Transforming Pediatric Care: The Neuropsychologist's Role in Managing Disorders of Consciousness in Children

Kristen Hoskinson, PhD
Christine Koterba, PhD, ABPP
Megan Kramer, PhD, ABPP
Sarah Lahey, PhD, ABPP

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Learning Objectives

1. Identify key differentiating characteristics of disorders of consciousness (DoC)
2. Explain at least three roles that the pediatric neuropsychologist can serve in the diagnosis and care of children with DoC
3. Demonstrate an understanding of at least three factors relevant to the outcome, including social and demographic influences

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Outline

1. Introduction to Disorders of Consciousness (DoC) – Christine Koterba
2. Neuroanatomy of DoC – Kristen Hoskinson
3. Levels of DoC and Similar Conditions – Sarah Lahey
4. DoC Guidelines – Christine Koterba
5. Roles of Pediatric Neuropsychologist in DoC – Megan Kramer
6. Unique Considerations for Discharge and Beyond – Sarah Lahey

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Introduction to Disorders of Consciousness

Christine Koterba, PhD, ABPP

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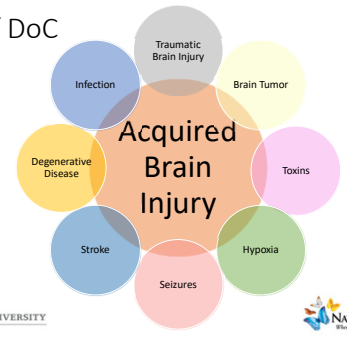
Causes of DoC



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Disorders of Consciousness

A state when consciousness has been affected after severe damage to the brain

Consciousness = both wakefulness AND awareness

Wakefulness: the ability to open eyes, have basic reflexes; easy to assess

Awareness: more complicated and complex thought processes; harder to assess

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What does it mean to be awake and aware?

- ***Awake*** – eyes open (can also be assessed with brainstem response)
- ***Aware*** – able to respond to internal and external stimuli in an integrated way

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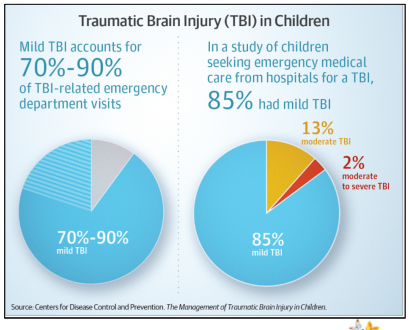

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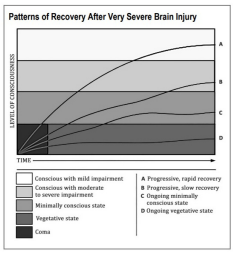
MSKTC
SCI · TBI · BURN

Facts About the Vegetative and Minimally Conscious States After Severe Brain Injury was developed by Sherer M, Vaccaro M, Whyte J, Giacino JT, Childs N, Eifert B, Katz, DI, Long DF, Novak P, Cho S, & Yablon SA and the Consciousness Consortium in 2007.



This image shows patterns of recovery that may follow coma. Some people wake up quickly from coma; they may briefly stay in the MCS before further recovery. They may also have mild impairments. Others may be in the MCS for a long time after emerging from the VS. They usually have more long-term impairment. Slow recovery may continue for several years, especially for those with traumatic injuries. Sometimes, people stay in the VS or MCS for a long time. In some cases, these conditions may be permanent.

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DoC in Children

The majority of research in DoC has been done in adults – but DoC also happens in children

"Due to the complex pathophysiological response to acute injury in the developing brain, it is likely that both prognosis and therapies for children with DoC will differ from adults" (Kirschen & King, 2023)

Causes may also differ with higher rates of non-accidental trauma and drowning in children

Many unique challenges (limited long-term care, assessment can be harder, prognosis may differ, etc.)

Children interact in home and school environments – both must be modified following severe brain injury

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Neuroanatomy of DoC

Kristen Hoskinson, PhD

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Neuroanatomy of DoC

What impacts wakefulness and/or awareness?

- Normal level of consciousness depends on integration of cerebral hemispheres and the ascending reticular activating system – it is NOT pathognomonic
- Location on the continuum of wakefulness and awareness is related to the site of injury
  - Disruption of neurotransmitters is also an important factor

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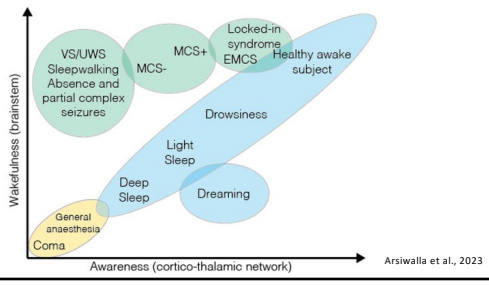
Neuroanatomy of DoC



Arsiwalla et al., 2023

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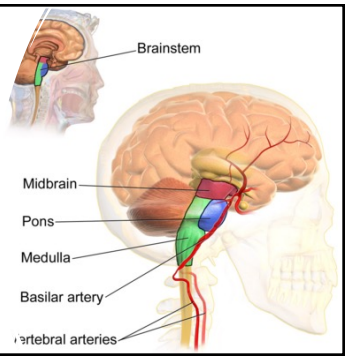
Neuroanatomy of DoC

- Four main mechanisms that can result in DoC
  - Brainstem injury
  - Thalamic injury
  - Bilateral cortical injury
  - Neurotransmitter disruption



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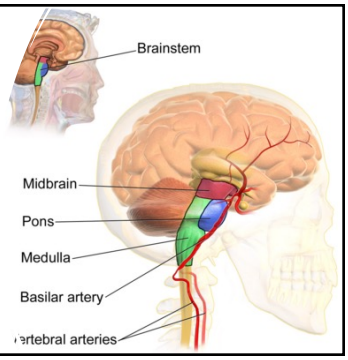

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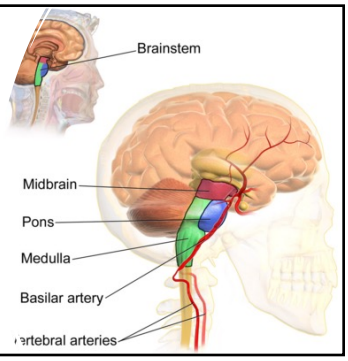
Brainstem Injury

