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FULL-LENGTH ORIGINAL RESEARCH

Impact of pediatric epilepsy on sleep patterns and behaviors in children and parents

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Summary

Purpose: Disrupted sleep patterns in children with epilepsy and their parents are commonly described clinically. A number of studies have shown increased frequency of sleep disorders among pediatric epilepsy patients; however, few have characterized the association between epilepsy and parental sleep quality and household sleeping arrangements. The purpose of this study was to explore the effect of pediatric epilepsy on child sleep, parental sleep and fatigue, and parent-child sleeping arrangements, including room sharing and cosleeping.

Methods: Parents of children 2 to 10 years of age with and without epilepsy completed written questionnaires assessing seizure history, child and parent sleep, and household sleeping arrangements. Children's Sleep Habits Questionnaire (CSHQ) scores were used to evaluate sleep disturbances for the child. The Pittsburgh Sleep Quality Index (PSQI) and the Iowa Fatigue Scale (IFS) were used to evaluate parental sleep and fatigue, respectively. The Early Childhood Epilepsy Severity Scale (E-Chess) was used to assess epilepsy severity.

Key Findings: One hundred five households with a child with epilepsy and 79 controls participated in this study. Households with a child with epilepsy reported increased rates of both parent–child room sharing ($p < 0.001$) and cosleeping ($p = 0.005$) compared to controls. Children with epilepsy were found to have greater sleep disturbance by total CSHQ score ($p < 0.001$) and the following subscores: parasomnias ($p < 0.001$), night wakings ($p < 0.001$), sleep duration ($p < 0.001$), daytime sleepiness (<0.001), sleep onset delay ($p = 0.009$), and bedtime resistance ($p = 0.023$). Parents of children with epilepsy had increased sleep dysfunction ($p = 0.005$) and were more fatigued ($p < 0.001$). Severity of epilepsy correlated positively with degree of child sleep dysfunction (0.192, $p = 0.049$), parental sleep dysfunction (0.273, $p = 0.005$), and parental fatigue (0.324, $p = 0.001$). Antiepileptic drug polytherapy was predictive of greater childhood sleep disturbances. Nocturnal seizures were associated with parental sleep problems, whereas room sharing and cosleeping behavior were associated with child sleep problems. Within the epilepsy cohort, 69% of parents felt concerned about night seizures and 44% reported feeling rested rarely or never. Finally, 62% of parents described decreased sleep quality and/or quantity with cosleeping.

Significance: Pediatric epilepsy can significantly affect sleep patterns for both the affected child and his or her parents. Parents frequently room share or cosleep with their child, adaptations which may have detrimental effects for many households. Clinicians must not only be attentive to the sleep issues occurring in pediatric patients with epilepsy, but also for the household as a whole. These data provide evidence of a profound clinical need for improved epilepsy therapeutics and the development of nocturnal seizure monitoring technologies.

KEY WORDS: Seizures, Nocturnal seizures, Child sleep dysfunction, Parental sleep dysfunction, Parental fatigue, Room sharing, Cosleeping.

Epilepsy is a common, chronic, neurologic disease occurring in approximately 1% of children. The household impact of childhood epilepsy depends on many factors including seizure severity and treatment response. Adequate sleep plays a vital role in overall health across all age groups. Unfortunately, disrupted sleep patterns for children and their parents are commonly seen clinically in tandem with childhood epilepsy.

Although the clinical intersect between pediatric epilepsy and sleep has been investigated in several prior studies (Stores et al., 1998; Cortesi et al., 1999; Becker et al., 2003; Wirrell et al., 2005; Maganti et al., 2006; Batista & Nunes, 2007; Byars et al., 2008; Ong et al., 2010; Chan et al., 2011), the neurologic mechanism underlying this relationship has proven dynamic and multivariable. Our clinical understanding of this interplay continues to follow a model of reciprocal influence in which sleep patterns affect

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seizure profiles and seizure profiles affect sleep patterns (Montplaisir et al., 1985). Sleep deprivation is a well-described trigger for epileptic events, circadian rhythms can predict seizure activity, and sleep disorders such as obstructive sleep apnea and restless leg syndrome can interfere with successful seizure control (Nunes, 2010). Furthermore, epileptic discharges have been shown to disrupt sleep–wake cycles (Maganti et al., 2005) and some antiepileptic treatments can secondarily degrade sleep architecture and quality (Placidi et al., 2000). Together, epilepsy and sleep problems confer lower quality of life across age groups (Wirrell et al., 2005; Piperidou et al., 2008) and negatively impact behavior (Stores et al., 1998; Cortesi et al., 1999; Becker et al., 2004; Maganti et al., 2005; Wirrell et al., 2005) and neuropsychological functioning (Byars et al., 2008) in children.

