Epilepsy in a health district in North-West Cameroon: clinical characteristics and treatment gap

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Abstract

Introduction: Epilepsy is a common yet misunderstood condition in Cameroon, including in the Batibo Health district.

Methods: This cross-sectional study describes epilepsy clinical characteristics, the treatment gap, and associated factors in a rural district in Cameroon. After screening for epilepsy using a door-to-door survey, physicians confirmed suspected cases of epilepsy. Detailed information on the medical, seizure and treatment history was collected from everyone with epilepsy, followed by a general and neurological examination.

Results: We diagnosed 546 people with active epilepsy (at least one seizure in the previous 12 months). The mean age of people with active epilepsy was 25.2 years (SD: 11.1). The mean age at first seizure was 12.5 years (SD: 8.2). Convulsive seizures (uncertain whether generalized or focal) were the most common seizure types (60%), while 41% had focal-onset seizures. About 60% of people had seizures at least monthly. One-quarter of participants had had at least one episode of status epilepticus. Anti-seizure medication was taken by 85%, but most were receiving inappropriate treatment or were non-adherent, hence the high treatment gap (80%). Almost a third had had seizure-related injuries. Epilepsy was responsible for low school attendance; 74% of school dropouts were because of epilepsy.

ConclusionThe high proportion of focal-onset seizures suggests acquired causes (such as neurocysticercosis and onchocerciasis, both endemic in this area). The high epilepsy treatment gap and the high rates of status epilepticus and epilepsy-related injuries underscore the high burden of epilepsy in this rural Cameroonian health district.

Abbreviations: ASM= anti-seizure medication; EEG= Electroencephalogram; LMIC=low and middle-income country; SSA=sub-Saharan Africa

Key words: convulsions; injury; treatment; Batibo, cysticercosis, onchocerciasis

Highlights

- Focal seizures are common in these people

- The epilepsy treatment gap in this area is high
- About one-quarter of people with epilepsy had experienced status epilepticus
- A tiny proportion of people with epilepsy on an ASM attained seizure freedom
- About a third of people with epilepsy had some seizure-related injury

1. Introduction

Epilepsy is a significant cause of disease burden worldwide, especially in sub-Saharan Africa (SSA) [1]. It is estimated to affect over 50 million people globally, irrespective of age, race or social status [2]. Epilepsy prevalence varies between countries in SSA and, although the factors are not entirely understood, differences in risk and genetic factors may be responsible. Epidemiological studies in Cameroon have focused on describing the prevalence of epilepsy in specific communities; this ranges between 39 and 135/1,000 depending on the population surveyed [3-5]. Despite the methodological limitations of some of these studies (mainly small population samples), it seems that epilepsy prevalence varies widely between communities in Cameroon. It is not apparent which factors are responsible for the variation in prevalence and clustering of cases in some communities. Case-control studies have suggested the role of parasitic infections, mainly onchocerciasis and neurocysticercosis [4, 6-8]. Longitudinal cohort studies are necessary for a better understanding of the risk factors and causes of epilepsy. These are costly in such communities and may take too long to set up, especially given the urgency of implementing preventive strategies. Recent data from retrospective cohort studies in Cameroon's Centre Region have shed more light on the relationship between onchocerciasis and epilepsy, suggesting a causal relationship [9, 10]. Little is known about clinical characteristics of epilepsy in the affected communities, yet this data may be critical in understanding possible causes and risk factors for epilepsy. A recent study of multiple SSA centers showed that 60% of seizures were focal and suggested that this may be attributable to acquired and preventable causes [11]. There has been recent interest in describing characteristics of people with onchocerciasis-associated epilepsy in a bid to appreciate the link between onchocerciasis and epilepsy [12, 13]. It is crucial to assess epilepsy characteristics in communities with a higher prevalence compared to features in populations where the causes and risk factors are known. Such information will significantly bridge the knowledge gap on the causes and risk factors of epilepsy in many parts of SSA.

