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The Need for Continuity of Care in Neurocritical Care and Recovery

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Abstract

Purpose of review After discharge from the Neurological Intensive Care Unit (NICU), patients often have new functional limitations and comorbidities requiring ongoing supportive care. In this review, we discuss the current state across the care continuum and identify opportunities for improvement.

Recent findings Patients often transition through multiple care settings after discharge from the NICU. Disposition to SNF (skilled nursing facility) and IRF (inpatient rehabilitation facility) varies significantly based on insurance coverage and geography. Opportunities for improvement in care transitions from the hospital to rehabilitative care include enhanced communication with patients and their caregivers to facilitate optimal rehabilitation location and services for long-term support. Standardized communication tools can reduce medical errors with early discharge planning. Early supported discharge can be considered to provide patients with coordinated community or home-based rehabilitation.

Summary After discharge from the NICU, patients need close outpatient follow-up for medication management, prevention, and management of medical and neuropsychiatric complications. Engagement of ICU providers in long-term outpatient follow-up as part of an organized post-ICU recovery clinic could help them learn about long-term patient experience and recovery, influence sensitivity to managing and preventing neuropsychiatric complications, help guide communication with patients and families, and may reduce provider burnout.

Introduction

Patients who are discharged from the Neurological Intensive Care Unit (NICU) often face new functional limitations necessitating a path to recovery lasting months to years. These patients require preventive care and close management of their neurological disease, medical complications, and psychiatric sequelae. Discharge from the NICU often entails discharge to a lower level of inpatient care followed by discharge to an inpatient rehabilitation facility (IRF) or subacute nursing facility (SNF), followed by a transition to home with support services and equipment. Throughout this process, patients are ideally following up after hospital discharge with a primary care physician, neurologist, physiatrist, and psychologist, as needed. This complex process poses numerous challenges, but many strategies have been proposed to improve the continuity of rehabilitative, neurological, psychiatric, and preventive disease management after discharge from the NICU. In this review, we describe the process of recovery after discharge from the NICU and highlight opportunities to improve the continuity of care (Fig. 1).

The implementation of prospective payment systems, which reimburse hospitals a set amount based on diagnosis, has led to a reduction in hospital length of stay [1]. From 1989 to 2014, the average length of stay for stroke patients decreased from 10.2 to 4.7 days increasing the need for discharge to IRF and SNFs [1–3]. Specifically, among patients with intracerebral hemorrhage (ICH) who are alive at 3 months, 53.5% have at least moderate disability [4•] and require rehabilitative services. While these trends are driven by economic factors, early initiation of rehabilitation is important for recovery from conditions treated in the NICU, such as ICH in which the most significant recovery is expected

