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# Knowledge and attitudes of parents toward children with epilepsy

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## Abstract

**Introduction:** The attitude towards people with epilepsy is influenced by the level of their knowledge about the condition. Parents usually do not accept the diagnosis of epilepsy in their children easily. This study was to assess 280 parents' knowledge and their attitude toward children suffering from epilepsy by answering a questionnaire.

**Aim:** To evaluate the knowledge and attitudes of parents toward children with epilepsy.

**Materials:** This was a prospective study in a tertiary hospital. All parents who had children suffering from epilepsy seen from April 1<sup>st</sup> 2009 to March 31<sup>st</sup> 2010 were recruited. Questionnaires were administered to all the parents who attended the neurology clinic with their children diagnosed of epilepsy.

**Results:** A total of 914 neurological patients were seen and treated during the study period. Of these, 280 parents whose children suffered from epilepsy participated in the study. Almost all, 267 (95.36%) parents had heard about epilepsy prior to presentation in the clinic. Some parents thought that epilepsy was contagious and linked with evil spirit/demonic attack. A few of them rejected the word epilepsy and did not think that an epileptic child could achieve much in life. The knowledge about the clinical characteristics and initial procedures to attend a person during a seizure were unscientific.

**Conclusions:** We concluded that more than 90% of parents and caregivers know about epileptic seizures. However, there is a need to disseminate more information to the public about its causes, clinical manifestation, approach to managing a convulsing child, and its outcome. In addition, periodic medical campaigns aimed at educating the public about epilepsy through the media could go a long way in reducing the morbidity and mortality associated with this disorder.

**Keywords:** Attitude, children, epilepsy, knowledge, parents, Port Harcourt

## Résumé

**Arrière-plan:** L'attitude à l'égard des personnes atteintes d'épilepsie est influencé par le niveau de leurs connaissances sur la condition. Les parents habituellement n'acceptent pas le diagnostic d'épilepsie chez leurs enfants facilement. Cette étude était d'évaluer les connaissances des 280 parents et leur attitude à l'égard des enfants souffrant d'épilepsie en répondant à un questionnaire.

**Matériaux:** Il s'agissait d'une étude prospective dans un hôpital de soins tertiaires. Tous les parents qui avaient des enfants souffrant d'épilepsie vu depuis le 1er avril 2009 au 31 mars 2010 ont été recrutés. Questionnaires ont été administrés à tous les parents qui ont assisté à la clinique de neurologie avec leurs enfants, un diagnostic d'épilepsie.

**Résultats:** Un total de patients neurologiques 914 ont vu et traités au cours de la période d'étude. De ce nombre, 280 parents dont les enfants souffraient d'épilepsie a participé à l'étude. Presque tous, 267 (95.36%) les parents avaient entendu parler de l'épilepsie avant de présentation à la clinique. Certains parents pensaient que l'épilepsie était lié avec l'attaque de mauvais esprit/démoniaque et contagieuse. Quelques-uns d'entre eux a rejeté l'épilepsie mot et ne pensent pas qu'un enfant épileptique pourrait atteindre beaucoup dans la vie. Les connaissances sur les caractéristiques cliniques et les procédures initiales pour assister à une personne au cours d'une saisie étaient non scientifique.

**Conclusions:** Nous avons conclu que plus de 90% des parents et des soignants connaissent des crises d'épilepsie. Toutefois, il est nécessaire de diffuser plus d'informations au public sur ses causes, la manifestation clinique, l'approche de la gestion d'un enfant de convulsions et ses résultats. En outre, campagnes médicales périodiques visant à informer le public sur l'épilepsie à travers les médias pouvaient aller très loin dans la réduction de la morbidité et la mortalité associées à ce trouble.

