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Quality of life and its relation with sleep habits of children with epilepsy from Eastern India

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Abstract:

BACKGROUND: Epilepsy is one of the most common chronic disorders of the central nervous system. The quality of life of children with epilepsy is influenced by various factors including their sleep. To assess the quality of life and sleep habits among children with epilepsy and to determine the association of QOL and sleep habits, with sociodemographic and clinical variables.

MATERIALS AND METHODS: A cross-sectional study was carried out among 50 epileptic children aged 4–18 years, recruited using a convenient sampling technique from the IPDs and OPDs of the Paediatrics department of a tertiary care hospital in Eastern India. The data were collected using QOLCE-16 and CSHQ from parents of children with epilepsy. The collected data were analyzed using descriptive and inferential statistics such as ANOVA and Pearson correlation test.

RESULTS: The overall mean score of QOL was 50.78 ± 17.98 , with the cognitive domain having the highest mean score of 65.50 ± 27.79 and the social domain having the lowest mean score of 29.87 ± 22.81 . The overall mean sleep score was found to be 56.98 ± 8.13 . Daytime sleepiness, parasomnias, and bedtime resistance were found to be frequent sleep problems in children with epilepsy. There was a significant negative correlation between QOL and sleep disturbances in children with epilepsy ($r = -0.65$, $P \leq 0.001$).

CONCLUSION: The QOL of children with epilepsy should be improved to reduce the effect of sleep problems. Epilepsy children should be treated appropriately with due focus on medication compliance as it was found to be one of the determinants in improving their QOL.

Keywords:

Children, epilepsy, quality of life, sleep habits

Introduction

Children are more likely to have various health problems during childhood, but for most children these problems are mild, and they do not interfere with their daily life and development. However, for some children, chronic health conditions affect everyday life throughout childhood. Chronic disease in children, as the term indicates, has a negative impact on various domains of life. Thus, they create an unanticipated crisis with consequences enduring into adulthood.^[1] Studies showed that 13–27% of children

are affected by various chronic disease conditions.^[2] Epilepsy was one of the first brain disorders to be explained. The normal brain is constantly generating electrical rhythms in an orderly way. In epilepsy, this order is disrupted by some neurons discharging signals inappropriately. Many superstitions and prejudices had shaped the strange behavior of some seizures through ages^[3] and it is the most stigmatizing disease leading to a negative impact on the quality of life of people with epilepsy.^[4] There are epileptic and nonepileptic factors including the age of onset, type of seizure duration of disease, and the number of antiepileptic

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drugs, which could adversely affect health-related quality of life among children with epilepsy.^[5] The studies on children and adults indicate relative and progressive compromising of quality of life not only because of physical and mental downshift but also the social behavior of others toward epileptic children.^[6]

As the quality of life matters in epilepsy, adequate sleep also plays a vital role in the quality of life in epileptic children. Sleep quality is more essential for performance and recovery from illness rather than sleep quantity.^[7] The increased maternal emotional symptoms and poor parental sleep quality are also linked with sleep problems in children with epilepsy.^[8] Even without medical conditions, sleep disturbances can be seen in early childhood associated with behavioral and psychiatric problems.^[7] Epilepsy can worsen sleep-related disorders, and at the same time, parasomnias can deteriorate epilepsy.^[9] Sleep disorders are more common in epileptic children along with other comorbidities associated with epilepsy. Unfortunately, disturbed sleep habits for children and their caregivers are commonly seen as associated with epilepsy and it is a commonly neglected behavioral problem of epileptic children.^[10] Sleep deprivation is one of the aggravating factors for epileptic events, and thus, this poor sleep makes epilepsy control difficult.^[11] Sleep problems not only predispose children to mood, cognitive, and behavioral impairments but also have a significant impact on physical health.^[12] Both epilepsy and sleep problems are depriving the quality of life across age groups and negatively affect children's behavior and neuropsychological functioning.^[13] Many studies were conducted on the quality of life of epileptic children and other variables, but no extensive information was found on quality of life and its association with children's sleep habits. As most anti-epileptic drugs taken by children have adverse effects on children's sleep patterns it is significant to know regarding both variables. Hence, the current study was undertaken to explore the quality of life and sleep habits among children with epilepsy.