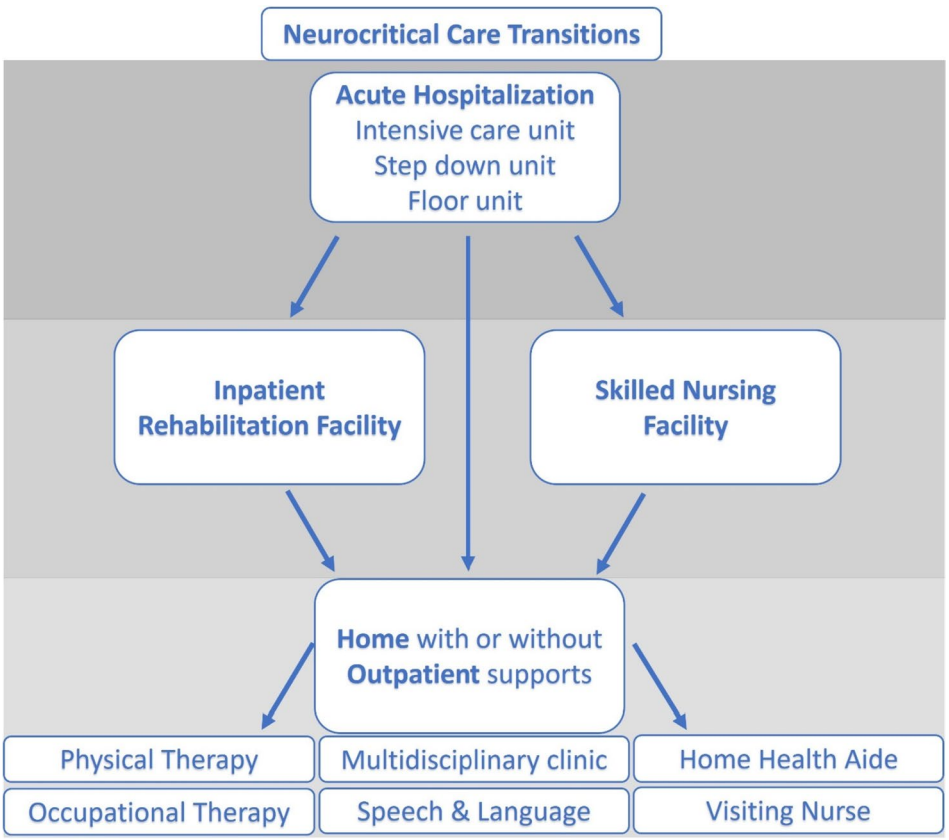

Fig. 1 Neurocritical care patient transitions of care and required support for recovery.

to take place in the initial weeks following injury [5•, 6]. It is therefore very important to start planning for rehabilitation during and after discharge early in the course of a hospitalization. Successful discharge to post-acute care rehabilitation requires a coordinated plan involving patients and families, social workers, case managers, and a multidisciplinary team of clinicians. These include physical therapists, occupational therapists, and speech and language pathologists. Early consultation with physiatry can also help improve transitions of care, as they have expertise in evaluating rehabilitation needs, understand local post-acute care regulations, and can help identify appropriate discharge disposition [1].

Post-hospitalization care continuum/services

Options for post-acute hospital disposition include discharge to IRF, SNF, and home, often with the support of equipment and physical therapy, occupational therapy, and speech and language pathology services. Disposition decisions vary significantly throughout the USA and are greatly impacted by insurance coverage [1, 7].

Rehabilitation facility discharges

Access to IRF services and SNFs is often limited under Medicaid plans, and compared to patients with Medicare FFS, those with Medicare managed care or HMOs are less likely to receive rehabilitation at IRF [1, 8]. The 2010 CMS IRF PPS rule stated that to be appropriate for an IRF facility, patients should be able to tolerate at least 3 h of daily physical activity for up to 5 days a week, leading to a decreased utilization of IRF. This compares to SNF, where patients receive 1.5 h of therapy per day [8, 9]. Prior to this rule, 32% of patients hospitalized with ICH were discharged to IRF, 22% to SNF, and 46% to home. But from 2010 to 2015, there was an absolute 1.5% decline in IRF admissions, with a 0.5% increase in SNF admissions and a 1% increase in discharge home [5]. In addition to differences in hours of therapy, IRF facilities may be better equipped to provide interventions such as intramuscular botulinum toxin or intrathecal baclofen, which can help address spasticity, a major barrier to walking after stroke, hygiene, and overall quality of life [1]. IRFs may also have specific disease focuses with tailored PT and OT programs for traumatic brain injury (TBI) and spinal cord injury (SCI). For example, SCI rehabilitation might focus on strengthening, stretching, range of motion, and transfer training, whereas TBI rehabilitation may place particular focus on cognitive training such as orientation, memory, and problem-solving [10]. Given these differences, IRF is associated with a higher daily cost. In 2020, the average length of IRF stay was 12.9 days, with a prospective payment per case of $21,765. This compares with a typical SNF length of stay of 30–35 days, with a median Medicare payment per stay of $23,494 [9].

Given the differences in functional status and insurance and socioeconomic status of patients discharged to IRFs versus SNFs, it can be challenging to compare the benefit between the two options. However, studies suggest that there may be benefits to discharge to IRF relative to SNFs [1, 5•]. Patients discharged from IRFs were more likely to have community-based discharge and improvement in motor function, mobility, and self-care compared to SNF

[11, 12]. In one study of patients who underwent mechanical thrombectomy for stroke and had similar infarct volumes, those who were discharged to IRF were found to have improved outcomes compared to those discharged to SNF [13].

Early supported discharge

For certain patients, early discharge home from the hospital may be ideal. Early supported discharge (ESD) allows patients to focus on realistic rehabilitation goals in the context of their home and may improve the chance of patients living independently [14]. ESD generally requires a multidisciplinary team that coordinates the transition home from the hospital with a plan for rehabilitation in the community or at home, usually for up to 3 months. ESD trials have been conducted in numerous countries including Thailand, Sweden, Canada, the UK, Australia, India, Portugal, Denmark, and Norway, with the interventions generally taking place in urban centers. A meta-analysis of these trials found that ESD was associated with a lower risk of death, dependency, and need for institutional care 6 months post-stroke compared to patients provided with conventional discharge care. Patients who underwent ESD were more likely to be satisfied with outpatient services, though some data also suggested an association between ESD and reports of depression and anxiety [15]. However, in the USA, limited coverage of outpatient rehabilitation services could be a challenge in the implementation of ESD and successful home rehabilitation [1].

