

# Child Neurology Practice and Neurological Disorders in East Africa

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## Abstract

Neurological disorders, including neurodevelopmental disorders, have been identified by the World Health Organization (WHO) as one of the greatest threats to global public health. It is generally believed that these conditions are more prevalent in the developing than the developed world because of multiple known risk factors such as infections, malnutrition, and limited resources for obstetric and neonatal management. In East Africa, few investigations have been conducted to obtain data on the magnitude and description of neurological disorders among children, and the practice of child neurology is faced with challenges cutting across areas of health personnel, patient diagnosis, management, and rehabilitation. This article reviews the burden, types, and causes of neurological disorders in the East African region. The challenges and successes in the practice of child neurology and recommendations for the future are discussed.

## Keywords

child neurology, East Africa, Burundi, Kenya, Rwanda, Tanzania, Uganda

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## Background—East Africa; Context of Health Care

East Africa is made up of 5 countries: Burundi, Kenya, Rwanda, Tanzania, and Uganda (Figure 1). Humanity is thought to have originated from here; some of the earliest fossilized hominid remains have been found in the Koobi Fora area in Kenya and the Olduvai Gorge in Tanzania. The region lies right astride the equator and covers an area of 1.82 million square kilometers. In 2007, the population stood at 122.1 million.<sup>1</sup> The age structure is that of a young population. The gross domestic product is about US\$ 60 billion.<sup>1</sup> There is a high disparity in health care between the urban rich and the rural and periurban poor, with very poor health worker to patient ratios. Although health care provision is officially state supported, for most common ailments, retail shops and small private clinics are the initial source of drug treatment for the majority of the population.<sup>2</sup> Established government health centers and hospitals are often utilized for more severe illnesses. Table 1 is a summary of some of the population and health indicators of the region.<sup>1</sup>

## The Burden of Neurological Disorders

The World Health Organization (WHO) estimates that up to 7% of the population living in developing countries have a moderate to severe disability.<sup>3</sup> In East Africa, there are few population-based studies that have comprehensively described

neurological disorders and disabilities. Available data are incomplete, nonspecific, or inadequate, because they describe events in small areas.<sup>4,5</sup> Administrative databases and medical records are not widely available or complete. Thus, the prevalence, types, causes, and rehabilitation needs of children with neurological disorders and disabilities, and the experiences of their families, are hardly known. Because of the scarcity of data and lack of appropriate personnel, the ministries of health have found it difficult to develop clear policies to guide the care of children with neurological disorders. Data from demographic and health surveys or disability surveys, however, suggest that the prevalence of moderate to severe disability is comparable to the WHO estimates for countries with limited resources. For example, the prevalence rate is 7.4% in Tanzania,<sup>6</sup> 7.2% in Uganda,<sup>7</sup> but was lower, 4.6%, in Kenya,<sup>8</sup> and 4.7% in

