Is there a crystal ball? Charting a Course of Recovery for Disorders of Consciousness
Kathryn Farris, OTR/L

Objectives
By the end of the session the participant will:

❖ define clinical and diagnostic criteria required for accurate diagnosis for patients in disorders of consciousness.
❖ identify key components of the interdisciplinary assessment and prioritizing treatment options for persons in disorders of consciousness.
❖ identify 3 methods of predicting outcome in persons with disorders of consciousness.
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**DOC Admissions Shepherd = 525**

- 136 or 26%
- 45 or 8%
- 344 or 65%

- Emerged to rehab
- Emerged at home
- Did not emerge

**Admitted Average Days Post Injury**

- 2004-2015
- 31, 35, 45

- Emerged Rehab
- Emerged Home
- Not Emerged

**Defining Disorders of Consciousness**

Consensus Statements from:
- Aspen Neurobehavioral Conference Workgroup (Giacino et al, 2002)
Coma
Clinical Features and Diagnostic Criteria

Definition of Coma
“Represents a state of unarousable unresponsiveness in which the eyes remain continuously closed and there is no understandable response to environmental or intrinsic stimulation.”

(Giacino & Whyte 2005)
Clinical Features and Diagnostic Criteria

- No evidence of sleep wake cycles on EEG
- Behavioral response consists of reflex activity
- Loss of function of both cortex and reticular system
- Lasts longer than 2-4 weeks

COMA: All criteria required on clinical examination

- No spontaneous or stimulus-induced eye-opening
- No command following
- No intelligible speech
- No purposeful movement
- No discrete defensive movements or capacity to localize noxious stimuli

Vegetative State
Clinical Features and Diagnostic Criteria
Definition of Vegetative State

“Characterized by complete absence of behavioral evidence for awareness of self and environment, with preserved capacity for spontaneous or stimulus-induced arousal.”

(Giacino and Kalmar, 1997)

*In 2010 the term Unresponsive Wakefulness Syndrome was introduced to replace Vegetative State as a better way to describe the state and move away from the negative connotation of VS.*

Vegetative state: All criteria must be met

- No evidence of sustained, reproducible, purposeful, or voluntary behavior responses to visual auditory, tactile or noxious stimuli
- No evidence of language comprehension or expression
- Intermittent wakefulness manifested by evidence of sleep-wake cycles on the EEG
- Periodic eye opening
- Sufficient preservation of autonomic functions to permit survival with adequate medical care
- Variable preservation of cranial nerve and spinal reflexes
- Incontinent of bowel and bladder

Diagnostic Exam and Pitfalls

- Bedside Exam Serially - Limited behavioral responses in frequency and complexity
- Results of neuroimaging and laboratory studies important but not all sufficient
- Roving eye movements may be present but often thought of as visual pursuit
- Head and limb movements may be evident but not ever purposeful
- Vocalization and emotional responses are noted but not provoked by environment events
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Vegetative - Rancho 2

Persistent Vegetative State
Clinical Features and Diagnostic Criteria

PVS: Prognostic Parameters Vary

- MSTF – 1 month after BI
- ACRM – Deferred until 12 months after onset
- Aspen Group – recommended term “persistent VS” be abandoned
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Parameters for Determining Vegetative State

<table>
<thead>
<tr>
<th>Etiology</th>
<th>Parameter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traumatic Brain Injury</td>
<td>After 12 Months</td>
</tr>
<tr>
<td>Non-Traumatic Brain Injury</td>
<td>After 3 Months</td>
</tr>
<tr>
<td>Metabolic and Degenerative Diseases</td>
<td>1 – 3 Months</td>
</tr>
<tr>
<td>Infants with Anencephaly</td>
<td>At Birth</td>
</tr>
</tbody>
</table>
| Congenital Malformations         | 3 – 6 Months      

(AAN 1995)

Prognostic Parameters

“Permanent VS refers to prognosis and identifies the point after which recovery of consciousness is highly improbable but not impossible.”