Gaps and challenges in care transitions

Early communication regarding the disposition after discharge

For patients discharged to IRF or SNF, patients and families must be engaged in an informed decision-making process before discharge to choose a high-quality facility. In 2020, readmission rates were 7.8% and 14.2% for patients admitted to IRF and SNF, respectively [9]. Among the 14.4% of stroke patients readmitted to the hospital within 30 days, 11.9% of these readmissions were thought to be preventable and were more likely among patients discharged to SNF [7, 16]. Readmission rates differed by 5% among patients discharged to the highest readmission quartile SNF versus the lowest readmission quartile SNFs, and hospitals have successfully reduced readmissions by discharging patients to SNFs that readmit fewer patients [17]. However, while patients and families are provided with a list of IRFs or SNFs to choose from, they are often provided with little information about the quality of the facilities [1, 18]. Patients and families tend to choose facilities based on the proximity of the facility to their homes [19]. If they were to receive better information about the quality of facilities and intensity of care at each facility, families and patients might make different choices, which could then prompt increased focus on quality improvement at IRFs and SNFs.

Preventing medical errors in transitions of care

The transition to inpatient rehab or SNF from the hospital and the transition home from the hospital, IRF, or SNF are both challenging processes with opportunities for error and improvement. During the transition to IRF or SNF, there is significant potential for medical error. Poor communication in transitions of care is one of the leading causes of medical error [20–22]. Inadequate sign-out between nursing and clinicians can lead to patients missing medications or timely follow-up of medical issues [23]. To address this, hospitals can take advantage of several standardized communication tools including "SBAR (Situation, Background, Assessment, Recommendation)," "TST (the Center for Transforming Healthcare's Targeted Solutions Tool)," and "I-PASS (Illness severity, patient summary, action list, situation awareness and contingency plans and synthesis by receiver)" [21]. A standardized verbal handoff implemented for stroke patients being transitioned from the hospital of the University of Pennsylvania to an affiliated rehabilitation facility reduced errors in the reconciliation of critical medications from 42% of patients in the control group to 23% in the intervention group [24]. One practice to avoid patients missing medications or enteral feeding during delays in the physical transfer is for hospitals to transport patients with supplies from the day of discharge, including unused enteral formula and medication [1]. Last, poor communication about patient acuity of care can lead to patients being inappropriately assigned to units with lower nursing staffing. In addition to improved communication during sign-out, programs such as the Rehab Matrix protocol in Houston, TX, are being developed to improve equitable assignment of nurses to patients being admitted to rehab [1, 25].

Post-discharge services delivery

Issues that arise on transition home from the hospital, IRF, or SNF include interruptions in the continuation of PT, delays in delivery of medical equipment, and discontinuation of medications. On discharge home, patients should ideally be already set up with a comprehensive neurorehabilitation program that may include PT, OT, SLP, social work, and rehabilitation nursing and physiatry as needed [1, 26]. Early coordination with outpatient OT teams and equipment suppliers is important for avoiding common issues including delayed delivery and ill-fitting equipment so that patients have the necessary equipment such as wheelchairs and lifts on return home [1, 27]. Early initiation of pre-authorization, and identification of co-pay assistance for high cost-medications, or alternative medications is important to prevent delays in filling medications on transition home. Effective family education training can help address concerns with rehabilitation, equipment, and medication and can also improve early identification of medical issues that could lead to readmissions. Family members can be trained in PT and OT exercises, safe walking, as well as with splint placement and orthotic wearing schedule, all of which can help improve mobility and avoid contractures and spasticity. Families can also be trained to promptly identify issues such

as skin breakdown and can help with medication adherence [1, 14, 28, 29]. Last, early and effective education and support are very important for family members themselves, who are often overwhelmed with coming to terms with their loved ones' change in functional status in the setting of the home, as well as their new role in providing support [27].

Outpatient care

Patients discharged from the NICU need close outpatient follow-up for medication management, preventive care, and treatment of long-term complications of their presenting illness.

Patients admitted to the NICU are often discharged with numerous new medications. Discharge medications such as antihypertensives, antipsychotics, and neuro-stimulants, need close monitoring and titration based on their effectiveness, soon after discharge. Some patients, such as those with a large territory ischemic stroke due to atrial fibrillation, will need to be started or re-started on anticoagulation at a time point after they leave the hospital [14]. Others such as those with deep venous thromboses diagnosed on admission might need anticoagulation stopped at a time point after leaving the hospital. At the Vanderbilt Intensive Care Unit (ICU) Recovery Center, staff of the post-ICU clinic report frequently identifying patients taking inappropriate medications after discharge [30].

