Research: Epilepsy in Malawi.
Report for Federation of Disability Organisation in Malawi in Partnership with Sue Rider Foundation in Malawi

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Acronyms

AED      Anti-epileptic drug
AIDS     Acquired Immune Deficiency Syndrome
CT       Computerised tomography
DFID     Department for International Development
DH       District Hospital
DHO      District Health Officer
EEG      Electroencephalography
FEDOMA   Federation of Disability Organisations in Malawi
GCAE     Global Campaign Against Epilepsy
HSA      Health Surveillance Assistant
HIV      Human immunodeficiency virus
IBE      International Bureau of Epilepsy
ILAE     International League Against Epilepsy
MRI      Magnetic Resonance Imaging
SRFIM    Sue Ryder Foundation in Malawi
TA       Traditional Authority
WHO      World Health Organisation
EXECUTIVE SUMMARY

Epilepsy directly affects around 10 million people in Africa and when left untreated can have a major adverse impact on families and communities\(^1\). Around 80% of the burden of epilepsy lies in the developing world where knowledge and access to treatment remains severely limited\(^2\). Although epilepsy is present across all age groups the highest prevalence rates are most often found in children and young people and it therefore plays a significant role in poor educational achievement and high rates of unemployment. Yet epilepsy is a significant neurological disorder for which effective and cost efficient treatment is available. If properly treated up to 70% of people with epilepsy have the potential to live independent and productive lives, free from seizures\(^3\). However an estimated 80% of people with epilepsy living in developing countries are excluded from treatment whether through lack of knowledge, stigma and discrimination, inaccessible health services or general levels of poverty. Given that on average it costs just $5.00 per person a year to treat epilepsy the economic effects of untreated epilepsy would appear to significantly outweigh the cost of treatment.

In 1997, the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) joined forces to initiate a Global Campaign Against Epilepsy (GCAE) with a mission to improve the acceptability, treatment, services and prevention of epilepsy worldwide. In Africa this Campaign resulted in the production of the African Declaration on Epilepsy formulated in Senegal in 2000 and signed by many countries, including Malawi. As part of the Declaration signatories acknowledge epilepsy as a healthcare priority which should be accompanied by a national plan of action.

In 2008 the Federation of Disability Organisations in Malawi (FEDOMA) began a three year ‘Empowering People with Epilepsy’ project funded by DFID and managed through the Sue Ryder Foundation in Malawi. The aim of this project is to bring epilepsy ‘out of the shadows’ in Malawi by establishing for the first time clear leadership and representation for people with epilepsy and their families. The project works in collaboration with people with epilepsy to document and challenge the discrimination they face in accessing appropriate treatment and other services such as education. It seeks to help the government of Malawi to fulfil its obligations under the African Declaration and to work with interested Ministries,

\(^1\) Epilepsy in the WHO African Region: Bridging the Gap (WHO, 2004)
\(^2\) Global campaign against epilepsy - Giuliano Avanzini (2006)
\(^3\) Op cit
healthcare professionals, service providers, carers and people with epilepsy to formulate an effective National Epilepsy Plan.

As part of the initial phase of the project FEDOMA facilitated an action research process in seven pilot Districts across Malawi during early 2010. The fieldwork was completed in June 2010 with subsequent time being spent on analysing and discussing results. This report presents the findings of the research.

The research team included an international disability consultant, the project manager and a team of 70 local researchers – all of whom have personal experience of living with epilepsy. The research design, a population based survey employed both quantitative and exploratory qualitative methods for data collection. Since this was an action research process the volunteer researchers were all involved in designing the questions which set the themes for the research and their feedback during the fieldwork phase was critical. Their experiences helped to shape the eventual focus of the report and so all the issues raised here relate directly to those experienced by people with epilepsy in Malawi.

Although the research results are the main focus of this report it should also be noted that the process of using people with epilepsy to design, collect and collate data linked to living with the condition has had a significant impact on raising awareness and reducing stigma. It has contributed to a dramatic increase in treatment seeking behaviour within the pilot Districts and provides a very good model for how excluded and vulnerable groups can become agents for positive change.

