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Original Article

Qualitative study on parents' perspectives of the familial impact of living with a child with autism spectrum disorder who experiences insomnia

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ABSTRACT

Background: Sleep is an essential aspect of life and it is estimated that 40–80% of individuals with Autism Spectrum Disorder (ASD) present with insomnia. Insomnia relates to difficulties initiating and/or maintaining sleep which can be distressing for the child with ASD and their family. Despite the high prevalence of insomnia in children with ASD there is little qualitative data on parents' perspective on the impact it has on the family unit.

Methods: This study presents findings from a series of three focus groups representing 15 families of children with ASD who experience insomnia. Focus groups were audio recorded and transcribed intelligent verbatim. NVivo 9 software was used to enable a content analysis. Text was coded and according to its content emerging themes were identified. Six main themes to include anxiety, dietary implications, bedtime routines, social exclusion, familial implications, and educational consequences emerged.

Results: The findings are discussed in relation to future considerations that may contribute to the development of best practice for sleep interventions for children with ASD.

Conclusions: Qualitative data which considers parents' perceptions of familial impact of insomnia may provide in-depth information for sleep clinicians working with families which could inform clinical decisions.

1. Introduction

Autism Spectrum Disorder (ASD) is defined as a pervasive neurodevelopmental disorder which can be characterized by a triad of persistent impairments with core deficits in social interaction, language and communication, and restrictive, repetitive thoughts, routines, and behavior patterns [1]. Individuals with ASD can often experience several comorbid medical conditions including sleep disorders [2].

Sleep is an essential aspect of life. It promotes health, well-being and daily functioning. Sleep disruption, particularly insomnia-related problems are experienced by some children with ASD [2], and parents of children with ASD who experience sleep problems frequently report insomnia as a major concern [3]. Although not all children with ASD experience sleep problems, it is estimated that 40–80% of individuals with ASD present with insomnia-related problems [4–6]. Insomnia relates to difficulties initiating and/or maintaining sleep [7,8]. These may include difficulties adhering to bedtime routines, trouble falling asleep, frequent waking during the night, waking earlier in the morning, and co-sleeping with parents.

Sleep deprivation can exacerbate the symptoms of autism which can result in challenging day-time behaviors [9]. Insomnia-related problems have been correlated with increased aggression and noncompliance, increased social skills deficits, an increase in emotional behavior, deficits in daily life skills [10]; and a decrease in communication skills [11]. Inadequate sleep is distressing, may reduce day time functioning, social interaction, and could result in behaviors that can impede a child's learning and social inclusion [12]. In addition, disrupted sleep patterns are associated with increased parental stress, reduced sense of parental competence, and when these experiences are prolonged the subsequent negative impact on the child with ASD and their families can result in a reduced quality of life for the family unit [13,14].

Anxiety is prevalent in children and adolescents with ASD [15]. The current literature would suggest that sleep problems are

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associated with higher levels of anxiety in children with ASD [16–18]. Sleep anxiety, sleep onset delay, bedtime resistance, sleep duration, and night wakening have all been interrelated with anxiety experienced by children with ASD [17]. The harmful impact of insomnia experienced by children with ASD may have a negative impact on their mood and cognitive functioning [19].

Food allergies, restrictive diets, and eating problems are frequently experienced by children with ASD [20]. It has been found that gastrointestinal symptoms may be associated with sleep problems [5,21–23] and poor eating habits have been commonly reported in children with ASD who experience sleep disturbance [24]. Research has indicated a possible but unclear relationship between the eating behaviors of food refusal and disruptive mealtimes with sleep disturbances [25]. It is, therefore, important that qualitative approaches seek to understand the impact eating behaviors/dietary implications have as contributory factors to disturbed sleep in children with ASD.

Children's sleep problems are regularly associated with reduced family functioning which may in some circumstances either cause or be due to marital discord [26]. It is suggested that children's sleep problems may contribute to maternal depression [27], and when maternal depression and marital discord are combined with the reported high divorce rates for parents of children with ASD [28], it is imperative that research gains an understanding of parents' perceptions and experiences of insomnia. Within the current context quality rich in-depth data generated could be used productively to improve parents understanding of the impact of insomnia on personal relationships and thus improve treatment outcomes and the quality of life for the family unit.

Despite the high prevalence of insomnia in children with ASD and the profound direct or indirect impact it has on the family there is little qualitative data on parents' subjective experiences of the effect insomnia has on the child and the family unit. The effects of insomnia not only encompass the night-time sleep difficulties and day-time deficits, but also the social, occupational, and relationship implications. Research investigating sleep disorders has successfully adopted the quantitative approach to measure treatment outcomes. Conversely, the quantitative approach may find the subjective experience of insomnia difficult to measure objectively [29]. It is therefore important that the qualitative methodology is utilized to explore the complexity of individual perceptions and experiences of living with a child with ASD who experiences insomnia.

As previously identified sleep deprivation can escalate challenging behaviors, impede cognitive performance, negatively impact on day-time functioning, increase parental stress, and have long term negative effects on health, wellbeing, and quality of life for the individual with ASD and their families [3,12–14,19]. The aim of the current paper was to use a qualitative approach to explore parents' perceptions of insomnia experienced by their child with ASD. The current research used focus groups as a forum for parents to identify and describe their child's insomnia-related difficulties and the subsequent consequences encountered by the child and the family unit. Qualitative data which considers parents' perceptions of familial impact of insomnia may provide in-depth evidence to support sleep clinicians working with families and could inform their clinical decisions which could promote effective sleep treatments for the child with ASD.

