



Case Report

Improving Sleep in a Person with Down Syndrome and Alzheimer's Disease

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Introduction

Problems with falling asleep and sleeping through often occur in people with an intellectual disability [1]. Studies show that 15 to 50% of people with an intellectual disability suffer from sleep problems, and with children with an intellectual disability, this is as many as 58 to 80% [2-5]. Compared with older people in the general population, elderly people with ID (age 50 years and over) have a significant less stable, and more fragmented sleep [6]. The sleep problems can have intrinsic and extrinsic causes [7]. A common intrinsic cause in people with Down's syndrome (DS) is Alzheimer's disease (AD). Furthermore, the prevalence of Alzheimer's disease in senior citizens with Down syndrome is much higher than in the general population, at between 60 and 100%. People with DS are now living longer, and as they age, they are at risk of developing an Alzheimer's-type dementia [8]. Of all people with DS between 60 and 69 years of age, 54.5% suffer from dementia [9]. In the normal population, with only 1.4% of the population suffers from dementia [10]. A survey of 251 people with DS aged 45 years or more showed that 42% of those who had been diagnosed with dementia also had sleep problems [11]. The sleep problems which can be found in people with DS and dementia include early night waking and wandering around at night [12], but auditory hallucinations and anxiety also often occur [13]. Sleep problems begin to increase relatively early in the progression of AD [14]. With healthy elderly people, fragmentation of the rest-activity cycle and a low quality of sleep cause cognitive deterioration [15,16]. Medication is often used to treat this, in particular for the sleep problems that frequently occur with DS and AD. Medication used to slow down the process of AD, such as Donepezil, can worsen the sleep problems. The effects of this medication vary [17-20], and insomnia is frequently reported as a side effect [18,21].

The decision to administer medication for sleep problems is made for a number of reasons. The most used reason is that it seems like the obvious thing to do and seems to offer a quick solution. Such a train of thought is likely to occur when the sleep problems of one client causes problems for others who are as a result woken at night. In addition, the decision is sometimes made to administer sleep medication because it takes less time and effort for caregivers than do non-pharmacological interventions. With respect to the group of people with AD, the focal point of the Direct Support Staff (DSP) is more on feeding and bathing schedules, injury prevention and detection of medical

problems than on sleep and other issues related to quality of life [22]. Although most used, little is known as yet about the effectiveness of pharmacological treatments [22]. It is known that melatonin does not seem to help prevent sleep problems [23]. Scientific research into non-pharmacological interventions, such as improving sleep hygiene, has only been carried out on a limited scale [21,22,24-26]. As a rule, changes in the daily routine, such as changing bedtimes, causes problems in residential care facilities for people with an intellectual disability, because the extra burden it places on staff and hence on the budget [27]. A study by Epsie et al. [28] showed that, on average, people with a severe or a very severe intellectual disability spent 42% of a 24-hour period lying in bed. Furthermore, the group with very severe intellectual disability spent a significantly longer time in bed than the group with severe to mild intellectual disability (9.20 hours as opposed to 10.40 hours). The study shows that the longer period of time spent in bed can be attributed to organizational circumstances in the provision of care rather than to a need for sleep on the part of the clients. There is limited research done yet to improve sleep with non-pharmaceutical interventions like a better sleep hygiene. Given that sleep problems in people with ID and AD are much mentioned very frequently, it is worthwhile to gather data about non-pharmaceutical interventions. In this case study we tried by changing bedtimes to improve the sleep of the participant who had moderate ID, DS and AD.

Method

Participant

John (pseudonym) is born in 1947. He is diagnosed as having Down's syndrome (DS) and a moderate intellectual disability. John moved into a residential facility when he was 18. In 1980, when he was 33 years old, he moved to a group home in a district of a city in the northern part of the Netherlands. In this group home, DSP are present 24 hours a day. John responded well to the move. He continued to sleep well. In 2006, when he was 59 years old, he was diagnosed with Alzheimer's disease (AD). In this period, John also started to become anxious during the night. He had difficulty going to sleep, got out of bed and increasingly appealed to the DSP at the beginning of the night. He said he saw smoke coming from the ceiling, in particular at the beginning of the night. After local children had knocked on his window one night, John frequently said that he heard someone knocking on his window even when this was not the case. These appear to be persecutory delusions that can occur with DS and AD [9]. To help him sleep better, he was given 10 mg oxazepam. John was always healthy and alert but in 1997, John suffered from a sudden loss of strength in the right side of his body; a CT scan showed that he had had two TIA's. After some months John recovered, but he was still troubled by tiredness. He did not have any complaints falling asleep or staying asleep until 2005 when the first symptoms of AD were discovered. In 2006 he started wandering at night and his sleep complaints grew worse. The Oxazepam seemed to give no positive effect on John's sleep anymore. A few years later his problems to fall asleep became more serious and although his anxiety diminished John started wandering at night. That was when the DSP called in the assistance of the multidisciplinary sleep team of the facility.

