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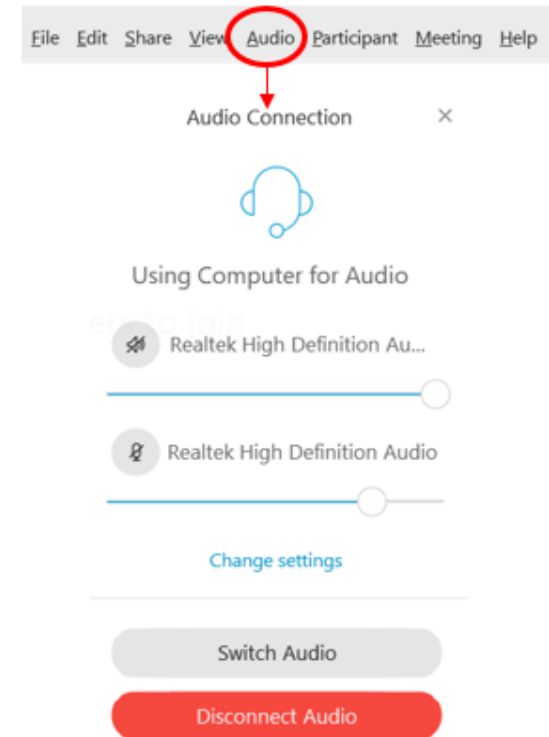
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# Advancing the Care of Patients with Disorders of Consciousness

**Sunil Kothari, MD**

Medical Director,  
Catastrophic Care Management

**Deborah M. Benson, PhD, ABPP**

Associate Vice President, Clinical Services  
Catastrophic Care Management

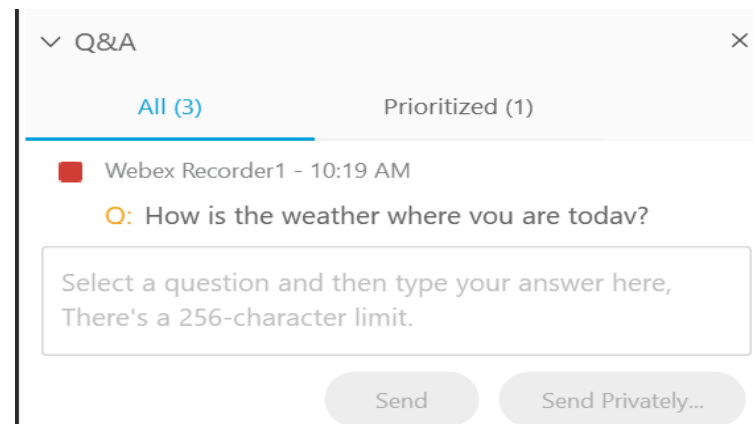
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- ▶ Submit questions at any time
- ▶ Q&A panel at lower right of your screen
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# Presenters and Objectives

# Presenters



**Sunil Kothari, MD**  
Medical Director,  
Paradigm Catastrophic Care Management

- ▶ Physician with 20 years of experience in brain injuries and PM&R
- ▶ Director of the Disorders of Consciousness program at TIRR-Memorial Hermann
- ▶ Assistant professor in PM&R at Baylor College of Medicine
- ▶ Director of the Baylor College of Medicine fellowship in brain injury medicine



**Deborah M. Benson, PhD, ABPP**  
Associate Vice President, Clinical Services,  
Paradigm Catastrophic Care Management

- ▶ Licensed psychologist with a PhD in clinical neuropsychology and board certification in rehabilitation psychology
- ▶ Background in neuroscience research, undergraduate/graduate teaching, clinical supervision and clinical practice with patients and families
- ▶ Numerous presentations and publications; served on regional and national advisory boards/councils serving individuals with disabilities and families
- ▶ Supervises/supports Paradigm teams to develop clinical management plans that ensure positive outcomes for patients with complex/catastrophic injuries

## Paradigm's Aim

**With a mission to help as many people as possible, we work to restore an injured worker's health, their spirit, and their hope for a brighter future.**



# Objectives

- ▶ What are Disorders of Consciousness (DoC) and how can care be improved post catastrophic injury?
- ▶ Emphasize the expertise with DoC that is needed to appropriately assess the indications and goals of admission to a DoC program
- ▶ Recall the distinguishing differences between coma, vegetative state, and the minimally conscious state
- ▶ Explore the challenges commonly experienced by patients and families regarding DoC treatment, and how to support their adjustment

# Former Paradigm

## ▶ **Diagnosis**

- ▶ Straightforward
- ▶ Distinctions unimportant

## ▶ **Prognosis**

- ▶ Uniformly poor

## ▶ **Treatment**

- ▶ No significant benefit
- ▶ Rehabilitation delayed and contingent on emergence