Overall the research found a 2.8% prevalence rate although this varied considerably across the different Districts. The age group which appear to have the highest incidence of epilepsy are those between 6-18 years, but interestingly this study found a higher proportion of males affected compared to females in all categories (55% and 45% respectively). This is in contrast to most national data which tends to show higher incidences amongst females. Although this study did not ascertain why this should be the case in Malawi it is probable that the cultural affects of stigma combined with rural poverty play a significant role in reducing female access to treatment. However this is an area for which more detailed research would be beneficial.
On the supply side this research highlights the gaps in capacity of the health sector in particular to deliver effective services for people with epilepsy. There are recurrent shortages of appropriate drugs, a lack of trained staff, poor diagnostic protocols and an overall high treatment gap. Although treatment seeking behaviour is on the increase, especially since the project started there is still a significant gap in available public health information on epilepsy. In the rural areas especially this is leading to an over reliance on traditional medicines and widespread beliefs that epilepsy is spiritual rather than organic in nature. Ignorance and lack of knowledge about epilepsy is also contributing to the overall poor management of epilepsy from grassroots to national strategic levels.

Given the high prevalence of epilepsy amongst children and young people the research was also concerned to note that levels of education for people with epilepsy are lower than the national average. Of those surveyed 69 out 100 people with epilepsy had never been to school leading to a high rate of illiteracy among people living with epilepsy. The situation for girls with epilepsy seems even more difficult with girls experiencing an average of just 4 years education compared with 8 years for boys. Once again cultural attitudes may be contributing to poorer outcomes for women with epilepsy.

Based on the findings the research team recommends the following strategic directions:

- Give a voice to people living with epilepsy;
- Foster competence of relevant ministries to plan for and manage epilepsy;
- Ensure the integration of people living with epilepsy into education, health, and development sector planning at National level;
- Strengthen the capacity of local service providers to deliver appropriate health, education, economic and social services to people with epilepsy and their families;
- Empower rural women in particular, to understand epilepsy and seek appropriate treatment;
- Put guidelines in place for the appropriate ordering and stocking of anti-epileptic drugs to ensure health service providers do not run short;
- Collect accurate data on the numbers of people with epilepsy at District level on a regular basis;
- Launch a nationwide public health campaign to raise awareness about epilepsy, the possibilities for treatment and its long term management;
• Tackle the discrimination and stigma faced by children and young people with epilepsy from within the education system paying particular attention to girls.
BACKGROUND

Malawi is a landlocked country in the Southern part of Africa with a total population of just over 15.6 million people. Malawi is predominantly rural with just 20% of the population living in urban areas. The spatial distribution of the population shows that 45 percent of the country’s population lives in the Southern Region of the country, 42 percent in the Central Region and 13 percent in the Northern Region. There are 6.2 million people over the age of 18 years of whom 3.2 million are female. Economically it is amongst the poorest countries in the world with an HDI of 153 and a life expectancy at birth of just 54.6 years. School enrolment rates currently stand at 61.9% but there are still significant gender disparities in education with 56% of young women illiterate compared to 27% of young men. The public health expenditure, though improving, stands at around 5.9% of GDP falling well short of the required 15%. This has an impact on the range and quality of services that can be provided for by government. According to this research there is one local neurologist and two expatriate neurologists (at the time of research) at work in Malawi. The most common epilepsy drug in use across Malawi is Phenobarbital although Carbamazepine, Phenytoin and Valproate are also sometimes prescribed.

The situation for people with epilepsy in Malawi remains difficult. Epilepsy has both medical and social consequences for those who are affected which if left untreated can result in severe disability. Epilepsy is triggered by abnormal electrical activity in the brain resulting in an involuntary change in body movement, function, sensation, awareness and behaviour. The condition is characterized by repeated seizures or “fits” as they are commonly called. These take many forms ranging from the shortest lapse of attention to severe and frequent convulsions.

