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Original Research

The Cost of Care of Childhood Epilepsy in Southern Nigeria: Experience from a Tertiary Hospital in Port Harcourt.

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Abstract

Background: The financial burden of caring for a child living with epilepsy and its effect on the family's financial status and quality of life are understudied. This study aimed to determine the cost of care for children with Epilepsy in Port Harcourt.

Methodology: A purposive sampling method was employed. Participants were 37 children with epilepsy and their parents/caregivers. An interviewer-administered semi-structured questionnaire was used to obtain information on the socio-demographic, estimates of the financial costs of epilepsy care, the effect of caregiving on caregiver productivity and income.

Results: The average monthly income per family is \$332.80 ± \$116.82. The majority, 32(86.5%), financed epilepsy care via out-of-pocket payments. The average cost of epilepsy care is \$66 per month (\$792 per annum), accounting for 20% of the average family income. There was a negative correlation between hours spent on caregiving and household income (rho =-0.288; *p*-value = 0.084). Over two-thirds (67.6%) of the caregivers consider their overall well-being negatively affected by having a child with epilepsy.

Conclusion: The cost of care of childhood epilepsy in southern Nigeria is high and takes up a significant proportion of household income. Concerted efforts need to be made to encourage subscription to health insurance to alleviate the financial burdens on families.

Keywords: Childhood Epilepsy; Cost of health care; Southern Nigeria; Port Harcourt

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Introduction

Epilepsy is a leading cause of morbidity among children worldwide, especially in low-and-middle income countries.[1] At present, nearly 1 in 50 children in Africa are living with epilepsy[1]. This seems to be related to several factors, including the sequelae of perinatal asphyxia and poorly managed neuroinfectious diseases, amidst other non-modifiable genetic syndromes, developmental encephalopathies, and metabolic conditions.[2] Beyond empiric pharmacotherapy, the management of epilepsy is tending towards genetic testing and the potential for precision medicines and epilepsy surgeries.[3,4] These services are expensive and largely unavailable in the developing countries, which are still fraught with the challenges of manpower, lack of essential drugs, including anti-seizure medications, and, more importantly, severe financial constraints. With most families subscribing to out-of-pocket payments, it is suspected that a significant proportion of families of children with chronic illnesses, including epilepsy, could be spending beyond 10% - 25% of their income on health care.[5–8] The cost of caring for children with epilepsy has been shown to carry greater economic costs than those generated by more prevalent, chronic illnesses, even in developed countries.[9] Contributory factors to this trend include the age of the children with epilepsy, a higher number of hospital admissions and investigations, as well as the complexity of therapeutic trials, seizure frequency, the moment at which the illness cost was estimated and the local health care system. There is a paucity of data on the cost of direct care in terms of childhood epilepsy in Nigeria. Furthermore, clinicians and caregivers face challenges in different aspects of the care of these children, ranging from seeking care and therapeutics on the part of caregivers to utilization of contemporary investigations and treatment options on the part of the clinician. These are mostly related to financial difficulties.[9]Mass epilepsy screening, scaling up treatment coverage, and designing strict treatment follow-up and monitoring mechanisms have all been recommended as measures to bridge the treatment gap between the high burden of epilepsy and the suboptimal treatment outcomes in Africa.[1] These measures continually require significant financial involvement in terms of clinic consultations and access to skilled clinicians, including paediatric neurologists, availability and cost of electroencephalography and neuroimaging, procurement of anti-seizure medications and planning to incorporate epilepsy surgeries as a valuable option of treatment.

Stronger efforts to ensure that individuals with epilepsy access necessary healthcare without facing financial hardship, as targeted by Sustainable Development Goals (SDG) 3.8, need to be intensified, especially in high-burdened areas like Sub-Saharan Africa, where the access to affordable care is not readily available, limited insurance coverage and a very high level of out-of-pocket payment. Which are all risk factors for poor adherence to prescribed treatment. [6,7,8] However, data on the actual cost of managing childhood epilepsy in this region remain scarce.

Hence, this study was aimed at describing the cost of care of children with Epilepsy in Port Harcourt, Nigeria, and to make a case for implementation of policies targeted at mitigating the ongoing catastrophic and unsustainable out-of-pocket payment,[6] encouraging subscription to health insurance and advocating for subsidizing health care costs in a bid to improve basic healthcare among sufferers of childhood Epilepsy.

