Measurement in Pediatric Neurorehabilitation: Utility for severe DEEs?

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We are all born with great potential.
Shouldn't we all have the chance to achieve it?

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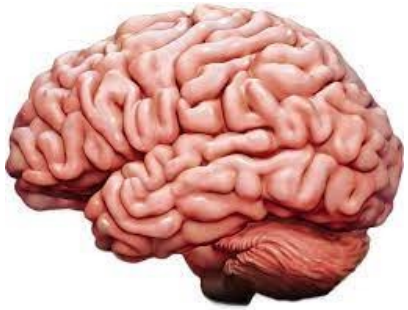
What is neuropsychology?



Cognition

Memory & Learning

Attention

Communication

Motor Skills

Functional skills

Emotional regulation

Behavioral Regulation

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Neuropsychology's role in DEEs

- Reasons for assessment
  - Baseline
  - Monitor progress
  - Monitor for regression
  - Track response to medications/treatment

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Neuropsychology's role in DEEs

The Problem

Typical neuropsychological measures are not appropriate for severely impacted individuals with DEEs. There is a **critical** need for measures that have utility for this group.

Could neurorehabilitation measures offer promise?

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Neurorehabilitation

- Children who have experienced a **decline** in cognitive/motor/communicative/adaptive functioning associated with a change to the brain
- Cognitive and functional deficits can vary from subtle concerns to severe impairments

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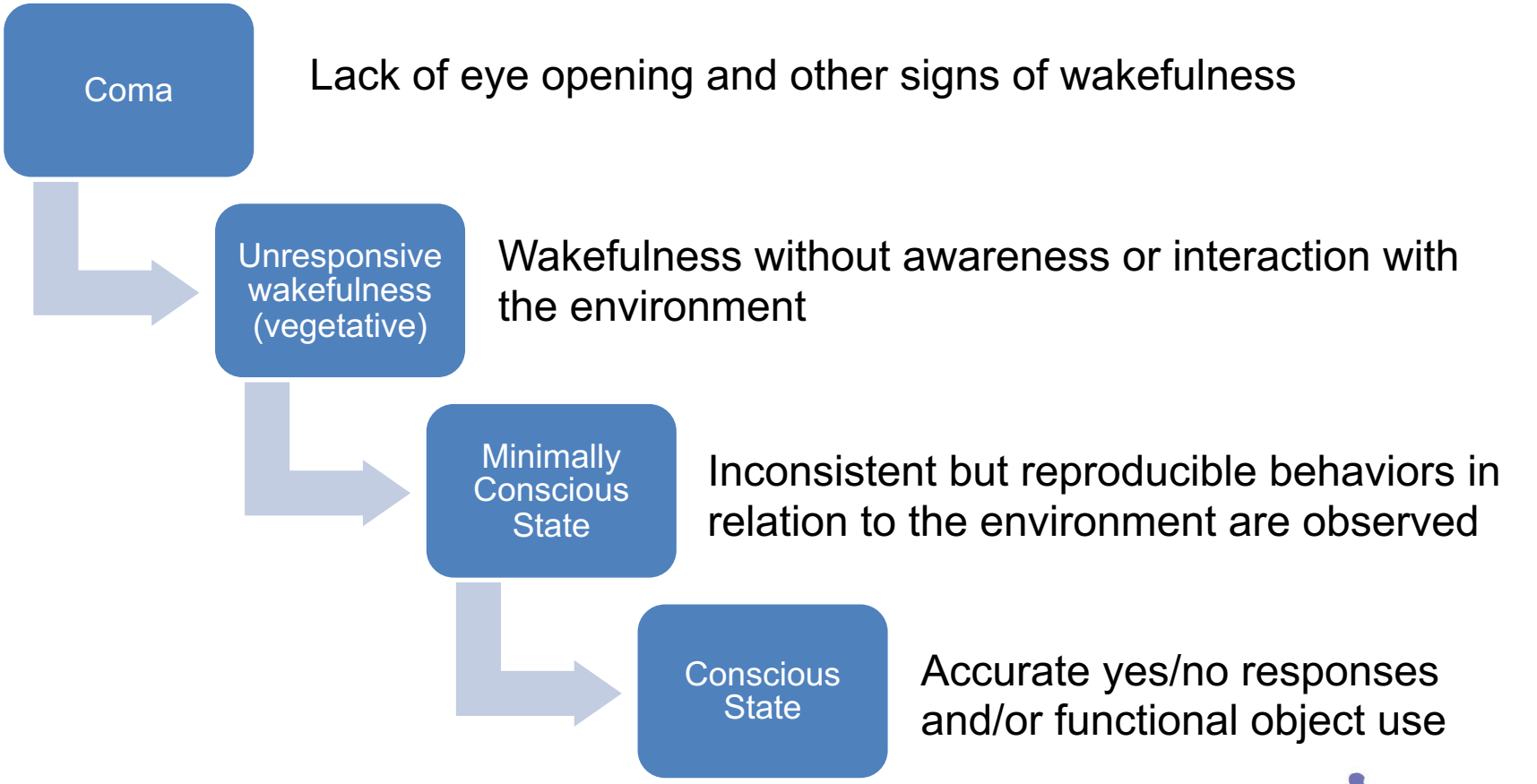
Disorders of Consciousness