People with epilepsy face many economic and social barriers in Malawi which has an impact on their quality of life. People with epilepsy face exclusion from education, employment, health and community life as a result of poor understanding of the condition. They are often shunned by their families and communities who fear their symptoms as being contagious or the result of witchcraft. Lack of public information and professional guidance means many people with epilepsy are unaware they can receive treatment so the treatment gap remains high. Even once diagnosed issues of poverty, poor

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4 Bridging the Gap (WHO, 2004)
infrastructure and poorly resourced health centres create barriers to people with epilepsy in receiving regular treatment leading to unnecessary injuries and deaths.

Malawi has yet to fully recognise epilepsy as a health priority despite the prevalence of conditions most likely to result in epilepsy (including poor perinatal care, a high risk of trauma, high levels of HIV, malaria and other viral, bacterial and parasitic diseases). There is no representative organisation of people with epilepsy and neither the International Bureau or International League Against Epilepsy have representatives in the country.

RESEARCH OBJECTIVES

The objectives of the research were two-fold: firstly to gather data on the prevalence of epilepsy in the study areas and to ascertain what level of treatment seeking behaviour exists; and secondly to begin to identify some of the main affects epilepsy has on the quality of life of those with the condition and their families. The final scope of the research was determined in consultation with people with epilepsy, their carers and relevant health professionals.

The specific objectives of the study are:

1. To estimate the prevalence of epilepsy in Malawi
2. To document and analyse information on the treatment gap
3. To determine the education levels of people with epilepsy
4. To determine the gender distribution of people with epilepsy

STUDY LOCATIONS

The Seven districts chosen for this pilot research are all part of the 'Empowering People with Epilepsy' project:

<table>
<thead>
<tr>
<th>District</th>
<th>Number of Traditional Authorities?*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balaka</td>
<td>3</td>
</tr>
<tr>
<td>Blantyre</td>
<td>3</td>
</tr>
<tr>
<td>Lilongwe</td>
<td>3</td>
</tr>
<tr>
<td>Ntcheu</td>
<td>3</td>
</tr>
<tr>
<td>Machinga</td>
<td>3</td>
</tr>
<tr>
<td>Mzuzu</td>
<td>1</td>
</tr>
<tr>
<td>Zomba</td>
<td>1</td>
</tr>
</tbody>
</table>

*Traditional Authorities are a group of villages put together
The research took place at village group level and involved an initial preparation phase during which the research team built up a strong rapport with village chiefs. Having learned more about epilepsy the chiefs assisted the researchers to identify suitable locations for the final data collection exercise. Locations were balanced between rural and urban areas with those being most densely populated favoured over those with fewer people.

Table 1: Basic information of Districts

<table>
<thead>
<tr>
<th>District</th>
<th>Total Population</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balaka</td>
<td>316,748</td>
<td>151,637</td>
<td>165,111</td>
</tr>
<tr>
<td>Blantyre</td>
<td>999,491</td>
<td>502,201</td>
<td>497,290</td>
</tr>
<tr>
<td>Lilongwe</td>
<td>1,897,167</td>
<td>938,985</td>
<td>958,182</td>
</tr>
<tr>
<td>Ntcheu</td>
<td>474,464</td>
<td>226,567</td>
<td>247,897</td>
</tr>
<tr>
<td>Machinga</td>
<td>488,996</td>
<td>234,747</td>
<td>254,249</td>
</tr>
<tr>
<td>Mzuzu</td>
<td>128,432</td>
<td>64,341</td>
<td>64,091</td>
</tr>
<tr>
<td>Zomba</td>
<td>670,533</td>
<td>324,159</td>
<td>346,374</td>
</tr>
</tbody>
</table>

The researched Districts represent 38% of the total population of Malawi.

**METHODOLOGY**

**Sampling**

The study began by using a convenience sampling method in order to first identify and recruit people with epilepsy and carers as research assistants. Hospitals and village health centres then acted as the main coordinating centres for informing villagers about the intended study and helped with putting the researchers in touch with people with epilepsy.

