Published in final edited form as:

Epilepsy Behav. 2012 March ; 23(3): 224–229. doi:10.1016/j.yebeh.2011.12.003.

Perceptions, social life, treatment and education gap of Tanzanian children with epilepsy: a community-based study

D. Mushi¹, K. Burton^{1,2}, C. Mtuya¹, J.K. Gona³, R. Walker⁴, and C.R.J.C. Newton^{3,5,6}

¹Community Health Department, Tumbaini University, Kilimanjaro Christian Medical College, Moshi, Tanzania

²Neurosciences Unit, Institute of Child Health, University College London, United Kingdom

³Centre for Geographic Research Medicine (Coast), Kenya Medical Research Institute, P.O. Box 230-80108, Kilifi, Kenya

⁴Northumbria Healthcare NHS Foundation Trust, North Tyneside General Hospital, North Shields, United Kingdom

⁵Muhimbili-Wellcome Programme, Muhimbili University of Health and Allied Sciences, Dar-es-Salaam, Tanzania

⁶Department of Psychiatry, University of Oxford, United Kingdom

Abstract

The effects of epilepsy on children and their families, factors influencing the treatment and education gap and socio-cultural beliefs about epilepsy in children in rural sub-Saharan Africa are not clearly defined.

We conducted a qualitative study, with 38 in-depth interviews and 2 focus group discussions with carers of children with epilepsy (CWE) in Tanzania.

Discrimination, isolation and lack of hope were identified as major issues. Poor school attendance was attributed to learning difficulties, behaviour problems, ongoing seizures and restricted school access. The treatment gap was related to misdiagnosis, preferential use of traditional treatment and cost of biomedical treatment. The hopes expressed for the future centred on access to treatment and education.

Improved access to diagnosis, cost-effective treatment, sensitisation of the community on epilepsy, collaborative care provision with traditional and faith healers and improved access to specialist schooling could improve the quality of life and future of CWE in this region.

Keywords

Epilepsy; children; Africa; perceptions; treatment gap; education

Introduction

The burden of epilepsy in children is greatest in low income countries (LICs); it has been estimated that of the 3.5 million people who develop epilepsy annually, 40% are less than fifteen years old and 80% live in LICs (1). Unfortunately, in LICs the epilepsy treatment gap (ETG) is considerable, much greater than in high income countries (HICs)(2). The global

disparity in the ETG between LICs and HICs was explored in a systematic review which found that the ETG was over 75% in LICs, less than 10% in HICs and that the ETG was significantly higher in rural areas compared to urban areas (3). Recent reviews of the ETG for children with epilepsy (CWE) from LICs recommended that more research was needed to understand the causes of the ETG in these countries (3;4).

The ETG has been defined by the International League Against Epilepsy 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 a percentage.” (5).

There are qualitative studies in adults with epilepsy which examine the causes of the ETG in Africa. These studies in adults from urban and rural areas found a range of factors contributing to the ETG including cultural beliefs, cost and side effects of antiepileptic drugs (AEDs) and long distance to health facilities (6;7). There has been only one previous qualitative study in CWE from Africa which was performed in rural Kenya. It revealed that inadequate knowledge and manpower, cost of treatment and distance to health facilities, inconsistent AED supply, alternative options for treatment and stigma contributed to the ETG (8). Identifying the cause of the ETG in different populations is a key step towards formulating effective interventions to reduce the ETG across the region.

A range of studies, mostly in adults with epilepsy, have examined the beliefs surrounding epilepsy in Africa. Studies from Tanzania have found that most people did not know the cause of epilepsy and many believed it was contagious through physical contact or attributed epilepsy to spiritual powers and witchcraft (9;10). There has been only one previous qualitative study of beliefs around CWE which found a wide range of beliefs divided into external and internal agents. External agents were spiritual forces, such as witchcraft, and direct injury such as head injury and birth trauma. Internal agents, such as fever and malaria, were recognised as causes by few people (8). The beliefs surrounding epilepsy influenced the choice of treatment.

