

2018

# I Survived the ICU: Post-Intensive Care Syndrome from Patient and Nursing Perspectives

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## Recommended Citation

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I Survived the ICU:  
Post-Intensive Care Syndrome from Patient and Nursing Perspectives

An Honors Thesis  
Presented to  
The University Honors Program  
Gardner-Webb University  
6 April 2018  
by  
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I Survived the ICU:  
Post-Intensive Care Syndrome from Patient and Nursing Perspectives

After a head-on collision with a drunk driver, Kathy Torpie had a long road to recovery ahead of her. After three weeks in the intensive care unit (ICU), sedation, and mechanical ventilation, she was left with a set of symptoms coined Post-Intensive Care Syndrome (PICS) (Torpie, 2005). PICS is defined as “a condition that encompasses new or worsening impairments in the patient’s physical, cognitive, or mental status arising after critical illness and persisting beyond the acute hospitalization” (Makic, 2016, p. 172). With technological advancements, ICU survival rates are on the rise. Now that survival has increased, it is time that the focus of intensive care expands to not only the survival of the patient but to encompass the patient as a whole; cognitively, psychologically, and physically in order to prevent PICS (Makic, 2016). Patient perspectives of PICS are a valuable asset in finding the most appropriate treatments for these patients. Furthermore, patient perspectives aid in applying possible preventative measures and treatment options to best nursing practice.

**What Causes PICS?**

Many times, medical conditions serious enough to bring a patient to the ICU call for invasive medical interventions. Mechanical ventilation, central line placements, surgeries, and frequent medication administration are just a few of the measures needed in order to treat ICU patients, but all of the above can cause significant psychological and cognitive stress to the patient. This stress can lead to sleep deprivation, anxiety, fear, delusions, delirium, and the need for sedative agents, all of which increase the propensity of developing PICS (Makic, 2016).

Several factors are known to place a patient at risk of developing PICS. These factors include: 48 or more hours spent in the ICU, delirium, advanced age, being female,

mechanical ventilation, and the use of sedation (Makic, 2016). In addition to the above, risk factors recognized specifically for cognitive impairment include hypoxia, hypotension, glucose dysregulation, renal replacement therapy, and prior cognitive deficit (Rawal, Yadav, & Kumar, 2017). Psychological impairment is more common among females, individuals with a low level of education, and use of sedation and analgesia (Rawal et al., 2017). Physical impairment is more likely among individuals mechanically ventilated for 7 days or longer, on prolonged bedrest or deep sedation, or diagnosed with sepsis or multi-system organ failure.

In a study by Torres et al. (2015), patients were screened with the Hospital Anxiety and Depression Scale (HADS) and the Post-Traumatic Stress Syndrome 14 question inventory during their hospitalization, as well as 3 months post-discharge. Results showed that 87.6% of ICU patients were at risk of developing PICS, and 52.4% actually developed symptoms at ICU discharge. At one week post-ICU discharge, 42% of patients displayed PICS characteristics, and at 3 months post-hospital discharge 30% of patients had PICS characteristics. Individuals that had PICS at hospital discharge had greater difficulty getting back to work, and even had a higher risk of mortality within the first three months.

### **What Does PICS Look Like?**

According to Makic (2016), PICS occurs in 25-75% of ICU survivors. Symptoms fall into three categories: Physical functioning, cognitive, and mental status. Lasting physical difficulties could include physical and pulmonary deconditioning, and muscle degeneration preventing the return to work or everyday activities. These symptoms may appear as generalized weakness and fatigue, and may result in decreased mobility and frequent falls. Physical impairments occur in more than 25% of ICU survivors (Rawal et al., 2017).

Cognitive difficulties may include memory impairment, difficulty concentrating, decreased attention, and decreased language function (Makic, 2016). Patients may also report difficulty processing situations or speech. Cognitive impairments may occur in 25-75% of ICU survivors (Rawal et al., 2017).

Mental status impairments include anxiety, depression, post-traumatic stress disorder (PTSD), insomnia and other sleep disturbances, and flashbacks (Makic, 2016). In addition to these psychological symptoms, some patients may report sexual dysfunction. Psychological impairments may occur in up to 62% of ICU survivors (Rawal et al., 2017).

The physical, cognitive, and mental status impairments caused by PICS can be clearly seen in the case of Kathy Torpie. Torpie (2005) expressed long-term difficulty getting in cars, getting up off of the toilet, shopping, gardening, walking down an incline, and more. Her activities of daily living (ADLs) were severely impaired. Torpie experienced difficulty with written communication during her intubation. She expressed, "...my letters came out backwards, I forgot words, and I couldn't spell" (p. 30). She stated that it seemed as though the world was moving too fast. She often found herself home alone, and when visitors came, it was difficult to find the cognitive energy to interact with them. Torpie experienced anxiety, depression, and PTSD after her hospital discharge. Her anxiety persisted for six years after discharge, and she once experienced a panic attack while she tried to make a meal and hold conversation with her guests at the same time. Torpie also developed a "who cares?" mindset, and often found comfort in suicidal thought, as it gave her a sense of control over her life once again. She describes her PTSD as a sense of "hypervigilant self-protection" that resumes anytime someone she depends on for help seems too busy or is too impatient to display truly caring behaviors.

In a study by Ramnarain et al. (2015), patients admitted to the ICU for more than 5 days were invited to attend an ICU follow-up clinic. Six weeks after discharge, these patients were sent a screening packet including a health questionnaire, a hospital anxiety and depression scale, and an IES-R questionnaire to screen for PTSD. Patients indicating need for further treatment were referred appropriately. Results indicated that out of 97 patients, 81.4% had somatic complaints affecting ADLs. These complaints were most frequently fatigue (74.4%), muscle weakness (48.8%), dyspnea (34.9%), impairment of daily activity (81.4%), pain (38.4%) and weight loss (33.3%). Hospital anxiety and depression (HAD) was present in 45.4% of patients, and PTSD was present in 43.3% of patients, however HAD and PTSD were considered to be more common in women than in men.

