USC SleepHuB Special Seminar
Co-hosted by the Chan Division of Occupational Science and Occupational Therapy

Sleep Disturbance and Chronic Neurologic Dysfunction
Donald Fogelberg, PhD, OTR/L
University of Washington
Welcoming Remarks

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Today’s Presentation

Sleep Disturbance and Chronic Neurologic Dysfunction

Donald Fogelberg, PhD, OTR/L
University of Washington
Sleep Disturbance in Chronic Neurologic Conditions

Donald Fogelberg, PhD, OTR/L
University of Washington
2024
WHY IS SLEEP IMPORTANT?
Why is sleep important?

• Sleep loss is associated with cognitive problems, including:
  – Decreased alertness
  – Problems remembering
  – Decreased attention span
  – Impaired judgment & decision making

Banks & Dinges, 2007; Harrison & Horn, 2000; Fulda & Schulz, 2001
Why is sleep important?

• Sleep loss can increase the experience of pain
• Sleep loss increases the risk of depression
• Sleep loss is associated with a number of health problems, including:
  – Immune and endocrine system dysfunctions
  – Obesity
  – Diabetes
  – Cardiovascular disease

Banks & Dinges, 2007; Lautenbacher, Kundermann, & Krieg, 2006
IMPORTANCE OF SLEEP IN THE CONTEXT OF NEUROREHABILITATION
Sleep disturbance following TBI

– Prevalence
  • Estimates range from 3% and 84% (Zeitzer et al., 2009)
  • Acute: 68% (Makley et al., 2008)
  • Chronic: 27% (Colantonia et al., 2004)
UW TBI Model Systems

— Participants

• N = 174
• Moderate to severe TBI
• 1 year post injury
## PSQI Subscale Scores

<table>
<thead>
<tr>
<th>Subscale</th>
<th>TBI</th>
<th>General Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep quality *</td>
<td>0.83</td>
<td>0.35</td>
</tr>
<tr>
<td>Latency *</td>
<td>1.32</td>
<td>0.56</td>
</tr>
<tr>
<td>Duration</td>
<td>0.43</td>
<td>0.29</td>
</tr>
<tr>
<td>Efficiency</td>
<td>0.29</td>
<td>0.10</td>
</tr>
<tr>
<td>Disturbances *</td>
<td>1.23</td>
<td>1.00</td>
</tr>
<tr>
<td>Medication use *</td>
<td>0.55</td>
<td>0.04</td>
</tr>
<tr>
<td>Daytime dysfunction *</td>
<td>0.74</td>
<td>0.35</td>
</tr>
<tr>
<td>Global scale *</td>
<td>5.54</td>
<td>2.67</td>
</tr>
</tbody>
</table>

* = p < .05

from Fogelberg et al., 2012
Sleep and Co-Occurring Conditions after TBI

- Global PSQI score correlated with depression (PHQ-9, \( r=0.72 \)), anxiety (GAD-7, \( r=0.39 \)), and pain (average pain intensity during past week, \( r=0.56 \))

from Fogelberg et al., 2012
## Sleep following TBI

<table>
<thead>
<tr>
<th></th>
<th>FIM</th>
<th>DRS</th>
<th>SWLS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sample Median</strong></td>
<td>≤118</td>
<td>&gt;118</td>
<td>≤1.5</td>
</tr>
<tr>
<td><strong>Sleep Quality</strong></td>
<td>1.10</td>
<td>0.59*</td>
<td>0.69</td>
</tr>
<tr>
<td><strong>Latency</strong></td>
<td>1.70</td>
<td>0.97*</td>
<td>1.14</td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td>0.56</td>
<td>0.44</td>
<td>0.49</td>
</tr>
<tr>
<td><strong>Efficiency</strong></td>
<td>0.52</td>
<td>0.51</td>
<td>0.44</td>
</tr>
<tr>
<td><strong>Disturbances</strong></td>
<td>1.43</td>
<td>0.81*</td>
<td>0.92</td>
</tr>
<tr>
<td><strong>Medication Use</strong></td>
<td>0.79</td>
<td>0.30</td>
<td>0.43</td>
</tr>
<tr>
<td><strong>Daytime Dysfunction</strong></td>
<td>1.05</td>
<td>0.45*</td>
<td>0.56</td>
</tr>
<tr>
<td><strong>Global Score</strong></td>
<td>7.12</td>
<td>4.04*</td>
<td>4.64</td>
</tr>
</tbody>
</table>

*from Fogelberg et al., 2013*
SCI AND THE EXPERIENCE OF SLEEP DISTURBANCE
Why would sleep be affected by SCI?

