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Utility of Staff Training on Correcting Sleep Problems in People With Intellectual Disabilities Living in Residential Settings

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Abstract While sleep problems in people with intellectual disabilities (ID) living in residential settings are very common, scant attention is paid to them. This study examined how to improve the knowledge and understanding of sleep quality and sleep problems in people with ID among care staff at a residential facility and, consequently, to reduce extrinsic sleep problems. Using a variation on a crossover design with two groups, sleep efficiency and sleep latency in people with ID (not suspected of having sleep problems) were measured four times. One group (Group A) of staff was offered a lecture after the first measurement and a workshop after the second one. A second group (Group B) of staff was only offered a lecture, between the second and third measurements. In both groups, sleep efficiency rose significantly. The time spent in bed by residents overseen by Group A was reduced significantly, and there was a significant reduction of daily napping time among group A's residents. In Group B, there was a significant increase of daily napping time and in the number of naps. The application of educational techniques, such as lectures and workshops, provided to staff can lead to significant improvements in residents' sleep efficiency.

Keywords: intellectual disabilities, residential settings, sleep problems, staff training, workshops

INTRODUCTION

Sleep problems are common in people with intellectual disabilities (ID). Studies have shown that between 15–50% of adults with ID and 58–86% of children with ID experience some type of problem associated with their sleep (Barlett, Rooney, & Spedding, 1985; Brylewski & Wiggs, 1998; Espie & Tweedie, 1991; Richdale, Francis, Gavidia-Payne, & Cotton, 2000). Poor sleep can negatively influence the functioning of the immune system and the growth hormones that are secreted during sleep (Reite, Ruddy, & Nagel, 1997), and lack of good sleep may aggravate behavioral problems or cause functional irritations during the day (Schreck, Mulick, & Smith, 2004).

The causes of sleep problems can be categorized as intrinsic and extrinsic factors (Stores, 1999). *Intrinsic factors* generally have a physical origin and can include the presence of physical (Lindblom et al., 2001) or visual disabilities (Asplund, 2005; Vervloed, Hoevenaars, & Maas, 2003) and epilepsy (Batista & Nunes, 2007). Such factors can cause sleep problems in people of both normal and abnormal intelligence, but such problems of the latter have only been studied to a limited extent in people with ID. *Extrinsic factors* are generally linked to environmental causes and include such factors as poor sleep environment (the bedroom being too cold or having too much light), poor sleep hygiene (such as going to bed too early or getting up too late) or spending too much time being inactive in bed. Espie et al. (1998) found that, on average, people with severe or very severe ID spent 42% of a 24-h period lying in bed. Compared with a control group, the time spent in bed was significantly longer (10.4 h as opposed to 9.2 h). Didden et al. (2007) found that in a group of six individuals with profound and severe ID, sleep duration was fairly normal (8 h 19 min) although they spent a much longer time in bed (12 h 13 min). Given that a portion of sleep problems that occur in people with ID are extrinsic, external influences such as the changing of the behavior of residential care staff (i.e., direct support professionals) can play a role in reducing sleep disorders.

If residential care staff lack understanding of the nature of sleep quality as a concept, and the nature of their clients' sleep quality specifically, when they assess their clients' sleep–wake cycles, such assessments maybe at times incorrect. Lack of understanding of the nature and quality of sleep can often cause care staff to mistake passivity and silent wakefulness for being asleep (Mudford, Hogg, & Roberts, 1997). Moreover, care staff are often not aware of the effect that sleep problems may have on the daily functioning of people (Brylewski & Wiggs, 1998). A study that compared sleep electroencepalographies (EEGs) with the sleep diaries completed by care staff showed that care staff had a tendency to overrate the sleep quality in people with ID (Espie et al., 1998). Care staff may also employ daily routines, such as

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incontinence care, that negatively impact their clients' sleep patterns. For example, in residential care facilities, it is a common practice for night staff to conduct rounds at specific self-set times during the night in order to assist with toileting residents who are incontinent. Studies examining the impact of this practice in elder care settings have shown that in 42% of the instances where clients were awake for four minutes or longer, noise, light and toileting assistance (i.e., incontinence care) affected sleep. Cruise, Schnelle, Alessi, Simmons, and Ouslander (1998) noted that it was prevalent in such instances that elderly residents were awakened during this routine. Although there are no quantifiable data available with respect to the wakefulness of people with ID during such practices, it seems plausible that this type of staff behavior would disturb the sleep of residents with ID.