### **Who Else Can Be Affected?**

When pondering the scope of PICS, it is important to reflect on who the client of the ICU nurse is. It seems obvious that the patient lying in the ICU bed is the nurse's client, but it is important to realize that the families of these patients are also clients that need to be cared for. Though they do not need the physical care that the nurse provides the patient, they require emotional support and education as they make decisions and try to figure out what comes next for them and their loved one. This could potentially be one of the most difficult times of their lives as well.

As many as 33-69% of ICU families or caregivers experience the symptoms of PICS, displaying symptoms such as stress, anxiety, depression, complicated grief, sleep disturbances, and PTSD (Petrinec, 2017; Rawal et al., 2017). This occurrence is called PICS-Family or PICS-F. Risk factors include poor communication between the staff caring for the patient, being in the decision making role, lower educational level, and loss or near loss of a

loved one (Rawal et al., 2017). Severity of patient illness, the gender of the family member, the relationship between the family and the patient, and the psychological history of the family member also have been proven to play a role in the development of PICS-F (Petrinec, 2017).

PICS-Family has been noted to be especially prevalent among family members in the decision-maker role during the patient's hospitalization. Family members must consent to treatments that may or may not be effective, and seemingly put the patient through much pain and suffering in order to keep them alive. Decision makers may blame themselves for the outcome of their loved one or suffer from PTSD. The effort exerted to care for their sick loved one may even place a strain on their body, causing weakness or other physical symptoms to develop (Petrinec, 2017).

After being hit by a drunk driver, Jane spent over a year in the hospital recovering. She had many broken bones, and required mechanical ventilation and sedation, leaving her barely able to move to press the call bell. Jane's prognosis was poor, and physicians held conversations with one another over her bed about her poor prognosis, never addressing her directly. Due to ICU protocols and visiting hours, her mother was made to leave her side, despite her desire to remain with Jane. The nurses stated they would call her mother if she pressed the call bell, but did not follow through with the promise. Jane had significant memories of fear due to her feelings of loneliness and abandonment. Terrified that her daughter would die alone, Jane's mother began to hide in the curtains or under the bed of Jane's room at night so she would not be asked to go home. "Emotionally traumatized" by their required separation and lack of caring by medical personnel, both Jane and her mother

suffered from PTSD after her ICU stay, and both received psychiatric care in order to properly cope (Davidson & Stutzer, 2016).

Davidson and Stutzer (2016) state: "...our best intentions at helping patients' family members get rest or respite can be counterproductive to their strong desire for presence and safeguarding their loved one's life" (p. 237). Restrictive visiting hours are justified as a measure to provide a restful environment for patients, but as seen in the case of Jane, some patients benefit more from having support persons present throughout their stay. In the case of Jane's mother, some support persons benefit from the ability to remain with the patient as well. In concordance with Davidson and Stutzer, it is important that the nurse does not inflict further harm to the patient or the family emotionally while trying to heal the patient physically.

### **How Can PICS Be Prevented?**

In the critical care setting, stabilizing the patient medically is the first priority of care, but in order to prevent PICS, additional standards of care must be met (Makic, 2016). There are many different strategies being researched and developed in order to find the best ways to prevent PICS. Below are just a few of the strategies that are emerging.

### **Assessment and Screening**

In the United Kingdom, clinical guidelines express that patients should be screened for PICS risk factors or manifestation throughout the ICU stay, with an official formalized assessment at ICU discharge to pinpoint any immediate physical need and begin screening for psychosocial symptoms such as anxiety that may begin after ICU discharge (Griffiths, Jones, & Gilmore, 2012). Rawal et al. (2017) suggest that during assessment of patient history, the psychological status should be assessed including ability to cope with past

stressors, along with medication history, current mental status, and environmental or family factors.

### **ABCDEF Bundle**

Prevention measures of PICS are often discussed in the form of acronyms. The Society of Critical Care Medicine and a team of experts came together to create an ABCDEF bundle of prevention.

**Assess, prevent, and manage pain.** Due to the nature of critical illness, pain is often present in most client cases. Trauma, complex surgeries, and severe illness are frequent causes of ICU admission, all of which cause pain. The most accurate measure of pain is by patient report; however, due to the nature of critical illness, patients may not be able to communicate their pain. Sedation, intubation, or level of consciousness changes inhibit verbal reports; therefore, alternative pain scales must be used in order to assess and manage pain. Possible pain scale options include the numeric rating scale (NRS), behavioral pain scale (BPS), and the critical care pain observation tool (CPOT).

The numeric scale is based on a 0-10 system, zero being no pain at all, and 10 being the maximum amount of pain. The scale is printed from 0-10 horizontally, and non-verbal patients are asked to point to the number that most accurately represents their pain level. CPOT and BPS are documented to be the most accurate scales in individuals who are non-verbal, but have observable motor response. The BPS is based upon facial expression, upper limb positioning, and compliance with the ventilator. Scores for the BPS range from 3-12, with a score greater than 5 indicating significant pain. CPOT is based on facial expression, body movements, muscle tension of the upper extremities, and compliance with the ventilator

or vocalization (if the patient is not intubated). The CPOT scale ranges from 0-8, with a score greater than two indicating significant pain.

In addition to verbal or motor responses to pain, elevation of vital signs may indicate pain. Though pain can be indicated, assessment of vital signs should not be used as the only measure of pain assessment. Vital signs are most useful as a measure to cue further pain assessment.