(Giacino et al, 2002)

Neuropathology

- Coma can result from:
  - Hemispheric or brainstem
  - Focal brainstem lesions involving midbrain or pons
  - Isolated medullary lesions – usually short duration
  - Diffuse cortical or sub-cortical white matter lesions – extensive involvement of both hemispheres

Picture Copyright © 1995-1999 Keith A. Johnson and J. Alex Becker.
Neuropathology for those who remain in Vegetative State

- 71% w/ diffuse axonal injury (DAI)
  - Of that, 80% had damage involving the thalamus
- 37% w/ ischemic damage in neocortex
- Grade II and III DAI manifested by punctate lesions in the corpus callosum (II) and rostral brainstem (III)

Interesting facts:
- 50% considered VS after initial injury recovered consciousness by 1 year
- 15-43% of VS were found to have been misdiagnosed, they were actually MCS

Minimally Conscious State (MCS)
Diagnostic Criteria and Clinical Indicators

Definition of Minimally Conscious

“A condition of severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated.”
Diagnostic Criteria for Minimally Conscious State

The key element is the requirement that there be at least one clear cut behavioral signs of consciousness.

- Simple command following
- Gestural or verbal yes/no response
- Intelligible verbalization
- Movements or affective behaviors occur in relation to relevant environmental stimuli
- Visual or auditory tracking or sustained fixation that is in direct response to moving stimuli
- Appropriate response to the environment or situation

Minimally Conscious State

- Episodes of crying, smiling or laughter in response to linguistic or visual stimuli versus at random times.
- Vocalization or gestures that occur in direct response to the linguistic content of comments or gestures
- Touching or holding objects in a manner that accommodates the size and shape of the object

Minimally Conscious - Rancho 3
Neuropathology for Minimally Conscious State

- Severe Disabled (SD) using GOS
  - Grade 2 and 3 DAI more frequent in SD cases (42%) vs. VS (22%)
  - Thalamic damage less prevalent in SD (50%) vs. VS (80%)

Predictive Factors: Minimally Conscious State

- Studies show that visual tracking or pursuit have higher incidence of progressing to inpatient rehabilitation
- MCS = 82% versus VS = 20% independent of time post injury*
- Of the 20% of the VS who exhibited visual pursuit, 73% went on to recover consciousness 12 months post onset while only ½ of the VS without pursuit emerged from VS
  
  (Giacino and Kalmar 1997, Ansell and Keenan 1989)

Predictive Factors: MCS

- Overall, studies suggest MCS appears to result in a reasonable prognosis for recovery of function when diagnosed early in TBI
- MCS studies – patients who continue to improve beyond 6 months and after attain significantly better outcomes*
  
  (Giacino and Kalmer)
Comparison of Coma, Vegetative State, and Minimally Conscious State

<table>
<thead>
<tr>
<th></th>
<th>Coma</th>
<th>Vegetative State</th>
<th>Minimally Conscious State</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye Opening</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sleep/Wake Cycles</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Visual Tracking</td>
<td>No</td>
<td>No</td>
<td>Often</td>
</tr>
<tr>
<td>Object Recognition</td>
<td>No</td>
<td>No</td>
<td>Inconsistent</td>
</tr>
<tr>
<td>Command Following</td>
<td>No</td>
<td>No</td>
<td>Inconsistent</td>
</tr>
<tr>
<td>Communication</td>
<td>No</td>
<td>No</td>
<td>Inconsistent</td>
</tr>
<tr>
<td>Contingent Emotion</td>
<td>No</td>
<td>No</td>
<td>Inconsistent</td>
</tr>
</tbody>
</table>

(NIDRR 2007 Conscious Consortium)

Emergence from MCS
Post-Confusional State: Rancho 4

- Requires reliable and consistent evidence of:
  - Functional communication – Yes/No Responses
  - Functional object use of two or more objects
- Prerequisite for meaningful interpersonal interaction and personal autonomy

Rancho 4
Clinical Predictive Factors of Severe TBI

Main Clinical Features:
- Age
- Severity
- Duration of coma
- Duration of post traumatic amnesia
- Site and extent of cerebral lesions
- Association with hypoxia

(Carlson et al, Espersen et al, Frowein et al, Miller et al, Pitts et al.)

