

Natural history of recovery and outcome after severe TBI: Separating fact from fiction

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Learning Objectives

1. Identify early behavioral signs of recovery of consciousness.
2. Determine the relationship between early behavioral signs of recovery in patients with disorders of consciousness (DoC) and degree of disability at discharge from inpatient rehabilitation.
3. Describe the course of recovery from the acute through chronic phases in patients with DoC.
4. Apply evidence to correct misperceptions about recovery after severe TBI



TBIMS

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Model System

Since 1987



TRACK-TBI

Transforming Research and Clinical Knowledge
in Traumatic Brain Injury

International Traumatic Brain Injury Research Initiative

The Traumatic Brain Injury Model Systems

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NINDS Common
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Recovery continuum

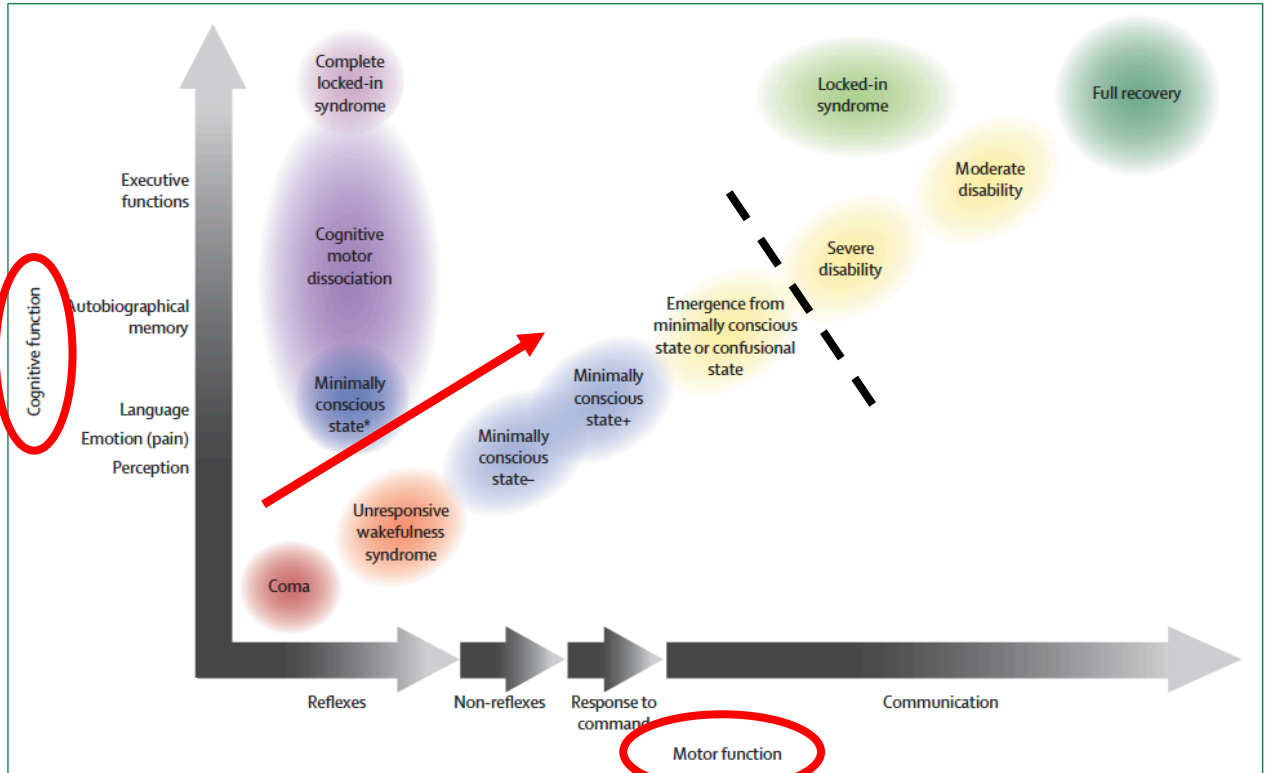


Figure 1: Motor and cognitive evolution following a severe brain injury

Phases of Recovery

- *Acute/Subacute (first 28 days post-injury)*
- *Post-acute (first 12 months post-injury)*
- *Chronic (1-10 years post-injury)*

***Recovery During the
Acute/Subacute Phase
(Day 1-28)***

Background

- Early prognostication in patients with severe TBI relies heavily on behavioral findings obtained on bedside examination.
- Outcome prediction often relies on imaging and lab findings, which have relatively low precision for discriminating unfavorable v. favorable outcome.
- Clinician knowledge of the frequency and time course to recovery of behaviors associated with recovery and functional outcome is very limited.
- Most common cause of death after severe TBI across all age groups is withdrawal of life-sustaining treatment (WLST)

Frequency and timing of withdrawal of Life-Sustaining Treatment (WLST)

Table 4: Deaths and percentage of deaths following withdrawal of life-sustaining therapy within the first three days of care

Centre	No. of admissions	Deaths within first 3 d of care, no.	Among all deaths within the first 3 d of care, deaths following withdrawal of life-sustaining therapy		Among deaths following withdrawal of life-sustaining therapy, deaths occurring within the first 3 d of care	
			No.	% (95% CI)	No.	% (95% CI)
A	120	15	11/15	73.3 (48.1–89.1)	11/26	42.3 (25.5–61.1)
B	120	28	26/28	92.9 (77.4–98.0)	26/46	56.5 (42.3–69.8)
C	120	4	2/4	50.0 (15.0–85.0)	2/9	22.2 (6.3–54.7)
D	120	22	14/22	63.6 (43.0–80.3)	14/39	35.9 (22.7–51.6)
E	120	23	7/23	30.4 (15.6–50.9)	7/18	38.9 (20.3–61.4)
F	120	22	13/22	59.1 (38.7–76.7)	13/22	59.1 (38.7–76.7)
Total	720	114	73/114	64.0 (54.9–72.3)	73/160	45.6 (38.1–53.4)

Note: CI = confidence interval.

