

Perceived impact of epilepsy on sleep: Views of children with epilepsy, parents and school staff

Emma C Johnson¹

Patricia Atkinson²

Amy Muggeridge¹

Samantha Chan^{3,4}

J Helen Cross^{1,3,4}

Colin Reilly^{1,4}

Affiliations

¹Research Department, Young Epilepsy, Lingfield, Surrey, RH7 6PW, UK.

²Child Development Centre, Crawley Hospital, West Green Drive, Crawley, RH11 7DH, West Sussex, UK.

³Great Ormond Street Hospital for Children NHS Trust, Great Ormond Street, London WC1N 3JH, UK.

⁴UCL Great Ormond Street Institute of Child Health (ICH), 30 Guilford Street London WC1N 1EH UK.

Correspondence to: Colin Reilly, Research Department, Young Epilepsy, Lingfield, Surrey, RH7 6PW, UK. creilly@youngepilepsy.org.uk 01342 832243

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Abstract

Objective: To gain an understanding of the views of school-aged children with epilepsy, their parents and school staff regarding the impact of epilepsy on sleep.

Methods: As part of the What I Need in School (WINS) study, school-aged children (n=18) with 'active epilepsy' (taking Anti-Seizure Medications, ASMs, for epilepsy), their parents (n=68) and school (n=56) were interviewed or completed bespoke questionnaires. Questions focussed on the potential impact of epilepsy on the child's sleep or tiredness in school and the potential impact of sleep/tiredness on learning and behavior.

Results: 56% of children believed that epilepsy affects their sleep whilst 65% of parents believed that their child had more difficulties with sleep than other children of their age. 78% of parents believed that their child's difficulties were due to epilepsy and 95% believed that their child's difficulties impacted their learning and behavior. 54% of school staff believed that the child with epilepsy they supported were more tired/fatigued than their peers, and 86% of school staff believed that the child's increased tiredness affected their learning/behavior. Parents of children with intellectual disability were significantly more likely to indicate that they felt that their child had more sleep difficulties than other children ($p=0.016$). Regarding the impact on their sleep, participating children felt that epilepsy contributed to difficulties in falling and staying asleep and daytime tiredness. Their parents reported a range of potential sleep difficulties and potential impacts in the child's learning and behavior. Parental reported difficulties included daytime tiredness, difficulty falling and staying asleep, and impact of nocturnal seizures. In terms of impact, parents felt that sleep difficulties impacted negatively on cognition and emotional-behavioral functioning. Additionally, parents reported that ASMs and medication for ADHD can contribute to sleep difficulties. School staff felt that many of the children appeared tired/fatigued during the day and this could lead to less engagement with classroom activities, impact negatively on attention and processing speed, and contribute to behavioral and emotional difficulties.

Conclusion: The majority of children and parents who responded believed that epilepsy affects the child's sleep. Most parents and school staff also believed that the child's sleep difficulties/excess tiredness were due to the child's epilepsy and that the difficulties significantly impacted on the child's learning and behavior. There is a need to better understand the role epilepsy plays in sleep difficulties and associated learning and behavioral impairments. There is also a need to develop interventions to reduce the subsequent impact on child learning and behavior.

Introduction

Children with epilepsy are at a higher risk for cognitive and behavioral difficulties than healthy children and children with other non-neurologic chronic diseases^{1,2,3}. In addition to cognitive and behavioral difficulties, parent reported surveys suggest that children with epilepsy are a high-risk group with respect to sleep difficulties, having more difficulties than siblings⁴ and healthy controls^{5,6} but not other children without epilepsy who have neurodevelopmental problems⁷. In relation to polysomnography data, there is no evidence that children with well-controlled seizures have a higher rate of obstructive sleep apnoea, but those with complex epilepsy may experience a clinically significant quantity of apnoeas in sleep⁸. Recently, it has been found that sleep homeostasis, the physiological regulation of sleep quantity and depth according to need, may be disrupted in some childhood epilepsies but preserved in others⁹.

