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# Clinical characteristics of children with epilepsy managed at a tertiary hospital in Africa: a retrospective study

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## Abstract

**Background:** Most children with epilepsy reside in resource-limited regions such as sub-Saharan Africa, where the majority of studies have been conducted in rural areas with limited investigations. Medical records from children with epilepsy seen at an urban hospital in Kenya were examined to provide a comprehensive description of epilepsy in children from this hospital.

**Methods:** A retrospective observational study was conducted which involved reviewing medical records of 426 epilepsy patients (260 males and 166 females) aged 0 - 18 years, seen in Nairobi, Kenya between February 2011 and December 2014.

**Results:** The most frequent age at presentation; documented in 29% was in infancy. Generalized seizures due to structural brain abnormalities were the most common form of epilepsy (28%). Lennox-Gastaut Syndrome was the most common electroclinical syndrome (7%). Focal seizures and focal seizures with loss of awareness were identified in 12% of the population. There were no cases of childhood absence epilepsy in this group. Brain atrophy was the most common MRI finding, occurring in a fifth of the population (20%), while cystic encephalomalacia occurred in 13%. Half (50%) of all EEG recordings performed for this cohort were abnormal. Generalized seizures due to structural brain abnormalities and Lennox-Gastaut Syndrome (LGS) were significant predictors of a treatment history of three or more AEDs. At the conclusion of the review period, 16% of the patients had not visited the clinic for more than 12 months and were considered to be lost to follow-up.

**Conclusion:** The highest frequency of epilepsy cases was documented in children less than one year of age. Generalized seizures due to structural abnormalities and Lennox-Gastaut syndrome were the most common seizure type and syndrome. Improvement of public awareness of different types of seizures in children may increase identification of children with childhood absence epilepsy.

**Keywords:** epilepsy, children, electroclinical syndrome, Kenya, sub-saharan Africa

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## 1 Background

The has identified epilepsy as presenting a significant burden as measured by Disability-adjusted life years (DALY) [1]. Epilepsy affects approximately 50-70 million peo-

ple worldwide [1-3] and up to 80% of those affected reside in low and middle-income countries (LMIC), such as those comprising the majority of Sub-Saharan Africa (SSA) [2][3][4]. According to studies in five SSA countries, the prevalence

of active convulsive epilepsy ranges from 7.0 - 14.8 per 1000 people [5]. Consistent with the global trend, the highest incidence of epilepsy in Africa occurs in the paediatric population [6]. The high prevalence of paediatric epilepsy in SSA is attributed to preventable risk factors including: poor perinatal care, endemic infectious diseases and head injury [6][7]. Factors contributing to the high epilepsy treatment gap in SSA include limitations in accessing adequate diagnostic and treatment services as well as negative cultural and social beliefs regarding epilepsy [3][4][6][8].

Following the 2010 proposal, Revised terminology and concepts for organization of seizures and epilepsies produced by the International League Against Epilepsy (ILAE) Commission on Classification and Terminology [9], Scheffer et al. proposed an organization of epilepsy diagnosis based on electroclinical syndrome and aetiology [10]. An electroclinical syndrome is a presentation of epilepsy that demonstrates specific outcomes, clinical and electroencephalogram (EEG) characteristics [9][10]. In resource-limited settings, various challenges present limitations for delineating epilepsy according to electroclinical syndrome and aetiology. Recent population and hospital-based studies conducted in Africa providing descriptions of epilepsy in children based on these electro-clinical syndromes or syndrome-associated outcomes are sparse to non-existent [6][10][11][12]. This paper describes the static and dynamic demographic characteristics of the patient population and seizure onset; electroclinical syndromes and seizure types; structural and electrophysiological brain abnormalities; types and number of anti-seizure medications (ASM) administered; co-morbidities and patient attrition rates.

## Methods

Paediatric neurologists and local medical personnel practicing in low-resource settings face multiple challenges. Access to neuroimaging and specialised neurophysiological testing, such as electroencephalography (EEG), is typically concentrated in single centres, usually located in larger cities.

This was a retrospective observational study based on a review of the medical records of children and adolescents (aged 0 - 18 years) with epilepsy who were seen at Aga Khan University Hospital, Nairobi, Kenya between 2011 and 2014. The hospital is an urban academic institution which functions as a primary referral hospital for clients in the vicinity and also acts as a tertiary university hospital with facilities for EEG and neuroimaging. The hospital further provides supportive funding for patients without capacity to pay for such services. Approximately 10% of patients seen at the paediatric neurology clinic were sponsored by the hospital and another 10% had their medical costs supported by the National Hospital Insurance Fund (NHIF), Kenya's national health insurance scheme. It is estimated that 65% of patients seen at this facility are referrals from outside of the Aga Khan University hospital network of facilities.

The patient medical records examined consisted of phys-

ical files and as well as information stored on the hospital's electronic databases. Physical files of patients seen at the hospital during this period indicating a history of seizures or diagnosis of epilepsy were obtained from the medical records department using ICD-10 (International Classification of Diseases, Tenth Revision) codes utilized at the time of archiving. From these records, all patients diagnosed with epilepsy, according to the ILAE 2014 definition of epilepsy, were selected for inclusion in the study [13]. According to the ILAE, epilepsy is defined as two or more unprovoked seizures occurring at least 24 hours apart, or one unprovoked seizure with a probability of recurrence determined to be greater than 60% [13]. Based on this definition, the following patients were excluded from the study: patients presenting with typical simple febrile seizures only; patients with a single seizure episode without an epilepsy syndrome diagnosis or identifiable structural brain abnormality; those with a single provoked seizure in the context of fever or hypocalcemia, for example; as well as those with episodes of syncope only; or non-epileptic, psychogenic seizures solely.

