

Getting a Good Night's Sleep: Sleep problems, their etiology, and potential interventions for children and adolescents with autism

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Abstract

Whereas historically sleep was considered to be a predominantly passive activity, research now strongly suggests that it is a time of neurological growth, where memories and skills are consolidated (Fallone et al., 2002). Good sleep is thought to influence cognitive, physical and emotional performance, and aid in effective emotional regulation (Alfano & Gamble, 2009). Whilst sleep problems are relatively common amongst children and adolescents, with estimates varying between 11% and 47% (Russo et al., 2007), they are significantly more common in those with Autism (30% to 80%, Goldman et al. 2012; Hirata et al. 2016; Krakowiak et al. 2008), Research also suggests that without intervention these problems are likely to persist (Goldman et al. 2012; Hodge et al. 2013). Emerging research finds that autistic children and adolescents experience specific sleep difficulties that are unique to this group. As research on the etiology of sleep problems in autism develops we are refining our approaches to intervention to more effectively meet the needs of these children and young people and their families. This article summarises current research into the ways in which sleep is different for children and adolescents with autism in comparison to the general population. It also considers the multifactorial etiology of sleep problems for this group, and evidence based interventions to date. The author argues that through increased awareness, professionals can do much to ameliorate challenges related to sleep, and improve family functioning and quality of life.

Introduction

Research suggests that between 50 and 80% of children with autism experience sleep problems (Richdale & Schreck, 2009), compared to 11 to 47% of non-autistic children (Russo et al., 2007). These problems often start from infancy and persist throughout childhood and adolescence

(Goldman et al., 2012; Malow et al., 2016; Mannion & Leader, 2016). Moreover these patterns are seen internationally, with researchers reporting similar prevalence rates in Australia (Polimeni et al., 2005), Canada (Couturier et al., 2005), and the UK (Wiggs & Stores, 2004). In Asian countries such as South Korea (Park et al., 2012) and Japan (Taira et al., 1998) prevalence rates may be even higher. The potential consequences of poor sleep can be varied and far reaching, impacting not only the functioning and quality of life of the child but also of the family (Liu et al., 2021). These consequences of poor sleep can also impact the efficacy of interventions focused on other areas of need because poor sleep impacts learning and development (Schreck et al., 2004). However, as this article will illustrate, there is reason to be optimistic. Research suggests that an increase of only 30 minutes of sleep per night can significantly impact daytime functioning (Sadeh et al., 2002).

This article seeks to describe the main issues around sleep for children with autism, describing the factors contributing towards poor sleep and reviewing the most efficacious intervention approaches identified to date. It is hoped that by extending our knowledge and awareness in this area professionals will be more able to support families with a problem that is both prevalent and highly impacting.

How is sleep problematic for children with autism?

The particular difficulties that children with autism have regarding sleep are primarily delayed sleep onset, shorter duration of sleep, and more frequent nighttime awakenings than typically developing children (Allik et al., 2006; Mazurek et al., 2019; Richdale & Schreck, 2009; Polimeni et al., 2005; Glickman, 2010). Alongside these primary sleep issues, children with autism are also more likely to experience bedtime resistance, parasomnias such as nightmares, and sleep disordered breathing (Liu et al., 2006). Their sleep-wake patterns demonstrate more night-to-night variability than typically developing children (Anders et al., 2011), complicating the issue further. Liu et al. (2006) summarise that there does not appear to be one particular problem that characterises sleep in this group, but many. Research has also consistently found severity of autism characteristics to relate to poor sleep (e.g. Cohen et al., 2014), suggesting unique combinations of issues contributing to poor sleep for this group. It is also important to acknowledge the high incidence of comorbidities between autism and other conditions which are known to impact sleep, for example gastrointestinal problems and seizures (see Mannion et al., 2013 for a summary).

What is the impact of poor sleep for children with autism?