Turgeon, et al., CMAJ, 2011

Table 3. Length of Stay and Disposition by Withdrawal of Life-Supporting Treatment

Characteristic	No withdrawal of LST	Withdrawal of LST	Total
No. of persons included	30 080	7869	37 949
Total LOS			
No. with data	30 040	7868	37 908
Mean (SD), d	15.4 (17.4)	9.5 (7.5)	13.3 (16.4)
Median (Q1–Q3), d	10.0 (3.5–21.0)	3.0 (1.0–7.0)	8.0 (2.0–19.0)
Range, d	(1.0–357.0)	(1.0–179.0)	(1.0–357.0)
Total ICU LOS			
No. with data	27 542	7909	34 751
Mean (SD), d	9.7 (10.0)	5.2 (6.3)	8.8 (9.5)
Median (Q1–Q3), d	6.0 (3.0–14.0)	3.0 (1.0–7.0)	5.0 (2.0–13.0)
Range, d	(1.0–178.0)	(1.0–180.0)	(1.0–180.0)
Total ventilator days			
No. with data	25 960	7327	33 987
Mean (SD), d	7.5 (9.0)	4.8 (6.0)	6.9 (8.5)
Median (Q1–Q3), d	4.0 (2.0–11.0)	2.0 (1.0–6.0)	3.0 (2.0–10.0)
Range, d	1.0–207.0	1.0–180.0	1.0–207.0
Discharge disposition, No. (%)			
Deceased/expired	5961 (18.3)	7026 (93.7)	12 987 (33.9)
Discharged/transferred to home	8572 (29.8)	28 (0.4)	8600 (23.7)
Discharged/transferred to hospital	13 562 (47.1)	74 (1.0)	13 636 (37.6)
Discharged/transferred to hospice	395 (1.4)	359 (4.8)	754 (2.1)
Other	987 (3.4)	10 (0.1)	997 (2.7)

Williamson, et al, JAMA Surg, 2020

Myth 1

An accurate prognosis about long-term outcome following severe TBI can be established within 72 hours of onset to guide decision-making regarding goals of care.



ORIGINAL ARTICLE

CLINICAL STUDIES

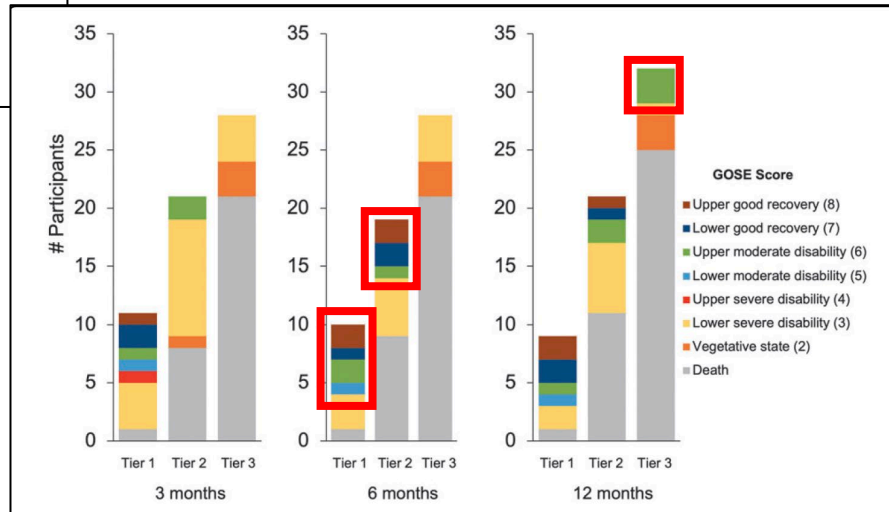
Recovery Potential in Patients Who Died After Withdrawal of Life-Sustaining Treatment: A TRACK-TBI Propensity Score Analysis

William R. Sanders,^{1,2,*} Jason K. Barber,^{3,**} Nancy R. Temkin,^{3,4} Brandon Foreman,⁵ Joseph T. Giacino,^{6,7}
Theresa Williamson,⁸ Brian L. Edlow,^{1,9} Geoffrey T. Manley,¹⁰ Yelena G. Bodien,^{10,7,†}
and the TRACK-TBI Investigators****

Propensity for WLST

- Tier 1: 0-11%
- Tier 2: 12-27%
- Tier 3: 28-70%

Outcome of WLST- patients who were matched to WLST+ patients by propensity for WLST



Recovery During the Acute/Subacute Phase

JOURNAL OF NEUROTRAUMA 37:267-285 (January 15, 2020)
Mary Ann Liebert, Inc.
DOI: 10.1089/neur.2019.0420

Behavioral Recovery and Early Decision Making in Patients with Prolonged Disturbance in Consciousness after Traumatic Brain Injury

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Flora M. Hammond,^{7,9} David Long,⁴ and Emilia Bajajella¹⁰

Abstract

The extent of behavioral recovery that occurs in patients with traumatic disorders of consciousness (DoC) following discharge from the acute care setting has been understudied and increases the risk of overly pessimistic outcome prediction. The aim of this observational cohort study was to systematically track behavioral and functional recovery in patients with prolonged traumatic DoC following discharge from the acute care setting. Standardized behavioral data were acquired from 95 patients in a minimally conscious (MCS) or vegetative state (VS) recruited from 11 clinic sites and randomly assigned to the placebo arm of a previously completed prospective clinical trial. Patients were followed for 6 weeks by blinded observers to determine frequency of recovery of six target behaviors associated with functional status. The Coma Recovery Scale-Revised and Disability Rating Scale were used to track emergence of target behaviors and assess degree of functional disability, respectively. Twenty percent (95% confidence interval [CI]: 13–29%) of participants (mean age 37.2, median 47 days post-injury; 69 men) recovered all six target behaviors within the 6-week observation period. The odds of recovering a specific target behavior were 3.2 (95% CI: 1.2–8.1) to 7.8 (95% CI: 2.7–23.0) times higher for patients in MCS than for those in VS. Patients with preserved language function (“MCS+”) recovered the most behaviors ($p < 0.002$) and had the least disability ($p < 0.002$) at follow-up. The findings suggest that recovery of high-level behaviors underpinning functional independence is common in patients with prolonged traumatic DoC. Clinicians involved in early prognostic counseling should recognize that failure to emerge from traumatic DoC before 28 days does not necessarily portend unfavorable outcome.

Keywords: consciousness; MCS; outcome research; TBI; VS

Introduction

MONITORING BEHAVIORAL RECOVERY in patients who develop disorders of consciousness (DoC) after severe traumatic brain injury (TBI) is an essential component of diagnostic and prognostic assessment. Following emergence from coma, patients transition into the vegetative state (VS) or the minimally conscious state (MCS). In VS, sleep-wake cycles are an essential hallmark in the behavioral evidence of awareness.¹ In MCS, there is at least one definitive behavioral sign of conscious awareness.² The diagnosis

of “MCS+” (i.e., “MCS-”) is made when the features of MCS include behavioral evidence of language comprehension or expression.³ This dichotomy is supported by functional neuroimaging evidence of language network activation following exposure to verbal instructions in patients who meet diagnostic criteria for MCS.^{4,5} Emergence from MCS is established when there are reliable yes-no responses to questions or reproducible instances of appropriate object use.⁶ There is also evidence that re-emergence of specific behaviors foreshadows subsequent cognitive and functional recovery.^{6–11}

