CNE
1.3 contact hours

Learning Objectives

1. Identify symptoms and risk factors for post-intensive care syndrome-families (PICS-F).
2. Describe techniques for preventing PICS-F.
3. Discuss management of PICS-F.

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Families and post-intensive care syndrome

Preventing, assessing, and treating trauma suffered by families of a hospitalized loved one.

By K. Renee Twibell, PhD, RN, CNE; Amber Petty, BSN, RN, CCRN; Amanda Olynger, BSN, RN, CCRN; Sheila Abebe, DNP, APRN, FNP-BC

JENNIFER* *leaned wearily against the bathroom wall and murmured, "What happened to my life, my world? How could this be? It's like a bad dream." Her distressed reflection in the mirror offered no word of explanation for how her daughter's 3-week hospitalization could change life so drastically.*

Jennifer and Megan are a family of two, sharing a home that has a small garden, enjoying friends, and working. When the phone call came about Megan's car accident, Jennifer suddenly found herself in a new, unknown world of lab tests and ventilator settings.

When Jason, an experienced intensive care unit (ICU) nurse, asks Jennifer how she's doing, Jennifer blurts out with unexpected emotion, "I don't know how I'm doing! It's all a blur—lying here beside her bed each night, alarms ringing, no sleep, different caregivers every day, no visitors because she's in isolation.... How do you think I am doing?" Jason touches Jennifer's arm lightly and nods, prompting her to add tearfully, "And today we move to a long-term care facility, and no one will even tell me if she's going to live or die!"

Jason recognizes that Jennifer is at risk for post-intensive care syndrome in family members.

PICS and PICS-F defined

Post-intensive care syndrome (PICS) is defined as new or increased physical, cognitive, or mental health impairment in a patient after hospitalization in a critical care unit. Similarly, post-intensive care syndrome-family (PICS-F) refers to new or increased cognitive or mental health impairment in family members after a loved one is hospitalized in a critical care setting. A common-language definition is: New or worse health problems after critical illness that remain after you leave the hospital. These problems can be with your body, thoughts, feelings, or mind, and they may affect you or your family. In this article, we'll focus on PICS-F.

Symptoms

PICS-F begins with a perceived or actual threat to the life or physical integrity of a family's loved one who's hospitalized in a critical care unit. During hospitalization, family members may begin to have symptoms of PICS-F, but it's typically not diagnosed until the symptoms persist for at least 1 month after the patient is discharged. (See *Recognizing symptoms*.) Symptoms can interfere with home and work responsibilities and make caring for loved ones after discharge difficult.

Recognizing symptoms

Post-intensive care syndrome-family (PICS-F) can be diagnosed if a patient's family member experiences these symptoms at least 1 month after the patient's discharge from an intensive care unit.

- Elevated anxiety, self-defined
- Increased depressive symptoms
- Attenuated fears, usually generalized, possibly specific to hospitalization
- Insomnia, nightmares
- Fatigue above baseline
- Intrusive, negative thoughts
- Reliving aspects of the hospitalization as if they're happening in real time
- Emotional "triggers" associated with hospitalization, possibly leading to panic attacks and dissociation
- Avoidance behaviors
- Difficulty remembering and concentrating
- Inability to identify sources of joy in life
- Easily startled
- Prolonged or complicated grief
- Exacerbation of chronic health problems
- Strained family dynamics and disrupted relationships.

Timeline and prevalence

PICS-F symptom intensity varies, so the syndrome's trajectory fluctuates. Acute symptoms may last for months, even years; PICS-F data show that symptoms can persist for 8 years, the longest period for which the data exists.

Estimates of the prevalence of PICS-F typically range from 14% to 50%. This wide range may be related to differences in how the syndrome is defined across settings, different assessment approaches, different times when assessment occurs, and different patients and families. For example, the prevalence of PICS-F is as high as 80% when families have to make surrogate end-of-life decisions with inadequate support and as high as 65% if the patient dies.

Risk factors

Factors that heighten the risk of developing PICS-F include patient and family characteristics, as well as the critical care unit's environmental characteristics. (See *Knowing the risk factors*.) The characteristics most amenable to nurses' preventive actions are those in the critical care environment and those related to family's needs.

Jason recognizes Jennifer's risk factors related to her age, gender, Megan's tracheostomy, the severity of Megan's injuries, and Jennifer's unmet need for information. He notices Jennifer's anxiety and fatigue and asks if she has a history of anxiety, depression, or post-traumatic stress disorder (PTSD).

Assessment

During a patient's hospitalization, nurses may detect early symptoms and risk factors for PICS-F, but screening tools to predict its development don't yet exist. Research studies use scales (such as the Hospital Anxiety and Depression Scale, Impact of Events Scale, Center for Epidemiologic Studies—Depression Scale, Stanford Acute Stress Reaction Questionnaire, and the Davidson Trauma Scale) to measure anxiety, depression, and PTSD.

