Estimation of the direct cost of epilepsy among Sudanese epileptic patients

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Abstract

Background

Epilepsy is a common disease, and its economic consequences are manifested in frequent hospital visits, examinations and treatments.

Objective

To estimate the direct costs of epilepsy among Sudanese epileptic patients. **Design and**

methods

The study was conducted on some clinical cases of epilepsy patients in Sudan. Data on clinical characteristics, utilization of medical services, and costs were collected from 380\ 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 overall mean annual cost for epilepsy per patient in our clinic was approximately (2,724 SDG, 474 USD).

Conclusion

The economic burden of epilepsy patients is relatively high, and payers in Sudan have many characteristics and significant differences from other countries.

Introduction

Seizures are short-term appearances of signs and/or symptoms caused by excessive or synchronized abnormal activities of brain neurons. The definition of epilepsy requires at least one seizure.¹ The prevalence rate of epilepsy in Sudan was estimated to be about 0.9 per 1000.^{2,3} The main investigations in patient with suspected epilepsy used are: Electroencephalography (EEG) and neuroimaging (EEG, MRI,

SPECT, and PET).⁴ Most people with onset of seizures can achieve seizure control with existing medications.⁵

Costs to society are defined as (a) the direct cost of medical resources devoted to diagnosing and treating persons with the disorder, and (b) the indirect cost from foregone earnings and reductions in household activities because of epilepsy-related morbidity and mortality.⁶ In determining the cost of illness, three elements direct costs, indirect costs, and psychological or intangible costs can be considered.^{7,8}

Direct costs are the easiest to quantify because they are related to the costs of inpatient or outpatient treatment, drug addiction treatment, and various tests and research.⁹ Indirect costs include underemployment and unemployment and the associated loss of earnings and excess mortality.⁹ A Chinese study showed that the overall mean annual cost for epilepsy per patient was approximately Chinese Yuan, RMB5,253 (USD 773).¹⁰ The estimated total cost of the disease in Europe was €15.5 billion in 2004, indirect cost being the single most dominant cost category (€8.6 billion). Direct health care costs were €2.8 billion, outpatient care comprising the largest part (€1.3 billion). Direct nonmedical cost was €4.2 billion.¹¹ Another Study in United States showed that the annual cost for the estimated 2.3 million prevalent cases of epilepsy is estimated at \$12.5 billion. Indirect costs account for 85% of the total and, with direct costs, are concentrated in people with intractable epilepsy.¹² A study in Nigeria showed that the total direct medical cost/month was N461,820.00 ((\$3,947.2), the biggest contributor was drug cost N375,350.00(\$3208.10) or 81.3% of the cost burden. The total estimated direct cost/ year was N5, 541,840.00 (\$47,366.15) with a mean cost/ year of N46, 182.00(\$394.70); 25% of those who worked spent more than 50% of their monthly income of seeking care for epilepsy.¹³ Another study in Indian calculated that the total cost per epilepsy case was US\$ 344 per year (or 88% of the average income per capita).¹⁴

Problem Statement:

Epilepsy is a common chronic neurological disorder that affects about 50 million people around the world, 10% of whom are in the Middle East.^{14,15} Developing countries carry 90% of the financial burden of epilepsy, as 85% of the world's 50 million people with epilepsy live in developing countries.¹⁶ Epilepsy is an economic burden on individuals and society because of increased health care cost as well as losses in employment, wages, and household work. Epilepsy has significant economic implications in terms of health-care needs, premature death and lost work productivity.¹⁴ According to the World Bank, 30% of the population of the Middle East and North Africa still lives on less than US\$ 2 per day.¹⁷ This low income together with the chronicity of epilepsy makes a huge financial burden on patients with epilepsy and their families.

Justification:

Patients with any age can develop epilepsy. Cost of illness (COI) studies have become increasingly important in both the substance and the rhetoric of developing interventions in battling illness and injury.¹⁸ The burden on the families of epilepsy patients is heavy especially in the developing countries, since these countries rarely have a well-developed insurance system or social security program that covers epilepsy-related costs. The burden may be even more intractable than the epilepsy itself.¹⁹ The economic burden caused by epilepsy has not been adequately examined in the developing countries. Even the studies that do exist neglect important economic concepts, leading to a significant underestimation of the burden.¹⁹ Cost of epilepsy in African region didn't receive enough attention in the literature. In fact no study on the costs of epilepsy had been carried out in Sudan. We would like to achieve accurate Information about costs of epilepsy in Sudan. Better cost data will make economic assessment a tool for decision-making and help increase investment and resource allocation for epilepsy treatment.