In order to adequately assess pain, it is recommended by the Society of Critical Care Medicine (SCCM) to assess pain at least every three hours, as well as on an as needed (PRN) basis when any of the nonverbal cues of pain are exhibited by the patient, or the patient verbally reports pain. Significant pain should be treated within 30 minutes of assessment, and then reassessed for effectiveness of the interventions. Opioids are the drug of choice for pain management; however, non-opioid options or combination options have been proven to effectively manage pain.

If pain is not adequately managed, the patient may become agitated, and require further sedation. Deep sedation is a known cause of PICS and can be avoided with proper pain assessment and management (SCCM, n.d.).

**Both spontaneous awakening trials and spontaneous breathing trials.** Both spontaneous awakening trials and spontaneous breathing trials are linked to PICS prevention. Sedation in the ICU is meant to keep patients calm and comfortable, facilitate mechanical ventilation, and decrease traumatic memories of the ICU stay. Though sedation has many benefits, deep sedation may increase the time that a patient is mechanically ventilated, as well as the length of the overall hospital stay. Prolonged deep sedation has also been correlated with lower six-month survival rates, and increased levels of stress to the body. In a

study by the SCCM, patients in ICU's with nursing sedation titration protocols led by the Ramsay sedation scale had reduced length of mechanical ventilation by one day. These patients also experienced a 1.5 day shorter length of ICU stay as opposed to patients on a set continuous infusion of sedative drugs. Continual assessment of patient sedation, and interventions based upon levels of sedation allow the nurse to maintain as light a level of sedation that can be tolerated by the patient (SCCM, n.d.).

Daily sedation interruptions (or sedation vacations) decrease length of mechanical ventilation and length of ICU and hospital stays. In order to perform a sedation vacation, the nurse turns off the patient's sedation until the patient is awake. In order to be considered awake, the patient must be following commands. After the patient is considered awake, sedation is restarted at 60% of the prior dose. In a study by the SCCM (n.d) using daily sedation vacations, mechanical ventilation time decreased by 2.4 days, and ICU length of stay decreased by 3.5 days. Patients must meet certain safety criteria in order to qualify for awakening trials. The safety criteria given by the SCCM are as follows: no active seizures, no alcohol withdrawal symptoms, no agitation, no use of paralytics, no myocardial ischemia, and a normal intracranial pressure. The patient fails the awakening trial if anxiety, agitation or pain is present, the respiratory rate is greater than 35 breaths per minute, oxygen saturation drops below 88%, the patient exhibits respiratory distress, or a cardiac arrhythmia develops. After an awakening trial failure, the patient's dose of sedative is resumed once again at half the previous dose. The awakening trial may last as long as the patient tolerates the absence of sedation.

When daily sedation vacations are paired with spontaneous breathing trials, patient outcomes further improve. Certain safety measures must be met in order to perform a

spontaneous breathing trial as well. The patient must not be agitated, he must have an oxygen saturation of 88% or higher, and display inspiratory effort. If the patient passes the safety screen, the breathing trial is started, allowing the patient to breathe on their own while still intubated. A breathing trial failure consists of a respiratory rate greater than 35 breaths per minute or less than 8 breaths per minute, an oxygen saturation less than 88%, respiratory distress, a mental status change, or the development of an arrhythmia. If the patient fails the trial, they will be placed back on full ventilator support. If they do well while on trial, extubation, or removal of the endotracheal tube, will be considered. Spontaneous breathing trials reduce weaning times and reintubation rates, which improve patient outcomes (SCCM, n.d.).

Barriers to light sedation include fear of patient self-extubation or discomfort, and concern of medical personnel about understaffing and lack of productivity due to the need for extra supervision in lightly sedated patients. A team approach is needed in order to choose the most appropriate and therapeutic time to extubate the patient. The utilization of a team allows for the most appropriate resources to be applied (SCCM, n.d.).

**Choice of analgesia.** According to the SCCM (n.d.), in order to prevent PICS, intravenous opioid medications are considered the analgesic of choice due to consistency across the class of medications in regards to titration. Non-opioids should only be considered in order to decrease the amount of opioids needed by the patient. Benzodiazepines should be avoided in order to prevent further respiratory depression. Overall, pain medications should be chosen on an individualized basis in order to find the regimen best for the patient. Pain type (neuropathic or other), duration (constant or intermittent), and severity should be considered, as well as other patient conditions (renal insufficiency, paralytic ileus, dysphagia)

when choosing types and routes of analgesia. Medications that cause hemodynamic changes should not be considered in order to keep the patient stable.

Pain should be treated prior to sedation administration or titration in order to facilitate light levels of sedation. If the patient is restless due to a high level of pain, a higher level of sedation will be required to achieve patient “comfort,” when in all reality, treatment of pain would allow patient comfort as well as a lighter level of sedation (SCCM, n.d.).

Two of the most common sedative agents used in ICUs are dexmedetomidine and propofol. Studies by the SCCM (n.d) show that dexmedetomidine is more appropriate in patients requiring light sedation, whereas propofol is recommended for individuals requiring deep sedation.

**Coordination of care.** In order to prevent or treat PICS, a well-coordinated multidisciplinary plan of care is needed. According to Rawal et al. (2017), the most agreed upon measures of prevention are limiting deep sedation, encouraging early mobilization, and aggressive occupational therapy. These three prevention measures alone require three different disciplines of care. Medical/nursing, physical therapy, and occupational therapy departments must be utilized to accomplish these three prevention measures alone. If these departments do not communicate in order to coordinate their care, appointments will overlap, care will not be as individualized to the current patient condition, and continuity of care will be lessened. Beyond this, the schedules and lifestyles of the patient and caregivers must be taken into consideration, especially if this aggressive treatment plan is to continue after hospital discharge.

