

Health-related quality of life of children with seizure disorder in Uyo, Nigeria

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Abstract

Background: Seizure disorder is a common chronic neurologic condition in children. Children with seizure disorder have been reported to have a more compromised health-related quality of life compared with healthy children. No known study has been undertaken in our environment. **Objectives:** To assess the health-related quality of life of children with epilepsy and to compare it with that of apparently healthy children in Uyo, Nigeria. **Methods:** Child self-report and parent-proxy report questionnaires (Pediatrics Quality of Life inventory version 4.0) were administered to 60 children and their mothers. Thirty of the children had seizure disorders and 30 were apparently healthy children who were age, gender and social class matched with the subjects. Parental education and occupation were used to allot a social class to the children. **Results:** Of the 30 subjects/controls, 10 (33.3%) were males while 20 (66.7%) were females giving a male to female ratio of 1:2. Thirteen belonged to 8-12 years age group, 12 were 13-18 years old while 5 were 5-7 years of age. Majority (27) belonged to the upper and middle social classes and 3 belonged to the lower social class. Twenty children had good seizure control while 10 had one or more seizure episodes per month. Children with seizure disorder had mean total score and mean score in the subscales that was significantly lower than that of the controls. Good quality of life was associated with good seizure control. **Conclusion:** Children with seizure disorder had lower health related quality of life than apparently healthy children. There is therefore need to maintain good seizure control in children with seizure disorder as it has a positive impact on health-related quality of life of these children.

Keywords: Seizure disorder, Health-related quality of life, Uyo, children.

Introduction

Seizure disorder is a chronic neurologic condition prevalent in children. It has been reported to negatively impact one's physical, social and emotional functions [1]. Worldwide, the prevalence of behavioural disorder in children with seizure disorder ranges from 20% to 60% [2-11]. Freilinger et al in Austria reported a prevalence of 22% [2] while Datta et al reported a prevalence rate of 53.8% among children with seizure disorder in India [3]. Lagunju et al reported that 46.6% of children with seizure disorder in Nigeria have behavioural and emotional problems [4].

Feelings of embarrassment, suicidal tendency, low self esteem, and stigmatization are often associated problems among children with seizure disorder [12]. Parents and siblings of children with seizure disorder

are equally affected by stigmatization. Studies have shown that they are more prone to psychiatric and emotional problems than parents and siblings of children without seizure disorder [13,14].

Health has been defined by World Health Organization (WHO) as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity [1]. Quality of life (QOL) is an essential aspect of mental and social wellbeing which is often ignored. It is defined as the individual's perception of their position in life in the context of culture and value systems to which they belong and in relation to their goals, expectations, standards and concerns [15].

Stigmatization is a major problem among children with seizure disorder and is associated with poor psychosocial health outcome and impaired Quality of Life (QOL) [12], [16].

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There is paucity of information on the quality of life of children with seizure disorder in Nigeria. Lagunju et al [16] in their study in Ibadan reported poor quality of life in children with seizure disorder but there is no study that compares the quality of life of children with seizure disorder with that of apparently healthy children. This study seeks to compare the quality of life of children with seizure disorder with that of apparently healthy children in Uyo, Nigeria.

Materials and Method

Study location/area: The study was conducted in the Paediatric Neurology clinic as well as Children's Out-Patient (CHOP) of the University of Uyo Teaching Hospital (UUTH), Uyo. UUTH is the only tertiary health facility in Uyo, the capital of Akwa-Ibom State.

The hospital serves as a referral centre for patients from within and outside the state. The Paediatric Neurology clinic is a specialty clinic which is run on Tuesdays along with the general Paediatric clinic. The clinic sees an average of 17-20 patients with neurological conditions per day of consultation. The clinic has a complement of staff from Resident doctors, doctors on internship, trained nurses with the Paediatric Neurologist as the leader of the team.

Study design and study period: This prospective study was conducted over a three-month period from 1st January, 2018 to 31st March, 2018.

Consent: Ethical clearance was obtained from the ethical committee of the University of Uyo Teaching Hospital, Uyo before embarking on the study. Written consent and assent were obtained from both the mothers and the older children before recruiting them into the study.