The epilepsy treatment gap has also been poorly assessed in Cameroon. The treatment gap is defined as "the difference between the number of people with active epilepsy and the number whose seizures are appropriately treated in a given population at a given point in

time expressed as a percentage" [14]. The epilepsy treatment gap indirectly measures the level of access to care for people with epilepsy and can be useful in planning and allocating resources for epilepsy. The epilepsy burden is exceptionally high in low- and middle-income countries (LMICs), where over 80% of people with epilepsy are inadequately treated. In LMICs, there is a wide range of causes for the treatment gap, the most critical being: high level of stigma with its negative effect on health-seeking behavior; inadequate skilled workforce; the unaffordable cost of treatment and unavailability of anti-seizure medications (ASMs) [15, 16]. In a country such as Cameroon, assessing the extent and consequences of the gap is a critical step towards redressing the burden of epilepsy. Therefore, we attempted to describe seizures and epilepsy characteristics in a rural population and estimate the epilepsy treatment gap and its associated factors. This information will help define public health policy to prevent epilepsy and reduce its treatment gap in Cameroon.

2. Methods

2.1. Study population

The study was conducted in the Batibo Health District, a rural part of Cameroon's North-West Region, about 400 Km from the capital, Yaoundé (Figure 1). It covers 58 Km^2, is divided into 16 health areas, and has an estimated 82,000 inhabitants. Most of them speak either Pidgin-English (lingua franca) or the Batibo language. Each health area has at least one health center, the primary point of contact for health. There is a 75-bed capacity district hospital which serves as the first level referral hospital. Epilepsy is believed to be common in this district, and the district hospital runs a monthly nurse-led epilepsy clinic supervised by a clinician. SAA set up this clinic in 2009 and, since leaving the community in 2012, he has regularly returned to train the clinic personnel. Neurocysticercosis and onchocerciasis are important risk factors for epilepsy and are endemic in Batibo. Subsistence farming is the primary source of income in this district.

