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Epilepsy is ubiquitous, but more devastating in the poorer regions of the world... or is it?

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Summary

The incidence and prevalence of active epilepsy are greatest in Africa compared to all other continents, even those with equivalent poor settings. This is a reflection of the high levels of structural and metabolic causes and may reflect an increased risk in parts of the continent. The full burden of epilepsy, which includes the social and medical morbidity of the disorder and where people with epilepsy are heavily stigmatized and frequently untreated, cannot be fully assessed even using the disability adjusted life-years, since the assigned disability weights are not specific to these regions. The burden is further exacerbated by social, geographic, and economic barriers to care and the inability of African health systems to manage people with epilepsy effectively because of lack of trained personnel, limited facilities, and poor access to effective or sustained supplies of antiepileptic drugs, or even therapy at all. The situation is compounded by a probable underestimation of the prevalence and incidence of people with epilepsy related to the major stigma associated with the condition in Africa, and the limited training available to most health care workers who are the primary point of assessing most people with epilepsy. Finding innovative ways to address the huge barriers faced by people with epilepsy in Africa needs to be a major goal for the millennium.

Keywords

Africa; Epidemiology; Epilepsy; Prevalence; Incidence

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Epilepsy is ubiquitous, found in every population throughout the world. Most people with epilepsy (PWE) face similar issues, but their significance and impact vary considerably. In particular, some of the most severe complications and comorbidities occur in PWE living in the resource-poor areas of world.¹ These areas include many regions of low and middle income countries, particularly rural areas, which have limited resources for diagnosis and treatment. Africa contains most of the poorest countries in the world, and has the highest incidence of many of the risk factors for epilepsy, in particular central nervous system (CNS) infections, perinatal insults, and traumatic brain injury.

The Burden of Disease from Epilepsy

Recent estimates suggest that epilepsy contributed to 0.7% of the global burden of disease in 2010,² with Africa contributing to 0.261% (or 37% of the epilepsy burden), South Asia to 0.131% (19% of the epilepsy burden), and Latin America 0.024% (3% of the epilepsy burden) to the total burden of epilepsy (<http://viz.healthmetricsandevaluation.org/gbd-compare/>). The models that were used to calculate the global burden of epilepsy underestimated the burden in the poorer areas of the world, since they considered only the previously termed idiopathic/cryptogenic epilepsy, and not epilepsy secondary to causes such as CNS infections or stroke, or even genetic syndromes. These models often had to extrapolate using data from high income countries (HICs) to account for the lack of data in the lower and middle income countries (LMICs). In cross-sectional surveys, the incidence and, to a lesser extent, the prevalence appear to be greater in these poorer areas than in HICs. However the surveys in the LMICs most often detect only convulsive epilepsies, and there are few, if any, accurate figures on the nonconvulsive epilepsies in these regions. The factors that contribute to the full burden of epilepsy are summarized in Table 1. The burden of epilepsy in total population terms is greater in Asia, because this region has a population >4 billion compared to Africa (1 billion) and South-Central America (<0.5 billion). However, the prevalence and incidence of epilepsy are higher in Africa^{3–5} and South-Central America^{4–6} than in Asia,^{4,5,7} and this is probably related to the higher incidence of risk factors, in particular perinatal complications, CNS infections, and head trauma.¹

Prevalence and Mortality of Epilepsy

The prevalence tends to be higher in rural areas than in urban areas,⁴ and it may decrease with the demographic transition to urbanization, particularly in Asia. The data are often lacking to make meaningful comparisons within these regions and between countries and/or continents. For example, there are limited data on the mortality associated with epilepsy, because of the difficulty in following cohorts of PWE and being able to compare the mortality with that in populations without epilepsy. Mortality appears to be increased in Africa.⁸ The recent data from rural Kenya^{9,10} confirm data from rural China¹¹ that the premature mortality is very high, particularly affecting older children and adults.

The Implications of Stigma

Stigma is significant, and PWE in the poor areas have reduced opportunities for education, employment, and marriage. The stigma often arises from cultural beliefs about the cause of

epilepsy, and in many societies epilepsy is not thought to be a biomedical illness affecting the brain, but caused by spiritual beliefs and thought to be contagious. These beliefs permeate society, including professions such as law enforcement personnel.¹² Where epilepsy is heavily stigmatized, the social and economic morbidity of the condition permeates every aspect of a person's life,¹³ thereby limiting opportunities for education,^{14,15} employment,¹⁶ and marriage¹⁷ and resulting in poverty, food insecurity, poor housing quality, and physical vulnerability.¹⁶ In some circumstances PWE are even more vulnerable and increasingly subjected to physical and sexual abuse.¹⁶ 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.¹⁸