# Current Paradigm

## ▶ **Diagnosis**

- ▶ Challenging
- ▶ Stakes high

## ▶ **Prognosis**

- ▶ Good outcomes not uncommon

## ▶ **Treatment**

- ▶ Early
- ▶ Specialized DoC programs

# Diagnosis

# Diagnosis

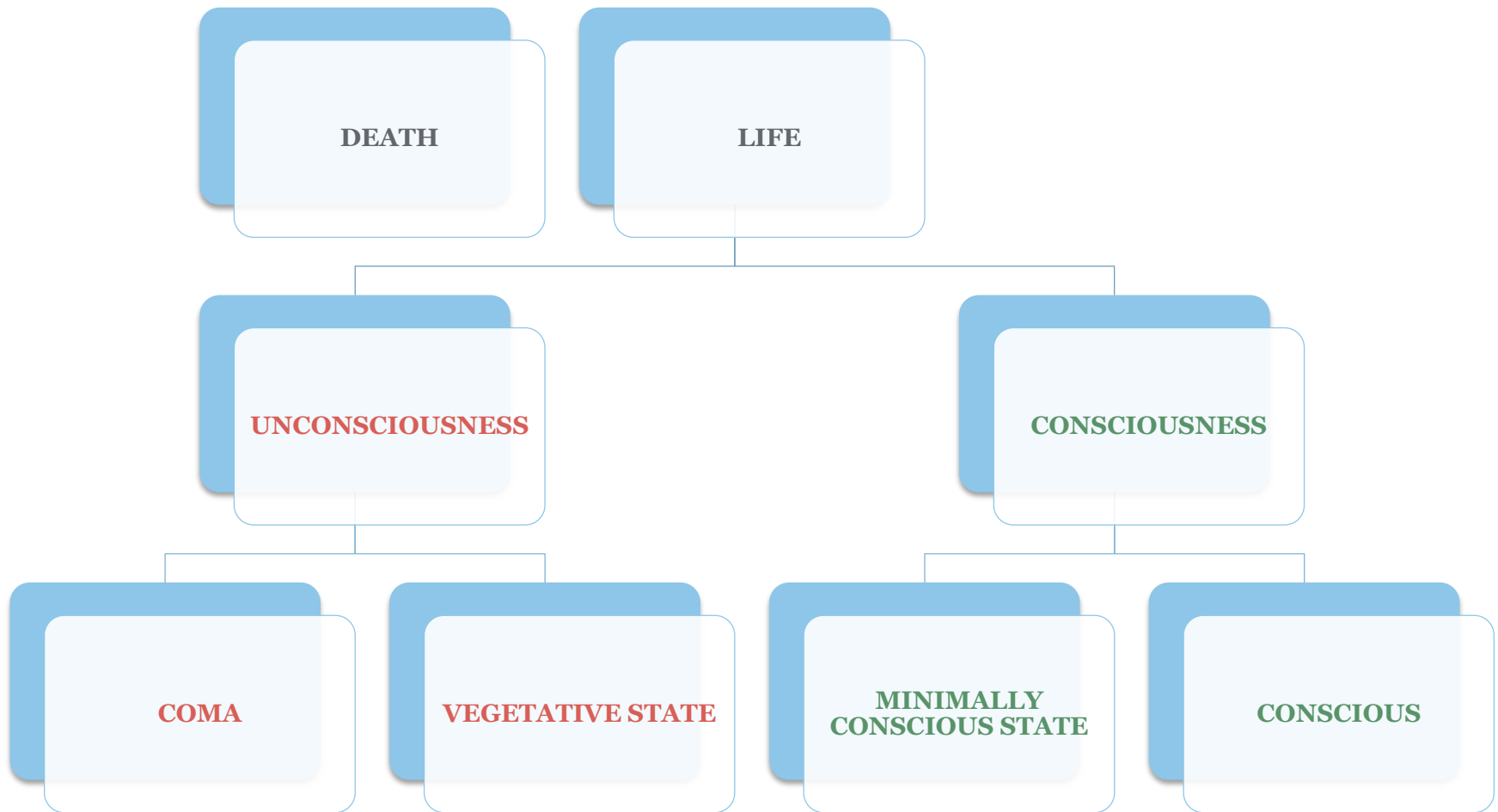
- ▶ **Former**

- ▶ Straightforward
- ▶ Distinctions unimportant

- ▶ **Current**

- ▶ Challenging
- ▶ Stakes high

# Disorders of Consciousness



## Definition of Consciousness

**Awareness of self and/or  
environment constitutes  
consciousness**

# Unconsciousness

## ▶ Coma

- ▶ Complete loss of spontaneous and stimulus induced arousal (eyes closed); self-limited state

