ORIGINAL RESEARCH

Familial sleep and autism spectrum disorder: a pilot actigraphy study of sleep quality, quality of life and psychological distress

Geraldine Leader[1],* 🄳 , **Carmel Glynn[1], Bernadette Kirkpatrick[2], June L. Chen[3], Páraic S. O'Súilleabháin[4,5] and Arlene Mannion[1]** 🄳

[1] *Irish Centre for Autism and Neurodevelopmental Research (ICAN), School of Psychology, National University of Ireland, Galway, Ireland*

[2] *University of Ulster, Coleraine, Northern Ireland*

[3] *Department of Special Education, Faculty of Education, East China Normal University, Shanghai, China*

[4] *Department of Psychology, University of Limerick, Limerick, Ireland*

[5] *Health Research Institute, University of Limerick, Limerick, Ireland*

Objectives: Sleep problems are common among children with autism spectrum disorder (ASD) and can have a negative impact on the child's behaviour and daytime functioning. The current pilot study examined objective measurements of child and parent sleep as factors associated with the stress, anxiety, depressive symptoms, social support and quality of life of parents of children with ASD.

Methods: Participants were nine children with ASD and their parents (nine mothers and three fathers). Participants wore an actigraph for 7 consecutive days and nights. Measures of sleep habits and quality were used to ascertain child and parent sleep. Measures of parenting stress, anxiety, depressive symptoms, quality of life and social support were collated.

Results: Results indicated the emergence of high parental stress, anxiety and depressive symptoms. Significant correlations were observed between parent depressive symptoms, and both subjective sleep quality and child sleep disruptions.

Conclusions: The present study found that parental well-being is affected by child sleep problems.

Introduction

Sleep problems are common in children and adolescents with autism spectrum disorder (ASD) (Richdale & Schreck, 2009; Mannion & Leader, 2013; Wiggs & Stores, 2004). Several studies have reported settling problems with some children with ASD taking more than an hour to fall asleep (Angriman *et al.* 2015; Cortesi *et al.* 2010; Kotagal & Broomall, 2012). The reported prevalence of sleep problems in ASD has varied in the research from 33% (Goldman *et al.* 2011) to 80% (Mannion *et al.* 2013). Sleep problems have been found to persist over time in children and adolescents with ASD (Mannion & Leader, 2016). Prevalence of sleep problems in children with ASD is much higher than in typically developing children (Souders *et al.* 2009), with research finding sleep problems were more than twice as common in children with ASD as in the general population (Reynolds *et al.* 2019).

Impact of sleep problems on the child

Sleep problems in children with ASD have a negative impact on various other aspects of the child's life. Many children with ASD and other developmental disorders experience other comorbid conditions such as behaviour problems, toileting problems, attention-deficit/hyperactivity disorder, overselectivity, epilepsy and gastrointestinal symptoms (Devlin *et al.* 2008; Francis *et al.* 2017; Kelly *et al.* 2015); Leader *et al.* 2018; Leader & Mannion, 2016a; 2016b; Mannion & Leader, 2014a; 2014b; Newman *et al.* 2015). Research has begun to investigate the relationships between sleep problems and other comorbid conditions in ASD.

Positive correlations have been found between sleep problems and daytime challenging behaviour (Adams *et al.* 2014; Goldman *et al.* 2011; Sikora *et al.* 2012; Tudor *et al.* 2012). Correlations have also been found between sleep problems and hyperactivity, and compulsive and ritualistic behaviours, compared to children without sleep problems (Goldman *et al.* 2009). Research has found significant positive associations between sleep problems, anxiety and challenging behaviour, with

*Address for correspondence: Geraldine Leader, Ph.D., Irish Centre for Autism and Neurodevelopmental Research, School of Psychology, National University of Ireland, Galway, Ireland.
(Email: geraldine.leader@nuigalway.ie)

medication, anxiety and sleep problems accounting for 42% of the variance in challenging behaviour (Rzepecka et al. 2011). Sleep problems have been shown to be a predictor of anxiety in children and adolescents with ASD (Williams *et al.* 2015).

Research has found that fewer hours of sleep per night predicted overall autism severity scores and social skills deficits (Adams *et al.* 2014; Schreck *et al.* 2004). Stereotypic behaviour was predicted by fewer hours of sleep per night and screaming during the night, and poor sleepers with ASD have a higher percentage of behavioural problems than good sleepers with ASD (Schreck *et al.* 2004).

Impact of sleep problems on parents

Sleep problems that affect children with ASD also affect parent's sleep quality and quantity. Children waking during the night usually need parental help and/or attention, resulting in sleep loss for one or both parents (McCann *et al.* 2015; Meltzer & Mindell, 2007). Parent sleep can be affected by other factors, such as stress. Parents of children with developmental disabilities reported poorer sleep quality than parents of typically developing children, and that the strongest predictor of poor sleep quality was parental stress (Gallagher *et al.* 2010).

Research has found that children's sleep problems have a negative impact on parent anxiety and depressive symptoms levels. Children's sleep behaviours have been shown to place a strain on marital relationships and financial insecurity (Kirkpatrick *et al.* 2019). Research has shown that maternal sleep quality was a significant predictor of maternal mood, stress and fatigue (Bar *et al.* 2016; Kouros & El-Sheikh, 2017; Meltzer & Mindell, 2007). Children with ASD who had significant sleep disruptions were significantly more likely to have mothers with more depressive symptoms, fatigue and daytime sleepiness (Delahaye *et al.* 2014; Hodge *et al.* 2013). Mothers of children who had significant sleep disruptions reported greater feelings of parenting stress and care-giving overload. Greater sleep and behaviour problems in children had a significant association with disturbed sleep and increased depressive symptoms, anxiety and stress levels in mothers (Chu & Richdale, 2009).

