SLEEP, FATIGUE AND WAKE DISORDERS AFTER BRAIN INJURY: A PRACTICAL WORKSHOP FOR CLINICIANS

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with special thanks to Marie-Christine Ouellet Ph.D.

Outline of Presentation

- Overview of Sleep and Human Function
- Sleep and ABI; epidemiology, pathophysiology, contributing/confounding factors, medical management
- Sleep & fatigue, an overview
- Breakout session: Clinical presentation, evaluation, adapting interventions, CBT
- One person’s experience
- Discussion & functional recommendations for your practice
Assessment of Sleep Disturbance: Insomnia Severity Index

Over the last two weeks
1. I have difficulty falling asleep (0= none, 4= very severe)
2. I have difficulty staying asleep (0=none, 4=very severe)
3. I have a problem waking up too early
4. How satisfied are you with your current sleep pattern (0 = very satisfied, 4 = very dissatisfied)
5. To what extent do you consider your sleep problem to INTERFERE with your daily functioning (e.g. daytime fatigue, ability to function at work/daily chores, concentration, memory, mood, etc.?)
   (0=not at all, 4=very much)

Assessment of Sleep Disturbance: Insomnia Severity Index (cont.)

Over the last two weeks
6. How NOTICEABLE to others do you think your sleeping problem is in terms of impairing the quality of your life?
   0 = Not at all, 4 = Very Much
7. To what extent do others consider your sleep problem to INTERFERE with your daily functioning (e.g. daytime fatigue, ability to function at work/daily chores, concentration, memory, mood etc.?)
   0 = Not at all, 4 = Very Much
Assessment of Sleep Disturbance:
Insomnia Severity Index (cont.)

Over the last two weeks

8. How WORRIED/distressed are you about your current sleep problem?
   0 = Not at all, 4 = Very Much

   Guidelines for scoring:
   0-7 = No clinically significant insomnia
   8-14 = Sub threshold insomnia
   15-21 = Clinical Insomnia (moderate severity)
   21-28 = Clinical Insomnia (severe)


Scope of the Problem

- Sleep and wake problems affect 30 to 75% of persons with TBI across continuum of recovery and levels of severity
- Fatigue is also common, most pervasive symptom after TBI, affect 50-80% of individuals living in the community
- Linked to problems with mood, cognition, pain
- Remains a major issue even several years post-injury

Sleep: That mysterious state; what exactly is it and why do we need it?

- A revitalizing, restoring and rejuvenating process
- A complex orchestration that occurs in the brainstem
- A critical function that serves to reverse or restore biological and/or biochemical processes that are progressively degraded during prior periods of wakefulness
Role of Sleep: Endocrine & Immune Function

- Essential for optimal immune function by influencing cellular (T-cell) immunity.
- Plays key role in hormone release
- Increase in growth hormone secretion observed immediately following sleep onset, concurrently with rise in cortisol during latter half of sleep
- Growth hormone important from perspective of recovery from trauma; stimulates growth and cell reproduction, and plays critical role in cell regeneration, supports cognitive function and aerobic capacity


Endocrine and Immune Function

- Cortisol, released during latter half of night, plays a crucial role in facilitating the body's adaptation to physical and mental stress,
- Increased production of erythrocytes (red blood cells).
- Suppression of inflammation, enhancement of wound healing, modulation of plasma glucose

Sleep and Human Function: Emotional Processing

- Ensuring adequate sleep important for modulation of mood
- Medial pre-frontal cortex allows us to ‘reason and objectively evaluate emotions’ is highly sensitive to sleep deprivation. With reduced sleep, there is loss of functional connectivity between limbic system (emotional processing) and MPFC
- Reduced sleep/sleep debt results in irritability, anxiety, heightened emotional lability and errors in judgment

Sleep and Human Function: Communication

- Sleep deprivation, fatigue and or excessive day-time sleepiness results in difficulty with word finding, following and responding in conversation
- Social communication abilities are significantly impaired with sleep disturbance

Sleep plays an important role in learning and memory consolidation.

Restricted sleep impairs/reduces the speed and efficiency of language and information processing.

Restricted sleep impairs all aspects of attention, particularly divided attention, working memory and sustained attention (vigilance).


How much sleep do we need?