## ▶ Vegetative State (VS)

- ▶ Return of basic arousal (eyes open); state of wakeful unawareness



# Consciousness

- ▶ **Minimally Conscious State (MCS)**
  - ▶ Return of awareness; but awareness may be minimal in degree and inconsistent in manifestation
- ▶ **Emerged From MCS (eMCS)**
  - ▶ Return of functional object use and/or functional communication

# Misdiagnosing Consciousness

**35%** misdiagnosis rate of the vegetative state in studies

- ▶ Likely *much higher*

# Misdiagnosis: Confounds

- ▶ Conditions that can mimic or overlap with DoC
  - ▶ Locked-In Syndrome
  - ▶ Akinetic Mutism
  - ▶ Catatonia
- ▶ Deficits that can mask the true level of consciousness
  - ▶ Bilateral eyelid apraxia, blepharospasm, cranial nerve III palsies
  - ▶ Widespread paresis or paralysis (e.g. critical illness polyneuropathy/myopathy)
  - ▶ Profound primary sensory deficits (e.g. deafness, blindness)
  - ▶ Higher-order sensory, motor, or cognitive deficits (e.g. apraxia, aphasia, etc.)

# Misdiagnosis: Reversible Causes of Impaired Consciousness

- ▶ Under-stimulation and under-mobilization
- ▶ Disrupted sleep-wake cycles
- ▶ Sedating medications
- ▶ Concurrent medical conditions (e.g. hypoxemia, infection, metabolic abnormalities, etc.)
- ▶ Neuroendocrine abnormalities
- ▶ Seizures (e.g. non-convulsive status epilepticus, etc.)
- ▶ Intracranial abnormalities (e.g. hydrocephalus, subdural hygromas, etc.)

## Misdiagnosis: “Signal to Noise”

**Evidence of consciousness can be subtle & inconsistent**

# Assessing Consciousness

## Behavioral

- ▶ Qualitative evaluation
  - ▶ Bedside evaluation
- ▶ Formal assessments
  - ▶ Standardized scale (e.g. CRS-R)
  - ▶ Individualized Quantitative Behavioral Assessment (IQBA)

## Non-Behavioral

- ▶ Pupillometry
- ▶ Electromyographic (e.g. surface EMG)
- ▶ Neurophysiological (e.g. ERPs, TMS-EEG, etc.)
- ▶ Functional neuroimaging (e.g. fMRI)

# Cognitive-Motor Dissociation

# Covert Consciousness

**Estimated approximately 15-20% of patients in VS have evidence of covert consciousness**



# Consciousness: What is at Stake?

- ▶ Clinical
- ▶ Psychological
- ▶ Legal
- ▶ Ethical

# Prognosis

# Prognosis

- ▶ **Former**

- ▶ Uniformly poor

- ▶ **Current**

- ▶ Good outcomes not uncommon

# Outcomes: Function

- ▶ **Early Recovery** (following commands prior to rehabilitation discharge):
  - ▶ By five years, independent functioning ranged from **56%** (problem solving) to **85%** (ambulation/wheelchair). Approximately **20%** employable.\*
- ▶ **Late Recovery** (not following commands prior to rehabilitation discharge):
  - ▶ By five years, **19% to 36%** of participants were independent depending on the functional domain. Further recovery occurred between year 5 to year 10.\*

\*Source: TBI Model Systems data

# Treatment

# Treatment

## ▶ Former

- ▶ No significant benefit
- ▶ Rehabilitation delayed and contingent on emergence

## ▶ Current

- ▶ Early
- ▶ Specialized DoC programs

## Standard of Care

*“Clinicians should refer patients with DoC who have achieved medical stability to settings staffed by multidisciplinary rehabilitation teams with specialized training to optimize diagnostic evaluation, prognostication, and subsequent management, including effective medical monitoring and rehabilitative care.”*

National Practice Guidelines for Disorders of Consciousness 2018

# Goals of Specialized DoC Treatment Programs

## Consciousness and communication

- ▶ Accurately assess the current level of consciousness
- ▶ Address reversible causes of impaired consciousness
- ▶ Trial interventions to enhance the level of consciousness
- ▶ If appropriate, establish a system of communication and environmental control

## Neuromusculoskeletal and medical

- ▶ Minimize restrictions in range of motion
- ▶ Identify and augment residual voluntary movement
- ▶ Intensive mobilization and environmental enrichment
- ▶ Prevent and manage secondary medical complications
- ▶ Optimize basic bodily functions such as respiration, nutrition, elimination, and skin integrity

## Context of care

- ▶ Provide family education, training, and support
- ▶ Establish a plan for after-care
- ▶ Establish prognosis and goals of care



*Accurately assess the current  
level of consciousness*

*Address reversible causes of  
impaired consciousness*

*Trial interventions to enhance the  
level of consciousness*

# Interventions to Enhance the Level of Consciousness

- ▶ General rehabilitation interventions
  - ▶ Sensory stimulation
  - ▶ Mobilization (sitting, standing)
  - ▶ Interpersonal interaction
- ▶ Pharmacological agents
  - ▶ Neurostimulants
  - ▶ GABA agonists
  - ▶ Other