The exact nature of sleep difficulties and causes of sleep difficulties in children with epilepsy are not well described⁸. With respect to sleep duration and efficiency of sleep, research to date has not found major differences between cognitively normal children with epilepsy and controls¹⁰. However, in children with epilepsy and cognitive impairment who often have a higher seizure burden¹¹ and are at higher risk for behavioral difficulties¹², the higher seizure burden could disrupt sleep including affecting circadian regulation, reducing REM and leading to sleep fragmentation⁸. Interictal Epileptic Discharges (IEDs) have also been associated with deficits in academic attainment and language skills in children with focal lesional epilepsies¹³. Anti-seizure medications (ASMs) may also impact on sleep in positive and negative ways independent of their anticonvulsant action, but little is known about the detailed effects of ASMs on sleep architecture, or about the mechanisms by which ASMs might cause such effects¹⁴. The presence of sleep difficulties in childhood predicts future cognitive, attentional, and psychosocial problems in the general child population^{15,16}.

The relationship between sleep and cognition in pediatric epilepsy is not well understood. It is likely that a high interictal discharge load during sleep may impair learning, as evidenced by the cognitive regression that can be seen in the syndrome of encephalopathy with status epilepticus in slow wave sleep (ESES)¹⁷. Memory task performance after a period of sleep is enhanced in children with focal lesional epilepsies, a group who show few interictal discharges¹⁸, but in epilepsies associated with frequent interictal discharges in sleep, such as SeLECTS (Self-limited epilepsy with centrotemporal spikes) it is impaired¹⁹.

Despite the frequency of sleep difficulties in children with epilepsy, previous studies have not asked young people with epilepsy, their parents and school staff about the impact of sleep difficulties on their learning and behavior. Understanding the impact can allow a better understanding of the relationship between epilepsy and sleep. An increased understanding may also suggest ways of supporting children with epilepsy who have sleep difficulties in relation to ameliorating the potential negative impact of sleep difficulties on learning and behavior at home and school. The 'What I Need in School' (WINS) - Experiences of children with epilepsy in schools' study focuses on the experiences of young people with epilepsy, their parents and teachers in schools in a defined geographical area of the South of England. The aim of the current study

was to garner the views of young people with epilepsy, their parents and school staff regarding the impact of epilepsy on sleep difficulties.

2. Method

All children born between 2003 and 2014 with 'active' epilepsy (prescribed one or more anti-seizure medication, ASM, for epilepsy) who were resident in the RH10 to RH13 postal districts in the south of the United Kingdom between April 2018 and December 31st, 2019 were eligible for inclusion. Children born before 2003 or after 2014, and/or who did not have 'active' epilepsy were not eligible for inclusion. Children, their parents, and school staff participated between 11th September 2018 and 17th March 2020. The prevalence of 'active' epilepsy in the study area during the study period was 4.20 per 1000 (1 in 238, 95% CI 1 in 200 to 1 in 285) or 0.42%.

2.1 Recruitment of children

Eligible children with 'active epilepsy' were identified at the two pediatric hospitals in the study area and recruited between 21st December 2017 and 31st December 2019. All children had to have had two unprovoked epileptic seizures more than 24 hours apart and be taking ASMs for their epilepsy. Eligible children were identified and verified by two link pediatricians (community pediatricians with a special interest in epilepsy) and a registrar working at a specialist centre for children with epilepsy.

At one of the participating hospitals the parents/guardians of eligible children were approached by their supporting pediatrician, informed about the study and given an interest form. At the other participating hospital, some eligible children were approached by the supporting pediatrician, others by an epilepsy support nurse and some via a letter sent to their home address. Additionally, an online portal was created whereby eligible participants could independently contact the research team and indicate an interest in participating in the study. All parents who were approached were offered a study interest form and asked to complete and return the form if they wished to learn more about the study. All parents who returned a form were contacted by a research psychologist via telephone and subsequently met in their home if they wished to participate. At this informed consent meeting, the study was described in detail and parents were asked for written consent for entry of their child into the study. Participating children, where developmentally appropriate, also gave assent. Anonymized information was obtained on non-participants who met inclusion criteria (n=68), including data on sex, ASM usage, deprivation index, ethnicity, age at median point in study, age of diagnosis/first seizure.

