

Epilepsy management in Africa: major obstacles and solutions

Traditional beliefs often stigmatise sufferers of epilepsy. Lida Lugthart looks at how this can be overcome

Introduction

Epilepsy is a chronic neurological disease that is common in the developing world. Approximately 10 million people are affected in Africa.¹ The daily life of many people with epilepsy (PWE) is disturbed and endangered by seizures and the stigma the disease gives. Phenobarbital is a cheap (US\$6 per year), safe and effective antiepileptic drug (AED) that can be used for treatment^{2,3} and is advised as first choice by the World Health Organization (WHO), starting with a low dose to prevent side-effects,¹ but many people are not treated well.

The Commission on the Developing World of the International League Against Epilepsy (ILAE) convened a workshop in 1999 to discuss the treatment gap (TG) and they accepted the following definition: '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.'⁴

The cause of the TG is multi-factorial, and at the ILAE workshop the potential reasons for the TG were summarised as: low level of healthcare development, cultural values and beliefs, economic problems of countries, lack of prioritising, distance to health centres, and unavailability of AEDs (see Figure 1).⁴

In a systematic review on the magnitude of the epilepsy TG in developing countries the overall estimate of the TG based on 12 studies was 56% (95% CI: 31.1–100%). The wide variation might be explained by the use of non-uniform methods to estimate the TG and by differences in study populations.⁵ To decrease this TG, programmes are set up for treatment of patients. In this review three different models for epilepsy treatment that have been used in Africa are described to show challenges and measures that can be carried out. But first the major obstacle of stigma will be discussed.

Stigma

PWE in Africa are disabled by stigma. A combination of traditional beliefs, poverty, lack of medical care, and inability to fulfil their social roles has a negative impact on the lives of PWE.⁶ Stigma is not only felt by PWE, courtesy stigma is the 'stigma by association' experienced by people close to someone who is stigmatised.⁶

In Europe, a three-question tool has been designed to assess the level of patient-perceived stigma, and this scale has also been used in Zambia. People are asked if

they feel that other people, because of their epilepsy: (1) are uncomfortable with them, (2) treat them as inferior, or (3) prefer to avoid them, with a total score of 0–3.^{7,8}

Seizures during cooking with open fires often lead to burns; a prospective study in South Africa showed that 50% of the adults admitted with burns had epilepsy.⁹ Scars, especially on the face, are visible to other people and lead to shame and discrimination. People see burns as a seal of the victim's fate, as said by traditional healers in Zambia.¹⁰



Seizures during cooking with open fires often lead to burns

Traditional beliefs

One aspect influencing stigma is that many people in Africa believe epilepsy to be contagious and that it can be spread by urine, saliva, flatus, or faeces excreted at all times or during a convulsion.^{11–13} This can result in isolation and unwillingness of witnesses to touch the patient and protect from injury during a seizure. Among 170 PWE, stigma was experienced most by people reporting contagious beliefs of themselves or their neighbourhood and in people with a forced disclosure.⁸

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The belief that seizures are a sign of bewitchment leads to stigma too. PWE will seek care from traditional healers who often emphasise these beliefs and medical care is delayed. In a door-to-door study in Zambia fewer than 4% of PWE had sought medical care while all had been to a traditional healer.⁶

Consequences of stigma

As a consequence of the seizures and the related stigma PWE might be unable to find a partner or are at risk of abandonment after disclosure.¹⁴ Anti-marriage laws were introduced in some countries over 200 years ago, even in England this law was not repealed until 1970.¹⁵

Because of discrimination or physical disabilities some PWE even face problems with basic needs like food. During a famine in southern Zambia, PWE had significant weight-loss and some reported they were excluded from food distributions.¹⁶ Roles in the community cannot be fulfilled, resulting in loss of status or income. Of 1250 inhabitants of rural Ethiopia 46% responded that they would not employ an epileptic.¹² Resulting poverty might lead to limited access to healthcare.

