

Behavioral Treatment of Sleep Problems in a Child with a Visual Impairment

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Abstract: In this study, treatment focused on parenting practices for a 4½-year-old girl with a visual impairment caused by Leber's congenital amaurosis and problems initiating and maintaining sleep. The sleep problem was effectively treated with a graduated extinction procedure.

Sleep problems are frequently found in children and adults with visual impairments (that is, blindness or low vision). In their longitudinal study, Jan, Freeman, and Scott (1977) found a prevalence of 20% for problems falling asleep in 85 blind children and only 5.9% in a control group of 85 sighted children. More recently, Tröster, Brambring, and Van der Burg (1996) found high prevalence rates of difficulties falling asleep or staying asleep in children from birth to age 6 with visual impairments. Of the 67 sighted children, 152 children with low vision, and 113 children who were blind, with and without additional impairments, they found that sleep problems occurred in 48.2% of the blind children, 43.7% of the children with low vision who had additional impairments, 63.2% of the blind children with additional impairments, 23.5% of the children with low vision only, and 21% of the sighted children.

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Mindell and De Marco (1997) also found more sleep problems in 28 blind children than in 22 sighted children aged 4–36 months. The blind children went to bed later at night, were more awake at night, and slept for an average of an hour less than did the sighted children. The parents of the blind children responded differently to sleep disturbances than did the parents of the sighted children. At nighttime waking, they tended to talk to their children more, to read to their children, and to stay with their children longer than did the parents of the sighted children. Leger, Prevot et al. (1999) also found shorter sleep duration in 77 blind children than in 79 sighted children aged 3–18 years. Significantly more blind children (17.4%) than sighted children (2.6%) slept less than 7 hours per night. Sleep problems were more prevalent in the blind children than in the sighted children. Of the children who were blind, 13.4% suffered from daytime sleepiness compared to only 1.3% of the sighted children. Also sleepwalking and grinding one's teeth, which fall into the category of parasomnias, that is, disturbances that intrude into the sleep process, were more prevalent among the children who were blind.

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In a review of sleep problems of persons who were visually impaired, Vervloed (2001) found that approximately half the population of children who are blind have some kind of sleep problem. This proportion is much higher than the prevalence of sleep problems in sighted children, which is estimated to be approximately 25% (Durand, 1998; Durand, Mindell, Mapstone, & Gernert-Dott, 1998). As a result, it can be concluded that sleep problems are a health problem for children who are visually impaired. Despite the lack of uniformity in defining sleep problems, these problems seem to be twice as prevalent in visually impaired children as in sighted children.

Another conclusion was that, assuming that sleep medication is effective in treating sleep problems, the estimated prevalence rates of sleep problems in persons who are visually impaired may be conservative, given that sleep medication is used more often by visually impaired persons than by sighted persons (see, e.g., Leger, Guilleminault, Defrance, Domont, & Paillard, 1999). A third conclusion was that among children with visual impairments, the presence of multiple impairments was strongly correlated with the occurrence of sleep problems. The final conclusion was that sleep disturbances are not always perceived as problems or complaints. Many parents of visually impaired children and people who are visually impaired themselves seem to accept the presence of sleep problems. In one way or another, they have learned to live and cope with these problems.

Etiology

Initially, sleep problems in people who are visually impaired were thought to be the result of psychological factors, such as fear or anxiety about losing attachment figures

(Fraiberg, 1977), or of less exploration and physical exercise by visually impaired persons, so that they would be less fatigued and therefore needed less sleep (Jan et al., 1977). The most important reason for sleep problems, however, seems to be of an endocrinological nature. In typically developing children, the sleep-wake rhythm becomes synchronized with the 24-hour day-night cycle at approximately 12 months of age (Stores, 2001a); in blind children, however, this synchronization sometimes does not occur at all.

A typical characteristic of sleep problems in persons who are visually impaired is a disturbance of the circadian rhythm of sleep and wake states (Durand, 1998; Jan et al., 1977; Mindell, Goldberg, & Fry, 1996; Stores, 2001b). This disturbance can be a shift of a normal day-and-night pattern, a non-24-hour ("free-running") disorder of the sleep-wake cycle, problems falling asleep, or problems sleeping through the night with or without daytime napping.