- Brainstem plays a crucial role in regulating arousal and consciousness, including through:
  - Maintaining wakefulness
  - Supporting vital functions
  - Relaying sensory and motor information between brain and spinal cord
  - Housing ascending reticular activating system



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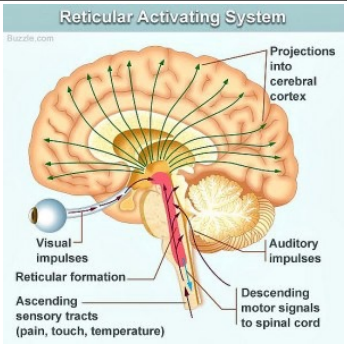

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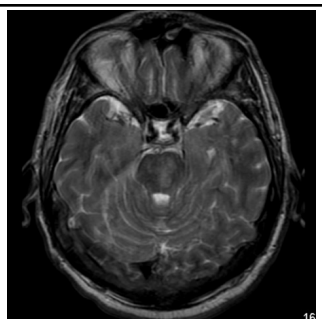
Brainstem Injury

Injury caused by (e.g.,) bilateral pontine stroke or hemorrhage could affect:

- Breathing, swallowing, and speaking
- Vision, balance, dizziness
- Emotional processing and responses

Severe damage can lead to:

- Altered consciousness, hypersomnolence, and coma
- When corticospinal, corticobulbar, and corticopontine tracts are all involved, this leads to Locked In Syndrome



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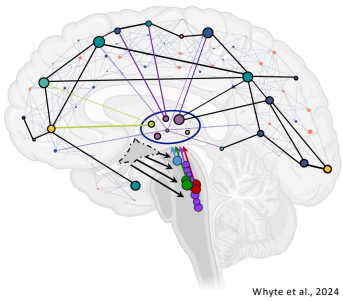

Whyte et al., 2024

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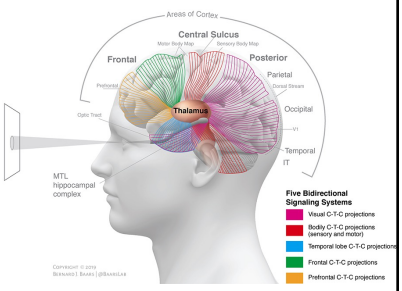
Thalamic Injury

- Thalamus is the "great relay station" of the brain:
  - Receives and processes most sensory information and relays information to the cortex
  - Involved in complex cognitive control
  - Reciprocal Thalamo-Cortico-Thalamic circuits are crucial for various cognitive and sensory functions



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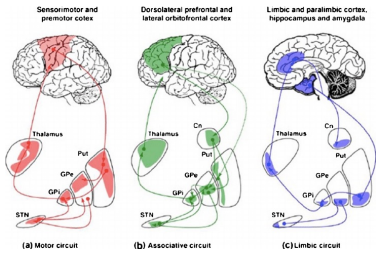
Thalamo-Cortico-Thalamic Circuits



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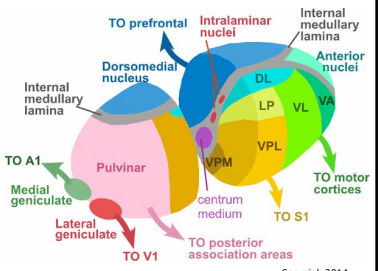
Thalamic Injury

- What happens when the thalamus is injured?
  - Can be damaged by restricted blood flow, DAI, and/or neuroinflammation
  - Lateral injury directly impacts corticothalamic connectivity

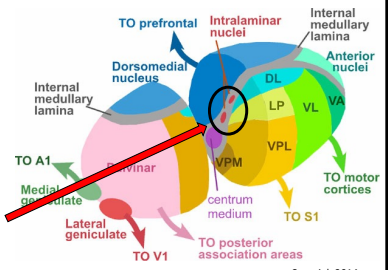


Carvajal, 2014

26

Thalamic Injury

- What happens when the thalamus is injured?
  - Can be damaged by restricted blood flow, DAI, and/or neuroinflammation
  - Lateral injury directly impacts corticothalamic connectivity
  - Medial injury can directly impact consciousness – deep layer neurons provide feedback to superficial layer neurons



Carvajal, 2014

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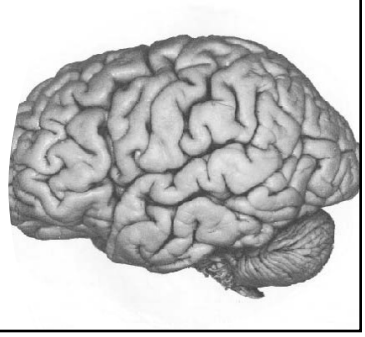

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Bilateral Cortical Injury

- "…the cerebral cortex is the "seat of consciousness," while the ascending reticular activating system and certain thalamic nuclei may provide gating and other necessary functions of the cortex."

Walling, 2000

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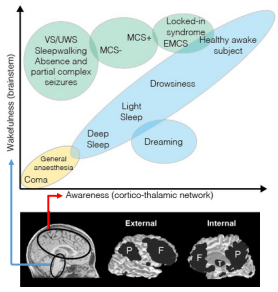
Neuroanatomy of DoC



Arsiwalla et al., 2023

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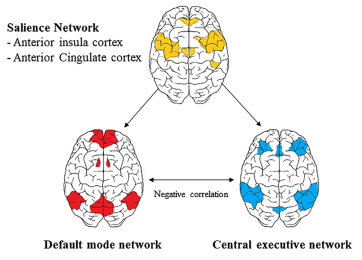
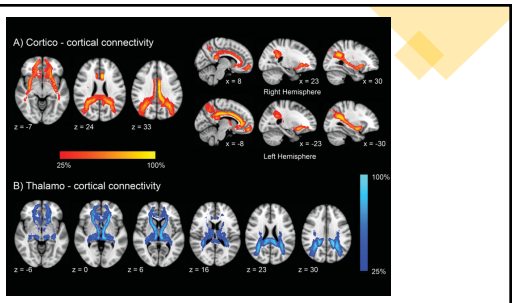
Cortical Injury in DoC