Studies have shown that caregivers of children with chronic illnesses exhibit disrupted sleep patterns and sleep deprivation (Meltzer & Mindell, 2006); however, surprisingly few studies have explored the effect of epilepsy on parental sleep habits and household routines. Following a single febrile seizure, prior reports have described evidence of increased parental anxiety, fatigue, nighttime checks, and cosleeping (Wirrell & Turner, 2001). Additional studies have described frequent parental sleep disturbances in epilepsy cohorts (Cottrell & Khan, 2005; Shaki et al., 2011) and increased parental anxiety and cosleeping behavior when compared to both healthy controls and parents of children with other chronic diseases (Cortesi et al., 1999; Williams et al., 2000; Ong et al., 2010).

We hypothesized that parents are sleeping poorly not only as a consequence of their child's disrupted sleep patterns, but also due to the fear and anxiety of their son or daughter having a seizure at night (Williams et al., 2000). In this study, household sleep patterns in families with a child with epilepsy were investigated and compared with controls. We aimed to assess the effect of pediatric epilepsy on child and parent sleep patterns and identify predictors of dysfunction. A second aim was to investigate alterations in household sleep routines, specifically room sharing and cosleeping.

Methods

In this institutional review board–approved study, two sets of prospective participants were identified and contacted by mail. The control population consisted of households with a child between 2 and 10 years old seen in an outpatient general pediatric care practice at Massachusetts General Hospital (MGH) between January 2010 and January 2011 (CG, control group). For the control cohort, a history of seizure was the criterion for exclusion. The second cohort included households with a child in the same age range, with a diagnosis of epilepsy (identified by ICD-9 code) who was seen in an outpatient pediatric neurology or epilepsy clinic at MGH over the same time interval (EG, epilepsy group). Questionnaires were mailed to 1,057 total households (27 were returned to sender due to an incorrect address). Implicit informed consent was obtained when the child's caregiver completed and returned the study questionnaires by mail to the study site. The data collection end point for the study was 4 months after questionnaires were mailed to prospective participants. Enrollees who returned an incomplete survey, specifically, less than two thirds complete, were excluded from the study.

Parameters measured in this study included child seizure history and treatment, child sleep, caregiver sleep and fatigue, and household sleeping arrangements and routines. The mailing included a series of investigator-generated questions in addition to the following four standardized questionnaires: Early Childhood Epilepsy Severity Scale (E-Chess) (Humphrey et al., 2008), Children's Sleep Habits Questionnaire (CSHQ) (Owens et al., 2000; Goodlin-Jones et al., 2008), Pittsburgh Sleep Quality Index (PSQI) (Buysse et al., 1989), and the Iowa Fatigue Scale (IFS) (Hartz et al., 2003).

Seizure severity was primarily indexed by E-Chess score and secondarily by age at seizure onset and lifetime number of antiepileptic drugs (AEDs). The E-Chess is a six-item inventory that provides a single composite score. Total scores (increasing with severity) are based on seizure frequency, time period over which seizures occur, number of seizure types, history of status epilepticus, number of AEDs used, and response to treatment (Humphrey et al., 2008).

Child sleep was measured using CHSQ scores. The CSHQ, a validated tool for both behaviorally and medically based pediatric sleep problems, is a 33-item psychometric assessment encompassing an inventory of eight domains: bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, parasomnias, disordered breathing, and daytime sleepiness (Owens et al., 2000; Goodlin-Jones et al., 2008). The following behaviors were included in the parasomnia domain: wets the bed at night, talks during sleep, restless and moves a lot, sleepwalks, grinds teeth during sleep, awakens screaming or sweating, and alarmed by scary dream. Individuals with total CSHQ scores of ≥41 were identified as having severe sleep problems (Owens et al., 2000).

Caregiver sleep was measured by PSQI scores. The PSQI assesses both sleep quality and degree of disturbance using 19 items to generate a composite score and the following seven subscores: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. Individuals with total PSQI scores of ≥5 were identified as having severe sleep problems (Buysse et al., 1989). The IFS, used to assess the degree of parental fatigue, is an 11-item composite score with the following four subscores: cognitive, fatigue, energy, and productivity. Individuals with total IFS scores ≥35 were identified as severely fatigued based on results of a prior study in which 75% of adults in a primary care setting received scores of ≤35 (Hartz et al., 2003).

