

## Health-Seeking Behavior of Care-Givers of Children With Epilepsy in A Resource-Poor Country

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### Abstract

Epilepsy is one of the most important neurological disorders. Healthcare seeking by epilepsy patients and caregivers is unique due to prejudice and stigmatization. Delay in presentation leads to delay diagnosis which is important in epilepsy care. The health-care-seeking behaviour and its associated factors among caregivers of epileptic children seen in a Paediatric Neurology Clinic in resource-poor country were determined. Two hundred and fifteen caregivers of epileptic children were selected consecutively at the Paediatric Neurology Clinic of a Teaching hospital in Nigeria and were interviewed with a pretested and semi-structured questionnaire on health care seeking behaviour of caregivers of epileptic children. Delay in presentation to the clinic occurred in 194 (90.2%) patients. Use of CAM was the reason in 84 (39.1%) respondents and ignorance of the type of disease in fifty-five (25.6%) patients. There was a significant association between intervention before presentation and delay with  $\chi^2=11.21$  and  $p = 0.01$ . There is an appreciable delay in presentation of epileptic children to a specialist centre by their care givers. Decision to use other forms of intervention before presentation is significantly associated with the delay time.

**Keywords:** Healthcare-Seeking Behavior; Female Caregiver; Epileptic Children; Resource-Poor Countries; Delay Time

### Introduction

Epilepsy is one of the most common chronic neurological diseases seen in most paediatric neurology units in developing countries. Prevalence rates in Nigeria vary between 5.3 and 37 per 1000 persons with the highest rates recorded in rural areas, especially communities without health care facilities [1]. Childhood epilepsy presents a major public health challenge to these countries. Various statistics on the prevalence of childhood epilepsy shows that epilepsy remains the most common neurological disorder seen in most paediatric neurology clinic in sub-Saharan Africa [1,2]. Across various hospital-based studies in Nigeria, the prevalence rate ranges 45.3-75.4% [1,3]. These studies being hospital-based are not truly representative of the burden of childhood epilepsy

in our environment, Social stigma, poverty, ignorance, and socio-cultural beliefs and practices usually present challenges to the epidemiological study of epilepsy [3-5]. The few community-based epidemiologic studies done so far in Nigerian communities have reported prevalence rates ranging 4.3-6.2 per 1,000 for active epilepsy [4,5]. In all these studies, a higher percentage of the patients were children.

In many parts of Africa there is still much superstition about epilepsy and it is linked either with evil spirits or witchcraft activities. Consequently, epilepsy is regarded by many as a spiritual problem which is not amenable to medical treatment. Apart from these negative social attitudes, poor management of epileptic seizures may lead to increased morbidity and mortality associated with epilepsy.

Healthcare seeking behaviour of epileptic patients and their caregivers varies widely and peoples' experiences with epilepsy are often influenced by their socio-cultural environment. The health seeking behaviour of illnesses such as epilepsy is influenced by the socio-cultural factors and societal beliefs especially myths surrounding the illness and availability and proximity of health facilities. The practice of using traditional healing methods for the treatment of epilepsy is common in sub-Saharan African societies, especially among the rural and uneducated dwellers [6]. In low and middle-income countries, the proportion of people receiving basic treatment for epilepsy is limited [7].

Desirable healthcare seeking behaviour towards epilepsy can reduce its morbidity and mortality rate. Therefore, this study is design to determine the healthcare seeking behaviour of caregivers of patients attending the Paediatric Neurology Clinic of University of Nigeria Teaching Hospital Enugu and also possible factors affecting such behaviour.

## Materials and Methods

The study was conducted in the Paediatric Neurology Clinic of University of Nigeria Teaching Hospital Enugu from February 2017 to May 2017 (a 4-month period). The Paediatric Neurology clinic receives patients from different parts of Nigeria especially the South Eastern part. It runs once a week and an average of 60 epileptic children are seen every week. All caregivers of children aged more than one month to 18years with the diagnosis of epilepsy were recruited consecutively into the study. A diagnosis of epilepsy was made when a patient presents with at least two unprovoked (or reflex) seizures occurring > 24 h apart or an epilepsy syndrome. The diagnosis was made by any of the four consultants in the unit. The caregivers must be the parent, close relation or guardian who takes care of the child and therefore able to give an accurate history otherwise the patient is excluded from the study. Each folder was properly coded to avoid duplication of a patient's record.

Two hundred and fifteen caregivers of children with epilepsy were recruited and data on health seeking behaviours and its associated factors were collected from them. A predesigned, pretested, semi-structured and interviewer-administered questionnaire was used. Ethical clearance was obtained from the institution before commencement of the study.

## Data collection and procedures

Trained residents and consultants in the unit obtained informed consent before administering the pretested and structured questionnaire to the caretakers of children. The study was also ex-

plained to caretakers who agreed to participate. Their decision to participate in the study or otherwise did not in any way influence the treatment any child would receive.

