

Original Articles

Extended Parent-based Behavioural Education Improves Sleep in Children with Autism Spectrum Disorder

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Abstract

Purpose: To investigate the longitudinal effects of an extended parent-based behavioural education workshop on sleep and daytime functioning in children with autism spectrum disorder. **Methods:** Families with children younger than 6 years diagnosed with autism spectrum disorder and sleep problems were recruited. Three parent-based sleep behaviour education workshop sessions were conducted over consecutive weeks (week 1-3). Weekly telephone interview took place from week 1-7. Sleep, behaviour, and parental stress were evaluated by questionnaires before the workshop and at week 3, 7 and 11. **Findings:** Assessments using the Children's Sleep Habits Questionnaire and Child Behaviour Checklist showed increased sleep duration (6.05 ± 1.85 vs. 5.24 ± 1.83 , $p=0.014$), improved internalising behaviours (67.90 ± 9.05 vs. 65.03 ± 10.46 , $p=0.015$) and fewer sleep problems after the workshop (64.50 ± 10.50 vs. 58.94 ± 8.35 , $p=0.002$). Pittsburgh Sleep Quality Index of parents' sleep also showed improvement in terms of shorter sleep onset latency (1.46 ± 1.02 vs. 0.96 ± 0.95 , $p=0.012$), less sleep disturbance (1.30 ± 0.63 vs. 0.98 ± 0.63 , $p=0.014$) and better daytime functioning (1.35 ± 0.89 vs. 0.98 ± 0.74 , $p=0.038$). **Conclusion:** Parent-based behavioural education was helpful in improving sleep of children with autism spectrum disorder, and sleep and daytime functioning of their parents.

Key words

Autism spectrum disorder; Behavioural education; Sleep disorders

Introduction

Autism spectrum disorder (ASD) is a devastating lifelong neurodevelopmental disability presenting in young age.^{1,2} It is characterised by restricted repetitive patterns of behaviour, interests or activities, and persistent impairment

in social interaction and communication.³ Sleep problems are common in children with ASD, which are apparent from an early age and persist into later life.^{4,5} Approximately 44-83% of parents complain about the presence of sleep problems in their ASD child, and these problems include bedtime resistance, difficulty in falling asleep, frequent awakenings after sleep onset, and early wake time.^{1,4-9}

Although current knowledge about the associations between sleep issues and behavioural problems remains limited, children with ASD and concurrent sleep problems have been shown to exhibit more severe ASD symptoms^{9,10} including communication difficulties,¹¹ repetitive behaviours, irritability and poorer daytime functioning⁹ than those who do not have sleep problems. In addition, sleep problems, especially short sleep duration, are associated with worse performance in overall intelligence, verbal skills, overall adaptive functioning, daily living skills, socialisation skills and motor development.¹¹ Furthermore, children's sleep problems may

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also affect their parents' sleep quality and hence increase their stress level.^{12,13}

Sleep problems in children with ASD is likely a result of complex interactions between biological abnormalities, psychological conditions, medications and family/social factors.¹⁴ Behavioural and pharmaceutical interventions are the two common strategies employed in the management of sleep problems in children with ASD.^{15,16} Behavioural interventions exhibit lasting benefits with minimal adverse effects and are therefore recommended as the first-line therapy.¹⁶ Only if behavioural interventions were not feasible or severe symptoms displayed, then medications would be considered. Behavioural problems in these children, especially communication deficits, impede the establishment of consistent and healthy sleep hygiene habits. Therefore, equipping parents and caregivers with practical strategies to promote good sleep practice represents an important avenue to tackle sleep problems in this population. Sleep hygiene education has been shown to be effective in improving sleep in children.^{16,17} Behavioural treatment with the following principles, namely consistent bed time and wake time, establishment of consistent bedtime routines, limiting naps, minimising exposure to electronic devices and reducing emotional or behavioural stimulation before bedtime are promising interventions.^{18,19} However, few studies have examined the sustained efficacy of such behavioural education in improving ASD children's sleep as well as effects on their parents.

