Misunderstanding seizures

Challenges and steps to improving the diagnosis and management of people with epilepsy in sub-Saharan Africa

Epilepsy is one of the commonest *non-communicable* neurological disorders and an important cause of disability and mortality, affecting almost 70 million people worldwide. It is characterised by an enduring predisposition to generate epileptic seizures and by the ensuing cognitive, psychological, and sometimes severe social consequences. Here, we shall briefly look through the magnitude of the problem and the pertinent reasons for the vast treatment gap that exists in the resource-limited sub-Saharan countries, introduce the recent classification of the epilepsies by the International League Against Epilepsy (ILAE) and examine its relevance and pragmatic use as a tool in Africa, and finally suggest possible practical ways to improve diagnosis and management of people with epilepsy (PwE) through education and training.

A synopsis of the problem

The prevalence of epilepsy (the proportion of PwE in the population at a given time) is higher in developing countries,[1] where 80% of PwE worldwide reside. In sub-Saharan Africa the prevalence varies widely between and within countries: notwithstanding methodological heterogeneity (for instance in terms of epilepsy definition and the ways of case ascertainment), and the varying incidence of risk factors, the median prevalence is much higher than in developed countries (14.2 per 1,000 vs. 5.8 per 1,000).[2] Yet, sub-Saharan countries are amongst the least equipped to deal with the complex diagnostic and therapeutic challenges because of poverty, illiteracy, and poor and unevenly distributed infrastructure and financial, human and material resources in the health sector. Under-nutrition, poor sanitation, spread of vectors of disease, endemic risk factors such as perinatal injuries and head trauma, and the increasing impact of HIV infection promote epilepsy. On the other hand, the substantial social stigma hampers access to PwE, while cultural beliefs that are negative about "western" anti-epileptic drug (AED) treatment (when this becomes available) and lack of knowledge about side effects and time to response are amongst the factors that affect compliance. On the other hand, insufficient knowledge about appropriate maintenance dosage of prescribed AED and the need of taking them regularly often leads to under-treatment (Figures 1 and 2). These problems are more augmented in rural areas where most PwE reside and access to health facilities and follow up are difficult. Nearly all neurologists practice in large cities or suburban areas where also (video) EEG and MRI are available mainly in the private sector.[3-5] As a result, most PwE who reach out for treatment are looked after by primary-care physicians who have little or no specific training in epilepsy diagnosis and management and practically no access to EEG and brain imaging given the long waits when the latter are available in the public sector. Limited or non-availability and increased cost of AEDs is a major obstacle to the care of PwE, partly related to low profitability of agents like Phenobarbitone.[6] As a composite dismal result, the "epilepsy treatment gap", defined as the proportion of people with epilepsy who require treatment but do not receive it, is enormous, reaching 95-100% in some rural areas of Tanzania, Nigeria, Uganda and Ethiopia.[7]

In contrast to the developed countries where, after a first peak in childhood, the prevalence of epilepsy peaks again in advanced age, the vast majority of the PwE in sub-Saharan Africa are younger than 20 years of age, reaching 80-90% in some areas. Compared to other non-communicable chronic diseases, such as diabetes and cardiovascular disorders, that peak at later stages of life and are not associated with stigma, epilepsy is a largely treatable condition with about 2/3 of patients achieving seizure control with AED in developed countries.[8] It is therefore more likely that, once the many complex challenges posed by epilepsy are successfully met, younger people will return to social life as fully contributing members.[6]

Diagnosis of epilepsy and an update on the ILAE classification

Diagnosis of epilepsy is essentially clinical, based on skilful history and examination, and reliable information provided by witnesses. Once paroxysmal imitators of epileptic seizures, such as reflex convulsive syncope and psychogenic non-epileptic seizures[9] are ruled out, diagnosis of the clinical type and identification of the underlying cause are mandatory for appropriate management and treatment. The accuracy of the diagnosis of the epilepsy type is decisively assisted by the EEG, while the recognition of aetiology typically requires brain imaging and other laboratory investigations.[10] The new ILAE classification of the epilepsies[11] provides an orderly diagnostic process through three steps (levels) of increasing complexity to adapt to the available resources. The first step is the diagnosis of seizure type (of

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focal, generalised or unknown onset). It is important to emphasise here that generalised convulsive seizures can be truly generalised in their onset (called generalised tonic-clonic – GTC) or can have focal onset and evolve into otherwise similar generalised convulsions (called focal to bilateral tonic clonic); here a focal onset is not always clinically obvious (Figure 1). Non-convulsive seizures include focal and generalised that are clinically different to GTC, such as myoclonic and absences;[12] these seizure types can be difficult to clinically detect. The second step is the diagnosis of the epilepsy type (focal, generalised, combined focal and generalised and unknown), according to the seizure or combination of seizures it manifests with. The third level is the diagnosis of the particular epilepsy syndrome. At each one of these three levels of clinical diagnosis identification of the underlying cause should be promptly pursued.[11]

Ideally, AED selection should be based on the type of epilepsy and the individual circumstances and needs. Phenobarbitone has been deemed as the front-line AED,[6] mainly due to its low cost compared to other agents and its relatively wide-spectrum action. Although treatment with Phenobarbitone is better than no treatment at all (Figure 2), other AED can be more efficacious in several epilepsy types and syndromes. Beyond its usefulness in the treatment of the individual person with epilepsy, and because of its adaptability, the ILAE classification framework is also an effective tool for epidemiological studies that will help us better understand the multiple aetiologies of epilepsy and their contribution. The highly probable clinical under-diagnosis of focal epilepsies provides a good example.[13] With only a few exceptions, which found a higher representation of focal seizures,[14-15] most studies in sub-Saharan Africa have shown predominance of convulsive seizures and by implication of "active convulsive epilepsy" (ACE) when it comes to epilepsy type diagnosis.