According to Coates et al. (1982), a sleep efficiency (i.e., total sleep time/time in bed multiplied by 100) of less than about 85% is the threshold for defining clinically significant sleep problems. This metric has used in several studies involving people with ID (e.g., Dodd, Hare, & Arshad, 2008; Espie et al., 1998; Hylkema & Vlaskamp, 2009).

By informing and advising parents on sleep and sleep problems, it has been found that such disorders can be prevented in children of normal intelligence (Kerr, Jowett, & Smith, 1996). Stores and Stores (2004) found the same for parents of young children with Down syndrome. Montgomery, Stores, and Wiggs (2004) noted a significant lessening of sleep problems in young children with ID following the application of a booklet-delivered treatment and that such an approach was almost as effective as face-to-face treatment. It is expected that some form of training with respect to sleep and sleep problems could help care staff to properly assess their clients' sleep patterns and change routines that may be causative of sleep problems. As studies have shown that both multiday training courses (Grey & McClean, 2007; Lowe et al., 2007) and group teaching workshops (Dowey, Toogood, & Hastings, 2007) involving care staff can have a positive impact on dealing with challenging behavior of people with ID, then such an approach should be applicable to enhance skills related to addressing sleep problems.

Although it has been noted that a lack of knowledge by care staff about the nuances of sleep could be a possible explanation for the sleep problems that people with ID experience, only rare studies have addressed increasing the knowledge of care staff on how to improve quality sleep (Brylewski & Wiggs, 1998; Carr & Neumann, 1999; Didden et al., 2007; Espie et al., 1998; Mudford et al., 1997). In one such study, Carr and Neumann (1999) used a graphic sleep monitoring system within a residential setting for people with ID. They used a time-sampling procedure where sleep data were collected every hour between 21:00 and 07:00. Also, for a period of 1 year, "sleep diaries" were kept for 471 residents; their contents were discussed monthly, and sleep time care routine adjustments were made. After a year, the residents' sleep had improved significantly. Carr and Neumann (1999) conclude that care staff can positively influence their clients' sleep quality, provided they have sufficient understanding of sleep and sleep problems.

Given the outcomes of Carr and Neumann (1999), it would be beneficial to improve knowledge and understanding relating to sleep and sleep problems in people with ID in situations where there are no known sleep problems and clients do not use sleep medications. In our study, we were interested in introducing training about sleep, sleep problems, and sleep problem corrections, among care staff working with residents with severe ID (and who had no known sleep problems and who did not use sleep medications) and comparing two training methods, one the provision of lectures and the other the provision of lectures combined with a workshop. Our outcome measure would be improved post-training quality of sleep of these residents.

METHOD

Participants

The study was carried out over a period of 19 weeks in two residential care institutions in the northern part of the Netherlands. At both institutions, five residential care units were selected at random, and all of the care staff employed at the units were included. We then randomly divided the participating staff into two groups: one which would be given the lecture and then participate in a workshop (Group A) and one which would be given only the lecture (Group B). At the beginning of the study, all of the care staff were asked to complete a questionnaire prior to the start of the first sleep quality measurement. The questionnaire asked care staff about their age, sex, years of work experience and experience with sleep problems among the residents at the institution. Table 1 shows the characteristics of the staff participants. It is notable that the two groups minimally differed in their mean age and years of work experience. With respect to having experiences dealing with sleep problems, the two groups also did not differ (more than half of the staff in both groups said that they had such experiences).