**Mots clés:** Attitude, enfants, parents de l'épilepsie, connaissances, Port Harcourt

## Introduction

Epilepsy is one of the most common neurological disorders with a prevalence rate varying from 2.8 to 19.5 per 1000 general population.<sup>[1-3]</sup> Seizures are common in the pediatric age group and occur in 10% of children. Most seizures in children are provoked by somatic disorders originating outside the brain, such as high fever, infection, syncope, head trauma, hypoxia, toxins, or cardiac arrhythmias.<sup>[1,2]</sup> Other causes include genetic syndromes, and cerebrovascular diseases.<sup>[1]</sup>

Discrimination against persons suffering from epilepsy is not uncommon. This is often due to sudden falls and convulsive episodes at unexpected times in public places resulting in rejection.<sup>[4]</sup> Sometimes, the social discrimination against these persons with epilepsy may be more devastating than the disease itself. Children with epilepsy may be rejected from their classes because of frequent seizures which makes their teachers and fellow students uncomfortable with their presence in class.<sup>[5]</sup> Also, some others are not enrolled in schools once the school authority become aware that such a child has epilepsy.<sup>[6]</sup>

Other social aspects of life are also adversely affected by the disease.<sup>[7]</sup> Older children and adults with epilepsy usually have problems with adaptation, institutionalization, and access to public accommodation.<sup>[7]</sup> The disease may also cause unemployment and difficulty to marry when children get to adulthood. Affected persons may be rejected from social events because there are people that still believe that the disease may be transmissible by contact with the patient's saliva. The attitudes toward people with epilepsy are influenced by the degree of knowledge of the condition.<sup>[7-9]</sup> Many parents still have a negative attitude about epilepsy. Some of them feel it is contagious and as such during an attack, some children are not assisted in anyway.<sup>[4,10]</sup> The availability of antiepileptic drugs and the prolonged medical care needed by children with epilepsy justify the careful planning of a social program for this public health problem. This study was therefore aimed to assess parents' knowledge and their attitude towards children with epilepsy by answering a questionnaire.

## Materials and Methods

This study was carried out in the neurology clinic of the University of Port Harcourt Teaching hospital in Nigeria. Verbal consent was obtained from those who accepted to participate and they were recruited. The parents have children attending the neurology clinic for management of epileptic disorders and accepted to participate in the study willingly. Two hundred and eighty parents were given questionnaires and participated in the study by answering the questionnaire [Appendix 1] derived and modified from a previous study.<sup>[11]</sup> The knowledge, attitude and practice toward children with epilepsy among parents and caregivers were assessed. Twenty two of the parents/caregivers did not give consent to participate and were not recruited.

The questionnaire had questions which were of the close ended type and comprised of yes/no/don't know variety of answers. The structured questionnaires were administered to the parents who completed them on the spot. Those who could not read and write were assisted by the researchers. The questionnaire was structured to elicit demographic information and to test the knowledge of the parents of the cause of epilepsy, the first-aid management of an epileptic attack and the attitude towards the child with epilepsy. For the question about the initial procedures in attending to a person during a seizure, we considered as main correct initial procedures: to protect and to turn the head to one side in order to permit the saliva flow, to keep ventilation on and to stay near the subject until the end of the seizure, avoiding any harmful situations. We considered as less important, correct initial procedures, acts like taking off clothes and removing nearby objects. Inadequate initial procedures were all the ones that may be harmful or helpless to the patient, like pulling the tongue, burning the feet, inserting crude oil into orifices or putting objects or water in the child's mouth.

## Results

A total of 280 parents, 220 females and 60 males, filled the questionnaires. The age of the parents ranged from 22 years to 53 years with mean age  $31 \pm 4$  years. Table 1 shows some demographic

parameters of the study group. Responses to questions about familiarity toward epilepsy are summarized in Table 2. More than 90% of all the parents had heard about epilepsy, while a few (less than 5%) of them knew nothing about epilepsy. One hundred and seventy six parents (63%) believed that epilepsy was contagious and 56 (20%) did not know the correct answer to this question.