2.2 Measures

Child-, parent- and teacher-report questionnaires and child and parent interview schedules for the WINS study were developed in partnership with children with epilepsy, their parents and teachers. Based on clinical experience and published research^{6,7,8}, study investigators developed possible topics for the questionnaires/interview schedules, to elicit perspectives on aspects of educational provision including the potential impact of sleep difficulties on school functioning. This list of topics was piloted at focus groups and through interviews. Focus groups and interviews were conducted between May and July 2018. Parents participating in focus groups had already agreed for their child to take part in the WINS study. As a result of

the piloting the final interview/questionnaire schedules were developed (see supplement 1).

Interviews/questionnaires for children, parents and teachers included questions with 'yes/no' responses. In addition to the yes/no questions each respondent was asked an open question regarding the potential impact of sleep difficulties on learning and behavior. In addition to the interview/questionnaire measures, all children underwent psychological assessment including measures of cognition/development and behavioral/emotional difficulties.

2.3 Analysis

The open question from the parental interview, child interview and staff survey were analysed using Thematic Analysis²⁰ by two research psychologists (EJ and CR). The closed questions were included requiring 'yes/no' responses were analysed in terms of frequencies and mean averages and are reported as descriptive statistics. Chi-squared tests were used to compare responses for children with intellectual disability and without for relevant teacher and parent questions. The alpha level for all analyses was $p < 0.05$. All analyses were performed with IBM SPSS version 25.0 (Armonk, NY, USA).

2.4 Ethical Approval

The study was approved by the Leeds East Research Ethics Committee and was registered with the collaborating hospital primary care organization: The Sussex and Surrey Community NHS Trust.

3. Results

3.1 Characteristics of the sample

During the study period, 136 children with 'active' epilepsy were identified in the study area and 68 (50%) families agreed to participate. There were no significant differences between the participants ($n=68$) and non-participants ($n=68$) with respect to gender ($p=0.441$), current number of ASMs ($p=0.074$) or deprivation ($p=0.872$). However, participants had a significantly younger age of epilepsy onset (mean=3.81years) than non-participants (mean =7.46) ($p=0.015$). The main characteristics of the children, parents and teachers who participated in the WINS study are shown in Table 1, Supplement 2a and 2b respectively. Twenty of 68 (29%) child participants were able to complete the WINS study questionnaire/were interviewed. Of these 18 (26%) answered the questions relating to sleep.

Of the 50 children not interviewed, nine (18%) were deemed too young to understand the questions and 31 (62%) were unable to respond due to their level of cognitive functioning. Two children (4%) did not wish to respond because of perceived worry/anxiety, and five (including two who answered other questions but did not answer the sleep questions) (10%) declined without providing a reason. Three children (6%) did not have the opportunity to respond due to the COVID-19 pandemic restrictions i.e. it was not possible to meet the child.

In terms of parental respondents, 61 (90%) were mothers and 7 (10%) were fathers. Fifty-six staff participated in the study (see supplement 2a and 2b).

3.2 Views on Impact of Sleep Difficulties

The views of children, parents and school staff regarding the perceived impact of epilepsy on sleep are displayed in table 2. Fifty-six percent of children who responded believed that epilepsy affects their sleep. Almost two-thirds of parents (65%) believed that their child had more difficulties with sleep than other children of their age. Additionally of those parents who believed that their child had more difficulties than peers, 78% believed that the difficulties were due to epilepsy and 95% believed that the difficulties impacted on the child's learning and behavior. Fifty-four percent of school staff believed that the child with epilepsy they supported were more tired/fatigued than peers and 62% believed that the increased tiredness or fatigue was due to epilepsy. Additionally, 86% of school staff believed that the child's increased tiredness affected their learning/behavior.

