



Comprehensive care of ICU survivors: Development and implementation of an ICU recovery center☆

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ABSTRACT

Purpose: To describe the design and initial implementation of an Intensive Care Unit Recovery Center (ICU-RC) in the United States.

Materials and methods: A prospective, observational feasibility study was undertaken at an academic hospital between July 2012 and December 2015. Clinical criteria were used to develop the ICU-RC, identify patients at high risk for post intensive care syndrome (PICS), and offer them post-ICU care.

Results: 218/307 referred patients (71%) survived to hospital discharge; 62 (28% of survivors) were seen in clinic. Median time from discharge to ICU-RC visit was 29 days. At initial evaluation, 64% of patients had clinically meaningful cognitive impairment. Anxiety and depression were present in 37% and 27% of patients, respectively. One in three patients was unable to ambulate independently; median 6 min walk distance was 56% predicted. Of 47 previously working patients, 7 (15%) had returned to work. Case management and referral services were provided 142 times. The median number of interventions per patient was 4.

Conclusions: An ICU-RC identified a high prevalence of cognitive impairment, anxiety, depression, physical debility, lifestyle changes, and medication-related problems warranting intervention. Whether an ICU-RC can improve ICU recovery in the US should be investigated in a systematic way.

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1. Introduction

Over 6 million patients become critically ill each year. Of these, an increasing number will survive due to advances in critical care [1]. This survival is not without cost. As the long term effects of critical illness become known, the need to design and implement effective interventions to rescue critical illness survivors from incomplete recovery has become a pressing priority for many clinicians. However, evidence based guidelines for intensive care unit (ICU) follow up and recovery remain elusive. In 2012, we started seeing patients in an outpatient team clinic designed to screen for and treat Post Intensive Care Syndrome (PICS), with the goal of promoting recovery for the sickest patients who survive the ICU. This effort was inspired by a patient in the Vanderbilt Medical

ICU, and was undertaken as a pragmatic clinical intervention in an attempt to address the multifaceted yet ICU-specific problems emerging in the literature and in practice.

At the time, there was little to guide us in the development of an ICU follow up program. ICU survivors have high rates of mortality and increased health care utilization following discharge [2–13]. The rise in survivorship has created a burgeoning population suffering from long-term consequences of critical care [13–18], including cognitive impairment [18–23], anxiety [16–18], depression [13,15–18], post-traumatic stress disorder [13–18,24], decreased quality of life [9,12,25–29], and physical disability [17,20,30,31]. This constellation of problems is now known as PICS, a condition of new or worsening dysfunction in key domains such as cognition and physical function that persists beyond the inciting critical illness [32]. Despite the success of survivorship programs in the treatment of other populations [33] and a call for action to improve the lives of ICU survivors [34,35], there are few programs aimed at decreasing morbidity and mortality in the post ICU recovery period in the United States (US).

Early attempts in the United Kingdom (UK) and Scandinavia were conducted in very different health care environments, with different

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providers (primarily advanced practice nurses), and distant from the index hospitalization [36–39]. The most commonly studied outcome was health related quality of life (typically defined by outcome measures that may or may not correlate with patient's "real world" concerns), and in this domain an ICU follow up program did not appear to have significant effect. In recent years, interest in real world approaches to caring for ICU survivors has continued to grow, but the interventions and outcomes needed in this population remain unproven [40–43]. In our tertiary US medical center, complex medical patients are often uninsured, or otherwise lacking in the support structures necessary for a successful recovery, including a preexisting relationship with a primary care physician. The concept of a post intensive care syndrome was not (and still is not) widely known nor understood by patient, families, and medical providers. And, the specialists or interventions that might prove effective in remediating the deficits experienced by patients after the ICU were not understood.

In an attempt to increase our understanding and outline the most pressing needs in the post-ICU period, we spoke with current and former patients, study participants, family members, and health care providers. We assembled some of the same team members who work closely together to care for patients in the ICU, and translated their expertise to the outpatient setting. Then, we identified patients thought to be at highest risk for post-ICU complications by the clinical criteria that were known in the literature at the time: septic shock; lung injury, especially when treated with mechanical ventilation, and delirium [2,8,14,15,20,23].

