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ORIGINAL ARTICLE

QUALITY OF LIFE OF EPILEPTIC CHILDREN AT THE GYNAECO-OBSTETRIC AND PEDIATRIC HOSPITAL IN YAOUNDE, CAMEROON

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ABSTRACT

Aim: To evaluate the quality of life of epileptic children.

Methods and Material: This descriptive cross-sectional study was undertaken from 1st January 2014 to 1st May 2014 in children aged 3-16 years with epilepsy who followed up in the pediatric neurology unit of the Yaounde Gynaeco-Obstetrics and Pediatric Hospital in Yaounde in Cameroon. Parents responded to the quality of life questionnaire for children with epilepsy,

Results: Eighty-six patients with a mean age of 8.8 ± 4.2 years were included in the study. Epilepsy was associated with poor quality of life in 18 (20.9%) patients and was mainly in children with non-idiopathic generalized epilepsy, behavioral disorders, and cognitive deficits. Social, behavioral, cognitive and depressive disorders were noted in 43 (50%), 17 (19.8%), 23 (26.7%) and 55 (63.9%), respectively. In 17 (19.8%) children, clinical examination was abnormal. Twenty (23%) children were not attending school.

Conclusion: Epileptic children have a decline in their quality of life, and this is multifactorial, and controlling epileptic seizures alone does not appear to be a sufficient factor to improve the quality of life of these children.

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quality of life, epileptic children, hyperactivity, attention, anxiety, depression, sociability

Introduction

Epilepsy is the most common chronic neurological disorder in children.[1,2] The reported prevalence of epilepsy in children ranges from 3.6 to 4.2 per 1000 children in developed countries.[3] In literature, it is recognized that almost half of the cases of epilepsy occur before the age of 15 years. Paradoxically, the number of studies on epileptic children remains low.[4,5,6] The management of epilepsy has been focused on controlling seizures and reducing seizure frequency as a primary goal of successful treatment. It has been observed that epileptic patients have a higher risk of physical, social, academic and psychosocial difficulties than healthy children.[7] Quality of life is a particularly important health tool used in children with epilepsy.[8] Few studies have been conducted on the quality of life of epileptic children. We conducted this study to assess the quality of life of children with epilepsy in order to provide a foundation for the comprehensive treatment program for children with epilepsy and their families.

Methods & Materials

This descriptive cross-sectional study was conducted in the pediatric neurology unit of the Yaoundé Gynaeco-Obstetric and Pediatric Hospital from 1st January 2014 to 1st May 2014. Eighty-six children with epilepsy aged 3 to 16 years were included in the study. Epilepsy was confirmed according to the 1989 International Classification of Epilepsies and Epileptic Syndromes.[9] Patients with epilepsy in progressive encephalopathy or with any chronic disease such as asthma, diabetes mellitus and sickle cell disease were excluded from the study. Data collected from the medical files included: age of onset of the epilepsy, type of epilepsy such as generalized non-idiopathic epilepsy, generalized or partial idiopathic epilepsy, non-idiopathic partial epilepsy and unclassified epilepsy[9], etiology, seizure frequency, number of antiepileptic drugs, and presence of learning and behavioral difficulties.

Parents responded to quality of life questionnaire for children with epilepsy, and this included: A general questionnaire including socio-demographic data (parental marital status, parental occupation, parents' level of education), education, presence of difficulties (academic, memory, attention, language, behavior and slowness), rehabilitation treatment and therapies, the degree of satisfaction with medical care and information, education and social support received. It also included a short scale of quality of life, adapted from Herranz and Casas[10], concerning the child's autonomy, behavior, learning, social relations and an appreciation of the quality of life of the child, a scale exploring the impact of the disease and its treatment on the child, parents and family[11], a behavioral questionnaire (hyperactivity/attention, anxiety/depression and sociability)[12-14], and, a questionnaire to assess the cognitive difficulties of

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the child.

Interpretation of data: In the quality-of-life scale, each item was associated with five possible answers with a score of 1 to 5 so that the overall score of this scale ranged from 5 to 25. A score below 15 corresponded to poor quality of life and more than 15 a good quality of life. For the five other scales, each item was associated with three possible answers, with the scores assigned to each of the responses ranging from 0 to 2. The impact of the disease included 23 items and was scored from 0 to 46. The behavioral score (hyperactivity/attention) consisted of 12 items scored from 0 to 24, that of depression/anxiety, had 10 items scored from 0 to 20. The sociability score included 8 items scored from 0 to 16. For the overall quality of life and sociability scales, the higher the score, the higher the quality of life and the better the sociability. For the other items (behavior, anxiety, cognition, and impact on parents), the higher the score, the more severe the disorder.

Parents gave their written informed consent to participate in the study and the questionnaires were given to them to fill. The study was approved by the Institutional Research Ethics Committee for Human Health of the Yaounde Gynaeco-Obstetric and Pediatric Hospital.

