

# Managing epilepsy in South Sudan

Ruth Robinson

Core trainee in Medicine, Ashford & St. Peter's NHS Foundation Trust

Correspondence to: Ruth Robinson [ruthrobinson2@nhs.net](mailto:ruthrobinson2@nhs.net)

## Introduction

Epilepsy is the most common serious chronic disorder of the brain. According to estimates, at least 50 million people and their families are affected worldwide across different socio-economic groups, of which one in five is resident in Africa [1].

Untreated epilepsy carries significant risks to physical wellbeing including the risk of death or traumatic injury during seizures and SUDEP (sudden unexpected death in epilepsy). In addition, the diagnosis carries a psychosocial burden which may result from societal prejudice [2, 3].

Data from resource-rich settings demonstrate that complete seizure control can be achieved in at least two thirds of individuals, making it one of the most treatable chronic neurological conditions [4]. A similar rate is seen when sufferers in South Sudan have access to appropriate treatment [3]. This implies that there is great scope to bring about effective management of epilepsy on a global scale, and a positive impact on the quality of lives of millions of people. However, identification and treatment of neurological disease in resource-poor countries is a challenge.

This article does not give a prescriptive account of how epilepsy should be managed in South Sudan, but considers a framework to approach it. It then describes current strategies in action around the globe of which elements may be transferable to South Sudan.

## Epilepsy in South Sudan and Sub-Saharan Africa

There is a lack of available data around epilepsy in South Sudan, which presents a challenge when addressing the problem. However we presume a degree of overlap with neighboring countries [3].

It has been estimated that 85% of those with epilepsy are in developing countries [5]. The incidence is higher here compared to industrialised nations - 100-190/100000 and 40-70/100 000 respectively – due to the presence of additional aetiological factors [6]. A recent survey in rural Tanzania showed age-adjusted prevalence of 13.2/1000 [7]. When measured in terms of disability-adjusted life years lost, the burden of epilepsy in lower or middle income countries is 13 times that of high income regions [8].

Seizure disorders may follow cerebral infections. Those in South Sudan include: viral encephalitis, bacterial

meningitis, granulomatous disease, HIV (and associated opportunistic infections) and parasitic infections - cerebral malaria, neurocysticercosis and onchocerciasis [2,3,9,10]. Onchocerciasis has been associated with 'Nodding syndrome' a subtype of epilepsy locally restricted to South Sudan, Tanzania and Uganda [11].

Perinatal factors have been cited as a cause of epilepsy in poorer countries - reduced access to obstetric care and higher frequency of unsupervised home deliveries gives rise to a high rate of complications including hypoxic brain injuries. In South Sudan only 19% of women were assisted by skilled personnel during delivery [10, 12].

Higher incidence of head trauma (e.g. road traffic incidents) and less availability of post-traumatic specialist care is also contributory [2, 9]. In sub-Saharan Africa traumatic brain injury occurs up to 170 per 100 000 – higher than the global average (106) [13].

The majority of those with epilepsy in developing countries are not appropriately treated; this is quantified by calculating the 'treatment gap' – the number of individuals who are not receiving treatment expressed as a percentage of those with active epilepsy in a given population and point in time. In poorer areas this may be as high as 90% therefore a significant number of individuals remain vulnerable to the risks of uncontrolled seizures [5, 8]. Disability and mortality from seizures globally is greatest in Africa [1]. In particular, drowning and burns are a greater risk for those who use open wells and cook on an open fire [10].

## Causes for the treatment gap

This gap mostly arises from resource deficiencies and cultural beliefs. There is a lack of access to: correct information about epilepsy, medical expertise, imaging and other diagnostic facilities and treatment. Barriers to accessing appropriate care may be geographical (lack of local availability); financial (inability to pay) or cultural (locally held beliefs meaning resources are under-utilised) [9,10].

## Available information

Information readily available to the general population is important in identifying patients with epilepsy and tackling taboos. Epilepsy may not be recognized as a medical condition; there may be widely held beliefs that seizure disorders are caused by evil spirits or that

epilepsy is contagious [2]. Poor literacy rates compound the difficulties in providing accurate information – only 13% of young women in South Sudan are literate [12]. Healthcare professionals may lack access to information about recent advances e.g. through unavailability of internet facilities or costly neurology journals [10].

### Policy

Compared with infectious disease, epilepsy has been under-represented in national health plans and in the millennium development goals [9].

### Medical expertise

Developing countries have few or no neurologists – 0.03 per 100 000 in the African region – and lack sub-specialists such as paediatric neurologists [6]. The management of epilepsy is therefore generally by primary care. Doctors tend to be unevenly distributed towards urban centres.

A study in 2010 estimated there were approximately 500 Southern Sudanese doctors with basic medical degrees, for a population of approximately 10 million people. None were found in the specialty of neurology [14].

### Diagnostics

The availability of neuro-imaging and basic diagnostic investigations (e.g. CSF analysis and EEG) is widely deficient in sub-Saharan Africa [10]. In South Sudan CT imaging has recently become available in the capital [15]. However for an MRI patients need to travel out of the country. The opportunity to discuss images with a neuro-radiologist is not readily available in South Sudan.