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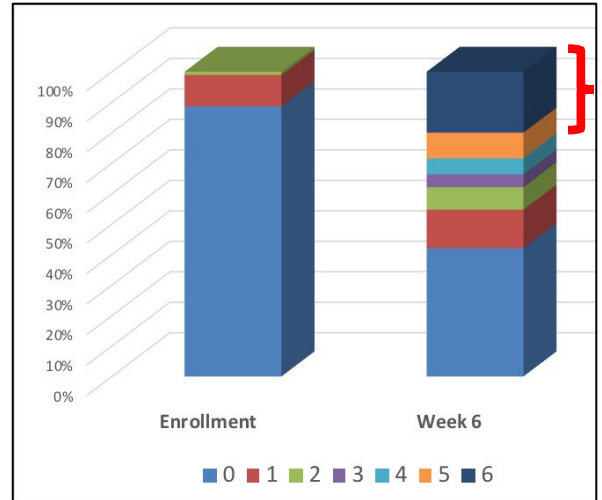
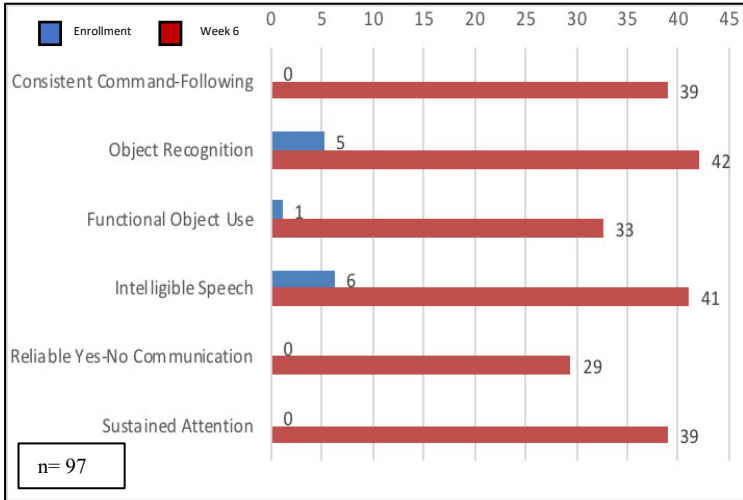
- **Aim:** To determine the relationship between behavioral recovery observed over a 6-week period *following acute hospital discharge* and degree of disability present at rehab discharge.
- **Sample:** 97 adults in traumatic VS or MCS enrolled in the placebo arm of a clinical trial (amantadine hydrochloride) conducted at eight rehabilitation hospitals in the United States and three in Europe.
- **Outcomes:**
 - Proportion of sample demonstrating pre-identified target behaviors over 6-week observation window
 - Total number of target behaviors present at week 6
 - Frequency of emergence from MCS by week 6
 - Median Disability Rating Scale (DRS) score relative to the number of behaviors present at week 6.



TRBIMS

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Key Findings



- For each behavior recovered, DRS score improved by ≈ 2 points, resulting in a 12-point spread between patients who recovered all six behaviors and those who recovered none.

Myth 2

Failure to demonstrate early improvement in behavioral responsiveness predicts lack of subsequent improvement.

Recovery During the Acute/Subacute Phase

Research

JAMA Neurology | Original Investigation

Recovery of Consciousness and Functional Outcome in Moderate and Severe Traumatic Brain Injury

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IMPORTANCE: Traumatic brain injury (TBI) leads to 2.0 million visits to US emergency departments annually and frequently involves a disorder of consciousness (DOC). Early treatment, including withdrawal of the sustaining therapies and rehabilitation, is often predicated on the assumed neuroanatomical outcomes of disrupted consciousness.

OBJECTIVE: To quantify the loss of consciousness, factors associated with recovery, and return to functional independence in a 31-year sample of patients with moderate or severe brain trauma.

DESIGN, SETTING, AND PARTICIPANTS: This cohort study analyzed patients with TBI who were enrolled in the Traumatic Brain Injury Model Systems National Database, a prospective, multitype, longitudinal database. Patients were survivors of moderate or severe TBI who were discharged from acute hospitalization and admitted to inpatient rehabilitation from January 4, 1992, to June 10, 2016, at 1 of 23 inpatient rehabilitation centers that participated in the Traumatic Brain Injury Model Systems program. Follow-up for the study was through completion of inpatient rehabilitation.

EXPOSURES: Traumatic brain injury.

MAIN RESULTS AND MEASURES: Outcome measures were Glasgow Coma Scale in the emergency department, Disability Rating Scale, posttraumatic amnesia, and Functional Independence Measure. Patient-related data included demographic characteristics, injury cause, and brain computed tomography findings.

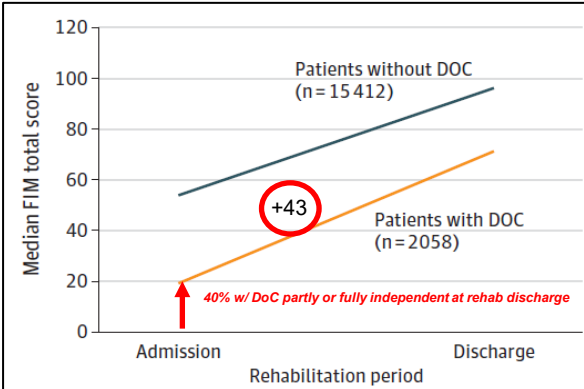
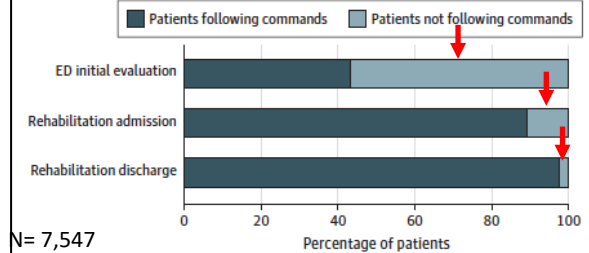
RESULTS: The 17 470 patients with TBI analyzed in this study had a median (interquartile range [IQR]) age at injury of 51 (25–64) years and included 13 654 male individuals (78%). Of these patients, 7547 (57%) experienced initial loss of consciousness, which persisted to rehabilitation in 2058 patients (27%). Those with persisting DOC were younger, had more high-velocity injuries, had intracranial mass effect, intraventricular hemorrhage, and subdural contusion, and had longer acute care than patients without DOC. Eighty-two percent (n = 1674) of comatose patients recovered consciousness during inpatient rehabilitation. In a multivariable analysis, the factors associated with consciousness recovery were absence of intraventricular hemorrhage (adjusted odds ratio [OR], 0.678; 95% CI, 0.532–0.863; P = .002) and intracranial mass effect (adjusted OR, 0.759–0.936; CI, 0.595–0.968; P = .03). Functional improvement (change in total functional independence score from admission to discharge) was +43 for patients with DOC and +37 for those without DOC (P = .002), and 803 of 2033 patients with DOC (40%) became partially or fully independent. Younger age, male sex, and absence of intraventricular hemorrhage, intracranial mass effect, and subdural contusion were associated with better functional outcome. Findings were consistent across the 3 decades of the database.

CONCLUSIONS AND RELEVANCE: This study found that DOC occurred initially in most patients with TBI and persisted to some patients after rehabilitation, but most patients with persisting DOC recovered consciousness during rehabilitation. This recovery trajectory may inform acute and rehabilitation treatment decisions and suggests caution is warranted in consideration of withholding or withdrawing care in patients with TBI and DOC.