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Instrument

John's sleep was measured using an Actiwatch (type: activity), which is manufactured by Cambridge Neurotechnology Ltd. Actigraphy is an objective and relatively non-invasive method of detecting sleep problems during the human sleep-wake cycle. The Actiwatch is a small, lightweight device that is worn on the wrist like a wristwatch [29] and, in comparison with polysomnography, is a valid instrument [30]. The epoch length was 0.5 minutes and the Actiwatch was worn 24 hours a day for 21 days.

Measurements were taken with an Actiwatch over a period of two weeks for 24 hours a day. Instruction regarding the use and purpose of the Actiwatch was given each time measurements were taken to the DSP. The results of the measurements were discussed by a multidisciplinary team consisting of a health scientist, a psychologist and a physician. The health scientist subsequently calculated the measurement results and drew up a preliminary report based on the results. The parameters measured by actigraphy include sleep efficiency (calculated as the total sleep time divided by the total time spent in bed), sleep onset latency (time between bedtime and falling asleep), total hours in bed, total hours of sleep and rising latency (time between waking up and getting up).

Results

John's sleep efficiency during the first measurement was 53.3% (Figure 1). His sleep onset latency was 131 minutes and his rising latency was 30 minutes (Figure 2). He spent 10 hours and 51 minutes in bed but slept only 5 hours and 34 minutes (Figure 3).

After the first measurements, the team advised ending oxazepam use and postponing John's bedtime. Both steps were taken, and five months later a three-week long control measurement was carried out for 24 hours a day. This showed that John's sleep efficiency had increased to 79.5% and his sleep onset latency had decreased to 21 minutes. Furthermore, his rising latency had decreased to 4 minutes, and he spent 8 hours and 13 minutes in bed, and slept for 6 hours and 38 minutes.

A few months after the second measurement it was discovered that the seriousness of John's AD was increasing. As a result, it was decided to move John to a residential setting where he would join a group of elderly people. In this residential setting there are separate DSPs at night, who start at 10.15 p.m., so it is customary to put the clients to bed before this time. The multidisciplinary team assumed that this would mean John would once again have to go to bed too

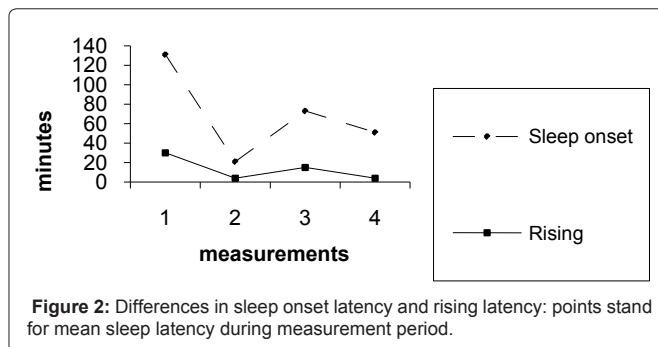


Figure 2: Differences in sleep onset latency and rising latency: points stand for mean sleep latency during measurement period.

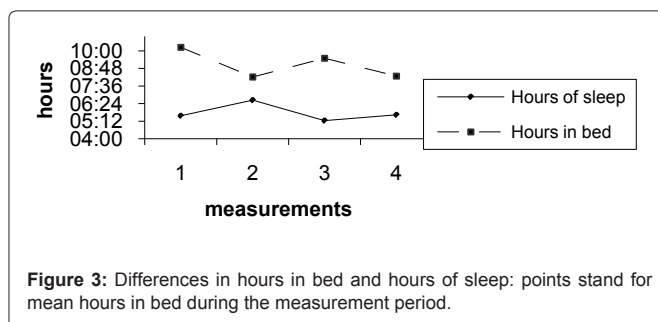


Figure 3: Differences in hours in bed and hours of sleep: points stand for mean hours in bed during the measurement period.

early, so a member of the multidisciplinary sleep team spoke to the daytime DSP and informed them about John's sleep problems and the necessity of late bedtimes. Three months after his move, we carried out a second control measurement lasting three weeks, almost a year after his first measurement, and found John's sleep problems had worsened.

