An African initiative
Epilepsy services in Sierra Leone

Sarah Snow of Medical Assistance Sierra Leone and Dr Radcliffe Lisk of Basildon Hospital outline their work in establishing Sierra Leone’s first epilepsy clinic

In Sierra Leone, people with epilepsy have virtually no access to medication or support for their condition. This West African country has some of the poorest health indicators in the world, including the worst maternal mortality rates and high infant mortality.

In its 2002 health policy paper, the government of Sierra Leone states its commitment to strengthen curative medicine. However, the country’s health service infrastructure requires a great deal of support at all levels. In practice, it cannot prioritise conditions such as epilepsy – despite its being an important cause of morbidity, unemployment and poverty.

Dr Radcliffe Lisk is a consultant neurologist at Basildon and Thurrock NHS University Hospitals, where he helped to establish a model clinical epilepsy service serving the South Essex area. The service won the Primary Care Trust Gold award for Innovative Service Delivery in 2008. Taking an unpaid 12-month sabbatical from his post at Basildon Hospital, Dr Lisk is spending this year establishing a comprehensive diagnosis and treatment facility in Sierra Leone, and training medical professionals. He is doing this with resources and logistical support provided by UK charity Medical Assistance Sierra Leone. This initiative forms part of a British Council-funded health link between Basildon and a hospital in Freetown, Sierra Leone.

Epilepsy in Sierra Leone
In Sierra Leone, people with epilepsy are less likely to receive an education than others without the condition. As in most resource-poor settings, the opportunity costs of accessing an education are very high. The indirect costs associated with attending school prevent substantial numbers of children from participating (UNICEF, August 2009). Such costs include things like uniforms, transportation, exam fees and the loss of family members’ engagement in economic activity.

For poorer communities, education is a high risk investment – the outcomes in relation to generating an income are long-term and are not guaranteed. In this context, children affected by epilepsy represent a high-risk investment that is beyond the capacity of the
People are rarely seen in general healthcare settings in Sierra Leone. This is due to the... lack of understanding that epilepsy is a medical condition related to problems at birth, including lack of oxygen. Epilepsy is most commonly seen in children and young adults. This is partly due to the age distribution of the population. Young people (defined as under 34 years of age) account for 34 per cent of the population in sub-Saharan Africa. In Sierra Leone, it is almost double that figure – standing at 60 per cent.

In younger adults, head injuries as a result of accidents and assaults are important causes of epilepsy, particularly in male patients. The Sierra Leone Civil War – which was officially declared over in 2002 – resulted in many injuries, some of these also leading to cases of epilepsy. We have seen post-conflict injuries such as machete scars and shrapnel damage to the head. Older adults tend to have underlying brain conditions such as stroke or brain tumours.

The Epilepsy Association of Sierra Leone (EASL) reports that large numbers of its membership have sustained injuries during seizures. Burns from open cooking fires present the greatest danger. Indeed, among the Bassa and Bambilike communities of Central Africa, epilepsy is known as ‘the disease of people with burns’.

Our new epilepsy clinic opened in February this year. Since then, many of the patients who have come to the clinic have presented with extensive and disabling burns. We are identifying plastic surgery support for the worst affected.

The stigma and the supernatural
In Sierra Leone, as in many African countries, epilepsy assumes an emphasis far beyond its medical implications. The sudden onset in an otherwise ‘normal’ person raises suspicion in others. People sometimes think the individual has been possessed by the devil or that some supernatural force has rendered them unable to control their bodily functions.

Many believe that one should keep clear of a person during these attacks and avoid contact with all bodily fluids. This is particularly the case with the saliva, which is widely believed to carry contagions. As a result, the person is often left unattended and may sustain severe injuries, such as fractures or burns. The person may even die from avoidable causes, such as obstructed breathing or inhalation of vomit – especially if lying on their back.

Families often spend large sums of money on local healers to try to cure epilepsy. Traditional local medicine employs herbal remedies, rituals, spiritual cures or combinations of all these. Some methods can be dangerous and can result in long-term health complications. Scarification of the arms or the face is a very common treatment. This can lead to skin infections, including tetanus.
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Some forms of seizure may chiefly affect a person’s behaviour, causing them to be aggressive or fidgety. Some may even perform complex tasks or walk for some distance without being conscious of their actions. These cases are very likely to be attributed to spirits or witchcraft in Sierra Leone. People with temporal lobe epilepsy (the particular epilepsy most commonly associated with these behaviours) may even undress themselves in public during a seizure. These are the patients who regrettably find themselves in psychiatric institutions in a country like Sierra Leone.

The perception of witchcraft as a cause of epilepsy is not uncommon. A study of a literate population in Nigeria in the 1980s found that witchcraft was the second most commonly cited cause of epilepsy. This is echoed by more recent research in 1997 among urban, literate communities in Ghana.

