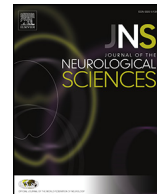


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Epilepsy 3

Estimation of the direct cost of epilepsy among Sudanese patients attending charity clinic in Omdurman 2014

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Background: Epilepsy is a common disease with economic impact in form of frequent clinical visits, investigations and management.

Objective: To estimate the direct and part of the indirect costs of epilepsy.

Design and methods: The study was performed on a case series of medically treated Sudanese patients with epilepsy in a charity clinic. Data on clinical characteristics, utilization of medical services, and costs were collected from 38 patients using a standardized pre-tested format. The patients' approval was obtained as necessary.

Results: Direct medical care costs was (2,395 Sudanese Pounds "SDG", 417 American Dollars "USD") per year per patient, of which antiepileptic drugs was the major component (1,587 SDG, 276 USD). Other costs are medical consultations and hospitalization charges (SDG 148, 26 USD), investigations cost (146 SDG, 25 USD), and cost of travel to clinics (514 SDG, 90 USD). Nonmedical direct cost - in form of traditional healers' visits were reported by 13.5% of the patients and estimated to be (1,422 SDG, 251 USD) per patient per year. The indirect cost was estimated for co-patients transportation, which is reported by patients who resides outside the state, making 7.9% of patients, and estimated to be (1,773 SDG, 308USD) per co-patient per year. The overall mean annual cost for epilepsy per patient in our clinic was approximately (2,724 SDG, 474 USD).

Conclusion: The economic burden on epilepsy patients is heavy, and the contributors to the cost in Sudan have many similar features and some noteworthy differences with that of other countries.

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Association of medications adherence with the quality of life and cost of epilepsy among Sudanese epilepsy patients attending charity clinic

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Objectives: To assess the association of medications adherence with the quality of life and the costs of epilepsy in a sample of Sudanese patients with epilepsy.

Design and methods: The study was performed on Daoud charity neurological clinic, from June to September 2014. Data was collected using standardized forms. Data on clinical characteristics, utilization of medical services, and costs were collected. Medication adherence was assessed using the eight-item Morisky Medication Adherence Scale (MMAS). Quality of life was assessed using the 26-item WHO Quality of Life Brief-26. Patients approval was obtained.

Results: There were 38 patients (71% males; mean age 32.9 years). According to MMAS-8, (23.7%) of patients had a high adherence, (39.5%) had a medium adherence and (36.8%) had a low adherence rate. The mean total score of WHOQOL Brief was (91.8 out of 130). The overall mean annual costs were 2,778 Sudanese Pounds (USD, 484). Adherence score was positively and significantly correlated with WHOQOL Brief total score ($P = 0.008$), Physical Health domain score ($P = 0.007$), Social relationships domain score ($P = 0.006$), and Environment domain score ($P = 0.007$). Similar significant correlation was found between the overall mean annual costs and the Environment domain score ($P = 0.041$). However, adherence was not significantly associated with Psychological domain score ($P = 0.054$), the annual total costs of epilepsy ($P = 0.568$) or the annual medications costs of epilepsy ($P = 0.87$).

Conclusion: Patients with low adherence to anti-epileptics are more likely to have lower quality of life.

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Epilepsy 3

Epilepsy with continuous spikes and waves during slow-wave sleep: a study of 22 children from a single centre

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Background: Continuous spikes-and-waves during slow-wave sleep (CSWS) is poorly studied in children.

Objective: To analyse clinico-radiological characteristics, treatment and short-term outcome of children with CSWS.

Materials and methods: 22 children, age-group 1-12 years with CSWS in >85% of non-REM sleep-EEG retrospectively reviewed.

