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Factors associated with treatment gap in children and adolescents with epilepsy in a rural Nigerian community.

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Abstract *Background*: The campaign against epilepsy is hampered by the difference between those with the active disorder and the number of them receiving appropriate treatment (treatment gap) in sub-Saharan Africa. Identifying the determinants of this gap is crucial to providing and achieving optimal care.
Objective: To identify the determinants of epilepsy treatment gap (ETG) in children and adolescents (Subjects) with epilepsy in a rural community.
Methods: Subjects were identified through a community house to house survey. Information obtained from Subjects and their care givers included: socio-demographic characteristics, type and frequency of epileptic seizures, current and past treatment options utilized, reasons for treatment options used, and treatment options utilized for other health complaints.
Results: Twenty three Subjects (6.4/1000 of the child and adolescent population) were identified as having epilepsy. Their age range was 4-19 years (mean 14.3±4.7 years). Most were males (82.6%) and adolescents (78.3%). Seizures were mostly generalized (95.7%) and occurred most frequently daily. Current treatment modalities were use of traditional medication (100%) and prayers (34.8%).None was currently on orthodox medical therapy (ETG, 100%) but 5(21.7%) had utilized orthodox medical therapy in the past. The main determinants of the ETG were strong cultural belief, weakness in the health system to epilepsy treatment and low socio-economic status. Fever was the commonest other health complaint and use of orthodox medical therapy was significantly ($p< 0.05$) the main (16, 69.6%) treatment option utilized.
Conclusion: Cultural belief, weak health system and low socio-economic status were determinants of an absolute ETG. It highlights the need to strengthen initiatives that enhance accessibility to standard epilepsy treatment.

Key words: Epilepsy treatment gap, determinants, children, adolescents, rural community

Introduction

Epilepsy affects 70million people worldwide and over 50% of its incidence is in the child and adolescent periods of life.[1,2] Majority of persons with epilepsy live in low and middle income countries (LMICs) and have limited access to effective treatment.[2]The resultant epilepsy treatment gap (ETG) has been defined as 'The difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point of time, expressed as percentage. This definition includes diagnostic and therapeutic deficits'.[2,3]Poor data collection and documentation of health statistics resulting from weakness in the health systems of most susceptible LMICs coupled with the stigma associated with epilepsy makes estimation of ETG highly variable.[2-4]In LMICs such as Nigeria, Togo, Zambia, and Pakistan, the ETG in active epilepsy is commonly between 75-100%.[1,4] In the high income countries (HICs) such as the United States, United Kingdom and Japan it is 10% or less.[1,4]The ETG from lifetime epilepsy also ranges from

six to 100% with gaps estimated from lifetime prevalence larger than those estimated from active epilepsy prevalence with exceptions in reports from India and Pakistan.[4] Furthermore in the LMICs the ETG is generally higher in the rural than the urban areas. However, treatment gaps have been noted to vary widely between and within countries. Factors identified as contributing to ETG in sub Saharan African countries like Nigeria include traditional beliefs, social stigma, inadequate supplies of anti-epileptic drugs (AEDs), and limited access to health facilities.[2]

In most LMICs, child and adolescent care is mainly dependent on what the family system offers unlike in the HICs where there is a strong statutory social support system that also oversees family care.[5]In these LMICs the limited socio-economic resources are stretched over a variety of family needs which could sometimes be at the expense of child and adolescent needs.Children and adolescents with epilepsy (CAWE) in this context are quite vulnerable to the enumerated risk factors for ETG. This is even more worrisome considering the fact that there is a high age specific incidence of epilepsy in the first two decades of life.[2,6]The occurrence of ETG results in negative epilepsy outcomes. These outcomes are detrimental to CAWE and ominous for succeeding adult populations with epilepsy. They include stigma, malnutrition, depression, poor quality of life and higher risk of mortality than the general population.[7-13] Furthermore there is increased economic and psychosocial burden, with their attendant counterproductive consequences, on other members of the family and caregivers of those affected.[14,15]

The World Health Organization Mental Health Gap Action Programme (WHO/mhGAP) and the Global Campaign Against Epilepsy (GCAE) are some interventional initiatives that have been created to bridge the ETG.[1,2]Most studies concerning ETG from the LMICs have focused on entire populations.[2,4]For these and other programmes to be effective in bridging the ETG it is important to continually appraise treatment of epilepsy among vulnerable populations, such as the CAWE populations, in susceptible communities. The aim of the study was to assess the ETG among CAWE in a rural Nigeria community.