Inclusion criteria

Subjects: - 1. Children between the ages of 5years and 18years with seizure disorder lasting not less than one month since diagnosis. 2. Children whose parents have given consent, or the children have assented to their recruitment into the study.

Controls: - 1. Children aged 5years to 18years who do not have seizure disorders or any other chronic health condition such as cerebral palsy, nephrotic syndrome, asthma or sickle cell anaemia but presented in hospital for follow up for an acute health condition such as malaria and upper respiratory tract infection that had been treated. 2. Children whose parents/ caregivers have given their consent/assent

Exclusion criteria

1. Children whose parents did not give consent /assent
2. Children with other chronic conditions in association with seizure disorders.

Instrument and method: The subjects were consecutively recruited as well as the controls and were matched by age, sex and social class with the subjects.

Information such as the age, gender, type of seizure, medications used in treating the seizures, age of the child at onset of seizure were obtained from the children's case-notes. Parental educational attainment and occupation were used to allot a social class to the children using the scheme proposed by Oyedemi [17].

Quality of life was assessed using pediatrics' quality of life inventory version 4.0 parent-reported scale as well as child reported scale [18,19]. The instrument categorizes the children into three groups: the young child aged 5-7years, the children aged 8-12 years, and the teens aged 13-18years. It is a modular approach to measuring health related quality of life (HRQOL) in children and adolescents. It consists of brief, practical, generic score scales which test four domains of physical, emotional, social and school functioning. It contains 23 items suitable for use in healthy school and community populations. It is also used in paediatric populations with acute and chronic health conditions. Standard questionnaires, adapted from the pediatric QOL Questionnaire, were administered to the children and their mothers.

Parents' as well as the children's scales were used to assess the children's QOL. This was done by asking the mother and the child about any problems the child had in the last month from the four domains: physical (eight items), emotional (five items), social (five items) and school (five items) functioning domains. The child's physical functioning was measured in terms of problems in walking more than a block, running, participating in sports activities, lifting heavy objects, taking a bath or shower by themselves, doing chores around the house, having aches, and low energy levels.

The child's emotional functioning was measured in terms of feeling afraid or scared, sad, angry, have trouble sleeping, and worry about what will happen to them. The child's social functioning was measured in terms of problems in getting along with other children, getting teased by other children, keeping up when playing with other children, worrying about not being able to do things other children their age can do, and

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other children not wanting to befriend them. The child's school functioning was assessed in terms of problems in paying attention in class, forgetting things, keeping up with the school work, missing school because of not being well, and missing school to go to the doctor or hospital. The scoring system was based on the terms of children's QOL. Each question was scored as grades 0, 1, 2, 3 and 4.

The question was scored 0 when the child or mother answered no problem, scored 1 when the response was almost never a problem, scored 2 when the response was sometimes a problem, 3 if the response was often a problem and scored 4 if the response was almost always a problem. Items were transformed to a 0-100 scale as follows: 0 =100, 1 = 75, 2 =50, 3 = 25 and 4 = 0 with the higher scores indicating a better HRQOL. The mean total score scale was computed as the sum of all the items over the number of items answered on all the

Results

Of the sixty children recruited during the study period, thirty were children with seizure disorder (subjects) while the remaining thirty were apparently healthy children (controls). Of the 30 subjects/controls, 13(43.3%) were in the 8-12 years age bracket, 12(40.0%) were in the 13-18years age bracket and 5(16.7%) were in the 5-7years age bracket.

Majority (66.7%) of the children were females with a male to female ratio of 1:2. Forty percent of the children belonged to social class III, 36.7% belonged to social class II and no child belonged to social class V. The socio-demographic characteristics of the children are as shown in table 1.

Table-1: Socio-demographic characteristics of the study population.