The research itself used a basic random sampling technique although initial work incorporated purposive sampling. This involved identifying key stakeholders ahead of the study teams visits and briefing them on the aims and purpose of the research. Key stakeholders included:

- Village chiefs
- District hospital and village health centre staff
- Epilepsy service providers

A total of 10,230 people representing 2,256 households were involved in the study.

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5 Source: National Statistic Office 2008
**Study tools**

Two main study tools were used during the fieldwork for primary data collection – a short questionnaire conducted by research assistants at household level and a semi-structured interview (referred to as the hospital audit form) for use with health professionals. All question areas were derived from the original project baseline report which had carried out some preliminary research during the inception phase. The study team comprising of the lead researchers, research assistants and project personnel reviewed together draft questionnaires and edited them several times before going to the field. Trial questionnaires were delivered in all districts and some questions modified as a result. All research assistants underwent training before carrying out the household survey and were supervised during the final data collection exercise.

**Data collection**

The research involved both quantitative and qualitative study methods and focused as far as possible on a participatory approach. Field data was collected between early April 2010 and mid May 2010. In addition to the primary data some secondary data was also collected and participant observations conducted at health facilities. Below is a summary of each research data collection activity:

**Household surveys**

A questionnaire with ten questions was used as the basis for the household survey which was categorised into the following sections: basic household information; information related to epilepsy; general household wealth. Training on the questionnaire was done six months before the research took place but the intervening time was used to give research assistants a chance to practice and familiarise themselves with the study area. Given the majority of research assistants were people with epilepsy considerable support had to be provided during the preparation phase in order to boost their confidence and to help with literacy skills.

**Study of Epilepsy patients records**

Epilepsy patient records from Ntcheu, Balaka, Queens, and Machinga District Hospitals along with Zomba Mental Hospital and Chikwewo and Lundu Health centres were reviewed. At each hospital a psychiatric nurse or mental health coordinator and pharmacist
worked closely with the project manager for a the period of two days to review all the records and information related to each client. At the health centres Medical Assistants provided the necessary information. A record form was developed by the project manager.

Observation of health facilities at district and village health centres
The researchers visited Ntcheu, Balaka, Queens, and Machinga District Hospitals along with Zomba Mental Hospital and Chikwewo and Lundu Health centres to observe at firsthand how epilepsy is diagnosed. A record of observations was kept during the research and the findings used to inform the final report.

Key informant interviews
There were four types of key informants who provided information on drug supplies in health centres during the research. Interviews were held at the offices or villages of each key informant. Mental Health and Psychiatric personnel play an important role in Malawi in epilepsy management as there are few specialized staff for epilepsy. Epilepsy management is carried out under mental health services, hence the emphasis on interviewing mental health staff.

Below are details of interview activities undertaken:

<table>
<thead>
<tr>
<th>District</th>
<th>Informant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blantyre</td>
<td>Mental Health Coordinators</td>
</tr>
<tr>
<td></td>
<td>Psychiatric Nurses</td>
</tr>
<tr>
<td></td>
<td>Pharmacists</td>
</tr>
<tr>
<td>Lilongwe</td>
<td>Pharmacists</td>
</tr>
<tr>
<td>Balaka</td>
<td>Information and Education Officers</td>
</tr>
<tr>
<td>Ntcheu</td>
<td>Psychiatric Nurses</td>
</tr>
</tbody>
</table>

Data Analysis and Reporting
All qualitative data including observations and informant interviews were summarised and incorporated into the research findings by the lead researchers. All quantitative data including the household survey and review of client records was coded and analysed using a statistical application.
Study Limitations

There are a number of study limitations that should be noted here. The main aim of the research was to identify prevalence rates and access to treatment for people with epilepsy in the seven Districts covered by the project and were not originally intended to be nationally representative. However since these seven districts represent 38% of the total population of Malawi some credence can be given to the assumption that the prevalence rate could be representative of Malawi as a whole. More research in the remaining twenty two districts will have to be undertaken before an accurate prevalence rate can be identified.

Although the research made extensive use of current patient records it has to be noted that there were many gaps in patient records which made tracing treatment histories difficult and it is likely there are more patients in the system than have been officially recorded.

