Socio-Ecologic Perspective: Barriers Complicating Post-Intensive Care Syndrome Mitigation

Ross I.S. Zbar, MD

Abstract

Objective: Post-intensive care syndrome (PICS) is a phenomenon whereby survivors of an intensive care unit (ICU) admission subsequently experience issues with physical, cognitive, or mental health status persisting beyond the acute hospitalization. Risk factors for developing PICS include prolonged mechanical ventilation with sedation and immobility. PICS is a devastating illness that negatively alters the life path of many individuals with tremendous economic impact. Methods: This qualitative study employed a grounded theory approach to understand the systemic barriers blocking mitigation and treatment of PICS in all seven ICUs across Essex County, New Jersey (NJ) through semi-scripted interviews conducted with 11 members of the healthcare teams with at least one from each site. Thematic analysis was performed with open, axial, and selective coding. Results: Applying socio-ecologic viewpoint to data illustrate significant barriers on both an interpersonal and organizational level that decrease the operationalization of PICS mitigation measures as identified by healthcare providers. Of those interviewed, eight (73%) were physicians and the remaining were nurses. Significant thematic issues included understanding the risk factors of PICS but feeling powerless to institute mitigation efforts; experiencing lack of enthusiasm due to the absence of institutionalized mitigation protocols; noting frustration about closing the gap between academic recommendations and the ability to operationalize these appropriately; and feeling unable to effectuate meaningful change. Conclusion: Providing education to the target population and healthcare provider stakeholders regarding the barriers against PICS mitigation can alter the status quo.

Keywords

Intermittent sedation interruption, post-intensive care syndrome, PICS, PICS clinics, prolonged mechanical ventilation, sedation vacation

Introduction

As the delivery of technologically advanced healthcare improves in the United States (US), there are growing numbers of people from all age groups who survive prolonged episodes of treatment in the intensive care unit (ICU). Although the metric of survivorship specifically from acute respiratory distress shows evidence of improvement (1), it is now clear that many patients face incapacitating physical disability, neuropsychiatric pathology, and cognitive dysfunction following discharge. Through academic consensus meetings, the term post-intensive care syndrome (PICS) has been applied to describe this phenomenon whereby survivors of an ICU stay subsequently experience new or worsening problems of physical, cognitive, or mental health status persisting beyond the acute care hospitalization (2). Recognition of this insidious problem is only in its nascency within the last decade (3). Nevertheless, improved quality of life following basic survivorship must become a priority of not only those patients—and their families—who experience prolonged mechanical ventilation, but all stakeholders, including healthcare providers, healthcare systems, and researchers.

Although people with PICS are but a small proportion of all individuals with physical or cognitive issues in the US, they represent a large proportion of people who survive an
ICU stay (4). These individuals are left struggling alone with the legacy of long-term physical, neuropsychiatric, and quality of life impairments. The major risk factors for PICS are prolonged mechanical ventilation with the requirement for sedation leading to delirium and immobility (5). Any individual who requires prolonged mechanical ventilation and sedation is at risk. As many as 40% of adult individuals with PICS cannot return to their former employment—leading to financial difficulties, polypharmacy use, and fragmentation of subsequent healthcare (6).

Furthermore, when these needs are unrecognized, this vulnerable population is at increased risk for subsequent hospitalization and emergency department visits, resulting in extraordinary costs (7). As many as 80% of those people who survive acute lung injury require inpatient readmission within 2 years for a median estimated cost of $35,259 per admission (8). Overall, ICU survivorship is associated with a higher 5-year mortality (9).

Targeting this vulnerable population for early intervention would have significant benefits for not only individuals, but for organizations and communities. Because all individuals—regardless of race, gender, or socioeconomic status—who experience prolonged mechanical ventilation with sedation are at risk for PICS; targeting this primary population is equitable as a public health initiative. Simply put, PICS is an equal opportunity disease for those with risk factors.