• Physiological
  – Melatonin
  – Antidiuretic hormone (ADH)
    • Lack of variation in daytime and nighttime levels
    • Leads to increased night-time urinary output
  – Body temperature regulation systems affected
  – Respiratory changes

• Psychological
  – Pain
  – Depression

• Behavioral
  – Pressure ulcer prevention routines
  – Changes in activity levels
  – Increased time spent in bed
## USC Pressure Ulcer Prevention Study

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD (Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at study commencement (Years)</td>
<td>43.6</td>
<td>±12.52 (28-78)</td>
</tr>
<tr>
<td>Time Since Diagnosis/Injury (Years)</td>
<td>14.9</td>
<td>±11.76 (1-37)</td>
</tr>
<tr>
<td>Age at Time of Injury (Years)</td>
<td>27.5</td>
<td>±12.65 (5-60)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>14:6 (70:30)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>High School Graduate or Less</td>
<td>8 (40)</td>
</tr>
<tr>
<td>Some College/College Graduate</td>
<td>11 (55)</td>
</tr>
<tr>
<td>Graduate School or Higher</td>
<td>1 (5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>6 (30)</td>
</tr>
<tr>
<td>Black/African American</td>
<td>8 (40)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCI Level</td>
<td></td>
</tr>
<tr>
<td>C1-C4</td>
<td>3 (15)</td>
</tr>
<tr>
<td>C5-C8</td>
<td>8 (40)</td>
</tr>
<tr>
<td>T1-S5</td>
<td>9 (45)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCI Completeness</td>
<td></td>
</tr>
<tr>
<td>Complete</td>
<td>16 (80)</td>
</tr>
<tr>
<td>Incomplete</td>
<td>3 (15)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (5)</td>
</tr>
</tbody>
</table>

Clark, et al 2006
Sleep Disturbance in PUPS Participants

- Transcripts for 18 participants (90%) contained sleep related data.
- Descriptions of sleep included:
  - Difficulties initiating or maintaining sleep
  - Poor quality, non-restorative sleep
  - Sleep restriction and deprivation
  - Irregular sleep patterns

Sleep Disturbance in PUPS Participants

- Barriers to sleep:
  - SCI-related motor and sensory dysfunction
    - E.g., pain, muscle weakness/paralysis
    - Bladder management
  - Co-occurring conditions
    - Pressure ulcers
    - Anxiety
    - Depression
  - Sleep environments and surfaces
Helen

- I've been on that [medication] for years and years. That's to help me sleep. ‘Cause I couldn't sleep... I could not sleep. You know, I just couldn't. So as result of not sleeping I couldn't think right. I just, I just wasn't functioning right at all. Now that I look back, I wasn't.
Dave

- I wish I could go to sleep at 1:00 at night and wake up at 9:00 in the morning. I used to sleep like you wouldn't believe, and I can't do that anymore. I am up all night long and then all of a sudden I’ll fall asleep for a few hours, and then I’ll be awake for a few hours and then I would fall asleep for a few hours or...
Mitch

• When I sleep, I'm not even sure I'm asleep 'cause I can hear stuff.... If I'm sleeping and you're talking, I can hear you.

• Mainly because of my arm, I couldn't really raise myself up and I would lie [down] and my face would be buried in the mattress, so it wasn’t too comfortable. And I couldn’t turn my head too much, because my neck [had] been fused....
Chris

• Sometimes it’s annoying, when you’re trying to take a nap and then my head will start sliding across the pillow.... I’m lying [there] and then I will go that way and my head will start [sliding] this way, and I’m like, oh, man!