The aim of this study was to examine the longitudinal effects of an extended group parent-based behavioural education on sleep problems and daytime functioning in children with ASD. Our secondary goal was to determine whether the education was helpful in improving parental sleep and stress. The hypothesis of this study was that an extended behavioural education would lead to sustained improvement in children's sleep patterns and parental sleep and stress.

Methods

Recruitment of Subjects

We recruited families with children younger than 6 years diagnosed to have ASD²⁰ and sleep problems as reported by parents. Subjects were attendants at the Special Child Care Centres (SCCC) of Heep Hong Society, Watchdog (WD) and the Spastic Association Hong Kong (SAHK) which are non-government organisations that provide training services for children with ASD. Children with

neurological and medical conditions (e.g. epilepsy and obstructive sleep apnoea) which could have affected their sleep were excluded. Sleep problems reported by parents included bedtime resistance, difficulty in sleep initiation (sleep-onset delayed by more than one hour), night time awakenings (awakenings that disturbed parents), and early wake time (child's wake up time earlier than 6:00 am). Ethical approval for the study was obtained from the Joint Chinese University of Hong Kong - New Territories East Cluster Clinical Research Ethics Committee. All parents provided written informed consent.

Outcome Measures

Each child's sleep habit was evaluated by the Children's Sleep Habits Questionnaire (CSHQ) and the Family Inventory of Sleep Habits (FISH). Children's Sleep Habits Questionnaire is a sleep screening instrument widely used to identify sleep problems in children with a variety of conditions including ASD.²¹ The questionnaire consists of 50 questions, and each item is scored as 3=usually (5-7 times/week), 2=sometimes (2-4 times/week), or 1=rarely (0-1 time/week). It yields a total score and 8 subscale scores (sleep onset delay, night awakening, sleep duration, sleep resistance, sleep anxiety, parasomnia, daytime sleepiness and sleep disordered breathing) reflecting key sleep domains that encompass the major medical and behavioural sleep disorders. Higher CSHQ scores represent worse sleep habits or outcomes. Family Inventory of Sleep Habits is developed to measure sleep hygiene and behaviours in children with ASD.²² There are 22 questions, and each question is scored 1 to 5 according to frequency of occurrence, namely never, rarely, sometimes, usually and always. In a validation study, the total score of FISH showed significant negative correlation with the total score from CSHQ.²²

The daytime behaviour of each child was assessed by the Child Behaviour Checklist (CBCL) and the Parental Concerns Questionnaire (PCQ). Child Behaviour Checklist is one of the most commonly used questionnaires to identify social/emotional and/or behavioural problems in children. It is used to assist in the diagnosis and evaluate emotional and behavioural problems in children with ASD.²³ It has well-documented reliability and validity, and has been standardised and validated in numerous countries throughout the world.^{24,25} The form comprises 100 problem items: 99 closed items and one open-ended item which requests the respondent to add any additional problems not previously listed. Parents are requested to rate each item as 0 for not true, 1 for somewhat or sometimes true and 2 for

very true or often true. The total problem score is the sum of scores on all items including emotional reaction, anxious/depressed syndrome, somatic complaints, withdrawal, sleep problems, attention problems, and aggressive behaviour. Internalising score is the sum of scores on items in withdrawal, somatic complaints and anxious/depressed syndrome profiles, and externalising score is the sum of scores on attention problems and aggressive symptoms. Parental Concerns Questionnaire is designed as a 13-item parent-interview screening instrument assessing the severity of core developmental and associated psychiatric symptomatology using a four point scale (1-4).²⁶ Parents are asked to describe the extent to which each symptom has been a problem with 1, 2, 3 and 4 representing no, mild, moderate and severe problems respectively.

Pittsburgh Sleep Quality Index (PSQI) and Parental Stress Index-Short Form (PSI-SF) were used to assess parental sleep and stress respectively. Pittsburgh Sleep Quality Index has been widely used to assess sleep habit, quality and quantity in various populations.²⁷ It is a self-rated questionnaire and consists of 19 questions generating a total score and seven sub-scores including sleep quality, sleep onset latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication and daytime dysfunction. Parental Stress Index-Short Form is a validated and reliable instrument widely used for measuring parenting stress.²⁸ Parents rate each of the 36 items on a 5-point scale ranging from strongly disagree (1) to strongly agree (5). The total score is an indicator of parenting stress.