Clinical Predictors of Outcome

- Coma Severity measured by Glasgow Coma Scale
- Glasgow Outcome Scale (GOS) measures final outcome
- Well known that GOS may continue to change for 1 year

Glasgow Coma Scale

<table>
<thead>
<tr>
<th>EYES OPEN</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Spontaneous</td>
<td>4</td>
</tr>
<tr>
<td>To Touch</td>
<td>3</td>
</tr>
<tr>
<td>To Pain</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BEST VERBAL RESPONSE</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Oriented</td>
<td>5</td>
</tr>
<tr>
<td>Inappropriate</td>
<td>4</td>
</tr>
<tr>
<td>Incomprehensible</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BEST MOTOR RESPONSE</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Obey Commands</td>
<td>6</td>
</tr>
<tr>
<td>Localizes Pain</td>
<td>5</td>
</tr>
<tr>
<td>Withdraws</td>
<td>4</td>
</tr>
<tr>
<td>Flexes To Pain</td>
<td>3</td>
</tr>
<tr>
<td>Extends To Pain</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
</tbody>
</table>
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Glasgow Outcome Scale -Extended

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Dead</td>
</tr>
<tr>
<td>2</td>
<td>Vegetative State</td>
</tr>
<tr>
<td>3</td>
<td>Low Severe Disability</td>
</tr>
<tr>
<td>4</td>
<td>Upper Severe Disability</td>
</tr>
<tr>
<td>5</td>
<td>Low Moderate Disability</td>
</tr>
<tr>
<td>6</td>
<td>Upper Moderate Disability</td>
</tr>
<tr>
<td>7</td>
<td>Low Good Recovery</td>
</tr>
<tr>
<td>8</td>
<td>Upper Good Recovery</td>
</tr>
</tbody>
</table>

Disability Rating Scale (DRS)

- Eye Opening - Arousal
- Communication - Awareness
- Motor Response - Responsivity
- Feeding
- Toileting - Cognitive Ability for Self Care Activities
- Grooming
- Level of Functioning - Dependence on Others
- Employability - Psychosocial Adaptability

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DRS Categories
Predictor of long term severity after acute injury

<table>
<thead>
<tr>
<th>Total DRS</th>
<th>Level of Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td>1</td>
<td>Mild</td>
</tr>
<tr>
<td>2-3</td>
<td>Partial</td>
</tr>
<tr>
<td>4-6</td>
<td>Moderate</td>
</tr>
<tr>
<td>7-11</td>
<td>Moderately Severe</td>
</tr>
<tr>
<td>12-16</td>
<td>Severe</td>
</tr>
<tr>
<td>17-21</td>
<td>Extremely Severe</td>
</tr>
<tr>
<td>22-24</td>
<td>Vegetative State</td>
</tr>
<tr>
<td>25-29</td>
<td>Extreme Vegetative State</td>
</tr>
</tbody>
</table>

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### Severity of Brain Injury Stratification

<table>
<thead>
<tr>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal structural imaging</td>
<td>Normal or abnormal structural imaging</td>
<td>Normal or abnormal structural imaging</td>
</tr>
<tr>
<td>LOC = 0-30 minutes</td>
<td>LOC &gt;30 minutes and &lt;24 hours</td>
<td>LOC &gt;24 hours</td>
</tr>
<tr>
<td>AOC = a moment up to 24 hours</td>
<td>AOC &gt;24 hours</td>
<td>Severity based on other criteria</td>
</tr>
<tr>
<td>PTA = 0-1 day</td>
<td>PTA &gt;1 and &lt;7 days</td>
<td>PTA &gt;7 days</td>
</tr>
<tr>
<td>GCS = 13-15</td>
<td>GCS = 9-12</td>
<td>GCS = 3-8</td>
</tr>
</tbody>
</table>

AOC - Alteration of consciousness/mental state  
LOC - Loss of consciousness  
PTA - Post-traumatic amnesia  
GCS - Glasgow Coma Scale

DoD/V A Definition and Symptomatic Taxonomy Working Group

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- Longer duration of coma is associated with worse outcomes
- Threshold values:
  - Severe disability is unlikely when coma last less than 2 weeks
  - Good recovery is unlikely when coma lasts longer than 4 weeks

Prognosis after Severe TBI: A Practical Approach

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Coma Duration

- Longer duration of coma is associated with worse outcomes
- Threshold values:
  - Severe disability is unlikely when coma last less than 2 weeks
  - Good recovery is unlikely when coma lasts longer than 4 weeks
**Posttraumatic Amnesia**
- Longer duration PTA is associated with worse outcomes
- **Threshold values:**
  - Severe disability is unlikely PTA lasts less than 2 months
  - Good recovery is unlikely when PTA lasts longer than 3 months