Torpie spent months in the hospital after her accident, but beyond her hospital stay she required many home visits from physical and occupational therapists in order to regain

many of the functions she lost over the course of her stay. She told of an instance when a caregiver came to the house earlier than expected and arrived during another scheduled appointment. The appointment was rushed and cut short due to the lack of coordination of care, and Torpie felt trampled upon as she did not receive the care she deserved and paid for (Torpie, 2005). Not only can this type of conflict happen in the home setting, but it can occur within the hospital setting as well. Medical personnel must focus on patient centered care, not on personal schedules and convenience.

Care cannot end at the point of life-saving, but the life the patient once had should be restored as fully as possible. Rawal et al. (2017) argues that not caring for the patient beyond saving their life is irresponsible on behalf of the medical team. The extra effort of forming a multidisciplinary plan of care can improve the quality of life and functionality of both patients and families.

Part of creating a multidisciplinary care plan requires that each member of the medical team has an understanding of PICS in order to encourage collaboration and appropriate referrals (Harvey, 2016). Harvey discusses the THRIVE Initiative by the Society of Critical Care Medicine as a method to educate all members of healthcare about PICS. The THRIVE Initiative has held conferences for non-critical care personnel to be educated about the signs of PICS and allow personnel to interact with patients during their recovery in order to increase understanding of PICS. Harvey suggests that the scope of critical care must extend beyond the time spent in the intensive care setting, and encompass the events precipitating the stay as well as care for related needs after the stay. Since it is non-critical care members of the healthcare community caring for these individuals before and after the ICU stay, it is important for them to be informed about PICS.

**Delirium: Assess, prevent, and manage.** Delirium occurs in 50-80% of patients on mechanical ventilation, and 20-50% of less severe patients. The results from Torres et al.'s (2015) study shows that out of 52% of ICU survivors that developed PICS, 35% of them experienced delirium at some point during their hospital stay. Delirium increases the length of hospital stay, increases cost, and increases the risk of death (SCCM, n.d.). Torres et al. also noted that the presence of delirium at ICU discharge was significantly linked with the later development of PICS.

Symptoms of delirium include hallucinations, delusions, agitation, lethargy, emotional disturbances, and sleep disturbances. Delirium develops in a short time span, and levels of delirium wax and wane throughout the day. Risk factors given by the SCCM include underlying brain disease, older age, visual or hearing deficits, and the presence of chronic diseases. Triggers of delirium given by the SCCM may include medications, infection, dehydration, immobility or restraints, poor nutrition, tubes and catheters, electrolyte imbalances, and lack of sleep. All patients should be monitored for delirium routinely, and prevention measures such as early mobility, sleep enhancement via non-pharmaceutical measures and hygiene, reducing unnecessary medications, reorientation, and proper oxygenation should be used. Interventions to reduce delirium once present include constipation relief, pain reduction, adequate nutrition and hydration, utilizing sensory assistance devices such as the patient's glasses or hearing aids, and cognitive stimulation (SCCM, n.d.).

In order to treat or prevent delirium, accurate assessment tools must be utilized in order to diagnose delirium at its start. The Confusion Assessment Method for the ICU Flowsheet may be used as an assessment tool for delirium. This tool assesses changes in

mental status (acute or fluctuating), inattention, altered level of consciousness, and disorganized thinking. The tool offers scoring methods in order to determine if a patient is experiencing delirium (SCCM, n.d.).

**Early mobility and exercise.** Mobility programs are individualized based on patient condition. Early mobility combats ICU acquired weakness and delirium. Studies show that as much as an 11% strength loss may occur for each day a critically ill patient is on bedrest (SCCCM, n.d.). Studies show that out of roughly 52% of ICU survivors that develop PICS after hospital discharge, 33% of them had ICU acquired weakness at the time of discharge (Torres et al., 2015). An early mobilization study by Bemis-Dougherty and Smith (2013) showed that patients on early mobility programs are frequently out of bed by day five, as opposed to traditional patients that are not out of bed until day 11. On average, these patients also exhibit a 3.3 day shorter length of ICU stay. Shorter length of stay, then leads to cost reduction for both the patient and the hospital. PICS symptoms such as pain, difficulty ambulating, and self-care deficits can be managed with physical therapy alongside patient education, and medical interventions. The focus of physical therapy may include bed mobility and repositioning, balance training such as sitting on the side of the bed, transfer training, pre-gait activities, strength or breathing exercises, airway clearance activities, and education. Passive and active range of motion exercises are also proven to lessen ICU acquired weakness, and provide positive benefits to metabolism, immunity, and cognitive function as well (Griffiths et al., 2012).

Bemis-Dougherty and Smith (2013), also discuss the benefits of integration of a physical therapist as a permanent member of the ICU team. Integration of physical therapists is shown to produce positive patient outcomes, as physical therapy can be started as early as

24 hours after ICU admission, or when the patient's respiratory and hemodynamic status' are deemed stable. The expertise of a physical therapist allows each patient to receive an individualized treatment plan according to their specific condition. In a study by Griffiths et al. (2012), ICU acquired weakness was often not noticed by ICU physicians if it did not affect weaning from the ventilator. Weakness was then left to be dealt with by ill-equipped general physicians and healthcare personnel on general medical floors, as well as distressed family members. The integration of a physical therapist to the ICU team would introduce another set of skilled assessment techniques to assure that ICU acquired weakness does not go unnoticed.

Not only can early mobility be optimized through physical and occupational therapy consultation, but the nurse can encourage patients to perform active movements as well, such as lifting arms and legs, or sitting on the side of the bed or in a chair (SCCM, n.d.). Though it is within the nursing scope of practice to encourage mobilization, nurses often become busy with medications and other treatments, and mobility does not fall as a nursing priority. Integration of a physical therapist allows there to be an individual on the ICU team devoted to encouraging mobility. Torres et al. (2015), found that only 22% of PICS cases were given physical therapy consults. Physical therapy is a proven PICS prevention measure, yet many patients are not educated on this option or its benefits. Furthermore, physical therapists outside of the hospital setting, such as in rehab facilities, or in home care, should be educated about the manifestations of PICS in order to recognize and diagnose PICS, and begin an appropriate treatment plan (Bemis-Dougherty & Smith, 2013).