Intervention

Following an initial screening telephone interview to determine eligibility, parents of recruited subjects completed the various outcome measure questionnaires before the start of the workshop.

Three educational workshop sessions were delivered by a trained research nurse over consecutive weeks (week 1-3). General principles on various sleep issues, most relevant for children with ASD were discussed (Table 1). The presentation took place for the first 60 minutes of each session, and the subsequent time was spent on group discussion and design of individual management strategy for each family. For each workshop session, we limited the number of families to a maximum of 8 to allow for more in-depth discussion between family members and the investigator. Weekly (week 1-7) telephone interview was conducted by the research nurse to answer queries, provide support and reinforce strategies decided for that particular family. Medical referral to the outpatient department for

further assessment +/- treatment was made for medical problems identified during and after the workshop. Parents were requested to complete the same set of questionnaires at the following time points: end of the workshop at week 3, end of the telephone interview at week 7, and finally at a face to face interview at week 11 (Table 1).

Statistical Analysis

According to findings from a previous study that examined change of total score in CBCL following parental education, a sample size of 19 would achieve 90% power to detect a mean paired difference of 7.0 with a known standard deviation of 9.2 at a significance level (alpha) of 0.05 using two-sided paired t-test.²⁹ Missing data of children who dropped out were omitted. Data were presented as mean and standard deviation for continuous data and percentage for categorical data. Changes in sleep and behavioural parameters at the 4 time points before and after the workshop were evaluated by univariate general linear models for repeated variables. Statistical analyses were carried out with SPSS version 20.0 (Chicago, IL, USA), and a p value <0.05 was considered statistically significant.

Results

Fifty four families took part in this study. Four families dropped out and fifty families (92.6%) completed all 3 workshop sessions and questionnaires for at least two time points before and after the workshop. Forty six families (85.2%) completed all the sessions and follow-up evaluations. The demographics and characteristics of the participants are summarised in Table 2.

Results from CSHQ, CBCL, and FISH showed improvements in the children's sleep. They included increased sleep duration, decreased sleep problems and better sleep hygiene, and such improvement maintained till week 11. The daytime internalising behaviour problem subscale by CBCL which included emotional reaction, anxiety/depression, somatic complaint and withdrawal also improved following the workshop. The score decreased from 67.90 ± 9.05 at week 0 to 65.03 ± 10.46 by week 11 ($p=0.015$, Table 3).

Parents' sleep including sleep onset latency, sleep disturbance and daytime dysfunctions due to sleepiness were also noted to improve. The results from PSQI showed that sleep onset latency score decreased from 1.46 ± 1.02 to 0.96 ± 0.95 ($p=0.012$); sleep disturbance score decreased from 1.30 ± 0.63 to 0.98 ± 0.63 ($p=0.014$); daytime sleepiness

Table 1 Parent-based sleep educational intervention workflow and outline

Time points	Sessions	Contents or topics	Distributed questionnaires
Week 0	Briefing session	Study aim, topics and workflow Introduction of sleep and behaviour related questionnaires	CSHQ, FISH, CBCL, PCQ, PSI-SF, PSQI
Week 1	Session 1	ASD children and categories of their sleep problems Influencing factors and health outcomes of sleep problems Sleep recommendations: <ul style="list-style-type: none"> • Comfortable sleep setting • Regular and better bedtime routine • Regular daytime schedule • Promotion of daytime behaviours 	
Week 2	Telephone interview	Immediate support, answer the enquiries and gain feedback	
	Session 2	Techniques for promoting sleep: <ul style="list-style-type: none"> • Bedtime fading • Stimulus fading • Graduated extinction • Visual supports • Reward program 	
Week 3	Telephone interview	Immediate support, answer the enquiries and gain feedback	
	Session 3	Other sleep concerns such as obstructive snoring apnoea and allergic rhinitis Sleep medication for insomnia and other sleep problems	CSHQ, CBCL, PSI-SF, PSQI
Week 4-6	Telephone interview	Immediate support, answer the enquiries and gain feedback	
	Weekly telephone interviews	Immediate support, answer the enquiries and gain feedback	
Week 7	Telephone interview	Immediate support, answer the enquiries and gain feedback	CSHQ, CBCL, PSI-SF, PSQI
Week 11	Post-workshop sharing session	Review sleep recommendations and techniques Case scenarios	CSHQ, FISH, CBCL, PCQ, PSI-SF, PSQI