• It’s hard for me to sleep with so much pain. It’s weird; my body is like freaking out on me...
COMMON MEASUREMENTS IN SLEEP RESEARCH
Self report

Consensus sleep diary

- Available online
- Multiple versions available, with varying degrees of complexity
- Online calculator being developed: http://opensleepcalc.com/getting-started/
- Widely used in behavioral sleep medicine and sleep research
## Sleep Diary

<table>
<thead>
<tr>
<th>Sample</th>
<th>Consensus Sleep Diary-Core</th>
<th>ID/Name: ____________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Today's date</strong></td>
<td><strong>4/5/11</strong></td>
<td></td>
</tr>
<tr>
<td>1. What time did you get into bed?</td>
<td>10:15 p.m.</td>
<td></td>
</tr>
<tr>
<td>2. What time did you try to go to sleep?</td>
<td>11:30 p.m.</td>
<td></td>
</tr>
<tr>
<td>3. How long did it take you to fall asleep?</td>
<td>55 min.</td>
<td></td>
</tr>
<tr>
<td>4. How many times did you wake up, not counting your final awakening?</td>
<td>3 times</td>
<td></td>
</tr>
<tr>
<td>5. In total, how long did these awakenings last?</td>
<td>1 hour 10 min.</td>
<td></td>
</tr>
<tr>
<td>6. What time was your final awakening?</td>
<td>6:35 a.m.</td>
<td></td>
</tr>
<tr>
<td>7. What time did you get out of bed for the day?</td>
<td>7:20 a.m.</td>
<td></td>
</tr>
<tr>
<td>8. How would you rate the quality of your sleep?</td>
<td>□ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor</td>
<td></td>
</tr>
<tr>
<td>9. Comments (if applicable)</td>
<td>I have a cold</td>
<td>□ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor □ Poor □ Fair □ Good □ Very good □ Very poor</td>
</tr>
</tbody>
</table>
Self report

Questionnaires

> **PROMIS**
  - Separate item banks for sleep problems and sleep-related problems
  - Publicly available via: PROMIS website (registration required)

> **Medical Outcomes Study Sleep Scale**

> **Pittsburgh Sleep Quality Index**
Patient Reported Outcome Measures

- Adults (age 18 and older) with either MS (N=461) or SCI (N=239)
- Medical Outcomes Study Sleep Scale
- Patient Reported Outcomes Information System (PROMIS) short forms
  - Sleep Disturbance (PROMIS-SD)
  - Sleep Related Impairments (PROMIS-SRI)
Figure 1: MOS-S, PROMIS-SD and PROMIS-SRI scores for MS, SCI, and General Population samples.

* From Hays, et. al., 2005
** From Buysse, et. al., 2010
MOS-S vs PROMIS

• Response options:
  – MOS-S: none, little, some of the time, a good bit, most, all of the time)
  – PROMIS: not at all, a little, somewhat, quite a bit, very much

• Time frames:
  – MOS-S: 4 weeks
  – PROMIS: 1 week
Drawbacks of self-report

> May be perceived as burdensome
> Dependent on accurate recall
> Missing data
Actigraphy

> **Consumer models**
  - Fitbit
  - Smartwatches

> **Research models**
  - Philips Respironics
  - Actigraph
Fitbit Alta HR

Sleep Stage Feature

At night, your body cycles through different Sleep Stages. It usually moves from light sleep to deep sleep, back to light, then into REM, though sleep cycles vary naturally.
Drawbacks of actigraphy

- Measures movement, not sleep
- Algorhythm
  - Population?
- Motor impairment
- Determining rest period
Polysomnography

- Gold standard
- EEG, EOG, EMG, EKG, O2, Nasal flow, Respiratory Effort, PLM
- Allows sleep staging, diagnosis of sleep related breathing disorders, other sleep disorders
Polysomnography
Polysomnography
SCI PSG Study

• 16 adults with SCI >1 year
• C5 and below
• 2 nights of in-home polysomnography
• 25 scored nights of PSG total
Drawbacks of PSG

• Complex to set up
• Complex to score and interpret
• Participant acceptance
• Difficulty accessing sleep labs
• Unattended in-home PSG (sensors, environmental issues)
Key Points

- Sleep is both complex and important
- Clinicians: have a conversation with your clients about sleep
- Researchers: consider adding sleep as a variable
- Importance of triangulation
- Consider mixed-methods
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