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Role of neuropsychology in neurorehabilitation

- Serial monitoring of cognitive and functional changes over the course of recovery
  - Informs therapies
  - Facilitates longer-term planning (i.e., predictors of outcome)

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Weaknesses of neuropsychological measures

- Typical neuropsychology measures may not work as well within the rehab context
  - Need to be alert, communicate clearly, and attend to task for a significant amount of time
  - Many children have severe sensory, motor, communicative impairments and would obtain the lowest possible score on these measures

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Testing children within a rehab context

- **The *art***
  - Assessment approaches are individualized and appropriate for developmental level and best response modality
  - Assessment is ongoing, focused on strengths/abilities, and includes family/therapist observation
  - Assessment targets are in line with family/therapist goals for treatment

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Testing children within a rehab context

- **The *science***
  - While assessment is very individualized in rehab settings, we do need some approaches that can be applied broadly to compare across patients and rehabilitation centers to explore outcomes

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Neurorehabilitation measures that may have utility for severe DEEs

Rappaport Coma/Near Coma Scale

- Identifies **changes in consistency of response to stimuli**
- Areas assessed:
  - Auditory Responsivity
    - Bell rings and response of eye opening or orientation towards sound
  - Command Following
  - Visual Responsivity
    - Fixation or avoidance of light
    - Fixation and tracking of face
    - Response to visual threat

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Rappaport Coma/Near Coma Scale

- Olfactory Responsivity
  - Withdrawals or other response to ammonia smell
- Tactile Responsivity
  - Head or eye orientation or shoulder movement to shoulder tap
  - Withdrawal, eye blink or mouth twitch to nasal swab
- Pain Response
  - Withdrawal or agitation to pinch on finger/ear
- Vocalization
  - Words, non-verbal vocalization

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JFK Coma Recovery Scale – Revised (CRS-R)

- Assesses auditory function, visual function, motor function, oromotor/verbal function, communication, and arousal

BRAIN INJURY
2019, VOL. 33, NOS. 13–14, 1640–1645
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Taylor & Francis
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Check for updates

Preliminary validation of the coma recovery scale for pediatrics in typically developing young children

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JFK Coma Recovery Scale – Revised (CRS-R)

JFK COMA RECOVERY SCALE ©2004

Record Form

This form should only be used in association with the "CRS-R ADMINISTRATION AND SCORING GUIDELINES" which provide instructions for standardized administration of the scale.