Statistical analysis

Statistical analysis was performed by the SPSS 17.0 software. Factor analysis was performed for each scale in order to check whether the quality of life scores had good internal consistency. The impact of age, education, and the characteristics of epilepsy on the different dimensions of quality of life were examined using univariate analysis (t-test, ANOVA, correlation of Pearson) or multivariate (regression line). A value of $p < 0.05$ was considered statistically significant.

Table 1. Population and characteristics of epilepsy

	Idiopathic epilepsy (n=28)	Non-idiopathic generalized epilepsy (n=15)	Non-idiopathic partial epilepsy (n=43)	P value	Total number of patients (n=86)
Age (years)	10.5 ± 4.7	5.9 ± 2.4	8.7 ± 3.8	0.002	8.8 ± 4.2
Age of onset of seizures (years)	6.3 ± 4.7	0.7 ± 1.6	3.7 ± 3.1	0.000	4.02 ± 3.9
Gender Boys (%) Girls (%)	 15 (53.6) 13 (46.4)	 9 (60.0) 6 (40.0)	 25 (58.1) 18 (41.9)		 49 (57.0) 37 (43.0)
Number of antiepileptic drugs	1.3 ± 0.6	1.6 ± 0.6	1.2 ± 0.4	0.036	1.3 ± 0.5
Frequency of seizures	1.8 ± 0.8	1.8 ± 1.3	1.6 ± 0.9	0.711	1.7 ± 0.9
Normal schooling (%)	82.1	46.7	83.7		76.7
Presence of learning disorders (%)	35.7	33.3	53.5		45.3
Attention disorders (%)	21.4	13.3	20.9		19.8
Memory disorders (%)	25.0	13.3	20.9		20.9
Language disorders (%)	7.1	20.0	11.6		11.6
Rehabilitation (%)	10.7	66.7	27.9	<0.001	29.1
Psychological support (%)	0.0	6.7	0.0		1.2
Tutoring (%)	7.1	6.7	7.0		8.1
Speech Therapy (%)	3.6	6.7	2.3		3.5
Physiotherapy (%)	0.0	53.3	18.7	<0.01	18.6

Results

Characteristics of the patients

The demographic data of epilepsy in these children in given in Table 1. The mean age was 8.8 ± 4.2 years. Twenty- nine (33.7%) children were in the age group of 3 to 6 years, 33 (38.4%) 7 to 11 years and 24 (27.9%) in the age group of 12 to 16 years. The etiology was known in 24 (27.9%) of the patients with 7 (8.1%) due to cerebral palsy, 6 (6.9%) due to sequelae of status epilepticus, 5 (5.8%) due to perinatal asphyxia and 4 (4.6%) due to sequelae of meningitis and 1 (1.2%) each due to kernicterus and electrocution respectively. Clinical examination was abnormal in 17 (19.8%) of children with spastic quadriparesis in 9 (10.5%), hemiplegia or hemiparesis in 2 (2.3%), psychomotor retardation in 4 (4.6%), deafness in 1 (1.2%) and choreoathetosis in 1 (1.2%). In the last 12 months preceding our survey, 44 (51.2%) of children had no seizures, 39 (45.3%) had at least one seizure per trimester, and 3 (3.5%) children had had at least one seizure in the past month. The number of antiepileptic drugs used by children ranged from one to four during the study. Monotherapy was used in 65 (75.6%) of children, 39 (60%) of whom were on carbamazepine, 25 (38.5%) on sodium valproate, and 1 (1.5%) on lamotrigine, two drugs were prescribed in 19 (22.1%), and only 2 (2.4%) children were on three and four drugs. In this study, 20 (23.3%) of children were out of school, 63 (73.2%) were in ordinary schools and 3 (3.5%) in specialized schools.

General questionnaire and epileptic syndrome

Thirty-nine (45.3%) parents considered that their child had learning difficulties. The main learning disorders were memory disorders in 18 (20.9%) cases, attention disorders 17 (19.8%) cases and language disorders in 10 (11.6%) cases (Table 1). Twenty-five (29.1%) patients received rehabilitation (motor physiotherapy, speech therapy, and school support) (Table 1). Seventy-eight parents (90.7%) were satisfied with the medical care received by their children and the information given by the doctor about their illness meanwhile 60.5% of parents were dissatisfied with the school or school attended by their child.

Dimensions of quality of life

Overall quality of life

The overall quality of life of children was rated as poor by 18 (20.9%) parents. It was considered worse in children with non-idiopathic generalized epilepsy (Table 2). Age of onset of seizures (p=0.000) and schooling (p=0.0001) was significantly associated with the overall quality of life.