2. Method

2.1. Design

The study adopted an exploratory qualitative design through a series of focus groups within one geographical area of 2374 square miles serving several towns and villages. Upon receipt of ethical approval from NUI Galway Research Ethics Committee recruitment commenced. An invitation letter and information sheet were initially distributed to the board directors of three comparable ASD community support groups to seek approval to approach their group members. Emails were sent to 119 group members inviting parents to coffee mornings with the view of participating in a focus group to specifically discuss current experiences of sleep problems in their child aged between 4 and 12 years with ASD. A poster detailing information about the study was also placed on each of the support groups social media webpage and in each of support groups venues providing community support services to those with ASD and their families. Recruitment used purposive sampling whereby an inclusion criterion restricted participation to parents of children with ASD aged between 4 and 12 years who experienced sleep problems. No incentives were offered for participating. Recruitment continued until it was evident that further focus groups would not obtain additional data. None of the current authors had previous contact with the participants prior to the study nor had they provided services for any of the support groups. The first researcher explained and discussed the purpose of the study at pre-arranged informal coffee mornings held at ASD charity group venues. Eighty-two parents received information sheets and informed consent was obtained from each of the 15 participants before commencement of the focus groups. Anonymity and confidentiality were assured. Confidentiality was achieved with raw data being stored securely. Participants' anonymity was protected as their identity could not be ascertained from the raw data or written reports. Participants' personal information and data were only viewed by the three authors. Focus groups were audio-recorded, transcribed using intelligent verbatim, and analyzed using a content analysis [30,31].

2.2. Facilitation

An experienced focus group facilitator (first author) encouraged an interactive environment where parents could express their views freely and in confidence. The facilitator used a specifically designed script across all three focus groups to introduce the research topic and inform parents of the focus group ground rules, for example respect for each speaker, the importance of confidentiality, and to remind participants that their attendance was voluntary, and they could leave the discussion at any time.

A set of structured questions were used to guide the focus group discussions. Open-ended questions along with prompts and additional probes (when necessary) guided the group contributions. Bedtime routine/sleep hygiene questions and additional questions were developed and modified by the first and third authors to address the current research aim (Table 1). The focus group questions were divided into sections and designed to obtain information about the impact of insomnia on the child with ASD, siblings, and parents. To identify the types of sleep problem encountered and provide opportunities for the parents to describe day-time and bedtime behaviors. To collect information on parents' experiences of sleep interventions and their attitudes towards sleep interventions. The questions were initially tested for clarity by the research team and then with a convenience sample of ASD service providers.

2.3. Focus group sessions and sample

The three audio recorded focus groups included between four and seven participants and were held in a quiet room located at charity group venues; the focus group timings ranged between 49 and 96 min until data saturation was reached. Prior to the

Table 1
Focus Group discussion guideline questions.

Engagement question	1. Parents were asked to describe their child's sleep problem.
Explorative questions	2. How do you feel these sleep problems impact on your child or family routines?
	3. In your experience how do sleep problems impact on the quality of life for the whole family?
	4. Do you feel your child, or any family member has missed out on any day time activities or social events due to tiredness?
	5. What are your thoughts about eating behaviors or dietary intake and sleep problems?
	6. Does any aspect of the sleep problems or bedtime routines cause you, your partner, your child or siblings' anxiety/distress?
	7. Have any experience of or have you taken part in a sleep intervention?
Prompts used throughout the focus groups.	Can you talk a little more about that?
	Can you give me an example?
	Does anyone else have anything to add to the previous person's experiences?
Exit Question	8. Is there anything else you would like to say in relation to sleep problems and the impact on the family?

commencement of the focus groups, 15 participants were asked to complete a questionnaire which collected demographic information regarding the age and gender of parent and the child with ASD, number of siblings living at the family home, if the child had a professional diagnosis of ASD, type of school attended by the child with ASD, and educational or sleep interventions received by the child with ASD (Table 2).

In addition, the Pittsburgh Sleep Quality Index (PSQI; [29], to measure the parent's quality of sleep and the Children's Sleep Habits Questionnaire (CSHQ [32]; were completed. There is difficulty validating a scale with a smaller sample size; it is suggested that reliability analysis should not be attempted for sample sizes <30 [33]. For this reason, reliability analyses were not computed and the PSQI and CHSQ data were solely used as a measure to ascertain that participant selection met the inclusion criterion.

The PSQI is a 19 item self-report questionnaire which measures sleep quality and disturbances over a one-month period. It has seven components, (1) subjective sleep quality, (2) sleep latency, (3) sleep duration, (4) habitual sleep efficiency, (5) sleep disturbances, (6) use of sleeping medication, and (7) daytime dysfunction. Answers ranged from 0 (good quality of sleep) to 3 (poor quality of sleep). The seven component scores are summed to provide an overall score ranging from 0 to 21, where lower scores indicate a healthier sleep quality. A total PSQI score above 5 indicates poor quality of sleep. Previous research has calculated internal consistency reliability for the PSQI and found Cronbach's alpha coefficients were consistent across participant groups at 0.80 for the global PSQI and ranged from 0.70 to 0.78 for the sleep disturbance components [34]. The PSQI has also demonstrated high test-retest reliability with Correlation coefficient of 0.87 for the PSQI global score [35].

The CSHQ is a 33-item parent-report sleep questionnaire for children aged 4–12 years, designed to screen for sleep habits and possible sleep difficulties within this age group. It has eight subscales, (1) Bedtime Resistance, (2) Sleep Onset Delay, (3) Sleep Duration, (4) Sleep Anxiety, (5) Night Waking, (6) Parasomnias, (7) Sleep Disordered Breathing, and (8) Daytime Sleepiness. Items are rated on a 3-point scale; usually (5–7 times per week), sometimes (2–4 times per week), and rarely (0–1 time per week). Three additional questions asked about usual bedtime, morning wake-up time, and total sleep duration. A score of 41 or higher on the CSHQ indicates a sleep disorder. The CSHQ was previously validated for screening sleep disturbances in school-aged children and Cronbach's alpha coefficients demonstrated internal consistency for the total score at 0.68 in a community sample, and 0.78 in a clinical sample with alpha coefficients for subscales ranging from 0.36 to 0.70 [32]. Test-retest reliability using Pearson's correlations were evaluated as good and ranged from 0.59 to 0.85 for the subscales [36].