Although the exact pathophysiology of PICS is unknown, contributing factors have been identified. In a recent prospective study, functional outcomes of survivors of prolonged mechanical ventilation clearly demonstrated increases in disability when compared to controls (10). But mechanical ventilation is not always avoidable. However, it appears that the mechanical ventilation does not stand alone as the causation of PICS but rather the sedation that is used along with it. The process of mechanical ventilation itself leads to agitation for patients due to discomfort. As a result, agitation is often managed with heavy sedation. Unfortunately, many pharmacologic agents used for sedation lead to delirium. Another prospective study analyzing the duration of delirium and use of sedative medications found a longer duration was associated with a worse global cognition (11). Additionally, the interaction between ICU-acquired weakness and morbidity is well established (12). Early mobilization in the ICU is associated with reduced delirium and faster return to self-functioning (13).

Perhaps most surprising is that in the US, despite growing awareness of PICS, few formal mechanisms are in place to identify or treat those who suffer PICS (14). This study seeks to identify barriers preventing the identification and mitigation of PICS both in the ICU and afterward.

Method

Design

This qualitative study employed semi-scripted, open-ended interviews to understand the systemic barriers blocking mitigation and treatment of PICS in all adult ICUs across Essex County, New Jersey (NJ). The interviews assessed current interventions in the ICU and unmet needs. This design was approved by an Internal Review Board. Participants signed informed consents.

Participants

There are seven acute care hospitals in Essex County, NJ with 281 adult ICU beds (15). These seven facilities belong to four different healthcare systems of which three systems and their three hospitals are for-profit and one system with four hospitals are nonprofit. There are 8.91 million people in NJ with 800,000 in Essex County (16). Of those in Essex County, 40% are White, 40% Black, and 18% Latino (17).

Healthcare providers were interviewed by telephone or in person at their chosen time and location. Participants were recruited from the purposive sampling method of lists of healthcare professionals provided by medical staff offices or by referral for this study from other participants. Participants were required to possess primary practice privileges in at least one of the seven ICUs of Essex County, NJ. Scripted questionnaires were administered one-on-one, via telephone or in person with probing as needed. Each person was interviewed one time. Strict confidentiality was guaranteed to encourage honest responses. Interviews were held at convenient times for the respondents, so they felt comfortable and unrushed. Those who interviewed in person were allowed to select the location of the interview.

All interviews were held in a semi-scripted format to obtain necessary information following the questionnaire yet allowing the free sharing of experiences with additional probing questions as needed. Nonverbal cues were noted as well. Interviews were not recorded to add an additional layer of anonymity. Copious note taking was performed during the interview process. Interviews were conducted by the author until theoretical saturation whereby new properties, dimensions, and relationships were no longer active based upon the structured format. Enrollment was predetermined to be finished as soon as three consecutive interviews did not provide substantively new findings after at least one individual was interviewed with primary privileges from each of the adult ICUs.

Data Analysis

Analysis was conducted using open, axial, and selective coding (18). Meaningful phenomena were conceptualized by naming them in the open coding stage with review of all interview notes repeatedly at least five times for each. These concepts were then grouped into categories so each category could be differentiated. A paradigm structure was then mapped by observing how these categories intersect and connect.

Results

There were 11 participants, of whom eight (73%) were physicians boarded by the Critical Care Specialty Board of the
American Board of Internal Medicine. The remaining three (27%) participants were nurses who have direct patient care in the ICU as their main responsibility. The interviews lasted between 22 and 38 min. Between the 11 interviewed individuals, all ICUs were represented in the county.

The main recurring thematic outcome included the disconnect between knowing the risk factors of PICS but feeling “powerless” to institute efforts to mitigate the syndrome. All participants (100%) recognized that PICS has risk factors. Within the ICU environment, all individuals were “aware of Clinical Practice Guidelines / Best Practices exist” that address identification and management of pain, agitation, sedation, delirium, immobility, and sleep deprivation. All interviewees could cite some, most, or all these measures.

Although recognized interventions mitigating PICS exist, the recurring thematic findings were that barriers are present at both the personal and organizational levels hampering efforts to decrease this syndrome both in the ICU and once patients are transferred elsewhere. According to 64% of the participants, these barriers must be managed if the epidemiology of PICS is to be truly tackled. The most common barrier rests at the personal level with “lack of enthusiasm” for mitigating PICS identified by all interviewed members of the treating medical team in the ICU. Thematically, all interviewees stated that members of the healthcare team are simply “not encouraged” to pursue mitigation of PICS by the facilities in which they work and subsequently “lack motivation.” Nearly one-third of the interviewees noted how although family members of patients can push for these interventions, the interviewees are “still unable” to meaningfully execute mitigation efforts.