Children's sleep significantly predicted maternal mental health, maternal sleep and maternal stress, and maternal sleep and maternal stress each predicted maternal mental health (Hodge *et al.* 2013). Children's sleep and maternal sleep were more closely related to maternal stress for mothers of typically developing children, and it was concluded that this may be because stress related to sleep is minor relative to other sources of stress relating to their child's disability (Hodge *et al.* 2013).

Actigraph for monitoring and tracking sleep

Strong evidence would support the use of the actigraph to objectively monitor and track sleep (Adkins *et al.* 2012; Meltzer *et al.* 2012; Wiggs & Stores, 2004). The actigraph device can be used at home and is considered a reliable and an objective method for measuring sleep–wake patterns, onset of sleep, continuity and sleep duration (Wiggs & Stores, 2004), making the actigraph suitable for the current study.

Current study

The current pilot study aimed to expand on existing research in critical ways. We primarily sought to extend current literature using objective sleep measurements through the use of actigraphy. In doing so, we sought to assess sleep in children with ASD and their parents. We also examined subjective measures of sleep, including further measures associated with well-being, namely parental stress, anxiety, depressive symptoms and overall quality of life. This pilot study sought to address several limitations in existing research at this critical research intersection, while providing a basis for future research in this area.

Method

Participants

Families of children with ASD were recruited for the current study if they had a child aged between 3 and 18 years and were recruited through special schools, schools with ASD units and from parent support groups. Once an interested individual contacted the researchers, and it was confirmed that their child had an independent diagnosis of ASD, and were aged between 3 and 18 years, they were recruited for the study.

The study sample comprised of nine children and adolescents with a diagnosis of ASD in accordance with DSM-IV-TR criteria (American Psychiatric Association, 2000). Diagnoses were provided by a licenced psychologist or paediatrician independent of the study. The participants received their diagnosis as a result of the formal diagnostic protocol which employs multiple diagnostic measures. Caregiver information on professional diagnosis, diagnostic setting/organisation and professional(s) who made the diagnosis was obtained.

The final sample consisted of a total of 21 participants (nine families – nine mothers, three fathers and nine children). Selection bias may have occurred. We attempted to address this by advertising that we were looking to recruit families where the child did not have sleep problems also. However, it is possible that only families where the child had sleep problems chose to participate in the study. Some children were not able to tolerate the use of actigraphs, which impacted upon

Table 1. *Descriptive statistics of participants*

	Mean (S.D.)	*n* (%)		Mean (S.D.)	*n* (%)
Parent			Child		
Age (years)	39.75 (6.57)		Age (years)	9.75 (2.53)	
Age range	31–53 years		Age range	7–14 years	
Gender			Gender		
Male		3(25%)	Male		6(67%)
Female		9(75%)	Female		3(33%)
Educational level			Diagnosis		
Primary school		0	Autism		8 (89%)
Secondary school		4(33%)			
Tertiary education		8(67%)	Asperger's syndrome		1(11%)
Marital status			Type of education		
Single		1(8%)	Applied behaviour analysis		1(11%)
Married		8(67%)	Eclectic		8(89%)
Divorce		2(17%)			
			Intellectual disability (ID)		5 (56%)
			Mild ID		4 (44%)
			Moderate ID		1 (11%)
			Epilepsy		1 (11%)
			Taking melatonin		1 (11%)
			ADHD diagnosis		0
			Anxiety diagnosis		0

ADHD, attention-deficit/hyperactivity disorder.
Standard deviations appear in the parentheses beside the mean score.

the attrition rate. The descriptive statistics for participants are presented in Table 1.

Measures

The questionnaire booklet consisted of a demographic questionnaire, the below questionnaires and sleep diaries for the parent(s) and child. The demographic questionnaire consisted of questions on the child's age, gender, diagnosis, comorbidity, education and medication.

Sleep diary

Participants completed a sleep diary for 7 days, for themselves and their children. They recorded when the actigraph was removed, and what time it was replaced, the start and end time of any naps taken, time got into bed and time turned out lights, time woke up in the morning, time turned on lights and time got out of bed. Research has suggested that it is useful to use a sleep diary, as it has been shown to be an important adjunct to actigraphy when used to edit data and remove artefacts (Wiggs & Stores, 2004).

The Pittsburgh Sleep Quality Index (PSQI)

The participants (mothers and fathers) completed the Pittsburgh Sleep Quality Index (PSQI) (Buysse *et al.* 1989). The 19-item self-report questionnaire assesses sleep quality and sleep disruption. Seven dimensions of sleep: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications and daytime dysfunction were measured. The component scores are summed to give a total sleep quality score, which ranges from 0 to 21. A total score of ≥5 has been recommended as clinically significant in terms of poor sleep quality. The scale has acceptable internal consistency and good test–retest reliability (Buysse *et al.* 1989).