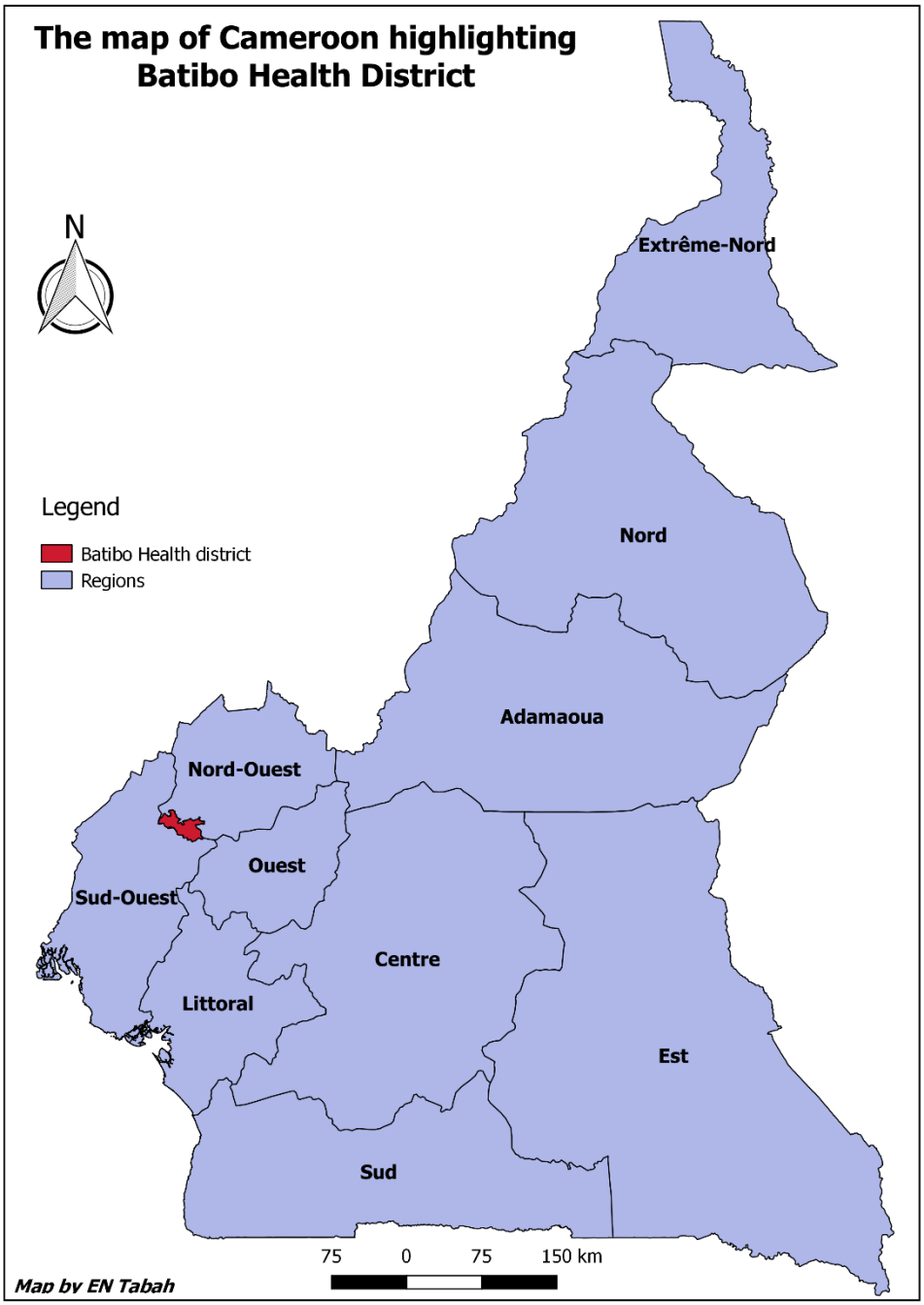

Figure 1. Map of Cameroon showing the Regions and the Batibo District Hospital

2.2. Identification of people with epilepsy

People with epilepsy were identified through a two-stage epilepsy screening process targeting all permanent residents of the health district (people living in the community for at

least the previous three months); this has been discussed in detail elsewhere [17]. In stage 1, household heads were approached by trained nurses and community volunteers. The presence of suspected epilepsy in any household member six years or older was identified using a five-item questionnaire. Children who were six years or younger were excluded, to minimize the risk of misclassification of febrile seizures or other acute symptomatic seizures as epilepsy. Those with a positive response to at least one of the five questions were invited to the nearest health center. Here, trainee neurologists assessed each one to confirm or refute the diagnosis after a detailed event and medical history, and a general and neurological examination. No EEG or imaging equipment was available. For those with confirmed active epilepsy, detailed information was obtained on seizure history and classification, and treatment history and associated factors. To enable consistency in seizure classification, a physician's workshop (SAA, LN, and LNN) was held at the beginning of the study during which algorithms for diagnosis and classification were discussed. The terminology and the classifications were based on recommendations by the International League Against Epilepsy (ILAE) for epidemiological studies [18]. Definitions of essential terms frequently used in the study are listed below:

Active epilepsy: Two or more unprovoked seizures, at least one of which must have occurred within 1 year preceding the study, irrespective of anti-seizure medical treatment

Status epilepticus: seizures lasting more than 30 minutes or repetitive seizures with no recovery of consciousness between seizures. When people with epilepsy or relatives were unable to time the duration of seizures, the duration was estimated by relating them to the duration of normal daily activities in their environment such as trekking time to market, health center, schools etc.

Inadequate epilepsy treatment: Someone with active epilepsy who has missed ASM treatment for more than a total of 7 days in the month preceding the study (poor adherence to ASM) or who is taking an ASM not prescribed by a health worker; or who has inappropriate ASM choice or dosage, is defined as having inadequate treatment.

2.3. Statistical Analysis

Statistical analysis was conducted using Stata software (version 16.0). The chi squared test was used to test for association between categorical variables. The significance level was $p<0.05$.

3. Ethical Considerations

Ethical clearance was obtained from Cameroon's National Ethics Committee (Ethical Clearance Reference: 2016/12/853/CE/CNERSH/SP). The District Medical Officer granted administrative authorization. Informed consent was obtained from all participants. Where the participant did not understand English or Pidgin-English, an interpreter was called to assist. Per Cameroon law, minors (≤21 years) who could not consent provided permission, and their parents signed an assent form. To protect the confidentiality of participants, data were anonymized before analysis. People with epilepsy identified were included in an epilepsy register shared with the District Medical Officer, who is duty-bound to respect the participants' confidentiality. Such a database enables an objective appreciation of the magnitude of epilepsy in the district and facilitates follow-up of cases and local planning to address the problem. At the end of the study, a two-day epilepsy training was provided for all the doctors and at least two nurses per health area to ensure continuity of care. Unfortunately, most of the people with epilepsy identified during the study were lost to follow up due to an armed conflict that started towards the end of this survey, causing the displacement of thousands of people. When necessary, we took photos of some people with serious epilepsy related injuries and all provided consent for their images to be shared.