As a result of this control measurement, further agreements were made with the daytime DSP and the DSP on night duty, and the importance of suitable bedtimes for John was once again pointed out. The agreements were implemented, and four months later another measurement lasting two weeks was conducted. As this final measurement was just before the DSPs' holidays, it lasted 14 days instead of the planned 21 days. The results were positive: John's sleep efficiency had increased again to 70.5% and his sleep onset latency had decreased to 51 minutes. His rising latency had dropped to 4 minutes again. He spent 8 hours and 13 minutes in bed, and slept 5 hours and 38 minutes.

Discussion

The improvements after the first intervention are more significant than the improvements at the fourth measurement. This could be caused by three factors. First, the sleep efficiency and latency were better at the third measurement than at the first, so the difference is smaller; this could be caused by the training in a better sleep between the first and second measurement. Second, John's dementia had grown worse between the first and the fourth measurement. This was also the reason why he was admitted to a residential setting. As the dementia worsens so do the patient's sleep problems [13]. Third, a move is difficult for people with AD to handle.

Our study shows that the living conditions for people with DS and AD are not always optimal. The nightshift staff of the facility involved in our survey stated that different bedtimes for John could be implemented provided this was restricted to him, because changes for more than one person it would be impossible. They did not have the staff to do this for other residents as well. In spite of the desired

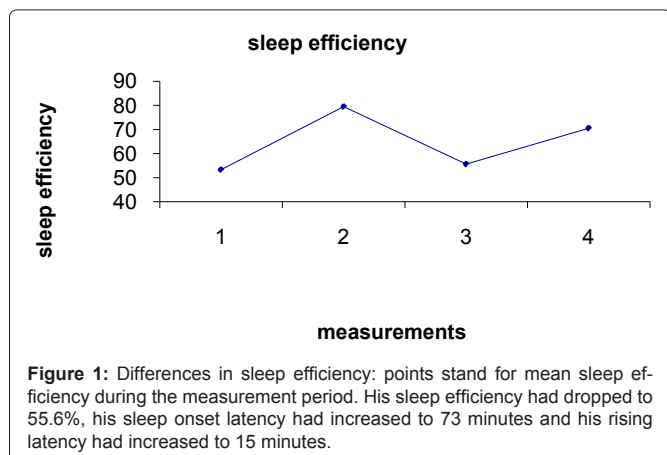


Figure 1: Differences in sleep efficiency: points stand for mean sleep efficiency during the measurement period. His sleep efficiency had dropped to 55.6%, his sleep onset latency had increased to 73 minutes and his rising latency had increased to 15 minutes.

adaptations to his sleep hygiene, John still spends some of his time in bed while not asleep. A further adaptation, more suited to his daily needs, was said to be impossible, although a more individual approach is desirable, particularly for people with DS and AD.

Almost no research has been conducted to demonstrate the effect of changing sleep hygiene as an intervention in sleep problems for people with DS and AD. In the future, it will be necessary to take a closer look at whether it is possible to influence environmental factors, in addition carrying out pharmacological interventions which are sometimes necessary. Residential facilities will have to become more aware that if they provide more client-oriented care regarding sleep, this can significantly improve their clients' sleep problems.

The results of the case study have made it clear that stopping the sleep medication and adapting John's bedtimes improved his sleep pattern. The temporary return to his former bedtime, due to practical considerations in a new setting, show that his 'old' sleep problems recurred and that adapting his bedtime again led to an improved sleep pattern.

People with DS and AD receive both non-pharmacological and pharmacological treatment. Although both treatments seem to have some effect, there is still a need to develop more effective interventions. A recent review mentioned non-pharmacological interventions such as cognitive training, environmental interventions, occupational therapy and individualized therapy [21]. Improving the sleep hygiene of people with dementia has also been studied [24,25]. In these studies, caregivers were trained to improve their clients' sleep hygiene. This appears to be effective and is in line with the results of a study in which DSP training appears to have a positive effect on the sleep of people with an intellectual disability [31]. This study showed that providing lectures and workshops for DSP on sleep patterns and sleep problems had a positive effect on the sleep of the clients in their care. Sleep efficiency improved, sleep latency decreased, and the number of hours the clients spent in bed significantly decreased. Carr and Neumann [32] found that care professionals could positively influence their clients' sleep quality, provided they have sufficient understanding of sleep and sleep problems. DSP are often not aware of the effect that sleep disorders have on the daily functioning of people with AD [3]. A survey by Hylkema and Vlaskamp [27] of 41 people with intellectual disabilities who lived in residential facilities also showed that using non-pharmacological interventions, such as improved bedtimes and stimulation during the daytime, could significantly improve their sleep. Also this case study shows an improvement in sleep as result of better sleep hygiene.

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