Lack of valid screening tools appropriate for use at the bedside means PICS-F can go unrecognized and untreated. However, nurses can evaluate and document patient and family characteristics that increase risk by asking family members to rate environmental characteristics of the hospital unit and the extent to which the healthcare team is meeting their key needs. (See *What families need*.)

Prevention interventions

Guidelines from the Society for Critical Care Medicine (SCCM) offer specific family-centered interventions during hospitalization for critical illness. The guidelines and research support four key interventions—family presence, family education, patient/family diaries, and family participation in care—that may mitigate or prevent the development of PICS-F.

Family presence

Providing the family with liberal access to the patient—even during life-threatening events such as resuscita-

Family voice

Chet, husband of Nina

"We both thought, 'If we can just get back home, everything will be OK.' But it's not OK. My wife of 19 years had a sudden cardiac arrest at work, just like her mother did years ago. Coworkers revived her, and we spent a week in the ICU and a week on a rehab unit before coming home. Nothing I saw, heard, or experienced in the ICU prepared me for what life would be like after she came home. She struggles to make a grocery list and can't take the right meds unless I hand them to her. I tried to go back to work because we need the money, but that didn't last a day and a half. She can't care for the kids on her own, cries a lot, and has fallen three times since we got home. I'm frustrated, scared, can't sleep, and I hear myself yelling a lot.

"What if things never get any better? I keep remembering that first time I saw her in the ICU with tubes running everywhere. I didn't recognize her—and I'm still having trouble reconnecting with her. I know it's crazy, but she's like someone I don't really know. I'm taking another week off work and hoping things will be better by then. What I really want to do is run away."

tions—addresses the family's need for proximity to the patient and timely information. This evidence-based best practice is supported by multiple studies and several healthcare organizations, such as the American Association of Critical-Care Nurses (AACN), the American College of Critical Care Medicine, and SCCM. AACN offers evidence-based guidelines for family presence in critical care units.

Lack of communication is the leading complaint of dissatisfied family members during critical illness. Letting them be with the patient and sharing timely information in the family's language builds trust. Nurses have five routine opportunities to provide updates to families at the bedside.

- **Bedside report**: Family members and patients can listen to nurses' end-of-shift handover report, ask questions, and make suggestions for care.
- **Five minutes at the bedside**: Nurses sit for at least 5 minutes near the beginning of each shift to listen to patients and families, to provide emotional support and information, and to set goals.
- **Communication boards**: Nurses can update boards posted in patients' rooms to convey goals and planned tests or procedures for the day.
- **Hourly rounding**: When nursing personnel round on patients and families every hour, they can offer updates and listen to questions.
- **Narrating care**: As nurses deliver bedside care, they can talk about what they're doing and why as a way of educating the family and sharing real-time information. For example, Jason can say to Jennifer, "I'm checking Megan's drain, and it looks like the bleeding has stopped after the platelets we gave her."

Healthcare team support of family members is especially important during ICU admission. One study found that up to half of parents who had a child admitted to a pediatric ICU had negative, intrusive memories from the early hours of hospitalization. Mothers who had the opportunity to talk about their feelings at the time of the admission had significantly lower PTSD stress scores at 8 months.

Jason sits by Jennifer and asks how the healthcare team can communicate better and what information she needs right now. She requests a family conference before Megan is transferred to long-term care.

Knowing the risk factors

Characteristics of the patient, family, and hospital environment can increase the risk for post-intensive care syndrome-family (PICS-F). Nurses can help address family member and environmental characteristics.

Family member characteristics	Environmental characteristics	Patient characteristics
Female	Absence of culture of family-centered care	Traumatic brain injury
Under 65 years old	Lack of open or flexible family access to patient	Tracheostomy
Limited postsecondary education	Inadequate staffing to allow time to build trusting relationship	Prolonged length of stay
Limited social support network	No place for family to rest or sleep near patient	High-severity illness/poor prognosis for functional recovery
Pre-existing anxiety and/or depression	Lack of involvement of family in rounding	Out-of-hospital cardiac arrest
Pre-existing mental health diagnoses	Perceived lack of communication	
Core needs unmet	Perception of poor care of patient	

weak evidence
moderately strong evidence

Family education

Family education strengthens coping strategies and reduces anxiety, depression, and the risk of PICS-F. Education can occur informally when nurses assess family members at the bedside as being at risk for PICS-F. More structured family education programs, provided by an interprofessional team that includes a psychologist or psychiatrist, can deliver information on PICS-F, new coping skills, strategies for self-care, and cognitive-behavior techniques. Written information serves to reiterate key content.