Objectives:

General Objectives:

- To estimate the Direct Cost of Epilepsy among patients attending private, governmental and charity clinics in Khartoum, Sudan 2014.

Specific Objectives:

- To estimate the Direct Cost of Epilepsy among patients attending private clinic in Khartoum, Sudan 2014.
- To estimate the Direct Cost of Epilepsy among patients attending governmental clinic in Khartoum, Sudan 2014.
- To estimate the Direct Cost of Epilepsy among patients attending charity clinic in Khartoum, Sudan 2014

Methodology

- **Study design:** Cross sectional study.
- Analyses of cost of illness can be either “prevalence-based” (examining the costs incurred on a cross-sectional basis) or “incidence-based” (measuring changes in the cost profile over the course of the disease in a longitudinal analysis); the latter is slightly more difficult logistically).²⁰
- **Study area:** Subjects with epileptic seizures were randomly recruited from three sectors; charity clinic, governmental hospital outpatient clinic and a private clinic :
- All the clinics are located in Sudan, Khartoum state.

- Sudan is now the third largest country in Africa and also the third largest country in the Arab world (estimated population is little over 30 million people)
- Khartoum is the second largest city in Sudan and Khartoum State, together With Omdurman and Khartoum Bahri; it forms the cultural and industrial heart of the nation.
- The clinics are:
 1. Daoud's charity Neurological Referral Clinic is a charity clinic, in which neurologists, psychiatrists, physicians, and medical registrars tend to see patients every week on Friday, which is the weekend, and many patients attend this clinic; they are from Khartoum state, but also many of them from different states of Sudan. Also the clinic has and an active epilepsy program.
 2. Fateh Elrahman Elbasheeroutpatient Clinic.
 3. Private Neurological Clinic, in which a qualified neurologist tend to see patients every day except for Friday.
- **Study population:** Patients who attend Daoud's charity Neurological Referral Clinic.

Inclusion Criteria: includes

- 1) All Ages;
- 2) Nationality: Sudanese;
- 3) Patient with epilepsy.

- **Exclusion Criteria:** Patients that attend these Clinics who are non-epileptic.

- **Sampling:**
- **Sample technique:** Random sampling.
- Sample size is calculated using the formula = $Z^2 \cdot p(1-p) / d^2$
- A prevalence rate of epilepsy of 0.9 per 1000 was estimated.^{2,3}
- According to that; prevalence= 0.09%.
- The sample size will be $3.84 \cdot 0.09(1-0.09) / 0.0016 = 197 (+10\% \text{ non-responders}) = 217$

- **Data collection:** Data collection and Tools:

- Detailed informations about the following were obtained through Pre-tested questionnaires from patients with epilepsy :

1. Personal data:

- Age:
- Gender:
- Educational Level
- Marital Status
- Annual household income (RMB) Income
- Residence
- Present Employment
- Health insurance

2. Variables Related to Epilepsy:

- Age at seizure onset /duration of epilepsy
- Frequency of seizures per month
- Seizure type.
- Etiology: Idiopathic, organic.
- AED type
 - Valproate
 - Carbamazepine
 - Lamotrigine
 - Phenobarbital
 - Phenytoin
 - Topiramate
- Dose of the AED drug

• **Variables Related to the Direct Cost of Epilepsy:**

- **Neurologic care:**
- Number of outpatient contacts per year.