Patient:	**Diagnosis:**									
Date of onset:	**Date of Admission:**									
Date										
Assessment	**1**		**2**		**3**		**4**		**5**	
AUDITORY FUNCTION SCALE	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**
4 – Consistent Movement to Command▪										
3 – Reproducible Movement to Command▪										
2 – Localization to Sound										
1 – Auditory Startle										
0 – None										
VISUAL FUNCTION SCALE	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**
5 – Object Recognition▪										
4 – Object localization: Reaching*										
3 – Visual Pursuit*										
2 – Fixation*										
1 – Visual Startle										
0 – None										

JFK Coma Recovery Scale – Revised (CRS-R)

MOTOR FUNCTION SCALE	#	TCC	#	TCC	#	TCC	#	TCC	#	TCC
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	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**
3 – Intelligible Verbalization▪										
2 – Vocalization/Oral Movement										
1 – Oral Reflexive Movement										
0 – None										
COMMUNICATION SCALE	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**
2 – Functional: Accurate†										
1 – Non-functional: Intentional▪										
0 – None										
AROUSAL SCALE	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**	**#**	**TCC**
3 – Attention										
2 – Eye Opening w/o Stimulation										
1 – Eye Opening with Stimulation										
0 – Unarousable										
TOTAL SCORE										

Oromotor/Verbal Function Scale **Score: _____**

3 – Intelligible Verbalization – at least **two different verbalizations/words that are C-V-C triads must be documented** by the examiner. Words need not be appropriate or accurate for the context, but must be fully intelligible; AND words are produced by writing or alphabet boards are acceptable. These verbalizations **can occur spontaneously** at other times during the assessment.

Spontaneous Intelligible Verbalizations – Words (list): _____

_____

USE INTELLIGIBLE VERBALIZATION PROTOCOL IF TWO SPONTANEOUS INTELLIGIBLE VERBALIZATIONS ARE NOT HEARD (next page)

If two different words are spontaneously produced OR two different words are produced from the Intelligible Verbalization Protocol: STOP HERE

2 – Vocalization/Oral Movement – **at least 1 episode of non-reflexive oral movement and/or vocalization** occurs spontaneously or in response to application of sensory stimulation. (ex: opening mouth, sticking out tongue, etc.)

- Observe for non-reflexive oral movements, spontaneous vocalizations or vocalizations that occur during administration of vocalization commands on the Oromotor/Verbal Function Scale. (ex: babbling, cooing)

Describe Vocalization/Oral Movement (list): _____

_____

_____

If 1 non-reflexive oral movement OR vocalization is produced spontaneously, OR if observed during the Intelligible Verbalization Protocol: STOP HERE

1 – Oral Reflexive Movement – there is clamping of jaws, tongue pumping, or chewing movement following introduction of tongue blade into mouth. Yawning is also scored as reflexive oral movement.

- Before presenting *tongue blade*, ask patient to "open your mouth"
  1) If patient opens mouth or shows some other non-reflexive movement (clenching mouth closed) score as vocalization/oral movement and do not administer item
  2) If patient does not follow command, present the *tongue blade* between patient's lips and/or teeth.

Oral Reflexive Movement Following Tongue Blade (circle): Yes or No

If oral reflexive movement is observed or produced with tongue blade: STOP HERE

0 – None – no response to any of the above.

Cognitive and Linguistic Scales (CALS)

- 20-item scale; rated from 1 (lower function) to 5 (better function)
- Not norm-referenced, compares the child to themselves over time
- Adaptable to sensory and motor needs

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Cognitive and Linguistic Scales (CALS)

- **9 Observed Items**
  - Arousal
  - Responsivity
  - Emotional Regulation
  - Inhibition
  - Attention
  - Response Time
  - Initiation
  - Pragmatics
  - Cognitive Safety

Telehealth!

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COGNITIVE AND LINGUISTIC SCALE (CALS) EVALUATION FORM © 2000, 2001

Beth Slomine Ph.D., ABPP and Janine Spezio Eikenberg M.S., CCC-SLP

Name:_____ Date:_____

Directions: The starred (*) items are observed while the other items are administered.