A limited number of equivocal responses were systematically managed by investigators as follows. For the CSHQ, 15.2% of all questionnaires were missing responses for 1–5 questions. In the event of an unanswered question(s), total scores were given as the product of the calculated average of the answered questions and the total number of items (answered or unanswered). Affected subscores calculated from four or fewer items (onset delay, duration, anxiety, night wakings, disordered breathing) were removed from analyses in the event of one or more missing question(s). Affected subscores calculated from five or more items (bedtime resistance, parasomnias, daytime sleepiness) were removed from analyses in the event of two or more missing questions. Individual questions for which N/A (not applicable) was circled were assigned a zero score. For the question, *Child wets the bed*, a subset of responders (n = 4) wrote in ''diapers,'' but did not assign a numerical value. In those cases, a score of one (never/rarely) was assigned for the given item. For the IFS, 4.4% of returned questionnaires were missing exactly one question response. In these cases, total scores were calculated as described above and subscores were removed from analyses.

For analysis of subject characteristics, categorical data were presented as frequencies (percentage) and were compared using a chi-square test or Fisher exact test, whichever suit best, and continuous data were presented as mean ± standard deviation (SD) unless otherwise specified. Means of the continuous data were compared by Student *t*-test. For comparing the mean degree and type of sleep disturbances between the epilepsy and control cohorts, multivariate analysis of covariance (MANCOVA) was employed to take into account the correlations among the sleep disturbance variables. Statistical significance level was set at 0.05 for the majority of tests. To correct for the multiple comparisons in Table 4, the significance level was set at 0.005.

Results

The study response rate was 18.7% (193/1,030). Five surveys were excluded when they were returned less than two-thirds complete and four were returned after the data collection phase. The final epilepsy and control populations included 105 and 79 households, respectively.

The mean E-Chess score for the EG was 10.74 (SD 3.823) and 25.7% (27/105) had severe epilepsy with scores of ≥14. The mean age of seizure onset was 2.3 years (SD 2.29) and 40.8% (42/103) had seizure onset within the first year of life. At least one seizure within the previous month was reported for 64.2% (61/95) of children and daily seizures for 36.8% (35/95). The mean number of current AEDs was 2.16 (SD 1.27), with 90.5% taking at least one pharmacotherapeutic treatment. Other treatments included vagus nerve stimulation (5.7%), epilepsy surgery (4.8%), and dietary therapy (1.9%).

Epileptic syndromes were identified in the following cases: absence epilepsy (6), Doose syndrome (4), Lennox-Gastaut syndrome (1), West syndrome (3), benign rolandic epilepsy (3), and electrical status epilepticus in sleep (1). Distribution of the known epilepsy etiologies for the cohort were as follows: tuberous sclerosis complex (18), Angelman syndrome (7), neurofibromatosis 1 (3), Down syndrome (2), 15q duplication syndrome (1), isodicentric chromosome 15 syndrome (1), Smith–Magenis syndrome (1), lissencephaly (1), Sturge-Weber syndrome (1), Krabbe disease (1), neuronal ceroid lipofuscinosis (1), posttraumatic epilepsy (1), and epilepsy with history of neonatal stroke (1).

A comparison of demographic, comorbidity, and sleep routine responses for the two cohorts are presented in Table 1. Among parents who reported cosleeping, 63.6% (28/44) did not cosleep before the onset of their child's seizures and 65.9% (29/44) did not cosleep with the child's sibling when of similar age. For the EG, the following reasons for cosleeping were endorsed (multiple reasons cited per respondent): 45.5% (20/44) due to sleep difficulty for the child, 31.8% (14/44) due to seizures, and 25.0% (11/44) due to illnesses. Among children within the EG, 31.4% (33/105) were taking one or more medication for sleep, compared to 1.3% (1/79) in the CG. Treatments reported in the EG included melatonin (75.8%, 25/33), benzodiazepines (21.2%, 7/33), antihistamines (12.1%, 4/33), and others (18.1%, 6/33).