The Parenting Stress Index-Short Form (PSI/SF-4)

The Parenting Stress Index-Short Form (PSI/SF-4) (Abidin, 2012) is a standardised measure used to evaluate stress in parents that are at risk for parenting problems or child behavioural problems. The questionnaire consists of 36 items pertaining to parental feelings and experiences, comprising 3 scales: Parental Distress, Parent–Child Dysfunctional Interaction and Difficult Child Characteristics. Parents rate their agreement for each statement on a five-point Likert scale, ranging from 1 (strongly agree) to 5 (strongly disagree). The scales have shown high internal consistency and adequate test–retest reliability and have been used widely in studies of parents of children with disabilities (Dardas & Ahmad, 2014).

Multidimensional Scale of Perceived Social Support (MSPSS)

The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet *et al.* 1988) is a 12-item self-report measure that evaluates a person's perceived social support, from three subscales – family, friends and significant other. It was utilised as an additional variable to analyse parent stress. The MSPSS has demonstrated good internal and test-retest reliability, with high levels of social support associated with low levels of depressive symptoms and anxiety (Canty-Mitchell & Zimet, 2000; Zimet *et al.* 1988).

The Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to assess parent levels of anxiety and depressive symptoms. The scale consists of 14 items, 7 assessing anxiety and 7 assessing depressive symptoms. It yields a total depressive symptoms score and a total anxiety score. A score of 0–7 is classified as normal for each score, 8–10 is classified as borderline abnormal (borderline case) and 11–21 is classified as abnormal. It has demonstrated good internal validity and concurrent validity and has been found to perform well in assessing the symptom severity and cases of anxiety disorders and depressive symptoms in somatic, psychiatric and primary care patients and in the general population (Bjellend *et al.* 2002).

WHOQOL-BREF (World Health Organization's Quality of Life Questionnaire-BREF)

Parent's quality of life was assessed using the WHOQOL-BREF (World Health Organization; The WHOQOL Group, 1998), an abbreviated version of the WHOQOL-100. The questionnaire consists of several demographic questions at the beginning, followed by 26 items which are rated on a 5-point scale. These items assess four domains: physical health, psychological, social relationships and environment. The mean score of items within each domain is used to calculate the domain score. The scale has been shown to have good reliability and validity in adult populations (Krägeloh *et al.* 2013).

Actigraphy

All participants (mothers, fathers and children) were asked to wear an actigraph (Actiwatch 2, Philips Respironics, Norfolk, UK) for 7 consecutive days and nights, worn on the non-dominant wrist. The actigraphs were configured using a 1-minute epoch, with medium threshold, as this is the most widely used epoch length in sleep research (Meltzer *et al.* 2012). Parents were instructed to press the event marker button on the side of the actigraph to mark sleep onset and sleep offset on their own actigraphs, and to do so on their child's actigraph also. Objective sleep quantity was measured by total sleep time (TST, total time within rest intervals scored as sleep). Additional data gathered and their definitions are as follows: (1) bedtime (time when the subject went to bed with the intent to sleep); (2) get-up time (time when the subject rose from bed for the final time); (3) time in bed (period of time between bedtime and get-up time); (4) onset latency (period of time between bedtime and sleep start time); (5) sleep efficiency (percentage of time in bed actually spent sleeping); (6) wake after sleep onset (WASO; the number of waking minutes between sleep start and sleep end times); and (7) #Awak (the number of continuous blocks of wake). A validated Philips Actiware software (Version 6, Philips Respironics) algorithm was used to estimate sleep parameters, based on thresholds for wake and sleep (Adkins *et al.* 2012). Actigraphy has been widely used in recent years in sleep studies with both children and adults and has demonstrated good reliability and validity (Sadeh, 2011).

Procedure

A home visit was arranged at a time convenient for the family. Data collection took place during the summer holidays. Informed consent was obtained from the parents, and verbal assent from the children. Parents were then given the actigraphs and shown how to use them and given instructions on proper care of them. They were also instructed on the use of the daily sleep diary. They were also given the questionnaire booklet, containing the questionnaires listed above. After 7 days, a second home visit was made to collect the actigraphs, sleep diaries and questionnaires.

Results

Parenting Stress Index-Short Form (PSI-SF)

The majority of parents scored highly on the PSI-SF, indicating high parenting-related stress. The means, standard deviations, range, minimum and maximum scores are presented in Table 2 below.

Multidimensional Scale of Perceived Social Support (MSPSS)

The majority of participants scored highly on the MSPSS. The means, standard deviations, range, minimum and maximum scores are presented in Table 2 above.

Hospital anxiety and depression scale (HADS)

The majority of participants scored highly on both the anxiety and depressive symptoms subscales of the

Table 2. *Descriptive statistics for WHOQOL-BREF, HADS, PSI-SF and MSPSS questionnaires*

Variable	Mean (S.D.)	Range	Minimum	Maximum
World Health Organization's Quality of Life Questionnaire-BREF (WHOQOL-BREF)				
WHOQOL-BREF domain 1 (physical health)	64.25 (17.70)	56	38	94
WHOQOL-BREF domain 2 (psychological)	52.00 (18.32)	56	25	81
WHOQOL-BREF domain 3 (social relationships)	66.67 (18.84)	69	31	100
WHOQOL-BREF domain 4 (environment)	56.33 (15.51)	50	38	88
WHOQOL-BREF average score	59.81 (13.72)	42.25	40.75	83
Hospital Anxiety and Depression Scale				
HADS depression score	7.83 (3.35)	12	2	14
HADS anxiety score	9.92 (3.63)	11	4	15
Parenting Stress Index				
PSI-SF Parental Distress (PD) subscale	37.25 (8.98)	33	21	54
PSI-SF Parent–Child Dysfunctional Interaction (P-CDI) subscale	31.75 (7.36)	21	22	43
PSI-SF difficult child (DC) subscale	41.67 (8.26)	26	28	54
PSI-SF total stress score	110.67 (20.91)	66	79	145
Multidimensional Scale of Perceived Social Support				
MSPSS total score	57.20 (12.78)	46	32	78

HADS. The means, standard deviations, range, minimum and maximum scores are presented in Table 2 above.