Information on the bio-demographic and seizure-related variables such as age of onset of seizure and type of seizure were documented for each child. Information on age at presentation, duration of delay before presentation (gap in presentation), reason for the delay, interventions before presentation and source of referral to the Teaching hospital was documented. Participants were interviewed in privacy and unique codes were used at data entry for confidentiality. Each interview lasted for about 15 minutes.

## Data analysis

Data was analysed using statistical package for social sciences (SPSS) 20.0 software's and descriptive statistics for categorical variables were displayed into frequencies, percentages and proportions. Test for significance was carried out using Chi-square with Fisher's exact test where applicable, and *P* values < 0. 0 5 were regarded as statistically significant.

## Results

### Bio-demographic characteristics of caregivers and patients

We interviewed 215 caretakers of children with confirmed diagnosis of epilepsy attending the Paediatric Neurology Clinic of the University of Nigeria Teaching Hospital Enugu, Enugu state, Nigeria over a 4-month period. The primary care givers were the mothers (47%) followed by both parents (32.1%) and fathers in 10.7%. Majority (65%) of the caregivers had secondary education while 31.6% had tertiary education. The rest had primary or no formal education and more than 70% were mainly petty traders and artisans. The distribution of the caregivers in social classes I-V was 32 (14.9%), 65 (30.2%) 74 (34.4%) 41 (19.1%) and 3 (1.4%) patients respectively. Therefore, 171 (79.5%) were in the upper social class (I-III), while 44 (29.5%) were in the lower social class (IV-V).

Majority of the patients (38.6%) were aged 2 years or less at the time of onset of seizure as shown in table 1. At the time of presentation, the age distribution of the patients ranged from 2months to 204months and those aged more than 120months were highest in number (53.24.7%). This was followed by those aged 13-24 months (24.1%). The patients were made up of 133 males (61.9%) and 82 females (38.1%) giving a male: female ratio of (1.3:1). The distribution of children with epilepsy by seizure type shows that the most common type of epilepsy was of the generalized onset in 126 patients (55.8%), Tonic-clonic type was the most common (55.6%) in this group. Seizure of the focal onset occurred in 61 (28.4%) patients.

Age in range (months)	Age of onset of seizure No of patients (n)	Percent
1 - 12	51	23.7
13 - 24	32	14.9
25 - 36	18	8.4
37 - 48	21	9.8
49 - 60	15	7.0
61 - 72	7	3.3
73 - 84	13	6.0
85 - 96	8	3.7
97 - 108	8	3.7
109 - 120	9	4.2
>120	33	15.3
Total	215	100.0

**Table 1:** Age of onset of seizure in range (months).

Mean age of 57.77 ± 52.49 months

Table 2 shows delay time before presentation. Presentation to the clinic within less than one month of onset of seizure was regarded as no delay. While 21 (9.8%) patients were presented to the clinic by the caregiver/s within less than one month of onset of seizure, 194 (90.2%) delayed to presentation. The time between the onset of seizure and presentation to the clinic ranged from <1month to 144months with a mean of 19.2 ± 28.4 months. A total of 116 (54.0%) caregivers brought their children within 12 months followed by 27 (12.6%) who presented within 13-24months. It was observed that 23(10.7%) patients were brought to the clinic by their caregivers after 48 months of onset of seizure (Table 2).

Delay time in months	n	Percentage
< 1	20	9.3
≥1 - 12	116	54.0
13 - 24	27	12.6
25 - 36	17	7.9
37 - 48	12	5.6
> 48	23	10.6
Total	215	100.0

**Table 2:** Distribution of study population according to delay in presentation.

As regards reasons for the delay in presentation, table 3 shows that use of CAM was the reason in 84 (39.1%) respondents while ignorance of the type of disease was the reason in fifty-five (25.6%) patients. The caregivers of 23 (10.7%) claimed that they visited healthcare facilities with no established neurology unit and some

of them after using CAM. A total of 83.7% of this group were managed by a doctor while the rest were managed by a trained nurse or a community health worker.

Reason for delay	Number of patients	Percentage
no delay	20	9.3.
CAM	84	39.1
Ignorance	55	25.6
Health care facility	23	10.7
Belief	10	4.6
Distance	10	4.6
self-medication	7	3.3
Financial constraint	6	2.8
Total	215	100.0

**Table 3:** Reasons for the delay before presentation.

Table 4 shows the distribution of the study population according to intervention before presentation. No form of intervention was sought for by 53 (24.7%) caregivers and 7 (3.3%) were on self-medication. A total of 112 (52.1%) caregivers resorted to use of CAM of different forms. While 84 (38.0%) resorted to traditional healers with 68 (31.6%) using only concoctions for their children, 28 (13.0%) visited spiritual homes and 16 (7.4%) caregivers had children that received only scarification. A combination of 2 or 3 methods were used by 20 (9.3%) caregivers and 7 (3.3%) were on self-medication. The remaining 23(10.7%) caregivers visited orthodox health facilities before presentation. The commonest orthodox medications used were phonobarbitone and carbamazepine tablets.