The negative impact of epilepsy on children and their carers is increasingly recognised as a significant burden. However, there is only one previous study from Africa of the effect of epilepsy on relationships in the community for children with epilepsy. It reported generally positive community responses to two children on direct observation (8). Indirect information was given in a study from Tanzania in which secondary school students without epilepsy were formally interviewed. Many students considered epilepsy to be contagious and this belief was a major reason for disapproving of a CWE playing with other children and going to school (11). There are only a few studies from Africa which have ascertained school attendance in CWE and there is little information on the causes for any lack of schooling. A study of Nigerian adolescents and adults with epilepsy reported that 20% were withdrawn from school because of epilepsy (12). In another Nigerian study, CWE had a higher rate of school absenteeism than age-matched controls (13). A community-based study of children with active convulsive epilepsy in rural Kenya found half of CWE were not attending school. More frequent seizures and cognitive impairment were associated with non-attendance (14).

Although there is emerging data from Africa on the perceptions surrounding epilepsy, on the ETG and the consequences of epilepsy, most data is from studies of adults with epilepsy. Few studies have been conducted in Africa focusing on the effects of epilepsy on children and factors influencing their relationships and educational opportunities. The aim of this study was to understand the socio-cultural beliefs surrounding epilepsy, the effects of

epilepsy on a child and their carers and the factors influencing their treatment and education in a rural African setting.

Design and methodology

The study applied a qualitative design and utilised a phenomenological methodology (i.e. investigating experience as it was lived) to establish an in-depth understanding of what carers and CWE experience.

Sampling procedures

This study was part of a larger community-based study of the prevalence, phenotype and treatment gap for epilepsy in children in Hai District, which is an established demographic surveillance site (DSS). There is an established network of local enumerators in the district experienced in conducting epidemiological surveys. We identified 6 to 14 year old CWE in Hai after a census in January 2009 which had found a total of 38,523 children to be resident in Hai.

During the census a nine-item, previously validated questionnaire was administered to all households in Hai (15). This instrument was translated into Swahili and back translated. The details of any children who responded positively to one or more questions in the screening questionnaire, together with those considered by trained enumerators as likely to have epilepsy, were identified. The study paediatrician (KB), who has training in paediatric epilepsy, assessed each child and the diagnosis of active epilepsy was confirmed by paediatric neurologists. Cases of epilepsy were defined as children with active epilepsy aged 6 to 14 yrs who were resident in Hai at the time of the census. Those children for whom consent was refused, or who were below 6 years old (to eliminate any children with febrile seizures), were excluded.

The carers of the CWE were purposively recruited for this qualitative study considering variation by age, gender and residence from all CWE attending Kilimanjaro Christian Medical Centre (KCMC) for investigation and follow-up as part of the larger study. The characteristics of the carers interviewed are presented in Table 1.

Data collection methods

In-depth interviews were performed with carers. In addition, focus group discussions were conducted in two villages; one semi-urban (Mungushi) and a rural village (Narumu). The data collection tool was developed using Kleinman's explanatory model (16) and examined issues related to community perception of epilepsy, experiences of CWE, the treatment and education gap. A carer was defined as a person who supported and accompanied the child to KCMC. As some children could express themselves, paired interviews were also conducted which involved both CWE and their carers.

Two experienced social scientists, who were both native Kiswahili speakers from KCMC, performed the interviews. All interviews were conducted in Kiswahili in a quiet room in the hospital and were tape-recorded. Data collection took place between February and April 2010.

Ethical approval was obtained from the National Institute of Medical Research (NIMRI) and locally from KCMC Research and Ethics committee. The objectives of the study were explained to study participants and written consent was obtained from parents or guardians of the children in advance. Permission to make audio recordings was sought from study participants prior to commencing interviews. Confidentiality and anonymity were strictly observed.

Data analysis

Recordings were transcribed verbatim and translated into English. Data were checked and cleaned and then stored as Microsoft Word files. Data were manually analyzed using content analysis approach which included familiarization, identification of themes, categorization and interpretation. Analysis was undertaken and discussed by the two social scientists involved in the study. The data were also analysed using the Nvivo (QSR, Version 7) to identify recurring themes and for purposes of triangulation.