Depression/Anxiety

Fifty-five children (63.9%) had anxiety and depressive disorders. The average score of anxiety obtained was 2.7 ± 3.9 with no significant difference between the 3 groups of epilepsy and according to the gender of the children (p = 0.611).

Behaviour (hyperactivity/attention)

Seventy (81.4%) children had behavioral issues. The mean hyperactivity score was 6.3 ± 5.9 with no significant difference between the different epileptic groups and gender. (Table 2)

Sociability

Parents reported that 50% of children had good sociability without any problems, with the mean sociability score of 12.8 ± 4.4. There was no significant relationship between sociability and type of epileptic syndrome. (Table 2). Age of onset of seizures (p=0.0006), the frequency of seizures (p=0.037) and schooling (p=0.018) were significantly associated with sociability.

Cognition

We found that 71 children (82.6%) had cognitive impairment. Mean cognition score was 5.5 ± 5.1 with no significant difference between the different epileptic groups (Table 2). Cognition was associated with overall quality of life (p=0.00), behavior (p=0.002), depression/anxiety (p=0.035), sociability (p=0.00) and the impact of disease on the family (p=0.00).

Impact of the disease

The mean score of the disease impact was 13.6 ± 11.6. There was no significant difference between the different groups of epilepsy.

Correlation between different dimensions of quality of life

The overall quality of life score was correlated with all the quality of life dimensions except anxiety (p=0.342). Children whose parents felt they had a poor quality of

Table 2. Quality of life (QOL) dimensions and epileptic syndromes

	Idiopathic epilepsy (n=28)	Non-idiopathic generalized epilepsy (n=15)	Non-idiopathic partial epilepsy (n=43)	Total (n=86)	P value	Number of suspected disorders (%)
Overall QOL (5 to 25)	18.4 ± 3.1	15.3 ± 4.5	17.2 ± 4.1	17.3 ± 3.9	0.046	18 (20.9)
Impact of the disease (0 to 46)	10.7 ± 9.5	19.3 ± 12.4	13.6 ± 12.1	13.6 ± 11.6	0.066	
Hyperactivity/ Attention (0 to 24)	6.1 ± 6.6	6.1 ± 6.1	6.6 ± 5.5	6.3 ± 5.9	0.937	70 (81.4)
Anxiety/Depression (0 to 20)	2.8 ± 4.3	2.7 ± 5.9	2.6 ± 2.9	2.7 ± 3.9	0.982	55 (63.9)
Sociability (0 to 16)	13.8 ± 3.4	10.5 ± 5.8	12.9 ± 4.2	12.8 ± 4.4	0.055	43 (50)

life were those who were suspicious of hyperactivity (p=0.004), sociability (p=0.00) and cognitive disorders (p=0.00) with an impact of the disease on family life (p=0.00).

Discussion

We assessed children aged 3 to 16 years as was done by Soria et al[15] and Sabbagh et al[16], because the age below 3 years represents preschool age. Above 3 years of age, the behavior of these children could be evaluated at home and in the school environment, and observing these disorders in the two environments makes it possible to pose the diagnosis as recommended by the DSM IV.

Children with non-idiopathic generalized epilepsy had an earlier onset of seizures compared to other children. Sabbagh et al found that early onset of seizures increased the likelihood of the child being excluded from mainstream schooling[16]. Soria et al, reported that the age of onset of seizures was associated with depression, so the earlier the onset of seizures, the more the depressive symptoms the patient presented[15], whereas we noted, that was associated with poor quality of life and bad sociability.

The frequency of seizures was associated with sociability, so less the child presented with seizures, the better the sociability. This could be explained by the fact that a child presenting with numerous epileptic seizures will have greater neuronal degradation thus altering his sociability. Aggarwal et al, observed that a recent episode compromised the quality of life.[17] Sabaz et al, reported that the quality of life was associated with seizure frequency.[18] Lagunju et al, observed a significant association between the severity of seizures and the parental emotional impact and deterioration in the quality of life of children with epilepsy in Nigeria.[19] The frequency of seizures is an important factor and was correlated with the lowest quality of life score.[20]

Regarding schooling, we found that 23.3% of children were out of school especially in the group of children with non-idiopathic generalized epilepsy, and could be explained by the severity of the type of epilepsy as reported by Lagunju et al. 2009 in Nigeria.[19] Our proportion of children in school (76.7%) was higher than that found by Ibinga et al in Gabon (63.0%), by Kouame-Assouan et al in Ivory Coast (35.6%), and by Mushi et al in Tanzania (50%).[21-23] This can be explained by the fact that enrolment in the study was made in a population of patients followed - up by neuropediatricians on one hand and, on the other hand, by the existence of some specialized schools in the city of Yaounde where the study was conducted.