Subjects and Methods

The study was conducted in Katari community which is 95km away from and south of the Federal Neuro Psychiatric Hospital (FNHP) in Kaduna, capital of Kaduna state in Northwest Nigeria. The community was randomly selected from the number of communities from which a high number of patients with seizure related disorders visit the FNPH Kaduna. The FNPH has a Child and Adolescent Mental Health (CAMH) Unit that is headed by a Consultant child psychiatrist and runs a weekly neurology clinic with a Consultant paediatric neurologist in attendance.

The members of the community are mainly petty traders and farmers.[16]Spoken languages are mainly Adara, Hausa and English. Administratively the community is made up of two districts, Katari North and South, each comprising of 20 and 18 villages respectively. Each district is administered by a District Head who is assisted by the village heads. Epilepsy is called 'Itohu' in the community. It is believed to be a mysterious disease caused by an evil spirit and characterized by unpredictability and falling to the ground. It is thought to affect those who come into contact with the body fluids of those with the disease or who share common utilities with those affected. It is also thought to be an affliction of those engaged in witchcraft. Traditional healers are thought to possess medicinal antidotes to its occurrence. There is at least one of such traditional healers in each of the villages. Orthodox medical facilities available in the community include six patent medicine shops, a primary health care centre, two privately owned health clinics and a government general hospital that is located 30km away from the community.

Definition of study population and terms

The study population comprised of all persons aged 19 years and below whose ages were ascertained by evidence of birth records or corroborated oral evidence.
According to the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) an epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain while epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological, and social consequences of this condition.[17] The definition of epilepsy requires the occurrence of at least one epileptic seizure. For epidemiological surveys, and in this study, epilepsy was defined as recurrent unprovoked seizures occurring at least 24 hours apart while active epilepsy was defined as occurrence of unprovoked epileptic seizures on different days in the preceding five years.[6,18,19]
A determinant of the ETG was defined as any factor that caused, contributed to or influenced lack of, inappropriate or inadequate treatment of epilepsy among the study population.

Conduct of study

The study was conducted in two phases between August and December 2012. In the first phase the authors and research assistants met with the District and Village Heads of Katari community. At the meeting the aim of the study was presented and communal consent sought. In the second phase a house to house survey was conducted and the research group was divided into four research teams. All members of the group could speak one of the traditional languages fluently.
Each team comprised of a Consultant (who had undergone specialty training in epilepsy care), one Registrar, one community health extension worker (CHEW), and one representative of the respective Village Head.

Villages were assigned randomly to the research teams until all the villages were surveyed. During the survey members of the study population with a recurrent history of the following characteristics and adapted from a previous study by Dent et al[19]

(a) Sudden unprovoked fall to the ground;
(b) Sudden loss of consciousness;
(c) Sudden loss of consciousness and / or sudden fall with associated stretching or jerking movements of parts of the body; and
(d) Unprovoked, unconscious and uncontrollable movement of a part of the body, were identified and assessed for epilepsy.

Each research team administered a structured questionnaire to the subjects, controls and their parents or caregivers independently and as applicable. Parameters assessed using the structured questionnaire included: Age, Sex, Social Class, Clinical features of epilepsy, Treatment options utilized and Reasons for using the treatment options. Social class classification was according to Ogunlesi *et al* classification.[20]

All those identified as having active epilepsy were provided with a month's dose of the AED phenobarbitone and referred to the child and adolescent mental unit of FNPH. In addition they and their families were introduced to a non-governmental organization that supports the management of persons with epilepsy and their families. Ethical approval for the study was obtained from the Research and ethics committee of the FNPH Kaduna. Consent was equally obtained from the District and Village Heads, and heads of all households in Katari community.

Data analysis

Epi Info version 3.5.3 statistical package was used in data analysis. Chi square test, with Yates' correction where applicable, was used in determining the relationship between ETG, clinical features of epilepsy and socio-demographic variables of the subjects. A *p* value less than 0.05 was regarded as significant.

Results

The total community population was 6,572 out of which 3,613(55%) constituted the child and adolescent population. Of the latter population, 23(Subjects) representing 3.5 per 1000 of the entire community population and 6.4 per 1000 of the child and adolescent population, had epilepsy.

Age, sex and social class distribution of subjects

The age range of the subjects was 4 to 19 years (mean 14 $\pm$ 4.7 years). There was a male preponderance (n=19, 82.6%) with a Male: Female ratio of 4.8:1. Most (n=18, 78.3%) of the subjects were adolescents

(Table 1). All the subjects were distributed only in the lower social classes of IV (n=6, 26.1%) and V (n=17, 73.9%).