- Awareness of *internal* stimuli → subserved by the default mode network
- Awareness of *external* stimuli → subserved by the central executive network



van der Linden et al., 2020

31



Group probability maps in healthy participants

Fernandez-Espejo et al., 2012

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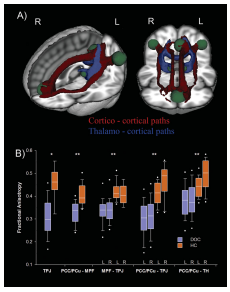

Fernandez-Espejo et al., 2012

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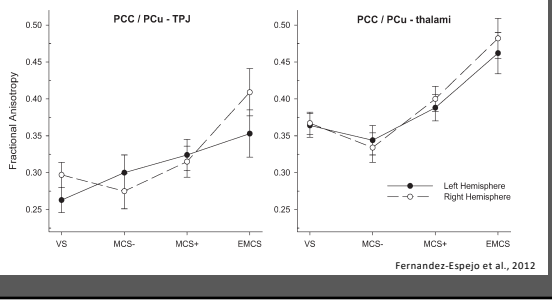

Fernandez-Espejo et al., 2012

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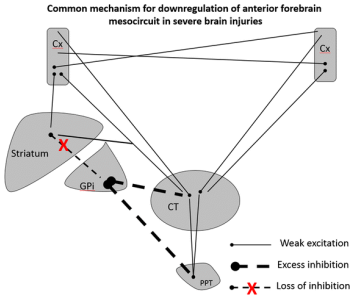
Linking DMN and CEN in DoC

Anterior Forebrain Mesocircuit

- What is it?
  - Involves the striatum, globus pallidus, thalamus, and their cortical projections
- What's the theory?
  - Striatum fails to inhibit the globus pallidus
  - Globus pallidus becomes overactive and excessively inhibits thalamus
  - Leads to broad downregulation of cortical projections, dampening down activity of the DMN and CEN
- Why?
  - Caused by diffuse axonal injury, hypoxia, and/or ischemia
  - Results in neuronal disconnection and cell death



Schiff, 2016

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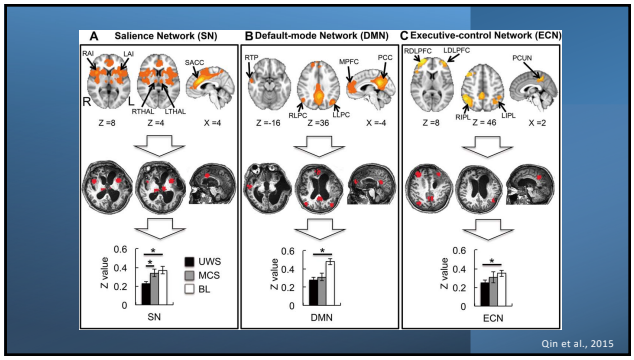

Qin et al., 2015

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Neuroanatomy of DoC

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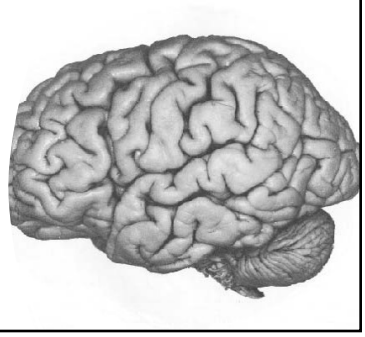

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Neurotransmitters in DoC

- Oxygen-reliant neurotransmitters
- Amino acid axis (glutamate/GABA)
- Monoamine axis (dopamine, norepinephrine, serotonin)
- Cholinergic system
- Others?

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Neurotransmitters in DoC – Why?

- Broad withdrawal of excitatory neurotransmitters → dysregulation of arousal
- Imbalances of monoamine neurotransmitters → affected arousal and attention
- Surge of inhibitory amino acids + depletion of excitatory neurotransmitters → diminished consciousness
- Alteration of cholinergic neurotransmitters found in consciousness-related disorders

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Levels of DoC and Similar Conditions

Sarah Lahey, PhD, ABPP

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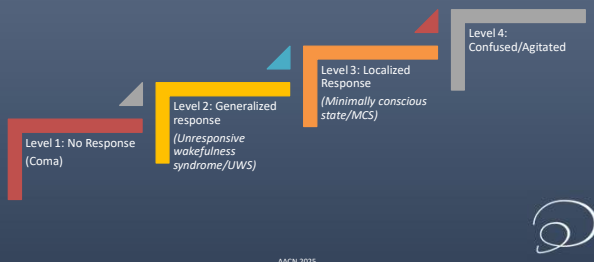
Rancho Los Amigos Scale (RLAS, Levels 1-4)



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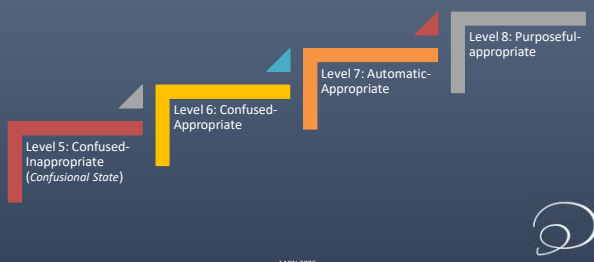
RLAS, cont. (Levels 5-8)



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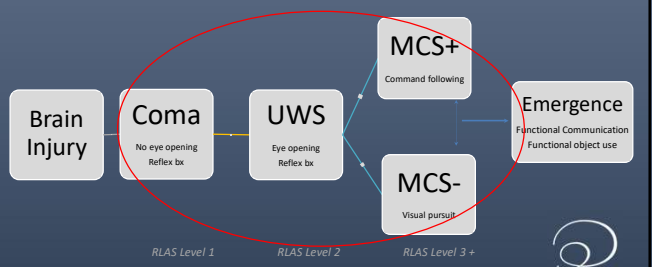
Disorders of Consciousness



USW = Unresponsive wakefulness syndrome; MCS = Minimally conscious state

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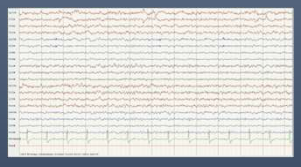
Coma

- Complete loss of arousal
  - No sleep/wake cycle on EEG
  - No eye opening
  - No purposeful motor activity



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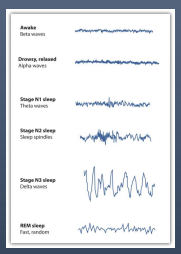
Unresponsive Wakefulness Syndrome (UWS)



- **Return of sleep/wake cycle**
  - Periodic eye opening
  - Sleep disturbance and fluctuating arousal
- **Absence of awareness of self/environment**
  - No purposeful motor activity
- **Reflexive responses**
  - Abnormal motor posturing
  - Startle response

Consensus definitions from Aspen Neurobehavioral Workgroup (Giacino et al. 2002); Bruno et al., 2011

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Minimally Conscious State

Move your arm.

