

Review Article

Addressing Sleep Disturbances in Children with Autism Spectrum Disorders

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Abstract

Up to 68 % of children with Autism Spectrum Disorders (CwASD) suffer from sleep disturbances that adversely affect their learning, emotional regulation, behavioral functioning, and safety, as well as impact their parents' sleep and stress levels. The most common sleep concerns reported by parents/caregivers include difficulty initiating or maintaining sleep and early rising, resulting in insufficient sleep time. Furthermore, sleep problems in CwASD occur early in development, persist into adolescence, and continue into the adult years, making this a life-long challenge. Inadequate sleep duration has been shown to increase ASD symptoms, disruptive behavior problems, and anxious symptoms; to reduce the effectiveness of therapeutic and educational interventions; and to impair family functioning; making sleep a critical area for intervention. Although more rigorous research is needed to establish the efficacy for behavioral interventions and sleep disturbances in CwASD, parents/caregivers prefer behavioral interventions over pharmaceutical treatment options, and a growing body of evidence suggests that behavioral interventions can be associated with behavior changes and positive outcomes for CwASD. This article describes factors related to sleep disorders, different types of sleep problems including poor sleep hygiene, assessment of sleep disturbances, and interventions to utilize in clinical practice.

ABBREVIATIONS

CwASD: Children with Autism Spectrum Disorders; ASD: Autism Spectrum Disorders; DD: Developmental Disabilities

INTRODUCTION

Sleep problems are fairly common in children and adolescents. Caregivers report that up to 41% of their typically-developing children ages 2 years to 13 years have difficulty initiating and maintaining sleep [1,2]. Those with developmental disabilities, including autism spectrum disorder (ASD), have an even higher prevalence of sleep difficulties, with upwards to 68% as reported by parents and caregivers [3]. Children with ASD (CwASD) have more problems than their peers in initiating and maintaining sleep, resulting in fewer hours of sleep than recommended for their age and development [4-6]. Sleep difficulties may exacerbate the symptoms and challenging behaviors associated with ASD as well as reduce cognitive and adaptive performance, interfere with family functioning, and adversely affect overall health and well-being [7-9]. As such, recognition and management of sleep problems becomes critical for pediatric health providers, especially when providing care for CwASD. In this article we discuss the prevalence and impact of sleep disturbances in

CwASD, sleep screening tools that are useful in clinical practice settings, and evidence-based interventions to improve sleep.

PREVALENCE AND IMPACT OF SLEEP CONCERNS IN ASD

According to the Centers for Disease Control and Prevention, about 1 in 68 children have been diagnosed with ASD [10]. Symptoms of ASD present before age 3 and last through the person's lifetime. Delays in communication, unusual interests, repetitive patterns of behavior, and limited interest in social relationships are the main characteristics of ASD. Other symptoms may include high levels of activity, short attention spans, high levels of anxiety, unusual sensory reactions, and poor sleep habits [3]. Sleep problems include irregular sleep habits, more frequent and longer nocturnal awakenings, and shorter sleep duration [4,6]. Inadequate sleep may exacerbate the communication challenges and repetitive behaviors commonly associated with ASD, and reduce the effectiveness of school and other therapeutic interventions [8,11]. As a result of dealing with their children's poor sleep, parents of CwASD may also develop irregular sleep habits resulting in chronic fatigue, stress, and lower parenting efficacy and satisfaction [12].

Sleep disturbances in CwASD are likely to be long term issues. In a prospective, cohort study of English children born in 1991 and 1992, Humphreys and colleagues regularly collected parent reports of child sleep duration and found that sleep differences in CwASD began by 30 months of age and persisted until adolescence [5]. These children slept 17-43 minutes less per day than their typically developing peers. Total sleep duration was decreased primarily due to later bedtimes and earlier awakenings. Waking three or more times per night was also common for CwASD. Other population-based longitudinal studies reported similar findings with school-aged CwASD being ten times more likely to develop sleep problems across the spectrum of low to high functioning autism [4,6,13,14]. Parents report that sleep problems persist into adolescence and adulthood [6,15].