The Treatment Gap for Epilepsy

The treatment gap, defined as the proportion of PWE who are not receiving biomedical treatment, is greatest in the poorer regions. It is particularly high (up to 90%) in low income countries or rural areas.^{19,20} The treatment gap may be caused by not accessing biomedical facilities for diagnosis and treatment due to the cultural beliefs in which PWE and their families do not believe in biomedical treatment, lack of health facilities and/or trained staff, and the cost of accessing these facilities.²¹ If the person with epilepsy does obtain a diagnosis of epilepsy, there are considerable barriers to treatment including distance to health facilities, cost of travelling to these facilities, the cost of attendance and antiepileptic drugs (AEDs), the availability of AEDs, and in some cases the quality of the AEDs.²² Phenobarbital is commonly used, since it is widely available, inexpensive, and effective.²³ However, it is associated with cognitive impairment and hyperactivity in children,²⁴ although this was not documented in Indian²⁵ or Bangladeshi²⁶ children. There are other strategies that can be implemented in poor areas to reduce the burden of epilepsy in these regions.²⁷

Conclusion

Although epilepsy is ubiquitous, the condition has been recognized for centuries and seizures can be controlled in most PWE with relatively inexpensive medication; epilepsy remains underdiagnosed, and under-treated, particularly in the poorer regions of the world. Access to AEDs remains problematic in many of these regions, and the lack of choice of AEDs means that some patients and their families have to tolerate side effects such as hyperactivity in children. These issues are particularly important in Africa and Asia, but many people in higher income countries are also poorly managed. There is a need to address all these issues, particularly in the poorer regions of the world. More research is required to estimate the burden of epilepsy, and to identify risk factors so that public health measures can be instituted to reduce the incidence and impact of epilepsy within the world.

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Biography



Jo Wilmshurst is Head of Paediatric Neurology at the Red Cross War Memorial Children's Hospital, which is the largest children's hospital in sub-Saharan Africa.

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Table 1
Conditions in Africa that contribute to the full burden of epilepsy

Condition	Factors	Effects
Epilepsy-associated social morbidity ^{12–15,17,28}	Epilepsy-associated stigma Limited social services support for marginalized and/or vulnerable populations	Deters people from care-seeking and results in falsely low prevalence estimates Negative impact on Access to education Marital opportunities Housing quality Environmental safety (increasing the risk of burns and drowning) Food security at the household level for adults Food security at the individual level within the household for children Personal safety, including increased risk of sexual assault for women with epilepsy
Epilepsy-associated economic morbidity ^{12–15,17,28}	Epilepsy-associated stigma Lack of legislation or limited enforcement of those laws to protect the rights of persons with disabilities	Negative impact on Access to education and therefore employment opportunities Employment opportunities Legal protections from economic and social abandonment with associated loss of economic resources Economic losses related to missed work and epilepsy-associated physical disabilities
High Incidence+/- Prevalence ^{2,4–11,29}	Limited maternal and child health services High rates of CNS infections and parasitic infestations affecting the brain High rates of HIV/AIDS	These factors result in higher incidence rates of epilepsy, but prevalence data, not incidence data, was used to derive GBD2010 estimates. Existing prevalence data likely underestimate the burden of epilepsy in Africa for several reasons: Given the high treatment gap and ubiquitous environmental exposures to burns and drowning common in Africa, early mortality rates likely exceed estimates from China, making prevalence data appear deceptively low as incident cases die early. Epilepsy-associated stigma limits case ascertainment even in door-to-door surveys Due to research and clinical resource limitations, African epidemiologic studies derive prevalence data based exclusively on people with generalized seizures, so 50–75% of epilepsy cases are systematically excluded from these estimates
High treatment gap, inadequate treatment ^{19–21}	Barriers to accessing care Barriers to good care delivery Poor to no AED supplies	Uncontrolled and/or poorly controlled seizures resulting in higher rates of seizure-associated injury and death The high cost of accessing and paying for epilepsy-care services increases the economic morbidity of the condition. Much of this cost is related to transportation beyond primary care services, since epilepsy care is usually not available at first line clinics
AED side effects ^{1,22–24}	Limited drug options, often only 1–2 first generation AEDs available Inconsistent AED supplies	Must tolerate AED side effects and/or opt for nontreatment Frequent changes in AED regimen based on drug availability results in more side effects and less efficacy Among people with HIV, there are often no reasonable options for AED/ARV combinations resulting in Increased adverse AED and/or ARV side effects Decreased efficacy for AEDs and ARVs A high risk of antiretroviral therapy (ARV) failure due to AED enzyme induction of ARVs