Finally, using research assistants with only basic literacy skills did lead to some inconsistencies in recording household data although supervision of the field work helped to limit this. Supervision also noted that some respondents were replying positively to questions linked to epilepsy because they thought there might be something to gain from this type of response. As far as possible suspect respondents were screened and followed up with a second interview to confirm the validity of their responses but there are likely to be some which were missed.
FINDINGS

Prevalence

Epilepsy prevalence is determined by the proportion of people in a population with the condition at a given time. Prevalence varies from country to country and district by district within the same country largely depending on the methods used for data collection. In this study we relied on the household survey results to determine prevalence rates because the medical records were so inconsistent. WHO Report: Epilepsy in the WHO Africa Region (2004): Bridging the Gap, reported a prevalence rate of 5.20 per 1000 people in Malawi but they relied entirely on estimates carried out by E Watts using patient records at Embangweni hospital and have always been considered an underestimate. This study confirms the underestimate with a median prevalence rate of 28 per 1000 people. This translates to an estimated 436,800 people with epilepsy in Malawi. The table below shows the prevalence distribution per district:

Fig 1 Illustrates prevalence per 1,000.

Prevalence per 1000

The research identified some areas which appeared to have higher prevalence rates than others. Geographically these districts have little variation in terms of climate or seasonal changes so environmental factors would not appear to be important. The biggest variations are in population density and the distribution of urban and rural populations. Blantyre and Lilongwe have high population densities (having 5.1% and 4.4% population of the whole country respectively) and are the most urban of all the Districts. Given parasitic diseases are a leading cause of epilepsy the poor sanitation and high population...
density found in urban areas could be contributing to relatively higher rates. Likewise the increase in accidents associated with urban life might also contribute. There is however a relatively high prevalence rate in Machinga which it would be good to investigate further. This District has both urban and rural populations which might contribute to the high rates but it also has very high rates of perinatal infections. Given that the results from this District also showed high numbers of children affected by epilepsy it would seem as though poor perinatal care could be contributing to high rates of epilepsy in Machinga.

It was not within the scope of this research to study in detail the relationship between the prevalence and other causes of epilepsy.

**Gender and Age Distribution of Epilepsy**

![Gender Distribution Chart]

**Fig 2: Number of people with epilepsy by gender**

Unexpectedly this research found a higher prevalence rate amongst men than women. Most national data tends to show little difference in gender distribution but where it exists it is usually more women than men. Unfortunately the scope of this research did not allow us to investigate this issue further but anecdotal evidence would suggest that differences in treatment seeking behaviour are responsible for the gender disparity.

Poverty could be a contributing factor along with cultural attitudes towards women and girls. The majority of Malawians are poor and when seeking treatment it is often men who are afforded priority. Although treatment is free the journey from home to hospital and the
time needed to make the trip can put extra pressure on poor families and can be a reason against seeking treatment.

Another factor may also be linked to stigma and cultural attitudes. Young women in particular may be reluctant to seek treatment for their condition for fear that the label of epilepsy will reduce their chances of marriage. It could also have led to an unwillingness to disclose their status to the interviewers for the same reasons. What this research shows is that gender is a factor in how people experience epilepsy and that there are many difficulties for women living with epilepsy. They are having to cope with pressure from families and society with poverty and discrimination having an adverse affect on their willingness to seek treatment. More research in this area is urgently needed to understand the complexities of this situation and to identify if there is need for a more gendered approach to awareness raising and the delivery of treatment.

**People with Epilepsy by Age**

![Graph showing the distribution of people with epilepsy by age groups.](image)

**Fig 3: People with epilepsy by age groups.**

This research found a particularly high prevalence rate of epilepsy amongst the younger age groups especially those around 6-18 years. As reported above some of this could be due to poor perinatal care and the effects of household poverty leading to increased risk of
parasitic, viral and bacterial infections amongst children. This age group are also at particular risk from both accidental and non-accidental trauma.