2. Clinic description

The ICU Recovery Center (ICU-RC) at Vanderbilt opened in 2012. The genesis of this clinic was grounded in clinical and research insights dating back at least a decade and borrowed elements from other successful team clinic models, notably those addressing cancer survivorship; there are over 300 of these highly specialized clinics in North America, where they are now considered standard care. Patients with severe critical illness, as indicated by mechanical ventilation, sepsis or septic shock, and/or delirium, were offered an ICU follow up appointment after discharge to home. As the ideal model for care of the post-ICU patient is unknown, the criteria for patient recruitment, the design of the clinic intervention, and the services offered to patients were iterative and continuously refined as patients were seen. A survey of early patients attending the clinic was administered at the end of the initial visit, in an attempt to refine the model down to those elements patients and family members found most useful (see Appendix A for a summary of responses). In addition, we conducted several community engagement studios and focus groups with ICU survivors and their families, in order to identify features and elements of ICU follow up that patients and families had found lacking in the recovery from critical illness. Studios and focus groups were facilitated and recorded by an experienced community engagement team, and major themes regarding post-ICU recovery needs and barriers were grouped by impact area [44]. See Appendix B for the major themes that emerged from this process, as well as some of the iterative changes that were made in response to patient and family feedback.

The clinical team was modeled on the interdisciplinary team caring for patients in the ICU: intensivist, including our innovative independent nurse practitioner team [45,46], critical care pharmacist, case manager, and neuropsychologist. This allowed us to identify patients at high risk for post-ICU complications during their ICU stay. Identified patients were then followed in the electronic medical record until hospital discharge, or death. Initially, patients were called after discharge to home to arrange ICU follow up, but this approach revealed a number of barriers to ICU follow up:

1) Many patients were so debilitated following discharge that they were unable to return to their personal residences, and thus, home based contact information was unreliable. Some of these patients stayed

with friends or families; others were simply lost to follow up. In response, efforts were made to verify contact information and obtain at least two backup numbers prior to hospital discharge.

2) The time lag and number of care transitions between ICU and home were large. In some cases patients were not discharged to home and therefore not ready to be seen in clinic for weeks to months following candidate identification in the ICU. Attempts to automate patient tracking have not yet been successful in our system. In addition, once patients left our system, e.g., transferred to inpatient rehabilitation, long term acute care, or skilled nursing, they were much more difficult to track, and some were lost to follow up this way.

3) Without an introduction to the concept of PICS, and possessing high rates of cognitive impairment affecting abilities such as awareness and comprehension, many patients and their families did not understand the urgent need for or potential benefit of ICU specific follow up, thus a number of patients declined to schedule an appointment, and no show rates for scheduled appointments were high. In response, we implemented a visit from a team member prior to hospital discharge. During this visit, the concept of PICS was introduced, written information provided, and a contact number for problems prior to the clinic visit listed. This represented an improvement, yet many patients still failed to fully appreciate the magnitude of problems they were about to face upon returning home and attempting to reengage in the normal activities that often reveal the presence and intensity of new limitations.

4) The population we are trying to reach is weak, sick, and cognitively impaired. Family members and other support people are encouraged to accompany the patient to their initial clinic visit. In reality, most patients are unable to attend without this support: they are usually too weak to drive or are afraid to drive, have trouble remembering appointments or engaging in planning tasks that would ensure they arrived at their appointments, and are often readmitted before they are able to attend clinic.

5) Mortality rates for critical illness remain high. Around one fifth of the patients we identify as candidate for ICU follow up do not survive to hospital discharge, and a number of those who did survive to discharge died in the year following their ICU stay.

In order to identify and treat early post-hospital issues that may contribute to readmission, and based on earlier literature that suggested that previous attempts at ICU follow up occurred too distant from the index hospitalization, the initial ICU-RC visit was targeted for approximately two weeks after discharge to home. Based on existing and emerging literature describing post-ICU deficits in physical function, including airway issues and weakness, medication management, cognitive function, mood, and socioeconomic parameters including health care utilization, driving, and return to work [4,6,19,25,28,30,47–49], the clinic visit was planned in six interdisciplinary stages:

1. Screening spirometry and six minute walk test
2. Medication reconciliation and counseling
3. Review of ICU course and related active medical problems
4. Screening for depression, anxiety, and post-traumatic stress disorder (PTSD)
5. Brief cognitive assessment and targeted psychotherapy
6. Targeted case management assessment

These parameters mirror the outcomes now defined by Needham et al. as imperative to understanding the long term effects of critical illness [50].

Given the increased mortality risk in this population, palliative care was a feature of the initial clinic design. However, the patients and families who returned for the clinic intervention were almost uniformly focused on recovery to baseline, leading us to move away from a formal palliative care element, and to change the name of the clinic from the ICU Survivor Clinic to the ICU Recovery Clinic at Vanderbilt. Elements that were added or emphasized based on the needs of early patients included starting the "intervention" during the acute hospitalization, with

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