

Wilson C. Igwe<sup>1</sup> Esther N. Umeadi<sup>1</sup> Sylvia T. Echendu<sup>2</sup> Amalachukwu O. Odita<sup>1</sup>

<sup>1</sup> Department of Paediatrics, Faculty of Medicine, College of Health Sciences, Nnamdi Azikiwe University, Awka, Nigeria

<sup>2</sup> Department of Paediatrics, Life International Hospital, Awka, Nigeria

Address for correspondence Sylvia T. Echendu, Department of Pediatrics, Life International Hospital, Awka 420107, Nigeria (e-mail: sylvianpc2015@gmail.com).

J Neurosci Rural Pract 2022;13:448-452.

Abstract	<ul> <li>Background Early presentation and initiation of appropriate anticonvulsants help in controlling epilepsy and reducing morbidity and mortality associated with epilepsy.</li> <li>Objectives This study aimed to assess the health-seeking behavior for pediatric epilepsy among caregivers in Southeast Nigeria and the associated sociodemographic factors.</li> <li>Methodology This study was a cross-sectional descriptive and questionnaire-based study. The participants were recruited consecutively.</li> <li>Results Majority of the caregivers were mothers, had some formal education, and were employed. While 50% of these caregivers did not seek any home treatment for seizures, the other half offered various types of unorthodox home treatments. Treatments in primary and secondary levels of care were the most common form of first point of care outside the home. The most common reasons for the choice of care outside the home were advice from relations and belief in the efficacy of care offered. About 45% of the caregivers presented to tertiary level of care within 6 months of seizure onset. The major motivators for seeking care in tertiary level of care were health</li> </ul>
Keywords	workers and families of children with epilepsy.
► care-seeking	<b>Conclusion</b> There is a need to strengthen the primary and secondary levels of care
<ul> <li>pediatric epilepsy</li> </ul>	through continuous medical education of health workers in these levels of care for
<ul> <li>sociodemographic</li> </ul>	effective management of epilepsy. This will help in making prompt and correct
tactors	diagnosis, classification, and initiation of appropriate therapy in epilepsy.

## Introduction

Epilepsy is the commonest neurologic disorders with approximately 10.5 million children affected globally.<sup>1</sup> To date, there are still a lot of misconceptions surrounding the

**published online** June 6, 2022 DOI https://doi.org/ 10.1055/s-0042-1748174. ISSN 0976-3147. disease in the developing countries leading to stigmatization, resulting from poor health-seeking behaviors in epileptics and their caregivers. An episode of convulsion is a lifethreatening event that evokes great fear and anxiety among caregivers and relations who, out of ignorance, proffer

© 2022. Association for Helping Neurosurgical Sick People. All rights reserved. This is an open access article published by Thieme under the terms of the

Creative Commons Attribution-NonDerivative-NonCommercial-License, permitting copying and reproduction so long as the original work is given appropriate credit. Contents may not be used for commercial purposes, or adapted, remixed, transformed or built upon. (https://creativecommons.org/ licenses/by-nc-nd/4.0/)

Thieme Medical and Scientific Publishers Pvt. Ltd., A-12, 2nd Floor, Sector 2, Noida-201301 UP, India

various harmful remedies. It is an illness associated with a lot of social stigma and diverse cultural beliefs regarding its etiology and treatment.<sup>2</sup> A caregiver's belief, perception, social, economic, and cultural background often influence treatment decisions regarding the choice of care. Some of these treatment choices are unorthodox and harmful involving consultation with traditional and spiritual healers. The decision to seek alternative remedies is often influenced by many factors such as traditional belief systems (influence of spirits and witchcrafts as etiologies in epilepsy), ignorance of the illness, and distance to health facility and cost of care.<sup>3</sup>

Caregivers, especially in resource-poor countries, face additional burdens of ignorance, lack of access to quality care, and availability of pediatric formulations of antiepileptic medications.<sup>4</sup> Many people still believe that epilepsy is medically incurable and consequently resort to traditional and spiritual remedies that have no proven efficacy.

We examined the sociodemographic factors influencing care seeking for pediatric epilepsy in Nnewi, Southeast Nigeria.

# **Patients and Methods**

The study was a descriptive cross-sectional study which involved caregivers of children with epilepsy who presented to the pediatric neurology clinic of Nnamdi Azikiwe University Teaching Hospital, a tertiary health institution in Nnewi, Anambra State, Southeast Nigeria. The hospital maintains a pediatric neurology clinic that runs once a week, every Tuesday 8 a.m. to 4 p.m. It is manned by three consultant pediatric neurologists, registrars, and medical officers. A person was considered a caregiver if he/she was directly and consistently responsible for the child's care and treatment. Caregivers who voluntarily agreed to participate in the study were consecutively recruited as they present to the clinic.