Research around the negative impact of poor sleep for children with autism is abundant. For example in this group poor sleep has been linked to poor behavioural inhibition and attention (Sadeh et al., 2002), hyperactivity (Goldman et al., 2011), and behavioural problems such as aggressiveness (Mazurek & Sohl, 2016). Poorer sleep is also associated with increased severity of autism characteristics such as heightened sensitivity to changes in the environment (Goldman et al., 2011), more stereotypic behaviour (Cohen et al., 2014), and poorer social skills (Fadini et al., 2015; Malow et al., 2016). As with the general population, for children with autism poor sleep is also associated with affective difficulties such as mood volatility (Goldman et al., 2011; Malow et al., 2016) and anxiety-related problems (Holloway et al., 2013; Mazurek & Petroski, 2015). This is particularly concerning in a population who are already at increased risk for affective disorders and mental health issues (May et al., 2015). Children with autism who have less sleep and poorer quality sleep are also more likely to experience challenges with learning than those who sleep well. For example sleep quality has been found to correlate with poorer cognitive performance (Malow et al., 2006), executive functioning (Reynolds et al., 2012), learning acquisition and memory consolidation (Johnson et al., 2013), and daily living skills such as eating and toileting (Taylor et al., 2012).

Sleep disturbance has consistently been shown to decrease the quality of life for children with autism and their families (Delahaye et al., 2014), suggesting that improving sleep for this group could decrease parental stress and enhance family functioning (Johnson et al., 2013). Sleep problems tend to be more prevalent and more significant in families with lower socio-economic status, and children in these families tend to be more negatively impacted by disturbed sleep when compared to children in families of higher socio-economic status (El-Sheikh et al., 2010; Waddington et al., 2020).

The etiology of sleep problems in autism

Researchers have emphasised the need to acknowledge the complexity of sleep difficulties for children and adolescents with autism, highlighting the multiple interacting factors that contribute to poor sleep. Richdale and Schreck (2009) suggest that a biopsychosocial model is necessary to fully understand the biological, psychological and environmental factors that predispose this group to poor sleep. Other researchers have suggested that these identified factors may interact in

complex and dynamic ways, whereby aspects of autism can exacerbate sleep problems and vice versa (Hollway & Aman, 2013).

Links between sleep and social skills

Sleep problems in children with autism have specifically been found to correlate with some of the key characteristics of autism, including difficulties relating to others (Shreck et al., 2004), communication and reciprocal social interactions (Hollway et al., 2013), and sensitivity to social cues (Glickman, 2010). These difficulties are hypothesised to have implications for autistic children's ability to develop regular sleep patterns through the process of entrainment i.e. aligning sleep-wake patterns to social cues (Richdale & Prior, 1995; Glickman, 2010). This leads to the further implication that autistic children may be less responsive to social skills interventions because of daytime tiredness, and the reduced efficacy of the social skills interventions would themselves exacerbate sleep difficulties (Schreck et al., 2004). As such the very characteristics of autism may be risk factors for poor sleep, and vice versa (Hollway et al., 2013).

Sleep and sensory sensitivities

Poor sleep has consistently been linked to heightened sensory sensitivity in children with autism (Mazurek & Petroski, 2015; Reynolds et al., 2012), with degree of sensory sensitivity in young children predicting future sleep difficulties (Mazurek et al., 2019). When compared to typically developing children, those with autism tend to have a higher prevalence of both sleep problems and atypical sensory behaviours, with one study reporting that behavioural indicators of sensory sensitivity were able to predict poor sleepers with 85.7% accuracy (Reynolds et al., 2011). Researchers have hypothesised that children who are hypersensitive to sensory stimuli may have difficulty tuning out from environmental stimuli in order to fall or stay asleep (Reynolds et al., 2012). Heightened sensory sensitivity may increase anxiety and therefore bedtime resistance when children are confronted with activities such as teeth brushing before bed (Hollway et al., 2013). It has also been hypothesised that children who are hyper- or hyposensitive to sensory stimuli may have difficulties filtering sensory information and may therefore miss environmental cues that entrain the sleep-wake cycle (Hollway et al., 2013). When combined with the tendency to miss social cues around sleep it is not surprising that children with autism have difficulty developing sleep promoting routines.