WHOQOL-BREF

The raw scores calculated for each of the four domains were transformed into a 0–100 scale score. Lower scores indicate lower quality of life. The majority of participants had lower than average quality of life scores. Hawthorne *et al.* (2006) investigated population normative values for the WHOQOL-BREF. The normative values they found were 73.5 for Domain 1, 70.6 for Domain 2, 71.5 for Domain 3 and 75.1 for Domain 4, with an average for the four subscales of 72.66. The means, standard deviations, range, minimum and maximum scores are presented in Table 2 above.

Subjective sleep quality

The mean PSQI total score was higher for mothers (Mean = 8.56, S.D. = 3.36) than for fathers (Mean = 7.00, S.D. = 4.00), with a high mean total score for parents (Mean = 8.17, S.D. = 3.41). Meltzer (2008) stated that a total score of ≥5 on the PSQI is recommended as clinically significant in terms of poor sleep quality. Two parents (17%) had a total score of <5 on the PSQI, while 10 parents (83%) had a total score of ≥5, indicating that the majority of parents had self-reported sleep problems. The means, standard deviations and range of scores are presented in Table 3 below.

Actigraphy

A week (7 days and nights) of actigraph measurement produced an average for each of the sleep variables for both parents and children. The means and standard deviations for the range of sleep variables for parents are presented in Table 4. Souders *et al.* (2009) stated that the Children's Hospital of Philadelphia's (CHOP) Sleep Centre recommends a sleep efficiency of <85% and a sleep-onset latency of >30 minutes as a cut-off for defining poor sleep quality. The majority of participants did not have poor sleep quality as indicated by poor sleep efficiency, with three participants (25%) having a sleep efficiency of <85%, while nine participants (75%) had a sleep efficiency of ≥85%. TST was less than recommended, with nine participants (75%) having ≤7 hours of sleep, with three participants (25%) having >7 hours.

The means and standard deviations for the range of sleep variables for children were included in Table 5. Eight children (89%) had a TST of ≤8 hours, with one child (11%) getting >8 hours sleep. Four children (44%) had ≤7 hours of sleep, with five children having >7 hours of sleep per night, indicating less than recommended sleep time. Five children (56%) had <85% sleep efficiency, while four children (44%) had >85% sleep efficiency. The mean sleep efficiency of 83% is lower than the recommended cut-off of 85% indicating poor sleep quality.

Correlation analyses

Subjective and objective sleep measures

Pearson's correlations were used to test for associations between the subjective and objective sleep variables. No significant relationships were found between the subjective sleep measures (PSQI) and any of the objective (actigraph) sleep variables.

Table 3. *Means, standard deviations and range for subjective sleep variables for parent*

Variable	Mothers (*n* = 9) Mean (S.D.)	Fathers (*n* = 3) Mean (S.D.)	Parents total (*n* = 12) Mean (S.D.)	Range
PSQI sleep quality	1.56 (1.01)	1 (1.00)	1.42 (1.00)	
PSQI sleep-onset latency	1.33 (1.00)	1.33 (1.16)	1.33 (.99)	
PSQI sleep duration	1.33 (.58)	1.33 (1.00)	1.33 (.89)	
PSQI sleep efficiency	1.00 (1.12)	.67 (.58)	.92 (1.00)	
PSQI sleep disturbances	1.56 (.53)	1.67 (.58)	1.58 (.52)	
PSQI sleep medications	.22 (.67)	.00 (.00)	.17 (.58)	
PSQI daytime functioning	1.56 (.73)	1.00 (1.00)	1.42 (.79)	
PSQI total score	8.56 (3.36)	7.00 (4.00)	8.17 (3.41)	3–14

PSQI = Pittsburgh Sleep Quality Index.
Standard deviations appear in the parentheses beside the mean score.

Table 4. *Means, standard deviations and range for objective sleep variables for parents*

Objective sleep variables (actigraphy)	Mothers (*n* = 9) Mean (S.D.)	Fathers (*n* = 3) Mean (S.D.)	Parents total (*n* = 12) Mean (S.D.), range
Bedtime	00:55 am (0:46)	01:40 am (2:50)	1:06 am (1:25), range = 23:52–4:06
Get-up time	8:48 am (1:34)	8:50 am (2:08)	8:49 am (1:37), range = 6:26–11.25
Time in bed (hours)	7 hours 53 minutes (0:58)	7 hours 10 minutes (0:51)	7 hours 42 minutes (0:57), range = 6 hours 17 minutes–9 hours 23 minutes
Total sleep time (hours)	6 hours 52 minutes (0:59)	5 hours 45 minutes (0:11)	6 hours 35 minutes (1:05), range = 4 hours 55 minutes–8 hours 22 minutes
Onset latency (minutes)	8 minutes (0:07)	11 minutes (0:11)	9 minutes (0:07), range = 1 minutes–24 minutes
Sleep efficiency (per cent)	87% (3.37)	80% (7.16)	85% (5.20), range = 73.28–91.14
Wake after sleep onset (minutes)	42 minutes (0:13)	50 minutes (0:09)	44 minutes (0:12), range = 23 minutes–1 hour 1 minutes
No. of wake intervals	22.44 (5.24)	26.86 (3.95)	23.55 (5.17), range = 15.86–31.86