The PSQI and CSHQ data were used to gain information on the sleep problems experienced by the parent and child with ASD to ensure the current sample was representative of the research aims understudy (Tables 3–5). The data were not used as a scoring tool to diagnose a sleep disorder for either parent or child.

2.4. Data analysis

The focus groups were transcribed using intelligent verbatim and transcriptions were reviewed for errors by the first and second authors. Familiarity with the data was achieved as the recordings were transcribed, read, coded, and reviewed by the researchers. The first and second authors independently checked the audio recordings against the transcriptions for accuracy before they were

Table 2
Demographics for parents and their children with ASD.

	n=	%	*M*	SD	Male	Female
Parents	15				3	12
Children with ASD	15				14	1
Parents age ranged from 38 to 49 years			42.73	3.10		
Childs age ranged from 4 to 12 years			8.00	2.17		
Professional diagnosis of ASD	15	100%				
Mainstream school with additional help	9	60%			9	0
Special Educational Needs Unit	6	40%			5	1
Parents living together	13	86.7%				
Single parent	2	13.3%				
Siblings living at home	13	86.7%			7	6
Parents perception of their child's sleep problems:						
1. Bedtime resistance	4	26.6%				
2. Trouble falling asleep	4	26.6%				
3. Frequent night wakening	3	20%				
4. Early morning wakening	1	6.7%				
5. Co-sleeping	3	20%				
Sleep intervention participation	0					

Table 3
Parents mean scores for the PSQI subscales and total global score.

	Range	*M*	SD
Total PSQI global score	0–2	11.00	3.16
1. Subjective sleep quality score	0–3	1.40	0.64
2. Sleep latency score	0–3	1.80	1.20
3. Sleep duration score	0–3	1.93	0.84
4. Habitual sleep efficiency score	0–3	1.73	1.03
5. Sleep disturbances score	0–3	1.60	0.74
6. Use of sleep medication score	0–1	0.07	0.26
7. Daytime dysfunction score	1–2	1.40	0.51

PSQI, Pittsburgh Sleep Quality Index [29]. Global score ranges from 0 to 21 and all subscale scores had a potential range from 0 to 3.

transferred onto NVivo 9 (QSR International Pty Ltd, 2010). NVivo software was utilized to repeatedly review each transcript prior to the commencement of subsequent focus groups which is congruent with the theoretical data saturation protocol suggested by [37]. Consequently, this enabled an update to existing coded text, formulated themes, and the development of new themes. In addition to this, within the current sample size it signified the point where theoretical data saturation was achieved as the third focus group did not yield new data [37]. Coded data were reviewed, and emerging categories were documented. The researchers analyzed the data for associations between categories and clustering of themes. Themes and their coded content were reviewed for appropriateness and coherence. An interrater reliability of 91% was achieved between the first and second authors.

Standards suggested by Ref. [31] to increase objectivity, reliability, creditability, and transferability of the data collected through the content analysis was achieved through the following: Objectivity of the data was preserved by careful recording and transcribing, along with participants verification of written notes taken during the group discussion at the end of each focus group. Reliability was achieved through the researchers agreeing on categories and themes. Creditability was promoted by researchers independently checking the transcripts for accurateness and assigning codes and themes. Transferability was established by participation of parents with children with a diagnosis of ASD who experienced insomnia.

3. Results

Fifteen parents completed the PSQI (Tables 3 and 4) as an evaluation of their own sleep problems and completed the CSHQ (Table 5) to measure the parents' perceived sleep problems experienced by their children with ASD. PSQI scores for parents ranged from 4 to 16 with (m = 11.0, *SD* = 3.16), a PSQI total global score above five indicates poor quality of sleep. Fourteen (93%) of the parents scored above five indicating poor quality of sleep. The overall PSQI global score and the results from the seven subscales which are presented in Table 3 indicated that parents experienced a range of sleep related difficulties.

Results displayed in Table 4 illustrate the percentage of responses from parents within the current sample for the PSQI scores relating to subjective sleep quality, sleep latency, sleep duration, and use of sleep medication. These results indicated that 73.3% of parents were dissatisfied with their quality of sleep and 93.3% were sleeping less than 7 h per night. Sixty percent of parents were taking longer than 30 min to fall asleep. However, only 6.7% (one parent) was using sleep medication.

The CSHQ total sleep disturbance scores ranged from 44 to 73 with (m = 63.87, *SD* = 7.69) indicating that the children within the current sample scored above the diagnostic cut off score of 41 for a sleep disorder (Table 5). Further calculations on the subscales revealed that 60% of children rarely fell asleep within 20 min of going to bed, 80% of children did not get the recommended duration of sleep for their age, and 86% awoke several times per night. Within the current sample 60% of children regularly resisted bedtime, 73% of children frequently experienced sleep anxiety, and 67% of children experienced daytime sleepiness.

The results from the PSQI and CSHQ data would suggest that the current sample met the research objectives of ascertaining parents' perspective of the familial impact of living with a child with ASD who experiences insomnia.

Parents' experiences of sleep interventions and their attitudes towards sleep interventions did not generate sufficient data to justify a theme as 14 parents (93%) reported they had no prior experience of sleep interventions for their child with ASD. One parent had experience of using a message therapy to relax the child before bedtime. Subsequently, many of the parents expressed neutral attitudes towards sleep interventions, with (n = 12), 80% of parents stating they would consider participating in a sleep intervention for their child and the remainder of the parents (n = 3), 20% indicated that they were unsure.

Six main themes to include (1) anxiety, (2) dietary implications, (3) bedtime routines, (4) social exclusion, (5) familial implications, and (6) educational consequences emerged. Social exclusion and sibling social restriction topic generated lengthy discussions among parents across the three focus groups, consequently, a social exclusion theme was created, and these data were not included within the familial implications theme. NVivo 9 software results indicated the total frequency of quotations relating to each of the main themes as anxiety (54), dietary implications (22), bedtime routines/sleep behaviors (56), social exclusion (69), familial implications (64), and educational consequences (26).

