



Care of the ICU Survivor: What Primary Care Providers Need to Know?

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Introduction

There are increasing numbers of ICU survivors who remain complexly ill with prolonged sequelae of their ICU stay post hospital discharge. These patients have Post-Intensive Care Syndrome (PICS), which affects one or more of three domains: physical health, behavioral health, and/or cognitive health. PICS increases mortality, morbidity, and consumption of health care resources [1-7]. PICS can also affect family members (PICS-F) [1,8]. Patients who survive ARDS, respiratory failure requiring mechanical ventilation, sepsis or prolonged delirium are at greatest risk for PICS [2-7,9]. PICS are not limited to elderly or chronically ill patients and can cause transient or permanent disabilities [2-4].

Recognition and management of PICS and PICS-F is crucial for patient and family caregiver recovery. While it is ideal to have ICU Survivor clinics, the reality is most ICU survivors currently receive their ICU recovery care from their primary care provider. Unfortunately, current primary care processes appear to be inadequate to meet the needs of PICS patients [4,10-13]. Given newly acquired behavioral health and cognitive dysfunctions in a significant proportion of ICU survivors, discharge and primary care processes that presume these patients are cognitively normal and can understand, retain and recall health education provided at discharge or by brief case management contact post discharge is dubious. To date, there is no proven best process to care for PICS and PICS-F, however some interventions are effective, and it is likely a combination of these interventions is required. Beneficial interventions include ICU survivor clinics, ICU diaries, ICU support groups and close follow up and coordination of care [4,14,15].

Geisinger's ICU Survivor Care Process is an interprofessional team approach to identify and treat PICS and PICS-F. Our care process starts while patients are in the hospital and delivers intensive case management by an experienced Nurse Case Manager (RN CM) through the first ICU survivor clinic about 4 weeks after return to home and for at least 90 days post hospital discharge [4]. Our RN CM provides recurrent telephonic education, support, and guidance on issues of recovery and navigating a complex healthcare system. Our first clinic visit is three hours long and includes a one hour evaluation with imbedded education by each of a neuropsychologist, a psychologist, and an intensivist to ensure every domain of PICS has been assessed, a patient specific treatment plan has been developed, and patient and family caregiver comprehension of the recovery care plan, and signs and symptoms for which they should contact the RN CM, is maximized. This comprehensive, interdisciplinary approach is likely the source of the statistically significant reduced mortality rates, the first care process in the ICU survivor literature to achieve this result, as well as a financially significant reduction in readmission events and a significant net cost savings attained by our care process [4].

Behavioral Health in ICU Survivors

There is a significant prevalence of psychological sequel experienced by patients and caregivers following ICU admission. PICS may include any combination of psychiatric symptoms or disorders, most commonly depression, anxiety, and posttraumatic stress disorders

(PTSD) [16]. Rates of psychological morbidity vary: roughly 30% of survivors experience depression [5,17-19], one in five survivors experience PTSD [5,16-18,20], and one in three survivors experience clinically significant anxiety [5,16,21]. Specific risk factors have been identified to increase the likelihood of psychological distress, such as acute respiratory distress syndrome [5].

In addition, PICS-F encompasses symptoms of distress in patient caregivers or family members, such as problems with sleep, anxiety, depression, PTSD, and complicated grief, that occur during or following the acute hospitalization or death of the loved one [8,16]. Prior studies suggest that caregivers commonly suffer from depression [22-29], more than half experience anxiety [22,24-26], and PTSD may be prolonged in one third of family caregivers [22-24,26-29].

Many psychological symptoms may not be apparent or offered by patients or caregivers if not asked appropriate questions to elicit them. In our clinic, we have observed a difference on self-report questionnaires versus by verbal report from patients, with symptoms gathered by patient interview frequently representing more severe symptomatology. It is not uncommon that patients will disclose more distress as the appointment progresses. This is likely due to an increased comfort level and information gathering that normalizes distress in patients and caregivers. Our patients commonly report symptoms of depression, sleep problems, nightmares, anxiety about future negative health events, and symptoms of PTSD. We have found distress in caregivers to vary as well – with some demonstrating significant PTSD, fears of leaving the patient alone, and of the possibility of the patient's premature death in the future.