There is also the possibility that inconsistent diagnostic protocols might be affecting results amongst this age group in particular. Younger children are more at risk of febrile convulsions and it could be that many cases of this transient condition are being mistakenly misdiagnosed as epilepsy by non-specialist healthcare workers. Anecdotal evidence from specialist healthcare professionals suggest that there is widespread misunderstanding of how epilepsy presents, especially in children from whom it is very difficult to get firsthand information. One issue seems to be that in local dialects there is no distinction made between the word for seizure and that for epilepsy, even amongst healthcare workers and this is likely contributing to misdiagnosis. This is an area which needs more detailed study but it would seem to suggest that guidance notes on diagnosing epilepsy for non-specialist healthcare workers is urgently needed.

**Reported causes of epilepsy and seizures regarding the age in sub Saharan Africa (adapted from Genton, 1992)**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Causes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5 years</td>
<td>Neonatal asphyxia, perinatal traumatism, infections(mainly meningitis; including HIV, bacterial, viral, malaria anther parasitosis), cerebral malformations, inborn errors of metabolism.</td>
</tr>
<tr>
<td>6-18</td>
<td>sequel of previous causes, idiopathic generalised epilepsy, post traumatic epilepsy, intoxication including alcohol and other drugs, primary tumours, malformations.</td>
</tr>
<tr>
<td>19-40</td>
<td>sequel of previous causes, post traumatic epilepsy, brain tumours, alcohol, infections, vascular diseases.</td>
</tr>
<tr>
<td>42-60</td>
<td>tumours, alcohol, head trauma, infections, vascular causes, metabolic disorders(mainly diabetes).</td>
</tr>
<tr>
<td>&gt;61 years</td>
<td>vascular causes and metabolic disorders, primary and secondary tumours.</td>
</tr>
</tbody>
</table>

**Treatment Gap**

The epilepsy treatment gap is defined as that section of the population with epilepsy who require treatment but are not receiving it. This definition includes both the diagnostic and therapeutic deficits. The treatment gap in developing countries can be as high as 56%. In Malawi this research identified a 32% treatment gap with regards to people with epilepsy.
not receiving medication. The research identified the following as major contributing factors to the treatment gap in Malawi:

**Social Perspective**

There are many factors at work in how people perceive epilepsy in Malawi many of which actively inhibit access to effective treatment (Chilopora et al., 1999). There is a strong belief that epilepsy is not an organic disease or condition but one that is linked to witchcraft and spirits. Seizures are linked with possession and this generates a great deal of fear amongst villagers and families. Very often the first place of choice for relief is with traditional healers and therefore many people with epilepsy can live for years without having attended a medical clinic. Given the strong beliefs surrounding the symptoms of epilepsy few actually realise that medication can be taken and so do not seek treatment. They are unaware they have a medical condition which can be treated.

Another issue is that even after diagnosis many people default in taking anti-epileptic drugs (AEDs) or fail to comply with the treatment regime. The research found that 28% of those on medication were not fully compliant. This research identified that one of the main reasons for this is a lack of understanding about the nature of epilepsy and the role of drugs in its management. Many people living with epilepsy and their carers expect anti-epileptic drugs to cure them, often within a short space of time. It takes time to settle on the right medication and dosage levels however but if people do not see any significant changes in their symptoms early enough there is a tendency to cease treatment altogether. The converse can also be true – where people do see a cessation of symptoms it can be tempting for them to stop taking medication in the belief that they have now been cured. What this points to is a lack of understanding about the causes and long term management of epilepsy and a widespread failure of healthcare professionals to adequately follow up and monitor clients.

Poverty is also a factor affecting treatment seeking behaviour. Whilst medication is free the regular monthly journeys to and from the clinics are costly for those who rely on subsistence living. People with epilepsy often have to be accompanied to clinics by a guardian or family member which means at least two people need to make this journey which for many involves an entire day. If the benefits of treatment are not obvious (for example the condition is not yet stabilised) then it can tempt families to believe the costs are too high. As mentioned above there is some indication that this can have a particularly
adverse affect on women and girls. This complex socio-cultural environment is contributing to the treatment gap.

