

2022

MANAGEMENT OF THE PATIENT WITH CHRONIC CRITICAL ILLNESS – PART 2

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Recommended Citation

Finn, Arkadiy; Selvaraj, Vijairam; Peterson, Elijah; Banerjee, Debasree; Lal, Amos; Grewal, Himmat; Martin, Edward; and Dapaah-Afriyie, Kwame (2022) "MANAGEMENT OF THE PATIENT WITH CHRONIC CRITICAL ILLNESS – PART 2," *Journal of Community Hospital Internal Medicine Perspectives*: Vol. 12: Iss. 5, Article 2.

DOI: 10.55729/2000-9666.1066

Available at: <https://scholarlycommons.gbmc.org/jchimp/vol12/iss5/2>

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Management of the Patient with Chronic Critical Illness – Part 2

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Abstract

Patients with chronic critical illness (CCI) represent a growing segment of the hospitalized population. Key aspects of care in CCI patients including tracheostomy, prolonged mechanical ventilation, nutritional support, wound care, and others require a comprehensive, goal-directed approach. Infectious complications of CCI including pneumonia, tracheobronchitis and urinary tract infection may be caused by nosocomial organisms requiring awareness and adjustment of treatment regimen. Finally, psychiatric, palliative, rehabilitative components of care impact heavily upon outcomes in CCI patients. As care that is typically associated with the intensive care unit is extended to the hospital ward, we aim to increase awareness among providers and outline a systematic approach to deliver high quality, patient centered care to CCI patients.

Keywords: Chronic critical illness, CCI, Persistent critical illness, Chronic illness, LTACH, Medically complex patients

1. Psychiatric complications

Psychiatric complications of intensive care and critical illness including delirium, agitation, anxiety, depression, sleep deprivation and Post-Traumatic Stress Disorder (PTSD) are prevalent in the CCI patient and may be difficult to treat. Delirium, a form of acute brain injury, is an acute confusional state defined clinically as deficits in attention and cognition and may be accompanied by agitation and aggressive behavior severely affecting the patient's functional status.¹ Causes of acute delirium include infection, hypoxia, sedative medications, metabolic derangements, uncontrolled pain, and many others.^{1,2} Among patients who had undergone elective tracheostomy for weaning, 9.4%

experienced severe delirium symptoms within four weeks which was associated with worse clinical outcomes.³ Prolonged delirium is associated with long-term cognitive impairment and decline in functional outcomes.² General concepts of delirium prevention may be extrapolated to the CCI patient through non-pharmacological, multi-component interventions including frequent assessments, increasing independence, self-care and mobility, pain management and family engagement.⁴ Sleep regulation and circadian rhythm, exposure to natural sunlight and maintaining sleep/wake cycles are key components of management. Among pharmacological interventions for delirium treatment, haloperidol and lorazepam provided the best response compared to placebo.⁴ In practice, anti-

Received 5 February 2022; revised 23 February 2022; accepted 1 March 2022.
Available online 9 September 2022

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<https://doi.org/10.55729/2000-9666.1066>

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psychotic agents such as quetiapine and olanzapine offer a safe and effective alternative to haloperidol.⁵

Post-Intensive Care Syndrome (PICS) is defined as new or worsened cognitive impairment, disabilities in activities of daily living, and depression arising after critical illness.⁶ Patients remain at risk even after discharge from the hospital with 64% of adults with an episode of respiratory failure or shock requiring ICU stay, reporting at least one symptom of PICS within three months and 56% within 12 months of discharge.⁶

Up to one third of ICU survivors may experience persistent anxiety and up to one fifth may experience PTSD in the year following the ICU stay.^{7,8} Risk factors include other comorbid psychiatric conditions, use of benzodiazepines and memories of frightening ICU experiences. Sleep deprivation in the hospital environment may exacerbate underlying psychiatric conditions. A holistic approach to treatment may involve psychiatric evaluation, pharmacologic and non-pharmacologic treatment of anxiety and depression, physical/occupation rehabilitation, nutritional support, and family engagement.

