Chapter 9
Challenges of Diagnosis and Treatment of Epilepsy at Mulago National Referral Hospital in Kampala, Uganda

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Abstract Epilepsy is a common condition in Low Income Countries like Uganda. These countries are overburdened by infectious diseases like Malaria, Tuberculosis and HIV/AIDS. Uganda is going through an epidemiologic transition from communicable diseases to non-communicable diseases including epilepsy. The country has not put in place strategies to address the new realities of the increasing burden of non-communicable diseases like diabetes, hypertension and epilepsy. There are tremendous challenges in terms of infrastructure, human resources for health, diagnostics and medical supplies for effective treatment of these conditions. Many communicable and non-communicable diseases may present with symptomatic seizures which are often mistaken for *epilepsy the disease.* This article discusses the challenges health workers meet in diagnosing, investigating and treating epilepsy in a limited resource setting at Mulago National Referral Hospital in Kampala, Uganda.

Keywords Epilepsy • Diagnosis • Low income countries • Limited resource setting • Challenges

Introduction

Health Statistics

Uganda lies in East Africa and has no direct access to the sea except through Kenya and Tanzania. It has an estimated population of 33 million people (UBOS 2012). More than 50 % of the population is below 15 years of age. Life expectancy is estimated to be 50.4 years. The HIV/AIDS prevalence rate has risen to 7.2 % in the last 2 years after it had dropped to 6.4 %. There are 1.2 million Ugandans living with HIV/AIDS.

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Table 9.1 Health statistics for Uganda

Health statistic	Estimate
Life expectancy	50.4 years
Maternal mortality ratio	438 per 100,000
Population per doctor	18,700
Population per nurse	3,065
Health service accessibility at <5 km	49 %
Per capita expenditure on health	12US$
Per capita expenditure on drugs	3US$

Over 30 % of the population lives below the poverty line and more than 70 % of the population is rural. Uganda has a GDP growth rate of 6 % per annum. The adult literacy rate is 66.8 %. Table 9.1 summarizes the statistics.

Organization of Health Services in Uganda

The health services are organized in order of size and complexity of services offered organized as from Health Centers: I (village) II (parish), III (Sub-county), IV (County) to District General Hospitals, then Regional Referral Hospitals and finally National Referral Hospitals at the top. There are two National Referral Hospitals namely, Mulago National Referral General Hospital and Butabika National Referral Mental Hospital. The latter hospital is a specialist facility for psychiatry disorders. Mulago Hospital is the main hospital for all other general medical conditions. It is also the teaching hospital for Makerere University College of Health Sciences as Butabika is also a Makerere University teaching hospital for mental disorders. Mulago hospital has a bed capacity of 1,500 beds and receives approximately 2,000 out patients per day. The Department of Internal Medicine is one of the bigger Departments and offers Neurology services for both in patients and out patients. The Neurology Clinic runs every week on Wednesdays. It is staffed by Physicians, Medical Officers and Nurses. It has EEG services and neuro-imaging with a one 16 slice CT scanner. On average, the Neurology clinic attends to 30 patients per day of which 6–0 patients will present with a seizure disorder (Ref). Some of the patients are referred from other health facilities but the majority of the patients are self referrals or follow-up patients who have been discharged from the inpatient wards. The main stay of a diagnosis of epilepsy is based on a thorough record of the patient's signs and symptoms followed by a carefully done clinical assessment of the patient with particular emphasis on the Nervous System. The history is collaborated by a reliable eye witness account of the event(s) or clinical observation of a seizure by a health worker. Wherever possible, EEG, brain CT scan, blood counts, Hb-electrophoresis, blood slide for malaria parasites, renal function tests, blood

sugar, VDRL and HIV serology are requested for. The drugs available at the Mulago neurology clinic include: Phenytoin, Carbamezapine, Sodium valproate, Phenobarbitone, Clonazepam and Ethosuximide. There are no neurology clinics in other hospitals. The neurologist per population ratio is 1:7,000,000 if we include the two paediatric neurologists. Most of the seizures are secondary to cerebrovascular disease, CNS infections or head trauma from road traffic accidents or birth injury.

Epidemiologic Transition

Like other developing countries, Uganda has been grappling with the burden of infectious diseases including, malaria, HIV/AIDS, Tuberculosis and Malnutrition. In the last decade, the prevalence of non-communicable diseases has increased partly due to the adaption western life styles especially the use of fast foods and beverages. The population is also living longer with those over 60 years increasing. This predisposes to hypertension, stroke and age-related degenerative brain diseases with all their complications including seizure disorders.