Major barriers to early mobility include safety, difficulty in managing many tubes, lines, and drains, and hesitation in determining if a patient is stable enough to become mobile

(SCCM, n.d.). Significant muscle weakness, respiratory and hemodynamic issues, and poor balance are all prevalent in the critically ill patient, placing them at high risk for falls (Griffiths et al., 2012). Tubes, lines and drains are also at risk for displacement with mobility, causing pain or possible complication to the patient. However, critical lines and drains can be stabilized in order to facilitate movement, and in regard to hemodynamic and respiratory instability, assessment techniques have been developed in order to determine when a patient should stop and rest to prevent collapse. Fatigued or pale appearance, elevated respiratory rate consistently 10 breaths or more per minute above baseline, diaphoresis, and loss of balance are just a few signs that a patient should stop and take a rest (SCCM, n.d.).

**Family engagement and empowerment.** It is frequently thought that family presence in the ICU interferes with care, tires the patient, adds burden to the family, and spreads infection; this is not true. Families in the ICU actually decrease length of ICU stay, have no correlation with increased infection, reduce patient loneliness, and decrease falls. Patients have less anxiety, confusion, and agitation, and have a shorter length of stay. In addition, feelings of security and safety are increased. Patient and family satisfaction increases, communication increases, and the family can be more involved in care. Due to these benefits, open visitation hours are supported. Guidelines given by the SCCM (n.d.) encourage no access restrictions for the primary support person, provide policies to prevent discrimination as to who the support person may be, and provide a protocol for the limitation of visitors that “infringe on the rights of others” (p. 14).

Families can also be a valuable resource in delirium management. Patients experiencing delirium and confusion require frequent reorientation. Family members are able

to provide reorientation by talking about familiar people and life events. They can also discuss current events, incorporating the current date and time (Makic, 2016).

Family participation in rounds is also supported in order to keep the family informed and increase understanding of the patient condition. Presence of the family also offers more opportunities for education, reducing the amount of information that has to be absorbed by the family upon discharge education (SCCM, n.d.).

The main resistance to patient and family-centered ICU care comes from healthcare workers. Family presence at the bedside is frequently not seen as a necessary part of care but as a privilege. It is important to remember that the family knows about the baseline functional status of the patient and can provide valuable information. The idea of family members witnessing a code meets even further resistance by healthcare personnel, but studies show that witnessing the code lessens the family member's occurrence of PTSD, depression, and complicated grief surrounding the event (SCCM, n.d.).

Part of family involvement includes assessing the family's culture and belief systems, language barriers, and medical literacy. Addressing these topics allows for more patient and family centered care, as well as a better understanding of the situation at hand, reducing the risk of PICS development (SCCM, n.d.).

### **Other Prevention Measures**

**ICU diaries.** In a study by Blair, Eccleston, Binder, and McCarthy (2017) at Madigan Army Medical Center in Tacoma, Washington, the use of ICU diaries was shown to reduce the occurrence of PICS by reducing anxiety and depression, PTSD, and improving health related quality of life after a critical illness. For the purposes of this study, diaries were implemented with patients mechanically ventilated for more than 24 hours, or patients that

were experiencing delirium according to the CAM-ICU delirium screening tool. Diaries included a welcoming page to the ICU and a Get To Know Me page that asked about nicknames, occupation, family, pets, hobbies, favorite music, TV shows, and stressors. Educational information about PICS, a list of available resources, blank diary pages, photos of the ICU, and a list of common medical terms with descriptions were also included. Along with the diary, patients and/or family members received a pamphlet including information about how to utilize the diary during their stay.

The diary was created by an ICU nurse or “diary champion”, welcoming the patient to the ICU and describing the reason for their admission in common terms. All members of the healthcare team were educated on the use of the diaries and were encouraged to write entries in the diaries every shift. The RN educated the patient and family on the purposes and benefits of the diary, and the symptoms of PICS. Sedated patients were introduced to the diary as soon as they were awake, educated about the benefits, and encouraged to keep using the diary throughout their stay. At discharge, an instant camera was provided for the patient to take a picture of themselves or of the hospital room. The diary did not become part of the medical record, and followed the patient throughout their hospital stay beyond the ICU, and was taken home upon hospital discharge (Blair et al., 2017).

ICU diaries allow patients to reflect upon their recovery and evaluate the magnitude of how far they have come. Diaries also improve communication between the healthcare team and family members, the patient and family members, and between caregivers. The improved communication and intentionality behind the creation of the diary creates an environment of family centered care, and explanations of the patient’s disease process

written in lay terms help the patient to have a better understanding about their condition and treatment process (Blair et al., 2017).

Patient memories of the ICU stay can interfere with recovery. Many times, patient memories are very abnormal due to delirium and delusions. It has been shown that frightening experiences in the ICU can lead to PTSD, but frightening delusional memories can also contribute to the development of PTSD. Delusional memories are often retained more vividly than actual memories. Amnesia and delusional memories are often combatted with the use of ICU diaries. The diaries are able to provide an accurate timeline of events to the patient in order to provide the patient with the actual events of their stay and negate their delusional memories (Griffiths et al., 2012).

Memory loss and amnesia are also prevalent during and after an ICU stay. Even patients who have appeared alert and oriented during hospitalization can later have no memory of their intensive care stay. This can interfere with recovery later on, as the patient may not be able to connect their decline in physical condition to what has happened to them and what they need to do to recover. This issue can be addressed by discussing a timeline of events; however, retention of memory is also impeded in these patients, and a timeline of events must be repeated frequently to the patient. Diaries may be used in order to provide the patient with a physical copy of the timeline of events in terms that they can understand and refer to as frequently as needed (Griffiths et al., 2012).