- Infants - toddlers: 16 hours
- Children: 12-14 hours
- Teenagers: 9-11 hours
- Adults: 7-9 hours; but there is a variation
Sleep and TBI

- Sleep too much
- Sleepy in the day
- Daytime fatigue
- Sleep too little at night
- Lack of restful sleep

“What managing patients with an ABI and Sleep Disorders sometimes feels like”
Introduction and Overview

- Sleep disorders are a difficult entity to identify, and manage, especially in the acquired brain injured (ABI) population.
- This is in large measure due to the number of other complaints that may overshadow sleep problems.
- A number of symptoms of sleep disorders such as cognitive difficulties occur as a result of brain injury by itself.

Epidemiology

- 46% of Traumatic Brain Injury patients have sleep disorders
  - 23% Obstructive Sleep Apnea
  - 11% Post-Traumatic Hypersomnia
  - 6% Narcolepsy
  - 7% Periodic Leg Movements in Sleep
- 25% Excessive Daytime Sleepiness (EDS)
- Sleepy subjects had a greater body mass index (BMI) than those who were not sleepy (p = 0.01)
- OSA was more common in obese subjects (BMI ≥30, p <0.001)
Epidemiology cont.

- GCS scores are not associated with the presence of EDS
- Comparisons of sleep-disordered versus non-sleep-disordered subjects disclosed no clear relationship between the presence of a sleep disorder and injury severity, cause of injury, or the presence of positive CT scan findings

Catriotto et al 2007

Sleep disorders as a cause of injury

- Both subjects with OSA and narcolepsy have a greater chance of MVA’s and hence TBI, it is not surprising that both conditions have a higher prevalence in post-TBI subjects
- It is very possible that some subjects may have had a pre-existing undiagnosed sleep disorder
- Presence of a sleep disorder may contribute to the occurrence of the accident that caused the traumatic brain injury
Factors predisposing to Sleep Problems after ABI

- Amount of brain damage
- Location of brain damage
- Neuropathology
- Neurochemistry
- Emotional impact of injury
- Response to intellectual impairments
- Development of epilepsy
  - Especially temporal lobe epilepsy
- Post-Injury lifestyle
- Compensation and litigation

Pathophysiology

![Diagram showing the relationship between ABI, Direct Effects, Indirect Effects, and Sleep Disorder]
Direct Damage

- Direct involvement of the hypnogenic neurons
- Hypofunction of the hypothalamic preoptic nuclei or the lower brain stem hypnogenic neurons alters the balance between the waking and the sleeping brain causing wakefulness or sleeplessness
- Disorders of the posterior hypothalamic region, or the ascending reticular activating system, responsible for waking and alertness, can cause hypersomnolence
Pathophysiology (3) cont......

Indirect Effects

Major Psychiatric Syndromes
Behavioral abnormalities
Mood disorders
Anxiety disorders
Psychotic disorders

Substance Abuse Dependence
Antidepressants

Pain

Physical problems
Impaired mobility

Medications
Anticonvulsants
Antipsychotics
Analgesics etc.

Psychosocial stressors

SLEEP DISORDER

Direct effects

ABI

........ Indirect Actions

- Pain, confusional episodes, changes in the sensorimotor system, or movement disorders can interfere with sleep
- Medications can have a direct effect on sleeping and breathing
- Neurologic diseases may change the neurochemical environment of the sleep generating and sleep promoting neurons
- Associated Neuropsychiatric disturbances can affect sleep
- Sleep-wake schedule disturbances
- Sleep related respirator dysrythmias may result in sleep fragmentation
Iatrogenic Sleep Disorders

- **Medications**
  - Anti-psychotics
    - Akathisia
  - Antidepressants
    - SSRI, SNRI
    - Akathisia like symptoms
  - Benzodiazepines
    - Paradoxical rage
  - Mood stabilizers
  - Anticonvulsants
  - Gabapentin
  - ...

