



Clinical Profile of Pediatric Neurological Disorders: Outpatient Department, Khartoum, Sudan

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Abstract

Background: There is no available data from Sudan reflecting the magnitude of the neurological disorders and disabilities in the pediatric age-group. This study aims to evaluate the pattern of neurological disorders among Sudanese children. **Patients and Methods:** This is a retrospective survey of children with epilepsy and other neurodisability disorders seen at pediatric neurology outpatient clinic, during the period from January 2007 to August 2013. The data of 9600 patients were analyzed. **Results:** A total of 6019 patients were included in the study. The majority of the patients had epilepsy that amounted to 52.8%, followed by cerebral palsy (19.1%), congenital anomalies of the central nervous system (6.2%), neuromuscular disorders (3.2%), stroke (2.4%), ataxia and movement disorders (1.9%), assumed genetic syndromes (1.2%), and others. **Conclusion:** Neurological disorders constitute a major cause of chronic morbidity in pediatric age-group.

Keywords

neurological, disorders, children

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Background

Neurological disorders account for more than 20% of the world's disease burden with a greater majority of people living in Africa affected. The factors that are producing this increased burden include malnutrition, adverse perinatal conditions, malaria, acquired immune deficiency syndrome (AIDS; human immunodeficiency virus HIV/AIDS), meningoencephalitis, demographic transitions, and persistent regional conflicts.¹ Due to late presentation and unavailability of certain diagnostic facilities in resource-limited countries including Sudan, neurology services are very challenging with a significant increase in morbidity and mortality.² This study aims to review the pattern of pediatric neurological disorders as seen in the Outpatient Department in Khartoum State (the capital) and to reflect on the main challenges of investigations and management.

Setting

This study had been conducted at the outpatient clinic devoted to children with epilepsy and neurodisabilities at Saad Abu el Ellah University Hospital, one of the University of Khartoum

Teaching Hospitals. The clinic was established in 2007 by the authors. In 2013, the clinic was relocated to soba University Hospital (one of the tertiary-level Khartoum University Hospital). The clinic is conducted once a week with an average of 60 to 80 patients per clinic. The official booked numbers are around 40 to 50, but the 20 extra include emergency referrals, previously seen patients with investigation results from outside the capital, drop in refractory epilepsy, inpatients coming from nearby hospitals via ambulance, and a few more come for free drug prescriptions from our outpatient department pharmacy. Down referrals do not exist, the authors can refer for consultations with orthopedic, ophthalmology, neurosurgery, and other departments, but even the general pediatric care of these patients becomes our responsibility. It is run by 3 pediatricians

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with special interest in pediatric neurology and an average of 3 pediatric residents. In our country, the number of pediatricians working in neurology field are only 4, 3 of them in the capital. In other states, patients with neurological problems are seen by general pediatricians and referred to Khartoum if needed. The authors have no data regarding number of doctors per population, but it is generally very low in comparison to developed countries. The physiotherapy, neurophysiology, neurosurgery, pediatric orthopedics, neuroradiology, and neuropsychology departments are under the same roof.

Although the majority of patients were from Khartoum and nearby states, there is considerable number of patients attending from all over Sudan and even from nearby countries such as South Sudan, Chad, and Eritrea. The clinic attracts a lot of undergraduate and postgraduate research students in addition to the training opportunity for residents in pediatrics.

Each patient has a card with a serial number, diagnosis, and a summary for his condition, which is usually kept with the patient. A medical record with the same serial number with detailed clinical data, investigations, and management plans is kept in the department of medical record and statistics. There is no software data service.

The outpatient clinic setup has been conducive to visits from Sudanese neurologists working abroad in their annual leaves. The authors established a dropbox link for uploading magnetic resonance imaging, videotapes, and patient consultations with senior consultants abroad. A visiting team of Speech and Language Therapists from United Kingdom have also had great impact on the management of children with oromotor dysfunction and communication disorders.

Methods

This is a longitudinal, descriptive, hospital-based study conducted at the Epilepsy and Neurodisability Outpatient Department. The medical records of the patients seen from January 2007 to August 2013 were revised. Patients were categorized into 24 groups according to their main clinical presentation although there is a lot of overlap between these groups.

The diagnosis of these disorders is clinically based and is supported by available neuroimaging facilities and basic neurophysiological tests. Metabolic tests and other relevant investigations were requested as deemed appropriate. There is no genetic service except for simple karyotyping. There are a few advanced genetic tests which are performed on research basis.