Thematically on an organizational level, this lack of enthusiasm manifests as an “absence” of institutionalized mitigation pathways for patients regarding PICS in all the ICUs according to participants. Not one participant could enumerate any policed protocols that were mandated by their institution to address the causation of PICS. All interviewees verbalized “frustration” about the “disconnect” between academic recommendations issued by their various professional societies regarding mitigation of PICS and their ability to operationalize these within their facilities. All interviewees identified that although COVID-19 has stressed resources significantly and “decreased available staffing” in the ICUs, these barriers specifically related to PICS existed “well before” the pandemic. All interviewees noted how they can “recognize determinants” contributing to PICS but are “powerless” to prevent them. All interviewees stated thematically that the “economics of healthcare” prevented them from using the required resources to mitigate PICS prior to COVID-19; from available sitters to guide patients during narcotic interruption to physical therapists managing early mobilization.

To further complicate these multifaceted interrelationships, additional secondary stakeholder communities exist not only within the ICU but similarly post-discharge in the other healthcare facilities and/or wards where patients with PICS may be transferred as well as in the out-patient setting. Most interviewees (91%) identified that despite

PICS originating in the ICU, treatment is well “beyond the scope” of the ICU and there is “little meaningful attention to prevention.” All interviewees noted that they were “aware of PICS but felt they could do little.” Compounding the treatment of PICS is that multiple medical teams managing the patient throughout the healing journey frequently lack communication between each other.

The healing journey of a patient with PICS, as garnered from the interviews, is shown as an infographic in Figure 1. Figure 2 shows the different levels of prevention for PICS as enumerated by participants in this study.

**Discussion**

There are existing, evidence-based interventions at the primary, secondary, and tertiary levels of disease prevention for addressing PICS (19).

![Figure 1. Infographic illustrating the healing journey for a patient with post-intensive care syndrome (PICS) identifying health determinants along the way as thematically enumerated by interviewees.](image-url)
Primary Prevention—Decreasing the Risk

Primary prevention involves transforming the ICU environment with the mindfulness toward preventing PICS. These are interventions implemented before the onset of PICS. Interventions include changes in the workflow such as an assessment-driven, protocol-based management of sedation for prolonged mechanical intervention that uses alternatives to opioids such as intravenous acetaminophen or nerve blocks (19,20). However, our findings suggest healthcare workers feel this is too labor intensive to be realistically employed by the facilities in which they work. With productivity and staffing demands of hospital systems, there are few experienced intensivists or anesthesiologists available to implement this in a timely fashion. Nonpharmacologic interventions to mitigate pain and agitation include music (21), cold (22), and relaxation (23) therapies. These are not commonly practiced in the US. Early mobilization of patients on mechanical ventilation in the ICU is associated with less delirium and decreased deconditioning (24). Again, however, interviewees noted how productivity and staffing demands of hospital systems in the US serves as a barrier to implementation.

High-quality evidence shows that daily sedation interruption (also known as sedation vacation) decreases the need for mechanical ventilation as well as the length of the ICU stay with the additional benefit of costs savings (25,26). These guidelines are considered actionable and utilize many alternatives to opioids; encouraging a light rather than heavy sedation to reduce the risk of delirium. Furthermore, these guidelines promote nonpharmacologic interventions such as hypnosis, distraction, and relaxation techniques. Use of physical restraints is discouraged at the expense of increased use of bedside sitters. Early mobilization is encouraged.

Using the socio-ecologic viewpoint, this study elucidates how there are barriers at both the interpersonal stakeholder and organizational/community level blocking mitigation of PICS. Although healthcare provider awareness exists, they cite the lack of power to implement change. But even if protocols were embraced by patients and healthcare teams, financial barriers at the organizational level appear to further block implementation. With the US healthcare system designed as it is, hospitals must provide care yet remain financially solvent; and in many cases, even generate profit. Although programs exist that mitigate PICS, these come at an increased cost of more staffing demands which may be eschewed by healthcare systems in the US. Ironically, even the onerous documentation requirements in the US have been identified as a major barrier to instituting these preventative practices (27).

