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NORMAL SLEEP DURATION, BUT INCREASED TIME IN BED IN INDIVIDUALS WITH PROFOUND/SEVERE INTELLECTUAL DISABILITY WHO LIVE IN A RESIDENTIAL FACILITY

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INTRODUCTION

Few studies have been conducted on the normal sleep and time in bed in individuals with profound to severe intellectual disability who live in a residential facility. In one of the first studies in this area, Piazza et al.\textsuperscript{1} recorded sleep in 51 disabled children and adults. Using 30-min time intervals (time sampling), they found that compared to healthy controls, participants showed higher sleep latency and sleep fragmentation. Espie et al.\textsuperscript{2} have investigated sleep in 28 adults using diaries and one night EEG recording. They found that these adults spend almost 10 hours in bed on average, had a mean sleep-onset latency of 30 min, and had a mean sleep efficiency index (SEI; calculated as the total time asleep in bed divided by the total time spent in bed) of 81\%. More recently, Lindblom et al.\textsuperscript{3}, also using time sampling, found an average SEI of 74\% in a large sample of people with profound to mild disabilities.

Still little is known about the sleep duration, compared to the total time they spent in bed, in individuals with profound to severe intellectual disabilities who live in a residential facility. None of the above studies used actigraphy to explore sleep and no associations between SEI and other variables were explored. Therefore, the aim of this study was to investigate sleep duration using time sampling and actigraphy among a small sample in institutionalized individuals. Further, associations between sleep parameters and other variables (e.g. age, nonambulancy) were explored as well. Outcomes of this study may provide cues as to the improvement of the quality of care to these individuals.

METHODS

Participants were 19 individuals with severe to profound intellectual disability. Their average age was 18 years (range: 9-42 years). Nine individuals had a seizure disorder, and seven were nonambulatory (due to cerebral palsy). No one had a diagnosed sleep disorder, nor were they taking sleep medication. Informed consent was given by the parents or family members of each participant.

Each participant was recorded as being asleep or awake at hourly intervals from the time that s/he was put in bed until they were taken out of bed in the morning. At each hourly interval,
the observer entered participant’s bedroom wearing socks, then waited for 5s, and projected a
dim flash light on the wall for 2 s. After leaving the bedroom, the observer recorded whether
the participant was asleep or awake. An interval was recorded as ‘awake’ if participant had
his or her eyes open while lying in bed, while seated or while out of bed. ‘Asleep’ was
recorded if s/he was lying in bed with eyes closed and if s/he breathed regularly Observations
were made 14 hr each night (between 6pm. and 8am) by two trained observers. Data were
collected during 7 consecutive nights. Interobserver reliability was assessed during 13% of all
observations. During reliability assessment, sleep was recorded by two observers at the same
time, albeit independently (when outside the bedroom). Cohen’s kappa for recording was .99.
Six randomly chosen participants from this sample wore an actigraph (i.e., Actiwatch,
Cambridge Neurotechnology Ltd) on their nondominant arm during seven consecutive 24hr
periods. In the present study, a 1-min epoch length was used. Also, for each participant, the
Aberrant Behavior Checklist was completed by a staff member. This checklist assesses the

RESULTS

Total mean SEI across participants was 72% (SD=13.5; range: 41-98%). Mean number of
hours of sleep per night was 8h19min (SD=1h20; range: 5h34-10h10) and mean number of
hours in bed was 12h13min (SD=1h03; 10h-14h10). According to a 85% cut-off point, 15 out
of 19 participants had unsatisfactory sleep efficiency.

When assessed by actigraphy all participants had unsatisfactory sleep efficiency (mean 63%;
range 41-82) (see Table 1). Participants spent almost 13h on average in bed (range: 11h28-
14h14), and mean nr of hours of sleep was 8h18min (range: 7h05min-9h32). Sleep latency
varied between 19min to 5h10min. Mean fragmentation index, indicative of restless sleep,
was 48%. These results corroborate those found by other researchers1-3.

Table 1. Mean values of sleep parameters as measured by actigraphy in six participants.

<table>
<thead>
<tr>
<th>Part.</th>
<th>SEI %</th>
<th>Time in bed</th>
<th>Hours of sleep</th>
<th>Sleep latency</th>
<th>Nr of wakings</th>
<th>Rising latency</th>
<th>Fragmentation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>81</td>
<td>11h48</td>
<td>9h32</td>
<td>1h01</td>
<td>16</td>
<td>0h25</td>
<td>34</td>
</tr>
<tr>
<td>2.</td>
<td>66</td>
<td>13h19</td>
<td>8h41</td>
<td>2h04</td>
<td>35</td>
<td>0h34</td>
<td>40</td>
</tr>
<tr>
<td>3.</td>
<td>54</td>
<td>14h14</td>
<td>7h36</td>
<td>5h10</td>
<td>38</td>
<td>0h07</td>
<td>75</td>
</tr>
<tr>
<td>4.</td>
<td>41</td>
<td>14h03</td>
<td>7h39</td>
<td>0h26</td>
<td>21</td>
<td>0h06</td>
<td>53</td>
</tr>
<tr>
<td>5.</td>
<td>56</td>
<td>12h37</td>
<td>7h05</td>
<td>0h59</td>
<td>23</td>
<td>3h37</td>
<td>41</td>
</tr>
<tr>
<td>6.</td>
<td>82</td>
<td>11h28</td>
<td>9h16</td>
<td>0h19</td>
<td>30</td>
<td>0h12</td>
<td>46</td>
</tr>
</tbody>
</table>

NB. Part.=Participant; SEI=Sleep efficiency index; Nr=Number.

Our actiwatch data suggest that some people may have relatively high sleep latency, which
means they have difficulty in falling asleep after being put in bed, and they have low rising
latency indicating that they sleep until they are taken out of bed. In contrast, others have short
sleep latency but long rising latencies, which means that they fall asleep relatively quickly but
wake up early and stay awake until they are taken out of bed.
Age was negatively associated with SEI: younger participants had higher mean SEI ($r=-.50$; $p<.05$). No correlations were found between mean SEI and ABC scores, gender and epilepsy. Mean SEI was higher for those who were ambulant (i.e., 76%) than for those who were non-ambulant (i.e., mean 62%), with $t=2.5$, $p<.05$. Individuals from the first group spent less time in bed. Those who were ambulant spent less time in bed (mean 11h37) compared to those who were nonambulant (mean 13h01), with $t=-3.4$, $p<.01$. There were no differences between both groups in terms of mean total number of hours of sleep per night. Anecdotal reports from staff members did not indicate daytime sleep in any participant, a finding that was supported by visual analysis of actigraphy data.

CONCLUSIONS

While sleep duration of participants in our sample was fairly normal, they spent a much longer time in their bed without actual being asleep. Participants did not show sleep problems, such as sleep deprivation. The relative large difference between sleep duration and time spent in bed is the result of organizational routines in the residential facility rather than of other factors. This holds especially true for those who have severe physical disability. They are almost completely dependent on direct care staff and have little control over their preferred bedtimes. The sleep duration and total time spent in bed should be critically evaluated within the framework of daily quality of care of these people. The organizational routines are not attuned to the individual sleep need and sleep duration. Following presentation of our results to the members of the management team of the residential facility, organizational routines of the ward staff (i.e., roster) have been rearranged which resulted in residents spending less time in bed, thereby increasing the SEI.

REFERENCES