Table 1: Age and Sex Distribution of the 23 Subjects

Age (years)	Sex		Total	Percent of Total
	M	F		
≤ 10	4(21.1)	1(25)	5	21.7
11 – 13	4(21.1)	0	4	17.4
14 – 16	2(10.5)	0	2	8.7
17 – 19	9(47.3)	3(75)	12	52.2
Total	19(100)	4(100)	23	100

Clinical features of epilepsy

Epilepsy was generalized tonic-clonic in 22 (95.6%) and partial in 1 (4.4%) of the subjects respectively. There was a positive family history in 9(39.1%) of the subjects among whom 2 (8.9%) were siblings. Seizures frequency was daily, weekly, monthly and yearly in 8 (34.8%), 7(30.4%), 6(26.1%) and 2(8.7%) subjects respectively.

Modalities of treatment and epilepsy treatment gap

All (100%) were on oral traditional herbal medication at the time of the study. In addition 8(35%) were receiving special religious prayers as part of treatment. Belief in its efficiency, cheap cost and availability of tradition were the major reasons for choosing the current treatment option while ignorance about orthodox medical therapy was the least common reason (Table 2). Five (21.7%) subjects had visited an orthodox health facility for treatment of epilepsy where they received an oral AED. All five later defaulted from visits to the health facility and treatment. Cost of transport to the facility and that of the drugs in addition to perceived failure of drug therapy to control seizures were the reasons adduced by all for default. Consequently epilepsy treatment gap in the subjects was 100% and mainly contributed to by a diagnostic gap (Fig 1). Fever was the commonest other health complaint indicated by all the subjects. The current treatment option for fever in the subjects was the utilization of orthodox medical treatment in 16 (69.6%) subjects and tradition herbal medication alone in 7(30.4%) of the subjects respectively. The preferential use of traditional medication for epilepsy was significant (χ^2=21.6, df =1, *p*=0.000).

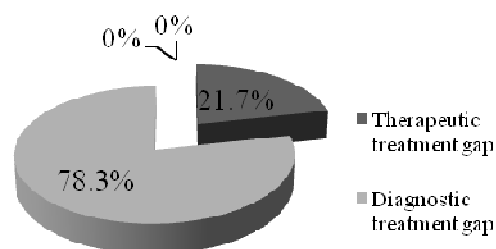**Fig 1:** Epilepsy treatment gap in the 23 subjects

Table 2: Main reasons for current choice of treatment modality in the 23 Subjects

Reason (s)	No of Subjects	Percent of Total
Belief in efficacy of Traditional Medication	23	100
Availability of Traditional Medication	23	100
Cheap cost of Traditional Medication	23	100
Cost of accessing Orthodox Therapy	20	87
Distance of definitive health facility from community	17	73.9
Family pressure	13	56.5
Failure of Orthodox Medical Therapy	5	21.7
Ignorant on how to access Orthodox Medical Therapy	4	17.4

Discussion

Epilepsy was active in all the subjects with a treatment gap of 100% and the major determinants were a strong cultural perspective, weakness of the health system towards epilepsy treatment and a low socio-economic status. Also the prevalence of epilepsy in the child and adolescent population which was 6.4/1000 is higher than the WHO world standard of 2.69/1000 but lower than reports from other LMICs such as Turkey (8.6/1000), Brazil (8.7/100) and India(7.0/1000).[21-23] Absolute (100%) ETG has been reported in several rural communities with similar characteristics as the study population.[3] However a lesser ETG has been reported in CAWE in rural Kenyan (70.3%), Tanzanian (69%) and Indian (40%) communities.[24-26] Much lower ETG values have been recorded in semi-urban and urban settings for CAWE.[3] The social and health systems in these latter settings were more sensitive to epilepsy management than was observed in the study population. The treatment gap in this study was contributed mainly to by a diagnostic deficit. This deficit is indicative of factors that either prevent use of orthodox health services such as strong cultural perspective and cost of accessing treatment, or absence of such a health service in a specific locality. These factors have been reported commonly from rural settings such as Katari.[2,3] They could also account for a therapeutic deficit which is indicative of a lack of sustained access to appropriate treatment or absence of specific therapeutic modality such as neurosurgery.

A number of factors have been identified severally as determinants of the ETG in LMICs particularly in the sub-Sahara African countries.[2,3] In bridging the ETG, identifying the roles of these factors cannot be over

emphasized. These factors include strong cultural perspectives, low socio-economic status, high cost of accessing care, poor knowledge of epilepsy and its care, stigma, discrimination and health systems that are weak in epilepsy management.[2,3] The negative impact of strong cultural perspectives on the management and wellbeing of CAWE is prevalent in many LMICs particularly the sub-Saharan African countries.[2,3] In these countries there is a strong association of evil spirits or witchcraft with the etiology of epilepsy and a strong conviction in the efficacy of traditional medication over orthodox medical treatment in the management of epilepsy. Such beliefs often result in the alienation of those with the disorder in utilizing or sharing common communal facilities, the refusal of those with epilepsy to come out and the use of health facilities for epilepsy treatment even where available.[2,3] In this study belief in the efficacy of traditional medication from the cultural perspective significantly influenced its use as a preferential treatment option for epilepsy and this was buttressed by the observed significant use of orthodox medical treatment for another ailment in the same subjects. These outcomes of a strong cultural perspective contribute to the widening of the ETG.