ASD: Autism Spectrum Disorder; CSHQ, Children's Sleep Habits Questionnaire; FISH, Family Inventory of Sleep Habits; CBCL, Child Behaviour Checklist; PCQ, Parental Concerns Questionnaire; PSI-SF, Parental Stress Index-Short Form; PSQI, Pittsburgh Sleep Quality Index

Table 2 Demographics and characteristics

	Week 0 (n=54)	Week 3 (n=50)	Week 7 and 11 (n=46)
Age (year)	4.78±0.85	4.85±0.85	4.84±0.88
Boy (%)	79.6	83.3	83
Term birth (%)	88.9	85.7	87.2
Gestational age (week)	36.70±1.13	36.70±1.18	36.66±1.20
Age when diagnosed (year)	2.42±0.84	2.40±0.83	2.42±0.80
Diagnosis (n)			
ASD	52	49	45
PDD	0	0	0
Asperger syndrome	1	1	1
Medication			
Psychotropic	1	1	1
Melatonin	1	1	0
Anti-allergic	3	3	3

ASD: Autism Spectrum Disorder; PDD: Pervasive Personality Disorders

score also decreased from 1.35 ± 0.89 to 0.98 ± 0.74 ($p=0.038$; Table 4).

Discussion

Our study longitudinally examined the benefits of parent-based sleep educational intervention in children with ASD and their parents. Many specialists in paediatric sleep agree that children with ASD have a lower response rate to behavioural intervention, which suggest that vigorous intervention, such as behavioural education with longer time span or even pharmacological management may be required to improve sleep problems in these children.⁶ To our knowledge, the duration of behavioural education in our study is the longest so far reported in the literature, with three weekly sessions, weekly telephone follow-up till week 7, and one final face-to-face interview at week 11. Our results demonstrated that such extended parent-based behavioural

education was indeed beneficial to both children and their parents. The children's sleep duration improved and they had less sleep problems as reported by their parents. The positive effects maintained till after 2 months following the workshop. The children's daytime overall internalising behavioural problems, including withdrawal, somatic complaints and anxious/depressed syndrome also improved. Furthermore their parents' sleep and stress also responded positively after the workshop.

Previous studies reported conflicting results on the effects of behavioural intervention on insomnia and sleep quality, which are the main sleep problems reported in children with ASD.^{19,29-31} Our current study had a long study duration with weekly telephone reminder by a research nurse. This study design could explain the positive response and maintenance effects recorded. We understand statistical significance does not necessarily mean clinical significance, and some of the changes reported in the study were modest. We did not assess any qualitative outcomes but during our final face-to-face

Table 3 Children's sleep habits and behavioural problems before and after the education