- Number of A&E contacts per year.
 - Number of hospital visits per year was.
 - Duration of hospital stay.
 - The indication for hospitalization.
 - Number doctors/professionals consulted for epilepsy
 - What was the delay (in months) in diagnosis of epilepsy.
-
- **Investigations:**
 - Brain MRI scan head Angiography, EEG, VEEG, Blood levels of AEDs, Other blood/urine tests for epilepsy or its treatment.
-
- **Drugs used**
 - (Where do you buy your drugs?)
 - Cost of the drug
-
- What is your expenditure (Rs/year) on the following?
 - Consultation fee
 - Investigations
 - Cost of drugs
 - Hospitalization charges
 - Travel for various purposes related to epilepsy
-
- reimbursement of your medical expenditure
-
- Transportation (distance from Hospital)
-
- Other consultations

- **Data analysis:** All collected data was entered into the computer using the statistical package program for social science (SPSS) to analyze the data via simple descriptive statistics. (Analyzer is specialized personnel in SPSS).
- **Ethical concern:** Consent was obtained verbally from All patients, and from the local ethical committee
- Limitations of the study:
 - The Indirect cost is not estimated
 - Sample size is small.

Results

Epilepsy was defined as the occurrence of at least two unprovoked seizures separated by 24 hour more. A total of 380 PWE were recruited into the study, (52%) were male and (48%) being female. The median age was 20 years (IQR: 15–29), and the median duration of epilepsy was 8 years (IQR: 3–14). 60% were diagnosed with focal epilepsy, 30% with generalized seizures and 10% with unclassified seizures. Direct costs such as consultation fee, paraclinical exams, hospitalization fee and price of AEDs were obtained from the PWE and their families. Some PWE consulted traditional healers on an irregular basis; for each PWE who did, we asked what it costs them every year (in cash and in kind), under normal circumstances, to visit the traditional healer because of epilepsy. The average traditional medicine expenditure for a normal year was divided by 12 to obtain monthly costs. 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). Non medical 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.

Discussion

To the best of our knowledge, this is the first study investigating the economic cost of epilepsy in Sudan. Our study evaluated the direct costs associated with epilepsy. Epilepsy has important soci-economic costs to a population. In order to determine healthcare priorities, it is important to estimate these costs. This is especially so with the introduction of the newer antiepileptic drugs and the resurgence of new surgical treatment options, which have the potential to considerably increase the cost of treating epilepsy. The costs of epilepsy may vary with the severity of disease, time since diagnosis, efficacy of antiepileptic drugs treatment, and health insurance coverage. We obtained data from 380 patients, we found a predominance of focal seizures. Almost 75 % of our patients were well control and they were seizure-free, this similar to what was reported worldwide.²⁰ Almost 40% of our patients were receiving monotherapy and 60% polytherapy. In case of treatment of epilepsy monotherapy is superior to

polytherapy, to reduce the chance of development of side effects of the drugs and to reduce the risk of interaction with other drugs.^{21–22}

Our study showed that direct medical care costs was (2,395 Sudanese Pounds “SDG”, equivalent to 417 American Dollars “USD”) per year per patient, of which antiepileptic drugs was the major component. This findings concurs with data from other developing countries where AEDs constitute a major expenditure in epilepsy management.^{23–24} Direct cost includes the cost of resources consumed when health care, social services, and patient or family member services are used to prevent, diagnose, treat, or rehabilitate persons with epilepsy. It is so difficult to compare our results with those studies conducted in other countries, since supply, availability, price, and consumption of health care differ widely. Direct cost of epilepsy in our study (417 American Dollars per patient per year) was higher than that in India (93 USD per patient) and in China (372 USD per patient) and Nigeria (163 USD per patient) this can be explained by the fact that antiepileptic drugs followed by the frequent outpatient clinic visits, both of them account for a majority of the overall out-of-pocket epilepsy-related expenditures in addition to non medical 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.^{25–26–27} Direct costs of epilepsy in our study was still lower than that from South Africa, USA and Europe.^{28–29–30} We found a positive correlation of seizure frequency with increased medication, hospitalization, and direct costs. Direct cost increased dramatically with the increasing number of AEDs especially new AEDs where the price is generally higher than that of traditional AEDs. The drugs combination rate is higher in this study, which can be also attribute to increase direct medical costs. Seizure severity is an index integrating seizure frequency, seizure type and side effects of treatment. Patients with more serious and complex seizures had to accept more frequent doctor visits, and drug adjustment or dose increasing, which all increase their economic burden.

Declarations

Consent for publication

Not applicable.

Availability of data and materials

The materials datasets used and/or analyzed during this study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

All authors participated in planning the study, data collection, results and discussion sections.

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