Evaluation for co-morbidities such as attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) were made by the paediatric neurologist who assumed care for the children. Screening for these co-morbidities was done using National Institute for Children's Health Quality (NICHQ), Vanderbilt Assessment Scales for ADHD and the Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition (DSM V) for ASD. Where other behavioural concerns were identified these children were evaluated by a child psychiatrist. Results of these evaluations were included in patient records. During regular clinic visits data on patient developmental progress was also included in the medical records.

Data on patient sex; age at seizure onset; electroclinical diagnosis; structural brain abnormalities; number and type of ASMs in treatment history; consistency of clinic follow-up and co-morbidities were extracted as previously documented in the patient's clinical notes. Further data was obtained from clinical notes and technical reports describing imaging and electrophysiological findings. The research assistant who collected and analysed the data was trained and supervised by the paediatric neurologist who assessed and managed the patients.

Electroclinical syndrome diagnoses were determined according to guidelines outlined in the Proposal for Revised Classification of Epilepsies and Epileptic Syndromes, by the Commission on Classification and Terminology of the ILAE [9][10]. Epilepsy that could not be classified as an electroclinical syndrome was described according to seizure type (i.e. generalized or focal) and cause (e.g. structural aetiology) [9].

Age at seizure onset was recorded in months and grouped into one of four periods of onset: i) neonatal - where onset of seizures occurred within the first 28 days of life; ii) infancy - where seizures commenced between 1 and 12 months of life; iii) childhood - where seizures began between 12 and 120 months (i.e. 1 - 10 years) of age; and iv)

adolescence - where onset of seizures occurred between 120 and 216 months of age (i.e. 10 years to 18 years). These groupings were based on WHO age classifications [14][15].

The findings of all EEG reports were counter-checked by the paediatric neurologist. Brain magnetic resonance imaging(MRI) and head computed tomography(CT) reports generated at both external hospitals and Aga Khan University Hospital were counter-checked by one neuroradiologist. Patients who had not visited the clinic for twelve months or longer were defined as being lost to follow-up.

This study was subjected to a full scientific and an expedited ethics review. The Aga Khan University Hospital Ethics Committee gave approval to conduct the study (reference number 2015/REC-27 (v1) dated 29th June 2015). Permission to access records from Aga Khan University Medical Records Department was granted from 30th June 2015 to 29th June 2016. As this was a retrospective review of medical records without direct patient contact, the Institutional Review Board(IRB) did not require patient consent to participate.

In analysing the data, patients were grouped primarily by electroclinical syndrome [9][10]. In cases where an electroclinical diagnosis could not be applied, patients were categorised according to seizure type and aetiology where known [9].

Variables including sex, age at seizure onset, use, results of investigations into structural and electrophysiological brain abnormalities, consistency of clinic follow up and co-morbidities were documented for all patients in the study group and these were analysed using descriptive statistics and presented in frequency tables and distributions.

## Results

A total of 1,106 children were seen at the paediatric neurology clinic between February 2011 and December 2014. Among these were 576 children with a history of seizures, of whom only 426 had a diagnosis of epilepsy and were included in the study as shown in Table 1.

### *Sex and diagnosis frequency*

The male: female ratio was 1.6:1 (260 males and 166 females), with males comprising 61% of the study population (Table 1). LGS was the most common electroclinical syndrome. Overall, of all the syndrome and seizure types, generalized seizures associated with structural brain abnormalities was the most frequent form of epilepsy.

### *Age at seizure onset*

Fifty-six percent of patients 56.6% (N = 241) developed seizures between 1 and 10 years of age while 29% (N = 125) of patients developed seizures in infancy (between 1 and 12 months of age.) Fewer patients, 7.5% (N = 32), presented with seizures for the first time between 10 and 18 years. This data is shown in Table 2.

### *Structural and electrophysiological brain abnormalities*

A total of 8.5% (N = 36) of patients had no investigation results available on file. The majority of the patients, 86.4% (N = 368) had a sleep EEG reported, while approximately half of the study population, 48.8% (N = 208) had a brain MRI scan with contrast. Reported findings from the brain MRI scans are summarized in Table 3. Ten children (4.8%) who had both brain MRI and head CT reports had their findings included in the brain MRI group. Four among these (0.9%) had both normal head CTs and brain MRIs while three children (1.4%) had delayed myelination on brain MRI. Two children (0.9%) had white matter hyperintensities and one child (0.4%) had polymicrogyria on brain MRI.

Among those who did not have brain MRI, 19.2% (N = 106) of patients had CT scans, of which 53.4% (N = 57) were abnormal. Brain atrophy and hydrocephalus were the most common abnormalities identified in 45.6% (N = 26) and (N = 10) 17.5% children respectively. A total of 47.2% (N = 50) had normal head CT reports. In this cohort 26.2% (N = 112) of children with epilepsy had no neuroimaging records.

