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The Challenges of Managing Children With Epilepsy in Africa

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Children with epilepsy who reside in the African continent are faced with some of the greatest challenges of receiving adequate care. The burden of disease is exacerbated by the high incidence of acquired causes and the large treatment gap. Skilled teams to identify and care for children with epilepsy are lacking. Many patients are managed through psychiatric services, thus potentially compounding the stigma associated with the condition. Little data exist to assess the true proportion of comorbidities suffered by children with epilepsy, the assumption is that this is high, further aggravated by delayed interventions and adverse responses to some of the more commonly used antiepileptic drugs.
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Introduction

The incidence and prevalence of active epilepsy is greatest in Africa compared with that of all other continents, even those with equivalent poor settings.[1-3] Some of the most severe complications and comorbidities occur in children with epilepsy (CWE) who live in the resource-poor areas of world.[4] These areas include many regions of low- and middle-income countries, particularly rural areas that have limited resources for diagnosis and treatment. Africa, in particular, contains most of the poorest countries in the world and has the highest incidence of many of the risk factors for epilepsy, especially central nervous system (CNS) infections, perinatal insults, and traumatic brain injury.

Recent estimates in 2010 suggest that epilepsy contributes to 0.7% of the global burden of disease,[5] with Africa contributing to 0.261% (or 37% of the epilepsy burden) to the total worldwide burden of epilepsy (http://viz.healthmetricsandevaluation.org/gbd-compare/). These models underestimate the burden in the poorer areas of the world because they only include the previously termed idiopathic or cryptogenic epilepsy and not epilepsy secondary to causes, such as CNS infections, stroke, or even genetic syndromes. These models often had to extrapolate data from high-income countries to account for the lack of data in the lower- and middle-income countries. In cross-sectional surveys, the incidence and, to a lesser extent, the prevalence appear to be greater in these poorer areas than in high-income countries.[4]

In Africa, most people with epilepsy suffer the disease from childhood, particularly during the first few years of life. For example, in 5 sites across Africa, over 60% of people with active convulsive seizures reported that their first seizures occurred before 13 years of age. The incidence of epilepsy appears to be highest in childhood, with an incidence of 187 per 100,000 per year (95% confidence interval [CI]: 133-256) reported in children between the ages of 6 and 12 years living in a rural area of Kenya.[6] The prevalence is also high and tends to be higher in rural areas than in urban areas,[2] although this may reduce with the demographic transition to urbanization, as it appears to have occurred in Asia. In rural Kenya, the adjusted prevalence estimates of lifetime and active epilepsy were 41 of 1000 (95% CI: 31-51) and 11 of 1000 (95% CI: 5-15) in children between the ages of 6 and 9 years.[6]

The proportion of focal epilepsies appears to be higher in children living in Africa than elsewhere. The incidence of perinatal insults; infections of the CNS, such as bacterial and

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tuberculous meningitis; and head trauma in children is greater in Africa than elsewhere. In addition, Africa has the highest burden of parasitic infections, such as falciparum malaria and onchocerciasis, both of which are associated with the development of epilepsy.[7-10] In addition, parasitic infestations such as with Toxocara species and *Toxoplasmosis gondii* are ubiquitous in Africa, and infections with these organisms are associated with epilepsy.[10,11] Neurocysticercosis is common is some parts of Africa. Parasitic infections are believed to cause up to 27% of pediatric epilepsy in some areas,[10] with antenatal and perinatal risk factors of more effect in other regions.[10,12] Human immunodeficiency virus infection is prevalent across Africa, especially sub-Saharan Africa, where 90% of infected children reside. Most seizures associated with human immunodeficiency virus infection appear to be caused by opportunistic infectious organisms, although it is associated with epilepsy per se.[13]

Mortality appears to be increased in Africa[14] based on recent data from China[15] and Kenya,[10] which suggest that the premature mortality is very high in these settings, particularly affecting the older children and adults. In Africa, the mortality is particularly related to poorly controlled epilepsy, with a greater proportion of children dying with status epilepticus, drowning, and burns caused by seizures compared with other continents.