	N (%)
Age(years)	
5-7	5(16.7)
8-12	13(43.3)
13-18	12(40.0)
Gender	
Male	10(33.3)
Female	20(66.7)
Social class	
I	4(13.3)
II	11(36.7)
III	12(40.0)
IV	3(10.0)
V	0(0.0)

Table 2 shows the clinical characteristics of the children with seizure disorder. Twenty-six (86.7%) of the children had generalized seizures while 4 (13.3%) had partial seizures. Regarding seizure frequency, majority (66.7%) of the children had been seizure free for at least one month before being recruited into the study, 3 (10%) each had seizure once a month, twice a month and more than thrice a month while one (3.3%) had seizures thrice a month. Twenty-two (73.3%) were on one antiepileptic drug while eight were on two antiepileptic medications. For those on one anti-epileptic drug, twenty-one had carbamazepine while one had ethosuxamide.

Table-2: Clinical characteristics of children with seizure disorder.

	N (%)
Seizure type	
Generalized	26(86.7)
Partial	4(13.3)
Seizure frequency	
No seizure	20(66.7)
Once a month	3(10.0)
Twice a month	3(10.0)
Thrice a month	1(3.3)
More than thrice a month	3(10.0)
Seizure medications	
Monotherapy	22(73.3)
Two medications	8(26.7)

Mean scores of children with seizure disorder was significantly lower than the mean scores of apparently normal children on all the domains using both the children reported scales as well as parent-proxy reported scales.

Table-3: Mean self-reported health related quality of life in children with seizure disorder and children without seizure disorder.

	Children with seizure disorder Mean (SD)	Children without seizure disorder Mean (SD)	T	p-value
Total	76.12(18.45)	92.28(8.93)	-4.29	0.000
Physical	77.92(24.55)	93.54(11.49)	-3.12	0.004
Emotional	82.33(20.16)	91.67(11.55)	-2.10	0.045
Social	77.67(23.18)	92.67(12.02)	-3.45	0.002
School	65.72(25.34)	90.50(10.93)	-5.01	0.000
Psycho-social	75.26(18.49)	91.47(9.19)	-4.53	0.000

The child reported mean scores for both subjects and controls were as follows: total 76.12 + 18.45 versus 92.28 + 8.93 ($p < 0.01$), physical domain 77.92 + 24.55 versus 93.54 + 11.49 ($p = 0.004$), emotional domain 82.33 + 20.16 versus 91.67 + 11.55 ($p = 0.045$), social 77.67 + 23.18 versus 92.67 + 12.02 ($p = 0.002$), school domain 65.72 + 25.34 versus 90.50 + 10.93 ($p < 0.001$) and psycho-social 75.26 + 18.49 versus 91.47 + 9.19 ($p < 0.001$). This is shown in table 3

Table-4: Mean Parent-proxy reported health related quality of life in children with seizure disorder and children without seizure disorder

	Parent(Subjects) Mean (SD)	Parent (Control) Mean(SD)	T	p-value
Total	74.36 (26.47)	91.05(8.96)	-3.96	0.000
Physical	78.19(26.47)	90.83(12.36)	-2.29	0.029
Emotional	77.83(19.90)	89.00(10.54)	-2.59	0.015
Social	79.67(25.05)	94.83(9.87)	-3.02	0.005
School	63.33(25.47)	88.73(16.11)	-5.31	0.000
Psycho-social	72.96(20.81)	91.17(9.54)	-4.21	0.000

The parent-proxy reported mean scores for both subjects and controls were as follows: Total mean score 74.36 + 21.20 versus 91.05 + 8.96 ($p < 0.001$), physical domain 78.19 + 26.47 versus 90.83 + 12.36 ($p = 0.029$), emotional domain 77.83+ 19.90 versus 89.00 + 10.54 ($p = 0.015$), social 79.67 + 25.05 versus 94.83 + 9.87 ($p = 0.005$), school domain 63.33 + 25.47 versus 88.73 + 16.11 ($p < 0.001$) and psycho-social 72.96 + 20.81 versus 91.17 + 9.54 ($p < 0.001$). This is shown in table 4.

Table 5 shows the quality of life of children with seizure disorder. Twenty-one (70%) children each had good quality of life (total and psycho-social) on both parent- proxy reported scale and Self-reported scale, while 22(73.3%) and 8(26.7%) had good quality of life (physical domain) on parent-proxy reported scale.