A total of 557 EEG recordings were performed for the 426 patients in the study. Among these, 5.9% of all the EEG recordings (N = 33) demonstrated indeterminate findings, while 43.1% (N = 240) of these were normal and 50.1% (N = 284) were abnormal. Of the abnormal EEG recordings 56.7% (N = 161) showed generalized spike wave discharges, 25.3% (N = 72) showed focal spike wave discharges while 17.9% (N = 51) of abnormal EEG recordings showed slowing activity.

### *Anti-seizure medication use*

Of the total patient population, 89.4% (N = 381) had been treated with one or more ASMs since onset of epilepsy while 10.6% (N = 45) of patients had not been on MRI treatment (Table 4). Among those on antiepileptic medication, 42.7% (N = 176) of patients been treated with one ASM, 24.2% (N = 100) with two ASMs, 17.4% (N = 72) with three ASMs and 9.2% (N = 38) with four or more ASMs serially. Table 4 summarizes types of ASMs that were utilized in this population in order of frequency. As illustrated above individual patients may have utilized more than one medication. Valproic acid was the most commonly used ASM with 69.4% usage amongst the study participants, followed by Carbamazepine and Clonazepam with 24.2% and 20.8% usage respectively. In contrast, Pregabalin and Gabapentin were the least used (each having been utilized by 0.3% of study participants).

### *Co-morbidities*

Of the 426 children, 21.6% (N = 92) had psychiatric co-morbidities: Among these 10.1% (N = 43) had ADHD; 8.2% (N = 35) had ASD; 0.5% (N = 2) had mood disorders; 1.2% (N = 5) had a psychosomatic illness; and 1.6% (N = 7) had other behavioural concerns. Further, almost half of the patients with psychiatric co-morbidities 0.9% (N = 40) had focal seizures with loss of awareness. Various neurodevelopmental co-morbidities were observed in this study popu-

**Table 1** Distribution of the Epilepsy diagnoses within the study sample, by sex

Diagnosis	Total N = 426 -100%	Male N = 260 -61%	Female N = 166 -39%	Proportion of Cohort %
<b>Epilepsy syndromes</b>				
Lennox-Gastaut syndrome(LGS)	29	18	11	6.8
Infantile spasms (West Syndrome)	22	12	10	5.2
Epilepsy with myoclonic astatic seizures(EMA)	5	4	1	1.2
Juvenile myoclonic epilepsy(JME)	5	1	4	1.2
Juvenile absence epilepsy(JAE)	3	2	1	0.7
Childhood epilepsy with centro-temporal spikes(CECTS)	2	2	0	0.5
Dravet syndrome	1	1	0	0.2
<b>Seizure semiologies</b>				
Generalized Seizures with structural brain abnormalities	117	76	41	27.5
Generalized Epilepsies of unknown cause	99	60	39	23.2
Focal Seizures	52	28	24	12.2
Focal seizures with loss of awareness	40	26	14	9.4
Febrile seizures plus	44	24	20	10.3
Genetic Epilepsy with febrile seizures plus	7	6	1	1.6

N represents the number of study participants

**Table 2** Distribution of age at seizure onset

Diagnosis	Total	Neonatal < 28 days		Infancy 1-12 months		Childhood 12-120 months		Adolescence 120-216 months	
		N	%	N	%	N	%	N	%
<b>Epilepsy syndromes</b>									
Epilepsy syndromes	29	0	0	7	24.1	22	75.9	0	0
Infantile spasms (West Syndrome)	22	7	31.8	14	63.6	1	4.5	0	0
Epilepsy with myoclonic astatic seizures(EMA)	5	0	0	0	0	5	100	0	0
Juvenile myoclonic epilepsy(JME)	5	0	0	0	0	1	20	4	80
Juvenile absence epilepsy(JAE)	3	0	0	0	0	2	66.7	1	33.3
Childhood epilepsy with centro-temporal spikes(CECTS)	2	0	0	0	0	2	100	0	0
Dravet syndrome	1	0	0	1	100	0	0	0	0
<b>Seizure semiologies</b>									
Generalized seizures with structural brain abnormalities	117	18	15.4	54	50.9	37	34.9	8	7.5
Generalized epilepsies of unknown cause	99	0	0	19	19.2	68	68.7	12	12.1
Focal Seizures	52	3	5.8	16	30.8	31	59.6	2	3.8
Focal seizures with loss of awareness	40	0	0	5	12.5	32	80	3	7.5
Febrile seizures plus	44	0	0	8	18.2	34	77.3	2	4.5
Genetic epilepsy with febrile seizures plus	7	0	0	1	14.3	6	85.7	0	0
<b>Total</b>	<b>426</b>	<b>28</b>	<b>6.6</b>	<b>125</b>	<b>29.3</b>	<b>241</b>	<b>56.6</b>	<b>32</b>	<b>7.5</b>

N represents the number of study participants

229 lation. These included developmental delay in 27.9% (N =  
 230 119) of patients; speech delay in 17.4% (N = 74); intellec-  
 231 tual disability in 8.7% (N = 37); cerebral palsy in 15.3%  
 232 (n = 65); and developmental milestone regression in 7.8%  
 233 (N = 33) of patients. The greatest proportion of neurologi-  
 234 cal co-morbidities was observed among patients with (N  
 235 = 29), including developmental delay in 34.5% (N = 10)  
 236 of patients, speech delay in 20.7% (N = 6), intellectual  
 237 or learning disabilities in 27.6% (N = 8), and regression of  
 238 milestones was in 24% (N = 7).