Group A consisted of 28 care staff who supported 36 adults with severe ID. Group B consisted of 19 care staff who supported 30 adults with severe ID. Inclusion criteria for residents were the following: severe ID with sufficient arm motor performance (to permit use of a wrist mounted measure), no suspected sleep problems and not using sleep medications. Although epilepsy (Batista & Nunes, 2007; Hylkema & Vlaskamp, 2009) and Down syndrome (Urv, Zigman, & Silverman, 2008) do affect sleep quality, residents with these conditions were included because both groups comprised approximately the same number of

TABLE 1
Characteristics of care staff

	Group A ($n = 19$)	**Group B ($n = 28$)**
Age (mean/standard deviation)	36.71 (SD 12.31)	36.84 (SD 10.54)
Sex	5 male/23 female	8 male/11 female
Years of work experience	13.37 (SD 6.09)	13.36 (SD 9.07)
Experience with sleep problems	53.6%	57.9%

SD = standard deviation.

TABLE 2
Characteristics of residents

Sex	Age	Epilepsy	Visual impairment	Down syndrome
Group A				
Female	51	yes	—	—
Female	35	—	—	—
Male	72	—	—	—
Male	31	yes	—	—
Female	47	yes	—	—
Male	43	—	—	Down syndrome
Male	57	yes	—	—
Female	53	yes	—	—
Female	54	yes	—	—
Female	65	—	—	—
Female	59	—	—	Down syndrome
Female	29	yes	—	—
Male	52	yes	—	—
Male	24	—	—	Down syndrome
Male	45	—	—	Down syndrome
Female	59	yes	—	—
Male	60	—	light perception	—
Group B				
Male	21	—	—	Down syndrome
Male	45	—	—	—
Male	53	yes	—	—
Male	28	—	—	Down syndrome
Female	38	yes	light perception	—
Male	39	yes	—	—
Female	40	yes	—	—
Male	34	yes	—	—
Female	38	yes	light perception	—
Male	66	yes	—	—
Female	30	yes	—	—
Female	50	yes	yes	—
Male	61	—	—	—
Male	29	—	—	Down syndrome
Male	34	—	—	—
Male	51	—	—	—
Female	62	—	—	—

residents with such conditions. The residents mean age in Group A was 48.7 years (standard deviation (SD) 13.32) and in Group B was 42.9 years (SD 12.68). Table 2 provides details on the individual resident participants.

The care staff in Group A worked a shift from 07:00 until 11:00 and then from 12:00 until 20:00; a second shift, at night, worked from 20:00 until 07:00 in a central building where they watched over the residents using an acoustic nurse-call system. Group A's night shift staff usually woke up the residents at least twice during the night for toileting (continence) routines. During the course of the study, they were asked not to carry out these routines. In Group B, these night time routines were not common practice, as incontinence care was only carried out when the residents were awake and were heard through the acoustic nurse-call system. The shifts in Group B were the same as in Group A except that the night-shift staff started work 15 min later. Night duty in Group A started at 20:00, and the residents were supposed to be in bed by that time. Night duty in Group B began at 20:15. In both groups, the care staff began putting the residents to bed at around 19:30, irrespective of their sleep requirements. Consequently, the residents often spent between 9.5 h and 12 h in bed.

Instrument

The quality of sleep of the residents was measured by actigraphy using the Actiwatch (type: activity) manufactured by Cambridge Neuro-Technology Ltd (Cambridge, UK). Actigraphy is a non-invasive and objective way to measure human rest/activity cycles, can detect sleep problems during the human sleep–wake cycle, causes little discomfort (Carvalho-Bos, Riemersma-van der Lek, Waterhouse, Reilly, & Van Someren, 2007) and has more validity than polysomnography (Kushida et al., 2001). The actigraph unit, an Actiwatch (Philips Respironics, Herrsching, Germany), is a small, lightweight device that is worn on the wrist like a standard wristwatch. In our study, the Actiwatch was worn 24 h a day for 14 days and the unit of measure, or epoch length, was 0.5 min. Staff were given instruction on how to use the Actiwatch and its function each time they were asked to take measurements.