Sleep issues and stress

Pearson's correlations were conducted to determine if there was a relationship between self-reported sleep quality (PSQI total score) and parent stress (PSI total stress), and between actigraph variables and parent stress. There were no significant correlations between parent stress and subjective sleep quality, or between parent stress and any of the child actigraph variables. There was only one significant correlation for the parent actigraph variables, a positive association between PSI total stress and sleep efficiency (as measured by actigraph), (r (12) = .61, p = .04), with a large effect size.

Sleep issues and parent depressive symptoms

Pearson's correlations were conducted to determine if there was a relationship between self-reported sleep quality and parent depressive symptoms, and between actigraph variables and parent depressive symptoms. A large positive correlation was found between the global PSQI score and HADS depressive symptoms score, (r (12) = .70, p < .05). A significant negative correlation was found between HADS depressive symptoms score and parent sleep latency, (r (12) = -.70, p = .01), with a large effect size. Of the child actigraph variables, one significant correlation was found, between child WASO and HADS depressive symptoms score, (r (12) = .63, p = .03), with a large effect size.

Sleep issues and parent anxiety

Pearson's correlations were conducted to determine if there was a relationship between self-reported sleep quality and parent anxiety, and between actigraph

Table 5. *Means, standard deviations and range for objective sleep variables for children and adolescents with ASD*

Variable	Mean (S.D.), range
Bedtime	00:00 am (1:36), 22:07–02:57
Get-up time	8:34 am (1:27), 7:15–11:58
Time in bed (hours)	8 hours 33 minutes (1:38), 4 hours 58 minutes–10 hours 35 minutes
Total sleep time (hours)	7 hours 8 minutes (1:27), 3 hours 52 minutes–9 hours 11 minutes
Onset latency (minutes)	10 minutes (0:15), 1 minutes–50 minutes
Sleep efficiency (per cent)	83% (4.57), 76%–88%
Wake after sleep onset (minutes)	57 minutes (0:21), 24 minutes – 1 hour 45 minutes
No. of wake intervals	25.62 (6.97), 12–41.86

variables and parent anxiety, with no significant correlations found.

Sleep issues and quality of life

Pearson's correlations were conducted to determine if there was a relationship between self-reported sleep quality and parent quality of life, and between actigraph variables and parent quality of life. One significant positive correlation was found between average WHOQOL-BREF scores and sleep efficiency (actigraphy), (r (12) = .60, p = .04, with a large effect size.

Parent sleep variables and child sleep variables

Pearson's correlations were conducted to determine if there was a relationship between parent actigraph variables and child actigraph variables, with no significant correlations found.

Discussion

The current pilot study was the first study to use a multi-method approach to examine both child and parent sleep, and their relationship with parent stress, anxiety, depressive symptoms and quality of life. The current study diverges from previous findings that report child sleep disruption affects parent sleep, in that within the current sample child shorter TST, lower sleep efficiency and waking after sleep onset did not impact on parent sleep. One possible reason is that the child may not have sought parental attention, which is a factor which may warrant further investigation.

A significant association was found between parent depressive symptoms and self-reported subjective sleep quality, consistent with previous research (Chu & Richdale, 2009; Hall *et al.* 2017; Meltzer, 2011). A significant positive association was found between parent depressive symptoms and child WASO, that is, that higher parent depressive symptoms were associated with child sleep disruptions during the night. In addition to depressive symptoms, research has indicated

that sleep disturbance and sleep disorders could be linked to alcohol use and abuse in alcoholics and non-alcoholics (Roehrs & Roth, 2001). Caffeine consumption has also been reported as having a detrimental impact on sleep patterns, especially in adolescents (Snel & Lorist, 2011). Evidence also suggests that nicotine influences sleep and mood and that smoking increased sleep-related respiratory disorders which negatively impact on sleep quality and increased daytime tiredness (Jaehne *et al.* 2009). It is possible that parent self-reported reduced quantity and good quality of sleep could have been linked to alcohol use or abuse, caffeine and or nicotine consumption. Although beyond the scope of the current study, the measurement of the aforementioned sleep problem contributors would be considered beneficial to future research.

A positive correlation was found between quality of life and parent sleep efficiency, that is, lower quality of life scores was associated with lower sleep efficiency. This may be because individuals with a lower quality of life have many worries, for example, money, work, children, lack of social support, etc., which impact on their sleep quality. Although lower quality of life may not have an impact physically, it has an impact on psychological well-being, therefore contributing to the poorer sleep quality.