Circadian rhythms are entrained by factors termed Zeitgebers (German for time cues). Zeitgebers synchronize one's internal clock with the environment, especially with the 24-hour (solar) period. In humans, Zeitgebers are thought to be rhythmic changes in the environment, such as mealtimes, lighting, ambient temperature, feeding, and social activities (Lubkin, Beizai, & Sadun, 2002; Stores, 2001a). However, bright light is the strongest factor for entrainment of the internal clock. Light is passed through the retinohypothalamic tract (RHT) from the retina to the suprachiasmatic nucleus (SCN) of the hypothalamus. The SCN regulates the secretion of the hormone melatonin by relaying information on light to the pineal gland (Lubkin et al., 2002; Stores, 2001a). The SCN functions as the endogenous

pacemaker for several biological rhythms, including body temperature and the secretion of cortisol and growth hormone. Most people who are blind who have no light perception are not able to activate the RHT pathway, which leads to the desynchronization of the SCN and its target tissues, such as the pineal gland (Fouladi, Moseley, Jones, & Tobin, 1998; Lubkin et al., 2002; Skene, Lockley, Thapan, & Arendt, 1999; Tabandeh et al., 1998). When environmental input, such as the light–dark cycle, is removed artificially, sighted persons also manifest free-running circadian rhythms that are consistent with their own internal clocks of approximately 24.2 to 24.9 hours (Stores, 2001b).

Treatment of sleep problems

The oral administration of melatonin seems to be the treatment of choice in disorders of the sleep–wake cycle in children who are visually impaired (Espezel, Jan, O'Donnell, & Milner, 1996; Jan, Espezel, & Appleton, 1994; Palm, Blennow, & Wetterberg, 1997). However, the long-term effects of the oral administration of melatonin are poorly understood, and not all children profit from the administration of melatonin, especially when behavioral problems are prominent (Stores, 2001b). In the study by Espezel et al. (1996), treatment failed in cases of sleep problems accompanied by pain, noise, epileptic insults, poor sleep hygiene, and psychiatric disorders. Timing errors in the administration of melatonin may be responsible for some failures (Palm et al., 1997). Because visual impairment can be accompanied by other impairments, epilepsy, mental retardation, and psychiatric disorders, it is important to consider these conditions in analyzing sleep problems in visually impaired children and not

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to focus on disturbances in the secretion of melatonin caused by the lack of light perception only (Stores, 2001b).

Other forms of treatment for children who are visually impaired, besides the oral administration of melatonin, depend on the nature of the sleep problems. Treatment may include chronotherapy for disorders of the sleep–wake cycle, such as strict daily schedules (see, e.g., Mindell et al., 1996; Okawa et al., 1987) or bright-light therapy, which has been successful in treating some adults who are blind (see, e.g., Czeisler et al., 1995; Partonen, Vakkuri, & Lamberg-Allardt, 1995). According to Stores (2001b), the appropriate treatment for children with sleep problems is behavioral intervention when the problem arises from any combination of inappropriate bedtime parenting practices and behavioral problems, such as talking, screaming, and crying at bedtime or on waking at night or early in the morning. These interventions include establishing consistent daytime and bedtime routines, not allowing delaying tactics at bedtime, and discouraging parental attention or presence while the child is falling asleep or waking during the night. Techniques to implement these interventions include behavioral modification procedures, such as extinction, graduated extinction, bedtime fading, and stimulus control.

In extinction procedures, disruptive behavior is ignored. In graduated extinction procedures, the periods of ignoring the disruptive behavior are gradually extended. This procedure can be used whenever children come out of their beds or hurt themselves. In bedtime fading, the exact bedtime is gradually shifted toward the desired bedtime. This intervention is used whenever sleep duration is sufficient but at the wrong

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times. Stimulus control procedures are aimed mostly at changing bedtime routines and environmental factors, such as the number of toys available and lighting and temperature in the bedroom. For an extensive overview of these techniques, see Durand (1998). This article describes a behavioral treatment of sleep problems in a child who is visually impaired as a result of Leber's congenital amaurosis.