Materials and methods:

Study design: This was a descriptive cross-sectional study

Study location: The study was done at Paediatric Neurology Clinic, University of Port Harcourt Teaching Hospital, Nigeria.

Study duration: The study was conducted between July 2024 and September 2024.

Study participants: Children aged 6 months to 18 years who attended the Paediatric neurology clinic within the study period, with a diagnosis of epilepsy, and their parents/caregivers.

Inclusion criteria:

Children with a diagnosis of epilepsy, with the diagnosis made by a Paediatrician or a Paediatric neurologist based on clinical history, with or without an electroencephalograph. (EEG). The patient should have been on anti-seizure medication for at least 6 months. Children who did not have any other neurological or other comorbidities. Children who gave assent for the study and whose parents gave written consent for the study.

Sampling method: A purposive sampling approach was used. Participants who met the inclusion criteria were recruited consecutively as they attended the Paediatric Neurology Clinic at UPTH. During the study period, 37 participants who met the criteria took part in the study.

Study tool: This study used an interviewer-administered semi-structured questionnaire designed by the researchers. After obtaining informed consent from parents/caregivers and assent from the patients, it was administered to the parents/caregivers of the patients at the paediatric neurology clinic.

The questionnaire consisted of four (IV) sections, including
socio-demographic variables; Estimates of the financial costs of Epilepsy care, including average monthly income; Effect of caregiving on caregiver productivity and income and the impact of childhood epilepsy on some aspects of family life.

A verbal recall of financial earnings and estimated expenses within the last month before the interview was obtained from caregivers in Naira and subsequently converted to United States Dollars for ease of reference. We converted all Naira rates to dollars at the rate of 1 dollar to 1550 Naira using standard rates published by the Central Bank of Nigeria.[10].

Sections III and IV of the survey included some 5-point Likert questions scored from 1 to 5 and dichotomous questions (Yes/No), where participants rated their agreement with statements related to their perceived burden of childhood epilepsy on the family or economic productivity.

To determine the impact on family relationship: The questions on family relationship were graded on a 5-point Likert scale, which ranged from 1-5, translated into 1=none or no impact, 2 =mild impact, 3=moderate impact, 4=severe impact and 5=overwhelming impact.

Also, to determine the impact on work performance, a 5-point Likert question with scores ranging from 1-5 was used, which translates to 1=no impact, 2 =some impact, 3=Neutral, 4= major impact and 5= significant impact.

Statistical analysis was conducted using IBM SPSS version 26. The analysis involved descriptive statistics such as frequencies and percentages. Comparisons using linear regression analysis and Spearman's correlation were performed to identify associations between average monthly income and hours spent caring for children with epilepsy. A p-value of less than or equal to 0.05 ($p \leq 0.05$) was considered statistically significant. Results were presented as tables and charts.

Ethical approval was obtained from the University of Port Harcourt Teaching Hospital. Research and Ethics Committee with reference number UPTH/ADM/90/S.11/VOL.XI/1955. Written informed consent was confirmed with the individual participants at the beginning of the survey.

Results

Table 1. Sociodemographic characteristics of study participants

Variables	Frequency	Percentage
Age groups		
6 months to 5 years	14	37.8
6 years-12 years	15	40.5
13 years -18 years	8	21.6
Sex		
Female	18	48.6
Male	19	51.4
Marital status of the guardian		
Married	24	64.9
Not married	13	35.1
Residence		
Rural	11	29.7
Urban	26	70.3
Family size		
Three	17	45.9
Four	6	16.2
Five	9	24.3
Six	4	10.8
Seven	1	2.7
Monthly income ($)		
< $100	11	29.7
$100 - $500	21	56.8
> $500	5	13.5

Table 1 shows the socioeconomic characteristics of the study respondents. There were 19 (51.4%) males and 18(48.6%) females. The majority of these were school-aged children, 15 (40.5%) and children under 5 years, 14(37.8%). Most of the respondents were Urban dwellers, 26 (70.3%), while only 11(29.7%) were rural dwellers. Twenty-four (64.9%) of the caregivers/parents were married. The monthly income of the respondents ranged from $100 to above $ 500, with an average monthly income of $332.80 ± 116.82. 5 (13.3%) of the parents earned over $500 a month.

