Disorders of Consciousness
Introduction / Definitions / Assessment
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BIAA/ACBIS
EBIG 5.0
See Chapter 5!

Nationwide DOC News:
- Practice Guidelines: Disorders of Consciousness
  - AAN
  - ACRM’s DOC workgroup
  - NIDILRR
- Currently under formal review
- Opens for public comment April 8th.
Arousal & Awareness
- **Arousal**
  - primitive
  - involuntary responsiveness to the world
  - reflex (generalized) responses to internal and external stimuli.
  - Mediated by the brainstem / reticular activating system

Arousal & Awareness
- **Awareness**
  - receive and process sensory information
  - Use sensory information to relate to world
  - Intentional
  - Required for voluntary responses
  - Mediated by the cortex.

Classification Systems
- The Disorders of Consciousness:
  - **Coma** (−arousal, −awareness)
  - **Vegetative State** (arousal, −awareness)
  - Unresponsive Wakefulness Syndrome (UWS)
  - Post-Coma Unawareness (PC-U)
  - **Minimally Conscious State** (arousal, ± awareness)
    - **MCS−**
      - absence of signs of preserved language function (intelligible speech or command following)
    - **MCS+**
      - presence of signs of preserved language function (intelligible speech or command following)
Additional Terms:

- **Prolonged DoC**: lasting at least 28 days
- **Chronic VS/UWS**: lasting at least 1 year
- **Chronic MCS**: lasting at least 1 year
- The term “permanent” is no longer used.
- **Post-Traumatic Confusional State**: A period of attentional compromise immediately following traumatic brain injury which may or may not include impaired orientation and varying degrees of amnesia.

What is Coma?

- No behavioral evidence of arousal or awareness.
- Reflexive responses may be observed minimally.
- No eye opening or evidence of a sleep/wake cycle.
- Resolves in 2-4 weeks. Survivor either passes away or moves to a higher level.
- Owl very rarely receives anyone at this level.
- Tends to correlate to Rancho Level 1

What is a Vegetative State (UWS)(PC-U)?

- Behavioral evidence of arousal, but not awareness.
- Preserved capacity for spontaneous or stimulus-induced arousal.
- Evidence of a sleep/wake cycle and inconsistent eye opening (given intact motor pathways to allow eye opening).
- Rule of thumb: responses tend to be subcortical (reflexive / automatic / nonspecific).
- Tends to correlate roughly to Rancho level 2
What is a Minimally Conscious State?

- Behavioral evidence of arousal
  - Fluctuating, but reproducible behavioral signs of awareness
  - Responses to verbal directives (MCS+)
  - Smiling / crying
  - Localization
  - Verbalization
  - Simple directive following (not consistently reproducible)
  - Rule of thumb...responses require cortical activation

Misdiagnosis vis-à-vis DOCS

- Up to 40% of persons diagnosed with PVS or VS are actually misdiagnosed as being less responsive than they are, partly due to low functioning status and partly due to non-consistent use of appropriate instruments such as the DOC scale.

- Study of 103 patients found 41% to be in MCS; 10% had actually emerged out of the MCS! 89% of "uncertain diagnosis" were actually in the MCS.

- Diagnostic accuracy of the vegetative and minimally conscious state: Clinical consensus versus standardized neuropsychological assessment

  - Caroline Schnakers, Audrey Vanhaudenhuyse, Joseph Giacino, Manfred Ventura, Melanie Boly, Steve Majerus, Gustave Moonen and Steven Laureys

  - BMC Neurology 2009, 9:35

Position paper from the American Congress of Rehabilitation Medicine – Recommendations for Use of Uniform Nomenclature Pertinent to Patients with Severe Alterations in Consciousness:

- “The committee does not believe that use of descriptors such as ‘persistent’ and ‘permanent’ clarify either the diagnosis or prognosis of the patient in the VS”

- Dr. Teresa Pape – 35-50% of PS with PVS at 3 months post-injury will recover consciousness/emerge by the one-year mark
People make progress! Our experience at OWL – in the last 16 years, 77% of persons emerged from their DOC.

- Average % Change in Functional Outcome Measure by Length of Stay in Days

What is our experience at OWL?

- Up to 6 months duration of MC state, persons emerge and rehabilitate, to varying levels, some doing well.