---

**Age**
- Older age is associated with worse outcomes
- **Threshold values:**
  - Good recovery is unlikely in patients older than 65 years

---

**Neuroimaging**
- Certain features (e.g., depth of lesions) are associated with worse outcomes
- **Threshold values:**
  - Good recovery is unlikely when bilateral brainstem lesions present on early MRI

*From Kothari*  
**Abbreviations:** MRI, magnetic resonance imaging; PTA, post-traumatic amnesia
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Severe Disability

- As determined by the GOS is unlikely when:
  - Time to follow commands is less than 2 weeks
  - Duration of PTA is less than 2 months

Good Recovery

- As determined by the GOS is unlikely when:
  - Time to follow commands is longer than 1 month
  - Duration of PTA is greater than 3 months
  - Age is greater than 65 years

This summary of evidence-based guidelines is from Kothari. Reprinted with permission.

Outcomes at 1 Yr. Post Onset TBI

<table>
<thead>
<tr>
<th></th>
<th>Dead</th>
<th>Vegetative</th>
<th>Severely Disabled</th>
<th>Independent</th>
</tr>
</thead>
<tbody>
<tr>
<td>At 1 Month</td>
<td>33%</td>
<td>15%</td>
<td>28%</td>
<td>24%</td>
</tr>
<tr>
<td>N=434 Adults</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At 3 Months</td>
<td>35%</td>
<td>30%</td>
<td>19%</td>
<td>16%</td>
</tr>
<tr>
<td>N=218 Adults</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At 6 Months</td>
<td>32%</td>
<td>52%</td>
<td>12%</td>
<td>4%</td>
</tr>
<tr>
<td>N=123 Adults</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Outcomes of Patients at 3, 6, and 12 months after Non Traumatic BI

<table>
<thead>
<tr>
<th>Non- Traumatic injury (n=169)</th>
<th>3 Months</th>
<th>6 Months</th>
<th>12 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death</td>
<td>24%</td>
<td>40%</td>
<td>53%</td>
</tr>
<tr>
<td>Vegetative State</td>
<td>65%</td>
<td>45%</td>
<td>32%</td>
</tr>
<tr>
<td>Recovery of consciousness</td>
<td>11%</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>- Severe Disability</td>
<td>6%</td>
<td>0%</td>
<td>11%</td>
</tr>
<tr>
<td>- Moderate Disability/Good Recovery</td>
<td>1%</td>
<td>0%</td>
<td>4%</td>
</tr>
</tbody>
</table>

(Multi Task Force Data)
Assessment following severe Brain Injury

Coma Recovery Scale-Revised Assessment

- Hierarchical system of quantitative measurements
- Used for interdisciplinary treatment
- Auditory, motor, and visual function
- Arousal, oromotor/verbal & communication
- Captures subtle clinical changes over time
- Able to monitor rate of recovery

Coma Recovery Scale-R

<table>
<thead>
<tr>
<th>Auditory Function Sub-scale</th>
<th>Visual Function Sub-scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>0  None</td>
<td>0  None</td>
</tr>
<tr>
<td>1  Auditory startle</td>
<td>1  Visual startle</td>
</tr>
<tr>
<td>2  Localization to sound</td>
<td>2  Fixation</td>
</tr>
<tr>
<td>3  Reproducible movement to sound</td>
<td>3  Pursuit eye movement</td>
</tr>
<tr>
<td>4  Consistent movement to sound</td>
<td>4  Object localization: Reaching</td>
</tr>
</tbody>
</table>
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### Coma Recovery Scale-R

<table>
<thead>
<tr>
<th>Motor Function Sub-scale</th>
<th>0</th>
<th>None/Flaccid</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>Abnormal posturing</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Flexion posturing (instead of withdrawal)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Localization to noxious stimuli</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Object manipulation</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Automatic motor response (&gt;50% of time)</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Functional object use (&gt;75% of time)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Oromotor/Verbal Sub-scale</th>
<th>0</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>Oral Reflexive Movement</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Vocalization/Oral Movement</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Intelligible Verbalization</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication Sub-scale</th>
<th>0</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>Non-functional: intentional (&lt;50%)</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Functional: accurate (&gt;50%)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>None</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Arousal Sub-scale</th>
<th>0</th>
<th>Unarousable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>Eye Opening with Stimulation</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Eye Opening without Stimulation</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Attention</td>
</tr>
</tbody>
</table>
Pain Assessment

First question asked “Is my loved one in pain?”