MCS-
- Presence of (one):
  - Visual fixation
  - Visual pursuit
  - Object localization
  - Object manipulation
  - Automatic motor movement

MCS +
- Presence of (one):
  - Command following
  - Intelligible verbalization
  - Gestural or verbal yes/no response, regardless of accuracy

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MCS Subtypes

Akinetic Mutism
- Visual pursuit with minimal to no behavioral evidence of goal-directed behavior
- Telephone effect
- Bilateral or orbito-basal cortex

Hyperkinetic Mutism
- Heightened vigilance and non-goal-directed motor activity
- Continuous and unrestrained movement
- Bilateral temporal, parietal, and occipital junction lesions

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Emergence from DoC

- Functional object use
  - Two objects used correctly twice

- Functional communication
  - 6/6 situational questions

Visual	Auditory
Am I touching my ear? (+/-) (do not touch)	Am I clapping my hands right now? (+/-) (do not clap)
Am I touching my nose? (+/-) (touch nose)	Am I clapping my hands right now? (+/-) (clap)
Am I touching my nose? (+/-) (do not touch)	Am I clapping my hands right now? (+/-) (do not clap)
Am I touching my ear? (+/-) (touch ear)	Am I clapping my hands right now? (+/-) (clap)
Total ___/6	Total ___/6

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Posttraumatic Confusional State (PTCS)/emergence from MCS (eMCS)

- Core features
  - Disturbance of attention
  - Disorientation
  - Disturbance of memory
  - Fluctuation in symptoms
- disturbancesAdditional features: emotional/behavioral disturbance, confabulations, delusions, perceptual

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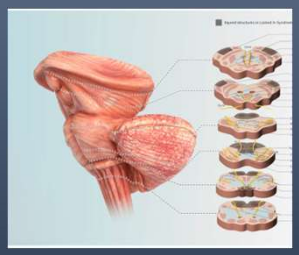
Locked-in-Syndrome (LiS)



- NOT DoC, but may be misdiagnosed as one.
- Vertical eye movements
- Voluntary blinking
- Mass lesions, infection, trauma, or demyelinating disorders that affect the ventral pons or caudal ventral midbrain

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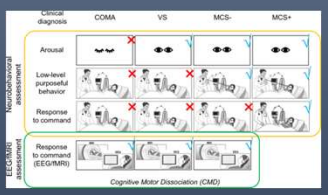
Cognitive Motor Dissociation (CMD)



- Hidden/covert consciousness
- May represent 15-20% of acute DoC

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DoC Differential Diagnostic Criteria

Dimension		Behavior	Coma	VS/UWS	MCS-	MCS+	PTCS
Awareness	Cognition	Reduced ability to focus or sustain attention					a
		Disorientation to place, time & situation					
		Impaired encoding & recall of new information					
		Symptom fluctuation over course of the day					
		Reliable yes-no responses or functional object use					
	+ Language	Consistent command-following				b	
		Reproducible command-following					
		Intelligible speech					
		Object recognition					
	- Language	Discernible but unreliable yes-no responses			b		
		Automatic motor behavior					
		Object manipulation &/or localization					
		Visual pursuit &/or fixation					
		Localization to pain					
Arousal		Eyes open spontaneously or to stimulation					
		Continuous eye closure					

Golden, Bodien, and Giacino, 2024

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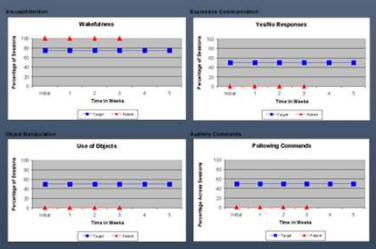
Unresponsive Wakefulness Syndrome



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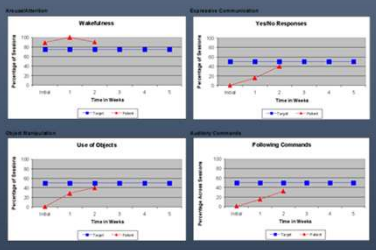
Minimally Conscious State



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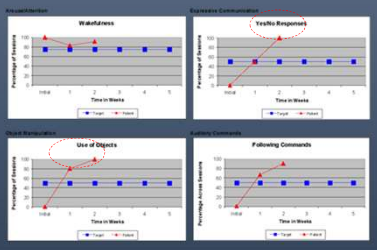
Emergence from DoC



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DoC Guidelines

Christine Koterba, PhD, ABPP

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2018 Practice Guidelines

Archives of Physical Medicine and Rehabilitation 2018;99:1699-709

ACRM ENDORSED PRACTICE GUIDELINE

Practice Guideline Update Recommendations Summary: Disorders of Consciousness

Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology; the American Congress of Rehabilitation Medicine; and the National Institute on Disability, Independent Living, and Rehabilitation Research

Joseph T. Giacino, PhD,[a,b] Douglas I. Katz, MD,[c,d] Nicholas D. Schiff, MD,[e] John Whyte, MD, PhD,[f] Eric J. Ashman, MD,[g] Stephen Ashwal, MD,[h] Richard Barbano, MD, PhD,[i] Flora M. Hammond, MD,[j] Steven Laureys, MD, PhD,[k] Geoffrey S.F. Ling, MD,[l,m] Risa Nakase-Richardson, PhD,[n] Ronald T. Seel, PhD,[o,p] Stuart Yablon, MD,[q,r] Thomas S.D. Getchius,[s] Gary S. Gronseth, MD,[t] Melissa J. Armstrong, MD, MSc[u]