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Figure 1. Progression in Percentage of Patients With Disorder of Consciousness During Treatment



Which behavioral signs of consciousness emerge first?

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Original article

Which behaviours are first to emerge during recovery of consciousness after severe brain injury?

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ABSTRACT

Background: Early detection of consciousness after severe brain injury is critical for establishing an accurate prognosis and planning appropriate treatment.
Objective: To determine which behavioural signs of consciousness emerge first and to estimate the time course to recovery of consciousness in patients with severe acquired brain injury.
Methods: Retrospective observational chart review of the Consciousness Scale-Revised from days to recovery of consciousness in 79 patients (51 males; 34 with traumatic brain injury; median [IQR] age 48 [20–61] years; median time since injury 28 [20–36] days) who transitioned from coma or unresponsive wakefulness syndrome (UWS) to patient behaviour data (PBD) for the study on conscious state (MCS) to emerged from MCS during inpatient rehabilitation.
Results: Visual pursuit was the most common initial sign of MCS (45% of patients; 95% CI [34–53]), followed by reproducible command-following (28% [14–51]) and automatic movements (24% [15–33]). Ten other behaviours emerged first in less than 10% of cases. Median [IQR] time to recovery of consciousness was 44 [31–60] days. Clinical delay significantly affected time to recovered consciousness. Conclusion: Recovery of consciousness after severe brain injury in most often signalled by reappearance of visual pursuit, reproducible command-following and automatic movements. Clinicians should use assessment measures that are sensitive but have behaviour because early detection of consciousness is critical for accurate prognostication and treatment planning.
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1. Introduction

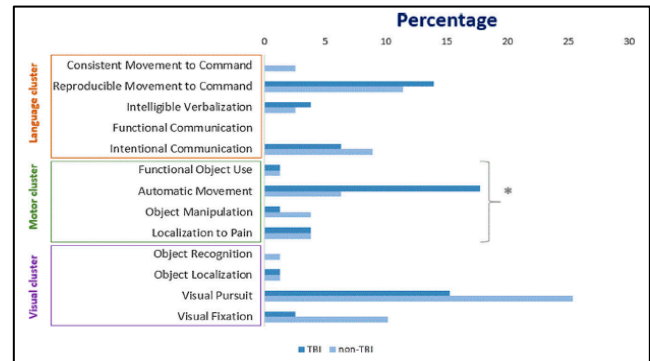
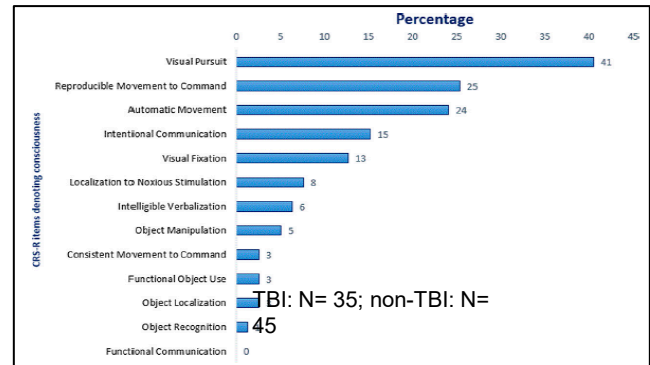
Severe brain injury frequently results in a period of altered consciousness characterized by impaired arousal and awareness [1,2]. Disorders of consciousness (DoC) include coma, a state of conscious eye closure and no behavioural signs of self or environmental awareness [3]; the vegetative state (VS), also referred to as unresponsive wakefulness syndrome (UWS) [4], in which there is eye-opening but still no behavioural signs of awareness [4]; and the minimally conscious state (MCS), a condition characterised by reproducible but fluctuating behaviour

signs of awareness. Emergence from MCS (eMCS) is marked by recovery of reliable communication and/or appropriate use of objects [5]. Detecting the transition from an unconscious to conscious state is critically important in clinical management, discharge disposition planning and family counselling. Unfortunately, diagnostic error remains high in this population, consistently reported to be around 40% [6–8].

The Consciousness Scale-Revised (CSR-R) [9], a standardized behavioural assessment scale consisting of 23 items hierarchically organized within 6 subclusters that assess auditory, visual, motor, verbal, communication and social functions, is recommended for clinical use in patients with DoC by the American Congress of Rehabilitation Medicine in view of its strong psychometric properties [10]. Diagnostic assessment with the CSR-R has been

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When does the ability to communicate reliably reemerge?

BRIEF REPORT

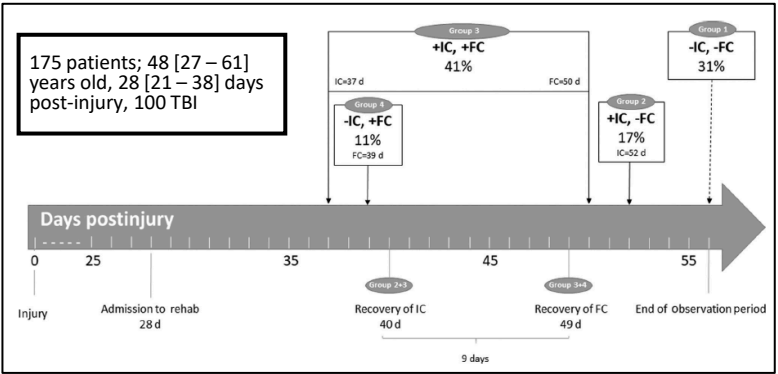
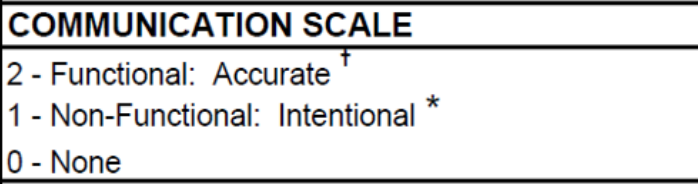
Temporal Profile of Recovery of Communication in Patients With Disorders of Consciousness After Severe Brain Injury