Specific manifestations of sleep difficulties may differ depending upon the age of the CwASD. In a study completed with 1,859 children and adolescents with ASD, sleep habits were measured by parent report using the Children's Sleep Habits Questionnaire [15]. Older children and adolescents had more problems related to delayed sleep onset, shorter sleep duration, and daytime sleepiness. Younger children had more bedtime resistance, sleep anxiety, parasomnias, and night awakenings.

Poor sleep patterns in CwASD are consistently associated with more reported behavioral problems at home and at school, worsening autism symptoms, and possibly poorer cognitive function [8]. Identified problems include shorter attention spans, hyperactivity, more compulsive/ritualistic behavior, higher levels of aggressive behavior, poorer social interactions and more self-injurious behavior [8, 16-20]. Children with ASD may find increased opportunities for elopement at night when they are supposed to be asleep and left unsupervised [21], thus increasing the potential for harmful consequences including death [22].

When CwASD exhibit sleep difficulties, parents not only become extremely concerned about their child's health and well-being, they often experience insufficient or poor quality sleeps themselves [12,23-25]. In one study, 43% of parents reported that their own sleep suffered as a result of the vigilance needed to prevent nighttime elopement [21]. Parents may experience chronic fatigue and stress as a result of the extra attention needed to supervise and protect their child from elopement during the night [12,15,23,26].

IDENTIFICATION OF SLEEP PROBLEMS IN CLINICAL SETTINGS

A careful clinical history is the first step in identifying the presence of sleep problems and in understanding how underlying medical issues such as allergies, medications, or pain may be contributing to those problems [11]. Reviews of sleep habits and bedtime routines, as well as sleep diaries, are useful in documenting wake-sleep behaviors. Sleep diaries are used to measure quantitative and qualitative indices of sleep and document patterns of behavior that may be interfering with sleep (<http://yoursleep.aasmnet.org/pdf/sleepdiary.pdf>). In addition, sleep screening tools offer a quick and reliable method to identify and differentiate sleep disturbances, to determine when multi-night sleep diaries might be needed, and to help in making treatment decisions or referrals. These screening tools

can also assist in identifying the presence of obstructive sleep apnea which would necessitate a referral to a sleep specialist for evaluation [27].

Sleep Screening Tools

There are many sleep screening tools available for pediatric sleep concerns. Screening tools offer an efficient and cost-effective way to elicit information about sleep disturbances that can be used to inform and guide clinical practice. Information is generally obtained via caregiver report, rather than through more objective (and costly) measurements such as actigraphy or polysomnography. However, only a few screening tools have robust psychometric properties, and none have been validated for use with specifically with CwASD [28,29]. We selected the following four screening tools because they are economical, user-friendly, and can help identify sleep concerns in pediatric care settings.

The BEARS sleep screening algorithm is designed to address the most common sleep issues in 2 to 18-year-olds. It incorporates five basic sleep domains: 1) bedtime problems, including difficulty going to bed and falling asleep; 2) excessive daytime sleepiness, which includes behaviors typically associated with daytime somnolence in children; 3) awakenings during the night; 4) regularity of sleep/wake cycles (bedtime, wake time) and average sleep duration; and 5) snoring. The health care provider asks parents about possible problems in each domain, eliciting a yes or no response. If the answer is 'yes' then the parents are asked to describe the problem. For example, if a parent responded 'yes' to snoring, he/she would then be asked to describe how often the child snored and whether apnea accompanied the snoring. The BEARS is an efficient tool to use to record sleep information and screen for sleep problems in the primary care setting [30].