A significant negative association was found between parent depressive symptoms and parent's sleep-onset latency, indicating that higher parent depressive symptoms was associated with shorter sleep-onset latency. No significant correlations were found between the subjective sleep measures (PSQI) and the objective sleep measures (actigraphy). This may suggest that subjective measures of sleep may be unreliable compared to objective measures such as actigraphy, and that self-report measures may overestimate or exaggerate sleep problems. It may also suggest that parents feel frustrated or burnt out. The subjective and objective measures of sleep did not match well, which indicates that subjective measures of sleep should be improved in the future. The concordance

between subjective sleep measures and actigraphy should be addressed in future research.

The main findings of the study indicate that parental depressive symptoms may be linked to self-reported sleep quality, and child sleep disruptions. Parental self-reported depressive symptoms were higher than average normative values (Hinz & Brähler, 2011), as was self-reported anxiety. No associations were found between parent anxiety and parent or child sleep, which may suggest that parental anxiety is linked to other child issues, for example, child behaviour problems, symptom severity, etc. Certain sleep issues were apparent in the children in this study, including TSTs that are less than recommended for children, with 89% of the children in the study getting less than 8 hours of sleep on average per night, and 44% getting less than 7 hours per night. Sleep recommendations indicate that children aged between 7 and 12 years of age should get 10 to 11 hours of sleep per night, and that children aged 12–18 years should get 8 to 9 hours of sleep (National Sleep Foundation, 2015). The average sleep efficiency was lower than the recommended cut-off of 85% (Souders *et al.* 2009), indicating less than recommended sleep quality. WASO was also an issue for children.

The sleep patterns of parents in this study did not appear abnormal. Bedtimes, get-up times and TSTs were wide ranging. Sleep-onset latency was short, with an average latency of 9 minutes, and average sleep efficiency was 85%, indicating that the sleep quality was quite good. The high PSQI scores did not appear to correlate with the actigraph variables, apart from less than recommended TST, with parents getting an average of 6 hours 35 minutes of sleep per night (7–8 hours is recommended for adults), and WASO was quite high, with parents spending an average of 44 minutes awake each night, with 92% of parents awake for longer than 30 minutes each night.

Results were found that also contradict previous research on parent stress and sleep, with a positive correlation found between parent stress and parent sleep efficiency, indicating that higher parent stress was linked to greater parent sleep efficiency. The results indicated that parents with high stress and/or depressive symptoms levels may be more tired and sleep better as a result. This result is in contrast to previous results (Gallagher *et al.* 2010), which found that parental stress was associated with poorer sleep quality. However, this result was based on subjective sleep measures, which may not be as reliable as actigraphy. Similar results have been found as the current study, where child and parent sleep were more closely linked to parent stress for parents of typically developing children than for parents of children with ASD (Hodge *et al.* 2013). This may be because stress related to sleep is minor relative to other sources of stress relating to their child's disability.

Parent stress, anxiety and depressive symptoms were all higher than average, with quality of life lower than average. The mean PSI stress score was in the 86th percentile, indicating very high stress levels for parents. As no associations were found between parent stress and parent or child sleep problems, it would appear that parent stress may be linked to other factors not examined in the current study, for example, child behaviour or child functioning. Furthermore, 89% of mothers and 67% of fathers scored above average for both self-reported anxiety and depressive symptoms. In support of this, previous research has found that 83% of parents reported lower than average quality of life (Hawthorne *et al.* 2006), which again was not found to be linked to parent or child sleep problems.

The current study had several methodological strengths, including objective measurement (actigraphy) of both parent and child sleep, which has been used in very few studies. The questionnaires used in the study have been validated and shown to be reliable. The study examined several relationships between parent sleep and parent issues, and child sleep and parent issues.

There were also several limitations. Firstly, this was a very small study, where the small sample size limited the statistical analyses that could be conducted on the data, as well as the generality and validity of the study. The failure to find relationships could be due to several uncontrolled factors or to the small sample size. Non-tolerance of the actigraphs was a major issue in this study, with several participants having to pull out due to being unable to tolerate the actigraphs. Tactile sensitivity is a major issue for many children with ASD; therefore, asking a child to wear a watch-like device can be difficult for many children. Data collection took place during the summer holidays, which may have affected the availability of families to participate in the research. The absence of a control group is also a limitation of the present study. A control group would have allowed comparisons to be drawn between the groups for each of the variables examined. A final limitation was the lack of fathers who participated in the study, with only three out of the nine families having both mother and father. This made it difficult to compare maternal data with paternal data due to the limited numbers.

The present study raises important points for future research. No correlations were found between subjective and objective measures of sleep, highlighting the lack of reliability of subjective sleep measures, which can overexaggerate sleep problems. There was a lack of relationships found between parent stress, anxiety, depressive symptoms and quality of life and child and parent sleep in the current study; therefore, the factors that affect these variables should be examined in

future research. Actigraphy is an emerging and more reliable method of sleep measurement. A multi-method approach to sleep measurement, which allows an examination of different aspects of sleep, should be used in all future sleep research. A replication of this study with a larger sample size and a typically developing control group should be conducted in the future.

Financial support

This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Conflicts of interest

The author has no conflicts of interest to disclose.

Ethical standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008. Informed consent was obtained from all individual participants included in the study. The study protocol was approved by the ethics committee of the participating institution.

References

Abidin RR (2012). *Parenting Stress Index*, 4th edn. Psychological Assessment Resource: Odessa, FL.

Adams HL, Matson JL, Cervantes PE, Goldin RL (2014). The relationship between autism symptom severity and sleep problems: should bidirectionality be considered? *Research in Autism Spectrum Disorders* **8**, 193–199.