### 239 **Attrition rates**

240 At the conclusion of the review period, one patient had  
 241 died and an additional 16.4% (N = 70) of study participants  
 242 who had not visited the clinic for more than 12 months were  
 243 considered to be lost to follow-up. In this group there were  
 244 60% (N = 42) males and 40% (N = 28) females. Among  
 245 these, 41.5% (N = 29) were aged less than 24 months at  
 246 initial presentation to the clinic. The diagnosis of patients  
 247 lost to follow up is summarized in Table 5.

## 248 **Discussion**

249 In Africa preventable factors such as perinatal insults dur-  
 250 ing complications of delivery, maternal and infant infections  
 251 and trauma contribute to the high prevalence of epilepsy  
 252 [16][17][18][19][20][21][22]. Limited access to quality  
 253 healthcare care facilities and services further negatively im-  
 254 pact prevention and management of epilepsy on the con-  
 255 tinent [19][23][24][25][26][27][28][29][30]. Epilepsy is  
 256 associated with significant personal and social consequences  
 257 including increased risk of injury, limited education, unem-  
 258 ployment and social ostracism [31][32][33][34][35].

259 Infants in their first year of life accounted for the highest  
 260 incidence of epilepsy overall and the highest proportion of  
 261 paediatric patients presenting with generalized seizures due  
 262 to structural brain abnormalities. These two observations  
 263 may be related to the significant proportion of infants who  
 264 had birth injury and various other congenital brain malfor-  
 265 mations. These findings are in keeping with a population  
 266 study by Ellenberg et al showed that the highest incidence  
 267 of non-febrile seizures occurred within the first year of life  
 268 [36]. Targeted efforts to identify infants with epilepsy in the  
 269 first year of life in this context would therefore be important  
 270 in ameliorating morbidity associated with this condition.

271 Generalized epilepsy has been found to be the most com-  
 272 mon kind of epilepsy in many paediatric, and adult popu-  
 273 lation studies [20][21][37]. This was found to be the case  
 274 among patients in this cohort, a significant proportion of  
 275 whom had generalized seizures due to structural abnormali-  
 276 ties. This observation would be reflective of the fact that  
 277 members of the cohort attended an urban medical facility  
 278 where appropriate neuroimaging facilities were available.  
 279 Data from various parts of rural Kenya regarding children  
 280 with epilepsy indicate that generalized seizure are the most  
 281 easily identifiable seizure presentations in the community  
 282 [38][39]. Studies which reported higher prevalence of fo-

283 cal onset seizures also reported a higher incidence of acute  
 284 symptomatic seizures in a malaria endemic area [40]. A  
 285 multi-site population study in the country may help eluci-  
 286 date the distribution of epilepsy seizure types better.

287 Generalized epilepsy of unknown cause was the second  
 288 most frequent type of epilepsy observed in this cohort.  
 289 Other studies in Africa have also demonstrated that the  
 290 cause of epilepsy can frequently be unknown [41][42][22].  
 291 Inability to determine the cause of epilepsy is largely due to  
 292 financial and diagnostic limitations at the point of care [18].  
 293 Further, genetic and metabolic testing is not available locally  
 294 and performance of these tests by overseas healthcare part-  
 295 ners is associated with significant financial costs and time  
 296 delays as has been our experience. This is particularly note-  
 297 worthy when considering that Kenya's per capita GDP in  
 298 2016 was USD 1,410 [43], meaning that patients lacking  
 299 medical insurance cover would struggle to access requisite  
 300 tests such as the early infantile epileptic encephalopathy se-  
 301 quencing panel that costs USD 2000 on average.

302 Since generalized epilepsy of unknown cause was a fre-  
 303 quent observation amongst patients in this cohort, as in  
 304 other studies, and in light of potential benefits of deter-  
 305 mining the cause of epilepsy where possible, interventions  
 306 to improve the quality of and access to local diagnostic  
 307 facilities such as neuro-imaging, electroencephalography,  
 308 metabolic and genetic testing would be beneficial to the  
 309 management of epilepsy patients in sub-Saharan Africa.

310 Positive family history of febrile seizures in children who  
 311 presented with atypical febrile seizures allowing a diagnosis  
 312 of Genetic Epilepsy with febrile seizures plus was rarely de-  
 313 termined in this cohort. This could be due to low rates of di-  
 314 agnosis of atypical febrile seizures in this setting or cultural  
 315 reasons where families rarely discuss seizures in children  
 316 openly due to associated stigma. Cultural reasons may also  
 317 contribute to the predilection for more significantly male  
 318 children presenting for care at this centre.

319 In this cohort we identified no children with childhood  
 320 absence epilepsy(CAE) which being a common form of  
 321 epilepsy, was an unexpected finding [40][44]. This is most  
 322 likely due to under-recognition and lack of referral of such  
 323 cases to the neurology teams. It is possible CAE is managed  
 324 by paediatricians and being generally responsive to widely  
 325 available first line ASMs, referral in such cases would not be  
 326 required.