The Pediatric Sleep Questionnaire (PSQ) is a questionnaire designed to detect sleep-disordered breathing, snoring, daytime sleepiness, and related behavioral problems in children ages 2 to 18 years [31]. There are 22 questions that caregivers respond to as yes or no, that help identify sleep-related problems, especially problems related to breathing and daytime hyperactivity. This tool was developed to help identify sleep-related breathing disorders without the expense of polysomnography, and may be especially useful in periodic screening for children at high risk for obstructive sleep apnea, including those with craniofacial abnormalities, genetic syndrome (such as trisomy 21), or obesity. The PSQ has been translated into other languages, making it a useful tool for parents of varying ethnicities.

The Sleep Disorders Inventory for Students (SDIS) is a standardized screening instrument used to identify children at risk for obstructive sleep apnea (OSA), narcolepsy, periodic limb movement disorder, restless leg syndrome, and delayed sleep phase syndrome, as well as parasomnias [32]. There are two versions of the SDIS: one for children ages 2 to 10 years (SDIS-C) and the other for adolescent's ages 11 to 18 years (SDIS-A). Parents are asked to rate their child's sleep behaviors on 41 items, which takes about 15 minutes to complete. Both versions are available in English and Spanish. A computerized scoring system takes less than five minutes to complete and generates a comprehensive report. This instrument can be very useful in

a clinical practice when determining the need for referral to the sleep specialist.

The Children's Sleep Questionnaire (CSHQ) is an assessment tool for children ages 4-12 [33]. The CSHQ includes items relating to the major presenting sleep problems for children of this age: bedtime behavior and sleep onset, sleep duration, anxiety around sleep, behavior occurring during sleep, night awakenings, sleep-disordered breathing, parasomnias, and morning waking/daytime sleepiness. Parents are able to complete this form in about 15 minutes, making this an efficient screening tool in clinical settings. A self-report form for children who are readers and are over the age 7 is available. Versions have been translated to Spanish and Chinese.

EVIDENCE-BASED PRACTICES TO PROMOTE BETTER SLEEP

Behavioral Management

According to the National Professional Development Center on Autism, behavior modification is highly effective in managing behavioral challenges of CwASD (<http://autismpdc.fpg.unc.edu/content/evidence-based-practices>). There is growing evidence for the use of behavioral treatment in addressing sleep problems such as initiating and maintaining sleep in the general pediatric population [2,34]. Behavior modification is both familiar to and preferred by many caregivers, who may have concerns about the potential risks of using medication with their children [9]. Two systematic reviews of studies examining the effectiveness of behavioral treatment for the general pediatric sleep problems [2,34], and one review specific to CwASD [9], supported the use of standard extinction and scheduled waking (both techniques described below). Other behavioral interventions documented by single case studies involving CwASD included improved sleep hygiene practices, graduated extinction, faded bedtime, stimulus fading, and chronotherapy [9,35]. While these interventions resulted in improved sleep, the evidence was limited by the sample size, experimental design, and/or generalizability. Notably, in the general pediatric population, behavioral treatments for sleep issues have received strong empirical support in terms of prevention and long-term management [2].

Researchers have evaluated the effectiveness of parent-based sleep education for CwASD in two recent studies both of which combined general sleep hygiene with behavioral therapy approaches. Malow and associates [36] developed and evaluated an intervention package that included general sleep hygiene, the bedtime routine, behavioral strategies to minimize bedtime resistance (including graduated extinction), and use of a bedtime pass with morning rewards. Outcomes from individually-trained parents and group-trained parents were compared; both groups reported improvement in the sleep habits of their CwASD. In a randomized control trial, Johnson and colleagues [37] developed and tested an intervention for young CwASD with sleep disturbances. Included in the eight training sessions was an overview of behavioral principals and prevention techniques and instructions regarding bedtime routines, extinction and planned ignoring, and reinforcement. Individualized behavioral strategies for specific sleep issues were also covered. Parents reported improvement in the presenting sleep problems and satisfaction

with this approach, although no objective changes in sleep could be detected with actigraphy.