All participants were asked to complete a designed questionnaire that sought information about their health careseeking behavior for epilepsy and their sociodemographic information via face-to-face interview. Other relevant clinical information about the patients was obtained from the medical records.

#### **Data Analysis**

Data analysis was done using Statistical Package for Social Sciences (SSPS version 20). Figures were presented as numbers and percentages and results represented in tables.

### Results

Ninety-five caregivers of children with epilepsy were recruited for the study. Of these children with epilepsy, 56 (58.9%) were males while 39 (41.1%) were females. More than 70% of the caregivers were mothers. Majority of these caregivers had some form of formal education (97.1%) and were employed (71.6%) as in **-Table 1**.

Generalized seizure was the commonest factor seen in these children. About 50% of caregivers were passive (choose

Table	1	Sociodemographic	characteristics	of	respondents
(patien	ts	and their caregiver:	5)		

Variable	Frequency	Percentage
Gender		
Male	56	58.9
Female	39	41.1
Family history of seizures		
Yes	18	18.9
No	76	80.0
Unknown	1	1.1
Relationship to patient		
Mother	70	73.7
Father	17	17.9
Others	8	8.4
Educational status		
Uneducated	2	2.1
Primary Education	26	27.4
Secondary Education	28	29.5
Tertiary Education	39	41.1
Occupation		
Unemployed	27	28.4
Self employed	49	51.6
Public servant	19	20.0

not to give any form of home treatment) and the rest of them gave various forms of unorthodox remedies (**-Table 2**). However, orthodox care was the most common type of care sought outside the home by the caregivers. Some of the caregivers gave more than one reasons for choosing a particular type of care outside the home. Choice of care outside the home was influenced by advice from relatives and belief on the efficacy of the care offered. Among the caregivers who had formal education, 84.2% preferred orthodox care as the first choice of care outside the home (**-Table 3**).

Only approximately 45% of caregivers presented within 6 months of seizure onset while approximately 26% presented more than 2 years after seizure onset as in **- Table 2**.

The main motivators of health-seeking behaviors were health workers (48.7%), families, and caregivers of children with epilepsy (33.7%).

### Discussion

Pediatric epilepsy in developing countries is surrounded by many myths and prejudices which are based on ignorance of the disease, stigma, and belief system. There are various forms of orthodox and unorthodox practices seen in pediatric epilepsy. Some of these unorthodox practices are harmful and worsens the morbidity and mortality in these patients. **Table 2** Seizure types, treatment seeking behaviors, and their motivators

Variable	Frequency	Percentage
Type of seizure		
Generalized seizures	70.0	73.7
Focal seizures	14.0	14. 7
Mixed	4.0	4.2
Unclassified	7.0	7.4
Treatment-seeking behavior (at home)		
No treatment	48	50.5
Herbal/native concoction	33	34.7
Crude/olive oil	9	9.5
Mother's urine	5	5.3
First point of care outside home		
Unorthodox (traditional/herbal/ spiritual)	15	15.8
Orthodox (private/family physician)	60	63.2
Orthodox (general/mission hospital)	20	21.0
Time gap		
<1 month	19	20.0
1–6 months	24	25.3
7–12 months	8	8.4
1–2 years	19	20.0
> 2 years	25	26.3
Motivators		
Health workers	46.0	48.7
Family/relations	32.0	33.7
Caregiver of child with seizure	8.0	8.4
Self	9.0	9.5

Stigmatization associated with the disease significantly alter their health care-seeking behaviors.<sup>5</sup>

This study reported slight male preponderance of epilepsy in children, with male-to-female ratio of 1.4:1. Some other studies also reported slight male excess.<sup>6–9</sup> The reason for this, though not clear, may be attributed to increased exposure of the brain to insults such as trauma to the brain, alcohol, and drugs, especially in adolescent males. Second, parents are often reluctantly presenting their female children to health facilities for treatment as this may impede their getting married and sometimes reflects badly on their family.<sup>10,11</sup> They will rather prefer taking them to other alternative but unorthodox places where they will be hidden from other children.