Assessment

  - Coma Recovery Scale - Revised (CRS-R)
  - The Disorders of Consciousness Scale (DOCS)
  - Sensory Modality Assessment and Rehabilitation Technique (SMART)
  - Sensory Stimulation Assessment Measure (SSAM)
  - Wessex Head Injury Matrix (WHIM)
  - Western NeuroSensory Stimulation Protocol (WNSP)
The Disorders of Consciousness Scale

- [https://www.hsrd.research.va.gov](https://www.hsrd.research.va.gov)
- [POWERPOINT PRESENTATION](https://www.queri.research.va.gov/tools/docs_training/)
- [TRAINING VIDEO](https://www.queri.research.va.gov/tools/docs_training/manual_2011.pdf)
- [MANUAL](https://www.queri.research.va.gov/tools/docs_training/manual_2011.pdf)

Current and/or Past Subject Recruitment Sites:
We would also like to recognize the contributions of the participating hospitals whose cooperation, collaboration, and support facilitated implementation of this research. Additionally, we wish to acknowledge the allied health associates at each hospital, including the speech language pathologists, physical therapists, occupational therapists, respiratory therapists, and nurses whose ongoing pursuit of excellence contributed to the quality of data collection. These hospitals include:

- Edward Hines Jr. VA Hospital, Hines, Illinois
- On With Life, Brain Injury Rehabilitation, Ankeny, Iowa
- Marianjoy Rehabilitation Hospital, Wheaton, Illinois
- Northwestern Memorial Hospital, Chicago, Illinois
- Minneapolis Veterans Affairs (VA) Medical Center, Minneapolis, MN
- RML Specialty Hospital, Hinsdale, Illinois
- Tampa VA Medical Center, Tampa, Florida
- The Rehabilitation Institute of Chicago, Chicago, Illinois

Purpose
The DOCS is a bedside test measuring neurobehavioral functioning during coma recovery. It was developed to detect subtle changes in observable indicators of neurobehavioral functioning.

Description
- 23 items
- Minimum score = 0; Maximum score = 100: Raw scores are converted to interval level data (logits) and rescaled on a 0 to 100 point scale.
- The rating scale describes levels of neurobehavioral integrity and a level is assigned to responses to test stimuli. The rating scale points are as follows:
  - 0 = No Response
  - 1 = Generalized Response
  - 2 = Localized Response
- The rating scale defines transitions from low to middle to high neurobehavioral functioning within the continuum of altered consciousness.
- Neuroanatomic structures important for function of each item are indicated in the manual (above link).
Sensory Modalities

<table>
<thead>
<tr>
<th>Sensory Modality</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual (seeing)</td>
<td>Mirror, familiar photographs, bubbles, scenery and setting changes</td>
</tr>
<tr>
<td>Auditory (hearing)</td>
<td>Pre-recorded voices of family members and friends, favorite music, environmental noises</td>
</tr>
<tr>
<td>Tactile (touching)</td>
<td>Touch, fabric, body sensations</td>
</tr>
<tr>
<td>Olfactory (smelling)</td>
<td>Fragrances, spices, environmental scents</td>
</tr>
<tr>
<td>Gustatory (tasting)</td>
<td>Lemon swabs, cotton-tipped applicators with preferred flavors</td>
</tr>
<tr>
<td>Proprioceptive / Vestibular (moving)</td>
<td>Movement of the body, changes in body position, pressure</td>
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</tbody>
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Measuring Responses to Sensory Stimulation

<table>
<thead>
<tr>
<th>Response Type</th>
<th>Description</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Response (NR)</td>
<td>No discernible reflexive or volitional response to stimuli</td>
<td>n/a</td>
</tr>
<tr>
<td>Generalized Response (GR)</td>
<td>Automatic, reflexive or non-specific response</td>
<td>Eye opening, changes in breathing or heart rate, changes in flexion or extension, nonspecific vocalization</td>
</tr>
<tr>
<td>Localized Response (LR)</td>
<td>Voluntary control of the response to the stimulation</td>
<td>Turning head toward a sound, focusing on objects, movement of the stimulated area, following simple commands</td>
</tr>
</tbody>
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DOC - The REAL outcomes...
Medical Management

- Dr. Ben Collins, Medical Director, On With Life

Possible medical complications:

- Hypertonia/Spasticity
- Agitation
- Sleep
- UTI
- Endocrine
Possible medical complications:

- Hypertonia/Spasticity
- Agitation
- Sleep
- URI
- Endocrine
- Pneumonia

Management of equipment:

- Tracheostomy tubes
- Gastric tubes
- Foley catheter
- CPAP / BIPAP
- Cough Assist

Disorders of Consciousness: Setting Therapy Goals

Alison Whitaker, MA CCC-SLP CBS
Disorders of Consciousness: Setting Therapy Goals

How (and why) do you design rehab intervention for someone who isn't fully conscious?