Parents of children with intellectual disability were significantly more likely to indicate that they felt that their child had more difficulties than other children of their age ($p=0.016$). School staff supporting children with intellectual disability were also significantly more likely to agree that the child was more tired/fatigued than peers ($p=0.008$).

3.3. Child views on how epilepsy affects their sleep (see table 3)

Three major themes with associated subthemes were identified with respect to children's views on how epilepsy can affect their sleep. The themes, their associated subthemes, and illustrative quotes are shown in table 3.

3.3.1 General sleep difficulties

Some children felt that having epilepsy contributed to both having difficulties falling asleep but also to frequent night waking.

3.3.2 Child feels tired during day

Children mentioned that their epilepsy meant that they were often very tired during the day.

3.3.3. Nocturnal seizures

Experiencing night seizures meant sleep disruption for some but also anxiety associated with potential nocturnal seizures lead to the child being reluctant to go to bed and sleep.

3.4 Parental views on impact of epilepsy on their child

Eleven major themes with associated subthemes were identified with respect to parental views on their child's sleep difficulties. The themes, their associated subthemes, and illustrative quotes are shown in table 4.

3.4.1 Some children experience no difficulties with sleep

A minority of parents reported that their children did not experience any difficulties with sleep.

3.4.2 Many children appear/report being more tired than expected for their age

Parents of many children indicated that their child could fall asleep during the day at school or at home. Excessive tiredness or "broken sleep" was sometimes a precursor

to seizures. The effect of tiredness seemed to be cumulative, building up over the week so that the end of the week the child was “very tired”. Parents also felt that the child’s poorer “physical functioning” was a sign of tiredness.

3.4.3 Children experience difficulties falling asleep/ with bedtime routine

Difficulty falling asleep or difficulties with the bedtime routine was also a theme identified in the thematic analysis process. This theme included children with epilepsy who had difficulty falling asleep or going to bed. It also included children for whom parents felt that they don’t appear to experience typical tiredness or would fight feelings of tiredness. Falling asleep also took longer than expected for some children.

3.4.4 Children experience difficulties staying asleep/wake during the night

Some children were reported to have difficulties staying asleep. Some parents reported that their children often had excessive physical movements and/or vocalizations during night which sometime resulted in the child waking. Some children woke up and starting to engage in activities instead of trying to go back to sleep. Sometimes the child would wake up and be upset and/or engage in disruptive behavior during the night and thus would struggle to fall asleep again.

3.4.5 Children experience nocturnal seizures or have seizures upon waking

Nocturnal seizure or the occurrence of seizures from waking were identified as disruptive for both the child and family. Seizures meant that the child may need additional rest/sleep and this would lead to missing some or all of the following school day. Nocturnal seizures were also identified as disruptive due to need to for the child to shower and/or bedclothes to be changed.

3.4.6 Child prescribed melatonin or similar medication to aid sleep

For children who were prescribed medication to aid their sleep parents felt that the medication often helped the child fall asleep but not to stay asleep or fall asleep again after waking. Parents also brought up that whilst medication helped the child’s sleep on some occasions that in other occasions it did not seem to work.

3.4.7 Sleep difficulties impact cognition/learning

The impact of sleep difficulties on a range of aspects of cognition including memory, attention, processing speed and language was often mentioned by parents. In addition, it was the potential negative influence on a child’s motivation to engage in learning activities was also identified.

3.4.8 Effects of sleep difficulties on behavior, emotional and social well-being

Parents believed that sleep difficulties often had a negative impact on the child’s emotional and behavioral wellbeing. This negative impact included negative impacts on child’s mood and social interactions in school.