Adkins KW, Molloy C, Weiss SK, Reynolds A, Goldman SE, Burnette C, … Malow BA (2012). Effects of a standardized pamphlet on insomnia in children with autism spectrum disorders. *Pediatrics* **130**, S139–S144.

American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders*, 4th edn. American Psychiatric Association: Arlington, VA.

Sadeh, A. (2011). The role and validity of actigraphy in sleep medicine: An update. *Sleep Medicine Reviews*, **15**, 259–267.

Angriman M, Caravale B, Novelli L, Ferri R, Bruni O (2015). Sleep in children with neurodevelopmental disabilities. *Neuropediatrics* **46**, 199–210.

Bar M, Efron M, Gothelf D, Kushnir J (2016). The link between parent and child sleep disturbances in children with attention deficit/hyperactivity disorder. *Sleep Medicine* **21**, 160–164.

Bjellend I, Dahl AA, Haug TT, Neckelmann D (2002). The validity of the hospital anxiety and depression scale: an updated literature review. *Journal of Psychosomatic Research* **52**, 69–77.

Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ (1989). The Pittsburgh sleep quality index: a new instrument for psychiatric practice and research. *Psychiatry Research* **28**, 198–213.

Canty-Mitchell J, Zimet GD (2000). Psychometric properties of the multidimensional scale of perceived social support in urban adolescents. *American Journal of Community Psychology* **28**, 391–400.

Chu J, Richdale AL (2009). Sleep quality and psychological wellbeing in mothers of children with developmental disabilities. *Research in Developmental Disabilities* **30**, 1512–1522.

Cortesi F, Giannotti F, Ivanenko A, Johnson K (2010). Sleep in children with autistic spectrum disorder. *Sleep Medicine* **11**, 659–664.

Dardas LA, Ahmad MM (2014). Psychometric properties of the parenting stress index with parents of children with autistic disorder. *Journal of Intellectual Disability Research* **58**, 560–571.

Delahaye J, Kovacs E, Sikora D, Hall TA, Orlich F, Clemons TE, Kuhlthau K (2014). The relationship between health-related quality of life and sleep problems in children with autism spectrum disorders. *Research in Autism Spectrum Disorders* **8**, 292–303.

Devlin S, Healy O, Leader G, Reed P (2008). The analysis and treatment of problem behavior evoked by auditory stimulation. *Research in Autism Spectrum Disorders* **2**, 671–680.

Francis K, Mannion A, Leader G (2017). The assessment and treatment of toileting difficulties in individuals with autism spectrum disorder and other developmental disabilities. *Review Journal of Autism and Developmental Disorders* **4**, 190–204.

Gallagher S, Phillips AC, Carroll D (2010). Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. *Journal of Pediatric Psychology* **35**, 728–737.

Goldman SE, McGrew S, Johnson KP, Richdale AL, Clemons T, Malow BA (2011). Sleep is associated with problem behaviours in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders* **5**, 1223–1229.

Goldman SE, Surdyka K, Cuevas R, Adkins K, Wang L, Malow BA (2009). Defining the sleep phenotype in children with autism. *Developmental Neuropsychology* **34**, 560–573.

Hall WA, Moynihan M, Bhagat R, Wooldridge J (2017). Relationships between parental sleep quality, fatigue, cognitions about infant sleep, and parental depression pre and post-intervention for infant behavioral sleep problems. *BMC Pregnancy and Childbirth* **17**, 104.

Hawthorne G, Herrman H, Murphy B (2006). Interpreting theWHOQOL BREF: preliminary population norms and effect sizes. *Social Indicators Research* **77**, 37–59.

Hinz A, Brähler E (2011). Normative values for the hospital anxiety and depression scale (HADS) in the general German population. *Journal of Psychosomatic Research* **71**, 74–78.

Hodge D, Hoffman CD, Sweeney DP, Riggs ML (2013). Relationship between children's sleep and mental health in mothers of children with and without autism. *Journal of Autism and Developmental Disorders* **43**, 956–963.

Jaehne A, Loessl B, Bárkai Z, Riemann D, Hornyak M (2009). Effects of nicotine on sleep during consumption, withdrawal and replacement therapy. *Sleep Medicine Reviews* **13**, 363–377.

Kelly MP, Leader G, Reed P (2015). Stimulus over-selectivity and extinction-induced recovery of performance as a product of intellectual impairment and autism severity. *Journal of Autism and Developmental Disorders*, **45**, 3098–3106.

Kirkpatrick B, Gilroy SP, Leader G (2019). Qualitative study on parents' perspectives of the familial impact of living with a child with autism spectrum disorder who experiences insomnia. *Sleep Medicine* **62**, 59–68.

Kotagal S, Broomall E (2012). Sleep in children with autism spectrum disorder. *Pediatric Neurology* **47**, 242–251.

Kouros CD, El-Sheikh M (2017). Within-family relations in objective sleep duration, quality, and schedule. *Child Development*, **88**, 1983–2000.

Krägeloh CU, Kersten P, Billington DR, Hsu PHC, Shepherd D, Landon J, Feng XJ (2013). Validation of the WHOQOL-BREF quality of life questionnaire for general use in New Zealand: confirmatory factor analysis and Rasch analysis. *Quality of Life Research* **22**, 1451–1457.