The diary can pass along feelings of hope or joy, describe support of family members at the bedside or those that cannot be present, and convey spiritual messages. The family is able to document their emotional support, while staff are able to provide clinical information in lay terms. The messages from staff show the patient that they were cared for by

professionals that saw them as an individual, not just another patient assignment (Blair et al., 2017).

Patients and families expressed that the diaries benefitted them in various ways. One patient stated that the diary helped keep track of the events of their ICU stay, because the “days ran together.” Another patient expressed the diary’s usefulness in understanding the events of her stay in chronological order, reminding her of support she received, and helping her to gauge her recovery progress. Family members reported that through writing notes in the diary, they felt as though they could communicate with their sedated loved one because the patient could go on to read the notes later. Families felt that the diary gave them an active and supportive role in the patient’s care. Writing in the diary may also allow the family member to better process the situation emotionally (Blair et al., 2017). More information, including diary templates, supporting literature, and networking opportunities may be found at <http://www.icu-diary.org> (SCCM, n.d.).

Any barrier to the use of ICU diaries falls within the healthcare team, but there were no significant barriers noted in the study. Upon survey, some providers noted a lack of time to write entries in the diaries, and some nurses expressed discomfort about what information to include in the diary entries. Overall, the staff expressed positive sentiment toward the diaries, listing positive outcomes for the patients, and an increase in staff satisfaction. One nurse even stated, “The ICU diary entries bring meaning to the work of caring for patients who may never even remember their ICU stay” (Blair et al., 2017, p. 7).

**Post-ICU clinics and rehabilitation.** In a study by Farley et al. (2016), clients were surveyed in order to determine the perceived usefulness of multidisciplinary follow-up clinics. The patients’ health-related quality of life and psychological status were screened

using the European Quality of Life 5 Dimensions questionnaire and the Hospital Anxiety and Depression Scale. Final results revealed that 59% of patients screened suffered lessened health related quality of life, and 30% reported anxiety, depression, or both. Overall, 81% of patients believed that a multidisciplinary follow-up clinic would have been beneficial to their recovery.

Follow-up clinics can take on many different forms. In an article by Khanna, Peters, and Kim (2016) a nurse tells the story of an individual that spent six weeks in the ICU. After a major surgery, multiple smaller procedures and a plethora of other treatments, he was discharged home, but discharge was not the end of his journey. He suffered from anxiety, a sleep disorder, muscle weakness that negatively affected his work performance, and much frustration over his physical and emotional condition. After a stay in intensive care, patients are discharged to the care of their primary physician who often is not informed of the events of the hospital stay beyond the information given to them by the patient. Follow-up visits with the critical care physician often do not occur, and since PICS is still a developing concept, many general practitioners are not informed of the signs and symptoms, and do not know the most effective treatment options. The concept of a follow-up clinic allowing patients to follow up with the same physician that managed their care throughout the ICU stay provides continuity of care and improves treatment for the patient.

Another discharge option for intensive care patients is a long-term acute care facility, otherwise known as LTAC. Though the patient is no longer in the critical care environment and hospital costs are reduced, discharge to another facility means the patient is handed off to another set of caregivers with another ideal treatment plan and another set of differing opinions. LTAC facilities have not been correlated with a lower prevalence of PICS, and

after an LTAC stay, patients are still discharged back to their primary care provider who may still be uninformed about the patient's progress or needs as previously discussed (Lin & Soto, 2016).

According to Rawal et al. (2017), a strong multidisciplinary approach is needed in order to prevent and manage PICS. Exercise, physical therapy, occupational therapy, symptom management, and rehab are all needed in order to support best outcomes for these patients physically. Psychologically, these patients need depression, anxiety, and PTSD treatment via pharmacologic and non-pharmacologic measures, including psychological and behavioral therapies. Patient families and caregivers may also need counseling and support. A clinic where an individual could receive all of the PICS treatment and follow up they needed would greatly improve the quality of care these individuals receive.

Though follow-up clinics are recommended to improve patient outcomes, it is important to note that follow-up clinics and rehabilitation are not synonymous. Rehabilitation should begin as soon as the patient is stable in the hospital in order to combat and prevent PICS development. Much like follow-up clinics, rehabilitation services must not be limited to the patient alone but must include family members. The effects of critical illness not only change the life of the patient, but of the family unit as a whole. Rehabilitation focuses on the needs of each individual and focuses care based on those needs. Pathology of PICS is different in each individual; therefore, recovery must be specialized and individualized. Prevention of PICS requires the establishment of a "culture of recovery and rehabilitation therapy" (Griffiths et al., 2012, p. 804). Nurses must provide coping support and help families understand the situation. The nurse may even allow the family to assist with physical care, as well as psychologically support and care for the patient during

recovery. When the patient feels that recovery is a team effort, morale improves. The nurse must apply caring attitudes and use critical thinking skills in order to individualize care to meet individual patient goals. Clearly defining a realistic recovery timeline for patients may also help prevent some of the psychological and emotional effects of PICS, and aids in the “culture of recovery and rehabilitation therapy” (Griffiths et al., 2012, p. 804). A general guideline for recovery time would be one week of recovery for every day in the ICU for younger patients, and two weeks for every day spent for older adults (Griffiths et al., 2012).

The concepts of follow-up clinics and rehabilitation are very similar, with the main difference being the timing of the start of such programs. Rehabilitation plays more of an active preventative role, whereas follow-up clinics focus more on fixing the problem once it has occurred and preventing further problems. Follow up also serves to gather information in order to inform care of future patients. This takes place in the form of surveys and questionnaires (Griffiths et al., 2012).