4. Results

4.1. Demographic characteristics

From the two-stage epilepsy screening process, 524 people were diagnosed with active epilepsy (17). A further 22 people missed during the screening process were enrolled from the epilepsy clinic of the Batibo Hospital. A total of 546 people with epilepsy (52% female) were enrolled for the study. The median age was 25 years (IQR: 18-30), and the mean age

25.2 years (SD: 11.1). The median age at first seizure was 11 years (IQR: 8-15) and the mean age at first seizure was 12.5 years (SD: 8.2). There was little variation between health areas (10-13), except Larinji where the median age at first seizure was 7 years (IQR: 6-10). Epilepsy was of adult-onset (over 18 years) in 16.3% of people; there was no significant difference in the proportion of adult-onset epilepsy between health areas (P=0.690).

4.2. Seizure characteristics and classification

Clinical characteristics are summarised in Table 1. Convulsive seizures (unclear whether focal or generalized) were the most common seizure type, experienced by 60%. Focal-onset seizures were also common (41%); almost one fifth had focal-onset generalized seizures while a quarter of participants had focal seizures without generalization. Seizures could not be classified in about a fifth due to the lack of a reliable eyewitness account. A fifth of participants reported mainly nocturnal seizures.

Sixty percent had seizures at least monthly; 4% had daily seizures, 8% had them weekly, and 48% had them monthly. One-quarter of participants had experienced at least one episode of status epilepticus. Daily seizures occurred more frequently in children (10.5%) than in adults (2.7%) (P=0.007) but there was no difference in seizure frequency between males and females.

Table 1. Seizure and epilepsy characteristics

	Number	**Percentage**
Age at seizure-onset	N = 435	
0-5	41	9.4%
6-10	160	37%
11-15	138	32%
16-20	64	15%
>20	32	7.4%
Seizure type*	N = 545	

Generalized convulsive seizures (uncertain whether focal or generalized onset)	329	60%
Generalized other motor	41	7.5%
Generalised absence	41	7.5%
Focal-onset secondarily generalized	95	17%
Focal (motor, non-motor, psychic, others)	129	24%
Unknown	106	19%
Self-reported status epilepticus	86/338	25%
Seizure frequency	N = 506	
Daily	21	4.2%
Weekly	39	7.7%
Monthly	244	48%
Less than monthly	202	40%
Seizure timing	N = 526	
Mainly daytime	24	4.6%
Mainly night-time	119	23%
Any time	378	72%
On awakening	5	1%

**People could have more than one seizure type*

4.3. Treatment gap and associated factors

Eighty-five percent of people with active epilepsy had taken ASM in the previous month, mainly phenobarbital (59%) or carbamazepine (27%). There was no difference in treatment between age groups and genders. The main reasons for not being on treatment were the ineffectiveness of ASMs (30%) and unavailability of ASMs (15%). About 65% of people had interrupted therapy for a continuous period of at least seven days in the previous month, and the main reason was the unavailability of ASMs (58%). Response to treatment was generally good; 79% of people reported either improved seizure frequency (78%) or seizure-freedom (1.8%) when on ASM treatment. In one fifth of people on treatment, seizures either remained the same or got worse. Physicians deemed treatment to be inadequate (treatment gap) in

80% of people. The gap was wider (88%) for people living further than 30-minutes' walking distance from the nearest health center than for those who lived closer to the center (77%) (P=0.002). There was no variation in treatment gap with age nor gender. Most people had tried some alternative treatment for epilepsy: 54% had taken traditional medicine, while 62% had consulted a cleric for prayers to cure epilepsy (Table 2).

Table 2. Treatment of epilepsy and related factors

ASM Treatment		
Currently on ASM treatment	459/543	85%
Phenobarbital	318/543	59%
Carbamazepine	144/543	27%
Valproate	1/542	0.2%
Phenytoin	10/543	1.8%
ASM prescriber		
Doctor/nurse	323/442	73%
Pharmacy attendant	46/442	10%
Relative/self-prescribed	73/442	17%
Effect of ASM on seizures		
Seizures stopped	8/434	1.8%
Seizures reduced	337/434	78%
No effect	81/434	19%
Seizures got worse	8/434	1.8%
Adequate Treatment	84/430	20%
Alternative treatments		
Use of traditional medicine	289/535	54%
Prayers by cleric	331/532	62%

4.4. Perceptions of epilepsy (Table 3)

Most people did not know the cause of epilepsy, but a quarter thought it was caused by witchcraft or other supernatural factors, and a few thought it was natural. Less than half believed that epilepsy could be cured; one third believed that the best treatment was ASMs, one in six thought that prayers provided a cure while only 2% felt the same about traditional medicine (Table 3). Neither the belief in a cure for epilepsy nor in witchcraft as a cause of epilepsy was significantly associated with being on ASM treatment (P> 0.5 in each case).