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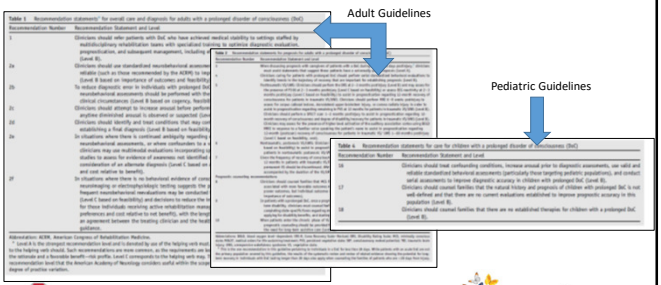
2

2018 Practice Guidelines



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1. Refer patients to multidisciplinary rehab team	A team with expertise in assessment, diagnosis, and treatment
	Specialized settings managed by clinicians who are knowledgeable about DoC and how to best address the unique needs
	Multidisciplinary teams include neurologists, psychologists, neuropsychologists, physical medicine physicians, physical therapists, occupational therapists, speech pathologists, nurses, nutritionists, internists, and social workers

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2. Use standardized neurobehavioral assessments that are valid and reliable to improve diagnostic accuracy	Serial assessment
	Increase arousal
	Treat confounding conditions
	When there is ambiguity, use multimodal assessment tools
	When there is no behavioral sign of consciousness but there are signs on functional neuroimaging, continue assessing

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3. Clinicians MUST AVOID statements that suggest a universally poor prognosis DURING THE FIRST 28 DAYS POSTINJURY	Hospital mortality is around 30% with 70% of deaths due to withdrawal of life support
	Withdrawal of life support was more closely related to facility than to patient characteristics
	Patients with DoC > 1 month may still show functional recovery after 1 year
4. Clinicians should do serial standardized behavioral evaluations to identify trends in the trajectory of recovery that are important for establishing prognosis	Fluctuations are common especially early on
	Patients with UWS may emerge to MCS over time
	Serial assessments can aid in prognosis

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5. Posttraumatic VS/UWS Prognostication	Patients with indicators of recovery (disability rating scale score >26, detectable P300 at 2-3 months post-injury, reactive EEG at 2-3 months, higher-level activation of auditory association cortex using fMRI in response to familiar voice) → increased chance of recovery at 12 months
	MRI at 6-8 weeks showing corpus callosal lesions, dorsolateral upper brainstem injury, or corona radiata injury are possibly associated with poorer outcome at 12 months
6. Nontraumatic, postanoxic VS/UWS Prognostication	CRS-R scores >6 1+ months and somatosensory evoked potentials from bilateral median nerve stimulation suggest increased likelihood of recovery of responsiveness by 24 months

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7. Use of the term permanent VS should be discontinued (this implies irreversibility; use *chronic* VS/UWS with the duration of the VS/UWS)	Although the majority of patients who remain in UWS across the first 3 (nontraumatic) and 12 (traumatic) months post-injury, a substantial minority will recover consciousness beyond this time frame
	Most will be left with severe disability but functional outcome ratings show that some regain the ability to communicate, perform self-care, and interact
	Prognostic counseling should emphasize the need for long-term care given that most with late recovery of consciousness will remain fully or partially dependent

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8. Counseling families	MCS within 5 months is better than those diagnosed with UWS
	Outcomes following traumatic injury are better than nontraumatic
	Individual outcomes vary – 20% of people with DoC at 1 month postinjury may still attain recovery 1 year postinjury
9. Counseling families with prolonged DoC	Once a prognosis has been made that severe long-term disability is likely, clinicians MUST counsel families members to get help in making care goals and completing process for medical decision making, disability benefits, estate/caregiver/long-term care

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10. Prognostic counseling in the chronic phase of DoC	Emphasize likelihood of permanent severe disability and the need for long-term assistive care
	VS/UWS 3 months after non-TBI
	VS/UWS 12 months after TBI
11. Clinicians MUST identify patient/family preferences	Assess early and throughout care
	Family wishes guide decision making for patients in prolonged DoC
	Values are variable and may change

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12. Attend to medical complications that commonly occur	Complication rates are high and negatively affect morbidity and mortality
	Early identification and treatment can help optimize long term outcomes
	Most common: agitation, aggression, hypertonia, sleep problems, UTI
	Most severe: hydrocephalus, pneumonia, paroxysmal sympathetic hyperactivity (all can disrupt rehab)
13. Assess pain	Clinicians should assess individuals with DoC for pain/suffering
	Treat when there is reasonable cause to suspect pain regardless of level of DoC
	Counsel families that it's hard to determine the degree of pain

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14. Use of amantadine to hasten recovery and reduce disability	Traumatic VS/UWS or MCS between 4-16 weeks postinjury should get amantadine 100-200 mg twice per day
	Faster recovery reduces the burden of disability, lessens health care costs, and minimizes psychosocial stressors in families and patients

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15. Counsel families about the limitations in existing evidence and potential risk/benefit of alternative tx	Nonvalidated treatments (hyperbaric oxygen, nutraceuticals, stem cell therapies, primrose oil) do not have enough evidence to support or refute their use.
	Provide evidence based information about projected benefits and risks and level of uncertainty – remember – caregivers are often distressed, desperate, and vulnerable
	Counsel families that in many cases, it is impossible to determine whether improvements early in recovery were caused by a specific intervention OR spontaneous recovery

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Pediatric	16. Treat confounding conditions, increase arousal before assessment, use valid and reliable standardized behavioral assessments (especially pediatric specific measures) and conduct serial assessments to improve diagnostic accuracy
	17. Counsel families that the natural history and prognosis of children with prolonged DoC is not well-defined and there are no current evaluations established to improve prognostic accuracy in this population
	18. Counsel families that there are no established therapies for children with a prolonged DoC

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Role of the Pediatric Neuropsychologist in DoC

Megan Kramer, Ph.D., ABPP

AACN 2025

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Role of pediatric neuropsychologist