Restrictive and repetitive behaviours

Increased expression of restrictive and repetitive behaviours (RRBs) has consistently been demonstrated to correlate with severity of sleep problems in children with autism (Cohen et al., 2014; Goldman et al., 2009; Hundley et al., 2016; Mayes and Calhoun, 2009; Schreck et al., 2004; Tudor et al., 2012). This relationship remains apparent even when researchers control for other impacting variables such as intellectual functioning and social-emotional aspects of autism (MacDuffie et al., 2020). Some researchers have proposed that the relationship between RRBs and poor sleep may be bidirectional, suggesting that whilst poor sleep may exacerbate RRBs, children with more rigidity around bedtime routines may have more difficulty falling or staying asleep than children who are more flexible (Patzgold et al., 1998). Researchers have also hypothesised that this difficulty may be specifically connected to high levels of insistence on sameness, making children more likely to ruminate and engage in compulsive thoughts which delay sleep onset (Hundley et al., 2016).

The role of anxiety

Another consistent finding in the research is the connection between anxiety and poor sleep. In some studies anxiety has been found to be the strongest predictor of poor sleep in children with autism (Holloway et al., 2013), and poor sleepers with autism are more likely to demonstrate anxiety than good sleepers with autism (Goldman et al., 2011). The relationship between anxiety and poor sleep in children with autism is further complicated when we consider the role of RRBs. Research suggests that children with higher anxiety tend to show increased RRBs than children who are less anxious (Rogers et al., 2012; Lidstone et al., 2014). In addition, some studies have suggested that anxiety mediates the relationship between poor sleep and RRBs (Hundley et al., 2016), although this has not been found consistently, with MacDuffie et al., (2020) reporting that anxiety was independently related to both poor sleep and RRBs but was not a mediating factor between the two. It is important to consider the nature of the relationship between RRBs and anxiety in terms of poor sleep, and whilst increased expression of RRBs is associated with higher anxiety and poor sleep, some researchers suggest that RRBs may in fact be more frequent when children are using them to ameliorate their anxiety (Rodgers et al., 2012). In which case, far from being a risk factor they may in fact be a useful strategy to minimise anxiety and therefore promote better sleep. Similarly Lidstone et al. (2014) reports that for children with autism in their study, the relationship between anxiety and insistence on sameness was mediated sensory hyper- and hypo-sensitivity. This leads us to conclude that sensory needs must be considered in relation to anxiety if we are to improve sleep for this group.

Biological factors

Melatonin is the main neurohormone which influences sleep-wake patterns. Research suggests that individuals with autism have lower concentrations of melatonin and differences in how melatonin is synthesised compared to those without autism (see Rossignol & Frye, 2011, for a systematic review). Research also suggests a possible genetic origin for these differences, with abnormal melatonin levels reportedly being present in parents of children with autism who do not themselves have autism (Melke et al., 2008). However the pattern is inconsistent, with other researchers finding that some individuals with autism and prolonged sleep latency have typical melatonin profiles (Goldman et al., 2017). Children and adolescents with autism are also more prone to gastrointestinal problems, which have been associated with poor sleep (Hollway et al., 2013).

Interventions

As can be seen from the summary above, there are patterns of sleep difficulty which are unique to children with autism, and whilst there are sleep issues that are more likely to be apparent for these children, there is little homogeneity within this group. As such, Richdale and Schreck (2009) suggest that simply translating sleep interventions used to support typically developing children may not be sufficient. They go further to suggest that sleep interventions designed for children with autism should incorporate the key features of autism, and the sleep profiles found within this group, and the unique needs of the individual and their family.

How do families access support?

Malow et al. (2012b) suggests that parents of children with autism may often see sleep problems as simply “part of autism” and therefore be less likely to address sleep as a key area of need. As such they may not express concerns about sleep to the professionals who could help. It is also suggested that sleep issues may be overlooked or underreported because of a focus on daytime behaviours by families and professionals (Reynolds & Malow, 2011). For those parents who do seek support for sleep issues, the first point of contact is often the paediatrician or GP (Jin et al., 2013). Worryingly though, the research suggests that medical doctors are often ill equipped to assess and advise on sleep related issues. In a study conducted by Malow et al. (2016) parent reports suggested that 71% of the children with autism in their study had problems with sleep. However sleep problems were only captured on 30% of the clinician reports for these same children. Malow et al. hypothesise that this is due to the limited time available in a clinician visit, and the prioritising of other areas of need. Interestingly in a survey of 700 GPs in the United