Results

The majority of patients were referred by pediatricians; however, some were referred by ophthalmologists, pediatric orthopedics, pediatric surgeons in addition to adult physicians, and neurologists. A total of 9600 patients were seen during the study period. Some of the patients who were initially seen in the clinic were referred to other disciplines, some had continued their follow-up in their local area or a nearby clinic, and there are a number of patients whose clinical data were missing

Table 1. Cost of the Commonly Used Investigations.

Investigations	Cost (Sudanese Geneh) (US Dollar)
Computed tomography scans	200 (22)
Magnetic resonance imaging of the brain with contrast	800 (88)
Magnetic resonance imaging of the spine with contrast	800 (88)
Magnetic resonance angiography	600 (66)
Magnetic resonance spectroscopy	500 (55)
Magnetic resonance venography	500 (55)
Electroencephalography	250 (28)
Electromyography	600 (66)
Nerve conduction studies	600 (66)
Metabolic screen	1500 (166)

or incomplete. The authors managed to analyze the clinical data of 6019 (62.7%) patients.

The age of the patients was between 3 months and 18 years, and the average period of time in the service follow-up was 2.5 years. The male to female ratio was 2:1. The majority (65%) of patients were from Khartoum State; however, there were considerable numbers (45%) coming from other states.

In our service, neuroradiology investigations are available including computed tomography scans, magnetic resonance imaging of the brain and spine with contrast, magnetic resonance angiography, magnetic resonance spectroscopy, and magnetic resonance venography. In addition to electroencephalography (EEG), electromyography (EMG), nerve conduction studies as well as visual and hearing assessments. All these investigations are available at high cost in comparison to the average family income in Sudan as shown in Table 1. About 30% of the patients had health insurance which covers 75% of the total cost for each investigation. Oral chloral hydrate syrup was commonly used for sedation if needed.

The patients were classified according to their main clinical presentation into 24 categories, however there is a lot of overlap between these groups. The biggest group is childhood epilepsies which accounted for 2,877 (47.8%) patients. This was followed by children with cerebral palsy which accounted for 1,149 (19.1%) of the patients. Three hundred thirty seven (6.2%) had a variety of congenital anomalies of the central nervous system. One hundred and ninety two (3.2%) had neuromuscular disorders including congenital muscular disorders and muscular dystrophies, 114 (2.4%) had acute stroke, 180 (3.0%) of the patients had neurodegenerative brain diseases, and 132 (2.2%) had spinal cord pathology of whom 56 (42.4%) had been diagnosed as spinal schistosomiasis, in addition to 126 (2.1%) with acute demyelination disorders including acute disseminated encephalomyelitis (ADEM), optic neuritis, and transverse myelitis. One hundred and fourteen (1.9%) had progressive ataxia including spinocerebellar ataxia and ataxia telangiectasia, and 100(1.6%) had behavioral problems. Seventy-two (1.2%) patients had myasthenia Gravis including patients with congenital myasthenia syndromes as shown in Table 2.

Table 2. Pattern of Neurological Disorder in Sudanese Children.

Disorders	Number (%)
Seizure disorders	2877 (47.7)
Cerebral palsy	1149 (19.1)
Congenital anomalies of the central nervous system	337 (05.6)
Muscular disorders	192 (3.2)
Neurodegenerative brain diseases.	180 (3.0)
Spinal cord pathology (spinal schistosomiasis)	132 (2.2)
Acute demyelinating disorders	126 (2.1)
Acute stroke	114 (1.7)
Ataxia	114 (1.7)
Behavioral problems	100 (1.5)
Myasthenia Gravis	72 (1.2)
Genetic syndromes ^a	70 (1.2)
Brain tumors	65 (1.1)
Neurocutaneous syndromes	55 (1.0)
Guillain-Barre syndrome	55 (1.0)
Mitochondrial disorders	50 (0.7)
Nonepileptic paroxysmal disorders	50 (0.7)
Movement disorders	50 (0.7)
Charcot-Marie-Tooth disease	26 (0.5)
Metabolic disorders	26 (0.5)
Idiopathic intracranial hypertension	10 (0.3)
headache and migraine	10 (0.3)
Miscellaneous ^b	100 (1.6)
Could not be placed in a diagnostic category ^c	89 (1.4)
Total	6019 (100)

^aIncludes patients with dysmorphic features and obvious syndromic diagnoses that were clinically identified but could not be proved due to lack of local genetic services.