Methods

PARTICIPANT

The participant was a girl aged 4½ years with visual impairment that is due to Leber's congenital amaurosis (visual acuity 5/100, or 1/20) and attended kindergarten at the time of the study. She was born 7½ weeks prematurely and subsequently stayed in the hospital for several weeks. At age 3 months, corrected for prematurity, she was hospitalized because of excessive crying and difficulty eating and drinking. At age 20 months, medication was prescribed because of sleep problems, but the medication did not eliminate the problems. In the last few months prior to the current study, the girl was repeatedly ill and feverish. The parents reported that she was often disobedient to them in the first three years of her life. According to the Child Behavior Checklist (CBCL) for 4–8 year olds (Achenbach & Edelbrock, 1983), there were some behavioral problems. The girl scored within the clinical range with regard to internalizing problems ($T = 71$) and the total number of behavioral problems ($T = 70$). The score for externalizing problems ($T = 60$) was within the borderline range, as were the scores on the scales Somatic Complaints and Anxious/Depressed. In addition, the girl scored within the clinical range for the scale Thought Problems.

The parents reported that their younger child, a boy aged 1 year, 3 months, who was also blind without light perception because of Leber's congenital amaurosis, had sleep problems, too. After conducting a curve-fitting and split-middle trend-line analysis, we found that the boy's baseline measurements showed a negative trend for sleep problems. Moreover, at the end of the baseline, the boy received ventilation tubes in his eardrums because of recurrent middle ear infections. After this operation, the sleep difficulties diminished to an extent that they were no longer a problem. Although the same intervention strategies as for his sister were in effect, the results for this boy are not described in this article. The negative trend in the baseline and the placement of the ventilation tubes could explain the change in sleep behavior besides the effect of the behavioral intervention.

PREINTERVENTION

Description of sleep problems

At the beginning of the study, the girl's sleep problems were less intense than they used to be. The parents got their daughter ready to go to bed at approximately 7 p.m. every day. Bedtime routines consisted of drinking, putting on pajamas, reading a story, and listening to music. At 7:40 p.m., the mother usually left the bedroom while the music was still playing. When the music stopped, the girl typically started to cry, asking her mother to play the music again. This situation continued until she fell asleep at about 9 p.m.

According to the parents, the girl slept restlessly and often woke at about midnight. Her nighttime waking was generally accompanied by crying and leaving the bed. The girl often sweated and was afraid at night and frequently had nightmares.

Parental intervention consisted of one parent either sleeping in her bed or taking her to the parental bed. Usually it took 15 minutes before she fell asleep again. Every day at 7 a.m., her parents woke her. When not awakened in the morning, the girl could sleep until about 9:30 a.m. The parents reported her to be generally moody in the morning and sleepy during the day. After a bad night of sleeplessness, the parents noticed that the girl was listless, less spontaneous, and whiny and did not want to play. On the weekends, her sleeping habits were the same, except that her parents took her to their bed. The sleep problems decreased when she attended nursery school but increased after she entered kindergarten.

According to her parents, the girl felt insecure, probably because her then-current teacher was less protective of her. She was preoccupied with death, since her grandmother and the father of her teacher had died recently.

Analysis of sleep problems

A functional assessment of sleep problems was performed during baseline recordings for 26 days. Information was obtained in an interview with the parents and with a sleep diary the parents kept during the baseline period. Sleep problems were assessed with a translated version of Wiggs and Stores's (1996) sleep questionnaire for children with severe learning disabilities. This questionnaire is an adapted version of the questionnaire by Simonds and Parraga (1982).

On the basis of the results of the functional analysis, we hypothesized that the sleep problems were maintained by parental attention. When the girl started to call for her parents or started to cry, the parents almost always reacted. They stayed with her

until she was quiet and asleep and occasionally allowed her to sleep in their bed, or one of the parents slept in her bed. Somatic factors could have influenced the sleeping behavior. The girl was, according to the parents, frequently ill or suffering from a skin rash and did not sleep well during those periods. On the basis of an accumulation of all sleep periods during 24 hours in the baseline period, we calculated that the girl's optimal sleep duration was 12–12.5 hours. Because her wake-up time was fixed by the time that school started, we calculated the ideal time for her to go to bed by subtracting the desired total sleeping time from the wake-up time.