3.4.9 Impacts of medications on child’s sleep

ASMs were perceived by some parents to have the potential to increase tiredness and make it harder for child to fall asleep/sustain sleep whilst medication for ADHD was perceived by some parents to cause sleep difficulties.

3.4.10 The frequency, intensity and impact of sleep difficulties can be inconsistent

Some parents described inconsistent patterns with regard to sleep and sleep difficulties indicating that the frequency intensity and overall impact of epilepsy could vary significantly over time and even from night to night.

3.4.11 Strategies used to improve child's sleep/tiredness

Parents brought up a number of strategies they employed to promote the child's sleep and reduce tiredness including allowing child to watch television when falling asleep, accompanying the child when falling asleep or sleeping with parent throughout the night and managing/limiting of day-time activities so child is not over-tired.

3.5. School Staff views on impact of sleep difficulties on child with epilepsy

Four main themes were identified with respect to staff responses (see table 5). The four themes were:

3.5.1 Child noticeably tired/fatigued during the school day

Some staff mentioned that that the child with epilepsy appeared more tired/fatigued than peers during the school day. They reported that the child appeared 'sluggish' and lacked 'energy'.

3.5.2 Decreased engagement

According to some teachers the child with epilepsy became less cooperative, was less willing to participate in classroom activities and displayed decreased motivation due to their sleep difficulties.

3.5.3 Impaired cognition

The child's sleep difficulties would also impact on cognition including difficulties with attention and slower processing time.

3.5.4 Behavioral and emotional difficulties

Teachers also felt that the child's sleep difficulties would also contribute to behavioral and emotional difficulties. Teachers mentioned that sleep difficulties could lead to the child being more irritable, less tolerant and more disruptive. Additionally, it was also mentioned that the children would display increased sensitivity to environmental stimuli and peers.

4. Discussion

This study provides data on the views of children with epilepsy, their parents and supporting school staff on the perceived impact of epilepsy on sleep and subsequent impact of sleep difficulties on everyday functioning. As such it contributes to an increased understanding of the perceived role of sleep difficulties on the learning and behavior of children with epilepsy. The majority of children who responded believed that epilepsy affects their sleep. Two thirds of parents believed that their child had more difficulties with sleep than other children of their age, most believed that the difficulties were due to the child's epilepsy and that the difficulties significantly impacted on the child's learning and behavior. Fifty-four percent of school staff believed that the child with epilepsy they supported were more tired/fatigued than peers and nearly two in three believed that the increased tiredness or fatigue was due to epilepsy. Parents and supporting school staff of children with intellectual disability were significantly more likely to indicate that they felt that their child had more difficulties than other children of

their age or agree that the child was more tired/fatigued than peers. The children with epilepsy perceived that epilepsy impacted on their ability to fall asleep, stay asleep and subsequently contributed to increased daytime tiredness. Parental responses indicated that children with epilepsy often appear more tired than peers, have difficulties falling and staying asleep and can experience nocturnal seizures or have seizures on waking. The difficulties with increased fatigue and tiredness could also be due to children with epilepsy having primary sleep disorders. With respect to impact, sleep difficulties are perceived to impact on cognition and emotional-behavioral functioning, but the experienced impacts can vary significantly from day to day in individual children according to parents. School staff perceive that the child with epilepsy's sleep difficulties can lead to the child appearing fatigued during the school days, decreased engagement with classroom activities, impairments in cognition and emotional-behavioral difficulties.