Descriptions of treatments

Standard extinction is a practice in which parents are instructed to ignore unwanted behavior, and in the case of sleep, involves implementing a predictable bedtime routine, and then ignoring the child's attempts to disrupt the sleep routine until the next morning (except to monitor for illness or injury). Commonly ignored behaviors include whining, crying, calling out for parents, and leaving the bedroom. Parents are instructed to ignore the child's behavior, no matter how long it lasts, so as to not unintentionally reinforce the problem behavior. Consistency is key to success in this approach, and parents must be forewarned to stay the course as bursts of negative behaviors (called extinction bursts) may occur during treatment. Some parents may find this approach stressful, and prefer an approach referred to as graduated extinction (also known as the Ferber Method), which allows parents to check on and comfort their child during brief intervals during the training period [2]. Standard extinction has been shown to improve self-settling and decrease night awakenings for CwASD [9] whereas graduated extinction needs more evidence to be considered an efficacious treatment for this population [35].

Sleep hygiene refers to the practice of developing a quiet, predictable bedtime routine that helps children achieve a quiet, relaxed state prior to sleep. The practice includes maintaining a consistent sleep schedule; ensuring that the child's room is cool, quiet and dark; and avoiding stimulating activities, beverages, or foods prior to bedtime. Sleep hygiene has been combined with more intensive behavioral therapy techniques, such as standard extinction, to improve effectiveness in CwASD [2].

Scheduled waking is a strategy used to treat chronic night terrors, and involves parents waking and consoling their child about 30 minutes prior to a typical night terror episode. The parent then soothes the child to return to sleep. The scheduled waking is gradually faded out by systematically increasing the time between the awakenings. This approach has been found to be possibly efficacious for CwASD, and is thought to increase the duration of consolidated, or uninterrupted, sleep [38].

Faded bedtime, stimulus fading, and chronotherapy have been studied for use in CwASD, but have not met the established criteria for evidence-based treatment needed to be considered as efficacious or possibly efficacious [39, 40]. Faded bedtime is used to help children initiate and maintain sleep. This intervention involves systematically setting bedtime earlier and earlier, while waking the child at the same time each morning and not allowing naps until the desired bedtime is reached. Stimulus fading is used to eliminate co-sleeping by progressively increasing the distance between the child and parent until the parent is out of the child's bedroom. For example, a mattress might initially be placed beside the child's bed and gradually moved away until it is out of the child's room. A single case study of a CwASD documented an overall decrease in sleep onset latency, reductions in night waking, and reduction in co-sleeping using stimulus fading [39,40]. Chronotherapy is used to treat severe sleep problems by systematically delaying bedtime and wake time each day, while

maintaining a regular schedule during waking hours. As with stimulus fading, only one single case study supported its use for CwASD [40].

Pharmacological Agents

Over-the-counter pharmaceutical agents are sometimes used to improve sleep in children. Antihistamines may help children fall asleep, but little is known as to their effectiveness at increasing sleep duration. Adverse effects of antihistamines include rash and daytime drowsiness, and they may be regulated differently in different countries. There is little to no evidence for the use of other pharmaceuticals to promote or maintain sleep in children, including the alpha-2 agonists, selective serotonin reuptake inhibitors, or antiepileptic agents [41]. Medication side effects can include fatigue, sedation, hypertension, and bradycardia. Because ASD is a neurological disorder, CwASD may be more susceptible to the adverse effects of the medication than typically developing children, and many are not able to communicate their discomfort. Long-term effects for these medications in children are unknown, and none have been approved by the Food and Drug Administration for use in sleep management with children and/or CwASD. The American Academy of Sleep Medicine has recommended against the use of pharmaceutical agents as the first treatment option for children's sleep problems, but if used, recommends that they accompany behavioral treatment methods and be used on a short-term basis only [42].

