Epilepsy in South Sudan

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Introduction

Faced with the magnitude of health care challenges in South Sudan, one could argue that epilepsy is a minor problem and that resources should not be diverted from more pressing needs. Yet epilepsy is a common and often devastating condition which in South Sudan burdens the lives of more than 100,000 sufferers and their families. In most cases it could be effectively and cheaply treated if resources and systems were available. This paper aims to:

- Estimate the likely patterns of epilepsy in South Sudan
- Give practical advice about managing epilepsy
- Suggest ways to bring epilepsy care to those needing it.

Describing epilepsy in South Sudan is difficult due to lack of local information and documentation. Therefore information on its prevalence, patterns, causes, treatment and attitudes must be extrapolated from data from nearby countries such as Tanzania, Uganda and Kenya. When data from South Sudan eventually becomes available comparisons can be made with epilepsy patterns from elsewhere in Africa

1. What can we conclude about epilepsy in South Sudan from published material?

Prevalence

The prevalence of epilepsy prevalence in South Sudan is not known but studies from nearby countries show a much higher prevalence than is reported from Western countries or other developing areas. In the West the prevalence ranges from 4-8 per thousand inhabitants but studies in African populations give rates as high as 28/1000. For example, in rural Tanzania, a recent door-to-door study gave an age-adjusted prevalence rate of 13.2/1000 with an incidence of 81.1/100,000. Fifty four per cent of these cases had generalised seizures for which no cause had been identified, and 76% had never received treatment (1). In Rwanda the prevalence rate was lower at 7/1000 (2) and in Ugandan children it was higher at 20.4/1000 (3).

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Figure 1. Burns caused by an epileptic seizure.

The high prevalence of epilepsy in Africa may be due to several factors including poor obstetric care with consequent increased perinatal brain injury, high levels of head injury in children and adults, CNS and other infections and, particularly, the aftermath of cerebral malaria. The younger age range in African populations compared with other societies may also be a factor in the higher prevalence, as epilepsy is commoner in young people.

The treatment gap

Few people with epilepsy in South Sudan receive orthodox medical treatment although when available this successfully controls most cases and leads to remission in at least 70%. Estimates of the Treatment Gap (the proportion of people with epilepsy who do not receive treatment) in some African countries are 85% and it is probably higher in South Sudan.

Epilepsy is associated with a significant morbidity. For example, a study in a burns unit in South Africa showed that 50% of people admitted with burns had epilepsy and that their injury occurred during a seizure (4) (Figure 1). Mortality is also significantly increased in epilepsy, with up to a six-fold increase identified in one African review (5), compared with a 2-3 fold increase in those with epilepsy in the West.

Schooling, employment and status in the community are adversely influenced by uncontrolled epilepsy. In a mild case the condition may be hidden within the immediate family and so does not adversely affect social standing, but in more overt cases there is a major adverse impact. There

is a deep-rooted prejudice against epilepsy and many still attribute it to witchcraft and curses (6,7). The result is that the person with epilepsy seeks treatment from traditional healers (herbal medicines, scarifications or other forms of healing) or Christian spiritual healing (8). Some traditional healers do recognise the need for orthodox health care in refractory epilepsy and collaborative relationships may be fruitful (9). The enlightened traditional practitioner may also help the patient and family to manage the problems associated with epilepsy.

Central nervous system (CNS) infections

Bacterial meningitis, encephalitis and the complications of HIV infection, common problems in South Sudan, are associated with epilepsy both in the acute period and chronically.

Neurocysticercosis frequently leads to epilepsy (Figure 2) and is found wherever domestic pigs are kept close to human homes. In an area of rural Tanzania, 50% of cases have been linked with Taenia solium infestation of the brain (10). There is no published work on the prevalence of neurocysticercosis in South Sudan (where cattle ownership predominates) but this disease is probably common where pigs are kept.

Cerebral malaria (Figure 3) is a potent trigger for seizures during the acute illness, and these can be differentiated from febrile convulsions. A study from South Sudan found convulsions in 25.6% of affected children (11). Epilepsy is often seen later in those who have recovered (12). Studies from Kenya show that approximately 10% of survivors develop this complication with 5% having active epilepsy, often associated with cognitive problems. Seventy per cent of children admitted with seizures have malaria which is usually causative rather than coincidental.