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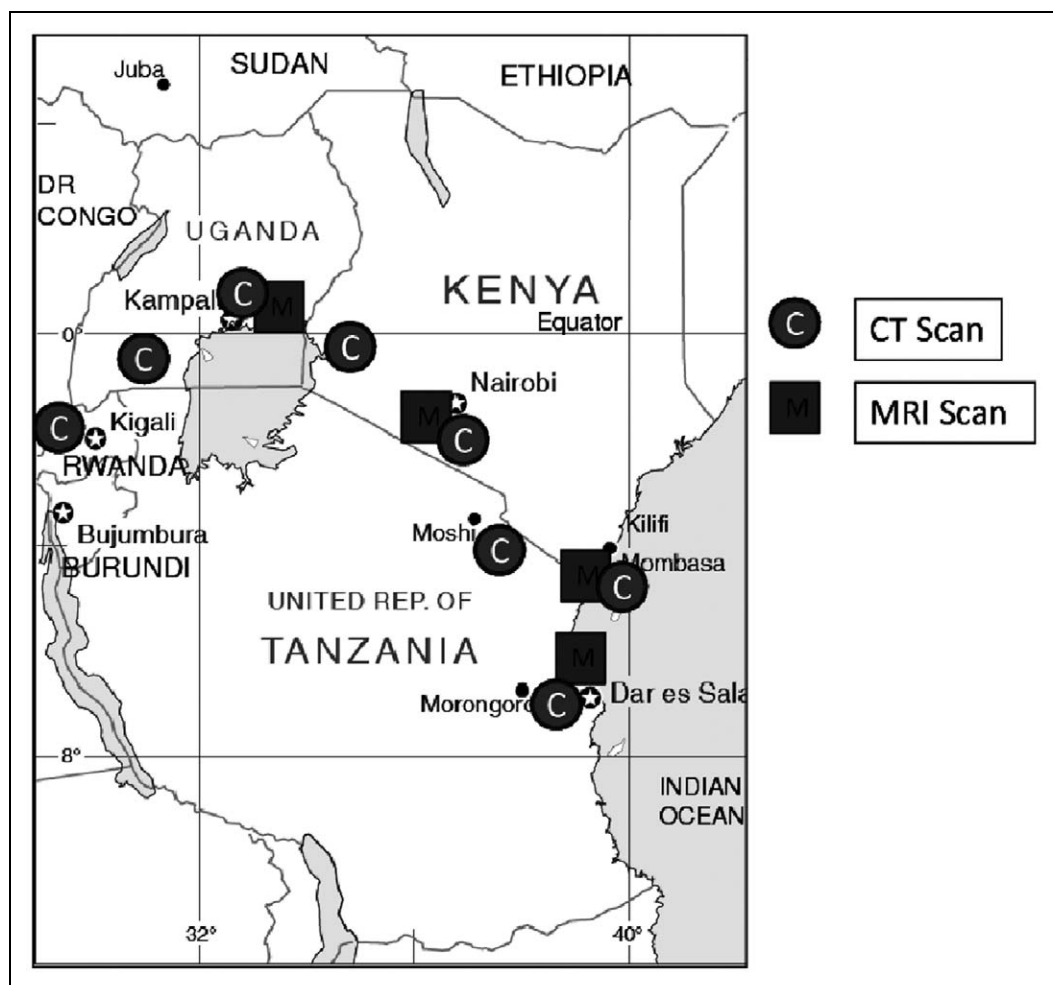
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**Figure 1.** The East African countries and locations of neuroimaging facilities. The 5 East African countries—Burundi, Kenya, Rwanda, Tanzania, and Uganda—are shown, along with the main cities—Bujumbura, Nairobi, Kigali, Dar es Salaam, and Kampala, cities with neuroimaging facilities and some of the neighboring countries.

Rwanda.<sup>9</sup> Differences in definition and methods of assessment could be responsible for the variation in numbers.

In 1 of the few comprehensive population-based studies in the region, the Ten Questions Screen<sup>10</sup> was used in a survey of children 6 to 9 years old to detect motor, speech, visual, hearing, and cognitive impairments or epilepsy in Kilifi, coastal Kenya,<sup>5,11</sup> an area in which a system of continuous demographic surveillance is maintained for a population of about 230 000. Children who tested positive on the questionnaire were referred to a hospital where they had a detailed neurological and epilepsy evaluation, and cognitive and behavioral assessments. The prevalence of any impairment was 61 per 1000 (95% confidence interval, 48-74) and the prevalence of impairments in specific domains were: epilepsy, 41 per 1000; cognition, 31 per 1000; hearing, 14 per 1000; motor, 5 per 1000; and vision, 2 per 1000. In addition, 56 of 251 (22%) of the neurologically impaired children had more than 1 impairment.<sup>5</sup> Similar prevalence studies are currently ongoing in Uganda and Tanzania, and results are expected in 2010/2011. Together they may provide a better picture of childhood neurodisability in the region. It should be

noted, however, that children with severe impairments, for example, spastic quadriplegia with associated feeding difficulties, have an increased risk of early death<sup>12</sup> especially from recurrent respiratory tract infections and malnutrition, and this early mortality may be responsible for the apparently low prevalence of motor impairments in older children.

