

A DAY IN THE LIFE OF A NEUROCRITICAL CARE TRAINEE



A Change of Course: The Case for a Neurorecovery Clinic

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Introduction

Everyday during neurocritical care rounds, we find ourselves obsessing over dips in sodium, liquid stool, and whether a urinary catheter is truly indicated. We scrutinize minutiae with the goal of keeping those teetering on the edge, alive. The long-term implications of the patient's brain injury are often left for whispered conversations or private contemplation, when we question whether our patient will ever be the person he once was. During family meetings, we describe in broad strokes the natural history of the patient's disease and potential outcomes. Often these conversations end with a discussion about goals of care (GoC) and questions posed to families—"If your loved one was able to make decisions; how would he want us to move forward? What amount of disability would be acceptable to her? In light of this, often uncertain, prognosis and potential for recovery, would they choose a medically-aggressive restorative path or ask to focus solely on comfort?"

Implicit but overlooked in this discussion is the idea that disability has a predictable effect on quality of life (QoL). As intensivists, we may place our patients within the literature to give the dire prediction of a modified Rankin score of 5, but we rarely see how patients and families experience such an outcome after they leave the intensive care unit (ICU). Acknowledging the complexity of the actual versus predicted psychosocial impact of neurologic disability on patients' and caregivers' QoL is paramount to guiding families to make the most informed decisions for their loved one's care. Recovery clinics for ICU survivors have consistently demonstrated

benefits in these realms for both patients and ICU teams [1].

A Not-so-Unusual Case

During the summer of 2019, a young father in his 30s was found unconscious in his home. Outside hospital imaging revealed an aneurysmal subarachnoid hemorrhage with blood casted in the right lateral, 3rd, and 4th ventricles. On arrival to our unit, he was comatose with unequal pupils and decerebrate posturing. An extraventricular drain was emergently placed, and he was taken to the interventional radiology (IR) suite for coiling of his anterior communicating artery aneurysm. Already, his angiogram demonstrated severe bilateral anterior cerebral artery vasospasm. Over the next 2 weeks, he required high-dose vasopressors and frequent trips to the IR suite for management of severe vasospasm. He developed a host of complications including stress cardiomyopathy, hypoxic respiratory failure, paralytic ileus, recurrent refractory fevers, and healthcare-associated infections. Prior to requiring paralytics for ventilator synchrony, at best, he could intermittently open his eyes to noxious stimuli and inconsistently attend briefly to voice.

Difficult Decisions

During early family meetings, the patient's mother and girlfriend agreed to press forward with aggressive restorative care, but as days passed, and they watched their loved one remain unconscious, connected to machines, and seemingly only getting sicker, they began to ask questions about transitioning to a more comfort-directed pathway of care. His girlfriend recounted previous conversations indicating that he would consider virtually any physical or mental disability to be worse than death, and his mother agreed that he had a high bar set for what might be considered an acceptable QoL. They agreed that he was strong-willed and independent and never would

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have wanted this kind of ICU care. However, they wondered whether some disability might be acceptable to him if he were still able to be a father figure for his son.

As the ICU team, we provided cautious optimism that meaningful recovery remained possible but would certainly involve a long and trying course with some degree of residual disability. It was up to his family to decide whether this “meaningful recovery” could result in an acceptable QoL for the patient. They therefore leaned on recollections of specific conversations and stated wishes, becoming certain of what he would have wanted. With heavy hearts but confidence that they were doing right by speaking for their loved one, they requested to transition to comfort-focused GoC, with a compassionate extubation planned.

The patient was extubated at 8 pm with family at bedside. But then he did something they weren’t fully prepared for—he kept breathing. Over the next few hours, they wondered, was he was trying to tell them something? Had they made the wrong decision? By 3 a.m., they felt convinced his strength was an expression of his will to live and requested to reverse his code status and have him re-intubated to give him more time. The next morning, his family, for the first time, appeared at peace.

Arriving to find the patient re-intubated, we were left in stunned silence. After many difficult discussions, his care providers had come to accept and agree with his family’s decision to withdraw life sustaining therapies. We were confused and emotionally drained but comforted by his family’s sense of peace. His remaining hospital course was uneventful with slow but steady improvements. When transitioning to acute rehab, he opened his eyes regularly to voice and intermittently followed simple commands. Later, while transferring to subacute rehab, he vocalized words and participated in selfcare tasks, albeit, with severe cognitive impairment requiring 100% supervision for activities of daily living.