Learning disabilities affected all 3 groups of children, but they appeared to be lower in the group of children with non-idiopathic generalized epilepsy because they had very little schooling; and those in the group with non-idiopathic partial epilepsy had significantly more behavioral problems in the classroom in correlation with a high frequency of class repetition. O'Leary et al, reported that the age of onset of epilepsy, the type, and frequency of seizures, the laterality of epileptic seizures, and the side effects of drugs are the most incriminated factors in epileptic children's learning problems.[24] For example, children who started generalized seizures before the age of five had problems with slowness and inattention.[24] Those with isolated point discharges on the left cerebral hemisphere had reading difficulties and behavioral problems.[24] Antiepileptic drugs may also be responsible for idiopathic slowness, impaired concentration or agitation, particularly phenytoin and phenobarbital.[25,26]

All children in our study were receiving at least one antiepileptic drug, while Ibinga et al in Gabon reported that 42.2% of children in their study did not take any antiepileptic drugs.[21] The main antiepileptic drugs used in our study were carbamazepine, sodium valproate, and lamotrigine, respectively. This is different from what was noted by Ibinga et al. In our study, the mean number of antiepileptic drugs prescribed was 1.3 ± 0.5, with a statistically significant difference between the different groups of epileptic syndromes. Children with non-idiopathic generalized epilepsy were on more antiepileptic drugs than children with other types of epilepsy as noted by Soria et al 2012[27]; this can be explained by the severity and the high frequency of seizures in this group. The number of prescribed drugs had no association with the different dimensions of quality of life.

We observed that children in the non-idiopathic generalized epilepsy group had more reliance on rehabilitation, which was due to the severity of seizures in this group. These children had more language disabilities thus justifying more speech therapy for rehabilitation although this proportion was very low in our study compared to that reported of Soria et al in 2012.[27]

The group of children with non-idiopathic generalized epilepsy had a worse overall quality of life compared to children from other groups; these results were similar to those observed by Soria et al in 2012.[27] This could be explained by the severity of seizures in the group of children with non-idiopathic generalized epilepsy. The overall quality of life was associated with age at onset of seizures and schooling (quality of life was better for children who had later onset seizures and had normal schooling). Quality of life was also influenced by the impact of the illness on family lifestyle, behavioral disorders and cognitive deficits in the child.

Behavioral disorders were suspected in 70 children with epilepsy. This result is higher than that noted by Ibinga et al[21], and other studies in African countries such as Tanzania, Kenya, and Nigeria.[28,29,30] Behavioral disorders were associated with cognitive and depressive disorders. Sabbagh et al, reported that children with epilepsy in institutional care were more hyperactive.[16] Lagunju et al[19] reported that boys were more affected with a sadness mood in 27.3% of the children and an anxiety mood in 22.7%.

We found that 71 children (81.4%) were suspected of cognitive impairment which is higher than that found by Ibinga (49.4%).[21] Cognition was associated with all other dimensions of quality of life. The more children had cognitive deficits, the worse their quality of life, the more their hyperactive, the less their sociability, and the greater the impact of the illness on family life. Sabbagh et al, observed that early onset of epilepsy was associated with less cognitive impairment, suggesting

that young children were less aware of disorders and thus less affected by these limitations.[16]

In our study, 43 children (50%) had good sociability, which was higher than the proportion found by Ibinga (39.8%).[21] We obtained a mean score of sociability (12.8 $\pm$ 4.4), similar with the findings of Soria et al in 2012 (12.0 $\pm$ 3.2).[27] In our study, this dimension was not altered but contrarily approached the highest score. Soria et al, reported a significant association of epileptic syndrome, and the number of antiepileptic drugs with schooling, whereas in our study, this dimension was significantly correlated with the age at onset of seizures, seizure frequency, schooling and the overall quality of life. This means that early onset of crises, low frequency of crises, and quality of life are associated with good sociability. Sabbagh et al, reported that children with epilepsy in institutional care centers were less sociable.[16] Aggarwal et al noted that the level of maternal education significantly affects social interactions.[17]

The overall quality of life scores strongly correlated with all the quality of life dimensions and can be used as a "quality of life" index. "Overall quality of life" and "sociability" were significantly associated with school attendance, so the least sociable children with poor quality of life were out of school. This result is similar to that of Soria et al, who found a strong correlation between school attendance and four quality of life scores: overall quality of life, hyperactivity, sociability and the impact of the disease.

Conclusion

This study suggests that children with epilepsy have an alteration in their quality of life. This alteration of the quality of life is multifactorial and the control of epileptic seizures alone does not seem to be a sufficient factor to improve the quality of life of these children. Age of onset, type of epilepsy, frequency of seizures, cognitive and behavioral repercussions are all factors likely to influence the quality of life of children with epilepsy and their families. This demonstrates the need for multidisciplinary management involving both medical treatments of seizures and the management of comorbidities.

Authors Contribution

All the authors contributed to the realization of this study

Compliance with Ethical Standards

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