- **Intrusive Cognitive Behavioral Programs**
- **Unsolicited therapies**

“**What happens if sleep disorders are not taken into consideration**”
Psychiatric Disorders that may contribute to sleep problems

- Affective Disorders
  - Depression
  - Bipolar Affective Disorder
- Anxiety Disorders
  - Generalized Anxiety Disorder
  - Panic Disorder with or without Agoraphobia
- Psychotic disorders
  - Paranoia
- Personality Disorders
  - Borderline / Antisocial / Narcissistic

Weight-gain post ABI

- 45% of patients exceeded a BMI of 30kg/m² and most of them gained significant weight in the time period following TBI
- Possible Mechanisms:
  - Direct injury to hypothalamic feeding and satiety centers
  - Inactivity due to pain or neurological handicap
  - Anti-epileptic drugs, anti-depressants & psychotropic drugs used to treat posttraumatic complications

Verma et al. 2007
Management of Sleep Disorders from a Medical Perspective

- Mange respiratory issues
- Manage insomnia mostly with medications (but CBT can play a role)
- No set regime identified in the literature as consistently effective in the long-term
- Variety of options and medication classes
- Treat antecedent conditions
- Treat medical condition
- Treat iatrogenic causes
- Manage Weight gain
- Periodically re-evaluate treatment

Therapies to Assist in Management

- Cognitive therapy to identify and modify thoughts and feelings that may initiate insomnia/hypersomnia
- Behavior therapy to identify triggers and modify responses
- Supportive and individual therapy to identify environmental and social needs
SLEEPINESS AND FATIGUE: RELATED, BUT TWO DIFFERENT ANIMALS!! (OR VEGETABLES)

Sleepiness and Fatigue; How are they different?

<table>
<thead>
<tr>
<th>Sleep</th>
<th>Fatigue</th>
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<tbody>
<tr>
<td>□ Objectively measureable physiological process due to sensitive balance of neurotransmitters</td>
<td>□ A subjective feeling of weariness or exhaustion</td>
</tr>
<tr>
<td>□ Results in a build up of sleep pressure (process ‘S’) throughout the day</td>
<td>□ A sense of being drained of energy</td>
</tr>
<tr>
<td>□ Characterized by increased propensity to sleep, &amp; increased sleep time proportional to period of sleep debt</td>
<td>□ Fatigue in neurologic populations different from general population</td>
</tr>
<tr>
<td></td>
<td>□ Does not respond to sleep or rest</td>
</tr>
<tr>
<td></td>
<td>□ Not accompanied by desire to sleep</td>
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How many of you consider sleep and wakefulness in your routine assessment of ADL’s???

Hint: We think it should be routinely assessed by all clinicians; this needs a collaborative effort.

WHAT ARE THE MAIN MANIFESTATIONS OR SIGNS OF FATIGUE AND OR SLEEPINESS IN YOUR CLIENTS?
Breakout session: Questions to Consider

1) What are the main manifestations or signs of fatigue or sleepiness in your clients?
2) Do you need to change or adapt your interventions to account for fatigue in your clients? If yes, how so?
3) Do you use specific tools to evaluate fatigue and sleep (questionnaires, scales)? If yes, which ones?
4) Do you give specific recommendations or advice to your clients about fatigue? If yes, which ones?

Manifestations and signs of fatigue and sleep/wake disturbance

- Five main themes:
  - Alterations of cognitive functions
    - Emotional reactions
    - Bodily signs
    - Endurance
    - Communication

- Attention
- Concentration
- Errors
- Difficulty processing instructions
Manifestations and signs of fatigue

Five main themes:
- Alterations of cognitive functions
- Emotional reactions
  - Bodily signs
  - Endurance
  - Communication

- Endurance
- Communication
Manifestations and signs of fatigue

Five main themes:
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For Discussion: Manifestations and signs of fatigue

Five main themes:
- Alterations of cognitive functions
- Emotional reactions
- Bodily signs
- Endurance
- Communication

- Decreased performance
- Decreased dynamism
- Need for rest

- Difficulty following a conversation
- Difficulty with speech
Research Study: Sleep and wake disorders following TBI; Impact on recovery of cognitive-communication performance

Principal Investigator: Catherine Wiseman-Hakes

- **Hypothesis:** Sleep and wake disorders following TBI exacerbate deficits in cognition and communication. Thus effective diagnosis and management of sleep and wake problems after brain injury may facilitate recovery of cognition and communication.

- **Brief Description:** The study involves a thorough baseline assessment and evaluation of cognitive-communication status, an assessment of sleep by Dr Brian Murray, neurologist and sleep specialist at Sunnybrook Health Sciences Centre, overnight sleep study and day-time wakefulness test, treatment and management of the sleep/wake disorder, and follow-up assessment of cognitive-communication status once sleep is effectively treated.