Most parents did not discriminate or object to having an epileptic child, although they recognized that there is a strong feeling of discrimination against persons suffering from epilepsy by the general population. Few of them 49 (17.50%) believed that someone who has epilepsy can become cured. One hundred and forty six (52.14%) of all the parents did not know about the initial procedures

**Table 1: Demographic data of parents**

Parents age	Number	Percentage
(Years)		
22–29	120	42.86
30–49	111	39.64
>49	49	17.50
Sex		
Male	60	21.43
Female	220	78.57
Educational level		
Primary	87	31.07
Secondary	133	47.50
Tertiary	60	21.43
Occupation		
Skilled	126	45.00
Non-skilled	154	55.00

**Table 2: Responses to questions about familiarity toward epilepsy**

Question	Yes	No	I don't know
1.	267	8	5
2.	10	263	7
3.	178	39	63
4.	268	10	2
5.	59	33	188
6.	271	9	0
7.	249	12	19
8.	49	154	77
9.	33	89	158
10.	118	85	77

- Have you ever heard or read something about epilepsy before now?
- Do you know the cause of your child's epilepsy?
- Do you think epilepsy is a contagious disease?
- Have you ever seen an epileptic seizure?
- Do you think all the seizures are accompanied with jerky movement and loss of consciousness?
- Do you feel frightened when your child has a seizure?
- Do you think there is discrimination against children who have epilepsy?
- Do you think a child with epilepsy can be cured?
- Do you think a child with epilepsy may be as intelligent as others?
- Do you know the initial procedures to attend a child during a seizure?

to adopt in attending to a person during a seizure and they were also not aware of other clinical features of a seizure except the muscular jerks. The different procedures to adopt when there is an attack of seizure are presented on Table 3. The other procedures included use of cow and or human urine to bathe the child and to give the epileptic child to drink 68 (24.29%); use of cow dung 55(19.64%); use of onion fruit juice inserted into the eyes 210 (75%); putting scarification marks on the child and dedicating the child to idol gods for protection 29 (10.36%), and inserting crude oil into orifices and giving some to drink 220 (78.57%). The attitudes of the parents to children with epilepsy are shown on Table 4.

## Discussion

Epilepsy is one of the most common neurological disorders worldwide.<sup>[12]</sup> Knowledge and familiarity with this disorder is widespread.<sup>[4,12]</sup> In this study, one hundred and thirty-three participants (47.50%) had secondary level of education and had been familiar with epilepsy as in other reports.<sup>[7,13]</sup> However, 178 (63.57%) have some misconception

**Table 3: Most frequent answers to question ("what initial procedures would you follow to attend a person during a seizure?")**

Procedure	Yes	No
To pull the tongue	198	82
To remove near objects	267	13
To protect the head	28	0
To insert crude oil and/ onions into the eyes	233	47
To wait for the end of the seizure	43	237
To put an object between the teeth	187	93
To offer prayers	220	60
To take objects out of the mouth	277	03
To burn the feet of the child	109	171
To ensure the child sleeps for a long time	77	203
To clean up the mouth permitting saliva flow	208	72
To consult a herbalist	187	93
To take to hospital	133	147
Other procedures	85	195

**Table 4: Attitude of parents towards children with epilepsy**

Distribution of attitude toward the epileptic by gender attitude	Female (%)	Male (%)	Total
Tolerance	233(83.21)	47 (16.79)	280
Kindness	199 (71.07)	43 (15.38)	242
Sympathy	260 (92.87)	20 (7.14)	280
Indifference	35 (63.6)	20 (7.14)	55
Fear	21 (7.50)	23 (8.20)	44
Suspicion	8 (2.86)	18 (6.43)	26
Avoidance	31 (11.07)	56 (20.0)	87

about the disease, they understood that the disease is contagious. The mythic idea of epilepsy as a contagious disease has been of old and has been reported in other studies.<sup>[8,10,11]</sup>

The cause of the disorder is not known to majority 263 (93.93%) of the parents. The different clinical manifestations of epilepsy are not familiar to 188 (67.14%) of the respondents. In fact, it is believed that only those with obvious motor activity really have a seizure, other subtle types are not known by many parents. This is unfortunate because some of the children may have many unnoticed episodes of such subtle seizures. This may result in delay in commencement of appropriate anticonvulsants and other modalities of treatment. In such a situation adverse consequence on learning and cognitive abilities could ensue.