No mental health screening tools have been validated for use in PICS, although multiple screening tools are useful for identifying psychological distress. We use three screeners to assess for symptoms of anxiety, depression and PTSD: the Patient Health Questionnaire-9 (PHQ-9) [30], the Generalized Anxiety Disorder-7 (GAD-7) [31], and Posttraumatic Stress Disorder Checklist for the DSM-5 (PCL-5) [32]. These are completed by both the patient and primary caregiver, if present. Questionnaires are an easy way to assess for distress in any setting in which an ICU survivor or caregiver is seen post discharge. It is recommended that screening for distress be done in two step fashion, initially screening patients using brief measures in an outpatient clinic setting and, if indicated, referral for more complete assessment of PICS by specialized providers [33].

Neurocognitive Health in ICU Survivors

Cognitive dysfunction impacts 30%-80% of ICU survivors, with

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executive functioning the most common domain affected [34], although memory, attention/processing speed, and verbal fluency can be impacted [2,33,35-37]. ICU survivors are at higher risk of developing dementia [33,38], especially if they experienced ICU delirium. Post-ICU cognitive dysfunction can diminish judgment/insight and the ability to adequately follow hospital discharge recommendations and/or adhere to new medication regimens, as well as engage in successful management of activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs).

Neurocognitive screening early in recovery is vital to ensure ICU survivors receive necessary care, with referral for neuropsychological testing, cognitive rehabilitation, or neurology referrals, as needed. Screening measures are not intended to be diagnostic and are not equivalent to a full neuropsychological evaluation, as neuropsychologists rely heavily on normative data from a standardized sample, as well as their clinical judgment and training. Medical professionals, including home healthcare staff, can perform basic screening to assess ICU survivors. A clock drawing task can quickly screen for executive dysfunction [39]. Word list recall is sensitive to memory impairment [40], a frequent concern in this population. The Mini-Cog is a 3 min-5 min screening tool that incorporates both executive functioning and memory, is simple to learn and administer, and requires only a form and a pen [41]. In older adults, it is beneficial to obtain a measure of semantic fluency (i.e., animal naming), which can be used to determine if there is risk of an incipient neurodegenerative process, such as Alzheimer's disease. Although the Montreal Cognitive Assessment (MoCA) has been favored in the literature, it now requires training, approval to administer and does not account for age or specific education level, which is imperative when determining a decline from cognitive baseline [42].

Research has shown a significant relationship between executive functioning and ability to complete IADLs [43-45]. An informant report of cognitive functioning (i.e., Quick Dementia Rating Scale: QDRS) [46], and an informant report of IADLs (i.e., Lawton Instrumental Activities of Daily Living Scale) [47], can help assess functional and cognitive status, if a caregiver is available. Cutoff scores are provided and help to delineate when a referral to neuropsychology is appropriate.

Our neuropsychologist performs cognitive assessment with a combination of clinical interview and brief neurocognitive screening to determine the need for further evaluation. We use the Cognistat Five, a graded measure designed for rapid testing of mild cognitive impairment Vs dementia. This is a shorter version than the original Cognistat and is convenient for serial testing.

Many of our patients describe mental fogging since hospitalization, but there is not always a corresponding decline on objective cognitive measures. There are many factors in addition to general recovery that may exacerbate cognitive dysfunction, such as mood/anxiety, medical history/cerebrovascular risk factors, education/neurodevelopmental history, pain, adjustment/acceptance to physical limitations, sleep, appetite, psychosocial stressors, and medications.

Conclusion

We are deeply concerned that current primary care processes do not meet the needs of a significant proportion of PICS patients. This patient population requires thorough screening of all three domains of PICS, as well as potentially very complex coordination of care that is beyond the ability of the patient or their family caregiver to pursue unassisted in the first weeks on return to home. In our System,

a primary care provider is allotted 40 minutes for the first visit post hospital discharge for an ICU survivor, regardless of the complexity of their PICS. This places an overwhelming burden on primary care providers and creates a disservice to ICU survivors, who depend on their primary care provider to keep track of all the details of their complex care needs in recovery. It is imperative that access to psychologists and neurocognitive specialists is available for primary care providers caring for PICS patients suffering from newly acquired and persistent behavioral or neurocognitive dysfunctions. A significant opportunity exists for research on how to help primary care providers improve their care delivery to PICS patients in a time efficient but medically effective manner, to deliver education to primary care providers on the importance of screening for all three domains of PICS, and for health care systems to re-examine their current processes of care delivery by primary care providers for PICS patients.

Based on the evaluation of the workshop, better workshop will be held in future to develop a better program. These collaborative workshops could help developing feasible obesity prevention programs as well as development of human resources of school health in urban Uganda.

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