Table-5: Quality of life of children with seizure disorder on both child self-reported and parent-proxy reported scales.

		Child Self report N (%)	Parent-proxy report N (%)
Total	Good quality	21(70)	21(70)
	Poor quality	9(30)	9(30)
Physical	Good quality	21(70)	22(73.3)
	Poor quality	9(30)	8(26.7)
Psycho-social	Good quality	21(70)	21(70)
	Poor quality	9(30)	9(30)

Table 6 shows the relationship between seizure variables and self reported quality of life (total). Nineteen children with generalized seizures had good quality of life while 2 children with partial seizures had good quality of life but the relationship between seizure type and health related quality of life was not statistically significant ($p = 0.345$). When health related quality of life was compared with the seizure frequency it was observed that children with no seizure the month before the study had good quality of life compared to those with seizures and this was statistically significant ($p = 0.021$). Health related quality of life was not influenced by the number of seizure medications the child is taking.

Table-6: Relationship between seizure variables and child self-reported health quality of life (total score).

	Good quality	Poor quality	X ²	p-value
Seizure type				
Generalized	19	7		
Partial	2	2	0.879	0.345
Seizure frequency				
No seizure	16	4		
Once a month	0	3		
Twice a month	1	2	11.587	0.021
Thrice a month	1	0		
>thrice a month	3	0		
Seizure medications				
Monotherapy	15	7		
Two medications	6	2	0.13	0.547

Discussion

This is the first study in Nigeria using the paediatrics quality of life inventory 4.0. Generic core scales (parent and child scales) to compare the health-related quality of life of children with epilepsy with that of apparently healthy controls.

The finding that majority of the children belonged to the upper and middle social classes could be due to the fact that these groups of people have the financial capability to shoulder the cost of investigations and treatment of seizure disorder. The female preponderance observed in this study is surprising as previous studies in this

environment reported male preponderance in hospital-based studies [21, 22, 23]. The reason had been that our society places more value on male children and so are given better healthcare for their survival and maintenance of family lineage. The observation that children with seizure disorder had significantly lower total mean scores than controls was also reported by other studies [24, 25, 26]. Miller et al reported that the health-related quality of life in children with seizure disorder compared with the controls is diminished in all functioning domains [24]. The mean scores on individual subscales of the health-related quality of life

were also significantly lower than those of apparently healthy controls. The sequence of scores from the lowest to the highest was as follows: school functioning, social functioning, physical and emotional functioning on the child self report scale; school functioning, emotional, physical and social functioning. School functioning was noted as the subscale that was most affected. In the school function domain, children with seizure disorder reported problems with paying attention in class, forgetting things, keeping up with school work, missing school because of not feeling well and missing school to go to the doctor or hospital.

School absence is a common problem among children with seizure disorder and this must have attributed to their poor school function [27]. Ibekwe et al reported that the mean school absence rate for children with seizure disorder was significantly higher than that of the controls ($p = 0.001$) [27]. In the social function domain, children with seizure disorder reported problems getting along with other children, other kids not making friends with them, other kids teasing them, not able to do things that other children their age can do, finding it hard to keep up when playing with other children.

Stigmatization is a major problem among children with seizure disorder in our environment due to belief that that seizure disorder is contagious and one can get infected by contact with saliva from the mouth of the child who is having a seizure episode [12,28]. In the emotional function domain, children with seizure disorder reported that they are easily angered, they feel sad, afraid and scared, they also have trouble sleeping and worry about what would happen to them. Seizure disorder in children can often be associated with anxiety, depression and low self-esteem. Emotional and psychiatric disorders have been reported among children with seizure disorder [2,3,4,29].

The findings that children whose seizures are well-controlled had better quality of life than those with poorly controlled seizures had been reported by other authors [25, 30].

Conclusion

Children with seizure disorder had lower health related quality of life than apparently healthy children. Children who had good seizure control had significantly higher quality of life than those with poor seizure control. Efforts should be geared towards achieving good seizure control among children with seizure disorder in our environment so as to improve the health-related quality of life of these children.

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