Secondary Prevention—Measures to Help Those Identified With Disease Early in the Process

Secondary prevention involves appropriate reactions from healthcare providers once PICS is identified. These same guidelines recommend aggressive management of delirium, tracking of adequate sleep, and early mobilization of patients on mechanical ventilation with sedation (19). There are currently resources available at minimal cost to increase awareness which could be leveraged (28). ICU journaling by family members and staff can be helpful. Upon admission to the ICU, patients and loved ones can document the ICU journey to help the patient understand what they cannot remember during recovery. These types of educational

Figure 2. Illustration enumerating evidence-based, best practices regarding the three stages of prevention/mitigation for post-intensive care syndrome (PICS) which can be practiced by the healthcare providers and healthcare systems as garnered through discussions with participants.
activities have demonstrated usefulness in the recovery from PICS (29).

Furthermore, there are various models to help guide healthcare facilities to create peer support PICS groups thereby ameliorating the healing journey following discharge from the ICU. These assorted models—known as the THRIVE peer support collaboration—include community-based, psychologist-led, ICU follow-up clinics, online, and peer/mentor (30). The Society of Critical Care Medicine also has the ICU Liberation Bundle with several constructive videos for patients as well as a Facebook page and Twitter hashtag (31). Although the infrastructure is present, there can be little success if those in need of these interventions remain unaware of these resources.

_Tertiary Prevention—Interventions to Decrease Poor Outcome_

Tertiary prevention is the long-term response to mitigate poor outcomes. Research is surprisingly weak, but qualitative evidence shows that patients are indeed more satisfied when involved with PICS clinics. There are no data however regarding decreased mortality from participation in these clinics (32). Nevertheless, there is an objective and short screening questionnaire for PICS (PICSQ), developed in South Korea, that has been shown to be both reliable and consistent in identifying patients with PICS once in the outpatient setting (33). Acute care hospitals and rehabilitation facilities should forward these screening tools to primary care teams managing those discharged from the ICU to aid identification and track improvement of those with PICS. Establishing PICS clinics and support groups regionally should be a priority based on improved patient satisfaction and therefore presumably quality of life (34). Peer support has also been identified as a helpful modality in attaining recovery (35).

_Limitations_

Limitations of this study include those issues which typically surround qualitative studies including selection bias of the interviewees and overall quality/reproducibility of the data. Nevertheless, the valuable information gleaned regarding the complex interrelationships between ICU survivors, their healthcare providers, and the healthcare systems in which these interactions occur should not be ignored.

There is clearly a tremendous gap in providing services to specifically treat PICS in an organized setting once a patient is identified. Perhaps, Essex County, NJ serves as a microcosm of the US? There are no PICS clinics associated with any of the ICUs in this county. The Society of Critical Care Medicine recognizes this quality gap across the US by advising patients with symptoms of PICS to seek care from their primary care provider and request a specialist when needed in occupational therapy, psychiatry, psychology, and/or speech therapy (30). This strategy, sadly, is a stopgap. It recognizes that existing services to treat this vulnerable population with PICS are disparate. There is a significant quality gap nationally when nearly half of individuals surviving an ICU stay suffer PICS (36). However, this lack of national coordination reflects the individualistic nature of the US healthcare system due to its structure whereby hospitals function independently with minimal guidelines regarding programs and service lines. If there are no state or federal mandates, the programs are simply not required to exist. It becomes the responsibility of the hospital to initiate the process. Moreover, due to the structure of the US healthcare system, if the hospital leadership fails to see an economic benefit, the program will fail.

_Conclusion_

Those with PICS are a vulnerable community that generates a significant financial cost with an emotional toll if left unaddressed. There are identified barriers unique to the US healthcare system on the personal and organizational levels that make the mitigation of PICS even more difficult. However, identifying these barriers will maximize the chance to end the status quo with respect to PICS by identifying how to positively alter the complex interactions in a cost-effective fashion.

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_ORCID iD_

Ross I.S. Zbar https://orcid.org/0000-0002-2532-3741

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Written informed consent was obtained from the subjects for their anonymized information to be published in this article. This is noted in the Methods section.

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