A comparison of mean sleep scores for the EG and CG is presented in Table 2. Children with epilepsy were found to have greater sleep disturbances by total CSHQ scores and the following subscores (listed in order of relative impact as measured by the standardized adjusted coefficients): parasomnias, night wakings, sleep duration, daytime sleepiness, sleep onset delay, and bedtime resistance. Significant differences were not observed between disordered breathing and sleep anxiety subscores. EG parents had higher PSQI total scores as well as daytime dysfunction, habitual sleep efficiency, and sleep disturbances subscores (order of relative impact). EG parents were also found to be more fatigued by IFS total scores and all four subscore domains.

Within the EG, the following significant correlations were observed: severity of epilepsy and child sleep dysfunction by CSHQ with E-Chess (0.192, p = 0.049); severity of epilepsy and parental sleep dysfunction by PSQI with E-Chess (0.273, p = 0.005) and lifetime AEDs (0.201, p = 0.39); severity of epilepsy and parental fatigue by IFS with E-Chess (0.324, p = 0.001) and lifetime AEDs (0.265, p = 0.006), and age at seizure onset (−0.227, p = 0.021).

Associations between specific sleep parameters and epilepsy determinants as well as household sleeping arrangements are delineated in Table 3. Nocturnal seizures and severe epilepsy (E-Chess ≥14) conferred increased sleep disturbances for parents. Nocturnal seizures were associated with only increased sleep anxiety subscores for children. Broader disordered child sleep and parental fatigue

Table 1. Demographics, comorbidities, and sleep routines for surveyed households with and without a child with epilepsy

	Control (n = 79)	Epilepsy (n = 105)	p-Value
Demographics[a]			
Mean age	5.32	6.19	0.028*
Sex			0.214
Male	49.4% (38/77)	58.7% (61/104)	
Female	50.6% (39/77)	43.3% (43/104)	
Respondent			
Mother	88.6% (70/79)	94.3% (99/105)	0.172
Comorbidities			
Neurocomorbidities			
ADHD/ADD[b]	1.3% (1/79)	7.6% (8/105)	0.048*
Dev. delay	5.3% (4/76)	66.3% (69/104)	<0.001*
Autism spectrum[c]	2.5% (2/79)	22.9% (24/105)	<0.001*
Resp. comorbidities[d]	0% (0/79)	7.6% (8/105)	0.012*
GERD[e]	1.3% (1/79)	18.1% (19/105)	<0.001*
Other comorbidities[f]	6.3% (5/79)	27.6% (29/105)	<0.001*
Sleep routine			
Child sleep Rx	1.3% (1/79)	31.4% (33/105)	<0.001*
Electronic monitor[g]	23.1% (18/78)	39.2% (40/102)	0.022*
Room sharing			<0.001*
<1 per week	5.2% (4/77)	13.9% (14/101)	
1–2 per week	10.4% (8/77)	10.9% (11/101)	
3–6 per week	5.2% (4/77)	11.9% (12/101)	
All nights	6.5% (5/77)	23.8% (24/101)	
Initiated by			0.037*
Child	84.2% (16/19)	55.3% (26/47)	
Parent	5.3% (1/19)	36.2% (17/47)	
Either	10.5% (2/19)	8.5% (4/47)	
Cosleeping			0.005*
<1 per week	3.8% (3/78)	9.6% (10/104)	
1–2 per week	9.0% (7/78)	5.8% (6/104)	
3–6 per week	3.8% (3/78)	10.6% (11/104)	
All nights	3.8% (3/78)	16.3% (17/104)	
Initiated by			0.017*
Child	80.0% (12/15)	57.6% (19/33)	
Parent	0% (0/15)	36.4% (12/33)	
Either	20.0% (3/15)	6.0% (2/33)	

[a]Child demographic information.
[b]Attention-deficit/hyperactivity disorder, attention deficit disorder.
[c]Autism, pervasive developmental disorder, Asperger syndrome.
[d]Respiratory comorbidities including obstructive sleep apnea, chronic lung disease, bronchopulmonary dysplasia, and pulmonary hypertension.
[e]Gastroesophageal reflux.
[f]Anemia, von Willebrand disease, Wolff-Parkinson-White syndrome, supraventricular tachycardia, hypertension, polycystic kidney disease, growth hormone deficiency, hypothyroidism, congenital adrenal hypoplasia.
[g]Audio, video, or apnea monitors.
*Statistically significant (α = 0.05).