^bInclude patients with Bell's palsy, Abducens/Trochlear nerve palsies, headache, migraine, nocturnal enuresis, learning difficulties (dyslexia and others), intracranial calcifications (TORCH and pseudo TORCH and others), systemic lupus erythematosus vasculitis, some rare disorders, for example, Stiffman syndrome, dysautonomia, hyperekplexia, chronic infantile neurological cutaneous articular syndrome.

^cThis group of patients has rare disorders that cannot be placed in any of the above mentioned categories needing further genetic and/ or metabolic workup which are not available in our setup. Some proved to have novel genes (under publication).

Abbreviations: TORCH, Toxoplasmosis, Rubella, Cytomegalovirus, Herpes Simplex.

Acute inflammatory demyelinating polyradiculoneuropathy, Charcot-Marie-Tooth disease, mitochondrial disorders, movement disorders including dystonia, genetic syndromes, neurocutaneous disorders, metabolic diseases, idiopathic intracranial hypertension, brain tumors, nonepileptic paroxysmal disorders, headache, and migraine in addition to a miscellaneous group amounted for 17.8% of the patients. The authors have a considerable number of patients that could not be placed in a diagnostic category which accounted for 89 (1.4%).

Discussion

Neurological disorders in children are a common cause for referral to tertiary care hospitals. The neurological disorders account for more than 20% of the world's disease burden with a greater majority of people affected living in Africa.^{1,2} Childhood neurology and developmental pediatrics are well-established specialties in high-income countries, where advances in diagnostic

techniques have aided the characterization and definition of disease. The application of recent therapeutic measures has resulted in significantly improved outcome.³ In resource-limited countries including Sudan, the main focus for the past decades has been on more acute treatable conditions with high fatality.⁴ Yet, epidemiological studies show that the prevalence of childhood disabilities is very high. There is a rising incidence of childhood epilepsy, where it reached up to 11.29 per 1000 in Africa.⁵⁻⁷ Despite this, neurology as a pediatric subspecialty rarely attracts attention and priority in the cramped health budget in Sudan and other African countries.⁸ The available neurology services are mainly found in big cities. Primary care centers do not provide adequate drugs and treatment facilities for chronic disorders that lead to treatment failure and poor compliance. Newer advances in treatment are largely confined to a few selected centers.^{9,10}

Pediatric neurology service in Sudan is a flourishing subspecialty that has a great potential to expand and improve. It includes services to the children with epilepsies, cerebral palsy, and other neurodisabilities through dedicated out patients clinics, established inpatient unit for pediatric neurology located at Gafer Ibn Auf specialized hospital which is a tertiary hospital at the center of Khartoum, where patients are referred from all over Sudan. This will be a nucleus for expanding the neurology service, training of under- and postgraduate students, and future research projects.

As of this date, these services are concentrated in the capital Khartoum, where this study was conducted in Medani, 186 km north of the capital. This leaves most of the country with no tertiary neurological services. The referral systems are not well established, and the traveling process from a peripheral area can take days and is quite expensive. In addition to the cost of necessary investigations, the lack of comprehensive insurance cover adds more burden to the already disadvantaged families.

The male predominance was found to be consistent with our local data.¹¹⁻¹³ The authors are not sure if this ratio denotes the cultural attitude of our population that favors males.

The age of the patients seen in the clinic ranges from 3 months up to 18 years, some of these patients continue to be seen in this clinic beyond 20 years of age, although recently the authors established a transition clinic joined with the adult neurologist to address medical, psychosocial, and lifestyle issues relevant to adolescent and young adults. Transition services are still uncommon in most neighboring African countries.

The logistics of the neurology service are quite unique in that it entails expensive investigations. In our setup, a lot of investigations are available but are unaffordable. Metabolic screen (tandem spectrometry) is done only through external links (Bioscentia lab, Germany) and for genetic workup, there are very few links through research projects. The authors strive to help our patients through our social workers, nongovernmental organizations, and raising funds for poor patients. The authors admit patients for social reasons until we get their investigations done and they get a physiotherapy input, counseling, and other treatment modalities especially if they live far from the Capital.