Onchocerciasis is prevalent in parts of South Sudan and there has been much debate as to whether this is linked with epilepsy. Some have found an association (13, 14) whereas others have not (15). More work is needed, although the author is sceptical in that brain infestation with the microfilariae of onchocerciasis is unlikely.

The intriguing condition of Nodding Syndrome.

This was noted first in Tanzania in the 1960s, has been seen in Uganda, and many cases have been detected in South Sudan (16). The disorder has not yet been satisfactorily classified. Some cases having nodding in isolation (possibly a form of tic rather than a seizure disorder) but in others there is a definite association with epileptic seizures. There seems to be a high burden of cognitive disorder in affected cases (17) and the few MR scans undertaken have shown hippocampal changes or gliosis (18). Some EEGs show a spike and wave pattern.

A comprehensive field study was recently published in this journal (19) where 96 cases were documented in Witto Payam, Western Equatoria mainly affecting children and teenagers. Speculation as to possible causes noted the high prevalence of onchocerciasis in the area. The authors concluded that Nodding Syndrome, a possible seizure disorder of unknown cause, is likely to be widespread in South Sudan and further research is urgently needed to explain and define the condition. A pilot study is underway under the auspices of the Centers for Disease Control, USA.

2. How is epilepsy managed?

The optimal management of epilepsy requires attention to the following points:

1. The diagnosis must be secure. Remember that febrile convulsions are usually not indicative of epilepsy. Syncopal attacks and hysterical seizures can superficially look similar to genuine epilepsy. In northern Uganda

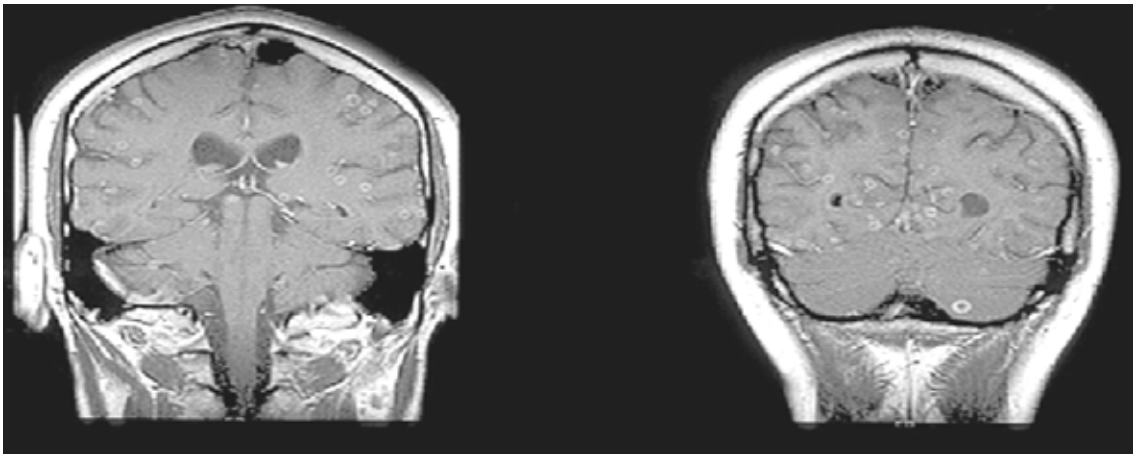

Figure 2. Brain scans showing neurocysticercosis.

among the population exposed to the LRA, people presenting with "seizures" have a 25% frequency of psychogenic, non-epileptic seizures triggered by the mental trauma. The long period of strife in South Sudan may have had a similar effect. Thus the diagnosis of epilepsy should be made after a competent healthcare worker with local as well as generic experience in the disease has taken a careful history.

At first presentation most cases of epilepsy have no obvious cause, and it is not feasible to investigate with tests like EEG and MR scans. However, consider the possibility of underlying CNS infection in acute onset of seizures particularly where there are additional systemic features, fever or neurological signs.