Procedure

Prior legal consent of the residents' legal representatives was requested via letter, consistent with normal practice in the Netherlands. In the mailing to legal representatives of the residents, the purpose and the method of the study and the voluntary nature of participation were explained. Legal consent was received for 17 residents in Group A and 17 residents in Group B, from legal representatives. University research study approval was obtained from the research review board.

To begin the study, the two groups were randomly designated as Group A and Group B. According to the facility's records, prior to the start of the study, none of the residents had been reported as experiencing sleep problems. Given this, baseline data were obtained at T0 in order to have a comparison for sleep quality at the end of the study. The study employed a variation on a crossover design in which the residents' sleep was measured for 24 h per day during periods of 2 weeks, alternated with 2-week dormant periods in which the lecture and workshop were given. After T2, control measurements were again taken in both groups. Table 3 provides information on the design, times of measurements and locations of interventions during the 19 weeks of the study.

To test whether information about sleep, sleep problems and possible interventions were useful and to test the efficacy of two methods of staff training, the study involved Group B being administered the lecture only and Group A being administered the lecture and workshop. Group B's lecture took place at the institution and involved a didactic session of approximately

1 h—see Table 4—and was held in the eighth week of the study following the T1 data collection. Group A received the lecture in the sixth week prior to T1, and then participated in the workshop in the 10th week after T1. The structure of the workshop was experiential with the data of each resident's T0 metrics beamed on the wall. To elicit discussion, the workshop participants were then given 30 min to evaluate each of the residents' data and to choose the most appropriate intervention to address any abnormalities (or sleep problems). During these discussions, the workshop participants were advised on how sleep problems might be addressed but asked to select solutions for the individual resident's sleep problems by group consensus.

RESULTS

The workshops were helpful in producing staff-initiated changes in routines and lives of the residents, which then lead to diminution of sleep problems. The staff arrived at the following alternatives for addressing identified sleep problems: (1) better sleep scheduling (meaning establishing bedtimes more corresponding to the resident's chronological age); (2) change in daily routines; (3) greater and more stimulating activities during the day (either an increase in activities or more physical activities); and (4) "other." These changes are illustrative, which were implemented following the workshops. Nine of the residents received changes in sleep scheduling. For example, a 25-year-old woman was put to bed at 20:00 because the staff routine was that they wrote their daily reports after everyone was in bed. The care staff agreed that it would be more functional to write their reports before everyone was put to bed, and thus reduce in-bedtime for some residents. As a result of this decision, the woman's bedtime was delayed by 90 min. Another example was a 37-year-old man who was often awakened as early as 06:00 simply to give him medications. The staff decided to delay waking him until 07:30 to permit him more quality sleep.

To provide for more stimulation during the day, and thus decrease day napping, five of the residents were scheduled to participate in more activities during the day. It was decided also to give one resident, a 29-year-old woman, more individual attention. Every time she was found napping, she was awaked and taken for a walk outside in the fresh air, or was given a massage and involved in other sensory activation activities. It was decided that for two of the residents, they would receive individualized intervention—the "other" category. One was a 39-year-old male who was found to be awake very early each morning. The problem, the staff ascertained, was that his bedroom was too bright at sunrise, and this caused him to awake early. To address this problem, the staff installed darkening curtains in his bedroom.