Nurses can coach family members to develop self-awareness and ask for support when they need it, so that they can stay balanced throughout their loved one's recovery. In addition, family members may benefit from a written list of community resources for support after leaving the hospital. (See *Resources*.)

Patient/family diaries

Family diaries kept at the bedside can help mitigate or prevent PICS-F. Nurses take the lead, documenting events, the patient's condition, and vital educational points. Families then make their own entries in the diaries; interprofessional team members also may contribute. These di-

What families need

Families have a well-defined set of needs during a loved one's critical illness that haven't varied for 25 years.

The evidence from 1994–2010	The evidence now
• To have hope and reassurance	• To receive timely information about the patient
• To receive information	• To talk with a doctor each day
• To have comfort	• To be with the patient
• To have support	• To have hope
• To be near the patient	• To be assured that the patient is receiving the best care

Source: Jacob 2016

ary entries can help reinforce real memories, not imagined ones. Nurses can give the diary to the family when the patient is discharged from the ICU; most patients and families report reading the diaries after discharge. Although research shows significantly less PICS among patients who keep diaries, the effect on PICS-F isn't yet clear.

Family participation in care

Nurses can engage family members in providing emotional support to the patient. One study revealed that patients wanted family members to talk with them about life outside of the ICU. Some family members can safely provide hygiene care, assist with range-of-motion exercises, and provide oral fluids or food. In many cases, family members experience less stress when they know what their loved one will need after discharge and develop confidence that they can provide that care. Most important, family members can be involved in decision-making if the patient is unable to participate in decisions. Surrogate family decision-makers need extensive information, dialogue, support, and affirmation to prevent PICS-F.

Treatment interventions

Treatment can begin when symptoms of PICS-F are noted at least 1 month after patient discharge. In addition to family education, two interventions may help—interprofessional post-ICU clinics and family support groups.

In some parts of Europe, post-ICU clinics have been used for decades, but outcomes measurement is weak. These outpatient clinics, led by nurses or an interprofessional team, typically focus on patient mobility and mental health/cognitive needs; however, recently, family members have started to attend some clinics. Family members may be assessed for post-ICU adjustment difficulties, acquire education on PICS-F, and receive resources or referrals to providers or support groups for follow-up. Research should explore how post-ICU clinics can more comprehensively include families to address PICS-F.

Family support groups provide validation and a sense of belonging. Participants gain practical knowledge from those ahead of them in the healing process, and they can learn self-care strategies and share resources for trauma resolution. Support groups, which can be nurse-led or lay-led, usually aren't held at a hospital, so family members with PICS-F can avoid painful memories. SCCM has developed the THRIVE initiative (myicucare.org/Thrive/Pages/Patient-and-Family-Resources.aspx) to improve patient and family support after critical illness, including a post-ICU community of volunteer peer-led support groups.

Jason talks with Jennifer at Megan's bedside about PICS-F and gives her a list of local support groups and a brochure about leaving the ICU. He contacts the nurses who will care for Megan in the long-term care facility and asks them to observe Jennifer and to refer her to community resources if needed. Jason asks Jennifer for permission to contact her primary care provider and explain what Jennifer is experiencing.

Nurses' role in ambulatory care

When patients transition out of the hospital, PICS-F management must occur in ambulatory care and community settings. Healthcare personnel in these settings may need education on PICS-F to screen family members. Key questions on an initial assessment may include:

- How would you rate your current physical functioning compared to before your loved one's hospitalization?
- How would you rate your current cognitive functioning, including your memory, compared to before your loved one's hospitalization?
- How would you rate your current emotional functioning, including anxiety and depression, compared to before your loved one's hospitalization?
- Have you been sleeping adequately? Any insomnia or nightmares?
- Have you been able to return to work and your normal daily activities?
- Have you been more fearful or anxious lately?
- Have you noticed any "triggers" associated with the hospitalization that may be causing increased stress, anxiety, or worries?

If healthcare personnel recognize symptoms of PICS-F 1 month or more after a family member's ICU stay, follow-up questions may include:

- What resources are you aware of that provide emotional and mental health support during times of adjustment in life?

Resources

Patients and families may find these resources helpful as they work to overcome post-intensive care syndrome–family.

After the ICU.com
This website includes a short form that patients and families can use to help determine if they might be suffering from post-traumatic stress disorder (afterthe icu.org/ptsd-checklist-pcl-civilian-version).

Society of Critical Care Medicine
The Patient and Family Resources page (myicucare.org/Thrive/Pages/Patient-and-Family-Resources.aspx) on this organization's website has information to help patients and families understand post-intensive care syndrome.

- What resources have you accessed so far and what care have you received?
- What's been most effective at improving your physical, cognitive, and mental functioning since your loved one was hospitalized?
- In what area of your adjustment do you most need additional support?