4.5. Consequences of epilepsy

Seizure related injuries were fairly common, occurring in 29% of participants: one fifth had burns, and one in six had wounds or bruises resulting from seizures (Table 3). Seizure-related injuries were significantly more common in females (33%) than in males (25%) (P=0.032). Burns were more common in people with convulsions (30%) than focal seizures (15%) (p<0.001). Burns were also significantly more common in people who had previously experienced status epilepticus (25%) than in those without such history (14%) (P=0.02). More people who were currently on ASM treatment had burn injuries than people who were not on ASMs; 20% vs 3.9% (P<0. 0001). There was no significant difference in the prevalence of burns between males and females or between children and adults. A selection of images of severe sequelae of burns caused by seizures among participants is shown in Figures 2 to 7.

Evidence of moderate to severe malnutrition was found in 45% of participants (tooth decay, glossitis, brittle hair, pale conjunctivae, emaciated appearance). Almost half (47%) had food taboos, and mainly avoided okra soup (63%), chicken (29%) and pork (33.9%). Epilepsy was associated with low school attendance; 40% of children were not attending school and, for 74% of them, epilepsy was the reason they dropped out of school.

Table 3 Consequences and perceptions of epilepsy

Consequences and perceptions of epilepsy		
Epilepsy related injuries	157/542	29%
Wounds	80/505	16%
Burns	91/505	18%
Moderate-severe malnutrition	245/545	45%
Food taboos	255/545	47%
Dropped out of school	216/545	40%
Perceptions of epilepsy		
Do not know cause of epilepsy	408/545	75%

Epilepsy is supernatural	123/545	23%
Epilepsy is a natural disease	14/545	2.6%
Epilepsy is curable	261/545	48%
Epilepsy is curable with anti-seizure medications	185/545	34%
Epilepsy is curable through prayers	83/545	15.2%
Epilepsy is curable through traditional medicine	13/545	2.4%

Figure 2. *This 24-year-old lady has had two episodes of burns which have left her with many scars and deformities. She cannot afford to keep away from the fire because she must look after her four children, having recently been abandoned by her husband because of her epilepsy*

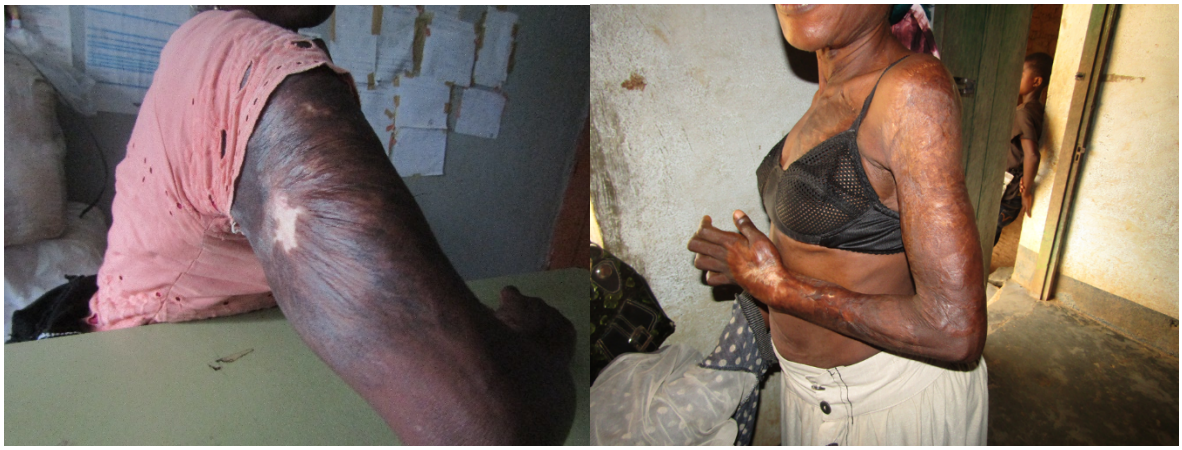

Figure 3. *These two adolescents are brother and sister, and both have disabling scars from burns. They also have a younger sibling with epilepsy. Their mother is a widow with six children and cannot afford their ASMs so they mostly depend on donations*