Looking for participants who:

- Have experienced a moderate-severe TBI (complicated mTBI considered) and are 18-58 years of age
- Have ongoing problems with sleep, and fatigue that is NOT currently being treated
- Have reported cognitive and communication difficulties with attention, memory, following and participating in conversations in complex situations
- Are interested in having their sleep assessed and treated
- Minimum 1 year post injury
- Can read, write and speak English

Contact **Catherine Wiseman-Hakes** at the University of Toronto information:

**Phone:** 416-451 7167

**Email:** catherinew.hakes@utoronto.ca
FATIGUE AND SLEEP DISTURBANCE AFTER BRAIN INJURY: ONE PERSON’S EXPERIENCE - ANNE ARCHER

Working together

HOW TO CHANGE OR ADAPT YOUR INTERVENTIONS TO ACCOMMODATE FOR FATIGUE AND SLEEPINESS IN YOUR CLIENTS
Functional Management of fatigue and sleepiness: Adaptations or changes to interventions

- Five main themes:
  - Plan interventions optimally
    - Shorter interventions
    - Manage demands within the treatment period
    - Control the environment
    - Integrate pleasure and humour

Adaptations or changes to interventions

- Five main themes:
  - Plan interventions optimally
    - Shorter interventions
    - Manage demands within the treatment period
    - Control the environment
    - Integrate pleasure and humour
    - Not planning two demanding treatments back to back
    - Planning treatment during ‘optimal energy window’
    - Augment demands progressively in function of the client’s capacity
    - Cancelling or aborting therapy sessions
    - Shorter sessions
Adaptations or changes to interventions

- **Five main themes:**
  - Plan interventions optimally
  - Shorter interventions
  - Manage demands within the treatment period
  - Control the environment
  - Integrate pleasure and humour

- **Examples:**
  - Alternate tasks more and less cognitively or physically demanding
  - Complete more complex tasks in the beginning of the session
  - Take breaks

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- **Examples:**
  - Noise
  - Visitors
  - Commuting
Results: Adaptations or changes to interventions

- Five main themes:
  - Plan interventions optimally
  - Shorter interventions
  - Manage demands within the treatment period
  - Control the environment
  - Integrate pleasure and humour

What specific tools can you use to evaluate fatigue and sleep problems?
Functional tools used to evaluate fatigue

- Four main themes:
  - Observation of the client
  - Specific questions directed to the client
  - Help clients evaluate their fatigue levels
  - Evaluate other aspects which could cause/exacerbate fatigue

Tools used to evaluate fatigue and sleepiness

- Four main themes:
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Tools used to evaluate fatigue and sleepiness

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Fatigue Severity Scale: Each statement is rated 1-7, 1= strong disagreement, 7= strong agreement

1. My motivation is lower when I am fatigued
2. I am easily fatigued
3. Exercise or mental effort bring on my fatigue
4. Fatigue interferes with my physical and or mental functioning
5. Fatigue causes frequent problems for me
6. Fatigue prevents sustained mental and or physical functioning
7. Fatigue is among my 3 most disabling symptoms
8. Fatigue interferes with my work, rehab, family or social life
Tools used to evaluate fatigue and sleepiness

- Four main themes emerged:
  - Observation of the client
  - Specific questions directed to the client
  - Help clients evaluate their fatigue levels
  - Evaluate other aspects which could cause/exacerbate fatigue

BEHAVIOURAL AND ENVIRONMENTAL MANAGEMENT OF SLEEPINESS AND FATIGUE

- Medical disorders
- Medication
- Sleep disorder
- Anxiety
- Depression
- Unhealthy life habits
Functional Recommendations for management of fatigue and sleep disturbance

- Seven main themes:
  - Teach clients to recognize signs of fatigue and respect their limits
  - Education
  - Teach the client effective planning of activities
  - Make a judicious use of breaks and rests periods
  - Modulate the environment
  - Encourage healthy habits
  - Teach stress management
  - Regular verification of signs of fatigue
  - Help clients recognize and name signs of fatigue
  - Experimenting with the progression of fatigue

Recommendations:

- Seven main themes:
  - Teach the clients to recognize signs of fatigue and respect their limits
  - Education
  - Teach the client effective planning of activities
  - Make a judicious use of breaks and rests periods
  - Modulate the environment
  - Encourage healthy habits
  - Teach stress management
  - Present multidimensionality of fatigue
  - Normalize
  - Give handouts
  - Use of metaphors (battery, traffic light, bank account)
Recommendations:

- Seven main themes:
  - Teach the clients to recognize signs of fatigue and respect their limits
  - Education
    - Teach the client effective planning of activities
  - Make a judicious use of breaks and rests periods
  - Modulate the environment
  - Encourage healthy habits
  - Teach stress management
  - Chose timing of activities
  - Separate activities into more manageable units
  - Alternate between activities

Recommendations:

- Seven main themes:
  - Teach the clients to recognize signs of fatigue and respect their limits
  - Education
    - Teach the client effective planning of activities
  - Make a judicious use of breaks and rests periods
  - Modulate the environment
  - Encourage healthy habits
  - Teach stress management
  - Naps (a tough one...sometimes helpful, sometimes not)
  - Rest without sleeping (lying down, relaxation, walking, listening to music)
Recommendations:

Seven main themes:

- Teach the clients to recognize signs of fatigue and respect their limits
- Education
- Teach the client effective planning of activities
- Make a judicious use of breaks and rests periods
- Modulate the environment
- Encourage healthy habits
- Teach stress management

- Plan visits
- Inform significant others
- Prepare for social occasions
- Refrain from over-stimulating environments

- Regular exercise
- Sleep hygiene
- Regular meal times
- Limit caffeine or energy drinks
Recommendations:

- Seven main themes:
  - Teach the clients to recognize signs of fatigue and respect their limits
  - Education
  - Teach the client effective planning of activities
  - Make a judicious use of breaks and rests periods
  - Modulate the environment
  - Encourage healthy habits

Mindfulness Based Cognitive Therapy for Treating Depression in Traumatic Brain Injury

- Patients with TBI are at great risk for developing depressive symptoms (Seel, Kreutzer, Rosenthal, Hammond, Corrigan & Black, 2001).
- Major depressive disorder was observed in 30 (33%) of patients during the first year after sustaining a TBI (Jorge, Robinson, Moser, Tateno, Crespo-Facorro & Arndt).
- 2 previous smaller studies have found that MBCT helped persons with TBI become less depressed, and reported that they dealt better with problems and stressful situations.
- During group classes people are taught skills to help deal with unpleasant thoughts, feelings or experiences that cause tension, anxiety, stress and depression.
- May also help with sleep!
Looking for participants who:

- Have experienced a traumatic brain injury
- Have feelings of sadness or low mood
- Can commit to 10 weekly, 1.5 hours sessions
- Are willing to participate in a group setting
- More than one year, but less than 10 years after the onset of injury
- Can read, write and speak English

Contact Jordanne Dalgleish at Toronto Rehab for more information:
Phone: 416-597-3422 ext.7813
Email: dalgleish.jordanne@torontorehab.on.ca

Further Resources:
Workbooks to support healthy sleep


With thanks to Dr Jaan Reitav: Toronto Rehab Institute
WHEN AND WHERE TO REFER FOR FURTHER ASSESSMENT AND HELP

When to Refer

- Insomnia Severity Index score of 8 or more
- Fatigue Severity Score of 25 or more and not responding to behavioural and environmental interventions
- When the fatigue and or sleepiness are interfering with therapy, community integration and QOL
- When there is any mention of excessive snoring, leg twitching
- Client falls asleep routinely during the day
- When you are concerned that depression and or pain may be affecting sleep and wakefulness
Where to Refer

- To a facility where a physician will interpret the results and there will be a full assessment including blood work. For example, Toronto Western ABI Clinic – Chanth Seyone; Sunnybrook Health Sciences Centre - Brian Murray
- Important for the facility to assess all possible confounders; should evaluate endocrine function, wakefulness, blood iron, magnesium and B12 levels

“If patients with ABI are managed appropriately, life is so much simpler”
Summary and Conclusions

- Fatigue and Sleep Disorders are relatively common in ABI patients
- Its causality is multimodal
- It can be iatrogenic
- Its treatment should be multipronged
- Its prognosis is ?

Thank-you!

Marie-Christine Oulette, Ph.D.
Neuro-Rehab Services Inc.
Toronto Rehab Institute

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