- Unique role in neurorehabilitation
- Develop, implement and monitor environmental modifications, behavior management strategies, and pharmacological interventions
- Tailor interventions to a child's age, developmental level, preexisting functioning, the nature of brain injury, and the specific pattern of neurobehavioral impairments
- Provide compassionate, accurate, and effective caregiver psychoeducation

Watson et al., 2022

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Role with DoC

Lahey et al., 2017

Shared/overlapping competencies among disciplines

3

Practice Settings

- Intensive care unit
- Inpatient or day rehabilitation program
- Outpatient or multidisciplinary clinic setting

4

Role with DoC during rehabilitation

Assessment	• Serial neurobehavioral assessment focused on responsivity and arousal/wakefulness
Monitoring and data synthesis	• Integration of sleep/wake and neurobehavioral data
Direct intervention	• Environmental management; stimulation schedule; light exposure; activity/rest schedule
Co-treat and modeling strategies	• Collaboration, consultation, and observation; assessment and observation of patient in variety of settings, times, positions
Family education and support	• Prognosis; balancing stimulation; types of responses

Watson et al., 2022

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Behavioral Assessment: Limitations

- Cannot directly measure consciousness, so we observe behavior
- Obvious limitations to valid and reliable assessment
  - Examiner, patient, and environmental factors
- Accurate diagnosis is important
- Misdiagnosis rates up to 40%

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Behavioral Assessment: Considerations

- Adequate stimulation should be administered to ensure maximal arousal level
- Factors adversely affecting arousal (e.g., sedating meds, seizures) should be addressed if possible
- Consider confounding factors (e.g., sensory, motor, communication)
- A variety of different behavioral responses should be investigated using a broad range of eliciting stimuli
- Serial reassessment incorporating systematic observation and reliable measurement strategies should be used to confirm the validity of the initial assessment
- Observations of family members, caregivers, and professional staff participating in daily care should be considered in designing assessment procedures

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Neurobehavioral Pre-Assessment Checklist

Keech et al., 2025

- Developed by panel of experts
- Goal to optimize the patient and environment in preparation for neurobehavioral assessment
- Can be used before any assessment

Neurobehavioral Pre-Assessment Checklist

Name	
Preferred name/Nickname	
Date of Birth	
Hand Dominance	
Native Language	
Cultural/Religious considerations	

Medical Condition and Assistive Devices	Yes	No	Comments/Concerns
Hearing Devices	☐	☐	
Glasses	☐	☐	
Orally Intubated	☐	☐	
Tracheostomy	☐	☐	
If tracheostomy, use of speaking valve	☐	☐	
Supplemental Oxygen	☐	☐	
Ventilatory support	☐	☐	
Metabolic disorders	☐	☐	
Please list any relevant premorbid medical history			

8

Please take the following conditions into consideration that may influence the neurobehavioral assessment results.

Motor	Cognitive	Sensorial	Neurological/ Neurosurgical	Behaviour
• Spinal cord injury • Neuropathy/myopathy • Tremor/Myoclonus • Spasticity/retractions • Fractures • Others:	• Aphasia • Apraxia • Agnosia • Others:	• Blindness • Deafness • Others:	• Uncontrolled seizures • Active hydrocephalus • Craniectomy • Ptosis* • Others: *If suspected ptosis, consider manual eye opening	• Agitation/aggressivity • Paroxysmal sympathetic hyperactivity • Suspected pain or discomfort • Others:

Patient Testing Position
(Reposition as needed to maintain optimal positioning, avoid discomfort, and avoid fatigue)

- ☐ Supine
- ☐ Supine with head of bed elevated (please specify degree of incline___)
- ☐ Sitting in wheelchair
- ☐ Sitting on the mat
- ☐ Supported standing
- ☐ Other:_____

Keech et al., 2025

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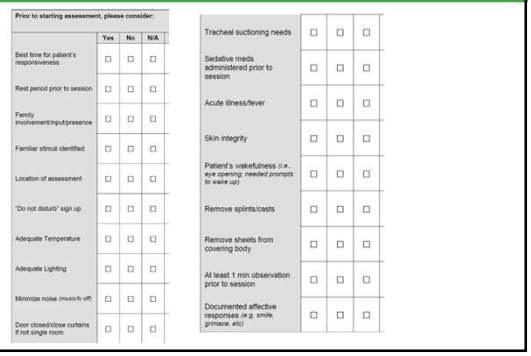

Prior to starting assessment, please consider:

	Yes	No	N/A
Best time for patient's responsiveness	☐	☐	☐
Rest period prior to session	☐	☐	☐
Family involvement/input/presence	☐	☐	☐
Familiar stimuli identified	☐	☐	☐
Location of assessment	☐	☐	☐
'Do not disturb' sign up	☐	☐	☐
Adequate Temperature	☐	☐	☐
Adequate Lighting	☐	☐	☐
Minimize noise *(music/tv off)*	☐	☐	☐
Door closed/close curtains if not single room	☐	☐	☐

Tracheal suctioning needs	☐	☐	☐
Sedative meds administered prior to session	☐	☐	☐
Acute illness/fever	☐	☐	☐
Skin integrity	☐	☐	☐
Patient's wakefulness *(i.e., eye opening; needed prompts to wake up)*	☐	☐	☐
Remove splints/casts	☐	☐	☐
Remove sheets from covering body	☐	☐	☐
At least 1 min observation prior to session	☐	☐	☐
Documented affective responses *(e.g. smile, grimace, etc)*	☐	☐	☐

Keech et al., 2025

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Neurobehavioral Assessment Tools

- Coma Recovery Scale Revised (CRS-R)
- Coma Recovery Scale for Pediatrics (CRS-P)
- Rappaport Coma Near Coma Scale (CNCS)
- Post-Acute Level of Consciousness Scale (PALOC-s)
- Western Neurosensory Stimulation Profile (WNSSP)
- Level of Cognitive Functioning Scale (LOCFAS)

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Coma Recovery Scale –Revised (CRS-R)

- Coma Recovery Scale - Revised | RehabMeasures Database
- 2020 Update by Bodien, Chatelle, & Giacino
- Developed to characterize and monitor patients in DoC
- Scoring based on presence/absence of very specific behavioral responses to stimuli
- Lowest score: reflexive activity (brainstem functions)
- Highest score: cognitively-mediated behaviors (cortical functions)
- Recommended to be used in clinical practice for diagnosis
- Valid for children as young as 5