**Healthcare**

Malawi, as in many African countries, suffers from a healthcare system that is generally under-resourced but the situation with regards to epilepsy is particularly acute. There are very few trained personnel specialising in epilepsy. Most dedicated epilepsy services are run by mental health professionals whose training and skills focus predominantly on psychiatric disorders. Mental health generally is not a popular specialism and with little in the way of in-service training and promotion prospects many trained personnel eventually leave to take up positions in other departments\(^6\). At physician level the ratio of neurologist to client currently stands at 1:3,500,000. There are no EEG, CT or MRI facilities in Malawi which makes definitive diagnoses extremely difficult and limits significantly the opportunities for treatment.

Unfortunately the HIV/AIDS pandemic has hit Malawi hard and this appears to have affected how resources are prioritised. An interesting issue emerging from this research is the possible relationship between HIV and epilepsy – healthcare professionals are noticing a significant number of clients are being treated for both conditions. What is surprising is that HIV and epilepsy treatments are not being monitored together. If there is a link between HIV and epilepsy then some of the resources going to HIV should be focused specifically on epilepsy and clients treated holistically rather than separately. This could ensure a safer more effective and efficient delivery of services for this client group.

AEDs are available free of charge across Malawi but there are significant issues with regards to access and distribution. This research identified a regular pattern of drug shortages in most Districts linked directly to the seasons. For four months out of every twelve most Districts experience drug shortages which coincide exactly with the rainy season. When it rains many roads become impassable and as a consequence mobile clinics cannot operate and health centres run short of supplies. People with epilepsy have to wait until the roads dry out before they can access their medications. In the meantime the research uncovered anecdotal evidence of people with epilepsy dying as a direct result of their epilepsy because they were unable to access their medication.

\(^6\) Personal communication with key informants
Mobile clinics are also hampered by a lack of transport. Despite planning weekly clinics at least six months in advance most government health services do not guarantee transport is made available. Consequently clinics are often delayed or even cancelled as nursing staff try to find vehicles. In response to the unpredictable nature of the supply of drugs people with epilepsy have started to organise themselves into groups in an attempt to gain access to medication. Group leaders are being charged with collecting members health passports and travelling to the District hospitals to collect prescriptions on their behalf. Whilst health professionals admit this is not safe practice it is nevertheless a pragmatic response to the need for regular medication which is not reaching people on time. The stocking and distribution of AEDs is an issue which needs urgent attention to prevent unnecessary suffering and deaths.

**Pharmacotherapy**

There is a limited number of drugs available for use in Malawi; Phenobarbital, Carbamazepine, Phenytoin and Valproate are the only drugs stocked. As mentioned previously 80% of health centres experience drug shortages at least two or three times a year. District Health Offices (DHO) and District Hospitals (DH) give low priority to AEDs and do not take pre-emptory actions to avoid shortages. About 80% of Health Centres in rural Malawi rely on supplies coming from Central Medical Stores through the DHO or DHs but the supplies are inconsistent. Patients on average miss medication at least two months per year due to lack of stock at all levels in the healthcare system not just in rural areas. This has a serious affect on people living with epilepsy leading to increases in seizures, an inability to work or live independently and an over reliance on traditional medicines as alternatives.

**Education Levels**
The household survey found that 69% of respondents with epilepsy have never been to school. Of the 31% that have attended just 0.3% went beyond secondary level. Where people with epilepsy have gone to school the average number of years spent in education is lower than the national average with boys averaging 8 years and girls just 4 years\(^7\). Lack of education means people’s prospects for employment are reduced and there is an increased risk of poverty.

The young respondents sampled during the research mentioned several common reasons for why people with epilepsy do not proceed with education. Children with epilepsy are strongly discouraged from attending school by both parents and teachers as it is felt that the condition means they are not able to learn in a mainstream school environment. Around 60% of respondents cited being expelled (or told to leave unofficially) from school for having repeated seizures during class time. Others took themselves out of school because of bullying, shame and fear of peers, teachers and the community. About 20% of respondents mentioned additional problems such as attention disorders, mood swings and anxiety as being a reason for non-attendance at school.