Results: Mean age at presentation was 6.75 ± 2.19 years (range 4-12), 77% were boys. First neurological symptom was seen at mean age of 23.41 ± 23.04 months (range 3-72) as seizures (45.5%), developmental delay (40.9%), poor scholastic performance (9.1%) and behavioural abnormalities (4.5%). Most (68%) children had >1 type of seizure; focal (54.6%), generalized (51%), atypical absences (50%) and atonic seizures (27.2%); convulsive status-epilepticus was noted in 31.8%. Mean age of epilepsy-onset was 2.68 ± 1.76 years. Clinically, microcephaly (27.3%), ataxia (18.2%), hemiplegia (13.6%) and dysmorphism, hydrocephalus, spastic quadriparesis and spastic diplegia (4.5% each) were noted. CSWS was diagnosed at mean age of 6.14 ± 2.26 years. Average number of anti-epileptic drugs used was 2.77 ± 1.37 . Majority (68%) had abnormal MRI; hypoxic-ischemic-encephalopathy and polymicrogyria - 2 each, non-specific white-matter changes/mild cerebral atrophy ventricular asymmetry - 3 each and aqueductal stenosis, perinatal stroke - 1 each. Pulse-corticosteroid therapy was used in 86%. Follow-up was for 2.18 ± 0.9 years (range 1-4); CSWS persisted in 54% of patients. Seizures were controlled in 45.4% and 27% had >50% reduction in frequency. Behavioural, scholastic and cognitive problems persisted in 59%, 50% and 36% respectively as per the parent/teacher's reports; 67% had IQ

Conclusions: CSWS is commonly drug-refractory; pulse steroid therapy is effective; most cases have residual neurological problems.

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Epilepsy 3

Diagnostic yield of genetic testing in epileptic encephalopathy in childhood

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Background: Epilepsy prevalence is 300-600 per 100,000. The majority of the time, the underlying etiology is not known.

Objective: To determine the diagnostic yield of genetic testing in childhood epilepsy, we performed a retrospective cohort study in a single Epilepsy Genetics Clinic.

Methods: We obtained Institutional Review Board approval. We included all patients with epilepsy, global developmental delay seen between January 2012 and April 2015. Electronic patient charts were reviewed.

Results: 120 patients were divided into two groups according to underlying genetic causes: (1) Group-1: Inherited metabolic disorders (IMDs) (10/120: 8%); (2) Group-2: Other genetic causes (33/120: 28%). Group-1 includes PDE caused by ALDH7A1 mutations, Menkes disease, PNPO deficiency, cobalamin G deficiency, severe MTHFR deficiency, GLUT1 deficiency, glycine encephalopathy, PDH complex deficiency and CDG1p caused by ALG11 mutations. Group-2: a) 9 patients diagnosed by either microarray, single gene testing, MRI or clinical features including pathogenic CNVs, Simpson-Golabi-Behmel syndrome, Rett syndrome, *KCNQ2* related epileptic encephalopathy (EE), lissencephaly caused by *TUBA1A* mutation, CHARGE syndrome caused by *CHD7* mutation; b) 19 (19%) patients diagnosed by targeted next-generation sequencing for EE including *SCN1A*, *SCN2A*, *SCN8A*, *KCNQ2*, *STXB1P1*, *PCDH19*, *SLC9A6* related EE; c) 5 (45%) patients diagnosed by whole exome sequencing including *KIAA2022*, *KCNQ2*, *VPS53*, *EP300*, *CHD2* genetic disorders.

Conclusion: Our study combines IMDs and other genetic causes of EE. 36% (43/120) had a genetic cause: 44% diagnosed by clinical features, metabolic investigations, MRI, or microarray, 44% by

targeted next-generation sequencing epilepsy panel and 12% by whole exome sequencing. 14% had a treatable disease.

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Epilepsy 3

The prognostic value of cortical thickness asymmetries for surgical outcome in patients with neocortical epilepsy

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Background: Presurgical evaluation is challenging in patients with intractable epilepsy and normal conventional MRI. In such cases, advanced imaging can provide localizing and prognostic information. A study in temporal lobe epilepsy suggested that cortical thinning may predict poor surgical outcome (Bernhardt et al. *Neurology*, 2010;74:1776-84).

Objective: To evaluate if cortical thickness measures are associated with surgical outcome in non-lesional neocortical epilepsy.

Patients and methods: Lobar and hemispheric cortical thickness was measured on volumetric MRI by the Freesurfer software in 21 young patients (mean age: 9.9 years) with neocortical epilepsy who underwent subsequent two-stage epilepsy surgery. Absolute values and ipsilateral/contralateral asymmetries of cortical thickness were compared between patients who were seizure-free and those who continued to have seizures one year after surgery. We have obtained Institutional Review Board approval for this study.

Results: Hemispheric and frontal lobe cortical thickness showed no/minimal asymmetry in seizure-free patients (n = 14) but smaller values ipsilateral to the resection in patients with recurrent seizures (p = 0.02). More robust group differences were found in patients ≥6 years of age (n = 14, p < 0.01 for hemispheric and frontal asymmetries). By using an optimal cutoff threshold established by a receiver operating characteristic analysis, hemispheric cortical thickness asymmetry predicted one-year seizure freedom with 93% sensitivity and 71% specificity in the whole group and 100% sensitivity and 92% specificity in patients ≥6 years old.

