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Economic evaluation of childhood epilepsy in a resource-challenged setting: A preliminary survey

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ABSTRACT

Background: Considerable disease variability exists between patients with epilepsy, and the societal costs for epilepsy care are overall high, because of high frequency in the general population especially in children from developing countries.

Materials and methods: A cross-sectional study where children with established diagnosis of epilepsy were interviewed using a semi-structured questionnaire. Prevalence-based costs were stratified by patients' sociodemographic characteristics and socioeconomic scores (SES). The 'bottom-up' and 'human capital' approaches were used to generate estimates on the direct and indirect (productivity losses) costs of epilepsy, respectively. All estimates of the financial burden of epilepsy were analyzed from the 'societal perspective' using IBM SPSS statistics software, version 20.0.

Results: The study had 103 enrollees with most in the age group of 0–5 years (45.6%). Majority (61.3%) belong to the low socioeconomic class (Ogunlesi SES class IV and V) and reside (80.6%) in an urban setting. The total direct and indirect costs per month were N2,149,965.00 (\$8497.88) and N363,187.80 (\$1435.52), respectively. The cost of care per patient per annum was N292,794.50 (\$1157.29), and the total cost for all the patients per year was N30,157,833.60 (\$119,200.92). Investigative procedures are the principal cost drivers (N15,861.17 or \$18.15) comprising approximately 58.7% of the total direct costs per patient.

Conclusions: Cost of investigations contributed immensely to the total direct cost of care in our study. With the present economic situation in the country, out-of-pocket payments may contribute significantly to catastrophic expenditures and worsening of secondary treatment gap in children with epilepsy.

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1. Introduction

Epilepsy is defined as an enduring predisposition of the brain to seizures [1]. It is one of the most common chronic neurological disorder found in all age groups and whose impact varies considerably among patients and their families, because of disease heterogeneity in terms of type, etiology, age at onset, responsiveness to pharmacological treatment, prognosis, and comorbidity. It has a bimodal distribution in terms of incidence, having the highest risk during both infancy and in old age [2].

Despite improvement in the public understanding of epilepsy, there is still reluctance by pediatricians to make its diagnosis even after repeated seizures, because of the adverse social consequences of stigmatization [3]. The euphemism 'seizure disorder' is frequently employed by them to avoid the term 'epilepsy' which is the tendency to have repeated seizures (at least two) as a consequence of a brain disorder that is not provoked by an acute systemic or brain insult [4]. It may also refer to a clinical situation characterized by recurrent seizures provoked by an identifiable stimulus, for example, febrile convulsions, which stresses a problem of brain function, and the patient has the potential for more seizures. It, however, excludes acute symptomatic seizures due to exogenous factors, such as drugs withdrawal and metabolic disorders like hypoglycemia [5].

Antiepileptic drugs are indicated usually after two unprovoked seizures or a single unprovoked seizure if there is an increased risk of a second unprovoked seizure, which include an abnormal neurological examination, abnormal EEG (epileptiform discharges), or evidence of a structural CNS abnormality presumed to be the underlying cause of the seizure [6].

Achieving optimal seizure control with drugs is the mainstay of treatment in most patients. However, about one-third may have seizures that would fail to improve with the medical treatment in addition to the possibility of having adverse drug side effects which may necessitate exploring other more costly treatment options like ketogenic diet, surgery (resective and functional), neurostimulation (devices), hormonal manipulation therapies, and behavioral modification techniques [7–9].

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The financial burden of epilepsy care has been shown to be the highest in the first year, which reduces thereafter [10]. Because of changes in patient's medical, social, and occupational conditions, especially in those who will be managed over a long period of time, treatment becomes a challenge in view of its dynamic nature [11]. Economic concerns are important in health system design, provider payment, and decisions on research funding [12]. They provided the needed insight into cost estimates, potential opportunities for cost-savings, and lay the groundwork for research to determine how to treat epilepsy more effectively without incurring catastrophic medical expenditures.

2. Material and methods

2.1. Study site and design

The study was a cross-sectional survey, conducted in the Paediatric Neurology Clinic of Aminu Kano Teaching Hospital (AKTH), a tertiary health facility located within Kano metropolis in Kano State Northwestern province of Nigeria, from August 1, 2016 to March 31, 2017. We enrolled one hundred and five new clinic attendees aged 6 months to 14 years who have satisfied the inclusion criteria with established diagnosis of epilepsy during the study period, using systematic random sampling. The inclusion criteria included patients who have presented with at least two or more unprovoked seizures, a single unprovoked seizure if there is an increased risk of a second unprovoked seizure required for the diagnosis of epilepsy and have utilized a form of health facility in the last 2 months before presentation, and have a written informed consent from their parents/caregivers or have assented in children old enough to give it. Additionally, patients whose diagnosis of epilepsy could not be determined clinically or who have only a single provoked seizure, who have refused to give consent or assent, who have not utilized any form of health service in the past two months, and who are on any form of health insurance were excluded from the study. To reduce recall bias, cost of illness for epilepsy was estimated for the last two months, and the average expenditure was calculated and used in the analyses.