Results

We identified four broad themes: knowledge of epilepsy (explanations of the causes and health seeking), effects of epilepsy (which included education gap, friendships and socialisation and effect on the carers), treatment of epilepsy (treatment gap, modalities of treatment and sources of support), and expectations of carers

1. Knowledge of epilepsy

Participants' explanation of epilepsy in children revealed that nearly all respondents defined epilepsy from a non-biomedical point of view:

It's the disease of falling down.

It is a fainting disease.

Epilepsy in children was described from experience as a 'bad illness' with an emphasis on convulsions whose unexpectedness produced fear:

I will explain according to what happened to my son; it is a very scary situation when someone is losing consciousness and falls down suddenly and doesn't remember anything and it can happen anywhere.

From what I can see it is when someone falls down and has a convulsion and other people are saying it is not a good illness; it can drop you anywhere.

The range of symptoms described as part of epilepsy was varied. A large proportion of carers mentioned epilepsy symptoms to be urinating, spitting, screaming, being angry, and shaking with falling down and loss of memory. The cause of epilepsy was for the most part unknown by carers. Perceived causes included socio-cultural beliefs (influence of evil spirits, witchcraft and failing to follow traditions):

We thought that it started because we have not observed some traditions.

Some people inherit it from their family, or are cursed by an evil spirit.

Also some mentioned biomedical causes, particularly accidental or birth-related brain injury and high fever:

He was born by caesarean, and he didn't cry at all, that's how it started.

I thought maybe when she was born the doctors pulled her and squeezed her head which caused her epilepsy; because the other kids are fine; they don't have that kind of disease.

There was a consistent belief that epilepsy was inherited:

I don't know, but people do say it is an inherited disease which goes in a family.

I don't know, but if there is someone in the family who has it, others can inherit it.

The diagnosis of epilepsy was mostly made by the medical team involved in the epilepsy project and the diagnosis had not been made prior to this consultation:

She started to faint at age 2. I went to a nearest dispensary, the doctor told me that is normal for the kids, but she continue to faint; later I decided to take her to a health centre then doctor told me she might be epileptic.

When he was 8 years old, we thought it is Malaria, so we gave her anti-malarial medicine, but after six months she started to shake again. When went to the hospital they said it is malaria. But in our family they thought it was convulsion, or something to do with cultural issues. She didn't get any relief until one day a visiting doctor came and said it might be epilepsy and he gave her some anti-epileptic drugs.

Late or misdiagnosis caused distress. The majority of caretakers said they had negative feelings on hearing that their child had epilepsy and expressed feelings of powerlessness:

When we were told by doctors from KCMC about the problem, I was very angry with the doctors in our health centre because we have spent a lot of money and they didn't tell us what was the problem with our child.

I feel very bad, it is painful and I am praying to God because he knows what happened.

I feel bad to have a child with problems but I just received him; there was nothing I could do.

Health seeking behaviour—Carers chose to use both modern and traditional forms of treatment. Initially, when the problem started, the majority of the carers took their children to a nearby health facility. When a problem persisted they went to faith or traditional healers. The choice of therapy was influenced by relatives and friends, by perceived cause and effectiveness:

We tried to go to the traditional healer, and use herbal medicine but she didn't get any relief, so we are now using the modern medicine only.

Other parents said this problem doesn't have treatment; and some of them lost their children by going to the traditional healer and they tried to convince me but I said I believe the treatment of the hospital.

I made the decision to treat but my friends advised me to go to the faith healer.

2. Effects of epilepsy

Epilepsy had a profound effect on the children in terms of education and wider cultural integration. Carers and children with epilepsy described adverse consequences of epilepsy such as abuse, discrimination, inability to learn, lack of schooling and self-esteem and many had suffered both ridicule and isolation.

Education gap—Carers reported many adverse effects of epilepsy on educational opportunities and achievement. Half the children did not attend school regularly and the main factors which prevented CWE from attending school were ongoing seizures, learning difficulties, behavioural problems and poor access to school. A few children seemed to function well at home and at school:

I am very sad my son couldn't finish his primary school education because of epilepsy.

Yes the big problem is when she was going to school, she will not stay for a long time; they will bring her back when she has falls, so she is missing the lessons at school. But her friends didn't discriminate against her; they are all helping her a lot.

He is very angry, he likes to beat others, it is not easy for him to go to school.