Epilepsy: Definition and Classification

Seizures are the hallmark of epilepsy. An epileptic seizure is a transient occurrence of signs and or symptoms due to abnormal and excessive neuronal activity in the brain [3]. Epilepsy is characterized by at least one seizure, an enduring predisposition to recurrent epileptic seizures and associated cognitive, psychological and social sequelae. The classification of epilepsy as follows:

A. Partial Seizures (Focal seizures)

- Simple partial seizures: These can be motor, sensory, autonomic or psychic and do not alter consciousness
- Complex partial seizures with impairment of consciousness
- Simple partial or complex partial with secondary generalization

B. Primary generalized seizures

- Absence seizures: typical and atypical
- Myoclonic seizures
- Clonic seizures
- Tonic seizures
- Tonic-clonic seizures
- Atonic seizures

C. Unclassified because of incomplete data

Challenges in Epilepsy Management in Uganda

The diagnosis and subsequent treatment of epilepsy poses several challenges in a resource limited setting as obtains at Mulago Hospital and in Uganda and Africa at large. The following is an elaboration on some of these challenges as they apply in Uganda.

Challenge 1: Epilepsy Is Common

Although epilepsy is common in Uganda, there is no accurate data to guide the process of diagnosis. However it is the most common neurological disorder in both children and adults.

The factors that are responsible for the high prevalence of epilepsy in Uganda include:

- High prevalence of cerebral malaria and CNS infections e.g. meningitis and encephalitis
- Perinatal causes including birth trauma from poor obstetric care.
- Head trauma from road traffic accidents especially boda – boda motor cycle accidents
- Cerebrovascular disease including ischemic and hemorrhagic strokes
- Brain tumors
- Arterial-venous malformations
- HIV/AIDS and its opportunistic CNS infections: Cryptococcal meningitis and Toxoplasmosis
- Parasitic infections like neurocystercercosis
- Neurosyphylis
- Alcohol and substance abuse as well as other brain toxins
- Degenerative diseases of the brain including multi-infarct (vascular) dementia, pre senile and senile dementias such as Alzheimer's disease, Parkinsonian dementia, Fronto-temporal dementia etc.

Challenge 2: Epilepsy Diagnosis Carries Stigma

- Most of the Ugandan population still thinks that epilepsy is caused by witch craft, evil spirits or is infectious.
- A large proportion of the population believe that western type of medicines do not cure this disease hence many would seek the services of a traditional healers before coming to the hospital and even afterwards.
- Many families keep the patient at home for fear of bringing shame to the family.

Challenge 3: Difficulty in Differentiating Epilepsy from Non-epilepsy Disorders

Misdiagnosis of epilepsy is common even in even in more advanced centers that care for epilepsy patients. This problem may explain none response to anti-epilepsy drugs that has been observed in presumed epilepsy patients (Chadwick and Smith 2002). Many patients who are misdiagnosed as epileptic have an EEG recording that has been misread and therefore misinterpreted as epileptiform. Many clinicians still equate an abnormal EEG recording to proof that epilepsy exists and are likely to conclude that a negative EEG excludes the diagnosis of epilepsy. Below are some of the conditions that are often misdiagnosed as epilepsy in the Uganda situation. The problem is made worse by lack of more advanced diagnostic facilities like EEG – video monitoring.

Some of the Conditions Misdiagnosed as Epilepsy in Uganda

- Psychogenic Non-Epilepsy Seizures (PNES)
- Syncopal attacks
- Transient ischemic attacks
- Cardiac dysrhythmias
- Sleep disorders e.g. night terrors
- Cataplexy
- Sleep starts
- Psychiatric disorders
- Transient global amnesia
- Episodic Dizziness and vertigo
- Hemifacial spasm
- Non epileptic Myoclonus
- Acute dystonic reactions secondary to the use of neuroleptics
- Complicated migraine
- Twilight or fugue states
- Panic attacks
- Hypoglycemia especially in diabetics on medication
- Benign non specific symptoms misinterpreted as seizures

Challenge 4: Limited Epilepsy Services

- There are no trained Epilepsy specialists in Uganda. Neurologists are only a handful.
- There are no facilities to train epilepsy specialists in Uganda
- There is inadequate exposure of medical students to the basics of epilepsy and neurology

- There are scarce imaging facilities and EEGs in the country
- The supply of antiepilepsy drugs is inadequate and erratic

Challenge 5: Lack of Reliable Data

- No epilepsy prevalence and incidence studies have been done in Uganda
- No large community based studies have been done to guide the planning process for the provision of epilepsy services
- We don't know the epilepsy burden in Uganda and the factors responsible for this silent epidemic
- Some diseases have been branded epileptic without adequate epidemiological and clinical data and causes have been attributed to them e.g. Nodding Syndrome and O. volvulus.

Opportunities on the Horizon

The epidemiologic transition from communicable to non-communicable diseases has been recognized by the Uganda Ministry of Health and Development Partners. There has also been started a more integration of Neurology in the Medical School curriculum and there are promising collaborations with Universities abroad.

Conclusion

Epilepsy is a common condition in Uganda but under diagnosed and also often misdiagnosed. Most of the epilepsy cases are symptomatic of underlying brain disorder. Infective and traumatic causes are common. The prevalence of degenerative diseases of the brain is increasing and contributing to symptomatic epileptic seizures. There is an urgent need to carry out population surveys to establish the prevalence and incidence of epilepsy in Uganda and to address the causes for the many symptomatic epileptic seizures.

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