Materials and Methods

Study design and setting

The present adopted a quantitative approach using a cross-sectional design to assess the quality of life and sleep habits in children with epilepsy. The setting of the present study was in the Epilepsy clinic of Psychiatry OPD, Paediatric OPD as well as Paediatric inpatient department at AIIMS Bhubaneswar. The epilepsy clinic used to open every Monday for a week and around 20 children with epilepsy used to attend the clinic.

Study participants and sampling

The participants were the children with epilepsy seeking treatment in the current setting and a total of 50 participants

were selected by convenient sampling technique fulfilling the inclusion criteria of children diagnosed with epilepsy at least for 6 months, aged between 4 and 18 years, and excluded those children with epilepsy associated with other comorbidities, developmental conditions such as mental retardation, autism, developmental delay, ADHD, or any other childhood psychiatric conditions, etc., attending the setup.

Data collection tool and technique

The children were surveyed using the validated QOLCE-16 (Quality of Life in Childhood Epilepsy Questionnaire) and CSHQ (Children's Sleep Questionnaire) tools. Children diagnosed with epilepsy at least 6 months, aged between 4 and 18, were included in the study. Those children with epilepsy associated with other comorbidities, developmental conditions, or any other childhood psychiatric conditions, and whose primary caregivers who are not able to understand English/Odia were excluded from the study. QOLCE-16 with four subscales covering four domains of life function: cognitive functioning (four items), emotional functioning (four items), social functioning (four items), and physical functioning (four items) was used to assess the quality of life. CSHQ with 33 items named under the domains of bedtime resistance (six items), sleep onset delay (one item), sleep duration (three items), sleep anxiety (four items), walking during the night (three items), parasomnias (seven items), sleep-disordered breathing (three items), and daytime sleepiness (eight items) was used to assess the sleep habits in children with epilepsy. Permission to use the tools was obtained from respective authors.

Ethical consideration

The eligible parents of children with epilepsy were asked to complete the Questionnaire after obtaining written consent. Ethical permission was obtained from the Institute Ethical Committee of AIIMS Bhubaneswar (IEC/AIIMS BBSR/Nursing/2019-20/08).

Data analysis

The collected data were arranged, coded, tabulated, analyzed, categorized, summarized presented using both descriptive and inferential statistics. In descriptive statistics, the frequency, percentage, mean, and standard deviation were used and in inferential statistics t test, ANOVA, and Pearson correlation coefficients were used.

Results

The mean age of children was 8.3 ± 3.2 . Among the children who participated, more than half of them (60%) were males and 40% were females, 58% of them had primary education, and half of them (50%) were in second birth order. More than half of the children resided

in rural areas (68%). More than 50% of the children had suffered from epilepsy for more than one year. More than three-fourth (78%) of them had no family history of seizures. Most of them were on monotherapy (52%) for epilepsy and 90% of the children were regular in taking prescribed medications. Half of them (50%) had complex partial seizures, 34% had generalized seizures, whereas 12% and 4% of the children had simple partial and other types of seizures, respectively.

The mean score of overall QOL of children with epilepsy was 50.78 ± 17.98 with a cognitive domain of 65.50 ± 27.79 , an emotional domain of 54.87 ± 27.29 , a social domain of 29.87 ± 22.81 , and the physical domain of 52.87 ± 24 [Table 1]. The total mean sleep habit score was 52.87 ± 24.39 with bedtime resistance with a mean of 8.24 ± 1.77 , sleep onset delay of 1.98 ± 0.77 , sleep duration of 4.80 ± 1.93 , sleep anxiety of 7.58 ± 2.46 , night-waking of 5.08 ± 1.83 , parasomnias of 9.70 ± 2.30 , sleep-disordered breathing of 4.50 ± 1.89 , and daytime sleepiness of 15.10 ± 3.76 [Table 2]. There was a significant association between medication compliance and QOL in children with epilepsy ($F = 3.077$, $P = 0.03$). Also, the study revealed that the number of siblings had a significant association with QOL in children with epilepsy ($t = 2.72$, $P = 0.008$) Multiple linear regression analysis revealed medication compliance was the significantly predicted QOL among children with epilepsy. Fifteen percent of the QOL score was predicted by medication compliance keeping the number of siblings constant ($\beta = -17.5$, $P = 0.008$) [Table 3]. There was a significant relationship between the type of seizure and the sleep habits of children with epilepsy ($F = 3.65$, $P = 0.0192$).