To better understand sleep quality, data obtained from using the Actiwatch were analyzed. The data analysis produced six

TABLE 3
Study design

Week	Group A	Group B
1 + 2		T0
3 + 4	T0	
5 + 6	Lecture	T1
7 + 8	T1	Lecture
9 + 10	Workshop	T2
11 + 12	T2	
16 + 17		T3
18 + 19	T3	

TABLE 4
Content of lecture on sleep and sleep problems

Topic	Content	Time	Literature sources
Sleep and sleep problems in general	Nature of sleep and structure, physiology and prevalence of sleep problems	15 min	Coenen and Kerkhof, (2001); Maquet et al. (2000); Tassi et al. (2006); Weerd and van den Bossche (2003)
Sleep problems and intellectual disabilities	Sleep structure and prevalence of sleep problems in people with intellectual disabilities	10 min	Barlett et al. (1985); Hylkema and Vlaskamp (2009); Quine (1992)
Sleep problems with applications to other conditions	Sleep problems associated with autism, epilepsy, Attention Deficit Hyperactivity Disorder, and physical disabilities	10 min	Chervin, Dillon, Bassetti, Ganoczy, and Pituch (1997); Lancioni, O'Reilly, and Basili (1999); Ming and Walters (2009); Quine (1992); Stores (1999); Van der Heijden, Smits, and Gunning (2005); Weerd et al. (2004); Wiggs and Stores (1996)
Case reports	Discussion of interventions that could improve sleep quality (including proper sleep hygiene, bedtimes, and day activities)	20 min	

TABLE 5
Results of the measurements

	Group A ($n = 17$)					Group B ($n = 17$)				
	T0	**T1**	**T2**	**T3**	***p***	**T0**	**T1**	**T2**	**T3**	***p***
Sleep efficiency (in %)	79.9	80.9	82	83.7	0.084**	77.8	76.6	79.8	80.3	0.093**
Sleep latency (in min)	29	29	26	20	0.142	36	33	29	28	0.155
Time spent in bed	11:31	11:10	11:07	10:59	0.001*	10:26	10:42	10:23	10:30	0.551
Total sleep time	9:07	9:00	9:07	9:12	0.856	8:09	8:15	8:15	8:32	0.222
Daily time spent napping (in min)	97	96	92	82	0.079**	85	105	100	107	0.033**
Daily number of naps	10	10	9	8	0.254	8	9	9	10	0.060**

*Significance ($p < 0.95$).
**Significance ($p < 0.90$).
T0 = first measurement; T1 = second measurement; T2 = third measurement; T3 = fourth and control measurement; $p = p$-value between T0 and T3 in groups.

indicators. The first indicator was *sleep efficiency* (i.e., the percentage of time spent asleep while in bed), and the second one was *sleep latency* (i.e., the time before sleep onset following bedtime). The other indicators were the time spent in bed, the total sleep time, the daily napping time and the daily number of naps taken. Table 5 shows these results. We found that the sleep problems noted in the Group B were related mainly to falling or staying asleep. The sleep problems noted by Group A were related mainly to problems associated with falling or staying asleep and to shifts in the circadian rhythm. Our data showed that at T0, sleep efficiency in 14 of the 17 (82%) participants in the Group B was lower than 85% and that sleep efficiency in 13 of the 17 (76%) participants in Group A scored lower than 85%.

Using the Wilcoxon Signed Ranks Test, the difference scores between T0 and T3 were tested as to significance. In both groups, sleep efficiency rose significantly. Also the time spent in bed in the Group A was reduced significantly. Furthermore, there was a significant reduction among Group A residents of the daily napping time. Among Group B residents, there was a significant increase of daily napping time and an increase in the number of naps. The differences between the two groups were also compared, so that T0 in Group A was compared with T0 in Group B. The results showed no statistically significant differences. The results after the lectures and after the workshops also showed no significant differences between Group A and Group B. Using the definition of sleep problems given by Coates et al. (1982), we then checked again how many participants had sleep efficiency scores less than 85%. This time at T3, it appeared that 55% of Group A and 65% of Group B still experienced sleep problems.