States, 96% saw sleep management as being part of their role, whilst only 18% of these GPs had received any formal training (Fariqui et al., 2011). In another study 828 community-based physicians were surveyed on their knowledge and confidence in managing sleep issues in children. Less than 50% reported feeling confident in screening for sleep problems and only 25% felt confident in treating sleep problems. Nonetheless medication is prescribed following around 80% of GP visits for sleep related issues (Stojanovski et al., 2007). Delemere & Dounavi (2018) raise concerns that when treated in this manner sleep problems are likely to persist because medication alone does not address any of the environmental or behavioural contingencies that may be maintaining sleep problems. Front line health professionals do however have a valuable role to play in addressing sleep problems for children with autism. As they are often the first point of contact their assessment and intervention can be crucial in identifying treatable problems such as sleep disordered breathing, or other comorbid medical problems that are impacting sleep (Stein et al., 2001). These professionals can also be crucial in ensuring families get support from other professionals with different areas of specialism as required.

Behavioural interventions

Behavioural sleep interventions have been found to be efficacious for typically developing children, with Mindell et al. (2006) reporting in a systematic review that 94% of all studies reviewed resulted in clinically significant improvements in sleep. There is increasing evidence that such interventions can also improve sleep in children with autism (Cortesi et al., 2012; Reed et al., 2009; Malow et al., 2014). The principles of behavioural sleep interventions are to promote sleep through stimulus control and positive reinforcement. There are a range of approaches commonly utilised, all of which seek to reinforce patterns of sleep promoting behaviour. In practice these interventions usually involve supporting parents to develop bedtime routines and sleep conducive bedroom environments for and with their children. These activities help with entrainment of sleep patterns to circadian rhythms and social cues (Karthikeyan et al., 2020). Behavioural interventions can vary greatly in their approach, but usually include the development of pre-bedtime calming activities, and daytime activities which ensure adequate light exposure and exercise (Hundley et al., 2016). These interventions vary regarding how behaviourist they are, with those incorporating principles of extinction (providing no reinforcement of the undesirable behaviour) being the quickest to improve sleep but generally the least acceptable to parents (Delemere & Dounavi, 2018). Approaches such as bedtime fading involve temporarily moving bedtime to coincide with the child's natural sleep onset time, then gradually moving the bedtime to towards the desired time whilst ensuring the sleep onset latency remains short. This type of behavioural intervention has not only been shown to be highly effective for many families, but is also generally more acceptable to parents than

extinction-based approaches (Delemere & Dounavi, 2018). For a more comprehensive review of behavioural approaches to sleep management in children see Meltzer and Mindell (2014).

Pharmacological intervention

Given that lower levels of melatonin are often found in children and adolescents with autism, researchers have investigated the potential for melatonin treatment to improve sleep for this group. Findings have been promising, with melatonin reducing sleep onset latency and number of nighttime awakenings (e.g. Giannotti et al., 2006; Rossignol & Frye, 2011). The research literature reports few side effects if any for most people (Malow et al., 2016), and for many the improvements in sleep are maintained for several months post-treatment (Malow et al., 2012a). Where melatonin treatment improves sleep for children with autism it also appears to positively impact associated issues such as symptom severity, hyperactivity, and stereotyped and compulsive behaviours (Malow et al., 2012a). Positive impacts have also been reported in daytime mood, daytime behaviour, and parental stress levels (Giannotti et al., 2006).

However the picture is not entirely positive. Whilst melatonin treatment can effectively improve sleep for many children with autism, there appear to be a significant number whose sleep improvements are not maintained after discontinuation treatment (Giannotti et al., 2006). Giannotti et al. propose that for these children their ability to respond to environmental cues that facilitate entrainment may be so impaired that periodic melatonin treatment in low doses may be required. For these children the authors suggest that such treatment should be combined with behavioural therapy to ameliorate some of the perpetuating factors. Other authors have also argued that pharmacological approaches may not be as effective when social and emotional factors are contributing to the maintenance of sleep difficulties (Cortesi et al., 2010). Others go further still and suggest that melatonin may be over-prescribed. For example Malow et al. (2016) found that of the 1518 children with autism they surveyed, medication was frequently prescribed in cases where the presenting issues suggested that behavioural insomnia or unhelpful sleep habits were the maintaining factor. As the authors point out, where the etiology of the sleep disorder is behavioural or environmental, intervention that focuses on parent education either alone or alongside melatonin is more likely to be effective.