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Abstract
Objective: Characterize the temporal profile of recovery of communication after severe brain injury.
Design: Retrospective cohort study.
Setting: Inpatient rehabilitation hospital.
Participants: Patients with severe acquired brain injury and no evidence of communication on the Coma Recovery Scale-Revised (CRS-R) (N=175).
Main Outcome Measures: Time from injury to recovery of intentional communication (IC, inconsistent verbal responses) and functional communication (FC, consistent and accurate verbal responses) on the CRS-R Communication subscale.
Results: Patients (N=175) were included in the primary observation period of the first 8 weeks of inpatient rehabilitation (median [interquartile range, IQR] 46 [27-61] years old, 105 men, 28 [21-38] days postinjury, 100 mean age; etiology). Fifty-four patients (31%) did not recover IC or FC. Thirty patients (17%) recovered IC only (median [IQR] days from injury to IC=40 [24-54]), 12 patients (4%) recovered IC followed by FC (days from injury to FC=50 [42-61]), and 19 patients (11%) recovered FC without first recovering IC (41 [32-60]). The patients who recovered neither IC nor FC within 8 weeks of admission were admitted to rehabilitation later than those who recovered IC or FC (P<.05). Sixteen patients who did not recover communication within 8 weeks of admission to rehabilitation subsequently recovered IC prior to discharge.
Conclusions: In patients with severe brain injury receiving inpatient rehabilitation, discernible responses or emergent approximately 6 weeks postinjury and became reliable 1 week later. Approximately 1 in 3 patients did not demonstrate IC or FC within 8 weeks of admission to rehabilitation, although 33% of these individuals recovered communication prior to discharge. In total, 61% of patients recovered IC prior to discharge from rehabilitation.
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Patients who sustain severe brain injury may experience prolonged disturbance in consciousness during which they are unable to follow commands or communicate.¹ Recovery of reliable communication is a highly anticipated milestone for both families and clinicians in related domains such as locked-in syndrome and stroke.^{2,3} The ability to answer questions and express needs are prerequisites for autonomous decision making and meaningful social interaction. However, the temporal profile of recovery of communication in patients with disorders of consciousness (DOC) after severe brain injury is not known. Two early studies investigated communication in patients with prolonged DOC and showed that most patients eventually (ie, between



The Facts

- *Critical prognostic decisions are generally made within 72 hours of injury, prior to recovery of command-following, speech and other conscious behaviors.*
 - ➔ >80% of patients with disturbance in consciousness persisting across the ICU stay recover consciousness by rehab discharge.
 - ➔ ~20% of patients who remain in VS or MCS for 6 weeks recover complex behaviors (eg, consistent command-following, intelligible verbalization, reliable yes-no communication) that may not emerge for 10 or more weeks after injury.
 - ➔ ~50% of patients with DoC admitted to inpatient rehab recover functional communication within 12 weeks of injury
 - ➔ Patients with DoC tend to show *greater* absolute improvement during rehab than those w/o DoC.

***Recovery During the Post-Acute
Phase of Recovery
(Month 1-12)***

Background

- During the post-acute period, spontaneous recovery is mediated by a variety of different neurobiological mechanisms
 - Reversal of diaschisis
 - Restitution
 - Redundancy
 - Vicariation
- This variability contributes to the difficulty predicting the likelihood and time course of recovery at the single-case level.

Myth 3

Spontaneous recovery rapidly trails off after the first 3 months post-injury.

JAMA Neurology | Original Investigation

Functional Outcomes Over the First Year After Moderate to Severe Traumatic Brain Injury in the Prospective, Longitudinal TRACK-TBI Study

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Supplemental content

IMPORTANCE: Moderate to severe traumatic brain injury (msTBI) is a major cause of death and disability in the US and worldwide. Few studies have enabled prospective, longitudinal outcome data collection from the acute to chronic phases of recovery after msTBI.

OBJECTIVE: To prospectively assess outcomes in major areas of life function at 2 weeks and 3, 6, and 12 months after msTBI.

DESIGN, SETTING, AND PARTICIPANTS: This cohort study, as part of the Transforming Research and Clinical Knowledge in TBI (TRACK-TBI) study, was conducted at 18 level I trauma centers in the US from February 2014 to August 2018 and prospectively assessed longitudinal outcomes, with follow-up to 12 months postinjury. Participants were patients with msTBI (Glasgow Coma Scale scores 3-12) extracted from a larger group of patients with mild, moderate, or severe TBI who were enrolled in TRACK-TBI. Data analysis took place from October 2019 to April 2021.

EXPOSURES: Moderate or severe TBI.

MAIN RESULTS AND MEASURES: The Glasgow Outcome Scale-Extended (GOS-E) and Disability Rating Scale (DRS) were used to assess global functional status 2 weeks and 3, 6, and 12 months postinjury. Scores on the GOS-E were dichotomized to determine favorable (scores 4-8) or unfavorable (scores 1-3) outcomes. Neurocognitive testing and patient-reported outcomes at 12 months postinjury were analyzed.

RESULTS: A total of 484 eligible patients were included from the 2670 individuals in the TRACK-TBI study. Participants with severe TBI ($n = 362$; 283 men [78.2%]; median [interquartile range] age, 35.5 [25-53] years) and moderate TBI ($n = 122$; 98 men [80.3%]; median [interquartile range] age, 38 [25-53] years) were comparable on demographic and premorbid variables. At 2 weeks postinjury, 36 of 290 participants with severe TBI (12.4%) and 38 of 93 participants with moderate TBI (41%) had favorable outcomes (GOS-E scores 4-8). 301 of 322 in the severe TBI group (93.5%) and 81 of 103 in the moderate TBI group (78.6%) had moderate disability or worse on the DRS (total score ≥ 4). By 12 months postinjury, 142 of 271 with severe TBI (52.4%) and 54 of 72 with moderate TBI (75%) achieved favorable outcomes. Nearly 1 in 5 participants with severe TBI (52 of 270 [19.3%]) and 1 in 3 with moderate TBI (23 of 71 [32%]) reported no disability (GOS-E score 0) at 12 months. Among participants in a vegetative state at 2 weeks, 62 of 79 (78%) regained consciousness and 14 of 56 with available data (25%) regained orientation by 12 months.

CONCLUSIONS AND RELEVANCE: In this study, patients with msTBI frequently demonstrated major functional gains, including recovery of independence, between 2 weeks and 12 months postinjury. Severe impairment in the short term did not portend poor outcomes in a substantial minority of patients with msTBI. When discussing prognosis during the first 2 weeks after injury, clinicians should be particularly cautious about making early, definitive prognostic statements suggesting poor outcomes and withdrawal of life-sustaining treatment in patients with msTBI.

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Author Affiliations. Author affiliations are listed at the end of this article.

Group Information. The TRACK-TBI Investigators and authors appear at the end of the article.