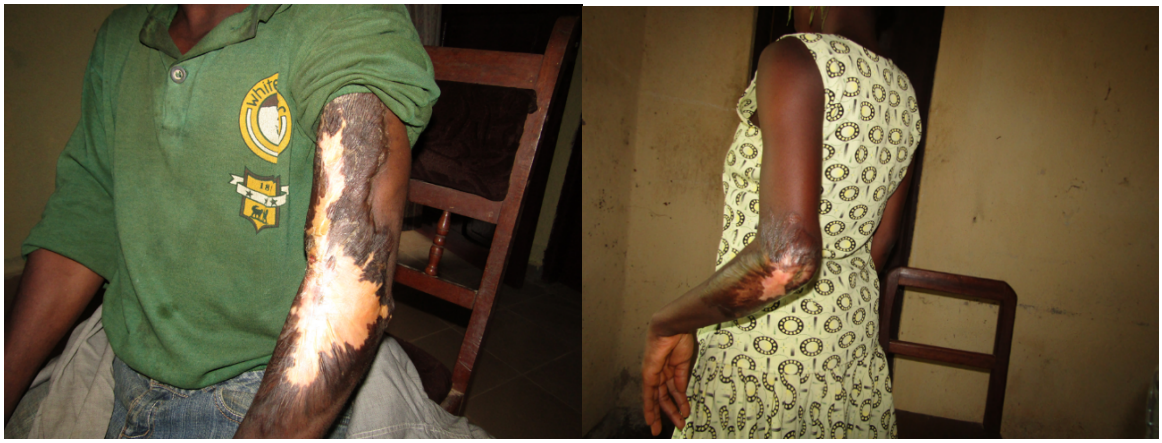

Figure 4. *The burns of this 14-year-old girl were so severe that her right forearm and left fingers had to be amputated. Thanks to a philanthropic organization, she received plastic surgery on her left hand*

***Figure 5**. This 19-year-old boy developed these deformities after having a seizure by the fireside and has since been unable to use his fingers; he is totally dependent on relatives*

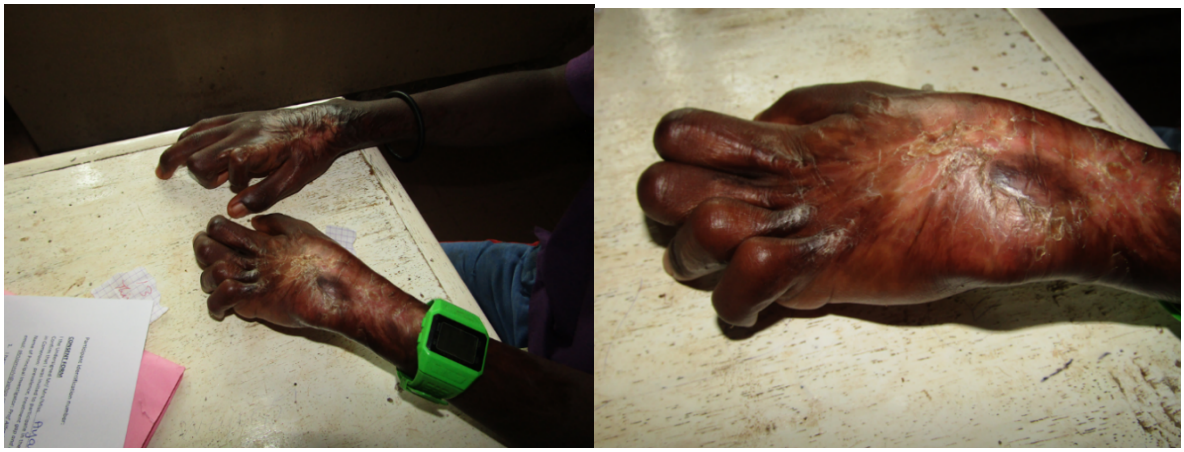

***Figure 6.** The severe burns on this 25-year-old man left him blind in the right eye and with extensive scars on most of his face and upper torso.*