INTRODUCTION: "*Hi my name is _____. I am going to have you do a number of different things today, but the first thing I will do is hide a toy. I want you to remember what I hide and where I hide it.*" After you hide the toy ask, "*What did I hide and where did I hide it?*" Wait for the patient's response then remind them to, "*Remember what I hid and where I hid it because I will ask you again later.*"

***AROUSAL:** Observe the patient's level of arousal and score accordingly. The ability to be awake with eyes open unless there is a medical reason that the eyes can not be opened (i.e., bilateral ptosis). Signs of fatigue such as yawning or dozing off are evidence of decreased arousal.

1. not awake or almost never is awake (20% or less) ____
2. awake sometimes (21-40%) ____
3. awake half of the time (41-60%) ____
4. awake most of the time (61-80%) ____
5. awake almost always (81-100%) ____

***RESPONSIVITY:** Observe the responsivness and score accordingly. The ability to react to stimuli in a non-purposeful or purposeful way. (Present visual, auditory, tactile stimuli to the patient and examine responses).

1. minimally responsive (20% or less) ____
2. responds to stimulation sometimes (21-40%) ____
3. responds to stimulation half of the time (41-60%) ____
4. responds to stimulation most of the time (61-80%) ____
5. responds to stimulation almost always (81-100%) ____

***EMOTIONAL REGULATION**: Score whether or not the patient exhibited the following emotions in the CALS sessions (e.g., does the patient smile appropriately, what is their overall affect, do they have a full range of emotions and what is the appropriateness of emotions). *Note: If responsivity was rated a 1-4 automatically score a 1 for emotional regulation. (Circle + or – for each item).

1. smiles/laughs appropriately + –
2. displays a range of appropriate emotion (through facial expressions and tone of voice) + –
3. no lability (i.e., no rapid change in affect, no unstable affect) + –
4. appropriate frustration tolerance + –
5. no signs of agitation + –

Score- /5 or %

***INHIBITION:** Mark whether the behavior was observed (+), not observed (-) or not assessed (N/A). *Note: If a patient scores a 1-4 on responsivity automatically score a 1 for inhibition.

Does the patient:

1. wait his/her turn (i.e., refrain from interrupting others) + –
2. think/listen before responding (i.e., refrain from blurting out answers) + –
3. carefully complete his/her work and works slowly + –
4. refrain from perseverative speech/behavior + –
5. not need to be told "no," "stop that," or "wait" (i.e., does not grab items or toys prior to being told). + –

Score- /5 or %

COGNITIVE AND LINGUISTIC SCALE (CALS) EVALUATION FORM © 2000, 2001

Beth Slomine Ph.D., ABPP and Janine Spezio Eikenberg M.S., CCC-SLP

***FOCUSING AND RESISTING COMPETING STIMULI:** Score the following based on a 5-mintue task (i.e., problem solving task).

1. unable to focus momentarily ____
2. able to focus momentarily ____
3. able to sustain attention with > 3 cues during a 5-mintue task ____
4. able to sustain attention with 1 to 3 cues for re-direction during a 5-mintue task ____
5. does not need re-direction during a 5 minute task ____

***RESPONSE TIME/PROCESSING SPEED:** Observe the time it takes to respond to tasks. *Note: If Responsivity was rated a 1-4 automatically score 1 for response time/processing speed.

1. does not respond or delay >30 seconds ____
2. average response time >10 and <30 seconds ____
3. average response time <10 and >5 seconds ____
4. average response time <5 seconds ____
5. average response is immediate ____

Cognitive and Linguistic Scales (CALS)

Rehabilitation Psychology
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Psychometric Properties of the Cognitive and Linguistic Scale: A Follow-Up Study

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- No age group had a floor or ceiling effect
- Scores improve significantly between admission and discharge for children of all age groups and subgroups with limited responsiveness

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Next Steps…

- **Explore the utility of select rehabilitation measures in children with DEEs who are severely impacted**
  - Rappaport, CRS-R, CALS observational items
    - Examine the feasibility, acceptability, and appropriateness by families and providers
    - Examine domains/items that have variability in response and are sensitive to change
    - Examine how these measures compare to established functional measures (e.g., Vineland-3)
    - Examine telehealth vs. in-person administration

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