A STUDY ON THE SLEEP QUALITY IN PATIENTS WITH EPILEPSY AND THEIR CO-SLEEPING FAMILY MEMBERS

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Abstract:
Caregiver burden and disturbed sleep in patients with epilepsy (PWE) has been well established. Recent studies show that pediatric epilepsy significantly impacts sleep patterns for the child as well as the parents. Very few studies describe the sleep quality of family members of adult patients with epilepsy. Our study aimed to assess the sleep quality in co-sleeping family members of adult patients with epilepsy. This observational study was conducted at the Institute of Neurology, Madras Medical College, Chennai on patients with epilepsy attending the Neurology outpatient services. Demographic details were recorded and Pittsburg Sleep Quality Index (PSQI) was administered to the patients as well as their co-sleeping family members. To assess impact on the sleep of their children, Sleep Disturbances Scale for Children (SDSC) was used. We included 64 PWE (male-30, female-34) with mean age of 28.07 years (range-13 to 55). The mean duration of epilepsy was 6.92 years. 41 patients (64.06 per cent) co-slept with their family members in the same bed, 19 (29.68 per cent) slept in the same room and the rest slept alone. 17 (26.56 per cent) had co-sleeping children in the same room or bed whose SDSC showed mean T-scores of 59.94. Twenty seven patients (42.18 per cent) showed decreased sleep quality with PSQI scores more than 5. Interestingly, 58.33 per cent of the co-sleepers had PSQI scores more than 5, which however when compared with patients with epilepsy was not statistically significant. The proximity of the epileptic patient to the co-sleeper during sleep time did not show any statistical significance. Significant disturbances in sleep quality of PWE and their co-sleeping family members have been noted and may be an important issue to be addressed while managing patients with epilepsy and their family.

Keyword: sleep, epilepsy, co-sleeping, PSQI, quality of sleep

Introduction:
Epilepsy is a chronic neurological illness requiring long-term medical management and follow-up. Not only does the stigma of a diagnosis of epilepsy affect the patient’s...
subjective sense of well-being, it also shows its profound effects on the social and mental status of their caregivers. Sleep is a poorly understood complex physiologic process requiring proper functioning of multiple brain foci. It is not simply an absence of consciousness, but is an actively generated state. Studies have demonstrated the complex bidirectional relationship between sleep and epilepsy. Sleep deprivation can provoke seizures, whereas some epilepsy disorders manifest most depending on the different stages of sleep. Patients with epilepsy also suffer from various co-existing sleep disorders like obstructive sleep apneas, sleep disruption, nocturnal awakenings and excessive daytime sleepiness. Caregiver burden in epilepsy not only impacts the physical, mental and social wellbeing of the apparently normal caregiver, but also shows its adverse impact on the sleep of the caregiver. In addition to the parental stress that it produces, recent studies show that pediatric epilepsy significantly impacts sleep patterns for the child as well as the parents. Very few studies describe the sleep quality of family members of adult patients with epilepsy. This study aimed to demonstrate the magnitude of the impairment of sleep quality in family members co-sleeping with epileptic patients.

**Methods:** Aim: To study the quality of sleep in patients with epilepsy and their co-sleeping family members including their children aged 6 years and above.

Materials and methods: Type of study-A cross-sectional descriptive study was done using standard questionnaires: Pittsburgh Sleep Quality Index (PSQI) and Sleep Disturbances Scale for Children (SDSC). Subjects: 64 patients with epilepsy (PWE) attending the Neurology outpatient services at the Institute of Neurology, Madras Medical College, Chennai, were randomly included in this observational study after obtaining informed consent for participation in the study. Demographic details were recorded and Pittsburgh Sleep Quality Index (PSQI) was administered to the patients as well as their co-sleeping family members. Sleep Disturbances Scale for Children (SDSC) was used to assess impact on the sleep of their children. Strict confidentiality of the data obtained was ensured. Pittsburgh Sleep Quality Index (PSQI): It is a self-rated questionnaire which assesses sleep quality and disturbances in sleep in the preceding month. There are nineteen individual items used to generate seven "component" scores: subjective sleep quality (SLP QUAL), sleep latency (LATEN), sleep duration (DURAT), habitual sleep efficiency (HSE), sleep disturbances (DISTB), use of sleeping medication (MEDS), and daytime dysfunction (DAYDYS). Each component has a minimum score of '0' and a maximum score of '3'. The sum of scores for these seven components gives the global PSQI score. A global PSQI score greater than 5 is indicative of poor sleep quality. PSQI TOTAL = SLP QUAL + LATEN + DURAT + HSE + DISTB + MEDS + DAYDYS MINIMUM SCORE = 0 (BETTER); MAXIMUM SCORE = 21 (WORSE) Sleep Disturbances Scale for Children (SDSC): It is a parent-reported 26 item Likert-type (5 point) rating scale used to assess sleep disorders in children and includes 6 sleep subscales or disorders: disorders in initiating and maintaining sleep (DIMS), sleep breathing disorders (SBD), disorders of arousal (DA), sleep-wake transition disorders (SWTD), disorders of excessive somnolence (DES) and sleep hyperhydrosis (SHY). The total score is the sum of the 26 items retained with a range from 26 to 130. A total cut off of 39 had the best diagnostic confidence.
in the construction of this sleep disturbances scale in children. Higher scores indicate greater sleep disturbances.