### Types of Neurological Disorders

In 1 of the earliest descriptions of neurological disorders in East Africa, Egdell and Stanfield in 1972 conducted a hospital-based study of 138 Ugandan children who attended the child neurology clinic in Mulago Hospital in Kampala, Uganda. The study found that the most common neurological disorders in children were cerebral palsy, epilepsy, behavior problems, and visual, hearing, learning, speech, and language impairments. In many cases, multiple problems existed in 1 child. Malnutrition and psychiatric disorders secondary to social deprivation or mental retardation were common comorbidities. However, psychosomatic disorders were hardly

**Table 1.** Population and Health Indicators in East Africa, 2007

Population and health indicators	Burundi	Kenya	Rwanda	Tanzania	Uganda
Population density per km <sup>2</sup>	286	64	368	45	141
Infant mortality per 1 000	124 <sup>a</sup>	74	62	86	76
Under five mortality per 1 000	—	108	103	137	141
Maternal mortality per 100 000	608 <sup>b</sup>	414	690	580 <sup>c</sup>	435
Life expectancy at birth	45 <sup>d</sup>	57	53	50	50
Pediatric neurologists in the country	0	5	0	0	1
Neurosurgeons in the country	0	16	1	6	4
CT scanners	0	15	1	10	8
MRI scanners	0	5	0	2	1

<sup>a</sup> Figure of 2006 used.

<sup>b</sup> Figure for 2005.

<sup>c</sup> Figure for 2005.

<sup>d</sup> Figure for 2006.

**Table 2.** Main Presenting Neurological Problems in Children Attending a Tertiary Neurology Clinic in East Africa, 2007

Type of neurological disorder	N = 389 (%)
Epileptic seizures	175 (45.0)
Motor deficits	109 (28.0)
Mental handicap, severe developmental/cognitive delay or regression	66 (17.0)
Behavior problems	15 (3.9)
Movement disorders	8 (2.0)
Hydrocephalus	7 (1.8)
Other disorders (eg, chromosomal disorders, narcolepsy)	9 (2.3)
Total	389 (100.0)

reported, possibly because they are more of a problem to the child than to the community.<sup>13</sup> Similar findings were described in Kenyatta Hospital in Nairobi, Kenya.<sup>14</sup>

Five hundred eight new patients were attended to in the same clinic in Mulago in 2007. Records of 389 were available for review. As in the earlier study, epileptic seizures and motor deficits were the most common reasons for attendance (Table 2). A similar pattern was observed in the research clinic at Kilifi District Hospital in Kenya. In interpreting these data, however, the limitations of hospital-based studies, such as attendance based on access, patient beliefs on the causation of illness (eg, epilepsy), stigma, and the influence of traditional medical practices should be kept in mind.

## Causes of Neurological Disorders

Most neurological disorders in the region are a result of perinatal and neonatal brain injury<sup>5</sup> or postnatal central nervous system infections and, in particular, cerebral malaria, bacterial meningitis, or viral meningo-encephalitis.<sup>5,13,15</sup> Thus, in coastal Kenya, neonatal insults were the most important risk factor for neurodisability<sup>5</sup>; whereas in a recent study of epilepsy in Ugandan children, more than 70% had either symptomatic or remotely symptomatic epilepsy, and perinatal and

neonatal insults or central nervous system infections were the most important risk factors (Grace Mirembe, unpublished data, August 2009). Similar results were previously described in Tanzania in 1980s where more than 70% of children with epilepsy had an early history suggestive of central nervous system infection or birth insult.<sup>16</sup>

To date, the burden of acute neurological disorders is still very high; the incidence of acute seizures and status epilepticus is 2 to 4 times that in Western countries.<sup>17,18</sup> The HIV/AIDS epidemic has added another dimension to neurological disease. HIV is associated with neuron injury and encephalopathy with cognitive, motor, and behavioral dysfunction.<sup>19-21</sup> In addition, there are the HIV-associated opportunistic infections (eg, tuberculous meningitis and toxoplasmosis)<sup>20,22</sup> and drug treatment-related toxicities. Stroke, most often associated with sickle cell anemia and HIV, is a prominent cause of disability in the older child. Human deprivation and malnutrition, commonly due to poverty, conflict, or displacement, directly or indirectly cause some of the disorders, for example, visual impairment (vitamin A deficiency) and delayed psychomotor development (iron and iodine). However, there are no newborn screening programs to detect children at risk. Similarly, other than HIV and syphilis, there is no maternal screening to detect babies at risk of intrauterine infections. Thus, congenital infections (toxoplasmosis, cytomegalovirus, rubella, and herpes simplex) are not detected nor are the inborn errors of metabolism.