### **Family Support Resources**

There are many resources available for family members of ICU patients. The ICU can be a disorienting experience for the loved ones of the critically ill. A new set of terminology, foreign equipment, and new disease processes can be overwhelming for individuals new to this environment to try to understand. The Society of Critical Care Medicine has organized an informational website for patients and families that includes information about roles of different critical care team members, frequently asked questions, a glossary of medical terms frequently used in the critical care setting, and access to an informational booklet titled “Understanding Your ICU Stay”. The booklet has explanations of common disease processes in ICU patients, explanations of life support equipment, information about PICS, and more.

This website also provides links to videos explaining the SCCM's THRIVE Initiative. The THRIVE Initiative seeks to improve support for patients and families after critical illness in order to prevent and manage PICS. This information can be found at [mycucare.org](http://mycucare.org) (Davidson, Hopkins, Louis, & Iwashyna, 2013).

### **How Can PICS Be Treated?**

The best method of treatment for PICS is prevention; however, if this cannot occur, elimination of causative factors, administration of anxiety and antipsychotic medications, reduction of environmental stressors, and frequent family and patient communication are all options for treating PICS. Aggressive physical and occupational therapy are also options in order to rebuild lost strength and either re-strengthen weakened skills or learn new adaptive techniques to compensate for skills lost during the time of illness (Rawal et al., 2017).

### **Patient Accounts**

Allison Clay, M.D., suffered from an underlying disease that caused respiratory failure, resulting in intubation and an ICU stay. She shared stories of unrecognized awareness beneath sedation, delirium, and significant ICU acquired weakness. Upon discharge, Dr. Clay was not offered a physical therapy referral to rebuild strength or durable medical equipment like a shower chair. PTSD was never discussed, and follow up with the ICU physician was never addressed. Since her recovery, she has shared her experiences and the need for medical follow up post-discharge. She also discussed how many primary care physicians are not informed of the events of the ICU stay or what specific care is most needed to move forward (Clay, 2013).

### **Application to Nursing Practice**

#### **Nursing Actions**

After educating themselves about the signs, effects, and prevention measures of PICS and PICS-F, nurses possess many skills that equip them to care for critically ill patients and prevent the development of PICS as much as possible. Davidson and Stutzer (2016) offer six nursing actions that can easily be taken to prevent the development of PICS. First, the nurse should be aware of the patient and family's right to participate in their care. This means resisting the urge to focus all attention on the patient and leaving the family in the corner or waiting room during care. Second, the nurse should encourage families and patients to participate in rounds with the doctor (Davidson & Stutzer, 2016). Patients and families should feel the freedom to ask questions, provide input and opinions, and express feelings about the information presented to them by the doctor. The patient and family deserve to understand what the doctor has to say. Third, nurses should inform families of patient condition, and encourage the use of open visiting hours (Davidson & Stutzer, 2016). As previously discussed, informed families have less risk of developing PICS-F, and patients with strong family presence and support are less likely to develop PICS. By simply providing family updates and information regarding visitation, the nurse can easily lessen risk factors of PICS and PICS-F. Fourth, nurses should answer families' questions honestly (Davidson & Stutzer, 2016). As caring individuals, it can be uncomfortable for the nurse to break difficult news to families about patient conditions, especially when it comes to conversations about death and dying. It is important for the nurse to realize that it is the right of the family to know about the true patient condition, and in the long-run it is more beneficial for them to know the truth. Fifth, the nurse should be aware of the words they say, and how they say them in order to communicate caring (Davidson & Stutzer, 2016). Patients and families alike

are comforted by knowing that they are being taken care of by someone who genuinely cares for them. The nurse should be cognizant of their word choices in order to convey caring to patients and their families. Sixth, nurses can create and maintain ICU diaries for patients as previously discussed. Diaries increase feelings of being cared for, and patients that feel cared for are less likely to develop PICS (Davidson & Stutzer, 2016).

### **Prevention of Compassion Fatigue**

Many times, a nurse exhibiting non-caring behaviors is experiencing compassion fatigue. Compassion fatigue is defined as “nurses losing their ability to nurture in their relationships with patients and patients’ families” (Davidson & Stutzer, 2016, p. 238). Nurses directly interact with patients and their families during their entire shift, exposing themselves to both the successes and defeat experienced by the patient and their families. Compassion fatigue develops gradually over time as the stress of these emotionally involved relationships begin to use up all of the nurse’s “compassionate energy”. When this energy is not replaced, and compassion fatigue sets in, “...changes in ethical and clinical values may occur, including lack of identification of patients’ needs and lack of enthusiasm for patient care” (Davidson & Stutzer, 2016, p. 238). The Native American saying, “each time you heal someone, you give a piece of yourself away” seems to be true in this situation (Davidson & Stutzer, 2016, p. 239).

Davidson and Stutzer (2016) share that according to the nurses’ code of ethics, “The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person” (p. 238). Compassion fatigue may be the reason for nurses exhibiting behaviors that break this portion of the nursing code of ethics. Not only does the nursing code of ethics call for the nurse to care for patients, but it calls the nurse to care for

themselves: “The nurse owes the same duty to self as to others, including the responsibility to promote health and safety, preserve wholeness of character and integrity, maintain competence, and continue personal and professional growth” (Davidson & Stutzer, 2016, p. 238). The critical care nurse is especially susceptible to compassion fatigue due to the compassionate energy exerted by scrupulously monitoring patients in order to detect signs of deterioration, as well as through witnessing suffering and death.