Knowledge and attitude and effect of education

In Zambia, several studies were done among different groups of people (teachers, clerics, policemen, traditional healers, and health workers) to describe their knowledge of epilepsy and attitude to PWE.^{8,10,17-20}

In general these studies showed a lack of knowledge regarding causes and treatment. There are not many studies examining the effect of education on stigma.

In a comparative study in Tanzania the attitude of the community to epilepsy changed positively in a rural region with a well functioning health system for epilepsy compared to another region with lack of good care.²¹

A survey in Ethiopia showed ongoing negative

attitudes towards epilepsy; for this reason the authors stressed the importance of continuing educational programmes.²² In Canada, a retrospective study showed that children who had seen a public service announcement about epilepsy on the television had a better knowledge and a more positive attitude.²³

Global initiatives to decrease stigma

In 1997, the three leading organisations in the field of worldwide epilepsy started working together to reach better general awareness – the ILAE/IBE/WHO Global Campaign Against Epilepsy. Their mission statement is: *To improve the acceptability, treatment, services and prevention of epilepsy worldwide.* Activities include the organisation of regional conferences with the development of Regional Declarations which are used in communication with stakeholders, regional reports, and demonstration projects.²⁴ In the African Declaration governments are called to develop national plans for the education of health workers, patients, and the general public; to eliminate discrimination; to promote interactions with traditional health systems; and to declare a National Epilepsy Day.²⁵

Treatment models in Africa

Different models have been used for epilepsy care in Africa of which three examples are described below.

Ethiopia: nurse-led epilepsy clinics

In 1998, nurses from five health centres in Ethiopia received a 2-week training course with seminars and practical training in the hospital epilepsy clinic.²⁶ The population was informed about the project by community leaders and health workers during other activities such as vaccination sessions. Each month a physician from the hospital visited the clinic to see new patients and to give supervision. Patients were started on phenobarbital and had to pay for the drugs to ensure sustainability, except those with an exemption from treatment charges. Patients were seen every month until they had a stable drug dose and then every 3 months. 813 patients were included and with an estimated prevalence of 5/1000 this was only 20% of predicted cases.

Because of movement of nurses the training had to be given every year. A Regional Chronic NCD Office was set up to ensure drug supplies. After 2 years, 312 patients (38%) were still under