![Fig. 4 Highest education levels attained by people with epilepsy](image)

The survey indicated that many teachers lack awareness and confidence in dealing with epilepsy. Their lack of knowledge makes it hard for them to deal with both the symptoms of epilepsy and the bullying or stigma that accompanies it. The respondents highlighted that the teacher-pupil relationship suffers considerably and as a result many found it very hard to integrate into classes. There is urgent need to help raise awareness about what causes epilepsy, how it can be treated and what to do when someone has a seizure with teachers and school children.

\(^7\) The national average is 8.9 years (UNDP HDI report 2010)
DISCUSSION

The 2.8% prevalence rate identified by this research is only an estimate but it is highly likely to be less than the true rate. Communities and professionals lack knowledge and awareness on epilepsy and with very strong cultural beliefs surrounding the condition it is probable that many remain undiagnosed. During the first half of the ‘Empowering People with Epilepsy’ project as a direct result of awareness raising health clinics have been reporting significant increases in numbers of patients – sometimes increases of 100%. A widespread public health campaign is urgently needed if the message about epilepsy is to be heard nationally. The positive experiences so far with the project demonstrate that with factual information on epilepsy uptake of medical treatment increases, reliance on traditional medicine decreases and attitudes towards people with epilepsy improve. In addition once people are stabilised on medication they go from being totally dependent and unable to work or attend school to becoming independent and economically productive. In some communities this has already started to transform local economies and improve development.

Epilepsy should be considered as a health priority and included in the minimum package of services offered by all health centres at all levels. It should be placed on the same level as other non-communicable diseases and incorporated into national health programmes. International programmes developed by agencies such as International Bureau of Epilepsy, World Health Organisation and International League Against Epilepsy should be adopted and put into practice. This also implies the need for government to commit to resourcing the issue in order to ensure universal access to treatment.

As this research highlights unfortunately in Malawi there is still a significant proportion of people with epilepsy who are not seeking treatment. The ‘Empowering People with Epilepsy’ project is demonstrating that epilepsy care models can be successfully developed and implemented by primary health workers and that mobilization of people with epilepsy significantly improves treatment seeking behaviour. Models can also be used to enhance uninterrupted drug supply and improve prioritization at health centres.

This research also highlights the need for education institutions to be fully involved in epilepsy care. Teachers as well as children need to have awareness training in schools.

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8 Evidence from interviews in Ntcheu District
Awareness about epilepsy and the effects AED’s can have on children is needed for teachers and students to avoid negative stereotyping of behaviour as sluggishness or lacking interest. Lack of knowledge about epilepsy and a lack of collaboration between service providers presents a major problem in Malawi despite the few efforts done by service providers.

There is need to develop a National Epilepsy Plan which is inclusive of all socio-economic issues that affect people living with epilepsy. This calls for action that encompasses all relevant ministries including the Ministry of Health, Ministry of Persons with Disabilities and the Elderly, Ministry of Education, Ministry of Gender, Child and Women Development and Ministry of Youth and Sports.

Based on the findings the research team recommends the following strategic directions:

- Give a voice to people living with epilepsy
- Foster competence of relevant ministries to plan for and manage epilepsy
- Ensure the integration of people living with epilepsy into education, health, and development sector planning at National level
- Strengthen the capacity of local service providers to deliver appropriate health, education, economic and social services to people with epilepsy and their families
- Empower rural women in particular, to understand epilepsy and seek appropriate treatment
- Put guidelines in place for the appropriate ordering and stocking of anti-epileptic drugs to ensure health service providers do not run short
- Collect accurate data on the numbers of people with epilepsy at District level on a regular basis
- Launch a nationwide public health campaign to raise awareness about epilepsy, the possibilities for treatment and its long term management
- Tackle the discrimination and stigma faced by children and young people with epilepsy from within the education system paying particular attention to girls.
REFERENCES

2. Epilepsy in the WHO African Region: Bridging the Gap (WHO, 2004)