Clinical and ethical implications of evaluating pain in persons with disorders of consciousness.

Nociception vs. Pain

Nociception is the actual or potential tissue damaging event transduced and encoded by nociceptors, the basic processing of a noxious stimuli. Necessary for pain perception but does not always lead to a conscious experience.

Pain defined as an unpleasant sensory and emotional experience associated with real or potential tissue damage, a conscious 1st person experience that can be reported.

*Neuroimaging studies suggest these are mediated by different networks.
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**Best tool to assess nociception**
Tools developed and validated to detect pain in non-communicative patients, newborns or people with dementia.

- **FLACC** - Face Legs Activity Cry Consolability

Not until recently was a tool developed for the DOC population.

- **NCS-R** - Nociceptive Coma Scale-Revised

**New Directions in Neuroimaging**

- Pace of research of disorders of consciousness increased over 10 years
- Advances in neuroimaging technologies for allowing more accurate diagnosis and prediction
Is there a crystal ball? Charting a Course of Recovery for Disorders of Consciousness.
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---

**Positron Emission Tomography (PET)**

- Patients in MCS, but not VS retain function in association cortices – responsible for mediatory self and environmental awareness. (Boly et al, 2004)

---

**Functional Magnetic Resonance Imaging (fMRI)**

- Designed to interrogate the integrity of sensorimotor, language, and visual processing systems
- Evidence that cortical connections in above networks are largely intact even with little or no behavioral evidence by function (Schiff et al)

---

**Insights into Neuroimaging**

- Hopefully provide a road map for development of novel treatment interventions
- Individually-tailored neuro modulation strategies to facilitate still viable but down regulated network activity
- Offer promise of restoring function during acute and chronic phases of recovery

---
New (or old) Directions in Treatment

- Transcranial Magnetic Stimulation (TMS)
  - Non-invasive, task independent method of exciting/inhibiting the cortex using electromagnetic induction

- Transcranial Direct Current Stimulation (tDCS)
  - Non-invasive, constant weak current delivered via scalp electrodes into cerebral cortex. Studied since 1960’s.

- Intrathecal Baclofen (ITB)
  - Earlier use for dysautonomia and spasticity, may also have unexpected improvements in level of consciousness, mental function and participation.

- Deep Brain Stimulation (DBS)
  - Invasive bilateral DBS to central thalamus can induce behavioral/arousal responses. First studied in 1968.

DOC Advocacy

- Congressional Brain Injury Task Force
  - The Mohonk Report

- Disorders of Consciousness Task Force
  - Publications
  - DOC Minimal Competency Recommendations
  - Education Materials
  - Professional Instructional Courses
  - Advocacy → McKesson Group

DOC Minimal Competency Recommendations

- Specialized knowledge and skill is required to deliver optimal care to patients with DOC.

- Questions:
  - If insurers were to agree to reimburse for DOC rehab, what facilities should they look for?
  - If caregivers are seeking expert care, where should they look?
  - If a facility wishes to be skilled in DOC rehab, what attributes should they pursue?
DOC Minimal Competency Recommendations

- Result: 21 recommendations for facilities
  - Diagnosis and Prognosis
  - Treatment
  - Transitioning Care/Long Term Care Needs
  - Management of Ethical Issues

Family Perspectives & Decision Making

- Severity of injury and associated short & long term deficits
- Limited knowledge and experience for families to draw from
- Wondering if there’s pain and suffering
- Family/Caregiver feelings of guilt and loss

End of Life Conversations

- Who has the difficult conversations with families?
- When to have the conversations?
- What should be considered with each conversation?
- How should the wishes be handled?
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Summary
- Accurate differential diagnosis is an essential first step
- Consensus-based criteria differentiating VS and MCS
- Intent to minimize the risk of misdiagnosis & inaccurate prognosis ➔ inappropriate treatment decisions
- Need for specialized care - DOC Minimal Competency Recommendations
- New directions in interventions
- Perspectives and considerations of families

Never say never
6 weeks post MVA… …and 2 years later.
Is there a crystal ball? Charting a Course of Recovery for Disorders of Consciousness.
Kathryn Farris, OTR/L

The power of the mind.
The strength of the human spirit.

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THANK YOU!

References

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