Increasingly, road traffic accidents and traumatic brain injury are becoming another prominent cause of neurodisability,<sup>23-26</sup> and civil strife, conflict/war, and genocide, particularly in Uganda, Burundi, and Rwanda, have resulted in massive psychosocial stress and epidemics of psychiatric disorders.<sup>27-29</sup> In specific areas, however, genetic risk factors<sup>30</sup> and other neglected tropical diseases (eg, neurocysticercosis)<sup>31</sup> are important.

In recent years, however, there have been major public health interventions in the region. Other than Tanzania and Burundi, vaccination against *Haemophilus influenzae* type b was introduced in early 2000s, and *Haemophilus influenzae* type b meningitis, previously the leading cause of pyogenic

meningitis in children, has declined.<sup>32-34</sup> Vaccination against pneumococcal infections was recently introduced in Rwanda and will be introduced in Kenya in 2010 and Uganda in 2011. Malaria control has improved. Malaria is now treated with the more effective artemisinin-based combination drugs, and insecticide-treated mosquito nets are widely available and distributed free in antenatal clinics to expecting mothers (who, in addition, receive intermittent preventive therapy for malaria) and for their children less than 5 years old. Thus, there are reports to suggest that malaria-related morbidity is declining.<sup>35</sup> Moreover, the coverage of safe water sources has improved, and primary school education is free and universal. This and other improvements in social services and health care, in particular, the Save the Children Fund-led program to improve newborn care, suggests that the epidemiology of acute and the resulting chronic neurological disorders in the region may change over the coming years. It is not surprising, therefore, that infant mortality has dropped from about 100 to 70 per 1000 in recent times, and life expectancy has risen (Table 1).

### **Service Delivery—Personnel, Diagnosis, Treatment, and Rehabilitation**

There are 6 pediatric neurologists in a region with more than 122 million people—5 in Kenya and 1 in Uganda, and most are based in the capital cities. There is no pediatric neurology training program. Even where there are trained persons, the investigative capacity is severely limited. With the exception of some bigger centers, electroencephalography is rarely used in the classification and management of epilepsies. Genetic testing and investigations into the metabolic causes of neurological disease is almost nonexistent. Although some neuroimaging facilities exist, for a region where the average per-capita cost for health care is under \$10 (US), the cost of brain imaging is prohibitive for the majority of the population. Computerized tomography scan costs approximately \$90 (US) and magnetic resonance imaging costs \$500 (US).

Besides epilepsy and cerebral palsy, there are no separate services for neurological disorders. Instead, services are provided for within the existing health care systems. The level of care often depends on the training and skills of the attending health worker. Again, depending on the health unit (dispensary, health center, subdistrict hospital, district hospital, or referral hospital) clinical care is provided by nurses, clinical officers (health workers with a diploma in clinical medicine following 3 years of training), medical officers (doctors with basic bachelor's level medical training), or pediatricians. Most district hospitals have 1 or 2 physiotherapists responsible for physical therapy and orthopedic assistants who help with prostheses. There are very few occupational therapists. In Uganda, psychiatric clinical officers and psychiatric nurses attend to people with epilepsy. Thus, health unit-based care for epilepsy is a domain of psychiatry. No equivalent cadre of staff exists for other neurological conditions. Training programs for specialized health care workers are limited. It was only in 2007 that

the first training program in speech and language therapy was initiated in Uganda by United Kingdom volunteers.

The few trained specialists, inadequate rehabilitation, and poor social support systems imply that the majority of patients never receive medical attention or rehabilitation. This predisposes them to increased morbidity, malnutrition, poor quality of life, and premature death. Moreover, even the available resources are the most basic; for example, phenobarbital is the only available antiepileptic drug in most health units. The exception is private clinics, referral centers, and some clinics supported by the Kenyan and Ugandan Epilepsy Societies where other antiepileptic drugs such as carbamazepine and phenytoin may be available. Facilities for antiepileptic drug level monitoring are also not available. Care mostly focuses on major symptoms such as seizures and there is very little focus on other aspects. Thus, psychological and specific educational needs assessments are lacking. The Kenyan Epilepsy Society has prepared guidelines for care and the ministries of health have policies on community-based rehabilitation, but for the majority, patient assessment is not standardized and there is no agreed-on tool. Specifically, there are no programs for the assessment of child development or early referral except inquiries on gross motor development during vaccination visits.