A Humbling Clinic Visit

Nearly 3 months after his initial presentation, he returned via ambulance crew and stretcher along with his girlfriend for follow-up in our neurorecovery clinic. On the surface, he appeared attentive and cognitively appropriate. But, after a 30-min interview with his girlfriend, she caught him off-guard by asking whether he was paying attention. He responded, “No,” blankly, and she explained that he spends the vast majority of his waking life tuning out, not interacting with the outside world. Bedside testing revealed a Montreal Cognitive Assessment score of 13/30 and significant lack of insight. He knew that he was not quite himself, but the details were minced. He was convinced that he was able to walk and care for himself

independently, while his girlfriend described a state of complete dependence requiring continuous care.

This was the kind of outcome his family initially expressed not wanting for him, the kind of disability he had told his girlfriend that he would not want to live with. Yet, she reported that he was doing well, that he had made great strides, and that she felt distress over the family’s brief decision to withdraw life-sustaining therapies. When the patient himself was asked whether he felt happy when he woke up in the morning, he replied brightly, “yeah!” and indeed his girlfriend reported that he seemed perfectly content playing Jenga with his 4-year-old son. Ever since his brain injury, he had become “calmer,” “less sarcastic,” and “easier to please.”

As this young father was transported out of our clinic, we were reminded of the night when his death was imminent, and we were left wondering whether this was the right outcome for the patient and his family. If it was, had it been wrong to withdraw care based on his previously expressed predicted intolerance for a life with neurologic disability? While our patient in follow-up may now experience an acceptable QoL, would the patient before SAH be satisfied in this situation? How can anyone predict how they will cope with brain injury-related disability, when that injury may affect one’s core personality, capacity for self-reflection, and overall satisfaction with life [2]?

Neurorecovery Clinic as a Learning Tool

While these visits often leave us with more questions than answers, they also open our eyes to the staggering complexity of brain injury, coping and recovery. They illustrate in real time the disability paradox and contribution of the expectation gap on the most human of levels [3, 4]. We have read the data from trials of decompressive craniectomies in malignant stroke patients suggesting good QoL despite significant disability, but without this human interaction, it is hard to fathom what this might look like. Our clandestine concerns stem from the expectation that we counsel families making difficult care decisions based on an expertise we lack; we watch so many patients leave the ICU but only rarely see the results of our efforts in the form of durable patient outcomes when the “miraculous” patient returns to visit [5, 6].

Our neurorecovery clinic generates an interaction that is beneficial to both the patient and the medical team (Table 1). We help patients and families to fill in the gaps of their emotionally charged memories from their time in the ICU and to make sense of everything that happened to them. The visit also provides an opportunity to make certain that medications are appropriate for the patient’s stage of recovery, to engage rehabilitation services, and to provide support and resources for caregivers in their new roles. Meanwhile, through these follow-up visits, we

Table 1 Benefits of a neurorecovery clinic

Benefit category	Beneficiary	
	Patient/family	ICU Team
Past reflection	Review of diagnosis, imaging, and other testing	Insight into patient/family remembrance of hospital course
	Clarification regarding timeline of critical illness	Recognition of challenges faced by family in ICU
	Opportunity to ask questions	Hindsight reflection on medical decision making
	Opportunity to unload and reflect	Opportunity for feedback regarding family engagement during ICU course
Current updates	Re-establish rapport and therapeutic relationship	Re-establish rapport and therapeutic relationship
	Medication reconciliation	Follow-up comparison of actual vs expected outcome
	Identify gaps in care	Understanding of trajectory for individual recovery
	Identify obstacles for continued recovery	Combat burnout with longitudinal human connection and clinical change of pace
Future planning	Re-engagement of rehabilitation, and social services as indicated	Application of medical decision-making lessons to future cases
	Reassessment and communication of prognosis	Application of patient/family feedback to future ICU family engagement
	Clinical referrals as indicated	Better anticipate post-ICU patient obstacles
	Readdress goals of care as indicated	Better counsel patients regarding prognosis and expected clinical course

can begin to develop a true understanding of what recovery from neurologic critical illness really means; we see first-hand the challenges patients and families face while adjusting to new lives they never expected; we listen to caregivers maintain positivity and gratitude until their voices crack under the weight of their burdens. We grapple alongside them, bearing the consequences of our joint decisions. In the end, this intimate portrait of coping and recovery has the potential to shape our views and color our conversations for future patients [2]. While these clinics for now are uncommon, creating this opportunity for engagement can be simply attained by co-managing selected patients in resident clinics following their stay, inviting survivors and families back to the ICU to speak about their experiences or working to develop a clinic of your own [7, 8].

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The authors declare that they have no conflict of interest.

Ethical Approval and Informed Consent

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