In this study, the main groups of neurological disorders seen in the clinic are childhood epilepsies, cerebral palsy, and developmental brain anomalies. This is quite different when compared to reports from many neighboring African countries where the epilepsy and cerebral palsy are usually followed by central nervous system infections such as human immunodeficiency virus encephalitis, and in some areas, there is high incidence of central nervous system cysticercosis and tuberculosis, patterns which are not seen frequently among our population.¹⁴⁻¹⁶ Khartoum, the capital of Sudan, does not lie in the zone of the endemic diseases that are well known to present with neurological morbidity in the pediatric age groups and patients with human immunodeficiency virus infection may be seen outside the capital or in human immunodeficiency virus program clinics. Our clinic is not based in a hospital that receives acute admissions. The authors receive lots of phone call consultations from the secondary care pediatric hospitals and can guide their management in the acute phase; however they do not necessarily show up in our clinic unless they have long-term sequelae. Our colleagues in psychiatry and neuropsychology attend to the problems of behavior, autism, and learning difficulties. The authors see these patients only when they have neurological comorbidities and this can explain the underrepresentation of these ailments in our patients.

Epilepsy and seizure disorders are the commonest neurological disorders seen and managed in our clinics. This is similar to reports from other African countries.^{17,18} This high prevalence of epilepsy may be due to increasing awareness that epileptic seizures are medical conditions which are treatable as opposed to prior beliefs that they were caused by evil spirit manipulation and witchcraft attacks.¹⁹

There are considerable numbers of patients referred from outside Khartoum as the primary health centers in rural areas are not well equipped with manpower, antiepileptic drugs, or investigations which can help in the management of these patients. In a recent study from Sudan, it was found that unaffordability of Anti Epileptic Drugs (AEDs) is the main cause of intractable seizures among these patients.²⁰ Although the authors have access to many of the AEDs such as sodium valproate, carbamazepine, oxcarbazepine, lamotrigine, topiramate, and clonazepam, the increasing costs of these drugs make them relatively unavailable and compliance issues prevail. Other African countries suffer from the lack of these drugs altogether.⁹

Cerebral palsy was the second commonest neurological condition seen in the outpatient department. This was similar to the reports from other parts of the world.²¹⁻²⁴ Many of the affected children require specialized care and rehabilitative services and multidisciplinary team work. In our setup and in spite of the high incidence of cerebral palsy, no facilities exist for the adequate care of these patients. The available rehabilitation centers are mostly nongovernmental charity organizations such as Voluntary Organization for International Co-operation (OVCI) and Cheshire home. Some private centers, that most of the affected children cannot afford, are available in big cities only. To date, there is no governmental Child Development Centre even in the capital of Sudan.

Congenital brain anomalies and syndromes accounted for a large proportion of childhood neurological disorders in this study. The majority of these disorders are inherited in an autosomal recessive manner and this is not surprising in our community, where there is a high rate of consanguineous marriages. This is similar to what has been reported from communities with similar cultural backgrounds.^{25,26}

Spinocerebellar ataxias are very common in view of our high consanguinity rates and intertribal marriages. Lack of genetic services is a major barrier for further classifications, adequate diagnosis, and hence proper genetic counseling.

The tropical diseases such as spinal cord schistosomiasis account for most of our spinal cord pathology in Sudan especially during the summer months whereby children present with lower limb weakness characteristic of transverse myelitis. Schistosomal transverse myelitis was reported earlier from Sudan.^{27,28}

Of note in this study is the amount of missing data and patient dropouts which emphasizes the common problems seen in resource-limited countries which do not have proper paramedical support services, secretarial back up, and processes of data accessibility and retrieval. The patient held records provide the means by which problems will be identified wherever patients land. Our system needs improvement with introduction of computerized software for data storage and probably links with outreach services. In the era of telemedicine, that is no longer impossible.

This study showed a wide spectrum of childhood neurological disorders well represented in our population. However, the authors are still short of manpower, infrastructure for neurology care services, multidisciplinary team involvement, and access to antiepileptic drugs in remote areas. The referral systems from primary and secondary care facilities to tertiary care are often unpredictable and chaotic.

Recommendation

Improving facilities, manpower recruitment, promotion of multidisciplinary team involvement, facilitation of training and research will have a great effect on improving child health care in our country. Collaboration with neighboring African countries and building links with international organizations and institutes has the capacity to improve on the current level of care and is capable of positively impacting on training and future research.

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Author Contributions

Authors are directly responsible for patients care, medical records, data entry, data analysis, literature review, writing, and editing.

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Ethical Approval

This work had been approved by the Research and Ethical Committee at the faculty of Medicine-University of Khartoum.

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