To generate the direct and indirect costs (productivity losses), estimating 'bottom-up approach' and 'human capital approach' was used respectively [13]. Cost of illness was analyzed from the 'societal perspectives', i.e., captured cost estimates of the types of health care, social services, and family resources used on patients without regard to individuals or entities that incurred them [14]. Direct costs of illness included expenditures incurred for medical goods and services, i.e., medications, consultation fees, investigations, and other diagnostic procedures. They are further classified into direct medical and direct nonmedical costs depending on whether or not the resources were expended directly in the production of a service or treatment. The direct nonmedical costs also included items like transportation to clinics, their feeding, lodging, telecommunication bills, home modifications, and other social services.

Economists consider health to be a human capital investment and its value measured in terms of its contribution to production activity and national income [15].Therefore, indirect cost estimates were based on the human capital approach, which used the data from the labor markets (i.e., lost school or workdays multiplied by the wage rate). Indirect costs or productivity losses are the labor earnings foregone because of adverse health outcome, i.e., the value of the time spent when unable to work as productively because of an illness or drug side effects. The decreased productivity can result from patient's illness, death, drug side effects, time spent receiving a treatment, and school or work absenteeism. It also includes lost earnings while traveling to the healthcare facilities or productivity losses associated with a caregiver's time. The official Naira exchange rate to one US dollar (USD) averaged N253.00 over the 8-month study period.

2.2. Socioeconomic status scoring

The study also used the socioeconomic scoring of educational qualification and occupation by Ogunlesi and colleagues into classes I to V [16]. Scores were awarded for the highest level of education and occupation of each parent, and the mean of these four scores to the nearest whole number was the SES assigned to each child:

- Class 1: High-level skilled worker/Professional/Businessman/Manager/ Large-scale trader/Contractor
- Class 2: Senior government employee
- Class 3: Junior government employee/Middle-scale trader/High-scale farmer/Religious or community leader & clergy/Retiree/Teacher/ Technician
- Class 4: Artisan/Security agent/Sentry
- Class 5: Unemployed/Student/Apprentice/Subsistence farmer/Driver/ Motorcyclist/Laborer/Messenger/Low-level skilled worker.

Classes I and II were further assigned to the 'high social class', class III to the 'middle social class', and classes IV and V to the 'lower social class'.

2.3. Ethical approval

The hospital research Ethics Review Committee approved the study. All patients or their surrogates completed a written informed consent prior to the interview, and the provisions of the Helsinki declaration respected throughout the period of study.

2.4. Data analyses

We performed statistical analyses with Microsoft excel and IBM SPSS statistics software, version 20.0 (SPSS Inc. IBM, Armonk, NY). Sociodemographic characteristics were summarized as frequencies and percentages. Costs were summarized using means with their minimum and maximum values. Means between and within groups were compared using *t*-test for equality of means using Levene's test of equality of variance when equal variance was assume, and analysis of variance (ANOVA) for comparison of 3 or more group means. Statistical significance was assumed when p < 0.05 throughout the analyses.

3. Results

During the study period, 103 patients (62 males and 41 females) with diagnosis of epilepsy completed the study, with a response rate of 98.1%. Most of the patients (51.4%) belong to the lower socioeconomic class (Ogunlesi SES classes IV and V) and most of them in the age group 0–5 years (45.6%). Majority of the participants (80.6%) reside in an urban setting and about half (46.6%) live in a bungalow house, depicting the likelihood of staying in medium to low density areas. Ninety-three (90.3%) participants had the generalized form of epilepsy; 79 (77%) had EEG done before presenting to the specialty clinic; 21.1% had a positive family history; and 47.6% believed that the disease is destiny from God. Most of the patients (89.3%) were supported financially by their fathers, most have not had their drugs switched (71.8%), and less than half (41.7%) of them perceived their state of health as satisfactory. There was also significant reduction (90.1%) in the total frequency of seizure per month after commencement of antiepileptic medications (Table 1).

The total annual cost was $\aleph 30,157,833.60$ (\$119,200.56) with a mean yearly cost per patient of $\aleph 292,794.50$ (\$1157.29). The total cost of epilepsy care per month was $\aleph 2,513,152.80$ (\$24,399.54) with a mean cost per patient per month of $\aleph 24,399.54$ (\$96.44). Further breakdown of the monthly healthcare expenses from the study showed that the total direct cost of care per month was $\aleph 2,149,965.00$ (\$8497.88) and the mean cost per patient per month was $\aleph 20,873.45$ (\$82.50), which comprise \$5.6% of the total costs incurred every

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