Epilepsy & Behavior 28 (2013) 481–488

Contents lists available at SciVerse ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Subjective sleep disturbances in children with partial epilepsy and their effects on quality of life

Th. Gutter [a,*], O.F. Brouwer [b], A.W. de Weerd [a]

[a] Department of Clinical Neurophysiology and Sleep Centre SEIN, Zwolle, The Netherlands
[b] Department of Neurology, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

ARTICLE INFO

Article history:
Received 10 April 2013
Revised 13 June 2013
Accepted 18 June 2013
Available online 25 July 2013

Keywords:
Child
Partial epilepsy
Sleep disturbance
Quality of life

ABSTRACT

Purpose: The purposes of this study were to explore the prevalence of sleep disturbances in a large cohort of school-aged children with partial epilepsy, to compare the findings with those in children without epilepsy of the same age and gender, and to evaluate the relationship between sleep disturbances and health-related quality of life (HRQoL).

Methods: One hundred thirty children with partial epilepsy aged 4 to 10 years, who were treated in the outpatient setting of a Dutch epilepsy clinic, and 161 age- and sex-matched controls participated in this study. In addition to providing information about their child's demography and health, parents of both groups of children completed three questionnaires to measure their child's sleep [Sleep Disturbance Scale for Children (SDSC), Medical Outcomes Study-Sleep Scale (MOSS-S), and Groningen Sleep Quality Scale (GSQS)] and one questionnaire to measure quality of life (Kidscreen-27). Parents of children with epilepsy also completed the Hague Scales to measure the severity of epilepsy. The prevalence of sleep disturbances and scores on HRQoL in children with and without epilepsy were compared. Additionally, the HRQoL scores were compared between children with and without sleep disturbances in children both with and without epilepsy.

Results: The answers for all three questionnaires suggested worse sleep in children with epilepsy than in children of the same age and gender without epilepsy. Pathological scores (T-value > 70) for total SDSC were seen twelve times more frequently in children with epilepsy (36.92% vs. 3.01%, $p < 0.001$). Children with epilepsy also scored significantly lower for all dimensions of HRQoL. Between subgroups of children with and without disturbed sleep, insignificant differences in quality of life were found, with the lowest scores in children with sleep disturbances in both groups.

Conclusion: This study confirms the high prevalence of disturbed sleep, as well as its effect on quality of life, in a large group of children with partial epilepsy. The abnormalities are both more prevalent and more severe than in children without epilepsy.

1. Introduction

The interaction between epilepsy and sleep is complex and reciprocal. In adults with epilepsy, the prevalence of complaints about sleep is higher than in controls [1–3], with more daytime sleepiness and insomnia in adults with epilepsy [4]. It has also been shown that children with epilepsy have more sleep problems than their nearest-aged siblings or healthy controls [4–10]. Excessive daytime sleepiness, bedtime difficulties, and parasomnias are common in these children. On the other hand, disturbed sleep may result in sleep deprivation, which can provoke seizures [11–13].

Quality of life in both adults and children with epilepsy may already be low because of epilepsy itself and the ensuing morbidity, such as anxiety or depression [14–17]. Sleep problems have an additional negative influence on the quality of life in adults with epilepsy [1,2,7,18,19]. In children with epilepsy, it has been shown that sleep disorders have negative effects on cognition and behavior [6,7,9,20–22], but their influence on quality of life has not previously been studied. Furthermore, previous questionnaire studies measuring the prevalence of sleep disturbances were performed in small populations [7,8,21], in children with mixed generalized and partial epilepsies, or in groups of children with a wide age range [5–9,22], with inherent large variations in sleep parameters [23]. Studies in a large cohort of school-aged children, before their onset of puberty with its own problems, could strengthen the evidence that children with epilepsy are more likely to have sleep disturbances than children without epilepsy of this age.

The aims of this study, therefore, were to explore the prevalence of sleep disturbances in a large cohort of school-aged children with partial epilepsy, to compare the findings with those in children without epilepsy of the same age, and to investigate the relationship between sleep disturbances and the quality of life.

---

* Corresponding author at: Stichting Epilepsie Instellingen Nederland, Dr Denekampweg 20, 8025 BV, Zwolle, The Netherlands. Fax: +31 38847170.
E-mail addresses: tgutter@sein.nl, theagutter@gmail.com (T. Gutter).

1525-5050/$ – see front matter © 2013 Elsevier Inc. All rights reserved.
http://dx.doi.org/10.1016/j.yebeh.2013.06.022

2. Patients and methods

2.1. Inclusion and exclusion criteria

All children with epilepsy treated in one of the outpatient units of the Epilepsy Institutes of The Netherlands Foundation (SEIN) and who were aged between 4 years and 10 years (inclusive) were eligible for the study. They had to have a definite diagnosis of partial epilepsy, currently taking a maximum of two different AEDs and having a score on the Hague Seizure Severity Scale of 45 or less, implying that the epilepsy was active but of medium or less severity [24]. Children not using AEDs could only be included when they had at least one seizure during the previous twelve months. A school level below special elementary education (SBO) was a reason for exclusion. Their parents were asked to search for children without epilepsy with the same gender and approximately the same age as their own child to serve as controls. In children without epilepsy (controls), the use of AEDs for indications other than epilepsy and a school level below SBO were reasons for exclusion.