It has affected him, he can't do anything, he can't even pick a cup, or go somewhere, he can't go to school, and he can't read or write.

Friendships and social integration—Friendships for some were maintained but were often disrupted and children with epilepsy were frequently isolated and rejected:

His friends do try to play with him but because he hits them, they go away.

My friends do discriminate against me, when it happens, they are all run away from me, and if I call someone, they pretend not to hear me.

Her friends discriminate against her; she only has the youngest children as her friends, not her own age.

Effects of epilepsy on the carer—The pressures mentioned by carers were the priority of the child and the responsibility to care for them. Depending on the degree of dependency of the child for care, this could impair the carer's ability to work and provide for the family. Emotionally carers could feel worried for the future, lack of money for treatment and expressed psychological distress. The community could respond positively or negatively to the carer and child so that some carers suffered rejection:

His mother felt very bad and sad and even lost hope because he was her first born but we tried to encourage her and gave her support.

The family think that I am a witch.

Since my child started falling my husband ran away and left us, till now I don't know where he lives.

We can't go to work, both me and his mother. If I have to go to work that means his mother must be at home taking care of him, and we have been spending a lot of money trying to find his treatment and it's very hard.

3. Treatment

There were mixed views as to whether epilepsy could be cured. Some thought there was no absolute cure through medicine; others thought prayers were a better option while another group did not know. Extra precautions were taken by most carers to protect the child with epilepsy.

It is very difficult to prevent if he is not using any medicine but if he is using the medicine he will be fine; he won't fall in the fire, water, or hurt himself using knives, so we are trying our best to look after him, keeping him away from the fire or getting lost.

Yes she is going everywhere with her relative, and because in our area there are no cars, she is safe.

Treatment gap—The majority of CWE were not on antiepileptic drugs (AED). Of the 112 CWE who were identified in the larger community-based survey, 98 required regular antiepileptic treatment for ongoing seizures but only 30 (31%) were receiving daily doses of AED thus the treatment gap is 69%. There were several factors that prevented CWE from receiving appropriate treatment. Frequently misdiagnosis occurred at local health centres so treatment was not offered until they were referred to the distant tertiary hospital or until the epilepsy team came to their village as part of the research project. Carers often sought only traditional forms of treatment. Also, the cost of antiepileptic medication was prohibitively

high for some families. Distance and therefore cost of attending hospital was also mentioned:

They are very expensive and we don't know how long he is going to use this medicine; we only give it to him now and hope he will be cured soon.

Sometimes it is difficult, we can't get the medicine, the pharmacist will ask for the money and you just find you don't have the money, so we can stay for 1 or 2 days without the medicine and she will fall down until I get the money and buy the medicine.

I can't afford going to hospital; so when she is sick I normally use herbal medicine.

Treatment modalities—Beliefs around the effectiveness of different treatment options were explored. Antiepileptic medication for some had been ineffective at doses given in the community. However, antiepileptic drugs were generally felt to be effective when used consistently and brought positive improvements and reduced the number of seizures. Faith was expressed as a deep held conviction and consistently helped carers to cope. Faith healing, which principally involved prayers, was an important part of treatment for families and was used widely:

Yes there are lots of changes because it doesn't happen frequently like before; they have given him some medicine to take and now he can remember some things and understand a little bit; I am very pleased about that.

The medicine didn't help him in any way; he is still falling down frequently.

When I saw that she is not getting better, I took her to prayers; the faith healer told us that my child is filled with evil spirits, he advised me to attend prayer sessions on a regular basis.

Sources of support—Some carers were poorly supported. For those who received support, the main sources of support were family, especially grandparents, and also health care professionals, neighbours, teachers and friends. The family seemed most important and sponsors were expected to provide to the family especially for education:

No, he doesn't get any help from anybody except from his grandmother.

I get some help from my neighbour and my sister who is a businesswoman.

The family are all helping, and give us some hope.

I am asking if there is a special school for children like him, to get a sponsor and go to that school; it will help him.

4. Expectations and hopes for the future

Carers felt little hope and expressed longing for a cure and that the CWE could attend school:

I heard there is a school for children like him but I have to stay with him there, which is very difficult for me because there is no one to look after the house. So because he is taking some medicine, I hope one day he will get cured and be able to talk and go to school.