327 Critically, patients who are lost to follow-up are likely  
 328 to remain untreated. Long-standing, untreated epilepsy  
 329 has detrimental and enduring personal and social con-  
 330 sequences, including impaired intellectual performance  
 331 [31][32][33][34][35]. For these reasons, there is an ur-  
 332 gent need to determine the reasons for defaulting on clinic  
 333 follow-up [37]. Findings from these studies which may be  
 334 applicable to other similar hospital settings would enable  
 335 this institution to address these specific risk factors and po-  
 336 tentially reduce the number of children with epilepsy who  
 337 remain untreated.

### 338 **Study limitations**

**Table 3** Brain MRI findings in order of frequency

Brain findings	Total N = 208	Proportion of Cohort %
Normal	55	26.4
Brain atrophy	41	19.7
Cystic encephalomalacia	26	12.5
Mesial temporal sclerosis	20	9.6
White matter hyper intensities	16	7.7
Hydrocephalus	11	5.3
Benign enlargement of the subdural space	8	3.8
Periventricular leukomalacia	6	2.9
Agenesis of corpus callosum	6	2.9
Delayed myelination	4	1.9
Tuberous sclerosis complex (sub-ependymal nodules, hamartomas, calcifications)	3	1.5
Hemimegalencephaly	3	1.5
Meningeal enhancement	3	1.5
Holoprosencephaly	2	0.9
Schizencephaly	2	0.9
Lissencephaly	1	0.5
Polymicrogyria	1	0.5

N represents the number of study participants

**Table 4** utilized in epilepsy management

Medication	N = 381	Proportion of cohort %
Valproic Acid	267	69.4
Phenobarbital	77	20
Clonazepam	80	20.8
Levetiracetam	46	11.9
Phenytoin	34	8.8
Vigabatrin	12	3.1
Carbamazepine	93	24.2
Lamotrigine	26	6.8
Topiramate	10	2.6
Pregabalin	1	0.3
Gabapentin	1	0.3
Clobazam	4	1

N represents the number of study participants

Findings presented here represent the context of an urban hospital and would be beneficial to the populations in similar contexts but would not be directly generalizable to most of the sub-Saharan African population who lack access to care and facilities of this nature. Cognitive, motor and behavioural outcomes for the different syndromes or seizure groups were not studied as this information was not measured in a standardised fashion for all the patients in the study population. This was a retrospective study and as such, missing data as well as other factors could impact on the quality of data generated. Future prospective studies in this area should make provision for two reviews of each laboratory investigation and plan to address inter-rater variance.

## Conclusions

The study identified that males comprised the majority of paediatric epilepsy patients seen at this paediatric neurology service while LGS was the most common electroclinical syndrome. Generalized seizures associated with structural brain abnormalities were the most frequent form of epilepsy overall. Half of all EEGs performed displayed abnormalities including generalized spike wave discharges, focal spike wave discharges and slow background activity in decreasing occurrence respectively. Majority of patients had been treated with one ASM only, with valproic acid being most common utilized ASM. Psychiatric co-morbidities were more commonly identified in children with focal seizures while and those with Lennox Gastaut syndrome were more likely to present with developmental delay. The findings from this study hold significant relevance for the improved diagnosis and management of epilepsy among paediatric patients in urban SSA, including need for: greater preventive and diagnostic care predominantly targeting children in the 1 to 10 year age group; increased efforts to address patient attrition rates; and improvement of practitioner and public awareness of common forms of epilepsy to facilitate early detection and appropriate referral and management. This paper's contribution to existing research concerns its potential to address a dearth of recent studies conducted in sub-Saharan Africa describing electro-clinical syndromes or syndrome-associated outcomes among children in the region. Prospective studies may seek to explore precise relationships between specific syndromes and variable such as psychiatric and neuro-developmental co-morbidities and responses to anti-epileptic drugs.



**Table 5** Diagnosis of patients lost to follow up

Diagnosis	N = 70	Proportion of cohort %
Focal seizures with loss of awareness	6	8.3
	5	7
Generalized epilepsies of unknown cause	39	55.7
Focal seizures	4	5.7
Epileptic spasms (West syndrome)	2	2.8
Generalized Seizures with structural brain abnormalities	4	5.6
	2	2.8
	1	1.4

N represents the number of study participants

## Abbreviations

<b>ADHD</b>	Attention deficit hyperactivity disorder
<b>ASD</b>	Autism spectrum disorder
<b>ASM</b>	Anti-seizure medication
<b>CAE</b>	Childhood absence epilepsy
<b>CECTS</b>	Childhood epilepsy with centro-temporal spikes
<b>DALY</b>	Disability-adjusted life years
<b>EEG</b>	Electroencephalogram
<b>EMA</b>	Epilepsy with myoclonic astatic seizures
<b>ILAE</b>	International League Against Epilepsy
<b>JAE</b>	Juvenile absence epilepsy
<b>JME</b>	Juvenile myoclonic epilepsy
<b>LGS</b>	Lennox-Gastaut syndrome
<b>LMIC</b>	Low and Middle Income Countries
<b>MRI</b>	Magnetic resonance imaging
<b>SSA</b>	Sub-Saharan Africa
<b>WHO</b>	World Health Organization

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## Competing interests

The authors declare no competing interests. No funding was sought for this study. The Aga Khan University catered for research time for PS, AB and SL.

## Authors' contributions

PS designed the study. AB and SL analysed the patient data regarding the following variables: electroclinical syndromes, seizure types, patient gender, age at seizure onset, structural and electrophysiological brain abnormalities, medication history, co-morbidities, and other relevant medical and family history. KD, JW and CN were major contributors in writing the manuscript. All authors read and approved the final manuscript.