Sleep parameters	Baseline (mean, SD)	Week 3 (mean, SD)	Week 7 (mean, SD)	Week 11 (mean, SD)	Change1 (mean, SD)	Change2 (mean, SD)
<i>Children's Sleep Habits Questionnaire</i>						
Total score	55.11 (8.38) ^a	53.93 (7.88) ^a	51.76 (7.53) ^b	52.55 (9.50) ^a	-3.34 (6.52)*	-2.55 (9.92)
Sleep onset delay	1.95 (0.85) ^a	1.86 (0.84) ^a	1.65 (0.74) ^a	1.76 (0.79) ^a	-0.25 (0.67)	-0.18 (0.80)
Night waking	4.52 (1.53) ^a	4.19 (1.40) ^a	3.98 (1.25) ^a	4.31 (1.37) ^a	-0.51 (1.60)	-0.17 (1.99)
Sleep duration	6.05 (1.85) ^a	5.93 (1.89) ^a	5.57 (1.73) ^{a,b}	5.24 (1.83) ^b	-0.48 (1.52)	-0.81 (1.61)*
Bedtime resistance	10.74 (2.49) ^a	10.95 (2.58) ^a	10.48 (2.54) ^a	10.76 (2.90) ^a	-0.26 (2.18)	0.02 (2.32)
Sleep anxiety	7.34 (1.86) ^a	7.17 (1.81) ^a	6.94 (1.74) ^a	7.29 (2.06) ^a	-0.41 (1.38)	-0.06 (2.01)
Parasomnia	11.07 (2.57) ^a	10.38 (2.57) ^a	9.83 (1.96) ^b	10.41 (2.82) ^a	-1.12 (2.06)**	-0.55 (3.20)
Daytime sleepiness	13.98 (3.54) ^a	14.03 (3.41) ^a	14.09 (3.37) ^a	13.30 (3.28) ^a	0.11 (2.40)	-0.68 (2.99)
Sleep dis. breathing	3.76 (1.06) ^a	3.90 (1.28) ^a	3.72 (1.15) ^a	3.81 (1.24) ^a	0.01 (1.09)	0.12 (1.21)
<i>Child Behaviour Checklist</i>						
Total	67.11 (10.73) ^a	65.69 (12.06) ^a	64.97 (12.12) ^a	63.67 (10.46) ^b	-0.91 (5.73)	-3.20 (5.71)*
Externalising	59.65 (8.81) ^a	58.55 (9.71) ^a	58.83 (10.19) ^a	58.68 (10.21) ^a	-0.81 (5.90)	-1.24 (6.71)
Emotion	65.17 (8.81) ^a	63.89 (11.43) ^a	64.17 (11.75) ^a	63.47 (11.29) ^a	-0.65 (13.90)	-1.11 (14.20)
Anxiety/dep.	60.73 (9.86) ^a	59.35 (9.26) ^a	60.48 (10.53) ^a	58.73 (9.90) ^a	-0.07 (8.12)	-1.96 (6.85)
Somatic complaint	58.97 (8.21) ^a	58.36 (10.03) ^a	58.44 (10.01) ^a	57.58 (9.65) ^a	-0.74 (12.11)	-2.61 (11.94)
Withdrawn	76.85 (9.76) ^a	77.62 (10.18) ^a	77.10 (9.72) ^a	74.62 (9.97) ^a	-0.05 (7.45)	-2.74 (7.51)
Attention	63.35 (7.19) ^a	63.40 (8.42) ^a	63.32 (8.56) ^a	62.68 (7.95) ^a	-0.47 (6.51)	-1.89 (6.75)
Aggressive beh.	58.90 (8.25) ^a	14.55 (7.01) ^b	58.65 (8.05) ^a	58.78 (8.65) ^a	-0.19 (5.29)	0.04 (6.00)
Sleep problem	64.50 (10.50) ^a	60.33 (9.47) ^b	59.17 (7.92) ^b	58.94 (8.35) ^b	-5.02 (12.11)**	-5.26 (14.20)**

Dep., depression; beh., behaviour.

The letters on top of the values indicate significant differences, $p < 0.05$.

Change1, value changed between baseline and 7th week; change2, value changed between baseline and 11th week; * $p < 0.05$; ** $p < 0.01$.

interview with the parents, nearly all expressed positive response to the workshop. A few parents commented that the various sleep behavioural strategies discussed at the workshop would offer a greater impact to their children's well-being if started early on, for example soon after the diagnosis of ASD was made.

Group parent-based education intervention used in our study has been shown to be more cost-effective compared to individual interview-based interventions.³⁰ Group education workshops provide shared experience and intra-participant encouragement from families, therefore enhancing the potential for learning and social support for families of children with ASD. The improvement of parental sleep in our study may be derived from the peer support, improvement of their children's sleep, or the knowledge of sleep hygiene gained from the workshop. Our data added further evidence attesting to the effectiveness of such programme in improving sleep even in the parents.