Trained in counseling, Torpie (2005) offered insight into both the patient and nursing perspectives of PICS. She stated, “I saw that we were all caught in the same pressure cooker with conflicting personal needs interfering with our mutual goal- the patient’s recovery” (p. 73). The seemingly frequent situations of understaffed and overworked nurses constantly faced with human suffering become emotionally exhausting. In order to prevent emotional distress, nurses cope in various ways. Some may create distance between themselves and their patients, while others objectify their patients. Some nurses may even offer empty reassurances to their patients or families of patients in order to feel as though they are doing some form of good. Each of these coping mechanisms are not therapeutic for the patient or the family, and ultimately impede healing. Torpie (2005) also added, “Budget cuts and time pressures turned patient ‘contact’ into patient ‘load’ which in turn fostered hierarchical rather than collaborative relationships between patient and staff and passive rather than active involvement by patients in their recovery” (p. 73). As nurses feel the pressure to complete tasks, and are overloaded with patients, they may begin to rush through care, and insist that the patient perform certain tasks in a certain way in order to save time. This is an abuse of the power of the nurse, and patients begin to take a passive role in care because the nurse does not seem to have time to listen to their concerns. Torpie expressed that she felt as though she

had to be passive in order to receive the care she needed or prevent being seen as a difficult patient. She felt as though her quality of life was seen as less important than the task at hand.

Signs of compassion fatigue include chronic absenteeism, high turnover rates, and interpersonal conflict among staff. Nurse leaders and managers should consistently monitor for these signs in their employees, and work to create an environment of support among nurses. Preventing compassion fatigue is not only the responsibility of the nurse leader or manager, but of the nurses themselves. Nurses should monitor themselves as well as their peers for signs of fatigue and show support to individuals experiencing fatigue in order to help relieve it. Nurses need an awareness of self in order to realize compassion fatigue is present, but with the additional help of peers, individuals can realize and address this problem. A balance between work and personal life must be developed in order to prevent compassion fatigue. Institutional resources to address ethical issues also appear to be promising in preventing compassion fatigue (Davidson & Stutzer, 2016).

Margaret Urban Walker describes critical care nurses as responsible and accountable to their patients, using their possessed knowledge for good. She states:

The competent critical care nurse (physician or other clinician) presumes that an unconscious patient can hear, can understand, and thus is mindful to touch the patient, to reassure, to explain, to give the unconscious patient or even dying patient ‘the benefit of the doubt’. (Davidson & Stutzer, 2016, p. 238)

Torpie (2005) wrote:

Beeping monitors were attached to measure my pulse and the air in my blood while faceless strangers took readings, changed tubes, gave injections and wrote notes in my chart. Trapped in this horror, my hearing seemed supersonic, searching through

all the noises of a busy critical care unit for any information about what was happening to me! I desperately wanted to be included in whatever that was. (p. 23)

For weeks after her accident, Torpie's eyes were swollen closed and she was intubated in order to breathe. This means that she could not see what was going on around her and could not speak in order to ask questions or express her fears (Torpie, 2005). In a video interview, Torpie expressed her deep gratitude for one specific nurse that took the time to speak to her about the weather outside, touched her arm in a reassuring manner, and explained the tasks he was performing before he began (Hearts in Healthcare, 2014). These tasks seem self-explanatory in regards to caring for people, but many times, sedated or seemingly unconscious patients are not treated with the same regard as alert patients. Most of the nurses in these stories exhibited signs of compassion fatigue, but by exhibiting the behaviors discussed by Walker, nurses can show the patient that they care and acknowledge their value as a fellow human being, thus reducing anxiety, and other risk factors for PICS (Davidson & Stutzer, 2016).

Considering the knowledge and skill set possessed by nurses, it becomes an ethical obligation for them to use this knowledge and skill set for the benefit of the patient, thus making it unethical to act in any manner that is harmful to the patient or family. The nurse has a duty to "do no harm" to patients or families and provide beneficial treatment. The ethical principles of beneficence and non-maleficence should be practiced by nurses and institutions (Davidson & Stutzer, 2016). Beneficence refers to a moral responsibility to act in a beneficial manner toward others, and not for their harm. Some of the core concepts of beneficence include prevention of harm, removal of harmful items or situations, and assessing situations in order to weigh the benefits versus the possible harm of actions. A

subcategory of beneficence is the concept of non-maleficence. Non-maleficence is the responsibility to act in a manner that does not intentionally harm others. Many times, the patient suffers from lasting side effects of the life saving measures used to treat the condition placing them in the ICU rather than the condition itself. One such side effect is PICS (Bemis-Dougherty & Smith, 2013). Allowing the prevalence and suffering of PICS to continue is unethical as seen by the principles of beneficence and non-maleficence and goes directly against the nursing code of ethics (Harvey, 2016).

As seen in the patient accounts of Jane and Torpie, uncaring behaviors by nurses and other medical professionals can cause significant psychological distress among critically ill patients. Torpie (2005) stated, "...when we are helpless and dependent on others, we are all-regardless of age- hard wired to seek comfort and safety from those we are dependent on. And that, in such circumstances, impersonal, detached care can be terrifying" (p. 239). Torpie felt as though she had lost her identity after her accident, frequently addressed as "the multi-trauma" or by pet names.

In Jane's case, she was dependent upon her mother for comfort, but the nurses' uncaring behaviors in sending her mother home, and not following through with their promise to call her mother when Jane requested led to psychological distress in both Jane and her mother. Both had to seek psychological counseling after this experience (Davidson & Stutzer, 2016).

### **Conclusion**

This study has found that in order to prevent PICS, one must know and eliminate the causative factors as much as possible, but when causative factors are inevitable, it is important that medical professionals utilize researched prevention and treatment techniques

in order to alleviate the suffering PICS causes this vulnerable population. As the nurse strives to prevent or eliminate the suffering of their patients, it is important to remember that, “we are merely the interim guardians; ultimate recovery involves rejoining the patient with the family and social network” (Griffiths et al., 2012, p. 809). This leads nurses to not only treat the physical condition of the ICU patient, but to adopt a more holistic approach in patient care. This holistic approach expands the goals of ICU treatment, eliminating the idea that physical survival is enough, and promoting the total physical, cognitive, and mental health of the patient.

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