2. Physical rehabilitation – critical illness neuromyopathy

Intensive care unit stays are associated with Critical Illness Myopathy (CIM) and polyneuropathy (CIP), conditions which cause limb and respiratory muscular weakness, and limit recovery. CIP is distal axonal polyneuropathy, affecting sensory and motor nerves, and is associated with failure to wean from ventilation. It presents with limb weakness and electrophysiological evidence of axonal polyneuropathy. CIM is a primary myopathy and has specific findings on electromyography. Risk factors include prolonged critical illness, septic shock, and multi-organ failure, with the incidence of either disorder approaching 50% in patients with acute respiratory distress syndrome.⁹

Rehabilitation therapy includes physical and occupational therapy and may employ strength and mobility training, transfers out of bed, and performance of ADLs. Full recovery occurs in up to 50% of patients with CIM/CIP. Severe cases may face a prolonged rehabilitation course and may remain with a significant permanent disability. Early rehabilitation after ICU stay has been shown in small studies to improve functional status and decrease length-of-stay.⁹

3. Palliative and end-of-life care

Management of patients with CCI is complex and challenging as they approach end-of-life. Often,

there are unmet palliative care needs which require a thoughtful, multidisciplinary approach. Patients near end-of-life may experience physical, emotional, and psychosocial symptoms. Palliative care teams focus on preventing, diagnosing, and managing symptoms experienced by patients with CCI and advanced illness. Additionally, they help patients and families understand the nature of their advanced illness and prognosis and align the patient's goals of care with that of the healthcare team. Early involvement of the palliative care team is helpful in goals of care discussions and establishing the need for health care proxy and advanced directives as these patients near end-of-life.

Many seriously ill patients may not have spoken with their doctors about prognosis. Research has shown that only 10% of dialysis patients who have an expected annual mortality of 20–25% reported having discussed end-of-life issues with their nephrologists.¹⁰ Conversations with the palliative care team are likely to go beyond discussions of survival as patients have been shown to have other important concerns such as being mentally aware and not being a burden.¹¹

Dyspnea and unrelieved pain are two of the most noted conditions and can be a great source of distress to patients and families. Opioids are a common and effective treatment to relieve dyspnea and manage pain in patients with CCI and advanced illness regardless of the underlying etiology.^{12,13} Despite concerns that opioids have the potential to hasten death in patients with CCI and advanced illness, the use of opioids has not been associated with a significant decrease in time to death.^{14–16} Symptoms such as pain and dyspnea are also often under reported due to patient sedation, encephalopathy, agitation, delirium, or cognitive changes associated with end-of-life. Providers need to continually monitor symptoms and make adjustments to control their symptoms. Numerous scales have been validated for use, such as Respiratory Distress Observation Scale (RDOS).¹⁷ Utilization of these scales may help address these symptoms early on during their hospital stay.

Complementary and alternative medicine (CAM) practices such as massage, reiki, acupuncture, and pet therapy that help in addressing patients' symptoms. Integrative medicine is a total approach to medical care that combines standard medicine with CAM practices to treat the mind, body, and spirit. Social workers, chaplains, dieticians, and art and music therapists (if available) also play an important role in managing patients with CCI and end-of-life care.

4. Medical record review

Modern healthcare institutions place emphasis on clinical documentation and generate a large amount of clinical data typically contained within the electronic health record. A medical record for a CCI patient with a prolonged hospital stay may contain voluminous notes, radiographic studies, laboratory values, and various other clinical data.¹⁸ Searching, reading, and assessing the relevance of this data is a clinical skill that is integral to a hospital clinician caring for a CCI patient during prolonged hospitalization.¹⁹ Decision-making must be based on accurate and reliable information obtained from the record or other sources.

Standardized best practices for efficient data acquisition from medical records are not widely available.²⁰ We recommend a tiered approach: 1) Generate an accurate active problem list; 2) Focused review of key clinical data including recent vital signs, laboratory values and radiology; 3) Historical record review as pertaining to key problems; 4) Obtaining a “hand-off” or information from previous providers that may not be easily retrievable from the record. The current provider should always assume that they are operating at an information deficit and seek out varying sources of information including nursing and other disciplines who may have critical information pertinent to patient care.

Finally, the provider should employ clear and concise clinical documentation to anticipate the next transition in care providers. Hospital course summaries should include key procedures, dates, antibiotic courses and ICU stays.

5. Patient and family perspective

Prolonged hospital care for CCI takes a psychological toll on patients and their families.²¹ In a study of 62 prolonged medical ventilation patients in Jerusalem, Jacobs and his colleagues found that severe ($\geq 7/10$) anxiety, drowsiness, tiredness, and impaired well-being were reported by 15%, 12%, 27%, and 15% of their sample, respectively.²² Furthermore, 38% of the study cohort screened positive for depressive symptomatology, considerably above the baseline estimate of 20% among the similarly-aged local Jerusalem population and on par with rates of depressive symptomatology in long-term care facilities.²² As caregivers and decision-makers, families of CCI patients must navigate an uncertain trajectory of critical illness that is rife with psychological stressors. These stressors are compounded when family members must make decisions on behalf of the CCI patient in the absence of an advanced directive, living will, or a robust

understanding of the patient's treatment preferences. An atmosphere of increased psychological distress, negative emotions, and incomplete knowledge of the patient's preferences and values can affect the family's ability to make rational and informed decisions about the care trajectory of the CCI patient.²³