Table 2. Summary of Epilepsy related expenses

Variables ($)	Mean ± SD	Min – Max
Average monthly income	332.80 ± 116.82	9.09 – 4242.42
Medication cost (per month)	49.03 ± 17.13	0.00 – 606.06
Investigation cost (per month)	10.83 ± 6.88	0.00 – 252.53
Doctors' visits/consultation cost (per month)	2.45 ± 0.84	0.00 – 21.72
Travel cost for epilepsy care (per month)	1.86 ± 0.64	3.27 – 15.15
Other epilepsy care-related expenses (per month)	1.95 ± 0.83	0.00 – 20.20
Total cost of managing epilepsy(per month)	66.13 ± 23.82	0.00 – 862.63
Total cost of managing epilepsy per annum	793.56 ± 285.79	0.00 - 10351.52
Proportion of monthly income spent on medications.	15% of monthly income	
Proportion of monthly income spent on the total cost of managing epilepsy.	20% of monthly income	

Table 2: Shows the summary of Epilepsy related expenses. The average monthly income of study participants was $332.8. The average expenditure on medication was $49.03. Investigations amounted to $120 per annum. The total expenditure on Epilepsy is $66.13 per month. Over 15% of family income is spent on medications per month, while approximately 20% of total monthly income goes into the overall care of Epilepsy per month.

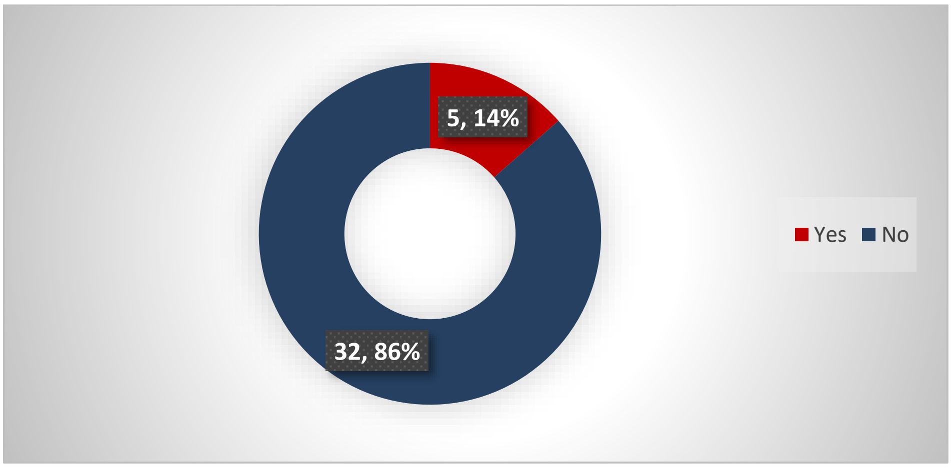

Figure1. Proportion of participants with complete health insurance coverage.

Figure 1, depicts the proportion of study participants who had full subscription to a health insurance scheme; Only 5(14%) of respondents were on a health insurance scheme, while the majority, 32(86%), were not subscribed to any health insurance scheme.

Table 3. Effect of caregiving on caregiver productivity

Variables	Frequency	Percentage
Caregiver employment status		
Employed	27	73.0
Unemployed	10	27.0
Hours spent caring for the child per week		
<50hrs/wk	17	45.9
>50 hr/wk	20	54.0.
Impact on work performance		
1- no impact	9	24.3
2- Some impact	4	10.8
3- Neutral	10	27.0
4- Major impact	2	5.4
5- Significant impact	12	32.4

Table 3: Shows the Impact of epilepsy caregiving on productivity and income

The majority of respondents admitted to losing man-hours to caregiving. Over 50 hours of work hours per week are lost to childcare among 20(54%) of respondents, and 32% of these consider it to have a significant impact on their earnings.