**Results:**

**Age distribution of patients and co-sleepers:**

**Age distribution of patients and co-sleeping family members**

Of the 64 patients with epilepsy enrolled in the study, 21 (32.81%) belonged to the age group between 13-20 years, another 21 patients (32.81%) belonged to the age group between 21-30 years, and the rest (34.38%) were aged between 31-60 years. The mean age was 28.07± 11.19 years (range-13 to 55). A total of 77 co-sleepers, including 17 children of age 6-12 years, were enrolled along with the patients. Of the 60 co-sleeping adults, 9 (15%) were of age group between 13-20 years, 20 (33.33%) were of age group between 21-30 years, and the rest (51.66%) were between 31-60 years.

**Sex distribution and seizure semiology:**

Of the 64 patients enrolled, 30 patients (46.85%) were male and 34 patients were female. The semiology of seizures were absence seizures in 2 patients, complex partial in 4 patients, simple partial seizures in 28 patients and generalised tonic clonic seizures in 30 patients. Five patients suffered from nocturnal seizures. Of the 64 PWE, 12 patients had symptomatic epilepsy and the rest fifty two patients had idiopathic epilepsy.

**Frequency, duration, investigative profile and antiepileptic therapy:**

Twenty six patients had suffered more than one seizure, 15 had suffered a single seizure, while 23 had remained seizure free in the preceding month. The mean duration of epilepsy was 6.92± 5.68 years. In those subjects, thirty two patients had a duration of epilepsy of - < 5 years, 24 patients had duration of 5 to 10 years, while the remaining eight had duration > 10 years. Eleven patients had neuroimaging abnormalities. Nineteen had abnormal EEG records while the rest showed no abnormality in the EEG. Eighteen patients were on monotherapy and the rest on polytherapy. Of those on polytherapy, 19 were on two drugs, 26 were on three drugs, and one patient was on four antiepileptics.

**Co sleeping members:**

**Co-sleeping children**

Most of the patients (93.75%) slept with their spouse or parent in their home. Four patients (6.25%) slept alone. 17 patients (26.56%) had their child also co-sleeping with them in same room/bed.

**Pattern of co-sleeping:**
Of the pattern of co-sleeping with family members in their home, 41 patients (64.06%) slept in the same bed with the family member, 19 patients (29.68%) slept in the same room, while 4 patients slept alone.

**Pattern of co-sleeping**

Sleep quality of patients and adult co-sleepers:
Sleep quality of patients and their co-sleeping family members:
Of the 64 patients with epilepsy, twenty seven patients (42.18%) showed decreased sleep quality with PSQI scores > 5. Interestingly, a greater proportion of co-sleepers appeared to have impaired sleep quality. Out of the 60 subjects co-sleeping with the PWE, 35 (58.33%) of them had PSQI scores > 5, which however, when compared with patients with epilepsy was not statistically significant (p=0.43). The proximity of the epileptic patient to the co-sleeper during sleep time and impairment in sleep quality also did not show any statistical significance. Significant disturbances in sleep quality of PWE and their co-sleeping family members have been noted and may be an important issue to be addressed while managing patients with epilepsy and their family.

The sleep quality of their co-sleeping children assessed using SDSC scores showed mean T-scores of 59.94± 4.05 indicating increased sleep disturbances in the children. Statistical significance could not be assessed due to the small sample size of co-sleeping children.