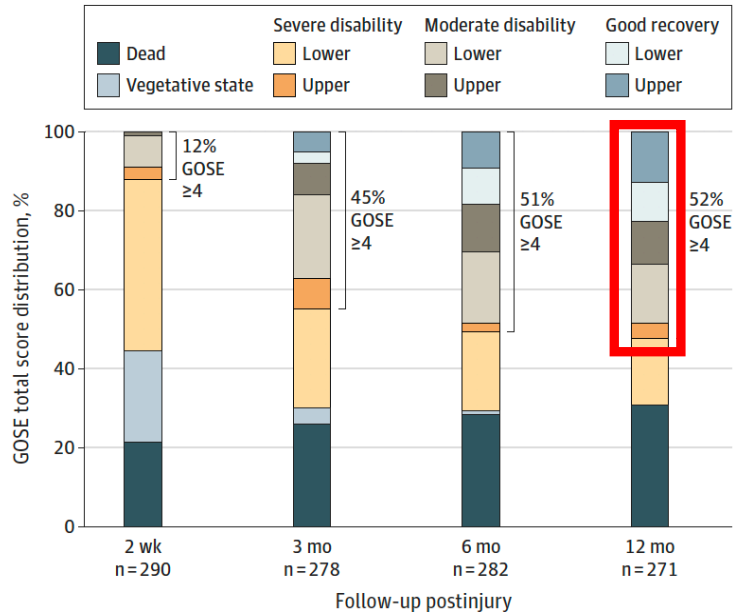
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- **Aim:** To prospectively assess outcomes in major areas of life function at 2 weeks and 3, 6, and 12 months after moderate to severe TBI (msTBI).
- **Sample:** 362 patients with severe TBI (GCS=3-8) enrolled in TRACK-TBI between February 2014 and August 2018.
- **Outcomes:**
 - Primary: Glasgow Outcome Scale- Extended (brain + peripheral injury scoring system)
 - Secondary:
 - Disability Rating Scale (DRS)
 - Rivermead Post-Concussion Scale, BSI-18, Satisfaction with Life, Rey Auditory Verbal Learning Test, Trail Making Test, WAIS Processing Speed Index

Key Findings

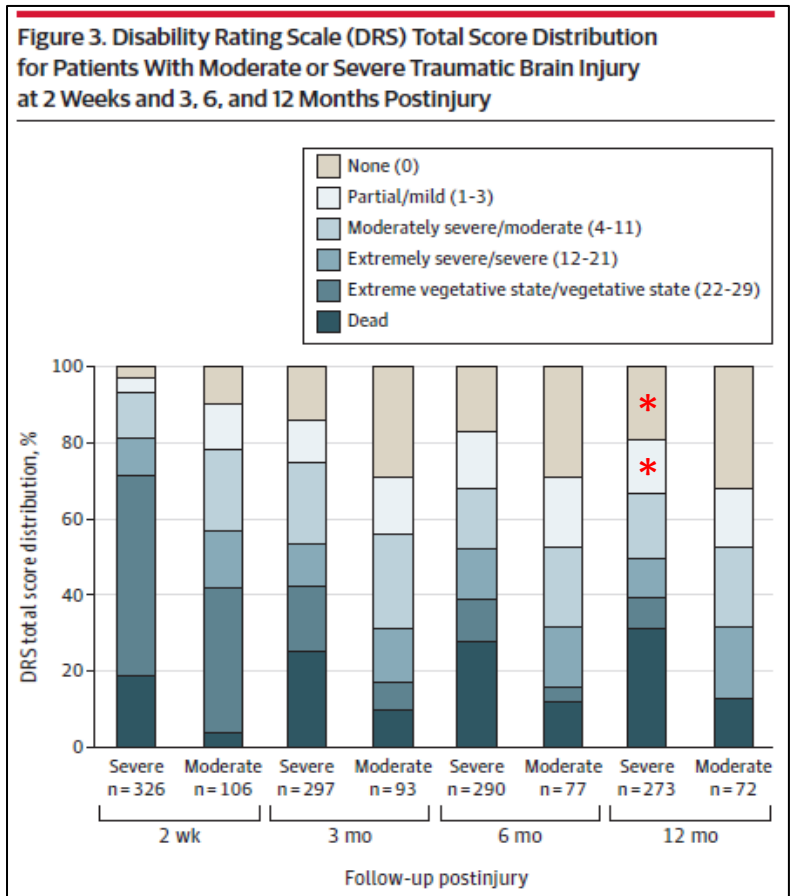
- Approximately 50% of those with severe TBI recovered the ability to function independently at home for at least 8 hours per day.

Figure 1. Glasgow Outcome Scale-Extended (GOSE) Total Score Distribution for Patients With Severe Traumatic Brain Injury at 2 Weeks and 3, 6, and 12 Months Postinjury



Key Findings

- Nearly 1 in 5 patients with severe TBI reported no disability (DRS score 0) at 12 months.



Key Findings

Table 2. Frequencies Within Each Glasgow Outcome Scale-Extended (GOSE) Domain for Severe and Moderate Traumatic Brain Injury (TBI) Groups at 2 Weeks and 3, 6, and 12 Months Postinjury

GOSE domain severity in unweighted analyses	No. (%) ^a		3 mo		6 mo		12 mo	
	2 wk Severe (n = 290)	Moderate (n = 93)	Severe (n = 278)	Moderate (n = 84)	Severe (n = 282)	Moderate (n = 75)	Severe (n = 271)	Moderate (n = 72)
Vegetative state and death								
Vegetative state	68 (23.4)	11 (12)	10 (3.6)	0	4 (1.4)	0	1 (0.4)	0
Died	60 (20.7)	4 (4)	73 (26.3)	9 (11)	78 (27.7)	9 (12)	83 (30.6)	9 (13)
Independence in the home								
No assistance	31 (10.7)	36 (39)	115 (41.4)	55 (65)	139 (49.3)	51 (68)	137 (50.6)	50 (69)
Infrequent assistance	5 (1.7)	2 (2)	9 (3.2)	3 (4)	6 (2.1)	2 (3)	5 (1.8)	4 (6)
Frequent assistance	126 (43.4)	40 (43)	71 (25.5)	17 (20)	55 (19.5)	13 (17)	45 (16.6)	9 (13)
Independence in shopping								
No assistance	33 (11.4)	36 (39)	115 (41.4)	54 (64)	140 (49.6)	48 (64)	135 (49.8)	47 (65)
Assistance	128 (44.3)	42 (45)	80 (28.8)	21 (25)	60 (21.3)	18 (24)	52 (19.2)	16 (22)
Independence in traveling								
No assistance	33 (11.4)	34 (37)	110 (39.6)	54 (64)	139 (49.3)	47 (63)	133 (49.1)	46 (64)
Assistance	128 (44.1)	44 (47)	85 (30.6)	21 (25)	61 (21.6)	19 (25)	54 (19.9)	17 (24)
Work ^b								
No deficit	2 (1.0)	8 (10)	25 (11.8)	21 (29)	57 (26.9)	23 (37)	70 (34.0)	30 (49)
Reduced capacity	3 (1.4)	4 (5)	25 (11.8)	12 (17)	26 (12.3)	12 (19)	20 (9.7)	7 (11)
Limited or unable to work	133 (63.3)	55 (70)	125 (59.2)	34 (47)	94 (44.3)	22 (35)	79 (38.3)	19 (31)

- All but 1 of the surviving patients who were in VS at 2 weeks recovered consciousness and 25% regained functional independence by 12 months

The Facts

- *Clinicians tend to overestimate the likelihood of poor outcome during the post-acute phase after severe TBI, negatively biasing decision-making about patient care.*
 - Great majority of those who survive vegetative state recover consciousness within 12 months.
 - Between 2 weeks and 12 months post-injury, the percentage of patients who achieve a favorable outcome quadruples.
 - 50-75% regain partial to full functional independence (GOSE ≥ 4).