2.2. Questionnaires

The parents of all children were asked to complete questionnaires measuring sleep quality, sleep problems, and quality of life:

- The Sleep Disturbance Scale for Children (SDSC) is a validated questionnaire to detect sleep problems and to estimate their severity over the previous 6 months [25]. It consists of 26 items rated on a 5-point Likert scale, which are divided over six factors: ‘disorders of initiating and maintaining sleep’ (7 items), ‘sleep breathing disorders’ (3 items), ‘disorders of arousal/nightmares’ (3 items), ‘sleep wake transition disorders’ (6 items), ‘disorders of excessive somnolence’ (5 items), and ‘sleep hyperhidrosis’ (2 items). Higher scores suggest more sleep problems. The raw total SDSC scores (range: 28–130) and the subscale scores were converted to T-scores. T-scores of >70 (2 standard deviations above the mean) were considered pathological.
- The Medical Outcomes Study-Sleep Scale (MOSS-S) is a validated 12-item questionnaire to estimate the sleep quality in the previous four weeks [26]. This questionnaire was used consistently over time in scoring and assessing the existence of sleep problems. A few adaptations were necessary to make the questionnaire suitable for completion by parents on behalf of their children. The mean hours of nocturnal sleep are recorded, while the other questions are answered with a 5-point or 6-point Likert scale (ten questions). Combinations of different items result in scores in specific sleep problem domains: ‘sleep disturbance’ (4 items), ‘snoring’ (1 item), ‘breathing disorder/headache’ (1 item), ‘sleep adequacy’ (sufficient sleep, 2 items), daytime somnolence (3 items), and ‘duration of sleep’ (1 item). The Sleep Index, the mean score of 9 items, is an indication of sleep quality. Apart from sleep adequacy, high scores suggest the existence of sleep problems.
- The Groningen Sleep Questionnaire Scale (GSQS) is a (not published) questionnaire to estimate sleep quality during the previous night [27]. This questionnaire was used consistently over time in scoring and assessing sleep quality. It has been evaluated in people with seasonable dependent affective disorder and population of shift workers and is used in many Dutch sleep centers and in research [28,29]. It consists of 14 items which are answered with ‘Yes’ or ‘No’ and are summed to get the total score. Higher scores indicate higher subjective quality of sleep. Scores less than 8 suggest disturbed sleep. This questionnaire was also adjusted on minor points to be suitable for use in children.
- The Kidscreen-27 is a questionnaire developed and widely used in European countries to estimate the health-related quality of life (HRQoL) of children and adolescents (8 to 18 years) during the previous week [30]. Although some children were younger than eight years, this generic instrument to measure subjective health and well-being is the best fitting questionnaire validated in Dutch children to use in our two groups with respectively chronically ill children (with epilepsy) and healthy children (without epilepsy). It consists of 27 items divided over five domains: ‘physical well-being’ (5 items), ‘psychological well-being’ (7 items), ‘autonomy and parents' relation (7 items), ‘social support and peers’ (4 items), and ‘school environment’ (4 items). A 5-point response scale is used. Within each domain, the sum of the raw scores was transformed into T-scores. (The European normative score is as follows: mean = 50, SD = 10. A lower score suggests lower HRQoL.)
- Parents of children with epilepsy were asked to complete three additional questionnaires: the Hague Seizure Severity Scale (HSSS), the Hague Side Effects Scale (HaSES) and the Hague Restrictions in Childhood Epilepsy Scale (HaRCES) [24] These scales are validated in a Dutch population of children 4–16 years of age and estimate the severity, side effects of epilepsy, and its treatment and impact on everyday life over the previous three months. These scales were designed to measure the parents' perception of basic aspects of epilepsy in their children. The HSSS consists of 13 items about the severity of the seizures in 4- and 5-point scales. Scores range from 13 (low severity) to 56 (high severity). In this study, a score above 45 was a reason for exclusion. The HaSES consists of 20 items that measure the side effects of antiepileptic drugs in 4-point scales. Scores range from 20 (no side effects) to 80 (severe side effects). The HaRCES is a 10-item scale that measures disability resulting from the restrictions due to epileptic seizures, again in 4-point scales. Scores range from 10 (no disability) to 40 (severe disability).

The answers of all questionnaires were digitized for further processing. If there were missing answers, the family was contacted. Missing answers in questionnaires to measure sleep resulted in exclusion from the study, while missing answers in questionnaires on quality of life and the Hague Scales (HSSS, HaSES, and HaRCES) were noted as such. In cases where questionnaires about a child with epilepsy were not sent back or were not included, the results of their individual controls were still used and vice versa.

2.3. Distribution of the questionnaires

The questionnaire study was performed in two time periods (Fig. 1). In 2008, questionnaires were sent to all 475 parents of children with partial epilepsy aged between 4 and 10 years treated in one of the outpatient clinics of SEIN (1st phase). In total, 166 were returned but were not analyzed at that time. When the study restarted (2nd phase), parents of all 81 children who were referred to the outpatient unit of SEIN in 2009–2011, who met the inclusion criteria, were also asked to take part. The parents of 33 children agreed to participate. The parents of 171 control children returned the questionnaires.

2.4. Statistical analysis

Statistical analyses were performed with SPSS 19.0 (SPSS Inc., Chicago, IL). Demographic data and data acquired from the questionnaires were compared between children with epilepsy and controls using independent sample *t*-tests for normally distributed data and Mann–Whitney U tests for data that were not normally distributed. Chi-square or Fisher exact tests were used for categorical variables. Potential confounding factors such as age, use of AEDs, seizure type, and frequency of seizures were included using logistic and linear regression, after log transformation of data which were not normally distributed. In multiple comparisons, Bonferroni correction was used. In the two-sided tests, a *p*-value of 0.05 was considered significant.