Generalized and focal epilepsies were the commonest forms of epilepsy observed in this study. This conforms with the study by Eyong et al.<sup>12</sup> Other studies in Southern Nigeria were also in tandem with this finding.<sup>8,13</sup> Sander also

Table 3 Reasons for choice of car
-----------------------------------

Variable	Unorthodox (traditional/ herbal/spiritual) n (%)	Orthodox n (%)
Reasons for choice of care		
Proximity	0	17 (17.5)
Cost of care	7 (7.4)	4 (4.2)
Belief on the care	7 (7.4)	44 (46.3)
Advice from people	1 (1.0)	15 (15.8)
Total	15 (15.8)	80(84.2)
Educational status		
Uneducated	2 (2.1)	0
Primary education	5(5.3)	21 (22.1)
Secondary education	6 (6.3)	22 (23.2)
Tertiary education	2 (2.1)	37 (38.9)
Total	15 (15.8)	80 (84.2)

reported the same finding in his study.<sup>14</sup> Alternative medicine practices are common in the management of most chronic illnesses globally, more so, in Nigeria.<sup>15,16</sup>

About 49.5% of the study participants had experienced some forms of unorthodox home therapies. These therapies include herbal concoction (34.7%), crude/olive oil (9.5%), and mothers' urine (5.3%). Ojinnaka et al<sup>9</sup> reported that 39.1% of the participants in their study were using traditional therapies in the management of epilepsies, while Tsigebrhan et al<sup>17</sup> and Sebera et al<sup>18</sup> reported 29.9 and 25% use of traditional medicines in epilepsies, respectively. Most of these home therapies are dangerous to health and neither play a role in the etiopathology pathway nor epilepsy management. High patronage of unorthodox medicine in these studies may be attributed to poverty, ignorance, cultural and religious beliefs, and perception of the cause of the disease.<sup>15</sup> Therefore, efforts should be geared toward education of patients and caregivers and emotional and financial support of children living with epilepsy.

Outside the home, approximately 80% of the study population sought for care from orthodox medicine. Similar findings were also reported by Bhattacharya et al<sup>19</sup> and Pal et al<sup>20</sup> in their studies in India. However, Sinha et al<sup>21</sup> reported a contrast finding in their study. They reported that most of the participants in their study visited quacks as their first choice. Most of the participants in this present study had some level of formal education, and this may have contributed to the high number of parents/caregivers seeking for care from orthodox medical practitioners. Second, some of these families may have had several attempts of failed home and unorthodox therapies and therefore fall back to orthodox medical practitioners as their last resort.

Educational status of the caregivers was directly related to their choice of first point of care outside the home. About 84.2% of the caregivers used in this study had some form of formal education. This stands to reason because education is one of the determinants of health and health-seeking behaviors. Educated caregivers are more likely ready to seek for care from orthodox practitioners than the uneducated. They are also more likely to be compliant to medications and counseling.

The timing between the onsets of seizure to presentation to specialist care was prolonged. About 45% presented within 6 month, while approximately 26% presented within 2 years. Within this period when patients with seizures have not presented to specialist care, several unorthodox remedies are given at home based on cultural and religious beliefs and also perception of the disease. Prolonged time gap increases morbidity and mortality in these patients. Several other studies have also reported delays in presentation to specialist care.<sup>9,21,22</sup> The cause of the delays may be attributed to the myths surrounding the illness, ignorance, poverty, and belief, that is, epilepsies are spiritual and not treatable by orthodox medicines.<sup>12,23–27</sup> This causal factors probably informed the choice of traditional herbalists by some of our patients prior to presentation. Early presentations to pediatric neurologists will make a world of difference in the management of these patients. The major reason for patronizing the unorthodox medical practitioners were belief on the care and cost of care, while the majority of those who patronized the orthodox medicine did that as a result of belief in care, proximity of care, and advice from people.

The role of health care practitioners and families in our health system cannot be overemphasized. As shown in this study, the health care practitioners and the family members were the major motivators for patients' presentation to specialist care with 48.7 and 33.7%, respectively.

### Conclusion

Education of the masses on the pathophysiology and causal factors of epilepsy will help reduce stigmatization and help patients make informed decision and choices concerning their management, enhance their self-esteem, and therefore should be encouraged. Periodic training of health care professionals should also be of immense benefit.

#### **Ethical Approval**

The Ethics committee of Nnamdi Azikiwe University Teaching Hospital, Nnewi gave approval for the study. The caregivers were educated on the need and impact of the study to the management of children with epilepsy. Only consented caregivers were recruited. Participation was voluntary and no penalty for children whose caregivers declined.

#### Authors' Contributions

W.C.I.: conceptual design and implementation of the project, writing, proofreading, and overall revision of the manuscript. E.N.U. and A.O.O.: data collection and revision of the manuscript. S.T.E.: manuscript preparation and proofreading. All the authors read and approved the final manuscript.

### Funding

This study was funded by the researchers. There was no direct or indirect cost to the patients and their caregivers.

Conflict of Interest None declared.

#### Acknowledgment

The authors thank all who contributed to this work from the initial design to its final form.