3.1. Theme: anxiety

Anxiety is often a contributing factor of poor sleep and several quotations from thirteen parents (86%) clearly indicated that children within the current sample experienced sleep related anxiety. These anxieties frequently resulted in delayed bedtimes, co-sleeping, night awakening, disruptive night-time behaviors, all of which had the propensity to reduce the quality and duration of

Table 4
Frequencies of responses to 4 PSQI questions (in %).

Response	Very good	Fairly good	Fairly bad	Very bad
Subjective sleep quality (total %)	6.6%	20%	73.3%	0%
Response	≤15 min	16–30 min	31–60 min	>60 min
Sleep latency (total %)	20%	20%	20%	40%
Response	<5 h	5–5 h 59 min	6–6 h 59 min	≥7 h
Sleep duration (total %)	26.7%	46.7%	20%	6.7%
Response	Not at all	<once per week	1 or 2 times < per week	3 or more times per week
Use of sleep medication (total %)	93.3%	6.7%	0%	0%

PSQI, Pittsburgh Sleep Quality Index [29].

Table 5
CSHQ mean scores for total sleep disturbance and for each of the subscales.

	Range	*M*	SD
Total CSHQ sleep disturbance score	44–73	63.87	7.69
Sleep Onset Delay	2–3	2.60	0.51
Sleep Duration	3–9	7.00	2.45
Night Waking	3–9	6.80	2.11
Sleep Disordered Breathing	3–6	3.20	0.77
Bedtime Resistance	6–18	11.80	3.49
Parasomnia	7–9	7.27	0.71
Sleep Anxiety	4–12	9.33	2.84
Daytime sleepiness	10–21	15.87	3.64

CSHQ, Children's Sleep Habits Questionnaire [32]. Score ranges for each CSHQ subscale are as follows: Sleep Onset Delay (1–3), Sleep Duration (3–9), Night Waking (3–9), Sleep Disordered Breathing (3–9), Bedtime Resistance (6–18), Parasomnia (7–21), Sleep Anxiety (4–12), and Daytime sleepiness (6–22).

sleep for the child, siblings, and parents. Parents expressed their worries and experiences of their child's inability to sleep alone and reoccurring bad dreams as one representative quotation illustrates: *“He suffers a lot from anxiety, he is afraid of sleeping alone in his own room, he does have bad dreams. I … just worry where this is going” (Parent 1).*

Other parents clearly expressed the enormity of the problem and their feelings of uncertainties around how long the sleep anxiety would last. For instance, one mother said: *“She has anxiety about darkness and the light has to be on all the time and she always wants to sleep with me … I wonder if she is ever going to grow out of it” (Parent 7).*

Another parent stated: *“The last say two years he really struggles with going to sleep in the first place, he would get quite anxious at night time, and he doesn't like the light turned off … in a few years he is going to be a teenager … what then” (Parent 2).*

Parents also discussed how delayed bedtimes were a challenge which not only reduced the child's sleep duration but also placed restrictions on parental opportunities to engage in other activities such as, household chores, interaction with other family members or social events as one parent expressed: *“He has a lot of anxiety around going to sleep and getting to sleep. So, he goes to bed quite late, waiting for me. It really, takes away from your own-space time. It's every night, you don't get time for anything.” (Parent 11).*

Another parent referred to the impact of night awakenings and subsequent disruptive behaviors during the night on the whole family as stressful, and frustrating: *“One or two nights now, when he's anxious, he would get up and walk around and doesn't realize that his movements are creating noise and disturbing his brother and sister. They get annoyed with him and then we all get stressed out.” (Parent 3).*

Fifty-three percent of parents expressed concerns about their children who often worried about up-coming events, which adversely impacted on their child's sleep patterns for a few nights prior to the event. This was illustrated by a parent: *“If there's something happening at school that he wasn't happy about like going on a trip or something, you know out of the ordinary, he wouldn't like that. So, he would be worrying about it and he wouldn't sleep.” (Parent 9).*

Parents articulated both unique and shared experiences of worries, stress, frustrations, and challenges related to sleep anxiety. Parents unanimously concluded that anxiety contributed to several nights of poor quality and often reduced sleep for the child with ASD which frequently had negative consequences for all the family members.

3.2. Theme: dietary implications

Poor eating habits and gastrointestinal symptoms may be correlated with sleep problems in children with ASD. Six parents (40%) described a range of dietary problems and eating habits which they perceived as having a negative impact on their children's sleep. One parent discussed a gluten allergy which triggered abdominal pain that disturbed her child's sleep patterns: *“Definitely very sensitive to gluten so we have to be careful, but we don't eliminate it we just reduce the amount. So that can wake him up sometimes too if he has pains in his tummy.” (Parent 6).*

Other parents referred to different aspects of eating habits which had a negative impact on their child's sleep. Parents viewed these habits as equally frustrating and worrying with one parent saying: *“He is always saying, I'm hungry, I'm hungry, especially at bedtime. I sometimes think is he hungry … and then … is he getting enough to eat but you just don't know. It's irritating, your tired after a long day, and you just want him to go to bed and sleep without all this hassle.” (Parent 10).*

Another parent explained what happened at mealtimes: *“He will only eat a bit of his dinner and he will walk away but he will come back 15 min later, “I'm hungry”, and wants treats. Even at night time before he goes to bed, he will raid the cupboards, usually for treats.” (Parent 4).*

The six parents who commented on dietary and eating habit implications provided an insight into the diversity of the problem, ranging from their child's experience of pain to the uncertainty surrounding their child's feeling of hunger. It also highlighted some the eating behaviors which regularly occurred around mealtimes and bedtime. However, caution should be exercised when interpreting the gastrointestinal sub-theme, which emerged within the current sample as it requires further investigation.

