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ORIGINAL RESEARCH

Parent's Knowledge, Attitude and Pattern of Care for Children with Epilepsy in Lagos, Nigeria

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Abstract

Background: Epilepsy is a common paediatric neurologic disorder associated with stigmatisation due to a lack of understanding of the disease and wrong beliefs.

Objective: To assess parents' knowledge about epilepsy, attitude towards the disease and care for the affected child in Lagos, Nigeria.

Methods: This was a descriptive cross-sectional study of parents of children with epilepsy presenting to the Paediatric Neurology Out-Patient Clinic in a tertiary facility between June and August 2019. Data collection was done using a semi-structured questionnaire.

Results: A total of 112 parent-child pairs participated in this study. The mean age of the fathers and mothers were 44.9 ± 10.4 years and 37.9 ± 9.0 years, respectively. Most (98.2%) of the parents had at least a secondary level of education, and about half (42.9%) belonged to the upper socioeconomic class. About three-quarters (73.2%) of parents have heard about epilepsy before presentation at the clinic. Twenty-eight (25%) parents had misconceptions or no idea of the causes of epilepsy. About a third of the parents did not know the correct measures to be taken during seizure attacks. Three-quarters (76.8%) of children received prescribed medication regularly, and one of the reasons given for non-compliance with medications poor effectiveness of the medications. (15.4%).

Conclusions: The attitude and care of parents towards children living with epilepsy were poor. A period must be dedicated to educating all parents as soon as they present to the clinic with their children.

Key words: Knowledge; Anti-epileptic drugs, Children, Epilepsy, Lagos, Seizure disorders, Social class.

Introduction

Epilepsy is a recurrent, sudden and stereotyped alteration in motor activity, sensation and behaviour due to abnormal electrical discharges of cerebral neurons. [1, 2] It is characterised by an enduring predisposition to generate epileptic seizures and neurobiological, cognitive, psychological, and social consequences. It is a universal problem involving all ages, races, social classes, and nations. [1, 2] However, the prevalence of epilepsy is higher in the low- and middle-income countries, particularly among those in sub-Saharan Africa and Latin America. [1-3] According to a recent World Health Organization report, approximately 50 million people worldwide have epilepsy, with nearly 80% of these people with epilepsy living in low- and middle-income countries. [4]

In the US, the prevalence of active epilepsy or seizure disorder was 1.2% among the entire population, corresponding to just over 450 000 children from birth to age 17 years. [5] A US study had shown that epilepsy was more common in children from families with income below the federal poverty level.[5] In Europe, the incidence of epilepsy in children was 3.2-5.1 per 1000 population, depending on the age range and country under consideration, [6] while in Africa, the incidence ranges from 5.2 per 1000 to 74.4 per 1000 population, depending on the study population and the methodology in the studies.[7] A recent systematic review and meta-analysis study, using a random-effects model, estimated the overall incidence of epilepsy in Nigeria to be 8 per 1000 people, which was highest (11 per 1000) in the southwestern part of the country. [8] The incidence was also higher among the rural (15 per 1000) than the urban (6 per 1000) dwellers. [8] Various hospital-based studies in Nigeria have shown that epilepsy is the commonest childhood neurological disorder, with a prevalence rate of 26.3% - 60%. [9-11]

In many parts of the world, misconceptions and myths about the cause, effect and treatment of epilepsy exist, resulting in stigmatisation which makes the provision of effective care very challenging. [12, 13] These problems are greatly influenced by sociocultural factors. [12, 13] For instance, in South Korea, even though advanced orthodox medicine prevails, traditional medicine, including herbal medicine, is very popular for treating epilepsy. [14]

Remission occurs in epilepsy, and it is also possible for affected children to live a normal and quality life. However, this depends on the knowledge of epilepsy, a positive attitude towards the disease and towards the sufferer, timely referral and diagnosis, and compliance with proven guidelines on the management of the disorder. As children depend on caregivers for decisions on medical treatment, a caregiver's knowledge, perception and attitude towards epilepsy may significantly influence both short- and long-term consequences of this disorder. Therefore, this study aimed to assess parents' knowledge about epilepsy, their attitude towards the disease and their care for children living with epilepsy.