A shift from a traditional patient-centered model of critical care to a more expansive approach that considers the impact of prolonged hospitalization on the family system may help mitigate some of these psychological stressors for both CCI patients and their families. Early intervention strategies in the form of structured family meetings; using experienced critical care professionals (social worker, chaplain) as liaisons between the family and the critical care team; early identification and ongoing assessment of family members for symptoms of depression, anxiety, and/or acute/post-traumatic stress disorder; and integrating informational, psychological, and social support resources for family members into the care plan of the CCI patient are all evidence-based, family-centered strategies that may improve CCI patients' clinical outcomes and lessen the psychological burden on family members.²⁴

6. Discharge disposition

Outcomes and discharge disposition in CCI patients are of paramount importance as the clinician is tasked with reducing iatrogenic risk from prolonged hospitalization. In a broad sample of CCI patients in 2009, 28.7% did not survive hospitalization, 21.8% were discharged home, 38.3% to a skilled nursing facility, 4.9% to LTACH and 2.6% to hospice.²⁵ Determining the optimal post-acute care setting depend on many factors including patient physical function, comorbidities, care requirements and goals. Health insurance considerations often impact transition planning as payer authorization is required for post-discharge nursing services, medical equipment, rehabilitation, and other care needs. Hospital case managers are essential to care coordination and transition planning as they must integrate the patient's complex medical needs, goals of care, capacity to deliver appropriate care, and payer requirements.

Transition planning must be interdisciplinary and patient centered. Clinicians should evaluate discharge options including home, skilled nursing facility and LTACH based on benefit to the patient and the practical reality of the care the patient is likely to receive. More research is needed to determine the impact of post-acute care settings on outcomes in the CCI patient population.

Management of Chronic Critical Illness Checklist

Mechanical Ventilation

- Weaning plan (consult with Pulmonary Medicine, Respiratory Therapy)
- Tracheostomy care (manufacturer; type – cuffed, uncuffed; size; date last exchanged)

Nutritional Support

- Nutritional Screening (Nutritional Risk Score 2002 (NRS 2002) or the Mini Nutritional Assessment short form)
- Evaluate routes of nutritional access (enteral, parenteral)
- Monitor weight, serum phosphate, potassium, magnesium. Evaluate for thiamine deficiency
- Consult with Registered Dietician/Nutritionist

Wound Care

- Identify location, duration and progress of known chronic wounds
- Maximize mechanical off-loading for pressure wounds and nutritional support
- Collaborate with Surgical Service and Wound Care Nurse service, if available

Infections

- Monitor for development of iatrogenic infection: tracheobronchitis, ventilator associated pneumonia, CA-UTI, bacteremia and others
- Lack of clinical improvement may indicate nosocomial organisms with antibiotic resistance

Psychiatric

- Assess for delirium, uncontrolled anxiety, depression and PICS syndrome
- Consult with Psychiatry service to assist with management

Rehabilitation

- Assess for critical care myopathy/polyneuropathy
- Consult with Rehabilitation Therapy (physical, occupation, speech/language pathology)

Palliative and End-of-Life

- Assess goals of care. Control symptoms of pain, dyspnea and nausea.
- Early involvement of Palliative Care services

Discharge Disposition

- Consider post-discharge settings: home, skilled nursing facility, LTACH, and hospice
- Consult with Case Management specialist

Fig. 2. Checklist for clinicians.

7. Conclusion

Management of the CCI patient spans various organ systems and can challenge the provider due to complexity. The burden of CCI is enormous, overwhelming and can affect patients, families, healthcare

providers and society at large. Iatrogenic complications such as complex wounds and nosocomial infection present barriers to desired outcomes. In addition, management of patients with CCI can be expensive and can strain the US healthcare system, especially during a pandemic. We believe that in order to

improve care, providers must gain comfort with multidisciplinary approaches for individual organ systems, while developing holistic and patient-centered goals through patient/family engagement and shared-decision making (see Fig. 1). We envisage that usage of such checklists will reduce the burden on healthcare providers, improve efficiency and provide an overall direction in their care.

Disclaimer

The manuscript has not been submitted to other publication or presented at a conference or meeting.

Conflict of interest

The authors whose names are listed immediately below certify that they have NO affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript. Arkadiy Finn, Vijairam Selvaraj, Elijah Peterson, Debasree Banerjee, Amos Lal, Himmat Grewal, Edward Martin, Kwame Dapaah-Afriyie.

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