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CRS-R

6 subscales, 23 items total

Auditory
Visual
Motor
Oromotor
Communication
Arousal

Minimal score: 0
Maximum score: 23

AUDITORY FUNCTION SCALE
4 – Consistent Movement to Command*
3 – Reproducible Movement to Command*
2 – Localization to Sound
1 – Auditory Startle
0 – None
VISUAL FUNCTION SCALE
5 – Object Recognition*
4 – Object localization: Reaching*
3 – Visual Pursuit*
2 – Fixation*
1 – Visual Startle
0 – None
MOTOR FUNCTION SCALE
6 – Functional Object Use†
5 – Automatic Motor Response*
4 – Object Manipulation*
3 – Localisation to Noxious Stimulation*
2 – Flexion Withdrawal
1 – Abnormal Posturing
0 – None
OROMOTOR/VERBAL FUNCTION SCALE
3 – Intelligible Verbalization*
2 – Vocalization/Oral Movement
1 – Oral Reflexive Movement
0 – None
COMMUNICATION SCALE
2 – Functional: Accurate†
1 – Non-functional: Intentional*
0 – None
AROUSAL SCALE
3 – Attention
2 – Eye Opening w/o Stimulation
1 – Eye Opening with Stimulation
0 – Unarousable
TOTAL SCORE

13

CRS-R

- Frequency of assessment is dependent upon the rate of change and clinical factors
- Multiple assessments often required to capture the optimal level of function
- Translated and re-validated in Spanish, Italian, French, Portuguese, Norwegian, Russian, German, Polish, Korean, and Chinese

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CRS for Pediatrics (CRS-P)

- Slomine et al., 2019
- Modification of CRS-R for use in young children
- For ages 12 months to 4 years
- Modifications
  - Age-appropriate toys as stimuli
  - Functional object use during spontaneous play
  - Functional communication with questions from book
  - Intelligible verbalization prompt ""What is this...this is a..."
  - Automatic motor responses with play

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CRS for Pediatrics (CRS-P)

- Functional object use seen starting at 12 months of age
- Functional communication seen after age 2 (and not consistently until age 3)
- Diagnosis of UWS vs MCS is difficult if child <4 and has significant visual and/or motor impairments
- Language-based items cannot be relied upon to inform diagnosis
- Multimodal assessment is recommended

Slomine et al., 2019; Alvarez et al., 2019

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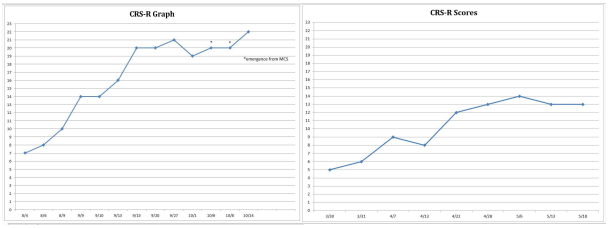
Example CRS-R graphs



MCS- to eMCS | UWS to MCS+

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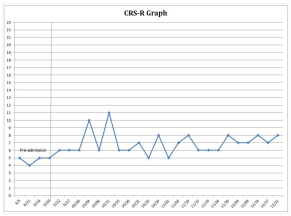
Example CRS-R graphs



UWS

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CRS-R For Accelerated Standardized Testing - CRSR-FAST

- Bodien et al., 2023
- Abbreviated version of the CRS-R
- Adults with TBI in the ICU
- 1/3 administration time; found to be "feasible, valid, reliable, and accurate method of detecting consciousness" in this population

Reproducible command following
Fixation/visual pursuit
Automatic motor response
Localization to noxious stimuli
Intelligible verbalization

Patient is rated as "conscious" if at least one of the core items is observed, or "not conscious" if none of the items are observed

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Coma/Near Coma Scale (Rappaport)

- Rappaport, Dougherty, & Kelting, 1992
- 11 items
  - Each item scored 0, 2, or 4
  - Lower score = more consistent, localized responses
  - Total score is the average across items, corresponds to level of functioning
- Unique items include tactile and olfactory stimuli
- Moderate agreement in CNCS and CRS-R in children (Frigerio et al., 2022)
- CNCS possibly more sensitive to subtle changes at lower levels of DoC, but less discriminatory ability at the higher levels of DoC (Frigerio et al., 2022)

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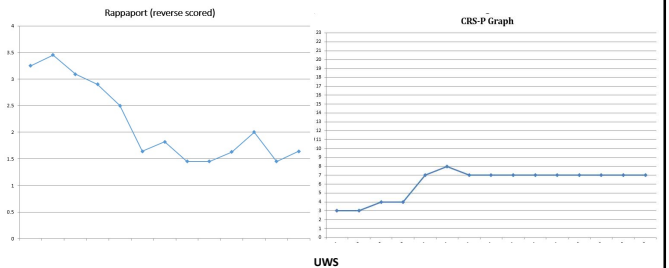
Example graphs



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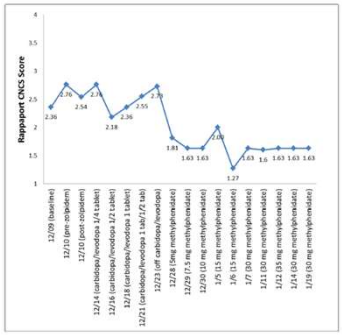
Example graph

From Yeh et al., 2019

Pair formal responsivity measures with qualitative data from the team



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Individualized Assessment Protocols

- Individualized quantitative behavioral assessments (IQBA; Whyte et al., 1999; Lahey et al., 2017)
  - Single subject quantitative experimental design procedures to address case-specific questions
  - Helpful when observed behavior and performance on standardized measures are ambiguous
  - "Is there evidence of command-following?"