# Interventions to Enhance the Level of Consciousness (cont.)

- ▶ Brain stimulation\*
  - ▶ Electrical
    - ▶ Deep Brain Stimulation (DBS)
    - ▶ Transcranial Direct Current Stimulation (tDCS)
    - ▶ Repetitive Transcranial Magnetic Stimulation (rTMS)
    - ▶ Vagus Nerve Stimulation (VNS)
    - ▶ Median Nerve Stimulation (rMNS)
  - ▶ Ultrasound
    - ▶ Low Intensity Focused Ultrasound (LIFU)
- ▶ Biological therapies\*
  - ▶ Stem Cell therapy

\* Not yet routinely utilized in clinical practice

# *Intensive mobilization and environmental enrichment*

# Body-Weight Supported Treadmill Training

*Minimize restrictions in  
range of motion*



# Spasticity and Contracture

*Identify and augment residual  
voluntary movement*

# Myo-Electric Orthosis

*If appropriate, establish a system of communication and motoric agency*

# Modes of Communication and Control

- ▶ Motoric
- ▶ Ocular
- ▶ Sub-clinical motoric
  - ▶ Surface EMG
- ▶ Non-motoric
  - ▶ Brain-Computer Interface (BCI)

# Brain-Computer Interface

*Prevent and manage secondary  
medical and neurological  
complications*

# Medical/Neurological Complications

- ▶ Infection
- ▶ Venous thrombosis
- ▶ Skin breakdown
- ▶ Heterotopic ossification
- ▶ Paroxysmal sympathetic hyperactivity
- ▶ Seizures
- ▶ Endocrine/metabolic abnormalities



*Optimize basic bodily functions such  
as respiration, nutrition, elimination,  
and skin integrity*

# Optimize Basic Bodily Functions

- ▶ Respiration
- ▶ Digestion/nutrition
- ▶ Elimination
- ▶ Integument
- ▶ Autonomic
- ▶ Sleep/wake
- ▶ Nociception/pain

*Provide family education, training,  
and support*

*“Brain damage is a family affair.”*

Muriel Lezak, PhD, 1988

# Unique Challenges Facing Families of Patients with DoC

- ▶ Early pressure/weight of decision regarding withdrawal of care
- ▶ Expectancy bias → mistrust
- ▶ Cognitive dissonance—survival → long-term disability
- ▶ Emotional fallout—regret, guilt, despair
- ▶ Ambiguous loss

# Family Education and Training

## ▶ **Establishing trust**

- ▶ Acknowledge the unknown and unpredictability
- ▶ Educate regarding conceptions of ‘consciousness’
- ▶ Encourage sharing of observations
- ▶ Engage collaboration with team to interpret patient’s behaviors

## ▶ **Gaining alignment**

- ▶ Collaborate regarding goals of admission
- ▶ Train family members as co-therapists
- ▶ Establish plans for after-care
- ▶ Consider ‘supported failure’ scenarios

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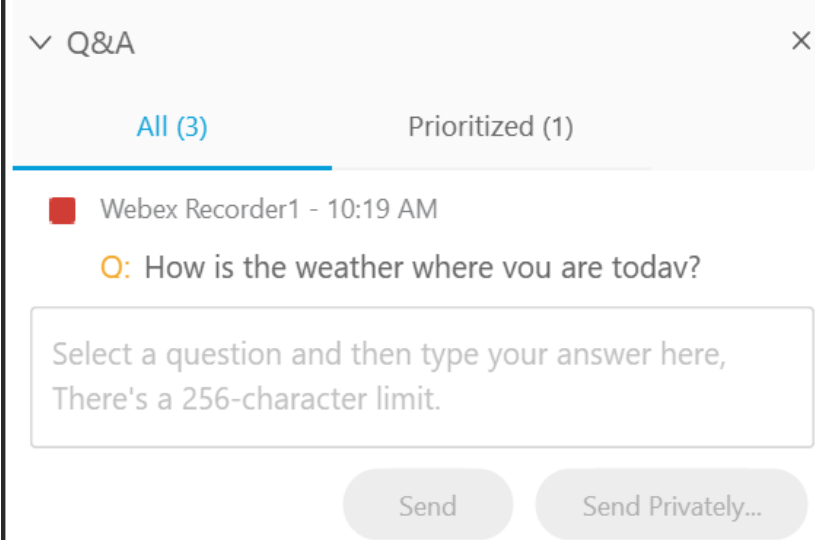
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Q&A

All (3)      Prioritized (1)

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Q: How is the weather where you are today?

Select a question and then type your answer here,  
There's a 256-character limit.

Send      Send Privately...

**Thank you**