Setting Therapy Goals

- Therapy for DOC
- Regular Rehab Goals vs DOC goals
- Sample Long-Term goals for DOC
- Case study

Therapeutic Interventions for DOC: Efficacy

- Early, continuous rehab for persons with severe TBI, including DOC, results in better outcomes than delayed rehab (Andelic et al., 2012)
- A study of DOC outcomes at Shepherd Center in Atlanta, where individuals received at least 90 minutes of daily rehab, showed:
  - Improved arousal
  - Improved auditory, visual, and motor response
  - Improved verbalization and functional communication
  - Improved respiratory airway function
  - Improved upper extremity hypertonia
  - Improved pressure ulcers
  - Improved ability to assist with face washing, hair brushing, upper extremity dressing, teeth brushing, and transfers (Seel et al., 2013)
**Therapeutic Interventions for DOC: Suggested Standards**

1. Optimal medical environment
2. Prevent and treat secondary conditions (e.g. dysautonomia, hypertonia)
3. Maintain bodily integrity (e.g. nutrition, oral and physical hygiene, etc.)
4. Facilitate functional communication and environmental interaction
5. Establish functional mobility (e.g. postural/positioning, stretching and ROM, etc.)
6. Provide family education and support

(Seel et al, 2013)

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**DOC Long-term Goals: Differences from Regular Rehab Goals**

- Take into consideration DOC-specific needs
- Promoting tolerance
- Optimizing physical management
- Improving response type and consistency
  - Response type: No response > generalized response > localized response
- Educating caregivers
- Allow for passive participation, such as tolerating sensory stimulation, due to absent or reduced voluntary responses
- Allow for uncertainty about eventual emergence into consciousness
- Add additional long-term goals when person emerges into consciousness

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**DOC Long-Term Goals: Similarities to Regular Rehab Goals**

- Specific
- Measurable
- Relevant to person
- Related to function
- Capitalize on that person’s strengths (e.g. incorporating the types of sensory stimulation with the best responses on assessment)
Sample Speech-Language Pathology Goals

- Consistently demonstrate localized responses to stimulation as evidenced by a "conscious" score on the DOCS.
- Tolerate auditory stimulation via a modified Familiar Auditory Sensory Training treatment without signs of distress (see Pajje 2012).
- Tolerate multimodal sensory stimulation for thirty minutes without signs of distress.
- Demonstrate a yes/no response in any modality.
- Follow a command with models and cues as needed.
- Consistently swallow in response to gustatory stimulation, without physiological signs of aspiration, such that trials of puree consistencies will be initiated.

Sample Goal – Breaking it down

"Tolerate auditory stimulation via a modified Familiar Auditory Sensory Training treatment without signs of distress"

How does the goal incorporate DOC-specific needs?

- Promoting tolerance
- Optimizing physical management
- Improving response type and consistency
- Response type: No response > generalized response > localized response
- Educating caregivers

Sample PT & OT goals

- Tolerate tilt table or Easy Stand for up to 30 minutes with stable vital signs for improving upright tolerance and weight bearing.
- Demonstrate at least 10 degrees of hip abduction bilaterally to allow for increased ease of cares and improved comfort.
- Consistently tolerate upright seated positioning at the edge of a mat table throughout a 30-minute session with no signs of distress.
- Family will independently perform passive range of motion exercises to a skillet with mild inflating range.
- Consistently follow simple 1 step commands in the context of various ADL/IADL tasks.
- Visually attend or orientate on an object for 30 seconds (or 1 min, 5 mins, etc.)
Caregiver Education Resources

- TBI Model Systems Knowledge Translation Center factsheet on Severe TBI
  and DOC

- Family Guide to the Rancho Levels of Cognitive Functioning

Case Study: “Ben”

- s/p Tumor Removal
- Completed the Disorders of Consciousness Scale on the day after admission and achieved a total, unadjusted score of 43.7, scoring in the “vegetative state” category
- Eyes generally closed during testing
- Gave inconsistent responses to tactile, olfactory, auditory, and gustatory stimulation
- No localized responses to visual stimulation
- Was observed to give a range of responses in therapy sessions, including command-following, inconsistent swallowing (2-3 times per session), and localized responses to visual stimuli. Emerging yes/no responses were noted with cues for verbalizations or thumbs up/down. Reliability was uncertain.
- Therefore, presentation at admission was more consistent with a “minimally conscious” category, with emerging awareness as demonstrated by inconsistent localized responses.

“Ben’s” Initial DOCS – Generalized and Localized Response to Bell
“Ben’s” Initial **DOCS** – No Response to ROM

- Consistently demonstrate localized responses to stimulation as evidenced by a “conscious” score on the DOCS or the OWL Scale.
- Consistently swallow in response to gustatory stimulation, such that trials of NDD1 consistencies can be initiated.
- Given cues and assistance as needed, will demonstrate yes/no reliability of at least 80% for basic autobiographical questions using any communication modality.

“Ben’s” Initial Long-Term Goals in Speech Therapy

“Ben’s” Second **DOCS** 2 weeks later: Localized Response to ROM
"Ben’s" Second DOCS, 2 weeks later: Localized Response to Whistle

Challenges in Assessment: He still scored in the "vegetative state" category despite giving responses indicating he was conscious. Indicates need for clinical expertise and behavioral observation.

"Ben" at Discharge. "What are some of the improvements that you’re most proud of?"

References