Table 4. Burden of childhood epilepsy on some aspects of the family's quality of life

Variables	Frequency (n)	Percentage (100%)
Impact on family relationships		
1-None	16	43.2
2-Mild	1	2.7
3-Moderate	4	10.8
4-Severe	4	10.8
5-Overwhelming	12	32.4
Experienced severe financial difficulties		
Yes	29	78.4
No	8	21.6

Use of Loans to Cover Health Care Costs		
Yes	23	62.2
No	14	37.8
Overall well-being affected		
Yes	25	67.6
No	12	32.4

Table 4. Shows the effect of epilepsy on the family's quality of life. The majority of respondents admitted to experiencing financial difficulties, 29 (78.4%). Twenty-three (62.2%) required the option loans to cover expenses. Twenty-five (67.6%) of the caregivers consider their overall well-being as affected by having a child with epilepsy in the family.

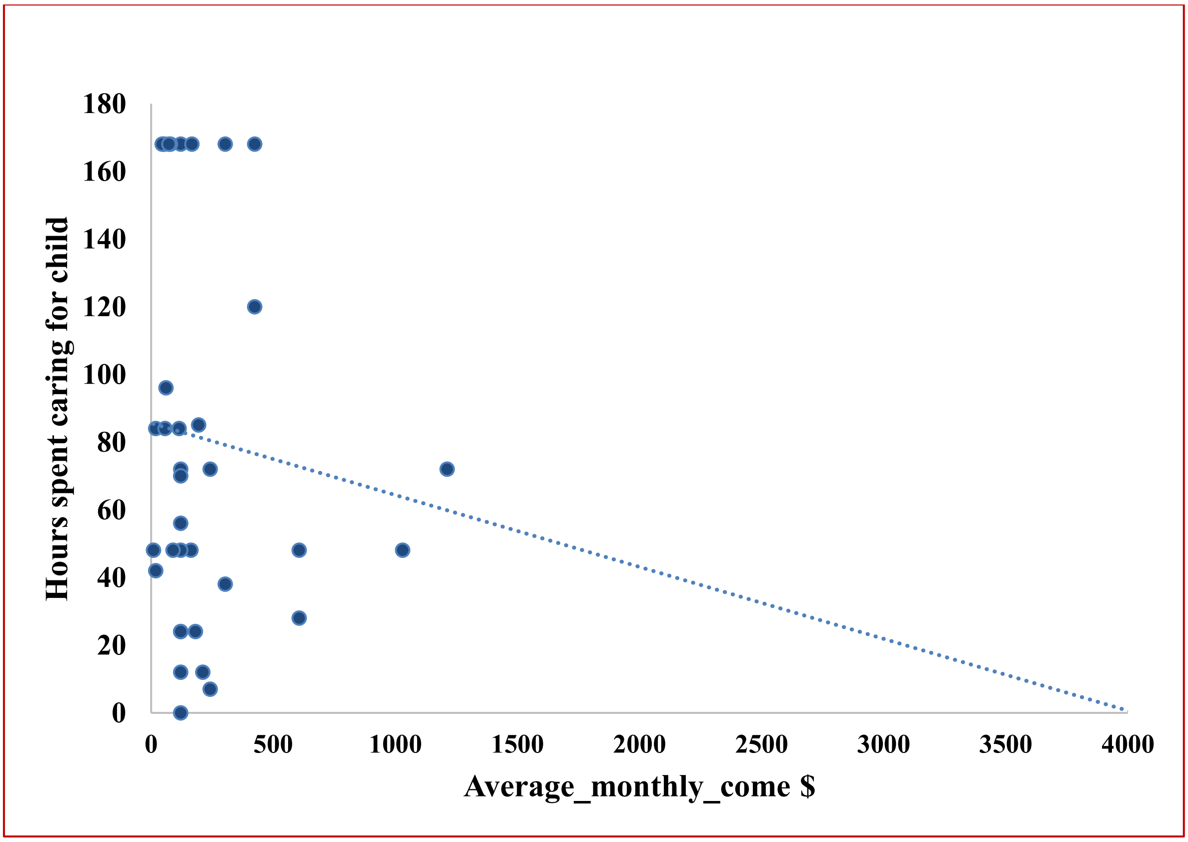

Figure 2: A simple scatter plot showing the association between average monthly income and hours spent caring for children with epilepsy (Spearman's rho =-0.288; p value = 0.084)

Figure 2. Depicts the association between hours spent in caregiving and average monthly income. There was an inverse relationship between the average monthly income and the man-hours spent in caregiving, with a negative correlation between the monthly income and manhours spent on caregiving.