Aiding a transition to a new world

PICS-F can diminish family members' quality of life after a loved one's critical illness. Nurses in acute-care settings can act early to prevent it, and nurses across the care continuum can be educators and spokespersons about PICS-F. Astute nursing assessment, care coordination, nurse-family relationship building during the ICU stay, and connections with community resources after patient discharge can mitigate the effects of PICS-F and offer families serenity, even in what might be a new world post-ICU. ★

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**All names are fictitious.*

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Family voice

Alina, daughter of Eduardo

"My dad was here in the States visiting me at my new college when he got really sick last month. I guess he didn't bring the right medications with him. I've never seen a dead person, but he looked like he was dead when they took me to his hospital room for the first time. I turned around and left, ran down the hall. The noises and smells and wires were more than I could take. He couldn't understand English, yet I was too out of it to help. I feel so guilty for not being there more for him. The nurses were nice to tell me how things were going, but I really didn't want to hear the details. I never saw my dad weak like that. He has always been strong.

"After discharge, which was a scary day, I took him to my little apartment and arranged for him to get a flight back home. I can't seem to stop crying. I've lost weight and lie awake most nights. I'm so nervous, and I jump at anything startling. My mother calls with updates, but I ignore her calls. I had to drop one class and may have to drop out all together for the semester. When will this shock wear off and let me feel normal again?"

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Please mark the correct answer online.

1. Which of the following indicates that someone may be suffering from post-intensive care syndrome-families (PICS-F)?

a. Continued insomnia 1 week after the family member was discharged from the intensive care unit (ICU)
b. Continued insomnia 2 months after the family member was discharged from the ICU
c. Fatigue similar to that experienced before the family member was discharged from the ICU
d. Less fatigue than before the family member was admitted to the ICU

2. Which statement about the prevalence of PICS-F is correct?

a. It is as high as 50% when families have to make surrogate end-of-life decisions with inadequate support.
b. It is as high as 65% if the patient dies while being cared for in the ICU.
c. It ranges from 2% to 40%.
d. It ranges from 20% to 85%.

3. Which patient would most likely put his or her family at risk for PICS-F?

a. A 64-year-old man with a poor prognosis for functional recovery after his stroke.
b. A 56-year-old woman with pneumonia who stayed in the ICU for 4 days.
c. A young man who was successfully resuscitated 24 hours after being admitted to the ICU.
d. An older man who was in a motor vehicle accident and has a large, nurturing family.

4. Which of the following family members has the highest risk for PICS-F?

a. Kwame, who's close to his two brothers and talks frequently with the nursing staff.
b. Blake, who's able to sleep near his partner, who's in the ICU for influenza.
c. Sofia, who's 74 years old and has a master's degree in genetics.
d. Marie, who's 44 years old and taking medication for depression.

5. An environmental risk factor for PICS-F that's associated with moderately strong evidence is

a. failing to include siblings in patient rounds.
b. perception of moderately good care of the patient.
c. lack of flexible family access to the patient.
d. inadequate staffing during the night shift.

6. Which statement about assessment for PICS-F is correct?

a. Screening tools for PICS-F don't exist.
b. Screening tools for PICS-F exist but are too long for practical use.
c. Researchers are unable to use the Impact of Events Scale to measure effects that may be associated with PICS-F.
d. Researchers are unable to use the Hospital Anxiety and Depression Scale to measure effects that may be associated with PICS-F.

7. Which of the following indicates that the nurse has implemented a strategy for improving communication with family members?

a. The nurse concentrates on delivering high-quality care instead of talking to family members.
b. The nurse keeps the handover report confidential to ease family anxiety.
c. The nurse sits at the bedside for at least 5 minutes near the beginning of the shift to listen to patients and families.
d. The nurse includes the patient's family during the rounds made every 2 hours.

8. To help prevent PICS-F and to support families who are experiencing it, nurses can do all of the following *except*:

a. Provide a structured family education program, given by an interprofessional team.
b. Limit the amount of information given to family members and provide it only in oral format.
c. Allow family members to participate in the patient's care as appropriate.
d. Suggest the Patient and Family Resources page on the Society of Critical Care Medicine website.

9. Which statement about an ICU diary is correct?

a. The diary should be kept as part of the patient's medical record after discharge.
b. The nurse should take the lead with the diary and invite family members to contribute.
c. Only family members should document their thoughts and experiences in the diary.
d. Evidence shows that keeping a diary is highly effective in reducing PICS-F.

10. All of the following statements about assessing for and treating PICS-F after the patient has been discharged are correct, *except*:

a. Interprofessional post-ICU clinics may be helpful, but more research is needed.
b. An appropriate question if PICS-F is suspected is, "What resources have you accessed so far and what care have you received?"
c. Those in community settings should know how to screen for PICS-F.
d. Family support groups haven't been found to be helpful in mitigating symptoms of PICS-F.