Unfortunately, many people still believe epilepsy is a disease observed always in mentally impaired persons.<sup>[14]</sup> In our study, some parents had doubts about the cognitive potential of children with epilepsy. They feel those children with epilepsy are not as bright as “normal” children; and as such may not amount to anything in life.

Many of the parents were not familiar with the initial procedures in attending to a person during a seizure. The initial procedures adopted by some parents were inappropriate, like to pull the tongue or to put objects in the children’s mouth. Some of the wrong procedures, which are potentially harmful, are still related to mythical concepts.<sup>[15]</sup>

Majority of the respondents admitted that there is a discrimination against children with epilepsy. Discrimination for this disorder has been a big social problem. It is common in every society.

Concerning cure in epilepsy, majority of the respondents admitted ignorance. As the parents are always in touch with epileptic children, public enlightenment program on health issues especially recognition and management of epilepsy must be created in order to ensure that people have sufficient knowledge about this disease, this will to improve the quality of life of those with epilepsy as reported in other study.<sup>[16,17]</sup>

Physicians especially pediatricians have an important role to play as they have an understanding of seizures, the various types, clinical manifestations, and medications. Epilepsy education program should be given to parents, caregivers, and the public in order to reduce the myths and fears surrounding epilepsy.<sup>[10,13]</sup> All these will ensure a more tolerant and positive attitude toward epilepsy. Health workers

should address this misconception about epilepsy. Adequate education and information about epilepsy should be given to the populace frequently.

## Appendix 1

### Questionnaire on knowledge and attitudes of parents toward children with epilepsy

1. Name \_\_\_\_\_ (Optional)
2. Age \_\_\_\_\_
3. Sex: Male \_\_\_\_\_ Female \_\_\_\_\_
4. Religion \_\_\_\_\_
5. Ethic group \_\_\_\_\_
6. Educational level
  - Primary \_\_\_\_\_
  - Secondary \_\_\_\_\_
  - Tertiary \_\_\_\_\_
  - Others \_\_\_\_\_
7. Occupation
  - Skilled \_\_\_\_\_
  - Non-skilled \_\_\_\_\_
8. Questions about Familiarity towards Epilepsy: Answer yes, No, I don’t know to the following questions appropriately.
  1. Have you ever heard or read something about epilepsy before now?
  2. Do you know the cause of your child’s epilepsy?
  3. Do you think epilepsy is a contagious disease?
  4. Have you ever seen an epileptic seizure?
  5. Do you think all the seizures are accompanied with jerky movement and loss of consciousness?
  6. Do you feel frightened when your child has a seizure?
  7. Do you think there is discrimination against children who have epilepsy?
  8. Do you think a child with epilepsy can be cured?
  9. Do you think a child with epilepsy may be as intelligent as others?
  10. Do you know the initial procedures to attend a child during a seizure?
9. What initial procedures would you follow to attend a person during a seizure?
  - To pull the tongue \_\_\_\_\_
  - To remove near objects \_\_\_\_\_
  - To protect the head \_\_\_\_\_
  - To insert crude oil and/onions into the eyes \_\_\_\_\_
  - To wait for the end of the seizure \_\_\_\_\_
  - To put an object between the teeth \_\_\_\_\_
  - To offer prayers \_\_\_\_\_
  - To take objects out of the mouth \_\_\_\_\_
  - To burn the feet of the child \_\_\_\_\_

To ensure the child sleeps for a long time  
 To clean up the mouth permitting saliva flow  
 To consult a herbalist  
 To take to hospital  
 Other procedures

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