***Figure 7**. This 30-year-old woman has had seizures since she was 13 and she sustained these injuries after stopping her ASMs, after assurance from a traditional healer that he had cured her epilepsy*

5. Discussion

5.1. Clinical characteristics

5.1.1. Age at seizure onset

The median age of seizure-onset varies between communities in SSA depending on the study population's prevailing risk factors and the recruitment criteria. The median age of seizure onset in this study (11 years [IQR: 8-15]) is higher than that reported in many studies in SSA, which is mostly less than 9 years [11, 19, 20]. Compared with a multi-country study in SSA, the median age at onset of unprovoked seizures in this study is higher than found in four out five countries involved [11]. It should, however, be noted that children less than 6 years old were excluded from our study, contributing to raising the median age of epilepsy onset. The mean age at first seizure was the same as that reported in a similar recent study of people with onchocerciasis- associated epilepsy in Bilomo in Cameroon's Centre Region [13]. A high peak age of seizure onset (14-15) was attributed to onchocerciasis as a possible etiology in a recent study in the Democratic Republic of Congo, [21]. We speculate that given the high frequency of focal seizures, acquired environmental factors likely drive the epilepsy burden in this community.

5.1.2. Seizure frequency and status epilepticus

Three fifths of people had frequent seizures (at least once a month), indicating that most affected people have uncontrolled seizures. Daily seizures were more common in children than adults and may be evidence of spontaneous remission of seizures with age, or high epilepsy-related mortality in children with epilepsy. The high rate of uncontrolled seizures is consistent with the high treatment gap observed. In over a fifth of cases, seizures occurred only at night-time during sleep, when they were less likely to be observed, and this contributed to the high proportion of unclassified seizures. About one-quarter of people in this study had experienced status epilepticus, within the range reported in African countries (4.7-40%) [11]. Differences in the frequency of status epilepticus between countries in SSA probably reflect differences in access to treatment and resource allocation for epilepsy care. The frequency of status epilepticus may thus reflect the quality of epilepsy treatment and adherence to treatment. This hypothesis needs to be investigated in future studies.

5.1.3. Seizure types

Seizures were classified according to the ILAE recommendations for epidemiological studies [18] which were also used in a multi-center study in five African countries [11]. The proportion of people with focal-onset seizures (41%) is similar to the average for the other African sites (45%), although there was variation between sites (31%-65%) [11]. The high proportion of focal-onset seizures in many African studies is consistent with acquired structural brain abnormalities as the main causes of epilepsy in SSA. We were unable to classify epilepsy because EEG and imaging were not available. Future studies need access to such investigative tools to estimate the proportion of focal epilepsy in this population; this may hence be attributed to acquired brain pathologies.

5.1.4. Seizure-related injuries

The high proportion of people with sequelae of seizure-related injuries, especially burns, is not surprising given the high frequency of uncontrolled seizures and status epilepticus. Among people with epilepsy in Bilomo in the Centre Region of Cameroon, burns were also common, having occurred in 14% [13]. In high-income countries, with better access to treatment and more awareness of seizure risks, seizure-related injuries are less common. Burns due to seizures accounted for up to 3.7% of burns unit admissions in high-income

countries [22] but were responsible for over 10% of admissions in a Malawian burns unit [23].

Seizure-related injuries, especially burns, further aggravate the burden of epilepsy among affected people and their families; they are the leading cause of premature mortality related to epilepsy [24]. Survivors of seizure-related burns are often left with severely disabling sequelae which can further aggravate stigma and compromise the quality of life of people affected. In rural communities in SSA such as Batibo, an individual's standing in the village is mainly determined by their contribution to the welfare of their family and community as roles are so clearly defined. In Batibo, and most rural communities in Cameroon, cooking is mainly carried out by girls and women, usually on an open fire. Older boys and men are expected to climb palm trees to harvest palm nuts. Meanwhile, children are responsible for fetching water from the stream and women and children do most laundry on the banks of the river or stream. Consequently, they often face an unfortunate dilemma: either they exempt themselves from such chores to avoid injuries, risking further stigmatization, or they perform their roles and expose themselves to severe injuries or premature death.