Methods

Study design and Study setting

This was a descriptive, cross-sectional study carried out at the Neurology Clinic of the Paediatrics Department, LASUTH, Ikeja, Lagos. The hospital is a tertiary health facility owned by the Lagos State Government, situated in Ikeja, a densely-populated city in Lagos. The hospital serves the inhabitants of Lagos State and the neighbouring Ogun State. Health care needs are provided at subsidised rates for children and the elderly. The neurology clinic has a total of 120 registered patients with epilepsy. The clinic is usually run by three residents, two medical interns, and a consultant. It runs every Thursday, and an average of five new patients are registered weekly, while appointments for subsequent routine follow-up visits vary between two and three months.

Sample size and patient selection

The participants in this study were children attending the clinic recruited through a sample of convenience method if they met the following inclusion criteria: a child with the diagnosis of epilepsy coming for routine paediatric care, the accompanying parents or guardians gave informed consent and if the patient had no other chronic illness. The diagnosis was established with the clinical presentation and or electroencephalographic features. We selected consecutive patients with epilepsy who came to the clinic for routine follow-up between 01 June and 31 August 2019. Ethical approval for the study was obtained from the Hospital Research Ethics Committee.

Each parent or guardian of the eligible child was interviewed on the knowledge and attitudes toward epilepsy and the care of their child with epilepsy. The interview was conducted by a medical officer trained purposively for this study. The self-designed questionnaire was semi-structured and had two formats of questions; open- and closed-ended. The instrument contained 25 items focusing on the socio-demographic information of the parents and children, knowledge of parents about epilepsy, and attitudes of the parents and their care for a child with epilepsy. The section on parents' knowledge focused on the potential causes of epilepsy, the effect of epilepsy on a child's behaviour and learning, and steps to take during a seizure attack. The section on attitude and care assessed the parents' or guardians' feelings towards a child with epilepsy, compliance with medications and estimated monthly cost of care. The responses to these questions were either binary (yes/no) or checklist type. The questionnaire was pilot-tested among 15 children to eliminate questions that were potentially misleading or difficult to comprehend.

The families were assigned to a socioeconomic class according to the method of Ogunlesi *et al.* [15] The occupation and highest education attained by the parents were scored from 1 (highest) to 5 (lowest). The mean score for both parents was determined by simple arithmetic and is expected to be in the range of 1-5. This score was subsequently used to rate the parents according to their social classes. Parents with a mean score of 1-2, 3, or 4-5 were in the upper, middle, or low socioeconomic class, respectively.

Statistical analysis

Data analysis was done by descriptive and inferential statistics using the Statistical Package for Social Sciences (SPSS) for Windows software version 22. Univariate analyses were performed for all the major variables of interest, such as socio-demographic, knowledge, attitudes, and care. Mean (and standard deviation) was determined for continuous variables, while the categorical variables were expressed as proportions and percentages. The categorical variables were compared using the Pearson Chi-Squared (χ^2) test. *P* values less than 0.05 were accepted as statistically significant.

Results

A total of 112 parent-child pairs participated in this study. The socio-demographic characteristics of the study subjects are shown in Table I. Most (88.4%) of the parents or guardians that accompanied the child to the clinic were the mothers. The mean age of fathers and mothers were 44.9 ± 10.4 years and 37.9 ± 9.0 years, respectively. Most of the fathers (98.2%) and mothers (98.2%) had at least a secondary level of education. Less than one-half (42.9%) of the parents belonged to the upper socioeconomic class. The age of the children ranged from 0.5 – 16 years, with a median of 7 (IQR 3.6-10.7) years. Most (64.3%) of the children were males, and most (68.8%) had onset of epilepsy at age <5 years old.

Table I: Socio-demographic characteristics of study participants

Parameters		*Frequency (n = 112)*	*Percentages*
Parents	Mother	99	88.4
	Father	13	11.6
Age of parents (Years)	<30	8	7.1
	30-39	49	43.8
	40-49	46	41.1
	≥50	9	8.0
Father's Education	None formal	1	0.9
	Primary	1	0.9
	Secondary	32	28.6
	Tertiary	78	69.6
Mother's Education	None formal	0	0.0
	Primary	2	1.8
	Secondary	39	34.8
	Tertiary	71	63.4
Socioeconomic class	Upper (I & II)	48	42.9
	Middle (III)	41	27.7
	Lower (IV & V)	36	29.5
Age of the Child (Years)	<5	35	31.3
	5-9	41	36.6
	≥10	36	32.1
Child's Sex	Male	72	64.3
	Female	40	35.7
Age at the onset of epilepsy (Years)	<5	77	68.8
	5-9	29	25.9
	≥10	6	5.3