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## References

- [1] World Health Organization. World Health Organization: Global Health Estimates 2015: DALYs by Cause, Age, Sex, by Country and by Region, 2000-2015;. Available from: [https://www.who.int/healthinfo/global\\_burden\\_disease/estimates/en/index2.html](https://www.who.int/healthinfo/global_burden_disease/estimates/en/index2.html).
- [2] World Health Organization. World Health Organization Fact sheet on Epilepsy; Available from: <https://www.who.int/en/news-room/fact-sheets/detail/epilepsy>.
- [3] Mbuba CK, Ngugi AK, Newton CR, Carter JA. The

- 450 epilepsy treatment gap in developing countries: a  
 451 systematic review of the magnitude, causes, and inter-  
 452 vention strategies. *Epilepsia*. 2008 sep;49(9):1491–  
 453 503. Available from: [http://www.ncbi.nlm.nih.gov/  
 454 pubmed/18557778](http://www.ncbi.nlm.nih.gov/pubmed/18557778)[http://www.pubmedcentral.nih.  
 455 gov/articlerender.fcgi?artid=PMC3573323](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3573323).
- [4] Meyer AC, Dua T, Ma J, Saxena S, Birbeck G. Global  
 456 disparities in the epilepsy treatment gap: a systematic  
 457 review. *Bulletin of the World Health Organization*. 2010 apr;88(4):260–6. Available from: [http:  
 458 //www.ncbi.nlm.nih.gov/pubmed/20431789](http://www.ncbi.nlm.nih.gov/pubmed/20431789)[http:  
 459 //www.pubmedcentral.nih.gov/articlerender.fcgi?  
 460 artid=PMC2855595](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC2855595).
- [5] Ngugi AK, Bottomley C, Kleinschmidt I, Wagner RG,  
 461 Kakooza-Mwesige A, Ae-Ngibise K, et al. Prevalence  
 462 of active convulsive epilepsy in sub-Saharan Africa  
 463 and associated risk factors: cross-sectional  
 464 and case-control studies. *The Lancet Neurology*.  
 465 2013 mar;12(3):253–63. Available from: [http:  
 466 //www.ncbi.nlm.nih.gov/pubmed/23375964](http://www.ncbi.nlm.nih.gov/pubmed/23375964)[http:  
 467 //www.pubmedcentral.nih.gov/articlerender.fcgi?  
 468 artid=PMC3581814](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3581814).
- [6] Wilmshurst JM, Kakooza-Mwesige A, Newton  
 469 CR. The challenges of managing children with  
 470 epilepsy in Africa. *Seminars in pediatric neurology*.  
 471 2014 mar;21(1):36–41. Available from: [http:  
 472 //www.ncbi.nlm.nih.gov/pubmed/24655403](http://www.ncbi.nlm.nih.gov/pubmed/24655403)[http:  
 473 //www.pubmedcentral.nih.gov/articlerender.fcgi?  
 474 artid=PMC5496661](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC5496661).
- [7] Dekker PA. World Health Organization: Epilepsy,  
 475 A manual for medical and clinical officers in Africa;  
 476 2002.
- [8] Meinardi H, Scott RA, Reis R, Sander JW, ILAE Com-  
 477 mission on the Developing World. The treatment gap  
 478 in epilepsy: the current situation and ways forward.  
 479 *Epilepsia*. 2001 jan;42(1):136–49. Available from:  
 480 <http://www.ncbi.nlm.nih.gov/pubmed/11207798>.
- [9] Berg AT, Berkovic SF, Brodie MJ, Buchhalter J, Cross  
 481 JH, van Emde Boas W, et al. Revised terminology  
 482 and concepts for organization of seizures and epilep-  
 483 sies: report of the ILAE Commission on Classification  
 484 and Terminology, 2005-2009. *Epilepsia*. 2010  
 485 apr;51(4):676–85. Available from: [http://www.ncbi.  
 486 nlm.nih.gov/pubmed/20196795](http://www.ncbi.nlm.nih.gov/pubmed/20196795).
- [10] Scheffer IE, Berkovic S, Capovilla G, Connolly  
 487 MB, French J, Guilhoto L, et al. ILAE classifica-  
 488 tion of the epilepsies: Position paper of the ILAE  
 489 Commission for Classification and Terminology.  
 490 *Epilepsia*. 2017;58(4):512–521. Available from: [http:  
 491 //www.ncbi.nlm.nih.gov/pubmed/28276062](http://www.ncbi.nlm.nih.gov/pubmed/28276062)[http:  
 492 //www.pubmedcentral.nih.gov/articlerender.fcgi?  
 493 artid=PMC5386840](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC5386840).
- [11] Birbeck GL. Revising and refining the epilepsy  
 494 classification system: priorities from a developing  
 495 world perspective. *Epilepsia*. 2012 jul;53 Suppl  
 496 2:18–21. Available from: [http://www.ncbi.nlm.nih.  
 497 gov/pubmed/22765500](http://www.ncbi.nlm.nih.gov/pubmed/22765500)[http://www.pubmedcentral.  
 498 nih.gov/articlerender.fcgi?artid=PMC3397392](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3397392).
- [12] Kariuki SM, Matuja W, Akpalu A, Kakooza-Mwesige  
 499 A, Chabi M, Wagner RG, et al. Clinical features, prox-  
 500 imate causes, and consequences of active convulsive  
 501 epilepsy in Africa. *Epilepsia*. 2014 jan;55(1):76–  
 502 85. Available from: [http://www.ncbi.nlm.nih.gov/  
 503 pubmed/24116877](http://www.ncbi.nlm.nih.gov/pubmed/24116877)[http://www.pubmedcentral.nih.  
 504 gov/articlerender.fcgi?artid=PMC4074306](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC4074306).
- [13] Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A,  
 505 Cross JH, Elger CE, et al. ILAE official report: a prac-  
 506 tical clinical definition of epilepsy. *Epilepsia*. 2014  
 507 apr;55(4):475–82. Available from: [http://www.ncbi.  
 508 nlm.nih.gov/pubmed/24730690](http://www.ncbi.nlm.nih.gov/pubmed/24730690).
- [14] World Health Organization. HIV/AIDS Definition of  
 509 key terms; 2013. Available from: [https://www.who.  
 510 int/hiv/pub/guidelines/arv2013/intro/keyterms/en/](https://www.who.int/hiv/pub/guidelines/arv2013/intro/keyterms/en/).
- [15] World Health Organization. Infant, Newborn;. Avail-  
 511 able from: [https://www.who.int/infant-newborn/  
 512 en/](https://www.who.int/infant-newborn/en/).
- [16] Burton KJ, Rogathe J, Whittaker R, Mankad K,  
 513 Hunter E, Burton MJ, et al. Epilepsy in Tanzanian  
 514 children: association with perinatal events and  
 515 other risk factors. *Epilepsia*. 2012 apr;53(4):752–  
 516 60. Available from: [http://www.ncbi.nlm.nih.gov/  
 517 pubmed/22308971](http://www.ncbi.nlm.nih.gov/pubmed/22308971)[http://www.pubmedcentral.nih.  
 518 gov/articlerender.fcgi?artid=PMC3467761](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3467761).
- [17] Gebremariam A, Gutema Y, Leuel A, Fekadu H. Early-  
 519 onset neonatal seizures: types, risk factors and short-  
 520 term outcome. *Annals of tropical paediatrics*. 2006  
 521 jun;26(2):127–31. Available from: [http://www.ncbi.  
 522 nlm.nih.gov/pubmed/16709331](http://www.ncbi.nlm.nih.gov/pubmed/16709331).
- [18] Kanu I, Anyanwu EC, Nwachukwu NC, Ehiri JE, Mer-  
 523 rick J. Clinical Microbiological Aspects of Epilep-  
 524 tic Seizures in the Tropical Countries with Spe-  
 525 cific Focus on Nigeria. *The Scientific World JOUR-  
 526 NAL*. 2005;5:401–409. Available from: [http://www.  
 527 hindawi.com/journals/tswj/2005/859645/abs/](http://www.hindawi.com/journals/tswj/2005/859645/abs/).
- [19] Munyoki G, Edwards T, White S, Kwasa T, Chengo  
 528 E, Kokwaro G, et al. Clinical and neurophysi-  
 529 ologic features of active convulsive epilepsy in  
 530 rural Kenya: a population-based study. *Epilepsia*.  
 531 2010 dec;51(12):2370–6. Available from: [http:  
 532 //www.ncbi.nlm.nih.gov/pubmed/20608962](http://www.ncbi.nlm.nih.gov/pubmed/20608962)[http:  
 533 //www.pubmedcentral.nih.gov/articlerender.fcgi?  
 534 artid=PMC3188844](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3188844).