5.2. Epilepsy treatment and associated factors

Most people with epilepsy were taking ASMs, with phenobarbital most frequently used. This is not surprising given its affordability. According to the Batibo Health District drugs price list, a year's treatment with phenobarbital costs less than 500 XAF (equivalent to about 1 USD) while carbamazepine and valproate are 5 to 10 times more expensive (Personal communication, District Medical Officer). This is consistent with recommendations that phenobarbital should be the first line ASM in rural communities in SSA [25]. It was also not surprising to observe that significantly more people who were currently on ASM treatment had burn injuries than those who were not on ASMs (20% vs 4%). While burns and injuries likely reflect the epilepsy severity and seizure frequency, compelling those affected to continue taking their medications, people with less severe epilepsy and fewer seizures may be less inclined to take medications.

The treatment gap we found is within the range of estimates for LMICs [15]. While most people were on treatment, they were either non-adherent or had an inappropriate ASM choice or dosage. Drugs in this area are often purchased from unreliable sources (mobile drug hawkers, roadside drug stores and unlicensed pharmacies). Living a long distance from the heath center was identified as a determinant of the treatment gap and could explain why most people procured their medications from mobile drug hawkers. Poor adherence was mainly attributed to the lack of ASMs at the health centers. An inventory of pharmacies showed that they were regularly out of stock of phenobarbital and almost none had an alternative option. In some areas, people reported that pharmacies inflated ASM prices during shortages, obliging them to purchase from alternative sources. A similar observation was made in a previous study in the West Region of Cameroon, where the lack of ASM supplies was the main factor affecting adherence [26]. This precarious supply of ASMs is often not addressed by health authorities. Thus optimism about ASM treatment benefits may be lost (one third believed that their epilepsy is treatable with ASMs) and more will be forced to purchase their ASMs from unreliable sources or seek alternative treatments with unproven effectiveness.

Traditional medicine and spiritual healing sessions by clerics were popular alternative treatment choices. This is consistent with the widely held belief in a supernatural cause of epilepsy in this community [27]. Beliefs about the causes of disease can significantly affect health-seeking behavior, in some cases leading people to seek alternative options such as traditional medicine, perceived to be more effective than hospital treatment. We found that a quarter of people believed in witchcraft as the cause of their epilepsy, but this belief did not seem to influence whether they took ASMs. This may suggest that people with epilepsy in this community perceive the treatment options (hospital, traditional, spiritual) as complementary rather than competitive. A similar observation was made in the West Region where almost all people with epilepsy were taking traditional medicine and ASMs [26]. In a previous study in Batibo, traditional healers expressed willingness to receive training about epilepsy and to cooperate with the health authorities in seeking ways to improve care delivery to people with epilepsy [28]. In the long-term, inadequate management and poor

seizure control reinforce the myth that ASMs are ineffective, predisposing people with epilepsy and their families to further exploitation. During this survey, it was found that some outsiders would periodically visit with fraudulent claims of an instant cure for epilepsy using African or Chinese traditional medicine, often extorting money from affected people (Personal communication, District Medical Officer). These anecdotes underscore the complex social, cultural and economic factors underpinning the epilepsy treatment gap in Batibo and emphasize the need for an integrated approach, involving all community stakeholders, to improve the quality of treatment for people with epilepsy.

6. Limitations

The second stage of the epilepsy screening involved confirmation of diagnosis and seizure classification by three senior trainee neurologists. Ideally, a reliability test and an interrater reliability score (Kappa statistic) would be used to determine the consistency between the physicians' classification of seizures. We are, however, confident that any inconsistencies between the physician reports are minimal as they all had previous epilepsy exposure during training. The workshop at the beginning of the study further minimized inconsistencies.

During the interview of people with epilepsy in the hospital, we did not record whether an eyewitness account was available or note the eyewitness's relationship to the person interviewed. This information would have enabled an objective verification of the seizure history and classification reliability. Future studies should address this shortcoming.

7. Conclusion

The high proportion of focal seizures suggests acquired aetiologies such as cysticercosis and onchocerciasis, endemic in this area. The high epilepsy treatment gap and the high rate of status epilepticus and epilepsy-related injuries underscore the high burden of epilepsy in this rural Cameroonian health district. Replicating this study in other parts of Cameroon will ensure the mapping of the epilepsy burden and guide the allocation of resources to redress the epilepsy burden in Cameroon.

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