Preventive care and early identification of recurrent injuries are one of the most important components of outpatient management for patients discharged from the NICU. Survivors of ICH have a 1.2–3% annual recurrence risk with the highest rate seen in the first year after injury [14]. Recurrence is partially due to non-modifiable risk factors such as underlying cerebral amyloid angiopathy but is also attributable to modifiable risk factors such as hypertension [31]. Hypertension accounts for 73.6% of the global attributable risk for ICH [14, 32]. However, many survivors of ICH have poor hypertension control [14, 33]. Other modifiable risk factors to reduce the risk of ICH, stroke, and cardiac arrest include smoking cessation, reduction in alcohol consumption, modifications to diet, and increased physical activity [14, 34, 35].

Neuropsychiatric complications

Neuropsychiatric complications are common after discharge from the NICU and require careful outpatient follow-up. In the immediate post-discharge period, patients need guidance on early anxieties after arriving home, such as fears about resuming sexual activity and weight lifting [14]. The development of depression, anxiety, and post-traumatic stress disorder (PTSD) is common among patients who suffer from stroke, ICH, aneurysmal subarachnoid hemorrhage (aSAH), TBI, and cardiac arrest. Depression affects 20% of patients after an ICH, 23–44% after aSAH, and 25% after TBI [14, 36–38]. Rates of suicide after stroke are nearly twice as high as the general population, and post-stroke depression has been linked to increased mortality, limited

mobility, and worse functional outcomes [14, 39–42]. This is possibly attributed to depression leading to reduced engagement in physical and cognitive rehabilitation [40]. Cognitive impairments are seen in 15% of patients after NCSE; in approximately 30–40% of patients after stroke, ICH, and SAH; up to 68% after TBI; and 73% after cardiac arrest [14, 37, 38, 43–47]. Post-traumatic symptoms are seen in 32% of patients after cardiac arrest and are associated with higher mortality and rate of cardiovascular events [48]. These neuropsychiatric sequelae, along with physical symptoms after critical illness, have been referred to as "post-intensive care syndrome (PICS)." However more work is needed to understand PICS within the population of the neurocritical care unit, as much of PICS research has excluded patient with primary neurological diagnoses [37].

Despite the prevalence of neuropsychiatric sequelae after admission to the neurocritical care unit, these issues are not adequately addressed in the outpatient setting. While approximately 70% of patients report cognitive and psychologic symptoms after cardiac arrest, only a third reported discussing potential neuropsychiatric symptoms with their outpatient providers [47]. Patients report frustration that potential neuropsychiatric sequelae were not discussed prior to discharge and were not addressed at outpatient appointments [35]. Interventions to prevent neuropsychiatric sequelae are limited. One large trial assessed strategies in the ICU setting to reduce PTSD, such as changes to the ICU environment, psychoeducation, and training of nurses in trauma-informed care, but did not show efficacy [35, 49]. However, in the outpatient environment, pharmacological therapy and psychotherapy, including cognitive behavioral therapy, have been shown to successfully reduce depression symptoms in patients after stroke [14, 50, 51]. Hyperarousal symptoms seen in PTSD after cardiac arrest have been addressed through interoceptive exposure—a process by which patients learn that physiological sensations that previously triggered anxiety are not harmful [35, 52, 53]. Cognitive impairments may be addressed through OT with a focus on improving working memory attention improving independent function and community integration [54].

Families often carry a significant burden from serving as caregivers and surrogate decision-makers [55]. Families of patients discharged from the NICU often experience a dramatic and sudden life change, loss, isolation, and a transformation in their role in the family [56]. Caregivers can develop neuropsychiatric sequelae, including depression, complicated grief, anxiety, acute stress disorders, and PTSD—a constellation of symptoms that has been termed post-intensive care syndrome—family (PCIS-F) [37, 57, 58]. Factors that have been attributed to PCIS-F include poor communication with ICU teams and discomfort with involvement in medical decisions [59].

Opportunities and future directions

Addressing medication management, preventive health, and health complications including neuropsychiatric sequelae of patients and caregivers after admission to the NICU requires multidisciplinary outpatient follow-up including primary care, neurology, physiatry, and involvement of other specialties, such as psychiatrists and cardiologists.