3.3. Theme: bedtime routine

This theme explored the parents' experience of their child's insomnia within the context of several sleep hygiene subthemes of daytime, early evening, and bedtime behaviors which may affect the initiation, duration, maintenance, and quality of sleep. All the parents contributed to this theme and the following quotations are representations of their comments on their child's bedtime sleeping and morning awakening routines, co-sleeping, daytime sleepiness/napping, stimulating activities before bedtime, and bedtime routines.

Ten parents (67%) commented on irregular sleeping patterns combined with either early or late morning awakening. Parents commonly discussed their child's inability to fall asleep within a reasonable time of going to bed and then not being able to awaken in the morning to suit the family routine. As one parent communicated: *“Generally, he has all sorts of issues with trying to go to sleep and would go to bed at 9 o'clock but wouldn't actually sleep until 12 or 1 o'clock. During the last month that could have been 1 or 2 o'clock. He's very restless and has difficulty getting up in the morning.” (Parent 3).*

Co-sleeping was discussed and 40% of parents expressed it was a problematic issue that caused a range of difficulties from parental conflicts with the child, conflicts between parents and it was not compatible with a restful night's sleep for the child or parent: *“Lately we've had to go into the room with him and lie down on the bed, not his bed but the bed beside him and stay with him until he falls asleep. But sometimes about every couple of night he wakes, and he comes into the bed in between us and then no one gets any sleep.” (Parent 5).*

Daytime sleepiness and napping was more common in the younger children with 27% of the parents stating their child took a daytime nap, as was evident from one of the parent comments: *“When he's really tired the teacher will let him go in and lie on the bean bag and put the big blanket on, he might then for five or 10 min go to sleep.” (Parent 9).*

Eleven of the parents (73%) contributed to the discussion on stimulating activities before bedtime which ranged from playing computer games to playing with friends or siblings, as the following quotations illustrate: *"He is always playing (name of computer game), day and night." (Parent 14).*

Really great to see (name), playing with the other lads, like crazy lads running around the place .... and I know when he comes in he will be awake way past ten o'clock still playing" (Parent 6).

The responses generated during the bedtime routine discussion were mixed with 9 of the parents (60%) verbalizing that a bedtime routine was a necessity for their family whereas six parents (40%) indicated that bedtime routines for their child with autism was either impractical or difficult to maintain. Nonetheless, there was opposing views expressed within the current sample of parents. Generally, parents expressed it would be unthinkable not to have a bedtime routine: *"It would be awful without some kind of routine at night, he would have a meltdown, he just couldn't cope without a routine." (Parent 8).*

Whereas other parents viewed it as unnecessary: *"We don't actually have a bedtime routine for our son with autism, it's difficult when you have other children, and when he's quiet, playing a game or watching TV, I'm inclined to leave him and get on with other things." (Parent 15).*

This theme highlighted several differences in parents' views, especially related to the importance of bedtime routines. Establishing and maintaining a bedtime routine was perceived as problematic for a few of the parents. Nonetheless, it also outlined the similarity of parental experiences to the other subthemes discussed, for example, their children's participation in stimulating activities just before bedtime. Getting up in the morning and going to sleep at a reasonable time created stressful situations for many of the parents.

3.4. Theme: social exclusion

All parents considered social interactions as a major issue and several of the parents stated social relationships were already difficult for their child without adding the lack of sleep to the problem. Daily experiences of social exclusion related to the lack of sleep were identified as missing out on day-time leisure activities, birthday parties, play opportunities, and extended family occasions. On occasions parents (60%) viewed their child's tiredness as a contributing factor to having temper tantrums: *"He would be tired during the day and that would affect things. He doesn't want to be bothered sometimes. Like, he loves swimming but then he can have a tantrum just because he's tired and that's the end of swimming" (Parent 10).*

Another parent perceived her child's tiredness as the reason to why her child often chose not to participate in play with others: *"He comes in from school, exhausted, and he can't face going out playing with the other kids. You see all the other kids out, on their bikes and everything and he's just curled up on the couch in a blanket because he's tired." (Parent 6).*

Twenty six percent of parents attributed tiredness to aggressive outbursts and correlated these with subsequent lack of play-date and birthday party invites: *"He doesn't really get invited to other children's houses for play dates and things like birthdays. He can be more aggressive when he's tired. Its hard for him to keep it together all day with so little sleep." (Parent 5).*

With relative consistency, parents (93%) expressed that the needs of their child with sleep problems were prioritized above the needs of their other children, and quite often social events and family days out were canceled: *"We try to go to the cinema as a family, he usually doesn't mind but if we've had a few late nights and early mornings. Well! he can be awkward and it's just not worth it, and that stops his brothers going." (Parent 13).*

Another parent commented: *"It's exhausting ... a strain on everyone. It's not fair on his older sister, I can't drop her off to meet with her friends if he is having one of his tiredness episodes .... It's just an impossible situation" (Parent 12).*

The lack of social interaction experienced by the child with ASD, and the occurrence of social restrictions enforced on their siblings was evident within the current sample. Ninety-three percent of parents expressed their concern that sleep issues were adding to the already existing social deficits experienced by their child with ASD by placing further restrictions on social opportunities. Parents referred to tiredness, unpredictable, and frequently unacceptable behaviors which often restricted the family from enjoying leisure activities together and placed social restrictions on their other children.

3.5. Theme: familial implications

Familial implications emerged clearly and had several subthemes relating to the emotional and practical impact on the family to include parent anxiety, stress, worry, impact on siblings, relationships between spouses, and financial consequences of insomnia.