Our initial follow-up investigated the sustained benefits of our behavioural education on sleep in both children and their parents. However, several limitations should be considered. First, our study did not include a control group of children who did not receive any intervention. As short sleep duration and poor sleep quality in children with ASD has been commonly observed from a young age and has been shown to persist until adolescence in the absence of behavioural treatment, it is unlikely that spontaneous

improvement of sleep-related parameters would have occurred should there have been a control group. Thus our results strongly suggested that behavioural education was beneficial and that it was unlikely that the children and their families would have improved on their own.⁵ Nevertheless, future controlled studies are warranted if further refinement of the intervention is needed. Second, sleep duration was evaluated based on parental report which is not an objective measurement.¹ However, the compliance of wearing actiwatches in children with ASD is often poor. Moreover, Souders et al compared sleep behaviour and sleep quality in children with ASD by using CSHQ and actigraphy and found that the subjective and objective measures yielded similar estimates of the rate of sleep disturbances in these children.¹

In summary, parent-based sleep behavioural education was feasible and effective with sustainable benefits in improving sleep duration and sleep problems in children with ASD. Day-time behaviour of the children and parental sleep was improved accordingly. The effectiveness of the behavioural education on insomnia and parasomnia among children with ASD is still controversial. Our study adds to the accumulating evidence for behavioural intervention as the first line management in children with ASD and sleep problems. However, future studies are warranted to refine the strategies, mode and duration of the behavioural interventions.

Table 4 Parental sleep and family questionnaires

Parameters	Baseline (mean, SD)	Week 3 (mean, SD)	Week 7 (mean, SD)	Week 11 (mean, SD)	Change1 (mean, SD)	Change2 (mean, SD)
<i>Pittsburgh Sleep Quality Index</i>						
Total score	7.37 (3.75) ^a	6.88 (3.09) ^a	7.27 (3.15) ^a	7.07 (2.99) ^a	-0.51 (2.90)	-0.33 (3.06)
Sleep quality	1.46 (0.74) ^a	1.30 (0.64) ^a	1.24 (0.70) ^a	1.32 (0.61) ^a	-0.29 (0.73)	-0.22 (0.87)
Sleep onset latency	1.46 (1.02) ^a	1.20 (1.07) ^a	1.04 (1.10) ^b	0.96 (0.95) ^b	-0.43 (0.94)**	-0.5 (1.13)*
Sleep duration	0.85 (1.02) ^a	0.98 (1.09) ^a	0.96 (1.18) ^a	0.80 (1.09) ^a	0.11 (1.54)	-0.06 (1.35)
Sleep efficiency	0.93 (1.15) ^a	1.17 (1.28) ^a	1.81 (1.43) ^b	1.87 (1.33) ^b	0.89 (1.67)*	0.94 (1.59)***
Sleep disturbance	1.30 (0.63) ^a	0.98 (0.63) ^{a,b}	0.96 (0.73) ^b	0.98 (0.63) ^b	-0.33 (0.82)*	-0.31 (0.73)*
Daytime sleepiness	1.35 (0.89) ^a	0.94 (0.68) ^b	1.07 (0.87) ^{a,b}	0.98 (0.74) ^b	-0.28 (0.92)	-0.37 (0.96)*
Sleep quality	1.46 (0.74) ^a	1.30 (0.64) ^a	1.24 (0.70) ^a	1.32 (0.61) ^a	-0.29 (0.73)	-0.22 (0.87)
Medication	0.33 (0.87) ^a	0.36 (0.82) ^a	0.24 (0.73) ^a	0.36 (0.85) ^a	-0.09 (0.51)	0.02 (0.77)
FISH score	42.58 (5.02) ^a	–	–	44.09 (4.24) ^b	–	1.38 (4.87)*
PSI-SF score	82.55 (8.15) ^a	82.91 (8.20) ^a	81.73 (8.32) ^a	80.27 (6.74) ^a	0.82 (8.24)	-2.28 (7.26)
PCQ score	30.73 (5.69) ^a	–	–	29.36 (5.19) ^a	–	-1.38 (4.87)

FISH, Family Inventory of Sleep Habits; PSI-SF, Parental Stress Index-Short Form; PCQ, Parental Concerns Questionnaire

The letters on top of the values indicate significant differences, $p < 0.05$.

Change1, value changed between baseline and 7th week; change2, value changed between baseline and 11th week; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

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Declaration of Interest

The authors declare no conflict of interest.

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