Other than health unit-based care, rehabilitation is supported by community-based rehabilitation programs. There are several community-based organizations that identify and support children with neurological disorders and disabilities. Examples of these include Handicap International in Burundi, Kenya Society for People with Epilepsy, Centre de Réadaptation des Handicapés in Rwanda, the Comprehensive Community Based Rehabilitation Tanzania, and the Uganda Society for Disabled Children. Otherwise, in the absence of formal health care, traditional healers serve as alternate service providers, because they manage at least 80% of the health care needs in rural and difficult-to-reach areas.<sup>36</sup> The ratio of 1 doctor for more than 20 000 people compares poorly to 1 traditional healer for 290 people.<sup>37</sup> The community perceptions about the causation of some of the neurological problems (eg, supernatural forces) urge them to seek these services, because they often share the same values and culture. Even among those attending formal health care, several patients may be receiving traditional medicines secretly in addition to treatment obtained from the health unit. This creates a potentially dangerous situation, because drug interaction with Western medicine is not known.

Opportunities for children with moderate and severe disability are limited. Special needs schools are scarce and few mainstream schools have teachers trained to offer such programs. Because of misconceptions and beliefs about disability, stigma is still a big problem. Stigma often stems from caretakers/parents because of beliefs that these conditions are caused by evil spirits or are punishment from the gods for some evil done or breach of some taboos. Children with epilepsy are frequently sent home from school “until the convulsions stop,” for fear of spreading it to other children. Sometimes the children themselves elect to leave school because they can no

longer stand the stigma or the challenges associated with the accompanying cognitive impairments. Even in the home, the stress of managing children with especially severe behavior or cognitive difficulties puts a lot of strain on family relationships. In a series of children with severe behavior problems after cerebral malaria, the strain on the family was so immense that 1 parent described life at home “almost like hell.” Some children were tied up to prevent them from wandering while grandparents were called in to help provide care.

### **Child Neurology in the Near Future**

Despite the limitations in services, personnel, and infrastructure, there is increasing demand for neurological, neurosurgical, and rehabilitation services. Some patients travel very long distances to seek such care. Certainly it is only the few with some resources who are able to seek specialized care in far-off referral centers. The desire for parents to try all that is possible for their children and the awareness that these services may improve survival and reduce morbidity are the main motivating factors. For example, the child neurology clinic at Mulago in Uganda has patients attending from Rwanda, Democratic Republic of Congo, and Southern Sudan.

### **Training and Organization of Services**

It will take a long time to train sufficient neurologists to offer neurological services to the population. Available resources may not even permit this. In the short term, therefore, a feasible and perhaps cost effective measure will be to identify and develop centers of excellence that can offer training and specialized care. District nurses, and clinical and medical officers, interested in neurology and disability can spend time in these centers training and obtaining skills in neurology that they can use to screen, and offer basic care and counsel, and to which they can refer families with disabilities. Each of the regional centers of excellence can focus on specific disorders or groups of disorders. Such an arrangement may improve specialization and provide an impetus for growth and research. They include centers for spina bifida and hydrocephalus, cerebral palsy and motor disorders, epilepsy, autism, and other behavioral and psychiatric disorders, dysmorphology and genetics, and orthopedic rehabilitation. Already there are examples of this happening in some charity-supported hospitals. These include Kijabe and Port Reitz hospitals (Kenya) and the CORSU Hospital (Uganda), which offer orthopedic surgery and rehabilitation for children with motor disorders and the CURE Hospital (Uganda), which offers care for spina bifida, hydrocephalus, and epilepsy. The ministries of health in the 5 countries can jointly identify centers to offer other services. Budget lines can be drawn to support these centers and increase their capacity to receive referrals and to train health workers. Visiting and volunteer specialists can help with the initial setup and training and later with support supervision for those who complete training. At a later date,

the same centers may provide specialist training in neurology when it becomes available.