DISCUSSION

Our research examined whether there would be changes in sleep quality in people with ID following the administration of two methods of educating care staff about sleep and sleep problems. We found that a combination of lecture and workshop presented to care staff, as in Group A, positively impacted the sleep quality of the residents in the study. The time spent in bed decreased significantly in this group. We also found improvements in sleep quality in the lecture-only group (i.e., Group B). The increase in sleep efficiency and the decrease in sleep latency were significant for both groups, but differences between the two groups were negligible. There may be several explanations for these findings. One is that we were dealing with a small group size. Second is that perhaps our study period was insufficiently lengthy to see more effects of changes in sleep patterns or behaviors following the staff training. Third is that prior to the research being undertaken, the care staff were convinced that their clients did not experience sleep problems, and it is possible that this belief had an impact on their motivation. Staff may have overestimated the sleep quality of their clients; this would be in accord with the findings noted by Mudford et al. (1997) and Espie et al. (1998). Fourth is that we did perform a control measurement after 6 weeks. This measurement was done without an additional intervention between T2 and T3. A repeated control measurement perhaps would have produced better results. It could be that the participating residents who woke during the research period did so because they had been accustomed for many years to being woken up by staff at specific times during the night. This may explain the lack of significance in differences between the Group A and Group B residents.

We did find that the improvement in sleep efficiency and time spent in bed was significant. This supports our contention that information and recommendations, in this case lectures and workshops, are a means of improving sleep conditions in people with ID. It is worth noting that a lack of knowledge on the part of the care staff in terms of attention to the sleep patterns of the residents seemed to affect their sleep efficiency. Given that two of the sleep variables in Group A improved, it seems that lectures in combination with workshops have more impact on work routines than just lectures alone. In Group B, sleep efficiency improved but the other variables did not. Remarkably, the number of naps and the total nap time increased. It should also be noted that the metrics derived from the use of the Actiwatch may overestimate sleep time (Kushida et al., 2001), which means that we cannot be certain whether participants were really sleeping during the periods noted by the Actiwatch as "napping" (i.e., being inactive).

As they could have been awake but inactive, it may have been wiser to mark these periods as "inactive" instead of "napping" when using an Actiwatch.

One additional point is the way in which the care for people with ID is structured, with separate day time and night time staff assignments. This segregation of day-night cycle assignments causes residents to lie in bed from 9 h to 12 h per each 24-h cycle. This is a significant contributory factor to the development of sleep problems. It is vital that work in residential settings should be client-oriented, not only during the day, but also at night. Rigid day routines should change into flexible routines focusing on the needs, including sleep needs, of the individual client. There can be a significant improvement in the sleep of people with ID when routines are more flexible (Hylkema & Vlaskamp, 2009).

In the literature, sleep efficiency percentages below 85 are considered to be indicators of clinically significant sleep problems, so any value below 85% is an indication of a sleep problem (Coates et al., 1982). Using this definition, a significant number of residents included in this research experienced sleep problems, both prior to and after the research study. There was a high prevalence of sleep problems among the institutionalized adults with severe ID in our study, consistent with findings of others (Barlett et al., 1985; Brylewski & Wiggs, 1998; Espie & Tweedie, 1991; Richdale et al., 2000).

Although the sleep efficiency threshold of Coates et al. (1982) is used in several studies in people with ID (e.g., Dodd et al., 2008; Espie et al., 1998; Hylkema & Vlaskamp, 2009), it may very well be that this threshold does not apply for people with ID with significant comorbidities, such as autistic spectrum disorder (Hughes, 2009; Wirojanan et al., 2009), physical (Lindblom et al., 2001) and visual disabilities (Asplund, 2005; Vervloed et al., 2003) or epilepsy (Batista & Nunes, 2007). All these conditions have been reported to compromise sleep quality. Also, it is known that some people with ID have rather fragmented sleep in comparison with the normal population (Doran, Harvey, & Horner, 2006). Although this could suggest that this 85% threshold is not suitable for people with ID, currently there is no literature that underlines that suggestion. Given this, we are left with the assumption that this same threshold should be appropriate for people with ID.

Given our findings, the scale of the problem calls for more research into sleep problems and remediations in people with severe ID who live in residential settings. There is still much clinical research that needs to be done, including research into the nature of the sleep problems and further possible treatments. Such outcomes could result in adjustment of daily routines and more attention to sleep hygiene.

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