I don't have any plan because I don't have any money and also I don't know if there is any school for children like him.

I don't know because we don't have anything to offer her.

Changes in the community that would help in the future were raising awareness and the level of knowledge about epilepsy through community education, providing accessible and appropriate treatment for epilepsy and providing more assistance:

To help especially those grandparents who are living with their grandchildren, without any help from the parents, will help those children in a very big way.

To advise those parents that this disease has treatment and you can get cured.

I want to ask if we can get help for our children to go to school.

Counselling parents to fight for their children and not to lose hope.

Carers repeatedly raised the need for specialist teachers within mainstream schools and for special schools which would be accessible to families:

Teachers in our schools do not have skills to educate or take care of epileptic children.

I would suggest having their own school, their own teacher who will teach them.

Discussion

This qualitative study explored the perceptions of epilepsy, the effects of epilepsy and the treatment and education gap in CWE from a rural area of sub-Saharan Africa.

The majority of carers from this rural community in Tanzania had a limited knowledge of epilepsy and most believed it was not a biomedical disorder. A few carers recognised biomedical causes, but many in the community attributed epilepsy to adverse spiritual influences. This is similar to other studies in East Africa (8-10) and other parts of Africa (17;18). It has been suggested that secondary school students themselves could be helpful in improving community knowledge of epilepsy (18). This study highlights the need for better community education about epilepsy to reduce unhelpful or stigmatising beliefs and to promote utilisation of appropriate care.

Epilepsy was found to have a profoundly adverse effect on CWE especially in terms of education and friendships. In our study, half of the CWE were not attending school regularly, as has been found in other studies in Africa (12-14). Our study provides further insights into the reasons for non-attendance, which include learning difficulties, behaviour problems and poor access to school due to distance and ejection from school because of ongoing seizures. Poor school attendance seems consistent with longer term follow-up studies from across the world which show that CWE receive less education and are less likely to be employed especially if they have cognitive impairment (19-21). Knowledge of epilepsy in communities may increase school attendance. Evidence supporting this was shown in a study of Zambian teachers, amongst whom there was little knowledge for the cause of epilepsy. More knowledge and personal exposure to epilepsy were associated with better acceptance of epilepsy. Importantly, the most tolerant teachers expressed the least stigmatizing practices such as sending CWE away from school (22).

Families often sought treatment from their nearest health centre; but limited training of local primary health care personnel led to misdiagnosis, and even after diagnosis, the cost of AED from private pharmacies made continuing treatment difficult. In Tanzania, Phenobarbital is the first line treatment for epilepsy in children and is provided free in government dispensaries. When supplies run out in the district, families are forced to buy medication privately. Some carers also only sought traditional treatment. Our findings concur with other studies from the region of the causes of the ETG (2;6-8). In a similar study of CWE from Kenya, factors that influenced treatment seeking behaviour were perceived cause,

knowledge of epilepsy, religious beliefs, severity of the problem, advice given by others, finances, effectiveness and accessibility of health services (8). Providing access to diagnosis and low-cost treatment for epilepsy within communities is likely to reduce the treatment gap for CWE.

Carers utilised a combination of treatments for CWE and the choice was influenced by effectiveness, accessibility and cost, faith and cultural beliefs and advice from others. The use of multiple types of healthcare was also shown in a survey of CWE in South Africa (23). Engagement and working with traditional and faith healers in the region would be helpful as they are working closely with communities and are able to provide ongoing psycho-social support (24). A community survey of the attitudes of traditional healers in Cameroon found that almost all would readily refer patients to hospital (25). These findings indicate that collaboration between modern medical services and traditional healers may significantly reduce the treatment gap for CWE in similar parts of Africa.

The outlook for many CWE was thought to be bleak and was focussed on access to education and treatment. Providing low cost, appropriate community-based treatment is important. Health care delivery systems have been developed for epilepsy in LICs (26) and more research is needed to identify effective health delivery systems for CWE in SSA, especially in rural areas. It is clear from carers that there is a need for training of teachers and provision of specialist education for many of the CWE in the region, as suggested by the World Health Organization (27).