Most children with epilepsy believed that epilepsy affected their sleep. Few previous studies have employed self-report of studies of children with epilepsy²¹ but self-report is likely to be important given that parents and children with epilepsy may differ significantly in rating emotions and health related quality of life^{22,23}. Most parents believe that their child had more sleep difficulties than peers which is line with previous studies which have employed parent report measures of sleep which have showed that children with epilepsy have a high level of sleep difficulties⁷ and a higher level of difficulties than controls without epilepsy²¹. Most parents perceive that the child's sleep difficulties are due to epilepsy and contribute to the child's learning and behavioral issues highlighting the need to screen for difficulties with sleep as has been previously suggested²¹ and consider sleep in the context of epilepsy treatment²⁴. The majority of school staff perceive that children with epilepsy are more tired/fatigued than peers. Although the views of school staff regarding children with epilepsy's daytime sleepiness has not been previously surveyed to our knowledge, excessive daytime sleepiness compared to peers has been reported by children with epilepsy compared with controls²⁵. In the current study parents of children with intellectual disability (ID) and the school staff who support them were significantly more likely to indicate that the child had more sleep difficulties than other children of their age and that the child was more tired/fatigued than peers. The increased risk for sleep difficulties in children with epilepsy with ID has been noted previously^{4,5}.

The children with epilepsy reported a range of ways in which epilepsy may affect their sleep including difficulties falling asleep and frequent night waking. Sleep onset latency has previously been reported to be a difficulty for children with epilepsy⁴, whilst night waking has also been reported to be greater in children with epilepsy than controls²⁵. These previous findings were based on parent report data. The children with epilepsy also mentioned that they were very tired during the day and excessive time sleepiness has been previously reported by parents of children with epilepsy²⁶ but also the children themselves²⁶. The occurrence of night-time seizures or fear of their occurrence was also cited by some children as a difficulty.

The themes identified in parent responses included increased child tiredness, difficulties for the child with falling asleep, bedtime routines, and difficulties staying asleep and potential impact of nocturnal seizures. These difficulties have all been identified in previous questionnaire based studies^{4,5,26}. Parents reported that the

effects of melatonin on child sleep can be inconsistent and whilst it may help the child get to sleep, it will not help them sustain sleep. This is consistent with data from a large randomised controlled trial of melatonin in children with neurodevelopmental difficulties²⁷. Parents also felt that sleep difficulties could adversely affect the child's learning and behaviour. There is some evidence in children with epilepsy that sleep difficulties may be associated with learning/cognitive problems¹⁸. This relationship is likely to be bi-directional as having ID, **Autism Spectrum Disorder (ASD)** or ADHD will likely increase rates of behavioural insomnia⁸. The link between behavioural-emotional difficulties and sleep difficulties has not been well established in children with epilepsy although has been evidenced in children without epilepsy^{28,29}.

Some parents mentioned that ASMs can impact negatively on sleep and tiredness and sleep difficulties and tiredness are noted side effects of ASMs³⁰. Parents also suggested that use of medication to treat symptoms of ADHD could impact on sleep. Delayed sleep onset latency is one of the most common adverse events associated with stimulant medications although in some individuals, no noticeable effect on sleep or even improved sleep may be noted³¹. Parents also reported that the frequency, intensity, and impact of sleep difficulties can be inconsistent. It is not clear if this inconsistency of difficulties is specific to epilepsy and thus related to occurrence of seizures, epilepsy or underlying disease or other reasons and warrants further investigation. Parents mentioned a number of strategies they employed in trying to help the child with their sleep. It is important that parents of children with epilepsy have access to evidence-based strategies to ensure that what they are doing is likely to help their child's sleep.

In the current study, the responses of school staff indicate that they perceive that the child they support with epilepsy often appears tired/fatigued during the school day. In children without epilepsy, excessive daytime sleepiness is associated with poorer cognitive and academic performance^{32,33}, highlighting the possible negative impact of daytime sleepiness on the school performance of children with epilepsy. School staff also perceived that sleep difficulties would lead to decreased engagement, increased emotional and behavioral problems and cognitive problems. In children without epilepsy, sleep difficulties, and in particular shorter sleep time is associated with increased emotional lability, hyperactivity³⁴ and learning difficulties³⁵. In addition to the impact on school performance, shorter sleeping time may also be associated with lasting changes in brain structure³⁵ highlighting the potential lasting detrimental impact of sleep difficulties.