Leader G, Francis K, Mannion A, Chen J (2018). Toileting problems in children and adolescents with parent-reported diagnoses of autism spectrum disorder. *Journal of Developmental and Physical Disabilities* **30**, 307–327.

Leader G, Mannion A (2016a). Challenging behaviors. In *Handbook of Assessment And Diagnosis of Autism Spectrum Disorder* (ed. J. L. Matson), pp. 209–232. Springer: Cham.

Leader G, Mannion A (2016b). Gastrointestinal disorders. In *Comorbid Conditions among Children with Autism Spectrum Disorders* (ed. J. L. Matson), pp.257–281. Springer: Cham.

Mannion A, Leader G (2013). An analysis of the predictors of comorbid psychopathology, gastrointestinal symptoms and epilepsy in children and adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders* **7**, 1663–1671.

Mannion A, Leader G (2014a). Attention-deficit/hyperactivity disorder in autism spectrum disorder. *Research in Autism Spectrum Disorders* **8**, 432–439.

Mannion A, Leader G (2014b). Epilepsy in autism spectrum disorder. *Research in Autism Spectrum Disorders* **8**, 354–361.

Mannion A, Leader G (2016). An investigation of comorbid psychological disorders, sleep problems, gastrointestinal symptoms and epilepsy in children and adolescents with autism spectrum disorder: a 2 year follow-up. *Research in Autism Spectrum Disorders* **22**, 20–33.

Mannion A, Leader G, Healy O (2013). An investigation of comorbid psychological disorders, sleep problems, gastrointestinal symptoms and epilepsy in children and

adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders* **7**, 35–42.

McCann D, Bull R, Winzenberg T (2015). Sleep deprivation in parents caring for children with complex needs at home: a mixed methods systematic review. *Journal of Family Nursing* **21**, 86–118.

Meltzer LJ (2008). Briefreport: sleep in parents of children with autism spectrum disorders. *Journal of Pediatric Psychology* **33**, 380–386.

Meltzer LJ (2011). Factors associated with depressive symptoms in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders* **5**, 361–367.

Meltzer LJ, Montgomery-Downs HE, Insana SP, Walsh CM (2012). Use of actigraphy for assessment in pediatric sleep research. *Sleep Medicine Reviews* **16**, 463–475.

Meltzer LJ, Mindell JA (2007). Relationship between child sleep disturbances and maternal sleep, mood, and parenting stress: a pilot study. *Journal of Family Psychology* **21**, 67–73.

National Sleep Foundation (2015). How much sleep do we really need? https://sleepfoundation.org/media-center/press-release/national-sleep-foundation-recommends-new-sleep-times. Accessed January 2020.

Newman I, Leader G, Chen JL, Mannion A (2015). An analysis of challenging behavior, comorbid psychopathology, and attention-deficit/hyperactivity disorder in fragile X syndrome. *Research in Developmental Disabilities* **38**, 7–17.

Reynolds AM, Soke GN, Sabourin KR, Hepburn S, Katz T, Wiggins LD, … Levy SE (2019). Sleep problems in 2-to 5-year-olds with autism spectrum disorder and other developmental delays. *Pediatrics* **143**, e20180492.

Richdale AL, Schreck KA (2009). Sleep problems in autism spectrum disorders: prevalence, nature, & possible biopsychosocial aetiologies. *Sleep Medicine Reviews* **13**, 403–411.

Roehrs T, Roth T (2001). Sleep, sleepiness, sleep disorders and alcohol use and abuse. *Sleep Medicine Reviews* **5**, 287–297.

Rzepecka H, McKenzie K, McClure I, Murphy S (2011). Sleep, anxiety and challenging behaviour in children with intellectual disability and/or autism spectrum disorder. *Research in Developmental Disabilities* **32**, 2758–2766.

Schreck KA, Mulick JA, Smith AF (2004). Sleep problems as possible predictors of intensified symptoms of autism. *Research in Developmental Disabilities* **25**, 57–66.

Sikora DM, Johnson K, Clemons T, Katz T (2012). The relationship between sleep problems and daytime behavior in children of different ages with autism spectrum disorders. *Pediatrics* **130**, 83–90.

Snel J, Lorist MM (2011). Effects of caffeine on sleep and cognition. *Progress in Brain Research* **130**, 395–401.

Souders MC, Mason TB, Valladares O, Bucan M, Levy SE, Mandell DS (2009). Sleep behaviours and sleep quality in children with autism spectrum disorders. *Sleep* **32**, 1566–1578.

The WHOQOL Group (1998). Development of the World Health Organization WHOQOL-BREF

quality of life assessment. *Psychological Medicine* **28**, 551–558.

Tudor ME, Hoffman CD, Sweeney DP (2012). Children with autism: sleep problems and symptom severity. *Focus on Autism and Other Developmental Disabilities* **27**, 254–262.

Wiggs L, Stores G (2004). Sleep patterns and sleep disorders in children with autistic spectrum disorders: insights using parent report and actigraphy. *Developmental Medicine & Child Neurology* **46**, 372–380.

Williams S, Leader G, Mannion A, Chen J (2015). An investigation of anxiety in children and adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders* **10**, 30–40.

Zigmond AS, Snaith RP (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica* **67**, 361–370

Zimet GD, Dahlem NW, Zimet SG, Farley GK (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment* **52**, 30–41.