***Recovery During the Chronic
Phase of Recovery
(Year 1-10)***

Background

- Few studies have followed patients with severe TBI beyond 12 months post-injury, limiting opportunity to investigate incidence of late recovery of key functional milestones.
- Studies that have followed patients longer than 12 months have not utilized tools that are sensitive to subtle but meaningful functional changes.

Myth 4

Spontaneous recovery plateaus after 1 year following TBI.

Recovery Between 1 and 10 Years Post-Injury

Background

- Few studies have followed patients with severe TBI beyond 12 months post-injury, limiting opportunity to investigate incidence of late recovery of key functional milestones.
- A few single-center studies have reported clinically meaningful recovery in a substantial minority of patients who remain in VS or MCS during the first year.

ACRM Archives of Physical Medicine and Rehabilitation
 Original Article

Functional Outcomes in Traumatic Disorders of Consciousness: 5-Year Outcomes From the National Institute on Disability and Rehabilitation Research Traumatic Brain Injury Model Systems

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Abstract
Objective: To characterize the 5-year outcomes of patients with traumatic brain injury (TBI) using following commands when admitted to acute inpatient rehabilitation.
Design: Secondary analysis of prospectively collected data from the National Institute on Disability and Rehabilitation Research-funded Traumatic Brain Injury Model Systems (TBIIMS).
Setting: Inpatient rehabilitation hospitals participating in the TBIIMS program.
Participants: Patients (N=108) with TBI met following commands at admission to acute inpatient rehabilitation were divided into 2 groups: recovery achieved commands before discharge (n=72); late recovery did not achieve commands before discharge (n=36).
Measures and Main Results: Not applicable.
Conclusions: Functional independence, cognition, and mobility improved significantly from discharge to 1 year post-injury. The proportion of independent patients increased significantly from discharge to 1 year and from 1 to 5 years.
Keywords: Traumatic brain injury (TBI). In addition, many utilized based.

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 DOI: 10.1089/neu.2018.0564

Disorders of Consciousness due to Traumatic Brain Injury: Functional Status Ten Years Post-Injury

Flora M. Hammond,^a Joseph T. Giacino,^b Risa Nakase-Richardson,^c Mark Sherris,^d Rose D. Zafonte,^e John Whyte,^f David B. Aronigen,^g and Xinyu Tang^h

Abstract
 Few studies have assessed the long-term functional outcomes of patients with a disorder of consciousness due to traumatic brain injury (TBI). This study examined functional status during the first 10 years after TBI among a cohort with disorders of consciousness (i.e., coma, vegetative state, minimally conscious state). The study sample included 110 individuals with TBI who were unable to follow commands prior to inpatient rehabilitation and for whom follow-up data were available at 1, 2, 5, and 10 years post-injury. The sample was subdivided into those who demonstrated command-following early (before 28 days post-injury) versus late (>28 days post-injury) or never. Functional Independence Measure (FIM) at 1, 2, 5, and 10 years following TBI was used to measure functional outcomes. Measurable functional recovery occurred throughout the 10-year period, with more than two thirds of the sample achieving independence in mobility and self-care, and about one quarter achieving independent cognitive function by 10 years. Following commands prior to 28 days was associated with greater functional independence at all outcome time-points. Multi-regression modeling of recovery of three FIM subscales (self-care, mobility, cognition) revealed four distinct prognostic groups with different temporal patterns of change on these subscales. More than half the sample achieved near-optimal recovery by 1 year post-injury, while the later command-following subgroup recovered over longer periods of time. Significant late functional decline was not observed in this cohort. Among a cohort of patients unable to follow commands at the time of inpatient rehabilitation, a substantial proportion achieved functional independence in self-care, mobility, and cognition. The proportion of participants achieving functional independence increased between 5 and 10 years post-injury. These findings suggest that individuals with disorders of consciousness may benefit from ongoing functional monitoring and updated care plans at least for the first decade after TBI.

Keywords: brain injury; cognition; consciousness disorders; minimally conscious state; prognosis; rehabilitation outcome; vegetative state

Introduction
 FEW STUDIES HAVE ASSESSED the long-term functional outcomes of patients with disorders of consciousness (DOC) due to traumatic brain injury (TBI). In addition, many utilized based, non-specific outcome measures with variable scales at follow-up intervals. There is consequently a lack of data on functional outcomes, and paucity in trying to plan for future needs, compare outcomes, and assess quality of interventions. Given the lack of knowledge regarding meaningful long-term outcomes, it is not

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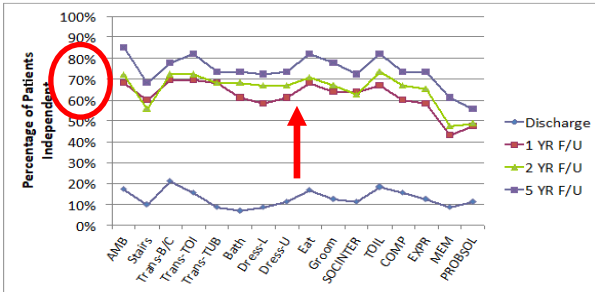
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Recovery Between 1 and 10 Years Post-Injury

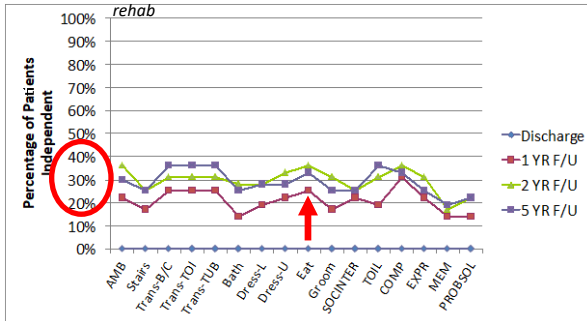
- **Aim:** To monitor long-term outcomes in patients with severe TBI not following commands when admitted to acute inpatient rehabilitation.
- **Sample:** 110 rehabilitation inpatients with moderate to severe TBI and no evidence of command-following on rehabilitation admission.
- **Outcomes:**
 - Functional Independence Measure
 - Self-care domain score
 - Mobility domain score
 - Cognition domain score
 - Followed at 1, 2, 5 *and* 10 years post-injury