A report of work in Tanzania and elsewhere in Africa looked at similar beliefs in combination with Christian missionary teachings. In these circumstances, epilepsy may be seen as a punishment or a result of possession by demons. Alongside effective medical treatment, education can change these ideas and improve the quality of life for people with epilepsy. The epilepsy project in Sierra Leone is taking this dual approach in order to do exactly that.

Making a change
It is hard to exaggerate the inadequate level of healthcare provision in Sierra Leone. An article in The Times described the situation as ‘apocalyptic’. Until Dr Lisk arrived in the country at the end of 2009, there had not been a single neurologist in the country since 1997.

Building up a comprehensive epilepsy service – with the skills and capacity to meet the needs of the tens of thousands of affected people – requires substantial commitment and input. The project is taking an ‘accelerated capacity building’ approach. This involves:

- training local medical personnel
- carrying out an extensive awareness-raising programme with EASL
- holding exchange visits between Basildon Hospital and Lumley Government Hospital in Sierra Leone; and
- creating opportunities for Sierra Leonean colleagues to attend professional epilepsy conferences to increase learning.

An epilepsy helpline has been set up to offer advice and support. As well as the lead ‘link clinic’, two further clinics have been opened in Freetown locations. A number of regional clinics have also been held at district hospitals. The government is providing no epilepsy medication to health services – our project is purchasing the range of medication available and shipping it to Freetown.

This will only change if anti-epileptic drugs appear on the National Essential Medicines List of Sierra Leone, produced by the Ministry of Health.

Two medical officers currently employed by the Ministry of Health have been identified to take on the running of the epilepsy clinic at the end of Dr Lisk’s sabbatical. These doctors are being given in-depth training on interpreting EEGs, identifying types of epilepsy and prescribing medication. A nurse is being trained in understanding epilepsy and recording EEG activity.

In year one of the project, the clinic team and EASL are carrying out a needs assessment in three provinces. They are visiting hospitals and clinics, gathering available data on prevalence, treatment and harmful traditional practices, and promoting awareness about the epilepsy service.

The results of the needs assessment will inform the development of educational materials, which will fulfil similar functions. The materials will aim to raise awareness about epilepsy by providing accurate information. They will also
address the truth about the harmful traditional practices used to treat the condition. Materials will be mostly visual to accommodate the low literacy levels of the target population. EASL outreach workers will visit hospitals, clinics, workplaces and schools. Their aim is to raise awareness, share literature and inform people about the clinic.

Other proposed activities include a training and observation visit to Basildon Hospital epilepsy clinic. Newly trained medical professionals may also attend the annual conference of the UK chapter of the ILAE to present the findings of the project. A detailed evaluation will assess the project’s progress, and inform the development of a strategy for the clinic’s future sustainability.

Many patients who come to the clinic tell us stories of social isolation. The injuries resulting from seizures — or from local healers attempting to treat the condition — are harrowing in themselves. The good news here is that with the right type and dosage of anti-epileptic medication, most people’s condition can be adequately managed. Already we are seeing lives transformed by our service — and this is spurring us on as we seek to make the project a national initiative.

Colleagues who may wish to support us in this endeavour are very welcome to join us for short-term training placements or clinical assignments at the Freetown clinic. Visiting medical personnel would develop local capacity and promote shared learning. Invitations for Sierra Leonean colleagues to contribute to international forums and conferences on epilepsy would have a similar effect.

We also have a number of ongoing initiatives to raise funds for the running of the treatment service. For further information please contact mail@masierraleone.org.uk or visit www.masierraleone.org.uk.

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Further reading


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Mamasu, a patient at the Freetown clinic

Mamasu is about 25 years old. She is illiterate. Mamasu was accompanied to the epilepsy clinic by her ailing mother and younger sister, who has been educated. I was told that Mamasu started school at the age of six years. Unfortunately, after only one year at school, she was forced to discontinue her schooling because she started ‘falling unconscious’. Her sister reported that the attacks usually start with shouting, followed by foaming at the mouth, shaking and incontinence of urine. Her symptoms strongly suggested that she had epilepsy.

Mamasu is currently unemployed and unmarried. The chances of her finding a husband are very slim, as her condition makes her socially unacceptable. On examining her, Mamasu was embarrassed to expose the extensive scarring on her right thigh. These scars resulted from burns acquired several years ago when she had a seizure while cooking on an open fire. She now spends most of her time indoors, reluctant to go to the market. She has accepted advice not to use the village well for fear of falling in during an attack.

Before learning of the new epilepsy clinic, Mamasu’s family had spent a vast sum of money seeking treatment from faith healers and witch doctors. Her family firmly believed that her illness was caused by demons. She had been deliberately scarred and forced to inhale fumes from burning leaves and drink concoctions of various herbs and roots.

At the clinic, Mamasu was counselled on epilepsy-related risks and safety issues, as well as the need to take her medication regularly and continuously. When she was reviewed four months later, Mamasu reported that she has had no attacks since she started on medication. She looked confident and hopeful.