Discussion

This study revealed that the average cost of care for children with Epilepsy every month is $66 per person ($792 per annum), amounting to about 20% of the average family income. About a decade ago in Nigeria, the average cost of epilepsy care per annum, as reported by Lagunju et al, was $717[7]. Like their findings, the expenses on epilepsy care in the present study were over 20% of household income.

This present study found that a high proportion (15%) of family income is spent on the procurement of antiseizure medications; this is lower than previous reports and maybe because this study did not include the cost of inpatient care. [7] The mean expenses on outpatient medications only and the monthly cost of care exceed the new monthly minimum wage in Nigeria, which is $47 (70,000).[11] Recent reports indicate that the average annual cost per person with epilepsy ranged from $204 in low-income countries to $11,432 in high-income countries.[12] An objective comparison between this present study is difficult because of the different methodologies used in these studies and the estimation of direct costs of some modalities of care, such as epilepsy surgeries, that are not utilized in low-income countries.[12] Considering that the estimates reported in this study excluded in patient care and may underestimate the overall cost of Epilepsy care, the findings depict a significant burden on family income on a day-to-day and monthly basis. The goal of the SDG 3.8 to protect individuals and families from financial hardship due to health care cost appears to be suboptimal with these indices and will likely impact on measures geared towards attaining substantial care among children with Epilepsy.[13] The findings from this present study do not suggest an improvement in the economic burden of epilepsy in the region compared to previous reports by Lagunju et al over a decade ago. This brings to the fore the persistent challenges of health care expenditure amidst economic hardship and the out-of-pocket payments in Nigeria.[7,8]

The subscription to health insurance schemes among caregivers in this study was low (14%), which is similar to larger-scale surveys, which showed that only 19% of Nigerians had national health insurance coverage.[5] Although there seems to be an improvement from previous reports,[14] 14% subscription remains suboptimal. The specific reason for low coverage was not explored in this study, however the subsisting factors that influence the low subscription to health insurance schemes in developing countries are likely in this situation including lack of awareness, drop outs due to high premiums and economic inequalities, displeasure from certain aspects of the scheme such as unavailability of certain medications necessitating out of pocket purchases despite enrollment, poor service delivery by providers among others.[14,15]

Most caregivers admitted to losing economic man-hours to caring for children with epilepsy. Over 50 hours per week of man-hours are lost, and at least 32% of respondents consider it to have at least a major impact on their earnings. Culturally, in our environment, the direct caregivers are mothers who may also be forced to give up their chosen careers and education to cater for the needs of children with epilepsy. This can have negative impacts on family income and female education, as their ability to engage in economic and educational activities is limited. Considerable indirect costs of seizures, including time away from work, school, and even loss of employment, have been reported among caregivers of children with epilepsy worldwide.[16,17] We found an inverse relationship between the average monthly income and the man-hours spent in caregiving. This finding, though not statistically significant, was expected and further buttresses the fact that the hours lost to productivity impact on the overall earnings of the family and has the potential to create a vicious cycle which can culminate in poor health outcomes. It is therefore not surprising that most respondents admitted to experiencing financial difficulties 29(78.4%), with 23(62.2%) requiring the option of loans to cover health care expenses.

Over two-thirds of caregivers, 25(67.6%) reported that their overall well-being is affected by having a child with Epilepsy in their care. These findings highlight the social and psychological challenges experienced by caregivers while caring for and living with children with epilepsy. These indirect costs of Epilepsy may be subtle; however, clinicians must take these factors into cognizance while managing children with epilepsy. Similar studies have shown the personal and psychological morbidities present among families of children with neurological conditions[1].Concerted efforts and holistic approaches to cater for these needs should be of priority for the health care provider to achieve good results for the child with Epilepsy.

Conclusively, the cost of care for childhood epilepsy in our setting is high. The high proportion of household income being taken up by medication expenses and the total cost of care has strong propensities for financial hardship and influences a decline in the overall quality of life in the family. At only a 14% subscription rate for the national health insurance scheme, advocacy for subscription to health insurance schemes is pertinent. We also advocate for other measures, including robust government funding and subsidization of medication and health care costs. These can significantly alleviate the financial burden of families of children with epilepsy.

Study limitations: The exclusion of the cost of in-patient care may have underestimated the total cost of care, this makes room for future studies.

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