Table 2. Comparison of pediatric epilepsy and control cohorts in degree and type of sleep disturbances reported for both parent and child; degree and type of parental fatigue also compared

Sleep scale	Control Mean (SD)	Epilepsy Mean (SD)	Adj. std. mean difference[a]	p-Value[b]
CSHQ total	41.10 (6.694)	48.25 (8.912)	0.419	<0.001*
Parasomnias	8.23 (1.601)	9.75 (2.214)	0.368	<0.001*
Night wakings	3.78 (1.216)	4.92 (1.819)	0.360	<0.001*
Sleep duration	3.43 (0.887)	4.31 (1.780)	0.319	<0.001*
Daytime sleepiness	10.76 (2.400)	12.49 (2.936)	0.307	<0.001*
Sleep onset delay	1.37 (0.647)	1.63 (0.946)	0.199	0.014*
Bedtime resistance	7.65 (2.475)	8.50 (2.943)	0.168	0.019*
Sleep disordered breathing	3.29 (0.770)	3.54 (1.005)	0.126	0.244
Anxiety	5.23 (1.640)	5.57 (1.802)	0.098	0.198
PSQI total	4.67 (3.217)	6.37 (3.495)	0.259	0.005*
Daytime dysfunction	0.67 (0.763)	1.07 (0.788)	0.265	0.003*
Habitual sleep efficacy	0.37 (0.803)	0.67 (0.987)	0.192	0.047*
Sleep latency	0.63 (0.754)	0.93 (0.973)	0.171	0.133
Subjective sleep quality	1.09 (0.737)	1.34 (0.830)	0.170	0.087
Use of sleep medication	0.11 (0.423)	0.33 (0.793)	0.142	0.119
Sleep disturbances	1.10 (0.496)	1.24 (0.528)	0.133	0.022*
Sleep duration	0.70 (0.952)	0.81 (0.867)	0.076	0.447
IFS total	24.93 (6.635)	30.00 (7.928)	0.347	<0.001*
Cognitive	8.00 (2.768)	10.39 (3.641)	0.372	<0.001*
Fatigue	4.50 (1.634)	5.54 (2.105)	0.295	0.001*
Energy	8.69 (2.182)	9.88 (2.663)	0.242	0.003*
Productivity	3.41 (1.338)	3.88 (1.423)	0.209	0.036*

Wilks Lambda p-value <0.001.
CSHQ, Children's Sleep Habits Questionnaire; PSQI, Pittsburgh Sleep Quality Index; IFS, Iowa Fatigue Scale.
[a]Adjusted standardized mean difference by multiple regression (covariates: age, sex).
[b]Multivariate analysis of covariance (MANCOVA) (dependent variables: sleep scores, fixed factor: epilepsy (y/n), covariates: age and sex).
*Statistically significant (α = 0.05).

were associated with room sharing and cosleeping behavior. Data on epilepsy covariates predictive of severe sleep scores and altered household sleeping arrangements are presented in Table 4. Current or lifetime AED polytherapy was associated with a high CSHQ score. None of the investigated epilepsy parameters predicted room sharing or cosleeping behavior.

Data on parent-perceived impact of their child's nocturnal seizures and the parent–child sleeping arrangement on his or her own sleep and fatigue are presented in Table 5. In response to the item, *Does your child having seizures at night impact your own sleep?*, 40.4% (38/94) endorsed always, frequently, or mostly. Furthermore, 44.0% (44/100) of epilepsy parents reported rarely or never feeling rested. Finally, 58.1% (34/62) and 61.7% (37/60) of parents described decreased sleep quality and/or quantity with room sharing and cosleeping, respectively.

Discussion

This questionnaire-based, case–control study demonstrated that pediatric epilepsy can deeply affect the sleep patterns and behaviors of both the affected child and the parents. Study investigators chose not to exclude control responses based on comorbidities (including those with the potential to impact sleep such as respiratory and nonepileptic neurologic disorders) or sleep medication use, so as to

Table 3. Associations between sleep parameters and epilepsy determinants as well as household sleeping arrangements

	Epilepsy versus control	Night seizures	E-Chess ≥14	Autism spectrum	Developmental delay	Room sharing	Co-sleeping
CSHQ total	•					•	•
Bedtime resistance	•					•	•
Sleep onset delay	•						
Sleep duration	•				•		•
Anxiety		•				•	•
Night wakings	•				•	•	•
Parasomnias	•					•	•
Sleep disordered breathing							
Daytime sleepiness	•					•	•
PSQI total	•	•					
Subjective sleep quality			•				
Sleep latency							
Sleep duration			•		•		
Habitual sleep efficacy	•				•		
Sleep disturbances		•					
Use of sleep medication				•			
Daytime dysfunction	•						
IFS total	•	•	•		•	•	
Cognitive	•	•	•			•	
Fatigue	•						
Energy	•			•	•		
Productivity	•				•	•	