Conclusion: Cortical thinning in the epileptic hemisphere, as compared to the contralateral side, may be an objective imaging marker for risk of poor surgical outcome in patients with neocortical epilepsy.

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Epilepsy 3

Malian cultural conceptions about epilepsy

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Introduction: Epilepsy, or popularly termed "out of the shadow", is the slogan chosen by the International League against epilepsy. This policy, in an attempt to bring epilepsy out of the shadows, is based on information, education and communication, and must be led

by realities including, but not limited to cultural values of a diverse background of people.

Goal: with this background, the study aimed at, investigating the conceptions in Malian culture about epilepsy, assessing the ways in which people with epilepsy are perceived through the prism of Malian beliefs, and finally, based on these findings, articulate the policies most appropriate, with an ultimate goal of ensuring that people with epilepsy can flourish in their life without any taboo.

Method: A review of the historical and socio-anthropological literature, correlated with interviews of resource persons about the local culture, was conducted and data were analyzed.

Results: Tonic-clonic seizures (70%), atonic seizures (30%) were the only seizures considered as epilepsy. Beliefs about the etiology and mechanisms were misconceived (100%) with a strong attribution of epilepsy etiology to the supernatural (45%). Treatments were ineffective and culturally bound. Epileptic patients were found to be stigmatized but not excluded and were living in their community.

Conclusion: In the Malian cultural context, the disease was in the "shade" and the patient were excluded from some community activities like work with fire for example, but were found to be living in full light with the rest of the society.

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Epilepsy 3

An epidemic of seizures and psychosis in a Sudanese village- a rare experience

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In January 2010 a wave of pathological laughter, crying, seizures and bizarre behavior affected about 122 people in a remote village in the far North West State of Kordofan in Sudan. Our team underwent a detailed investigation of the clinical presentations and possible underlying causes and provided medical treatment as well.

Children constituted 52% and were more severely affected than adults. The main presentations were visual hallucinations, uncontrolled laughter, twisting movements, delirium, and convulsions. No vascular manifestations were detected. Males were affected more than females (60%).

In a few of the severely affected patients a lumbar puncture was performed (7/122).

The patients were treated symptomatically with benzodiazepines. Carbamazepine was used in those presenting with recurrent seizures. Routine urine, blood and CSF basic parameters were all within normal

limits for routines, but the toxicology screen of urine missed the critical period for detection of the suspected toxic substances. Samples from the water sources were clear, but the wheat consumed by the villagers grew the fungus *Claviceps purpurea* in abundance. Further tests on the fungi revealed their production of very high level of LSD- like ergot alkaloids.

No long term neurological sequelae noticed on follow up.

The wheat came from stores in Darfur which is near the affected village.

The epidemic was contained and a public education campaign was launched to avoid recurrence of the event.

This paper includes videos and a literature review.

This study draws attention to the importance of vigilance about neurotoxins as causes of bizarre presentations.

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Epilepsy 3

Musicogenic epilepsy: cases series from Sudan

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Stimulus triggered epilepsy is well known although rare. Triggers include several sensory stimuli including light, patterns, tactile but rarely music. The trigger may involve crude or fine tunes

Reporting Three interesting cases as follows:

The First: was a 40 year old shop keeper who is known to have well controlled temporal lobe epilepsy. He suddenly started to behave out of character and had no recollection of what he did, till he was shown what happened to him on a video recording. **The Second:** a 53 year fit business man without any past medical history of note, suddenly fell from his chair to the ground and went into a tonic-clonic fit for about 30 seconds, after which he was confused for 5 minutes. He was in denial till shown a video recording of the event.

Later on a brain MRI, an ECG, and EEG were absolutely normal. He will be observed as that was the first time he ever a fit.

The Third: was a retired school teacher who developed a seizure in a public bus where some popular music was played. He didn't link it till he heard the same piece of music again at his home and developed a seizure. He was later put on EEG monitoring with safety precautions and the same piece of music was played. He developed marked EEG changes in the left temporal lobe which soon became secondarily generalized and he went in a fit.

Conclusion: A brief review of musicogenic epilepsy will be presented as well as the videos of these events. This series may be interesting, educational and a stimulus for further research into the epidemiology and mechanisms of music induced seizures.

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