- [20] Nicoletti A, Bartoloni A, Sofia V, Mantella A, Nsen-giyumva G, Frescaline G, et al. Epilepsy and tox-ocariasis: a case-control study in Burundi. *Epilepsia*. 2007 may;48(5):894–9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17508999>. 552 553 554 555 556
- [21] Ogunlesi T, Ogundeyi M, Olowu A. Pattern of child-hood epilepsies in Sagumu, Nigeria. *Indian journal of pediatrics*. 2009 apr;76(4):385–9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19205638>. 557 558 559 560
- [22] Ogunrin OA, Adeyekun A, Adudu P. Etiologies of epilepsy and health-seeking itinerary of patients with epilepsy in a resource poor setting: analysis of 342 Nigerian Africans. *Seizure*. 2013 sep;22(7):572–6. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23664807>. 561 562 563 564 565 566
- [23] Berhanu S, Alemu S, Prevett M, Parry EHO. Primary care treatment of epilepsy in rural Ethiopia: causes of default from follow-up. *Seizure*. 2009 mar;18(2):100–3. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18701322>. 567 568 569 570 571
- [24] Coleman R, Gill G, Wilkinson D. Noncommunicable disease management in resource-poor settings: a primary care model from rural South Africa. *Bulletin of the World Health Organization*. 1998;76(6):633–40. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10191559><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC2312489>. 572 573 574 575 576 577 578
- [25] Diop AG, Hesdorffer DC, Logroscino G, Hauser WA. Epilepsy and mortality in Africa: a review of the literature. *Epilepsia*. 2005;46 Suppl 1:33–5. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16393176>. 579 580 581 582
- [26] Elechi CA. Default and non-compliance among adult epileptics in Zaria, Nigeria. The need to re-structure continued care. *Tropical and geographical medicine*;43(1-2):242–5. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/1750124>. 583 584 585 586 587
- [27] Kaiser C, Asaba G, Mugisa C, Kipp W, Kasoro S, Rubaale T, et al. Antiepileptic drug treatment in rural Africa: involving the community. *Tropical doctor*. 1998 apr;28(2):73–7. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/9594671>. 588 589 590 591 592
- [28] Kalk WJ, Veriawa Y, Osler C. A survey of hospital out-patient services for chronic diseases in Gauteng. *South African medical journal = Suid-Afrikaanse tydskrif vir geneeskunde*. 2000 jan;90(1):57–61. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10721395>. 593 594 595 596 597
- [29] Nimaga K, Desplats D, Doumbo O, Farnarier G. Treatment with phenobarbital and monitoring of epileptic patients in rural Mali. *Bulletin of the World Health Organization*. 2002;80(7):532–7. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12163916><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC2567553>. 598 599 600 601 602
- [30] Sanya EO, Wahab KW, Desalu OO, Bello HA, Ademiluyi BA, Alaofin WA, et al. A 3 year audit of adult epilepsy care in a Nigerian tertiary hospital (2011-2013). *Annals of African medicine*;14(2):97–102. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25693817>. 603 604 605 606 607 608 609 610
- [31] Burton K, Rogathe J, Whittaker RG, Mankad K, Hunter E, Burton MJ, et al. Co-morbidity of epilepsy in Tanzanian children: a community-based case-control study. *Seizure*. 2012 apr;21(3):169–74. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/22130004><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3672980>. 611 612 613 614 615 616 617
- [32] Duggan MB. Epilepsy and its effects on children and families in rural Uganda. *African health sciences*. 2013 sep;13(3):613–23. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24250298><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3824457>. 618 619 620 621 622 623
- [33] Elafros MA, Sakubita-Simasiku C, Atadzhanov M, Haworth A, Chomba E, Birbeck GL. Stigma and psychiatric morbidity among mothers of children with epilepsy in Zambia. *International health*. 2013 dec;5(4):288–94. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24214528><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3850361>. 624 625 626 627 628 629 630 631
- [34] Koba Bora B, Lez DM, Luwa DO, Baguma MB, Katumbay DT, Kalula TK, et al. Living with epilepsy in Lubumbashi (Democratic Republic of Congo): epidemiology, risk factors and treatment gap. *The Pan African medical journal*. 2015;21:303. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26587151><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC4633807>. 632 633 634 635 636 637 638 639
- [35] Sebera F, Munyandamutsa N, Teuwen DE, Ndiaye IP, Diop AG, Tofighy A, et al. Addressing the treatment gap and societal impact of epilepsy in Rwanda—Results of a survey conducted in 2005 and subsequent actions. *Epilepsy & behavior : E&B*. 2015 may;46:126–32. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25936276><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC4464509>. 640 641 642 643 644 645 646 647
- [36] Ellenberg JH, Hirtz DG, Nelson KB. Age at onset of seizures in young children. *Annals of neurology*. 1984 feb;15(2):127–34. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/6703653>. 648 649 650 651
- [37] Ogunrin OA, Adeyekun AA. Profile of post-traumatic epilepsy in Benin City, Nigeria. *West African journal of medicine*;29(3):153–7. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20665457>. 652 653 654 655