**Discussion and conclusions:**
Poor sleep quality defined by an increased global PSQI scores has been noted in 6.3% of healthy individuals in a hospital based study from South India. Although incidence of pediatric sleep disorders in normal Indian pediatric population using questionnaires like Pediatric Sleep Questionnaire, Children Sleep Habits Questionnaire and BEARS screening tool have been reported, no published data regarding the SDSC scores in Indian children are available till now. Most of the available literature focuses on the quality of sleep in patients with epilepsy alone. There is scanty information on the sleep of their caregivers. Not only does the impaired sleep of these patients with epilepsy adversely affect their own lifestyles, it shows its unfavorable ramifications in the sleep patterns and well-being of their caregivers also. This study has highlighted the prevalence of sleep disturbances in patients with epilepsy as well as their co-sleeping family members inclusive of their children. The drawback in this study is the lack of objective data regarding the quality of life or seizure severity of these patients, which can also adversely impact the quality of sleep of patients as well as the caregivers. Further studies with larger sample sizes can help to understand the perceived as well as actual impact of the sleep patterns of PWE on their caregivers’ sleep. There is an urgent need to address the co-existing sleep disorders in PWE as well as that of the caregivers in the family including the management of the medical and social problems faced by them, which also needs to be interwoven carefully into the holistic care.
rendered to patients with epilepsy.

References:


Annexures:

Pittsburg Sleep Quality Index (PSQI):

1 During the past month, what time have you usually gone to bed at night? BED TIME __________

2 During the past month, how long (in minutes) has it usually taken you to fall asleep each night? NUMBER OF MINUTES __________

3 During the past month, what time have you usually gotten up in the morning? GETTING UP TIME __________

4 During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.) HOURS OF SLEEP PER NIGHT __________
For each of the remaining questions, check the one best response. Please answer all questions.

5. During the past month, how often have you had trouble sleeping because you . . .
   a) Cannot get to sleep within 30 minutes  
      Not during the Less than Once or twice  
      Three or more past month _____ once a week_____ a week_____ times a week_____  
   b) Wake up in the middle of the night or early morning  
      Not during the Less than Once or twice  
      Three or more past month_____ once a week_____ a week_____ times a week_____  
   c) Cannot breathe comfortably  
      Not during the Less than Once or twice  
      Three or more past month_____ once a week_____ a week_____ times a week_____  
   d) Cough or snore loudly  
      Not during the Less than Once or twice  
      Three or more past month_____ once a week_____ a week_____ times a week_____  
   e) Feel too cold  
      Not during the Less than Once or twice  
      Three or more past month_____ once a week_____ a week_____ times a week_____  
   f) Feel too hot  
      Not during the Less than Once or twice  
      Three or more past month_____ once a week_____ a week_____ times a week_____  
   g) Had bad dreams  
      Not during the Less than Once or twice  
      Three or more past month_____ once a week_____ a week_____ times a week_____  
   h) Other reason(s), please describe____________________________

How often during the past month have you had trouble sleeping because of this?

6. During the past month, how would you rate your sleep quality overall?
   Very good ___________ Fairly good ___________ Fairly bad ___________ Very bad ___________

7. During the past month, how often have you taken medicine to help you sleep (prescribed or "over the counter")?
   Not during the Less than Once or twice  
   Three or more past month_____ once a week_____ a week_____ times a week_____  

8. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?
   Not during the Less than Once or twice  
   Three or more past month_____ once a week_____ a week_____ times a week_____  

9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?
   No problem at all ___________ Only a very slight problem ___________ Somewhat of a problem ________ A very big problem ________

Do you have a bed partner or room mate?
   No bed partner or room mate ___________  
   Partner/room mate in other room ___________  
   Partner in same room, but not same bed ___________  
   Partner in same bed ___________  

If you have a room mate or bed partner, ask him/her how often in the past month you have had . . .
a) Loud snoring
Not during the Less than Once or twice
Three or more past month _____ once a
week_____ a week______ times a
week_____ b) Long pauses between
breaths while asleep
Not during the Less than Once or twice
Three or more past month _____ once a
week_____ a week______ times a
week_____ c) Legs twitching or jerking
while you sleep
Not during the Less than Once or twice
Three or more past month _____ once a
week_____ a week______ times a
week_____ d) Episodes of disorientation or
confusion during sleep
Not during the Less than Once or twice
Three or more past month _____ once a
week_____ a week______ times a
week_____ e) Other restlessness while
you sleep; please describe_____________________________
Not during the Less than Once or twice
Three or more past month _____ once a
week_____ a week______ times a
week_____