Epilepsy is a stigmatising condition in this part of Africa. It may be that interviewees withheld, or were unaware of, some information because of stigma. Also, carers may have felt uncomfortable revealing the full extent of their use of traditional healers. This study represents the view of one community in a rural part of Tanzania and may not be generalizable to other communities, to urban areas in Tanzania or other parts of Africa.

This study presents qualitative insights into the beliefs surrounding epilepsy and the effects of epilepsy in children from a rural area of Tanzania. Community sensitisation on epilepsy, improved access to diagnosis of epilepsy, cost-effective treatment of epilepsy, collaborative care provision with traditional and faith healers and improved access to specialist schooling could improve the quality of life and long-term future of CWE in this region.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Wellcome Trust, Northumbria Healthcare NHS Foundation Trust and Kilimanjaro Christian Medical Centre supported this study. We would like to thank all the health-care workers, officials, carers, and family members who assisted in identification of patients, examination and assessment. Prof. CRCJ Newton holds a Wellcome Trust Career post in Clinical Tropical Medicine (No. 083744).

Reference List

- (1). Guerrini R. Epilepsy in children. *Lancet*. Feb 11; 2006 367(9509):499–524. [PubMed: 16473127]
- (2). Mbuba CK, Ngugi AK, Newton CR, Carter JA. The epilepsy treatment gap in developing countries: a systematic review of the magnitude, causes, and intervention strategies. *Epilepsia*. Sep; 2008 49(9):1491–503. [PubMed: 18557778]
- (3). Meyer AC, Dua T, Ma J, Saxena S, Birbeck G. Global disparities in the epilepsy treatment gap: a systematic review. *Bull World Health Organ*. Apr; 2010 88(4):260–6. [PubMed: 20431789]