### Treatment

Anti-epilepsy medications are the cornerstone of treatment and generally needed long term. Treatment costs – medication itself and the costs of travel to the clinic - present barriers. Phenobarbital is the most widely used treatment in sub-Saharan Africa – it is generally efficacious and is the medication which can be most reliably delivered to pharmacies [3, 9] although this is not universally so [6, 9]. Without a guaranteed and regulated supply patients may be at risk of exposure to poor quality drugs. The drawbacks of phenobarbital include: long half-life; hepatic enzyme induction (impacting on the half-life of TB medication, oral contraception and anti-retroviral treatment) and risk of withdrawal if stopped suddenly [3,9].

Surgical treatment of epilepsy is rarely a viable option in resource poor settings [10].

### Cultural barriers

Those with epilepsy are at greater risk of discrimination and social isolation. This presents a barrier to seeking and

complying with treatment. The stigma around epilepsy may negatively impact on marriage prospects or cause loss of employment [3, 10]. Traditional healers may be the first point of contact for those seeking help [3, 9].

### Suggestions for improvement - general measures

There have been recent international motions to place the management of epilepsy on the global healthcare agenda.

The 'Out of the Shadows' campaign launched in 1997 was the result of collaboration between the World Health Organization, International League against Epilepsy and International Bureau for Epilepsy. It declared a mission to "improve acceptability, treatment, services and prevention of epilepsy worldwide". They aimed to achieve this by supporting departments of health and conducting demonstration projects to exemplify good models of care [5]. It is unclear whether there has been any discernable lasting impact of these projects in resource poor settings. A declaration for the African region was produced in Dakar in 2000 and proclaimed an intention to treat epilepsy as a healthcare priority [1]. Its message is summarized in information box 1.

A successful public health approach needs to include interventions at the level of:

- The population in question - for example, preventative strategies, increasing awareness.
- The individual - improving identification, diagnosis, treatment and education [2].

### Suggestions for improvement - specific examples

#### Population interventions

It would be ideal to prevent epilepsy from developing in the first place where possible, by targeting reversible causes: optimising the treatment of infections, road safety and perinatal care. Other community-based measures could include public information broadcasts via media outlets such as television and radio.

#### Supporting individuals

A significant barrier to identification and care has been the limited number of doctors. Short term solutions are not easily delivered. The role of existing community healthcare workers could be expanded to include identification of cases, utilizing pre-existing infrastructures [9]. However this would add to the burden of current services. Also, the diagnosis and treatment of epilepsy is no simple undertaking. Determining if apparent seizures represent epilepsy depends on clinical skills of history taking and pattern recognition.

There have been examples in other resource poor settings of how new and emerging technologies could be applied to this issue. In Nepal and India an 11-part questionnaire has been developed to simplify a

**Box 1. African Declaration on Epilepsy**

Epilepsy is a healthcare priority in Africa requiring every government to develop a national plan to:

1. Address the needs with respect to epilepsy in terms of access to trained personnel, modern diagnostic equipment, antiepileptic medication and surgical treatment, information communication, prevention and social integration
2. Educate and train healthcare and other relevant professionals about epilepsy
3. Educate those affected by epilepsy and the general public about epilepsy as a universal neurological, non communicable and treatable condition
4. Eliminate discrimination in all spheres of life, particularly at school and the work place
5. Encourage incorporation of prevention and treatment of epilepsy in national plans for other relevant healthcare issues such as maternal and child health, mental health, infections, head trauma, neurovascular diseases and community based rehabilitation programs
6. Encourage the public and private sectors and NGOs to get involved in the local activities of the Global Campaign against Epilepsy
7. Promote interaction with traditional health systems
8. Encourage basic and applied research on epilepsy
9. Proclaim a National Epilepsy Day
10. Encourage regional and continental co-operation

diagnostic strategy and empower non-medical healthcare workers. The questions result in a probability score for the likelihood of the episode being epilepsy. It has been developed as a mobile phone application –which enables data to be retained and communicated. This technique demonstrates principles of telemedicine i.e. utilizing non-conventional methods to expand the reach of medicine [2].

Personal mobile phone ownership in South Sudan was estimated at 1 million in 2013 but was predicted to rise rapidly since then along with plans to develop fibre-optic technology in the country [16]. This opens up opportunities to conduct follow up clinics by telephone. In Malaysia SMS has been used to support ongoing epilepsy education and support adherence with medication [17]. Low literacy rates may limit progress in South Sudan [12].

Making phenobarbital free of charge may encourage compliance – but evidence suggests that the journey to the clinic may be too difficult due to cost and safety factors [18].

**Conclusions**

The majority of the world population lives in developing countries of which sub-Saharan Africa makes up a substantial part. The spectrum of neurological illness here is different to those of more developed nations and the overall disease burden is greater. These qualitative and quantitative differences are particularly apparent when considering epilepsy specifically.

Tackling the problem of epilepsy in South Sudan and globally requires first and foremost a recognition of the scale of the issue by international communities. It will also require collaborative working and innovative approaches to optimise the available resources.

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