There was a moderate negative significant ($r = -0.652$, $P < 0.001$) correlation between QOL and sleep habits [Figure 1] which means that as the QOL score of

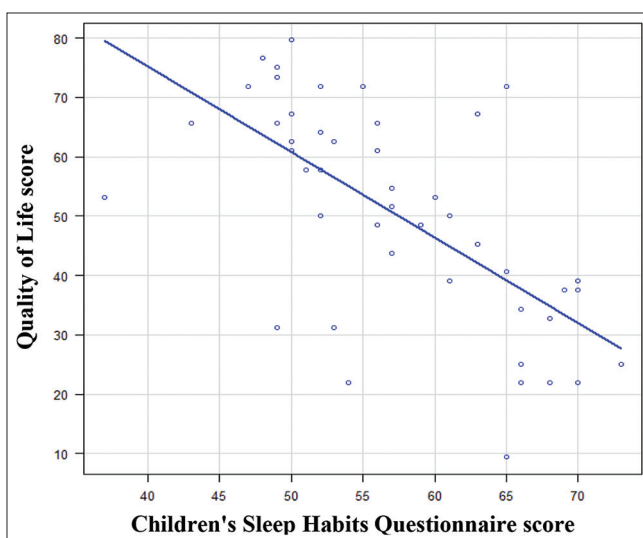


Figure 1: Correlation between QOL and sleep habits in children with epilepsy

children with epilepsy increases, sleep problem decreases. The sleeping habit significantly predicted QOL of children with epilepsy ($\beta = -0.29$, $P \leq 0.0001$). For every unit increase in QOL score, the average sleep score decreases by -0.29 and 43% of the variance in sleep score [Table 4].

Discussion

Sociodemographic and clinical characteristics of children with epilepsy

The present study had children with epilepsy between the age group of 4 and 18 years. The mean age of children in the present study was 8.3 ± 3.2 years. In par to this, the mean age of children with epilepsy was 8.75 ± 3.6 ^[13] and 7.84 ± 2.38 .^[14] More than half of the children were male (60%) in the present study. Similar study findings showed that male children were more in number compared to females among children with epilepsy.^[13,14] In the present study, 78% of children did not have a

Table 1: Mean and standard deviation of quality of life domains score among children with epilepsy (n=50)

QOL Domains	Mean±SD
Cognitive domain	65.50±27.79
Emotional domain	54.87±27.29
Social domain	29.87±22.81
Physical domain	52.87±24.39
Total QOL mean score	50.78±17.98

Table 2: Mean and standard deviation of sleep habits among children with epilepsy (n=50)

Sleep habit domains	Mean±SD
Bedtime resistance	8.24±1.77
Sleep onset delay	1.98±0.77
Sleep duration	4.80±1.93
Sleep anxiety	7.58±2.46
Night waking	5.08±1.83
Parasomnias	9.70±2.30
Sleep-disordered breathing	4.50±1.89
Daytime sleepiness	15.10±3.76
Total	56.98±8.13

Table 3: Sociodemographic and clinical variables predicting quality of life (n=50)

Outcome variables	β -coefficient	Standard error	t	P	R ²
Number of siblings	-4.4	2.6	-1.69	0.008*	0.15
Medication compliance	-17.5	8.1	-2.1		

*P significant at the level <0.05, multiple regression analysis model

Table 4: Predictor of sleep habits on quality of life in children with epilepsy (n=50)

Outcome variables	β -coefficient	Standard error	t	P	R ²
QOL	-0.29	0.04	-5.962	<0.0001*	0.43

