical care organizations are collaborating on an initiative to promote widespread application of the ABCDE Bundle, which addresses the risks of sedation, delirium, and immobility. They are risk factors for PICS (33). ABCDE stands for **A**irway management, **B**reathing trials, **C**oordination of care and **C**ommunication, **D**elirium assessment, and **E**arly mobility. To help reduce PICS, FGH can be added to the list. FGH stands for **F**amily involvement, **F**ollow-up referrals and **F**unctional reconciliation, **G**ood handoff communication, and **H**andout materials on PICS and PICS-F (8, 33).

STRATEGIES TO DECREASE PICS-F

Measures to reduce the family's stress and anxiety during the patient's time in ICU can reduce the impact of PICS-F. Family-centered care principles are designed to address these areas. Quality communication perceived as caring decreases adverse psychologic outcomes in families of the critically ill (35–38). Making sure the family has frequent and understandable updates about the patient's condition and prognosis, asking and incorporating the family's description of the patient's values and wishes into shared decision making, promoting family presence and participation in care (12–15). Involving psychologists in family support can improve the family's ICU experience and help prepare them for the patient's discharge (25). Involving case workers and social workers can help ensure families have the skills needed to care for the patient at home (38–40). Families should be given the ICU diary and advice on how to share it with the patient or how to schedule a debriefing (30, 41), the patient's functional reconciliation checklist (2), information on PICS, and a list of resources (8). Coaching the family on how to take care of themselves is essential (13–16).

STRATEGIES IN IMPROVING PICS CARE IN THE OUT-PATIENT COMMUNITY

Although the critical care team is not responsible for posthospital care, there is a responsibility for informing those that do. Healthcare delivery in the United States has been organized into silos of practice that take advantage of professional expertise and availability of resources needed, but continuity of care across the continuum of care is a challenge. In addition to improving awareness of PICS in noncritical care practitioners at the national and local level, efforts and methods are required to provide the patient's primary and specialty care providers with information about the patient's hospitalization, progress, and ongoing care needs (1, 2). Reimbursement of the costs of care for PICS could be facilitated by new appropriate diagnostic codes and approved coverage. Ultimately, reducing the prevalence and improving the management of PICS should reduce healthcare costs.

CONCLUSIONS

The responsibility to address the long-term consequences of critical illness in ICU survivors and their families adds to our role in a time when we are already stretched. However, the reality is if we do not promote awareness and better care of PICS and PICS-F, then who will? PICS is an outcome of critical illness. Critical care researchers discovered its prevalence and impact and published their findings in critical care journals. Noncritical care practitioners do not follow developments in our field. Although the process of minimizing and addressing PICS begins with us, it requires communication and collaboration with out-patient providers if our patients are to achieve the best possible outcomes from critical care. Ultimately our success as acute care providers will not be judged by survival rates alone. Survival is not the endpoint for our patients and their families—*return to the highest possible quality of life is*.

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