INTERVENTION

We recommended the graduated extinction of parental attention for maintaining sleep in an AB single case-study design with follow-up. Practical and ethical reasons prevented the use of stronger designs, such as a reversal design, in which there is a return to the baseline condition after treatment. Treatment was focused only on nightly disruptions because the parents reported only nightly disruptions, not problems initiating sleep.

The parents were strongly dissuaded from playing physical games as part of the bedtime routines. Furthermore, they were instructed to react quickly and firmly in the case of nocturnal awakenings and crying. After comforting the girl, they had to leave the bedroom. If the girl started to call or cry again, the parents were allowed to reenter the room after five minutes. Again, the girl was to be soothed and spoken to in a firm and decisive way. This procedure was to be repeated until she quieted down and fell asleep. After a night with just one parental visit to the girl's bedroom, the extinction

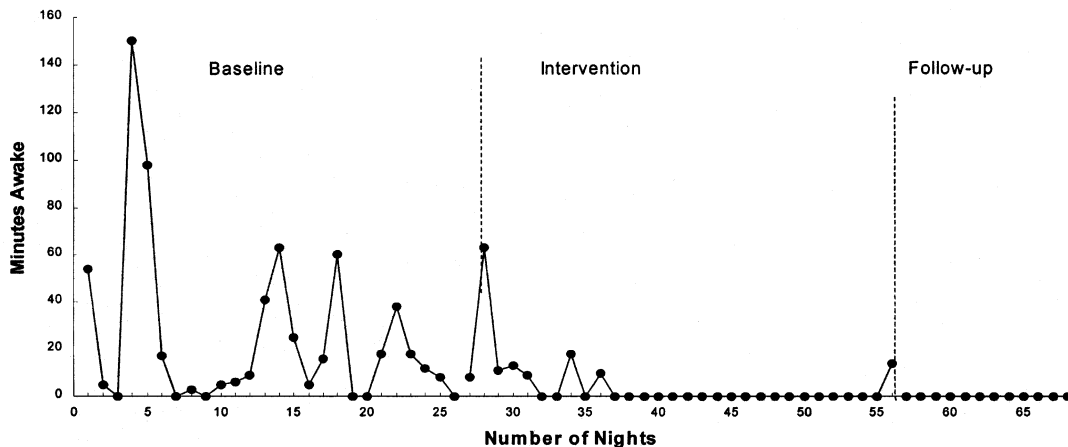


Figure 1. Number of minutes awake at night caused by difficulties maintaining sleep.

period of no parental attention was increased five minutes. The girl was allowed to sleep only in her own bed without her parents present. This stimulus-control procedure is meant to create the association that it is safe and comfortable to sleep on your own and in your own bed without parental attendance or parental company in bed. The bedtime routines were restricted to a maximum of 30 minutes.

Results

MAINTENANCE OF SLEEP

The baseline measurement was carried out for 26 days. The intervention, consisting of adjustments in bedtime routines and the graduated extinction of parental attention during nighttime sleep disruptions, was in effect for 30 days. Three months after the end of the intervention period, follow-up data were collected for 12 days. Between the intervention and follow-up period, the family moved to another city. This move might have influenced the follow-up data. Unfortunately, the parents changed their bedtime routines at the beginning of the baseline. They stopped taking the participant into their bed after nightly awakenings

and no longer played music after they put her to bed.

Figure 1 depicts the number of minutes the girl was awake during the night because of difficulties maintaining sleep. The girl was awake for 25 minutes (range 0–150 minutes) during the baseline, 5 minutes (range 0–63 minutes) during the intervention, and no minutes during the follow-up. Both curve-fitting and split-middle trend-line analysis showed an upward trend in the baseline data for the girl.

On days 17, 18, and 30, the participant had a cold, and on days 7 and 14, she reported having a headache. On night 56, the girl showed a sudden increase in time awake at night. The information from the sleep diary did not provide an explanation for this increase. The sleep diary revealed a decrease in parental attention during treatment. During treatment and follow-up, the parents noticed that the girl was more obedient and cheerful.