EEG machines exist in most African countries[16] but many may be sub-optimally used or in the very-low-income countries often badly maintained or out of order[3] due to lack of trained personnel to maintain hardware and interpret registrations. Further, there are no governmental or professional authorities to ensure quality control, and no minimum standards exist for EEG laboratories.[17] Technologists and paramedical personnel have no formal training in EEG recording, physicians trained to basic EEG interpretation are few and relevant educational guidelines are lacking.[18] Incorrectly performed and reported EEGs not only deprive clinical assessment from an invaluable diagnostic tool, but may also result in over-diagnosis of epilepsy (for instance by inducing artefacts misread as epileptic discharges), incurring needless AED treatment that is hardly affordable. Further, inappropriate referrals exhaust the already limited capability of the few EEG labs prolonging waiting times for those who really need the test.[19] For instance, EEG is not necessary when a focal onset for generalised convulsions is clinically obvious (Figure 1) or can be deduced by history taking, or when PNES are strongly suspected, but is useful after a first seizure, for reclassification of ACE or the diagnosis of non-convulsive seizures or status epilepticus.

Figure 1: If you don't have the money, you should save. This 32-year-old woman fell from a mango tree when she was 11 years old. One branch went through her skull right frontal. The surgeon in a rural hospital in Central Tanzania removed the branch, since when she suffered focal and generalised seizures. She was started on phenobarbital 30mg, an infant dosage of the only anti-epileptic drug available locally. A CT brainscan was requested, but with medication barely possible from the family budget a scan was out of the question. Last year she came to our clinic with her sister and brought with her a 13-year-old request for a CT brainscan. She had spent years inside her house because the dosage of anti-epileptic medication had never been raised. Upon examination, there was a subtle left pyramidal weakness and normal intelligence. The skull had a clearly visible depression in the right frontal region, indicating where the epilepsy comes from. We decided the indication for CT scan had long expired. The first step, however, is an adult dosage of anti-epileptic drug treatment. If only we could have seen her before. Recently we saw her again, proudly having travelled alone from Central Tanzania. And seizure free.

Where do we go from here?

From the practical clinical standpoint, training of local physicians and other health professionals is an absolute priority, recognised by the ILAE as one of its primary goals.[20] Major conferences organised under the auspices of the ILAE offer regular teaching sessions, but attendance may be impossible for the many who have no financial support. Most will never have heard of such educational opportunities in the first place, having no access to internet or scientific journals or websites. Smaller-scale conferences and informal workshops at a more local level and with free participation could concentrate on important clinical, EEG and specialist nursing aspects and help groups of concerned health professionals to develop their interests and expertise, fostering a feeling of ownership of care. In particular, dedicated specialist nursing teaching[21] can focus on the education of patients and their families in how to manage their condition independently, keep self-safe and maintain follow up and trust, with emphasis on

Figure 2: A lifelong breakthrough seizure. This 23-year-old accountancy student came into our clinic with his mother. He was born in our centre, and brought in his own file. When handing the file to us, it felt suspiciously thin. It turned out to be time travel: the unscathed, 23-year-old file only reported about the man's birth, mild birth asphyxia and convulsions, for which he was started on phenobarbital 30 mg, an infant dosage. Since then, he developed very well but kept having seizures. In the local dispensary on the sugar cane plantation where he grew up, medication had been refilled many times since. However, the dosage was never increased. Upon examination, he had no abnormalities on neurological examination except vivid reflexes, and a bit of a lisp. The explanation was that he had bitten off several chunks of tongue in the meantime. We tripled his dosage and he became seizure free.

women with epilepsy during pre-conception, pregnancy, delivery and beyond. Epilepsy nurses can help with the development of important liaisons with other social groups, such as teachers, traditional healers and community leaders who hold key roles in the primary care frontline. Finally, practical (hands-on) training sessions on EEG recording would benefit health workers who could take up the key role of the EEG technologist to ensure correct recordings.

Concurrent with small-scale face-to-face teaching, educational articles and books can be used as practical tools of wider reach. A clinical-EEG diagnostic tool for clinical practice in adult[22] and paediatric[23] epileptology was recently prepared by the ILAE Neurophysiology Task Force, and can be freely downloaded. An open access, clinically practical tool can be modelled on this work, adapted to the pragmatic needs and limited resources that exist in sub-Saharan Africa, and enriched with chapters on management and treatment pitfalls, specialist epilepsy nursing and EEG basic principles and technology skills.

We believe such a publication would usefully complement the existing comprehensive text book on Neurology in Africa (Figure 3).[10]

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