Key Findings

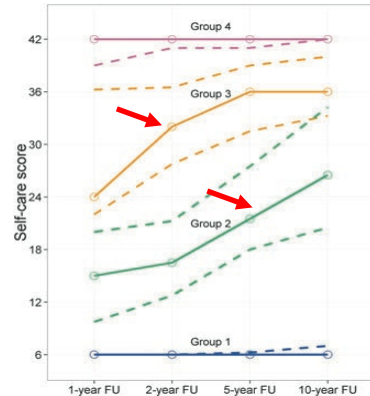
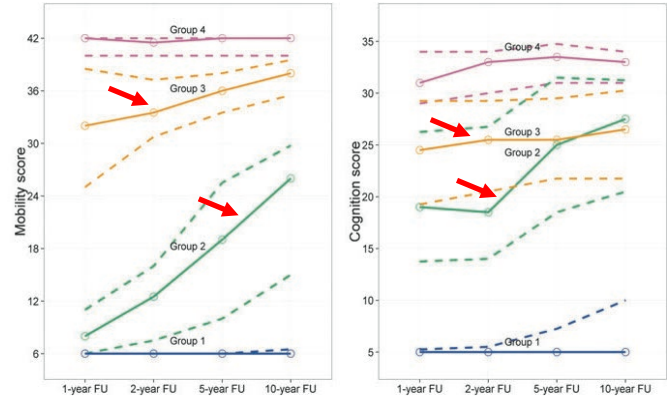
Recovered command-following during inpatient rehab



Did not recover command-following during inpatient rehab



All patients during inpatient rehab



The Facts

- *Prognostic and therapeutic nihilism remain prevalent attitudes during the chronic phase of recovery*
 - The majority of patients who survive acute hospitalization, but remain unable to follow commands, achieve independence in self-care, mobility and cognitive functions.
 - Recovery of functional independence continues between 5 and 10 years post-injury in a substantial proportion of patients.
 - No discernible pattern of deterioration exists in any functional domain among patients with DoC followed up to 10 years.

Recommendations for Clinical Practice

- Use standardized neurobehavioral assessment measures that have been shown to be valid and reliable to improve diagnostic and prognostic accuracy.
- Perform serial (v. one-off) assessments to account for fluctuations in behavioral responsiveness and establish rate of recovery.
- When discussing prognosis with caregivers of patients with a DoC during the first 28 days post injury, avoid statements that suggest a *universally* poor prognosis
 - 1/5 will recover ability to follow commands consistently, verbalize intelligibly, communicate reliably and use objects functionally).
- When discussing prognosis, in general, tie outcome prediction to specific indicators and disclose the level of uncertainty associated with the prognosis.
- Defer the “rush to judgement” (re WLST)
 - Among those do not survive the injury, death typically occurs during the acute hospitalization, reducing the need to rush to judgement about WLST within 72 hours.
 - Behavioral signs of consciousness frequently do not emerge until >14 days post-injury

2011 Atlantic Hurricane season



(JJ Fins: Disorders of Consciousness and Disordered Care. Families, Caregivers, and Narratives of Necessity. Archives PMR 2013:94:1934-9)

Data Visualization for Patients with Disorders of Consciousness



Alison M. Cogan, PhD, OTR/L
LeaRRn Scholar

User Group Needs

Clinicians

- Prognostication
- Treatment planning

Family Members

- Family conferences
- Personal medical records

Payors

- Rate, direction and degree of change

DoC eProfile - Coma Recovery Scale

[Return to Main Dashboard](#)

Disorders of Consciousness Program

Menu | Data through: 7/17/2024

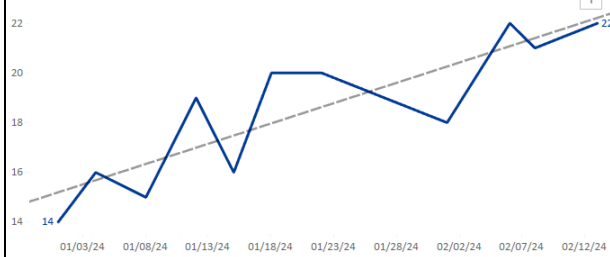
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Download Dashboard As: PDF PPT IMG

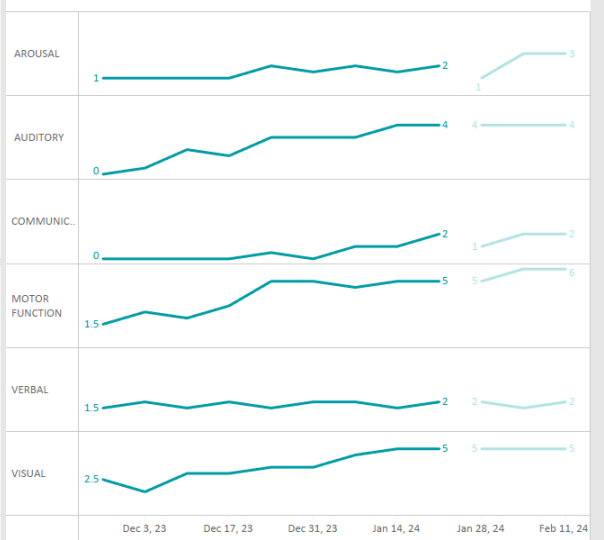
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Coma Recovery Scale

Coma Recovery Scale Total Recorded Date



Coma Scale Detail



Coma Recovery Scale Total Week in the Program



DoC eProfile

Disorders of Consciousness Program

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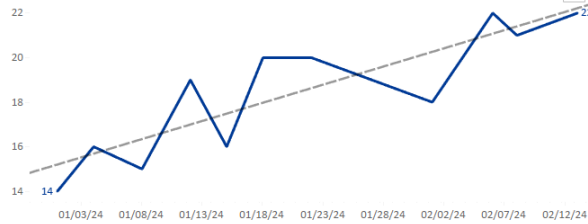
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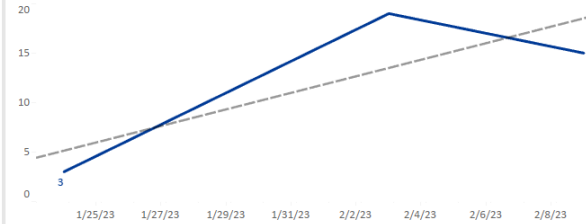
Coma Recovery Scale

Coma Recovery Scale Total Recorded Date

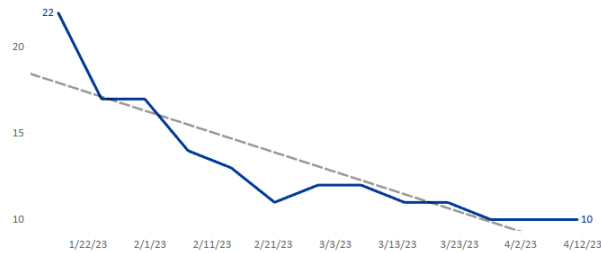


Limb Movement

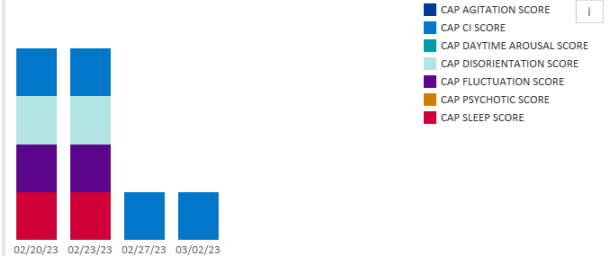
Limb Movement Total



Disability Index



Confusion Assessment Protocol



Thank You!