CSHQ, Children's Sleep Habits Questionnaire; PSQI, Pittsburgh Sleep Quality Index; IFS, Iowa Fatigue Scale; E-Chess, Early Childhood Epilepsy Severity Scale.
• Statistically significant ($\alpha = 0.05$) as determined by independent-samples *t*-tests for the sleep score or subscore between the given pairs: epilepsy versus controls and within the epilepsy group, history of nocturnal seizures (yes/no), E-Chess ≥14 versus E-chess <14, autism spectrum disorders (yes/no), developmental delay (yes/no), room sharing (yes/no), and cosleeping (yes/no).

Table 4. Seizure semiology, chronobiology, and indices of severity for the full epilepsy cohort (A). Association between epilepsy covariates and severe child sleep dysfunction, parent sleep dysfunction, parent fatigue (B), parent-child room sharing, and cosleeping (C)

	A. Full cohort	B. CSHQ score ≥41	PSQI score ≥5	IFS score ≥35[a]	C. Room sharing	Cosleeping
Semiology[b]						
Tonic	53/104	0.013	0.024	0.047	0.043	0.552
Atonic	31/104	0.006	0.007	0.003*	0.046	0.130
Myoclonic	38/104	0.305	0.008	0.011	0.022	0.936
IS	28/104	0.021	0.641	0.209	0.496	0.269
Chronobiology[c]						
Nighttime	45/97	0.618	0.034	0.078	0.679	0.928
Sleep-wake	53/97	0.207	0.675	0.118	0.036	0.148
Severity[d]						
Age at sz onset ≤1 year	42/103	0.087	0.837	0.824	0.066	0.025
Current AEDs ≥2	53/105	<0.001*	0.687	0.509	0.425	0.552
Lifetime AEDs ≥3	39/105	0.005*	0.962	0.260	0.146	0.537
E-Chess score ≥14	27/105	0.012	0.249	0.023	0.831	0.492

IS, infantile spasms; sz, seizure.
*Statistically significant ($\alpha = 0.005$); reported p-values for Fisher's exact and Pearson's chi-square tests; covariates for which p-values were >0.05 for all six listed dependent variables, were excluded from the table.
[a]75% of primary care patients found to have scores of <35 (Hartz et al., 2003).
[b]Focal, tonic–clonic, and absence.
[c]Morning, daytime, evening.
[d]Seizure frequency (daily, weekly, monthly, yearly, lifetime), history of status epilepticus.

generate a control sample most representative of the general population, in which sleep problems and parent–child cosleeping are not uncommon. In a sleep comparison study of school-aged children from the United States and China, mean CSHQ total scores were 38.7 (SD 5.51) and 42.1 (SD 7.43), respectively (Liu et al., 2005). These mean scores

Table 5. Parent-perceived impact of their child's nocturnal seizures and sleeping arrangements on his or her own sleep and fatigue

Concerned about night seizure	68.6% (72/105)
Degree of concern[a]	6.70 (3.085)
Impact of seizure on sleep[b] (n = 94)	
Always	20.2%
Frequently	7.4%
Mostly	12.8%
Rarely	29.8%
Never	29.8%
Feel rested (n = 100)	
Always	2.0%
Frequently	19.0%
Mostly	35.0%
Rarely	34.0%
Never	10.0%
Impact of room sharing	
Sleep quality (n = 62)	
Increase	11.3%
Decrease	58.0%
No change	30.6%
Sleep quantity (n = 62)	
Increase	3.2%
Decrease	71.0%
No change	25.8%
Impact of cosleeping	
Sleep quality (n = 55)	
Increase	9.0%
Decrease	67.3%
No change	5.5%
Sleep quantity (n = 60)	
Increase	10.0%
Decrease	63.3%
No change	27.7%

[a]n = 70, 1–10 scale, 1 = I rarely worry, 10 = I worry every day, mean (standard deviation).
[b]Response to the question: Does your child having seizures at night impact your own sleep?

were consistent with that of our control population (41.10, SD 6.694). In one of the most comprehensive prior investigations of cosleeping within the general population, 493 Swiss children were followed over time from 3 months to 10 years of age. Results indicated that cosleeping occurred at rates of <10%, 38%, and 21% (≥1 night/week) for children ages <1, 4, and 8 years (Jenni et al., 2005). In an additional study within the U.S general population, the rate of parent–child cosleeping was reported as 24% (>1/week, children ages 2–3 years) and occurred more frequently in households of lower socioeconomic status (trend) and of ''nonwhite'' race ($p \leq 0.01$) (Madansky & Edelbrock, 1990). Our control population reported cosleeping at a similar rate of 20.8%.