*P significant at the level <0.05, linear regression analysis model

family history of epilepsy. Consistent with this, 90% of children never had a family history of epilepsy.^[15] In contrast to this, 69.23% of children were having a family history of epilepsy.^[14] Half of the children had a complex partial seizure in the present study. Consistent with this Rozensztrauch A and Koltuniuk A. showed as more children (56.9%) had complex partial seizures.^[13] In contrast to this, other studies showed as generalized tonic-clonic seizures were common in children with epilepsy.^[14,15] In the present study, 52% of children were taken one anti-epileptic drug. In par with this, other studies showed as most of the children were receiving monotherapy.^[13-15]

Quality of life of children with epilepsy

The study revealed that the mean score of overall QOL of children with epilepsy was 50.7 ± 17.9 which was consistent with a study conducted in Telangana, India, with a mean score of 46.8 ± 10.9 .^[14] In this study, social domain was highly affected with the lowest mean score of 29.8 ± 22.8 , and the cognitive domain was least affected with the highest mean score of 65.5 ± 27.7 , which was consistent with a study finding conducted in Poland which revealed that children with epilepsy had a compromised quality of life in psychological, social, and behavioral functioning.^[13] Contradict to this, Riechmann *et al.*^[16] showed that children with epilepsy had a more compromised QOL in the cognitive domain with the least mean score of 48.4 ± 22.74 (overall mean QOL score of 62.6 ± 21.32).

Sleep habits in children with epilepsy

The overall sleep score of the study was 56.98 ± 8.13 which was consistent with the study conducted by Dehghani *et al.*^[7] to assess the relationship between the severity of epilepsy and sleep disorder in epileptic children in Hamadan, Western Iran, with a mean score of 55.08 ± 6.71 . Daytime sleepiness, parasomnias, and bedtime resistance were found to be the major sleep problems of children with epilepsy in the study with mean scores of 15.10 ± 3.76 , 9.70 ± 2.30 , 8.24 ± 1.77 , respectively, which was similar to a study done by Oyegbile-Chidi *et al.*^[17] to assess the relationship between sleep problems and neuropsychological functioning in children with first-recognized seizures wherein bedtime difficulties, daytime somnolence, and parasomnias were the most frequent sleep problems. Ekinci *et al.*^[18] in the study conducted in Turkey revealed that daytime sleepiness was the one with the highest mean score of 14.03 ± 2.74 , indicating that it was the major sleep problem in children with epilepsy.

Association between QOL, sleep habits, and sociodemographic, clinical variables of children with epilepsy

The study showed that regularity with taking prescribed

medication was a significant predictor of QOL. That is, it was found that regularity in taking prescribed medications had a higher QOL score. Consistent with this, the study conducted by Nagabushana D showed as poor adherence to the antiepileptic drug had a significantly lower total QOL score.^[19] The present study also showed that children with epilepsy having one sibling had a better quality of life (60.82 ± 12.16). The study conducted by Michelle Webster illustrated that the siblings were contributing a major part to for caring their brothers and sisters with epilepsy and further developed the alert assistant concept.^[20] The present study showed that the type of seizure was significantly associated with sleep habits which means those who had simple partial seizures had more sleep problems. In contrast to this, some studies showed that the type of seizure was not significantly associated with sleep habits among children with epilepsy.^[17,18,21]

Correlation between QOL and sleep habits in children with epilepsy

The study revealed that there was a moderate negative significant ($r = -0.652$, $P \leq 0.001$) correlation between QOL and sleep habits in children with epilepsy which was consistent with the study conducted by Oyegbile-Chidi *et al.*^[17] which showed that there were more sleep problems in children with epilepsy and compromised sleep affected health as well as behavioral outcomes.

Limitations and Recommendations

The current study helped to identify the quality of life and sleep habits and associated clinical variables of children with epilepsy. Also, the predictors of quality of life and sleep habits are observed. The limitation was that parent-rated QOL scores and sleep scores may be different from that of children's experience in quality of life domains and sleep.

Conclusion

The study found that there was a significant correlation between QOL and sleep habits among children with epilepsy. The study also found that QOL and sleep habits were associated with sociodemographic and clinical variables among children with epilepsy including the regularity of taking prescribed medications, the number of siblings in the family, and the type of seizure. Educating parents on regular drug intake and improving sleep hygiene would improve the quality of life and sleep habits among children with epilepsy.

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Conflicts of interest

There are no conflicts of interest.

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