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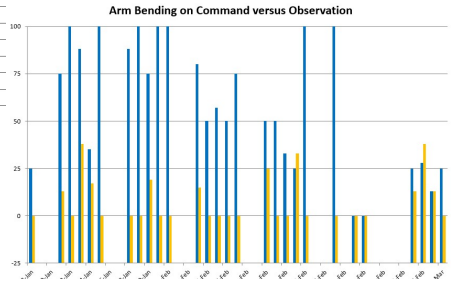
Command Following Protocols

Trials (15 seconds each)	Turn to right	Bring head to midline	Other Response (startle, grimace, other movement	No Response
Observation				
Turn to right				
Observation				
Turn to right				
Observation				
Turn to right				
Turn to right				
Observation				

24

Trials (15 seconds each)	Arm Bending	No Arm Bending
Bend your arm		
Observation		
Bend your arm		
Bend your arm		
Observation		
Bend your arm		
Observation		
Observation		



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Multimodal Assessment

- New techniques using specialized functional imaging and electrophysiologic studies are being studied, mostly in adults, to complement behavioral assessment
  - Visual evoked potentials, resting state fMRI
- EEG-based techniques and fMRI used to identify "covert" command following or cognitive motor dissociation in small groups of individuals
- *See Molteni Scoping Review for details of pediatric studies*

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What does therapy look like?

Establish a schedule: Get out of bed, out of the room, change environments, schedule rest

Promote arousal: Use multi-sensory stimulation and stimuli identified to be alerting and/or preferred

Play: Use age-appropriate activities as stimulation

Co-treat with other disciplines: Maximize windows of arousal

Incorporate movement: Use position change and supported movement as stimulation

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Multi-Sensory Stimulation

- Pictures of family, friends, pets
- Videos, voice recordings
- Music and show play lists
- Scents (e.g., lotion, scent tube)
- Toys with vibration and music
- Visual stimuli ideal for cortical vision impairment
- Favorite toys and sports equipment from home
- Cause and effect toys, switch access

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Practical Recommendations

"What's in the bag?"

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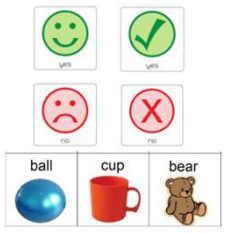
Assessing and using nonverbal communication



Van Tubbergen et al., 2008; Amari et al., 2017

- Signs of preferences often observed first
- Two consistent, distinct commands → yes/no response
- Re-establish and practice yes/no frequently
- First assess situational/factual questions with no new learning
- Then preferential → personal → factual (orientation/memory) → application of knowledge/abstraction
- Use same stimuli and orientation
- Use a field of at least 3 choices
- Change choice order
- Consult/collaborate with therapists and assistive technology

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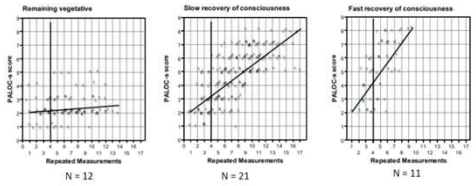
Recovery Trajectories



Eilander et al., 2013

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Predicting Outcome

Molteni et al. 2023

Scoping review

Children with traumatic brain injury have better outcomes than children with other etiologies, especially anoxic brain injury

- Kriel et al., 1994; Eilander et al., 2016

Earlier recovery of consciousness has been associated with better clinical evolution and long-term neurological outcome

- Eilander et al., 2013; Pham et al., 2019; Alvarez et al., 2019; Rodgin et al., 2021

Although infrequent, cases of late recovery from UWS and MCS are reported

- Rodgin et al., 2021

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Outcome

- Around 70% of children with TBI emerge from DoC during rehabilitation, and MCS more likely than UWS (Eilander et al., 2013; Pham et al., 2014; Watson et al., 2021; Chen et al., 2025*)
- Range of outcomes
  - Sequelae persists into adulthood
  - Individual, environmental, and injury-related variables impact outcome
  - 10+ years later: Moderate to severe disability with persisting cognitive challenges (Strazzer et al., 2023; Rodgin et al., 2021)

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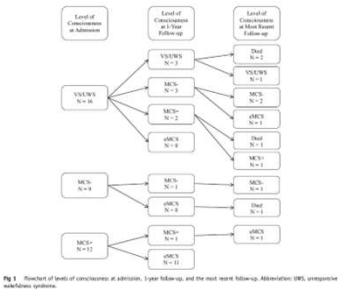
Very long-term outcomes in TBI

Rodgin et al., 2021

- 37 children with TBI
- 2-18 years old
- Range of outcomes, but majority continued to be functionally dependent on caregivers for many ADLs



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Unique Considerations for Discharge and Beyond

Sarah Lahey, PhD, ABPP

AACN 2025

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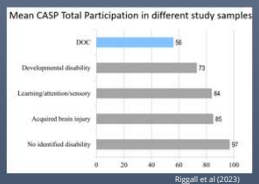
Long-Term Outcomes

- High risk for long-term severe disability
- Most children had adaptive skills that fell in the "very low" range
- Participation in all areas and quality of life are significantly impacted
- Long-term supports are critical

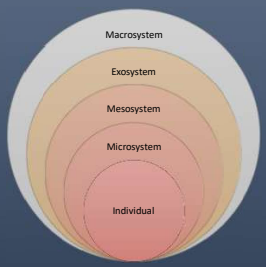


Riggall et al (2023)

PedsQL Family Impact Module

2

Real World Challenges



- Individual
  - Medical needs
  - Level of dependence
- Microsystem
  - Family/caregivers
  - School
  - Primary care doctor + specialists
- Mesosystem
  - Interactions between microsystems and higher levels
- Exosystem
  - Healthcare service delivery
  - Policies, local and state
- Macrosystem
  - Cultural beliefs
  - Economy
  - Sociopolitical movements
  - Healthcare policy/legislation

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Academic Supports

- Education
- Advocacy
- Prevention

	Behavior #1	Behavior #2	Behavior #3
	Horizontal visual tracking	Pushing button	Object use (cup, comb)
Monday	Right: 1/3 trials Left: 3/3 trials	3/5 trials	Cup: 2/4 trials
Tuesday			
Wednesday			
Thursday			
Friday			

4

Resources and Future Directions

- Curing Coma World Coma Day – International interest
- Common Data Elements – NIH
- Holding hope for patients and families

brainline
All about brain injury and PTSD

CURING COMA
AWAKENING HOPE
Provided by NEUROCRITICAL CARE SOCIETY

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