The results described here further strengthen the connection between aberrant sleep and seizures (Rodriguez, 2007; Kothare & Kaleyias, 2010; Nunes, 2010; van Golde et al., 2011) and confirm an association between pediatric epilepsy severity and degree of sleep disturbance (Wirrell et al., 2005; Batista & Nunes, 2007; Ong et al., 2010). In this study, we found parasomnia and night wakening sleep domains among those most affected by pediatric epilepsy. Although parasomnias are common in childhood, seen in >80% of preschool-age children (Petit et al., 2007; Kotagal, 2008), a marked association with epilepsy has been described in many (Cortesi et al., 1999; Wirrell et al., 2005; Maganti et al., 2006; Byars et al., 2008; Chan et al., 2011) but not all (Stores et al., 1998) prior investigations. Mechanistically, hypotheses suggest epileptic discharges may lead to sleep fragmentation, facilitating the subsequent occurrence of parasomnias (Hoeppner et al., 1984; Zaiwalla & Stores, 1989; Cortesi et al., 1999; Kotagal & Yardi, 2008). A limited number of epilepsy covariates surfaced as potential predictors of sleep problems in children, predominantly AED polytherapy. Our results support this connection, although it is difficult to know if the AEDs are directly affecting sleep or if polytherapy is acting as a surrogate for epilepsy severity. The literature delineating the link between number of epilepsy therapeutics and sleep problems is discordant, supported by some (Batista & Nunes, 2007; Byars et al., 2008), whereas others have found no such association (Wirrell et al., 2005; Chan et al., 2011). In addition, we saw higher rates of sleep medication use within the epilepsy cohort. Specifically, melatonin was the dominant treatment reported, which has proven effective for sleep problems in children with refractory epilepsy (Elkhayat et al., 2010). Finally, it is important to note that nearly one fourth of our epilepsy cohort also had a diagnosis of autism spectrum disorder (ASD), a comorbidity in which sleep problems occur in 44–83% of children (Olivié, 2012).

To date, our clinical understanding of the effect of childhood epilepsy on parent and/or caregiver sleep is relatively limited. In other chronic pediatric diseases, specifically asthma and cystic fibrosis, parents may similarly experience greater sleep disruption as compared to control populations (Meltzer & Mindell, 2006; Yilmaz et al., 2008). In the setting of pediatric epilepsy, the results of Shaki et al. (39 parents of children with epilepsy and 42 controls using PSQI measures) paralleled our findings, with pediatric epilepsy conferring increased parental sleep dysfunction compared to controls. Contrary to this study, however, we also found that the degree of parental sleep dysfunction correlated with the child's seizure severity (Shaki et al., 2011). Our data suggest that daytime dysfunction and habitual sleep efficacy were the two parental sleep domains with the greatest divergence between the epilepsy and control cohorts. These two parameters may strongly contribute to overall quality of life for both parents and the household as a whole. In a study of 50 epilepsy parents, Cottrell and Khan (2005) found that parental sleep quality not only associated with the child's seizure frequency, but also with quality of life factors including the parent's level of depression, physical health, experience of pain, emotional well-being, and spousal relationship satisfaction. Our study represents one of the first to

assess parental fatigue in the setting of pediatric epilepsy. The results displayed a high degree of internal fidelity, as the epilepsy parents were more fatigued according to all four investigated domains (cognitive, fatigue, energy, and productivity). These data further quantify parameters that may profoundly impact individual and household quality of life.