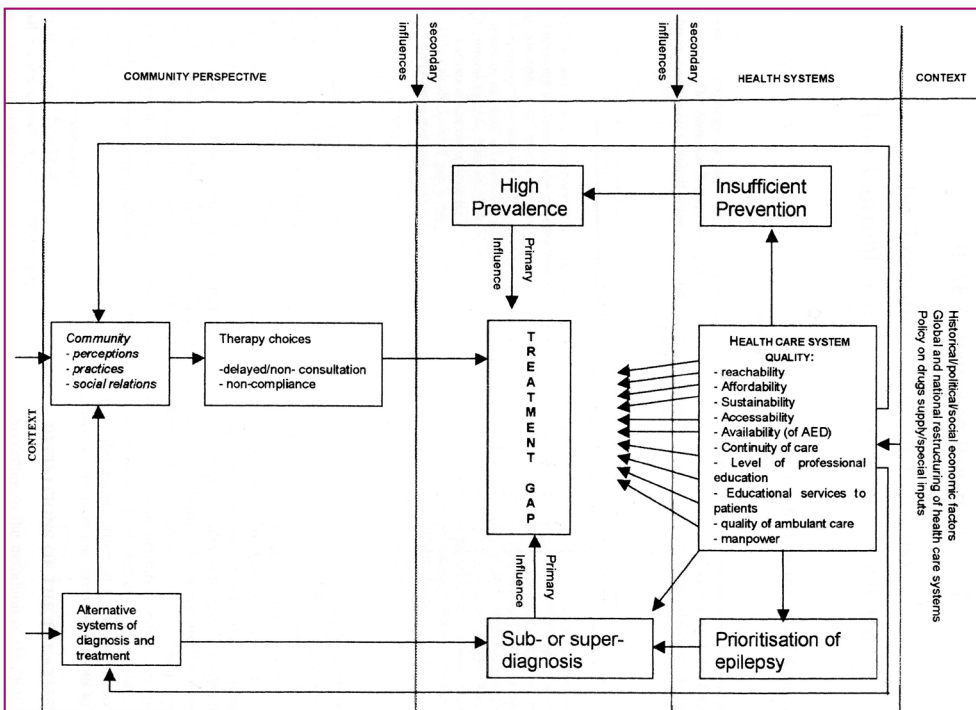


Figure 1 Factors determining treatment gap in epilepsy care

follow-up, of which 48% were seizure free for ≥ 1 year and 34% had a $>90\%$ seizure reduction; only 5% had a $<50\%$ reduction.³

In 2005, 7 years after the start of the nurse-led epilepsy clinics, a study was done to investigate the causes of default from follow-up.²⁷ Of the 113 patients that were traced who had defaulted from follow-up, 28 (25%) had died and 21 (19%) had moved to another region. Sixty-four per cent of the deaths were related to epilepsy. In Table 1 the reasons given by the patients or carers for loss to follow-up are given for the remaining 76 patients. This shows that problems with travel are the main reason in 44%. The time standard deviation (SD) needed for travel was compared with 72 patients who were still under regularly control, and was 6.75 hours (5.12) compared with 4.93 hours (5.56), $p < 0.05$. Only 22% of the patients who had defaulted had access to public transport and 25% had to travel over 10 hours to reach the clinic.

This shows the importance of having the service closer to the patients, which might also be a reason that only 20% of the predicted cases were included in the treatment during the start; 63% of the patients preferred traditional treatment.

Malawi: hospital base and mobile clinics

A E Watts, a medical officer at a mission hospital in Malawi noticed that he only admitted patients with epilepsy on the surgical ward with burns because they were unaware of treatment.²⁸ The model he created for management of epilepsy was characterised by the following:

1. Publicise availability of treatment.
2. Educate patients and staff.
3. Simple regimen with phenobarbital.
3. Adequate supplies of drugs.
4. No charge.
5. Monthly review clinics.
6. Patient always sees the same health worker.
7. Mobile clinics.

At the start just a few patients presented, but after a talk at a meeting of the area action committee with

100 village representatives, the number of PWE coming to the hospital increased dramatically. Epilepsy was diagnosed on the history of patients and witnesses as no electroencephalogram (EEG) was available. Treatment with phenobarbital was started at a dose of 30–60 mg for children and 60–90 mg for adults and reviewed every month. In cases of continuing seizures treatment was gradually changed to phenytoin. Mobile clinics were opened in two places, resulting in the registration of 461 patients after 2 years. Others adopted the model after a full description of the clinics was given in a national health extension magazine, and after 1 year 3000 patients in 45 church-related health units in Malawi were receiving regular treatment.

Community involvement in Uganda

In a rural community in West Uganda several surveys were carried out on the relationship between epilepsy and onchocerciasis.²⁹ In 1991 and 1992, 400 patients with epilepsy were identified in a survey. Treatment was started and then assigned to two health units that provided free antiepileptic drugs. This programme had major difficulties with adherence: when the health units were reviewed 3 years later only 6 patients were under continuous treatment and 47 under sporadic treatment. For a survey in a neighbouring region in 1994 the District Health Team discussed other forms of continuing care. In this region no health unit existed in 1994. Basic Health Services (BHS) agreed to cover the costs for AED and deliver them every 6 months. They provided one health worker for 1 week every 6 months to overcome the problem of patients having to travel to a health unit far away from their home. Outreach clinics were held by the health worker assisted by two community assistants. These community assistants informed patients about the next date of the clinic and distributed the drugs. Patients who did not attend the clinic were visited at home. A decision was made at a meeting of patients and families from the 12 villages that the assistants would be financed by payment from the patients. To have a buffer for the case drugs were not delivered on time by the BHS where a community drug stock was

set up and restocked when the drugs were delivered. After 1 year a committee was formed of families with a member suffering from epilepsy. These committees made decisions on cost sharing and appointed the village assistant and the trustee of the community drug stock. After 2 years, 32 patients (60%) had a good compliance and were coming to the distribution centre. In 1998 a health unit was completed in the region and the care for epilepsy patients was integrated instead of at the outreach clinics, with supply of drugs to patients for 1 month. In a follow-up study in 2001 the outcome of 57/61