Researchers studying typically-developing children have provided some evidence that melatonin may improve sleep-onset and increase total sleep time, with few reported adverse side effects. There is interest in the use of melatonin with CwASD for initiating and maintaining sleep, because there may be abnormally low levels of melatonin residing in these individuals [11]. However, there is little agreement as to melatonin dosage and timing needed for effectiveness [43-45]. The most common adverse effects reported were headache, dizziness, nausea, and drowsiness. Cortesi et al. [46] found that behavioral treatment combined with controlled-release melatonin resulted in a better treatment response in the short term. However, the lack of data on melatonin dosage and timing, the unknown long-term effects of melatonin on health and brain development, and the quality of melatonin [since it is not regulated by the Food and Drug Administration] remain caveats for use in CwASD.

DISCUSSION AND CONCLUSION

Sleep problems are common in CwASD, may persist into adulthood, and poor sleep is associated with greater levels of behavioral problems and ASD symptoms. Parents of CwASD are also affected by their child's sleep problems; often reporting higher levels of stress and poorer sleep themselves. There is a paucity of research on effective treatments for poor sleep in CwASD. Most of the research is limited by a small sample size or study design.

Screening for sleep issues is an important first step in the process of identifying and treating sleep disorders for CwASD. Sleep screeners provide a quick and economical assessment of sleep-related problems, and help to detect risk for sleep disorders.

However, most sleep screeners are based upon parent report, and thus subject to error that might result in miss identification. Few of the screening tools have documented sound psychometric and technical properties have been compared with more objective measures such as actigraphy, and none have diagnostic power. Fewer still have included CwASD or other disabilities in their standardization sample. Many more studies are needed to document the reliability, validity and utility of screening instruments used in clinical practice and in research studies, in order to ensure early identification and proper treatment for pediatric sleep concerns.

Because sleep problems in many CwASD are chronic and negatively impact outcomes, it is critical to identify effective treatments that can be implemented through primary care settings. A careful clinical history, followed by either sleep problem screening tools and/or multi-night sleep diaries is needed to identify the specific sleep concerns so that intervention can be tailored to the individual patient. For instance, younger children may be more resistant to the bedtime routine, while worry and anxiety may prevent the adolescent from falling asleep. Each necessitates a different treatment approach. Night awakenings in younger children may be related to bathroom needs or unpleasant night events, while in older children awakenings may be precipitated by intrusive thoughts regarding daily or life situations. Having the parent awaken the young child can possibly reduce unwanted nighttime awakenings, but for older children, self-management of anxiety would likely be a better treatment approach. As detailed above, a number of potential behavioral strategies might effectively address each of these issues, and randomized trials that are rigorous and longitudinal over longer periods of time are critically needed.

Additionally, safety issues need to be addressed when CwASD are awake unsupervised during the night as deaths do occur during elopements or unattended exits from home. Nighttime monitoring systems, as used by caregivers of persons with dementia [47,48], may prove effective in preventing unintended home exits of CwASD. Children with a high propensity for or previous history of exiting the home may be candidates for products that provide tracking and locating technologies using RFID and cellular signals so that they can be rapidly located when missing.

Finally, there is a pressing need to address parent sleep problems. In studies of dementia caregivers, changing the care recipient sleep patterns or improving home safety did not necessarily result in improved caregiver sleep [49, 50]. In that population, caregivers' sleep patterns more closely resembled chronic insomnia than situational risings, with both prolonged sleep onset latency and wake after sleep onset. It is possible that parents of CwASD may need specific therapies to improve their sleep even after the sleep of their child has improved.

As evidence continues to mount on the close relationship between normal sleep and good health, the importance of having effective sleep therapies for CwASD and their parents grows. This is particularly pertinent given the length of time sleep abnormalities exist in this population and the amount of time parents may be impacted. Researchers and clinicians together can develop and test these strategies.

CONFLICT OF INTEREST

Meredeth Rowe, RN, PhD is the inventor of a night home monitoring system and has equity in a company that will sell this system. The authors declare no other conflicts of interest.

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