Nocturnal seizures were associated with both increased parental sleep dysfunction and parental fatigue. The majority of parents reported strong concerns about their child's risk of having a seizure at night, many of whom attributed their own poor sleep quality to this concern. Nearly half of the epilepsy parents did not feel well rested. Despite the deep effect on parents, nocturnal seizures, apart from an increase in sleep anxiety, did not confer a similar risk of sleep dysfunction for the child. Prior studies, both in adults (Ekizoglu et al., 2011) and in children with epilepsy (Wirrell et al., 2005; Ong et al., 2010), also found nocturnal seizures to be independent of sleep dysfunction.

The relationship between child sleep problems and cosleeping in the general population has been explored in several prior investigations. In a study of Chinese school-aged children, Li et al. (2008) reported an increased probability of child sleep problems with cosleeping, by six of the eight CSHQ domains, most robustly in the areas of bedtime resistance and sleep anxiety. In a longitudinal study, Jenni et al. (2005) found night wakings were associated with cosleeping throughout development (except in 3-month-olds), whereas problems with bedtime resistance and sleep onset delay did not parallel cosleeping behavior with the same degree of consistency across age groups. In a cohort of U.S. preschoolers, cosleeping was associated with negative sleep patterns including irregular bedtimes, sleep onset delay, and increased night wakings. Behaviorally, in this same study individuals from the cosleeping group displayed decreased ''adaptability and rhythmicity'' by parental report. However, these behavioral observations were not confirmed by teacher report (Hayes et al., 2001). Prior studies have begun to characterize the effect of childhood seizures on household sleeping arrangements. Children with epilepsy more frequently go to their parents' bed during the night (Batista & Nunes, 2007), and as reported here, cosleeping occurs more frequently in epilepsy populations compared to healthy (Cortesi et al., 1999; Wirrell & Turner, 2001; Ong et al., 2010) and diabetic (Williams et al., 2000) controls.

Within the epilepsy population, parents are cosleeping in part as a response to their child's poor sleep, a functional solution to a household problem. Of interest, sleep scale data showed cosleeping to be independent of parental sleep disturbance. However, by subjective report, parents felt that their sleep quality and quantity decreased in the settings of both room sharing and/or cosleeping. This conclusive divergence, coupled with the observation that cosleeping was often initiated by the parent in epilepsy households, and almost exclusively by the child in control households, may in fact be capturing part of the complexity of the sleep seizure picture. Beyond child sleep disruption, multiple biopsychosocial factors, including parental fear, anxiety, and attachment, may influence these household sleeping arrangements (Williams et al., 2000). We submit that parents often fear for the safety of their child alone at night, fear missing a nocturnal seizure event, and may also fear sudden unexplained death in epilepsy (SUDEP). It seems, therefore, that parents are employing and modifying all the tools available—sound monitors, room sharing, and cosleeping—to maximize household sleep and to quell anxiety. Currently, there are no evidence-based guidelines for the prevention of SUDEP. A recent review describes behavioral prevention measures cited previously in the literature as conferring some degree of protection, including direct supervision, sound monitoring devises for awake caregivers, and frequent bed checks (Nashef et al., 1995; Langan et al., 2005; Devinsky, 2011). These interventions studied initially in residential care facilities, do not readily translate to the home.

This study was limited by the relatively low survey response rate and a statistically significant age difference between the two cohorts. The low response rate was likely due to the length of the survey as well as to the sensitive nature of the topic. This may have introduced a selection bias for families with higher degrees of sleep difficulties. The results of this study, not unlike many other epilepsy control studies, were confounded by the high rate of developmental delay and autism spectrum disorders in the epilepsy population. In addition, due to the large proportion of the epilepsy cohort with a genetic etiology, there may have been confounding variables affecting sleep behavior not measured in this study. Furthermore, given that the epilepsy cohort was seen at a tertiary referral center, our data may be skewed toward a more severe epilepsy population. Domains for future investigation include quality of sleep measured by objective polysomnographic features, parental depression and anxiety inventory, impact of epilepsy on sibling sleep, and psychosocial impact of parent fatigue on broader household function.

In conclusion, this study demonstrates the profound impact of epilepsy on sleep patterns and behaviors for the child and parent alike. In light of these findings, pediatric clinicians managing seizures must not only be attentive to the sleep problems frequently occurring in their patients, but also to those occurring in the parents. With a new epilepsy diagnosis, clinicians might provide sleep education and resources to families and provide guidance and support for household sleep solutions over the course of the child's clinical care. Furthermore, the results of this study call for improved epilepsy therapeutics and the development of innovative nocturnal seizure monitoring solutions and technologies.

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Disclosure

None of the authors has any conflict of interest to disclose.

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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