	Main reason for default (%) (n=76)	Percentage reporting this factor as contributory reason for default (n=76)
Too far to travel	33	64
Unable to travel because of epilepsy	4	26
Cost of travel	4	20
Lack of carer to accompany patient	3	5
Traditional remedies preferred	12	51
No improvement with treatment	9	28
Seizures much improved	8	16
Cost of treatment	3	11
Adverse effects of treatment	4	4
Dissatisfaction with the clinic service	5	7
Seizures returned when treatment finished	1	1
Did not understand the need for follow-up	1	3

Table 1 Reasons given by patients for defaulting from follow-up in Ethiopia²⁷

patients was assessed.³⁰ During 7 years, 18 deaths were observed. Seven of them died with a possible direct relation to epilepsy according to verbal autopsy (four status epilepticus, two infected burns, two sudden unexpected deaths, and one drowning with seizure).

General measures

Treatment gap

Political commitment is crucial in reducing the treatment gap in Africa, by ensuring that epilepsy remains on the agenda and that essential drugs are available.⁴ Epilepsy is classified by the World Bank as a highly cost-effective condition to treat.¹ Giving free drugs as in the project in Malawi can lower the costs for patients with a possible higher adherence. However, drugs are not the only expenses, for costs of travel were part of the reason for default from follow-up in a quarter of patients in Ethiopia. As described in these studies, distance to health clinics is an important obstacle to access of epileptic treatment; this fact stresses the importance of measures that make time and costs for travel lower. AEDs (especially phenobarbital) have to be prescribed in primary healthcare centres. Neurologists are most effective in the role of educator, advisor, and advocate.³¹

Education

As described above in the programme of Malawi, education is very important. Communities have to be made aware of the possibilities of medical care and prejudices need to be invalidated. Working together with key people in the community is important.¹ Health workers need to be trained in how to treat PWE. Also crucial is the education of patients.¹⁴ Issues to discuss are the delayed effect of AED and the importance of compliance. But education goes further; injury can be prevented by the avoidance of driving, cooking, swimming, and working in high areas. Other roles need to be identified by patients and families to help PWE fulfil their role in the community. Women are faced with additional issues regarding conception, pregnancy, and childbirth.¹⁴

Prevention

Many of the causes of epilepsy in Africa are preventable and it is important to promote preventive measures.^{1,32} Things to consider are related to prevention of sickness and neurological damage (primary prevention) and to treatment of diseases that have an impact on the brain (secondary prevention). Involved in the first group are safer pregnancy and childbirth, immunisation for measles, better hygiene to prevent cystercercosis, prevention of malaria attacks with impregnated bed nets, and prevention of road traffic accidents with better traffic rules and safer vehicles. Diseases related to the potential development of epilepsy are meningitis, malaria with changing resistance patterns, metabolic disturbances such as hypoglycaemia, electrolyte imbalance, and hyperbilirubinaemia. Early detection and adequate treatment of these diseases can lower the risk of the development of epilepsy. It is also important to prevent

and treat status epilepticus with prolonged seizures that can cause further brain damage.

Conclusions

Epilepsy affects millions of people in Africa where only a few neurologists are available. There is a lack of political involvement, unavailability of AEDs, and people are not aware of the possibility of treatment or do not have the money or time to travel to places with a trained health worker. Stigma has a huge influence on the lives of PWE. Cultural beliefs and preference for traditional healers delay treatment. Education of PHWs and other key persons, provision of phenobarbital, and information for patients can improve the quality of life of PWE. Raising public awareness with addressing of discrimination, measures to prevent neurological disease, and strengthening partnerships are all important to lower the treatment gap.

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