Several parents (53%) described the combination of co-sleeping, the lack of sleep and the emotional strain as having a negative impact on their marriages. Parents stated this ultimately contributed to additional arguments and further deterioration of marital relationships. As one parent stated: *"I think it affects us as a couple because sleeping separately is not good. At the beginning ..., it was okay because everybody sleeps but after six months, seven months we started to realize that something is going wrong in our marriage." (Parent 13).*

Another parent commented: *"The fact that he is almost nine and still sleeping with me and you know my husband is working so he sleeps in another room. I struggle with that because it's making our relationship strained" (Parent 12).*

Financial burden and the subsequent strain that it placed on the family emerged as stressful and worrying with many parents referring to the financial insecurity of reducing the family's income. In total, 7 (46%) parents (one father and six mothers) reported that work was untenable at times and they either had to give up work or reduce their working hours due to the direct and indirect impact of insomnia experienced by their child. The following quotations are representative of the parents' experiences within the current sample: *"I had to give up work in September because I couldn't keep it all going. I was tired and anxious all the time, ... but now we both worry about the bills coming in." (Parent 5).*

"I was working from six o'clock till whatever twelve in the morning or it could be the afternoon and I just had to cut my hours because at times I didn't get any sleep ... when you don't have that extra money coming in, everyone suffers" (Parent 8).

"He was never sleeping so I gave up my job, I had to give up my nine to five because I wasn't getting enough sleep. I worry where it's going to finish up." (Parent 11).

Other challenges that impacted on the family unit were described as stressful, restricting, and overwhelming. A frequently emerging subtheme experienced by the whole family was decreased opportunities to relax and pursuit of personal hobbies. As one parent commented: *"Well I suppose he would be fairly hyper in the evening time before getting to bed, so that it would impact on everybody. No-one gets any peace to do things." (Parent 2).*

As parents discussed the impact of insomnia on the family another common subtheme emerged of disturbed sleep for siblings and parents: *"Generally, the lack of sleep for the whole family, its broken sleep all the time. It's not good, it causes a lot of stress and arguing." (Parent 3).*

There were struggles in balancing a safe night-time environment for the child with sleep issues and not restricting the movements of his siblings. As one parent discussed the strategies she put in place to safe-guard her son's night-time behaviors of walking around the house and putting on electrical equipment: *“Oh, yeah, they have had to put up with alarms on the doors. He has got two younger brothers. One is just a year younger and one is five years younger, so they have had to grow up with alarms on the doors and having controls that you wouldn't normally put in place” (Parent 14).*

Eighty percent of mothers indicated that partners were working and needed their sleep, leaving them (the mothers) to undertake the responsibility for the sleepless nights, which exposed them to the daily stress, worry, and anxiety of living with a child with ASD who experiences insomnia. *“Basically, it comes down to me because my husband is working and I'm not so then I'm the one who is getting up every night and its stressful, very stressful.” (Parent 4).*

A range of familial impacts emerged which created tension among couples and frustration between siblings. Typically, the whole family suffered varying degrees of negative consequences from living with a child with ASD who experience insomnia. Impacts were discussed in terms of the emotional distress, decreased quality time, and the financial burden experienced through the reduced capacity to work.

3.6. *Theme: impact on education*

The last theme of impact on education indicated that 87% of parents perceived insomnia as having a negative impact on current and future educational opportunities. Parents discussed the high prevalence of morning tiredness, reluctance of getting out of bed, a reduction in daytime functioning, the lack of energy, poor concentration, reduced mood, and an increase in aggressive behaviors.

Sixty-seven percent of parents commonly referred to situations in the morning when their children were reluctant to get out of bed, expressed emotions such as anger, and appeared to be in low mood and quite often seemed tired: *“Getting him up for school in the morning is hard and your encouraging, encouraging, encouraging him to get up, and he just gets angry … you know it's not going to be a good day in school.” (Parent 3).*

“In the morning she's really tired, you can't get her out of bed, the mood is very bad in the morning, very low and very angry and getting her ready to get to school is a big huge issue, because she's so tired” (Parent 7).

“So, Monday to Friday you can't get him out of bed without dragging him out of bed …” (Parent 13).

Parents commented that the three most commonly reported problems by teachers were, lack of energy, poor concentration and unacceptable or challenging behaviors: *“As far as education, getting him out of the door in the morning is stressful, he usually doesn't want to go to school. His teacher would sometimes say he was lethargic and did not take part in the lessons … he's falling behind …” (Parent 1).*

“Her Teacher said, “She wasn't able to function at school because she was too tired to concentrate … makes me worry about her future” (Parent 7).

“It's very much, when my child isn't getting sleep of course he's going to be snappy, grumpy and sometimes a bit aggressive he's not going to maybe do as well in school that day” (Parent 9).

Contributing parents unanimously agreed that tiredness affected daytime behaviors which had the potential to impede learning and influence current and future educational opportunities.

4. Discussion

Sleep problems and their correlates with familial impact were investigated. The findings highlighted the unique and shared experiences of the negative impact of insomnia on the child with ASD and their family. Fifteen parents gave descriptions of insomnia and the challenges, frustrations, and struggles the family experienced, related to the lack of sleep. The six emergent themes of anxiety, dietary implications, bedtime routines, social exclusion, familial implications, and educational consequences showed several aspects of the unpleasant impact of insomnia within the current sample.

The emergent theme of anxiety where 86% of parent's narratives confirmed that several of the children with ASD who experienced insomnia also experienced several anxieties, which increased their child's inability to sleep. Inability to sleep within this context was a unique experience interlinked with the child's unpleasant perceptions or fears of interactions with up-coming events, environmental factors or situations. Sleep anxiety is commonly associated with co-sleeping, sleep-onset delay, and bedtime resistance [25,38]. Considering the parents within the current sample highlighted these bedtime behaviors as related to perceived stressful up-coming events and fears of darkness, it would be prudent to further assess these factors within this population to determine the impact on the duration and quality of sleep. Some studies have suggested that a high level of parental control is often related to parental anxiety, which is frequently correlated with a child's level of anxiety [39], and a link between anxiety and disturbed sleep has been found in children with ASD [6]. Anxiety could be bidirectional, as parents exert parental control to protect their child with ASD from what the parents perceive as undesirable experiences, they may unintentionally heighten anxiety around an event or situation. When inadequate sleep is experienced, this should indicate the need to evaluate anxiety. The importance of assessing anxiety experienced by the child and family unit cannot be overstated [25], as children with ASD are often associated with amplified emotional responses and poor emotional control [40], which could heighten anxiety symptoms. Qualitative data which considers parents' perceptions and experiences of their own and their child's anxiety may provide insightful information for the clinicians working with the family and help to identify additional family factors, which may contribute to insomnia and have the potential to reduce the efficacy of sleep interventions.