Knowledge of parents about epilepsy

Table II shows that 82 (73.2%) parents had heard about epilepsy before their child was diagnosed in the clinic. The parents identified heredity (30.4%), head injury (25.9%) and birth injury (18.8%) as potential causes of epilepsy in children. However, 9 (8.0%) parents had no idea of the possible causes of the disease. Seventy-eight (69.6%) parents believed that epilepsy could affect a child's behaviour, while 69 (61.6%) believed the learning ability of a child could be affected. Fifty-eight (51.8%) parents know that anti-epileptic medications were the major treatment option for epilepsy. Use of herbal remedies (7.1%), faith prayers (4.5%), and rituals to the gods (3.6%) were other treatment options reported by the respondents. Among first aid procedures to be performed during a seizure attack, 39 (34.8%) parents mentioned tilting a convulsing child to the side until the attack terminates, while 36 (32.1%) parents had no idea what to do during an epileptic attack.

Table II: Knowledge of participants about childhood epilepsy

Parameters		*Frequency (n = 112)*	*Percentage*
Heard about epilepsy	Yes	82	73.2
	No	30	26.8
Causes of epilepsy	Heredity	34	30.4
	Head Injury	29	25.9
	Fear	5	4.4
	Psychological stress	10	8.9
	Injuries during pregnancy and delivery	21	18.8
	No idea	13	11.6
Does epilepsy affect behaviour?	Yes	78	69.6
	No	19	17.0
	No Idea	15	13.4
Does epilepsy affect a child's learning?	Yes	69	61.6
	No	27	24.1
	No Idea	16	14.3
Awareness about appropriate treatment options	Anti-epileptic medications	58	51.8
	Psychotherapy	10	8.9
	Special diet	13	11.6
	Surgery	9	8.0
	Herbal remedies	8	7.1
	Rituals	4	3.6
	Faith prayers	5	4.5
	Wearing of charms and armlets	5	4.5
Awareness of side effects of anti-epileptic medications	Yes	38	33.9
	No	74	66.1
First aid instructions during epileptic attacks	Artificial respiration	12	10.7
	Opening the jaw and taking out the tongue	13	11.6
	Tilting the child on the side	39	34.8
	Injection of anticonvulsants	12	10.7
	Electric shock therapy	0	0.0
	No Idea	36	32.2

Attitude and care of parents toward epilepsy

In Table III, 42 (37.5%) parents believed that their child with epilepsy differs from other children, while 28 (25.0%) parents will not tell friends about the epileptic disease in their children. Most (74.1%) of the parents believed that epilepsy could be cured. Although 98 (87.5%) children were currently on anti-epileptic medications, only 86 (76.8%) children received the prescribed medications regularly. The reasons for non-compliance with medications included the parental belief that “the drugs don’t help the child” (4; 15.4%), “the child refuses to take the drug" (6; 23.1%), and non-affordability due to financial difficulties (16; 61.5%). The estimated cost of treatment of epilepsy in a child per month ranges from 700 to 50,000 Naira (1.6 to 120.5 USD) with a mean value of 11,670.92±10,777.46 Naira (28.1±25.9 USD).

Table III: Attitude and pattern of care of parents towards children with epilepsy

Parameters		*Frequency (n = 112)*	*Percentages*
The affected child is different from other children	Yes	42	37.5
	No	66	58.8
	No Idea	4	3.7
Would you tell your friend about your child’s epilepsy	Yes	78	69.6
	No	28	25.0
	No Idea	6	5.4
Is childhood epilepsy curable?	Yes	83	74.1
	No	17	15.2
	No Idea	12	10.7
Is the child on medications?	Yes	98	87.5
	No	14	12.5
Ever stopped the medications?	Yes	26	23.2
	No	86	76.8

Association between the socioeconomic class of parents and their knowledge and care towards children living with epilepsy

Table IV shows that the parents' socioeconomic status was significantly related to their awareness of the disease ($\chi^2 = 21.3$, p = 0.001).

Discussion

This study provides an insight into the current parents’ knowledge, attitude and care of their child with epilepsy in Lagos, Nigeria. The findings show that epilepsy is not a well-understood disease among parents, as 30% of the parents claimed not to have heard about the disease. This contrasts sharply with the findings in previous studies in Nigeria reporting widespread awareness of the disease among 95% of parents attending a tertiary health facility in Port Harcourt [16] and 99% among urban dwellers in Enugu. [17] However, the finding in the present study agrees perfectly with the rate of 70% previously reported in Saudi Arabia. [18] The relatively low awareness rate in the present study is disturbing because a majority of the parents had at least a secondary level of education and belonged to upper and middle social classes. The poor knowledge about epilepsy is further buttressed by the unsatisfactory findings relating to parents' responses about the potential causes and effects of epilepsy.