- (4). Farkhondeh M, Hill SR, Cross JH, Dua T. Antiepileptic drugs in children in developing countries: research and treatment guideline needs. *Epilepsia*. Nov; 2009 50(11):2340–3. [PubMed: 19744112]
- (5). Meinardi H, Scott RA, Reis R, Sander JW. The treatment gap in epilepsy: the current situation and ways forward. *Epilepsia*. Jan; 2001 42(1):136–49. [PubMed: 11207798]
- (6). Elechi CA. Default and non-compliance among adult epileptics in Zaria, Nigeria. The need to restructure continued care. *Trop Geogr Med*. Jan; 1991 43(1-2):242–5. [PubMed: 1750124]
- (7). Preux PM, Tiemagni F, Fodzo L, Kandem P, Ngouafong P, Ndonko F, et al. Antiepileptic therapies in the Mifi Province in Cameroon. *Epilepsia*. Apr; 2000 41(4):432–9. [PubMed: 10756409]
- (8). El Sharkawy G, Newton C, Hartley S. Attitudes and practices of families and health care personnel toward children with epilepsy in Kilifi, Kenya. *Epilepsy Behav*. Feb; 2006 8(1):201–12. [PubMed: 16275111]
- (9). Mushi D, Hunter E, Mtuya C, Mshana G, Aris E, Walker R. Social-cultural aspects of epilepsy in Kilimanjaro Region, Tanzania: knowledge and experience among patients and carers. *Epilepsy Behav*. Feb; 2011 20(2):338–43. [PubMed: 21216201]
- (10). Rwiza HT, Matuja WB, Kilonzo GP, Haule J, Mbena P, Mwang'ombola R, et al. Knowledge, attitude, and practice toward epilepsy among rural Tanzanian residents. *Epilepsia*. Nov; 1993 34(6):1017–23. [PubMed: 8243350]
- (11). Matuja WB, Rwiza HT. Knowledge, attitude and practice (KAP) towards epilepsy in secondary school students in Tanzania. *Cent Afr J Med*. Jan; 1994 40(1):13–8. [PubMed: 8082145]
- (12). Nuhu FT, Fawole JO, Babalola OJ, Ayilara OO, Sulaiman ZT. Social consequences of epilepsy: a study of 231 Nigerian patients. *Ann Afr Med*. Jul; 2010 9(3):170–5. [PubMed: 20710109]
- (13). Ibekwe RC, Ojinnaka NC. Childhood epilepsy and school absence. *Trop Doct*. Oct; 2008 38(4):258–9. [PubMed: 18820208]
- (14). Munyoki G, Edwards T, White S, Kwasa T, Chengo E, Kokwaro G, et al. Clinical and neurophysiologic features of active convulsive epilepsy in rural Kenya: A population-based study. *Epilepsia*. Jul 1; 2010 51(12):2370–6. [PubMed: 20608962]
- (15). Placencia M, Sander JW, Shorvon SD, Ellison RH, Cascante SM. Validation of a screening questionnaire for the detection of epileptic seizures in epidemiological studies. *Brain*. Jun; 1992 115(Pt 3):783–94. [PubMed: 1628202]
- (16). Kleinman, A. A patient and healer in the context of culture. Univ. of California Press; Berkeley: 1980.
- (17). Njamnshi AK, Tabah EN, Bissek AC, Yepnjio FN, Kuete C, Angwafor SA, et al. Knowledge, attitudes and practice with respect to epilepsy among secondary school students in the Kumbo West Health District - North West Region-Cameroon. *Epilepsy Behav*. Jul; 2010 18(3):247–53. [PubMed: 20627815]
- (18). Njamnshi AK, Angwafor SA, Jallon P, Muna WF. Secondary school students' knowledge, attitudes, and practice toward epilepsy in the Batibo Health District--Cameroon. *Epilepsia*. May; 2009 50(5):1262–5. [PubMed: 19507307]
- (19). Camfield C, Camfield P, Smith B, Gordon K, Dooley J. Biologic factors as predictors of social outcome of epilepsy in intellectually normal children: a population-based study. *J Pediatr*. Jun; 1993 122(6):869–73. [PubMed: 8501561]
- (20). Kokkonen J, Kokkonen ER, Saukkonen AL, Pennanen P. Psychosocial outcome of young adults with epilepsy in childhood. *J Neurol Neurosurg Psychiatry*. Mar; 1997 62(3):265–8. [PubMed: 9069482]
- (21). Wakamoto H, Nagao H, Hayashi M, Morimoto T. Long-term medical, educational, and social prognoses of childhood-onset epilepsy: a population-based study in a rural district of Japan. *Brain Dev*. Jun; 2000 22(4):246–55. [PubMed: 10838113]
- (22). Birbeck GL, Chomba E, Atadzhanov M, Mbewe E, Haworth A. Zambian teachers: what do they know about epilepsy and how can we work with them to decrease stigma? *Epilepsy Behav*. Sep; 2006 9(2):275–80. [PubMed: 16877045]

- (23). Christianson AL, Zwane ME, Manga P, Rosen E, Venter A, Kromberg JG. Epilepsy in rural South African children--prevalence, associated disability and management. *S Afr Med J.* Mar; 2000 90(3):262–6. [PubMed: 10853404]
- (24). Kendall-Taylor N, Kathomi C, Rimba K, Newton CR. Traditional healers and epilepsy treatment on the Kenyan coast. *Epilepsia.* Sep; 2008 49(9):1638–9. [PubMed: 18782213]
- (25). Njamnshi AK, Bissek AC, Yepnjio FN, Tabah EN, Angwafor SA, Kuate CT, et al. A community survey of knowledge, perceptions, and practice with respect to epilepsy among traditional healers in the Batibo Health District, Cameroon. *Epilepsy Behav.* Jan; 2010 17(1):95–102. [PubMed: 19932640]
- (26). Nizamie SH, Akthar S, Banerjee I, Goyal N. Health care delivery model in epilepsy to reduce treatment gap: World Health Organization study from a rural tribal population of India. *Epilepsy Res.* Apr; 2009 84(2-3):146–52. [PubMed: 19243918]
- (27). World Health Organisation. World Report on Disability. WHO; 2011.

Highlights

- Epilepsy had a profound adverse effect on children with epilepsy and their carers in this rural part of Tanzania.
- Social isolation, reduced school access and lack of hope were major issues.
- The treatment gap was considerable and misdiagnosis, cost, accessibility and choice of treatment were important.
- Improved access to diagnosis, cost-effective treatment, sensitisation of the community, collaborative care provision with traditional healers and improved access to specialist schooling could improve the quality of life and future of CWE in this region.