Less than half (40%) of the parents contributed to the theme pertaining to dietary implications. However, those parents who did comment discussed the challenges of their child's daily eating behaviors, food intake, and to a lesser extent, gastrointestinal symptoms of pain experienced by a child with a gluten intolerance. Although gastrointestinal symptoms are frequently reported in individuals with ASD [41] and research has associated these symptoms with sleep problems [5,21–23], the current sample of parents did not contribute significantly to this sub-theme. This could be attributed to several factors. It is possible that the sample size was not large enough to capture the full range of data within this sub-theme, or parents may have been more concerned by the sleep problems experienced by their child to consider the significances of dietary implications. Alternatively, a more specific inclusion criteria to include parents of children with gastrointestinal symptoms and insomnia may have yielded a more in-depth discussion on this sub-theme. Hence the data from the sub-theme of gastrointestinal symptoms should be interpreted with caution and requires further investigation. Poor eating habits are frequently reported in children with ASD who experience sleep disturbance [24]. Notably, the parents within the current sample mainly focused on eating behaviors which correlated with those commonly observed in children with ASD. For example, food refusal [42] and disruptive mealtime behaviors [43]. Research has indicated a possible but unclear relationship between the eating behaviors of food refusal and disruptive mealtimes and sleep disturbances [25].

Considering the comments made by the current sample of parents and previous research suggestions of a possible correlation between eating behaviors and sleep disturbance, it is evident that this matter requires further research. Eating behaviors as possible contributors to sleep disturbance could have implications for future treatment planning.

Sleep hygiene practice is essential to improving sleep problems [15,44]. Sleep problems can often occur due to aspects of reduced family functioning [26] or home and bedtime environment, including bedtime practices that are not conducive to good sleep [15]. Differing views on well-structured bedtime routines expressed by the parents indicated that 40% of the parents did not manage their child's insomnia with a focus on the benefits of sleep hygiene practice but instead related regular bedtime routines as more stressful and best avoided. It was clear from some of the parents' comments that parental knowledge of good sleep hygiene practice was lacking, and this was having an adverse effect on their child's sleep patterns. As research has indicated irregular bedtime routines are inconsistent with healthy sleep hygiene practice [45]. Several studies have found that gaining knowledge of, and implementing good sleep hygiene practice consistently can ultimately improve the quality and duration of sleep [9,44,45]. If clinicians had access to the complexity of parents' negative perceptions and associations with bedtime routines, they could individualize parent awareness to motivate a change in these perceptions of bedtime routines as stressful. Changing the parents' views of the importance of a regular bedtime is one step closer towards improving healthy sleep practices, and the introduction of regular and earlier bedtimes will improve sleep problems [45]. Clinicians are inclined to focus on the diagnostic criteria for insomnia instead of the subjective experience of insomnia [46]. It is in the best interest for all of those who are living with insomnia for the clinician to have access to subjective experiences and perceived impacts of sleeplessness on the family. Clinical practice may benefit from the in-depth insights which are achievable through qualitative research methods.

Social exclusion experienced by the child with ASD has been extensively documented [47], but qualitative evidence documenting the families experience of social exclusion/restriction related to sleep problems has received less research attention. Sleep deprivation can exacerbate day time behaviors [9], which can result in increased aggression, hyperactivity and anxiety [10], social skills deficits and reduced sociability [48]. It is feasible that these behaviors will have punitive implications and reduce opportunities for social inclusion. One or more of these behaviors which were reported by 93% of the parents resulted in a negative effect on daily activities and social inclusion for the families within the current sample. Akin to the present paper, other researchers have reported on the social restrictions placed on the families living with ASD [49,50], although not necessarily within the context of sleep problems. Within the current sample, all the parents discussed the implications on their child with ASD and their siblings within the context of social exclusion/restrictions experienced and the further negative impact this had on families' opportunities to socialize either as a family or with friends. The tension and frustration that was created within the family unit added further stress and anxiety which had the potential to contribute to additional sleepless nights. It is important to consider the impact on each family member before a clinician can effectively design and implement a sleep intervention that is suitable for the child with ASD and their family.

Children's sleep problems are regularly associated with reduced family functioning, which can occur due to marital discord, poor parental health, and inconsistent parenting [26]. Parents within the current study discussed the emotional strain on their marriages. They often referred to the change in the parents' sleeping arrangements and the impact that insomnia imposed on their relationships. Co-sleeping arrangements were often linked to conflict and deterioration in relationships, with parents stating that emotional reactions often escalated due to the child either sleeping in the marital bed or the mother sleeping in the child's bed. In addition, mothers reported that fathers were working, and this left the mothers to manage the consistent sleep problems experienced by their child with ASD. Which according to the mothers, this additional sleeplessness related stress and anxiety was not conducive to a cordial relationship between parents, consistency in parenting or to the parent's sense of wellbeing. [51]; found similar results wherein impairments on the mother's mood, stress, fatigue, and daytime functioning were significantly correlated with child sleep disturbance. Effective sleep interventions are vital, as there is evidence to suggest that on-going sleep problems experienced by a child with ASD is detrimental to parents' relationships [26]. Given the high rates of reported sleep problems experienced by children with ASD and the devastating consequences of marital discord on the family, it is important that the negative correlation between sleep problems and marital discord are considered when treating sleep problems. Improving the understanding of parents and clinicians in this aspect of insomnia may enable appropriate interventions and improve treatment outcomes.