4.1 Clinical implications and future directions

In line with previous suggestions^{21,36} there is a clear need for children with epilepsy to be screened for sleeping difficulties given the potential negative impact on quality of life, learning and behaviour. Given that some of the reported difficulties appear to be related to behavioural insomnia as opposed to nocturnal seizures, it is likely that for many children supports to improve sleep should focus on educating caregivers and young people (where developmentally appropriate) about simple sleep hygiene measures such as avoiding screens in the last hour before bedtime, exposure to morning sunlight and engaging in regular physical activity. These supports are successfully used in typically developing children and evidence although limited suggests that they will work in the paediatric epilepsy population³⁷. Additionally, it is important that caregivers are aware that the chief benefit of melatonin is to reduce

sleep onset latency, and that it may result in earlier waking²⁷. The reports of caregivers and young people in the current study also suggest that in some cases the children with epilepsy are displaying symptoms of parasomnia (e.g., excessive or abnormal movements)³⁸, primary sleep disorders (e.g., obstructive sleep apnoea)³⁹ or even unidentified seizures⁴⁰. Thus, in some patients, overnight EEG polysomnography may be indicated in order to clarify the cause of their disrupted sleep.

With respect to use of ASMs though most of the available data derive from healthy adults or adults with epilepsy⁴¹ it has been shown that nearly all ASMs can alter sleep architecture. The correlation of these changes to subjective sleep quality is unknown. Whilst there is as yet no data on the impact of ASMs on sleep homeostasis, it is likely that this is also impacted. More research is needed in this area. Many children with epilepsy have symptoms of ADHD and this may be alleviated significantly by stimulant or other medications, however these may contribute to a reduction in sleep⁴². ASD in children is also associated with increased sleep difficulties and children with epilepsy have an increased risk for ASD. There is evidence that behavioural interventions can improve sleep difficulties in children with autism and should be available for children with ASD who also have epilepsy⁴³.

Future studies are needed to explore the relationship between sleep difficulties as measured by objective methods and cognition and behaviour including specific domains of cognition (e.g., aspects of memory, processing speed) in children with epilepsy. It will also be useful to include control groups with other learning and behavioural impairments without epilepsy to understand if there is a specific contribution of epilepsy regarding the nature of sleep difficulties and their impact. There is some evidence that face-to-face sleep education sessions with parents can improve sleep quality and quantity in young children with epilepsy³⁷ but there is a need for more evidence exploring psychoeducation and psychopharmacology alone and combined in this population. Intervention studies must include an assessment of the impact on child quality of life, learning and behaviour as well as sleep parameters/quality. There is however, a lack of validated outcome measures in the paediatric epilepsy population and thus a need to develop these. Given the high level of sleep difficulties in parents of children with epilepsy^{6,7} there is also a need to assess the impact of interventions on parental sleep. Future studies should also consider examining whether themes identified differ by subgroups such as those with/without intellectual disability, older/younger children and epilepsy syndromes.

4.2 Limitations

The majority of children with epilepsy were unable to participate in surveys/interviews primarily due to cognitive impairment. We did not have responses from a representative school staff member for all participating children. We did not employ standardised or objective measure of sleep difficulties. Therefore, we were relying on perceptions of sleep difficulties and their impact. These is likely to be particularly problematic in relation to school staff who may notice fatigue or tiredness and attribute it to sleep difficulties due to the child's epilepsy which may or not be the case.

5. Summary

Children with epilepsy, their parents and school staff perceive that epilepsy confers a high risk for sleep difficulties and daytime tiredness. Difficulties with sleep are

perceived to have a negative impact on the child's learning and emotional and behavioral functioning. Children with epilepsy and ID are perceived to be at significantly higher risk for sleep difficulties and thus associated sequelae. Asking children with epilepsy and their parents about the child's potential sleep difficulties and associated impact would appear to be an important first step in the assessment and subsequent development of supports for this group.

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