Table IV: Association between socioeconomic classes and knowledge and care of parents for childhood epilepsy

Parameters		*Social Class*			*P value*
		Upper (n = 48)	**Middle (n = 31)**	**Lower (n = 33)**	
Have you heard about epilepsy?	Yes	42 (87.5)	25 (80.6)	15 (45.5)	0.001
	No	6 (12.5)	6 (19.4)	18 (54.5)	
Is childhood epilepsy curable?	Yes	34 (70.8)	21 (67.7)	28 (84.8)	0.873
	No	8 (16.7)	7 (22.6)	2 (6.1)	
	No Idea	6 (12.5)	3 (9.7)	3 (9.1)	
Is the child on medication	Yes	43 (89.6)	28 (90.3)	27 (81.8)	0.928
	No	5 (10.4)	3 (9.7)	6 (18.2)	
Awareness of the side effects of medications	Yes	16 (33.3)	12 (38.7)	10 (30.3)	0.709
	No	32 (66.7)	19 (61.3)	23 (69.7)	

For example, 11.6% of respondents did not know the causes of epilepsy, while another 4.4% believed it was due to fear. This is in spite of the improvement and advancement in information technology in the country, which is expected to increase access to valuable health information and reduce major prejudices and ignorance about disease conditions. Misconceptions about the causes of epilepsy are common in many countries of the world, especially the developing countries where epilepsy is perceived as a manifestation of supernatural forces such as witchcraft and sorcery. [12, 13]

The present study also revealed that a large number of the parents were not aware of the appropriate measures to take when a child suffers an epilepsy attack and the effect of epilepsy on learning and behaviour if uncontrolled. While one-third of the parents chose the most feasible and correct method to undertake during an attack, another one-third were completely unaware of the first aid measures. Close to one-fifth of the parents still believe in unorthodox ways of treating epilepsy, such as prayers in religious houses, performing rituals, and using herbal remedies. This is similar to the findings obtained in Enugu, southeast Nigeria, where 27.9% of the participants endorsed traditional and spiritual approaches as the most appropriate for epilepsy management. [16] These beliefs must have stemmed from misconceptions about the causes of epilepsy. Surprisingly, only 51% of the parents in the present study admitted to the knowledge of anti-epileptic drugs, even though all subjects are expected to be on anti-epileptic medications. It is not impossible that these parents did not totally trust the efficacy of orthodox treatment and, therefore, resorted to other approaches for the management of epilepsy with possible negative implications for the control of seizures and prevention of development of complications from epilepsy.

In general, parents' attitude towards epilepsy and their children with epilepsy was not poor. However, a relatively high percentage of the parents believed epileptic children are not different from other children and are willing to disclose the status of their children to non-family members. The issue of discrimination against children with epilepsy and the associated stigma has been a significant social problem. [12, 13] Many people with epilepsy have their seizures controlled with the appropriate medications and can live a normal life, especially after they have been seizure-free for a prolonged period of about 2 to 3 years. In this study, three-quarters of the children attending the clinic took their medications regularly. This was similar to the reports from Enugu, Nigeria [19] and Uganda,[20] where 79.5% and 85% of children, respectively, were adherent to their anti-epileptic medications. The parents' attitudes seemingly influence compliance with medication, as shown in this study where non-compliance with medication was based on the belief that the drug was not working or the child refusing the medications.

This study has some limitations. The study instrument was a self-administered questionnaire and subject to recall bias like other methods that rely on self-report. However, the research team ensured the subjects understood the questions and checked the filled questionnaires for completeness to minimise recall bias. It is also acknowledged that this questionnaire was used for the first time and has not been validated. The methodology in the present study may be adopted for subsequent attempts at validating the questionnaire.

Conclusion

Some of the findings in this study were consistent with findings from previous studies. The general knowledge of the parents in this study was low, and many information gaps still exist. There are misconceptions about the cause, effect and treatment of epilepsy, and there is poor knowledge of the measures to take during seizure attacks. To improve the management of children with epilepsy, paediatricians and the stakeholders need to create an avenue in various neurology clinics where parents are provided with information about epilepsy that will increase their knowledge of the disease and medications. These educational efforts and support for parents must be provided as soon as a child presents to the clinic. This may help overcome misconceptions and stigma and enhance good parental attitude and seizure control.

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