There have been a few studies that have discussed the general aspects of the financial burden of raising a child with ASD [49,50]. However, to the current authors knowledge there have been no studies specifically related to sleep problems experienced by children with ASD and the consequential financial burdens experienced by the reduction of family income. For this reason, the following findings should be considered as exploratory and warrant further investigations. Nonetheless, the qualitative narratives demonstrated the economic impact that insomnia had on the family unit. The reported economic strain and ensuing financial insecurity had a negative effect on the parents, which often caused additional burden and stress for the family. Lifestyle adjustments were forced onto all family members as parents had to make significant spending changes because of a reduced family budget. It was identified that mothers were usually responsible for the primary care of the family and as such it was most often the mothers who disengaged from employment. Parents (33%) within the current small sample who felt it was untenable to continue with their employment related this decision to inadequate sleep which resulted in their inability to function at work. Parents stated that the lack of sleep and trying to balance both work and home life decreased their capacity to care for the family, increased their sense of anxiety and guilt which reduced their sense of wellbeing. It is important to understand more about the effects and the related emotions of the financial burdens which may be a result of living with a child with ASD who experiences sleep problems. Obtaining insight of the financial impact on the family, the related stressors and emotions could inform the development of treatments, which could better support the families living with this additional stress.

The experience and impact of insomnia extended beyond the bed-time sleep behaviors as 87% of parent's narratives indicated a range of undesirable aspects which affected their child's current and potential future learning/educational opportunities. Parents expressed concern and apprehension for their child's future ability to access learning opportunities to improve long term life outcomes. Insomnia and the associated morning and day-time tiredness, challenging behaviors, and a reduction in cognitive functioning were viewed by many of the parents as barriers to learning, to the development of life skills and educational success. With the knowledge of the detrimental effects of inadequate sleep on learning and day time behaviors [12,52], it is a priority to improve the quality of sleep for children with ASD, as their development in communication and social interaction has already been compromised. It is therefore essential that children with ASD receive treatments which consider the social, emotional, and cognitive impact of insomnia on life skills development, educational opportunities, and the consequential anxiety and stress this caused the parents. By recognizing these factors and accessing in-depth information, clinicians would be in a better position to offer advice that may lessen the anxiety and stress reported by parents which could improve treatment outcomes.

Research would suggest that two to three focus groups will capture 80% of relevant themes in a study with a moderately homogeneous sample using a semi-structured guideline [37]. The current paper provided relevant and in-depth evidence of the familial impact of insomnia experienced by a child with ASD and how this evidence could be used to assist clinicians and possibly improve treatment outcomes, however there are a few limitations to consider. Sample size was small ($n = 15$), parent gender distribution imbalance (12 females and 3 males), all the participants were from one geographical location serving several towns and villages. Even though the sample were recruited through a similar type of ASD service provider ie, charitable support groups they did nonetheless attend different support group venues. To improve generalization of the findings, further research is required across a wider geographical area, of a range of service providers such as special schools, health care providers and day care services. In addition to this, a larger sample may have discovered a range of additional themes pertinent to insomnia in children with ASD or may have the potential to either support or challenge the themes which emerged from the current focus groups.

Insomnia does not discriminate, and many individuals with ASD experience a range of sleep problems. To date there is no definitive causation of what triggers insomnia in individuals with ASD but there are several possible explanations. Characteristics often related to ASD, such as repetitive behaviors, sensory issues, anxiety, dietary implications, dysregulation of melatonin, and difficulty understanding social cues, could make sleep initiation and maintenance problematic. Anxiety is a condition which is frequently associated with disturbed sleep in children with ASD [53]: [17], and especially sleep anxiety [54,55]. An individual's circadian rhythms will usually signal when it is time to go to sleep, using light and dark cycles and social cues. A child with ASD who has difficulty with communicating, may misunderstand or not even notice the social cues. For example, taking cues from other family members and the environment about how and when to fall asleep could be problematic [53]. Further to this, research has indicated that individuals with ASD may have mutations that affects their level of melatonin, which normally helps to regulate the sleep–wake cycle [53]. Research has indicated that some children with ASD may have reduced levels of melatonin [53], and possibly release higher levels of melatonin during the day and lower levels at night [56]. In addition to this, children with ASD may have trouble getting to sleep or experience multiple night waking due to sensory issues, like increased sensitivity to touch or sound [17,18]. Insomnia in children with ASD may occur as a result of multifaceted interactions between psychological, biological, social, environmental, and family aspects, that do not encourage quality sleep. Given the range of complex difficulties that individuals with ASD experience, and the familial impact illustrated within the current paper, sleep problems are a major concern, which merits further qualitative research.

In conclusion, the emergent themes across the three focus groups indicated that insomnia caused significant emotional, social, and economic stressors for the family. Overall, each theme was consistently related to feelings of stress and anxiety, two factors which previous research has identified as contributing to sleep problems. Although difficult to compare directly, these qualitative results have similarities with the quantitative results of other studies. Overall the current paper further extends on existing literature suggesting that sleep problems have profound familial implications. In particular, the emotional, social, economic, and educational consequences of insomnia. The findings from the current paper reinforce the need for healthcare professionals to be aware of, and be sensitive to, the subjective experiences and diverse needs of the family when considering the implementation of a suitable sleep intervention for a child with ASD. Incorporating qualitative data in future considerations for the treatment of insomnia may offer additional understanding to the existing knowledge of the barriers to sleep. In addition, it may offer an insight into the complexities of the impact of insomnia on the family, which may help to improve the effectiveness of treatments and thus quality of life. Continuous evaluation of emerging qualitative evidence of the changing circumstances to which the families are often exposed, due to the social, financial, and emotional impact of insomnia is essential.

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Conflict of interest

The authors have no conflict of interest to declare.

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