The health systems of a number of countries with the highest burden of epilepsy are weak and this weakness is often reflected in epilepsy management.[2] Poor infrastructure for health services, deficiency in trained manpower, provision of poor health services, and lack of AEDs characterize such settings.[2] These could lead to an increase in the incidence of epilepsy from preventable conditions such as complicated meningitis and onchocerciasis, increase cost of accessing care in equipped health institutions that are further away from the community, inhibit those who have epilepsy and are willing to come out for, or continue with, appropriate therapy and encourage patronage of less efficacious, non scientific and potentially hazardous options.

The comparatively high prevalence of epilepsy in the studied population could have been a function of a weak health system that is inefficient in dealing with epilepsy predisposing conditions. Katari is in the Northwest region of Nigeria, a region that has one of the highest childhood morbidity and mortality statistics in a country which has also poor child health indices.[27] The weakness was particularly evident in the lack of orthodox medical services against epilepsy in the community. Increased cost of accessing care and use of alternative care option were offshoots of this deficiency and were determinants of the observed ETG. The perceived failure of orthodox medical treatment, another observed ETG determinant, could also be a function of a weak health system. It could have resulted from poor counseling on the modus of drug therapy or lack of facilities for making a correct diagnosis and prescribing the appropriate drug.

Low socio-economic status has been associated with: a limited capacity to access health services; poor access to information that could influence understanding and attitude towards conditions like epilepsy and their management; and increased incidence of infectious diseases

including those that have been identified in the etiology of epilepsy.[28,29] Ignorance on how to access orthodox medical treatment and inability to afford orthodox medical treatment where available, both attributable to the subjects' socio-economic status, were determinants of ETG in the study. Further more, the total dependence of child and adolescent populations in most LMICs on adults in family settings and the lack of statutory social support system as observed in several HICs[5] makes the CAWE in the LMICs even more susceptible to the identified ETG determinants and more. In such settings the CAWE, such as observed in the study population, are subjected to the beliefs and capacities of the adults however appropriate or optimal. In addition, the lack of statutory guidelines for epilepsy care makes the CAWE susceptible to abuse and neglect.

This study has demonstrated that in rural settings where determinants of ETG are in existence active epilepsy is associated with a widened, mainly diagnostic, ETG. Disabling stigma, discrimination, poor quality of life and an increased risk of mortality are some of the dire consequences of epilepsy that could be obviated by bridging the ETG. Addressing issues that culminate in ETG and its consequences requires a multidimensional approach.[2] The first step should be to assess the magnitude of the problem. This should include identification and documentation of all with a history of epilepsy and the capacity to provide treatment for this population at community and national levels. Secondly the development of capacity for provision of treatment and care in the health and related systems is essential. Training of neurologists and that of other health care providers such as community health extension workers (CHEWs) and school health teachers should be given top priority. Additionally there should be institutionalization of social support programmes that also protect the rights of CAWE.

These would improve the amount and quality of epilepsy care services available. Thirdly more robust community based, culturally sensitive awareness and support initiatives should be instituted in communities with negative cultural perspectives on epilepsy and CAWE. In line with the African declaration on epilepsy such community oriented programmes should allay suspicion and foster cooperation with existing traditional health institutions.[2] Finally, there should be collaboration and integration with already existing global initiatives in order to bridge this gap. Such initiatives include the GCAE whose aim include improvement in acceptability, access to services, preventive and quality of care.[2] Another is the WHO/mhGAP initiative which aims at scaling up services for conditions, including epilepsy, especially in LMICs.[30] It has been opined that the WHO/mhGAP guidelines with local adaptation, could facilitate a sustained reduction in ETG and improve quality of care in resource limited settings.[1]

Limitation

The diagnosis of epilepsy in this study was devoid of the use of the electro encephalogram (EEG). Children and adolescents with more subtle epileptic seizures could have been missed.

Conclusion

This study highlights the presence of a widened ETG in a rural setting characterized by strong cultural perspective on epilepsy, a weak health system with regards to epilepsy treatment and a low socio economic status. It underscores the need for renewed promotion of community awareness and cultural reorientation on views on epilepsy, developing health and related systems to be more sensitive to epilepsy management, and improving the standard of living in rural settings of LMICs.

Acknowledgement

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