#### References

- 1 Guerrini R. Epilepsy in children. Lancet 2006;367(9509):499-524
- 2 Birbeck GL. Epilepsy care in developing countries: part I of II. Epilepsy Curr 2010;10(04):75–79
- 3 Shorvon SD, Farmer PJ. Epilepsy in developing countries: a review of epidemiological, sociocultural, and treatment aspects. Epilepsia 1988;29(Suppl 1):S36–S54
- 4 Lgwe WC. Challenges in the management of pediatric epilepsy in Nigeria. Trop I Med Res 2016;19(01):1–4
- 5 Kendall-Taylor NH, Kathomi C, Rimba K, Newton CR. Comparing characteristics of epilepsy treatment providers on the Kenyan coast: implications for treatment-seeking and intervention. Rural Remote Health 2009;9(04):1253
- 6 Olubunmi AO. Epilepsy in Nigeria- a review of etiology, epidemiology and management. Benin Journal of Postgraduate Medicine 2006;8:28–35
- 7 Taheri PA, Naseri M, Lahooti M, Sadeghi M. The life time prevalence of childhotxl seizures. Iranian I Publ Health 2009;38:69–73
- 8 Ekanem EE, Fajola AO, Usman R, et al. Management of epilepsies at the community cottage hospital level in a developing environment. Niger Med J 2019;60(04):186–189
- 9 Ojinnaka NC, Aronu AE, Ojinnaka GC, Uwaezuoke NA, Bisi-Onyernaechi AI. Health seeking behavior of caregivers of children with epilepsy. Acta Scientific Neurology 2019;2(02)
- 10 Elliott JO, Lu B, Moore JL, McAuley JW, Long L. Exercise, diet, health behaviors, and risk factors among persons with epilepsy based on the California Health Interview Survey, 2005. Epilepsy Behav 2008;13(02):307–315
- 11 Agarwal P, Mehndiratta MM, Antony AR, et al. Epilepsy in India: nuptiality behaviour and fertility. Seizure 2006;15(06):409-415
- 12 Eyong KI, Ekanem E, Asindi AA, Chimaeze T. Clinical profile of childhood epilepsy in Nigeria children seen in a tertiary hospital. Paediatr 2017;1:1138–1141
- 13 Wright J, Pickard N, Whitfield A, Hakin N. A population-based study of the prevalence, clinical characteristics and effect of ethnicity in epilepsy. Seizure 2000;9(05):309–313
- 14 Sander JW. The epidemiology of epilepsy revisited. Curr Opin Neurol 2003;16(02):165–170
- 15 Ricotti V, Delanty N. Use of complementary and alternative medicine in epilepsy. Curr Neurol Neurosci Rep 2006;6(04): 347–353
- 16 Oshikoya KA, Senbanjo IO, Njokanma OF, Soipe A. Use of complementary and alternative medicines for children with chronic health conditions in Lagos, Nigeria. BMC Complement Altern Med 2008;8:66–72
- 17 Tsigebrhan R, Charlotte H, Medhin G, Fekadu A. Help seeking and suicidalit y among people with epilepsy in a rural low- income country setting: cross sectionally. Int J Mental Health Systems 2017;11:44–52
- 18 Sebera F, Munyandamutsa N, Teuwen DE, et al. Addressing the treatment gap and societal impact of epilepsy in Rwanda–Results of a survey conducted in 2005 and subsequent actions. Epilepsy Behav 2015;46:126–132

- 19 Pal DK, Das T, Sengupta S, Chaudhury G. Help-seeking patterns for children with epilepsy in rural India: implications for service delivery. Epilepsia 2002;43(08):904–911
- 20 Bhattacharya AK, Saha SK, Roy SK. Epilepsy awareness among parents of school children–a municipal survey. J Indian Med Assoc 2007;105(05):243–246, 250
- 21 Sinha A, Mallik S, Sanyal D, Sengupta P, Dasgupta S. Healthcareseeking behavior of patients with epileptic seizure disorders attending a tertiary care hospital, kolkata. Indian J Community Med 2012;37(01):25–29
- 22 Thomas SV, Koshy S, Nair CR, Sarma SP. Frequent seizures and polytherapy can impair quality of life in persons with epilepsy. Neurol India 2005;53(01):46–50
- 23 Eyong Kl, Anah MV, Asindi AA, Ubi IO. . Nigerian secondary school teacher's knowledge and attitudes towards school children with epilepsy. I Paediatr Neurol 2012;10:111–115
- 24 Asindi AA, Eyong KL. Stigma on children living with epilepsy. I Paediatr Neurol 2012;10:105–109
- 25 Ojinnaka NC. Teachers' perception of epilepsy in Nigeria: a community-based study. Seizure 2002;11(06):386–391
- 26 Baskind R, Birbeck G. Epilepsy care in Zambia: a study of traditional healers. Epilepsia 2005;46(07):1121–1126
- 27 Ekanem EE, Fajola A, Usman R, Anidirna T, Lkeagwu G. Use of simple information technology to manage the epilepsy challenge at a community cottage hospital in Nigeria. JMSCR 2017; 5:2669