Numerous multidisciplinary care post-ICU clinics have been developed, and a network of these clinics organized as part of the Society of Critical Care Medicine's THRIVE collaborative are working to share best practices to address PICS [60]. The ICU Recovery Clinic at Vanderbilt consists of intensivists, ICU nurse practitioners, critical care pharmacists, case managers, and neuropsychologists. The clinic involves pulmonary and mobility tests, medication reconciliation, neuropsychiatric screening, review of ICU course and related problems, and case management [30]. There is limited evidence of best practices for post-ICU clinics [61]. However, research suggests that behavioral interventions should be "dyadic"—focused on addressing both patients and caregivers [28, 37, 62]. Results from the Recovering Together pilot study of patients discharged from a neurocritical care unit suggest a behavioral intervention that teaches resiliency skills focused on patients and families as dyads, successfully reduced depression and anxiety among patients and caregivers [35, 55, 63, 64]. Surveys of patients and families suggest that these clinics can provide significant relief to families, who can feel unsupported after discharge from the ICU, with one respondent reporting that discharge felt like being "popped out in the ocean to sink or swim" [65]. Barriers to setting up these clinics include funding, high no-show rates and difficulty tracking patients, and loss to follow-up when they are discharged to IRF or SNF [66]. High no-show rates and loss to follow-up may be attributed to the prevalence of impairments in cognition and language which can make it difficult for patients to schedule and confirm appointments, as well as impairments in mobility and limited access to transportation to appointments [7, 30]. Telemedicine is one proposed solution to issues with mobility and transportation. In the Telehealth After Stroke Care study, a multidisciplinary team worked with patients using telemedicine and remote monitoring of blood pressure to successfully reduce blood pressure in an underserved setting [67].

Participation in post-ICU clinics can also benefit ICU providers. Through participation in the clinics, ICU providers can learn about patients' and families' memories from the ICU as well as their long-term experiences. Hearing about these experiences can prompt ICU providers to reflect on how they may contribute to this process and lead them to develop quality improvement projects to improve patient care. For example, ICU providers who are exposed to long-term neuropsychiatric sequelae might better appreciate the long-term importance of improved sleep, early sedation holidays, and daily awakenings which have been shown to mitigate these complications [37, 68, 69]. Learning from patients and families could also improve sensitivity and empathy among providers. For example, in a THRIVE clinic, an ICU provider reported becoming more sensitive about the placement of a nasogastric tube—a procedure that may seem insignificant to providers

but can be very painful and memorable for patients [65]. Such experiences may help address burnout and compassion fatigue among ICU providers [65, 70]. Providers who only see patients in an ICU setting may be overly pessimistic about long-term patient outcomes. Feedback about long-term improvements could influence ICU providers' attitudes towards potential recovery and impact communication with families. Such feedback could provide an important counterbalance towards biases that contribute to the phenomenon of the self-fulfilling prophecy, a process by which patients thought to have poor prognoses undergo withdrawal of life support which then ensures the prognosis [71]. Additionally, feedback can help providers guide patients about complications they may encounter during survivorship. For example, working in post-ICU clinics can help ICU providers better understand PICS and PICS-F, and prompt them to start looking out for and discussing these potential symptoms with patients and families during the hospitalization. Emotional distress during hospitalization is a key risk factor for the later development of distress [37, 72]. A focus on addressing and preventing distress through strategies such as family meetings, which have been shown to improve family satisfaction, could be an effective intervention [37, 73]. Last, working in ICU clinics allows an opportunity for ICU providers to receive gratitude from patients and families, which alongside exposure to successful outcomes, may increase the meaning of their work, help them understand the role of their work within the pathway of recovery, and enhance their purpose in the ICU [65].

Conclusion

After discharge from the NICU, patients and families face a long path to recovery. This path often involves post-acute care rehabilitation, followed by the continuation of neurorehabilitation in the home setting. This process also involves multidisciplinary outpatient management of medications and numerous complications of their neurological injury and ICU treatment course. While there has been significant progress in advancing post-NICU rehabilitation and outpatient care, much more work is needed to identify best practices and ensure coordinated long-term follow-up involving a multidisciplinary group of providers, patients, and families.

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Compliance with Ethical Standards

Conflict of Interest
Jeremy Ader declares that he has no conflict of interest. Sachin Agarwal that he has no conflict of interest. Imama A. Naqvi that she has no conflict of interest.

Human and Animal Rights and Informed Consent
This article does not contain any studies with human or animal subjects performed by any of the authors.

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This article offers an understanding of risk factors that contribute to neurologic disability and mortality in addition to traditional vascular risk factors after intracerebral hemorrhage in a large cohort study. Novel risk factors identified included older age, pre-ICH modified Rankin score, and presence of infection in addition to size and location of ICH. These additional characteristics can be utilized to identify patients at greater risk of neurological disability and mortality for targeted transitional care interventions.

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