Working with the family

Sleep problems can be difficult to manage for any parent, but research suggests that for parents of children with autism these challenges are often exacerbated. Lopez-Wagner (2008) reports that poor sleep in children with autism had a greater impact on parents' sleep than similar sleep problem in children without autism. In this study severity of autism characteristics was also

positively correlated with parental sleep problems. Aside from the impact on parental sleep, poor sleep in children with autism has also been found to impact measures of parental quality of life, and parental physical health, presumably as an outcome of long-term poor sleep (Liu et al., 2021). These findings have led researchers to propose that the impact on families of poor sleep in children with autism may be qualitatively and quantitatively different from the impact on families with non-autistic children with poor sleep (Liu et al., 2021). It has also been suggested that the relationship between poor sleep and negative impacts on families is reciprocal, such that the poor sleep creates additional stress for parents, who may then struggle to maintain strategies that promote good sleep for themselves and their child (Richdale & Schreck, 2009).

With these concerns in mind researchers have investigated parent-targeted sleep interventions for children with autism. Sleep education for parents of children with autism has been associated with improved sleep, and consequently also with a reduction in challenging behaviours, parental quality of life, and parental sense of competence (Malow et al., 2014). Researchers have hypothesised that the efficacy of such interventions is related to a range of changes in the family, including improved behaviour management skills, greater attunement to sensory needs at bedtime, and increased use of calming techniques (Malow et al., 2014). Parental sleep education has also been shown to increase parents' sense of competence (Malow et al., 2014). This can lead to parents feeling more able to maintain strategies that promote good sleep, and could have additional benefits in terms of their confidence in following other programmes of support and advocating for their children in school and health settings (Malow et al., 2014). El-Sheikh et al. (2010) highlight the importance of parent education programmes being individualised in order to account for different family circumstances and resources, suggesting that parent education programmes that are more didactic are likely to be less effective.

Taking a person-centred approach

The research reviewed here highlights the variation in sleep profiles and sleep needs amongst children with autism as compared to typically developing children, suggesting that generic sleep advice will not suffice for this group. Cohen et al. (2014) suggest that in defining the individual autism and sleep profiles of these children we will be more effective in identifying and developing interventions. Whilst much sleep research for this group has centred on clinical and parent reports, a study conducted by Pavlopoulou (2020) highlighted the usefulness of a more person-centred approach. In this study 54 autistic adolescents collaborated with researchers to investigate self-reported behaviours and habits that promoted sleep. Participants identified strategies that met their individual needs, and helped improve their sleep, such as personalised relaxation techniques and making time to engage in highly preferred activities. Pavlopoulou

summarised that autistic adolescents should be seen as experts in themselves, with their preferences and ideas being given weight. In this way Pavlopoulou suggests that sleep practitioners will be more able to develop meaningful and authentic interventions, whilst also empowering these adolescents to contribute to improving their own mental health. Given the heterogeneity of this group person-centred approaches are likely to be far more effective than more standardised approaches.

Conclusions

Given the prevalence and impact of poor sleep for children and adolescents with autism, improving sleep for this group has the potential to positively impact their lives, and those of their families, in myriad ways. Key to this is ensuring that families access the right kind of support at the right time. In order to address sleep needs, comprehensive assessment is crucial, with many authors proposing that issues such as sleep, anxiety, and potential melatonin deficiencies be routinely screened for (Rossignol & Frye, 2011). However, assessment for this group should go beyond routine screening if it is to lead to effective and meaningful intervention. When viewed from a biopsychosocial framework it is apparent that a multi-disciplinary approach to assessment and intervention is required. There are also strong arguments in the literature for an approach that authentically includes the voice of the parents and the child or adolescent themselves (Pavlopoulou, 2020). If we are to be successful in this it will be important to both educate and empower the children and adolescents and their families. Good sleep is fundamental to learning and development, social relationships, and mental and physical health. Given this potential, sleep can and should be prioritised by anyone interested in improving the wellbeing of children and young people with autism.

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