Specific intervention		N (%)
No Intervention	.	53 (24.7)
Concoction	68	31.6
Spiritual home	28	13.0
orthodox	23	10.7
others	20	9.3
Scarification	16	7.4
Self-medication	7	3.3
Total	215	100.0

**Table 4:** Distribution of the study population according to intervention before presentation.

Of the 215 patients, 126 (58.6%) caregivers decided on their own to visit the Children Outpatient Clinic (CHOP) of our institution and were subsequently referred to the neurology clinic while 36 (16.7%), 23 (10.7%) and 22 (10.2%) were referred from private

hospitals, primary healthcare facilities and secondary healthcare facilities respectively.

There was a significant association between intervention before presentation and delay in presentation with  $\chi^2 = 11.21$  and  $p = 0.01$ . No other variable has a significant association with delay.

### Discussion

The proportion of patients who delayed to presentation to the Paediatric Neurology clinic in this study corroborates with that reported from other resource-poor countries but higher than those from Western countries [5-9]. The major reasons explaining the delay in presentation, not only in Nigeria but also in other low-income countries, are the beliefs in the cause of epilepsy, stigma and even availability of specialised care centres. In Nigeria, as in many other poor countries, patients are often taken to traditional healers for health-care needs [3,7,10]. Visit to orthodox health facility is often considered as the last option in the treatment of epilepsy by caregivers. On the contrary, Berge, et al. [8] noted a diagnostic delay ( $\geq 1$  month) for epilepsy in 70 (41%) children in a community-based setting, 48 (28%) were diagnosed between 1 and 12 months while 22 (13%) were diagnosed after more than 1 year had passed. Also Noronha, et al. [11] from Brazil noted in their survey that thirty-eight percent (38%) of patients with active epilepsy had inadequate treatment (19% on no medication) and the figures were similar in the different socioeconomic groups. This is not surprising since healthcare in the developed countries is more advanced compared to poor-resource countries.

Although 39.1% of caregivers gave the use of CAM as the reason for not presenting early to the clinic, 61.4% of the children were already on CAM of different types at the time of presentation. The use of complementary and alternative medicine is common in management of most chronic illnesses globally, more so in Nigeria [12-14].

Tsigebrhan, et al. [15] noted that a close to one-third (29.9%) of participants in their study reported using traditional and cultural healing practices while Sebera, et al. [6] reported 25% use of traditional medicines by their patients. These were mostly of plant origin, but also included some of animal origin, minerals, and a mix. The findings in these studies are not surprising since it is generally believed that epilepsy is a spiritual problem. For those that visited orthodox health facilities, first-line anti-convulsant administered to children with epilepsy was phenobarbitone, and carbamazepine. This agrees with report from most other developing countries [16-20]. Phenobarbitone is relatively very cheap and

available in our environment. Also, phenobarbitone being one of the oldest anticonvulsants, is popularly known in most communities.

In this study, 23.2% of the patients were presented to a health facility as their primary source of care before seeking specialist attention. This is close to what was reported by Udo, et al. in 2014 [21]. They reported that 28.57% of children with convulsions were presented to orthodox health facility as the first source of intervention. Social stigma, prejudice and cultural beliefs have been responsible for inappropriate management of children with epilepsy in most developing countries [5-7]. Ignorance especially inability to recognise a seizure is also a major issue in the management of epilepsy. Delayed diagnosis of epilepsy has been reported in adults and children, for whom non-convulsive seizures went undiagnosed for months or even years [8,9,22]. Seizures such as infantile spasms, absences and other non-motor types are easily missed by both observers and even the non-specialist. Some authors have studied infantile spasms and documented considerable delay in recognition of spasms by parents and diagnosis by the attending physicians [9,22].

Majority of the caregivers brought their children to the hospital without any referral and were seen at the Children's General Outpatient Clinic. The Paediatric outpatient department (POPD) of a tertiary hospital is often the main source of referral for most neurology cases in the developing countries [23]. A review of Child Neurology Services in Africa showed that patients presented to anywhere from a traditional healer to the tertiary center [24]. Few countries in the developing world had clear referral systems for the first point of contact for a child with presumed epilepsy [24]. It is therefore not surprising that these caregivers present to the tertiary centre without any referral.

Apart from intervention before presentation, no other variable had any significant association with delay time. Factors such as socio-demographic data, ignorance, beliefs, stigma, poor health delivery infrastructure and shortage of trained professionals have been reported by some authors as reasons for delay to presentation to specialised centres [22,23].

It is concluded that there is an appreciable delay in presentation of epileptic children to a specialist centre by their care givers in our environment and many of these children are managed with CAM before presentation. Also, decision to use other forms of intervention before presenting to the neurology clinic is significantly associated with the delay time.

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## Conflict of Interest

The authors declare that they have no conflict of interest for this study.

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