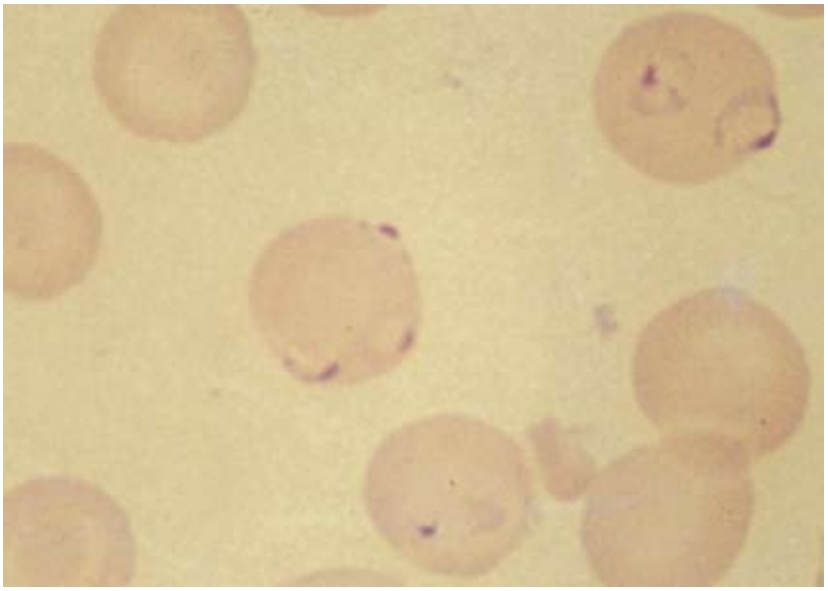

Figure 3. Cerebral malaria can trigger seizures.

2. Do not underestimate the influence of unorthodox beliefs.

3. In much of sub-Saharan Africa drugs for epilepsy are not obtainable or supplies are unreliable. If available they are too expensive for most people. Some antiepileptic drugs (AEDs) like phenobarbitone and phenytoin are cheap and effective, and although may have some adverse effects, it is better to control epilepsy by using them than to have no treatment at all. There are many examples of effective and sustained AED treatment programmes using these drugs, and many success stories of lives transformed after seizures are brought under control.

It is usual practice not to treat febrile convulsions or an isolated seizure with an AED, but in a case of epileptic seizures which recur, phenobarbitone or phenytoin can be started at the appropriate dose. Advise a patient who has passed one or two years free of seizures while on treatment to attempt a cautious withdrawal of their treatment. Sudden withdrawal is dangerous.

4. The management of convulsive status epilepticus is particularly challenging. In children and adults, suspect and treat an underlying infection, particularly bacterial meningitis or cerebral malaria, and always consider the possibility of hypoglycaemia in these cases (20). Where facilities are available for specifically treating the seizures, buccal midazolam may be as effective as rectal diazepam, and equally safe to use (21).

3. How could epilepsy care be made available in South Sudan?

The treatment of epilepsy is cheap and has a high impact on individuals and societies. It needs only systematic organisation and dedicated healthcare workers.

For example, in the1980s in Malawi, a doctor together with local chiefs and other influential people set up a network of epilepsy treatment clinics using phenobarbitone from the "essential" drugs allocation and treated thousands of people (22). This model utilises missionary or NGO healthcare already available at community level. Another model, widely used in resource poor parts of Africa, involves training nurses, clinical officers or medical assistants in simple epilepsy management and establishing nurse-led outpatient treatment clinics (23). The nurse-led system can link with community-based NGO activity to cover more of the population. In other countries epilepsy treatment and training has been linked with already organized leprosy, tuberculosis or HIV programmes.

The five steps needed to start an epilepsy programme in South Sudan are:

1. Identify and link the few NGO, charity or church groups which are treating epilepsy in their community and local programmes.
2. Train a small group of nurses in epilepsy care with the intention of setting up nurse-led epilepsy treatment clinics in the larger towns. These trained people cascade their expertise and knowledge to others.

3. Begin basic epidemiological research.
4. Ensure a steady supply of phenobarbitone to pharmacies in hospitals and community health centres.
5. Bring together those interested in epilepsy care and, with patient representation, form a South Sudan Epilepsy Association, thus establishing a pressure group and a forum for education about epilepsy.

If you would like to help develop epilepsy care in South Sudan contact the author at peter.newman@stees.nhs.uk

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