### **Assessment, Standards, Research, and Advocacy**

In the meantime, there is need for the development of culturally adapted, yet standardized, tools to screen and assess neurological and developmental disorders in children as well as develop treatment and rehabilitation protocols for both primary and tertiary care. Financing is a major issue, but with declining mortality rates, funding which previously targeted diseases that caused the high childhood mortality in the region should increasingly become available for chronic disorders. In addition, there is need to engage in advocacy for child neurology and develop links with industry and professional societies or international bodies for care and research. Within the countries, parliaments should be lobbied for increased funding. Marketing disability as a human rights issue may be a useful advocacy tool.

### **Services**

In caring for children with disabilities, a program for early detection is urgently needed. Such a program should equip midwives to screen for some disorders at birth, help and improve the well-child/immunization clinics to screen for disabilities, and refer those with possible impairments to follow-up clinics for children exposed to adverse neurological events (eg, perinatal asphyxia, acute central nervous system infections, traumatic brain injury, and other causes of acute seizures) for the early detection of neurodisability. Such a program will require a substantial investment in infrastructure and human resource. Trials in pilot areas may be useful.

Health workers may also need to learn to work with the traditional healers who manage the bulk of these patients. There is a need to develop a clearly defined referral system, both from a lower health unit to a more specialized unit and from traditional healers to health units, to improve access to appropriate health care. In the long run, it is hoped that through a process of knowledge sharing, collaborations can be set up between the two groups.

The prevention of brain injury is clearly important. The importance of vaccination against the bacterial causes of meningitis and measures to control malaria cannot be overstated, and the enforcement of traffic safety regulations that propagate the use of helmets for motorbike riders and their passengers is important. However, for children who develop acute central nervous system infections or traumatic brain injury, there is need to improve referral and inpatient management.<sup>38</sup> In particular, there is need to improve the management of acute seizures and febrile status epilepticus and also a need for improved trauma care. A steady supply of the first-line anticonvulsant drug for acute seizures—diazepam—should be maintained in all health units and at all times, and the second-line drug—phenobarbital—should be maintained in all units that admit and treat children with severe febrile disease<sup>39</sup> to cater

to status epilepticus. Clinicians and nurses who care for these children should have regular updates in the care of critically ill children and receive support supervisory visits. As the burden of malaria and bacterial infections decline and the viral causes of encephalopathy proportionately become more prominent, there is need to develop policies and management protocols for these. Currently, viral encephalopathies are not routinely investigated and antiviral drugs such as acyclovir are not readily available.

Better strategies for schooling, continuing care, rehabilitation, and family counseling and support services are needed. Avenues for funding rehabilitation and provision of assistive devices should be sought to help the majority of families who are unable to foot such bills. There is a need for an increased output of teachers specialized in special needs education and for community sensitization programs to reduce stigma. The good news, though, is that with the increasing school enrollment in the region (following the Universal Primary Education programs), in the near future, the population will become better educated and the benefits of education may overflow to children's well-being and health.

## Conclusions

Discrepancies exist in the health care system of the East African region, with a paucity of data on the burden of neurological disorders that could serve as a useful guide to inform policy and improve the care of affected children. There are limited resources for obstetric and neonatal management, which serve as a major contributor to the causation of many of these disorders. Infections, poverty, and conflict are the other major players. Lack of human resources, in terms of trained personnel to provide holistic care for children with neurological disorders, coupled with a severely limited investigative capacity, threatens the survival and quality of life of many of these patients. There is an urgent need to create feasible, cost-effective centers of excellence to offer training and specialized care for these children with support from collaborative partnerships with wealthier countries. The development of culturally adapted, screening tools to aid the early identification of these children to improve their long-term outcome should be encouraged. Preventive efforts such as immunization against *Haemophilus influenzae*, indoor residual spraying or use of bed nets for malaria, use of protective helmets for motor-bike riders, and sensitization through educative programs need to be supported. Improvement in the referral of children and in patient management of children with acute seizures and febrile status epilepticus, and the setting up of rehabilitation and support services for children with neurological disorders, will provide a more complete and precise service for the affected children and their families.

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