In 2010, the International League Against Epilepsy published a revised terminology for the organization of seizures.[16] This represented a logical progression in the light of the improved diagnostic techniques in the field of neuroimaging and molecular genetics. However, in the context that most people with epilepsy are based in resource-poor countries, with less than half gaining access to biomedical services, these recommendations are a challenge to implement.[17] Few centers in Africa have access to the screening tools, such as electroencephalography, neuroimaging, metabolic screens, or molecular genetics.[18]

Challenges to Accessing Care

Stigma, is significant and CWE in the poor areas have reduced opportunities for education as well as future employment and marriage. The stigma often arises from the cultural beliefs about the cause of epilepsy, as in many societies epilepsy is not thought to be a biomedical illness affecting the brain but is thought to be caused by spiritual beliefs and sometimes contagious. These beliefs permeate throughout society, including professions such as teachers and law enforcement personnel.[19] Where epilepsy is heavily stigmatized, the social and economic morbidity of the condition influences every aspect of a person's life,[20] thus limiting opportunities for education,[21,22] employment,[7] and marriage and resulting in poverty, food insecurity, poor housing quality, and physical vulnerability.[7] In some circumstances, CWE are even more vulnerable, increasingly subjected to physical and sexual abuse.[7] The effect appears greater in the poorer regions, particularly in Africa, where the stigma often results in people with epilepsy being hidden by their families.

The lack of access to quality, reliable, convenient, and cost-effective health care services is a key constraint to the management of CWE. Access to modern health care facilities may be nonexistent for the rural population[23] who often have to traverse great distances to seek medical assistance.[24] In many African countries where the public transportation system is poorly developed and is not subsidized by the government, this incurs an added expense that may not be affordable for all.[25] This expense is further heightened when the few patients and their caregivers who attempt to seek specialized epilepsy care in the urban health care facilities would have to meet the entire cost of the required medications and investigations. In the government units where the antiepileptic drugs (AEDs) may be free of charge, these medicines are frequently out of stock.[26]

Access to diagnostic equipment to assist in the management of epilepsy (electroencephalography and neuroimaging) is extremely limited in many parts of Africa.[27] Even where equipment is available, it is not uniformly affordable or accessible.[28] In this context, many individuals with epilepsy disorders remain undiagnosed because of the limited diagnostic facilities at health centers, which is even worse in rural settings. The use of cell phones has emerged as a mode of interventional health delivery through the use of the short message service or text messaging.[29] The use of the cell phone, which is widely accepted, makes it a potentially nondiscriminating service media that could be applied in long-term disease management programs, such as epilepsy care. It can also be used to record home videos of seizure events that could later be brought to the epilepsy specialist for review or also be used to set up reminders of the scheduled outpatient visit or when to pick up medications. Ongoing technology innovations using the cell phone may serve as a potential way to reduce geographic barriers.

Limitations in the availability, number, and geographic distribution of specialists trained in the care of epilepsy are a major cause of the delays in accessing care. Sub-Saharan Africa has the highest person-to-doctor ratio worldwide for neurologists, with most of these professionals located in the cities and practicing general medicine, psychiatry, or both. Within Africa there is variation among some countries having no neurologists, whereas others such as Tunisia have a ratio of 162,885 persons per neurologist, more typically the range is from 1,612,039 persons per neurologist to 5,099,908 persons per neurologist.[28] In addition, these few skilled health professionals tend to work in the private sector. Carers for CWE often choose to seek the more accessible traditional health providers (THPs) or other allied health providers who have limited options for epilepsy care to offer. In sub-Saharan Africa, the ratio of THPs to the general population is approximately 5:1000. It is estimated that 60%-80% of the population in Africa consult a traditional healer before going to a primary health care practitioner.[30] The reasons for this are several and include among others: being more physically accessible to patients; offering plausible explanations of disease causality in a naturally acceptable fashion, focusing more on the psychological and

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