- 656 [38] Feksi AT, Kaamugisha J, Gatiti S, Sander JW, Shorvon  
657 SD. A comprehensive community epilepsy pro-  
658 gramme: the Nakuru project. *Epilepsy research*. 1991  
659 apr;8(3):252–9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/1868825>.  
660
- 661 [39] Carter JA, Neville BGR, White S, Ross AJ, Otieno G,  
662 Mturi N, et al. Increased prevalence of epilepsy as-  
663 sociated with severe falciparum malaria in children.  
664 *Epilepsia*. 2004 aug;45(8):978–81. Available from:  
665 <http://www.ncbi.nlm.nih.gov/pubmed/15270766>.
- 666 [40] Kind CJ, Newton CRJC, Kariuki SM, Neurodevelop-  
667 ment Disorders study group. Prevalence, risk factors,  
668 and neurobehavioral comorbidities of epilepsy in  
669 Kenyan children. *Epilepsia open*. 2017;2(4):388–  
670 399. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/29588970><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC5862110>.  
671
- 672 [41] Lagunju IA, Oyinlade AO, Babatunde OD. Seizure-  
673 related injuries in children and adolescents with  
674 epilepsy. *Epilepsy & behavior : E&B*. 2016 jan;54:131–  
675 4. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26708062>.  
676
- 677 [42] Mung'ala-Odera V, White S, Meehan R, Otieno GO,  
678 Njuguna P, Mturi N, et al. Prevalence, incidence  
679 and risk factors of epilepsy in older children in  
680 rural Kenya. *Seizure*. 2008 jul;17(5):396–404.  
681 Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18249012><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3428880>.  
682
- 683 [43] The World Bank. GDP per capita (current US\$) -  
684 Kenya;. Available from: <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD?locations=KE>.  
685
- 686 [44] Buchhalter J. Treatment of childhood absence  
687 epilepsy-an evidence-based answer at last! *Epilepsy  
688 currents*. 2011 jan;11(1):12–5. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21852860><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3063575>.  
689  
690  
691  
692  
693