SLEEP LATENCY

To study possible shifts in problems maintaining sleep to problems initiating sleep, we also studied sleep latencies. According to

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Durand (1998), 30 or fewer minutes to fall asleep is considered normal; latencies longer than 30 minutes are pathological. The mean time to initiate sleep was 28.3 minutes (range 4–62 minutes) during the baseline, 35.2 minutes (range 8–67 minutes) during the intervention, and 41.2 minutes (range 8–65 minutes) during the follow-up. Difficulties initiating sleep, that is, sleep latencies of 30 or more minutes, were present in 10 out of 26 nights (38%) during the baseline and 14 out of 29 nights (48%) during the intervention. During the follow-up period, difficulties initiating sleep were present in 8 out of 12 nights (67%).

Discussion

Behavioral intervention, consisting of parental support and the use of a graduated extinction procedure, were effective in treating the girl's sleep problems. The baseline consisted of a large number of sessions so that we could study possible delayed sleep-phase syndromes or free-running sleep rhythms, which are common in people with visual impairments. However, although the girl's sleep behavior was variable, we did not find recurrent periods of good and bad nights or a shift in the time that it took for the girl to fall asleep. This finding strengthened the hypothesis that parental attitudes and behavior were in control of the deviant sleep behavior and that the girl did not suffer from a delayed sleep-phase syndrome, a free-running, or a sleep-wake schedule disorder.

Although during the intervention phase the girl woke up less at night, falling asleep was still a mild problem. Because the parents could live with a slightly longer time for her to fall asleep above the normal time of 30 minutes, this problem was not given further treatment. The intervention effects

were probably flawed by spontaneous interventions by the parents at the start of the baseline measurements. Although the parents were instructed not to change their habits during the baseline period, they stopped taking the girl into their bed after her nightly awakenings and stopped playing music after they put her to bed. Despite this premature behavioral change, the girl's baseline was stable.

In general, we recommend starting interventions for sleep problems in children with visual impairments with conventional behavioral treatment and behavioral modification techniques for two reasons. First, children with visual impairments show many of the developmental disturbances that typically developing children show, which, in turn, can easily lead to inappropriate parental practices. Treatment of these inappropriate parental practices, by giving pedagogical advice or by using behavioral modification techniques, has been successful both in typically developing children (Heyrman, 2000) and in children with varying developmental difficulties (see, e.g., Curfs, Didden, Sikkema, & De Die-Smulders, 1999; Didden, Curfs, Sikkema, & De Moor, 1998; Didden, De Moor, & Wichink Kruit, 1999; Wiggs & Stores, 1998, 1999).

Second, behavioral treatment is recommended because chronotherapy, bright-light therapy, and the oral administration of melatonin are not effective treatments for all visually impaired persons with sleep problems. Moreover, studies of the effects of bright-light therapy have been conducted with adults, not with children. A drawback of chronotherapy is that it is difficult for parents to implement because chronotherapy easily interferes with their own sleep. With regard to the administration of melatonin, studies on the dosage and timing of

melatonin administration are just beginning to appear (see, e.g., Lewy et al., 2001). Therefore, we agree with Stores (2001b) that because of insufficient knowledge about dosage, timing, and long-term effects, melatonin should be used only for short periods in children for whom behavioral factors are obviously not the cause of the sleep problem and for whom other forms of treatment have failed.

An interesting side effect in the case described here is that the girl's parents reported her to be more obedient and cheerful during treatment than during the baseline period. Whether these observations would be substantiated by CBCL data is not known because the CBCL was filled out only prior to the treatment. However, the relationship between sleep problems and daytime behavioral problems is interesting. Although there seems to be no one-to-one association between sleep problems and behavioral problems, studies of persons with intellectual disabilities have shown that treating sleep problems can alleviate challenging daytime behaviors (Brylewski & Wiggs, 1999; Wiggs & Stores, 1996; 1998, 1999). In a follow-up project, we plan to study the relationship between sleep and sleep problems with daytime behavioral problems in children who are blind, have low vision, and have additional impairments. The possible effects that sleep and sleep problems may have on cognition, attention, and behavior make it worthwhile to treat sleep problems, especially in children with visual impairments, given the high prevalence of sleep problems in this population.

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AUQ14: Ref not cited in text. Cite or delete it

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