

Burden of care for children with epilepsy in a developing country

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Introduction

Epilepsy is a common childhood morbidities world-wide and often associated with significant sociocultural, economic and health implications especially in the resource poor developing countries. It is an unpredictable, often chronic and debilitating disorder that impacts not only on the patient but also those who care for them.

Keywords: Epilepsy, Burden, Caregivers

Back ground

Epilepsy is a common childhood morbidities world-wide and often associated with significant sociocultural, economic and health implications especially in resource poor countries. The aim of the study is to evaluate the burden of care that caregivers of children with epilepsy experience.

Method

The study was a cross sectional involving 112 caregivers of children living with epilepsy seen in the Paediatrics Neurology Unit of the University of Teaching Hospital between July 2018 to June 2019. Ethical approval for the study was obtained from the ethics committee of the University of Calabar Teaching Hospital. Questionnaires were administered to consenting parents/caregivers of children with epilepsy. Socio-demographic characteristics of the caregivers including social class and average monthly income were obtained. Given the lack of a disease-specific questionnaire to assess their burden, the Zarit caregiver burden inventory questionnaire was used to determine the burden of care. Data obtained was entered into a Microsoft excel spread sheet and transferred into SPSS version 26 software for analysis.

Results

Fifty four (48.2%) of caregivers experienced high burden (moderate and severe). Caregivers who are 40 years and above are shown to experience higher burden compared to their younger counterparts. Low social class, longer duration on antiepileptic drugs and the presence of comorbidities especially cerebral palsy was found to significantly affect the burden of care ($p < 0.05$). No significant relationship was observed between caregiver's average monthly income and the burden of care.

Conclusion

Caregivers of children with epilepsy in a developing country experience burden mainly from cost of managing epilepsy and comorbidities. Efforts should be made towards prevention of comorbidities and provision of subsidised drugs to reduce the burden of care experienced by caregivers.

Epilepsy is thought to affect more than 100 million individuals and families worldwide, thus constituting a major, universal; public health issue. It is the most commonly encountered neurological condition in Pediatric Neurology clinics in many parts of the developing world. Eighty per cent of these children with epilepsy live in developing countries.

It is well established that epilepsy impacts the quality of life (QOL) of patients/ caregivers. Loss of control and independence, low self-esteem, fear, depression, stigmatization, lifestyle, social and employment restrictions, and financial strains are ways in which this impact occurs.

The psychosocial impact of epilepsy on the child and family's everyday life depends on several factors, including; the severity of the disease, the complexity of the clinical management, the understanding of the disease to the (child, family, and society), the restrictions in the child's and family's activities, the innate ability of the child and family to cope with the disease and the level of social support and extent of resources available to manage epilepsy.

Ioannis Karakis et al established that, the number of AED, the patient's neuropsychological state, the quality of life of the patient, and caregiver education are associated with caregiver burden; and that caregiver burden has a negative impact on caregiver health-related quality of life.

The aim of the study is to evaluate the burden of care that caregivers of children with epilepsy experience.

Method

The study was a cross sectional involving caregivers of children living with epilepsy seen in the Paediatrics Neurology unit of the University of Teaching Hospital between July 2018 to June 2019. A caregiver was defined as any family member or adults responsible for providing every-day care for the patient. Ethical approval for the study was obtained from the ethics committee of the University of Calabar teaching hospital

Questionnaires were administered to care givers and the following information were obtained; age, sex, religion, occupation, educational qualification, marital status average monthly income, average cost of AED/ month and time spent for patient care in hours per week). The social class was obtained using the Oyediji classification which utilizes the educational background and occupation of parents.

Given the lack of disease-specific questionnaire to access their burden, the Zariat caregiver burden inventory was used . of It is the most widely used standardized, validated scale to assess caregiver burden, administered previously in various neurological disorders, including epilepsy.

Data obtained was entered into a Microsoft excel spread sheet and transferred into SPSS version 26 software for analysis.

One hundred and twelve caregivers participated in the study made up of 78 female and 34 males. The mean age of the caregiver is 34 years

Table 1: Age – sex distribution of the respondents’ population.

Age(years)	Sex		Total
	Male	Female	
20years	2	6	8
21 - 40	20	32	52
>40 - 60	10	34	44
>60	2	6	8
Total	34	78	112

The caregivers burden of care using the Zarit inventory burden of care showed that 20(17.9%) of the caregivers had no burden, 38(33.9%) had mild, 22(19.6%) had moderate and 32(28.6%), had severe burden. Caregivers with moderate and severe burden are considered to have a high burden while others have low burden.

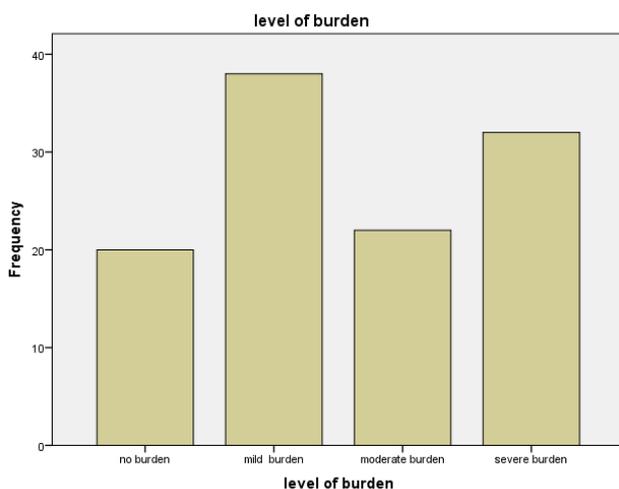


Fig 1: burden of care of respondents using the Zarit caregiver inventory.

A cross tabulation of age of caregiver and the burden of care shows that 20 of the 52 caregivers above 40 years experienced

high burden compared to 12 out of 70 below 40 years who had high burden. There is a significant relationship between the age of caregiver and the burden of care. ($X^2= 27.3, P<0.05$)

The social class of the children shows that majority of the children whose caregivers participated in the study 50(44.6%) are from the low social class this is followed by 34(30.4%) and 28(25%) in the middle and high social class respectively.(table II)

Table II: Relationship between social class and level of burden of care.

Social class	Level of burden				
	No burden	mild	moderate	severe	total
High	2	24	2	0	28
Middle	10	8	8	8	34
Low	8	6	12	24	50
total	20	38	22	32	112

$X^2 = 52.62 P < 0.05$

Of the twenty eight caregivers from the high social class only two had high burden. Thirty six of the 50 caregivers from the low social class experience high (moderate and severe) burden. There is a significant statistical relationship between the social class and the burden of care. ($p<0.05$)

Table III showed that the average monthly income of the caregivers ranges between N20, 000 and N150, 000. Majority of the respondents in this study have an average income of N50, 000 and below. There is no significant difference between the average monthly income and the level of burden ($X^2 = 7.59, P> 0.05$)

Table III: Level of burden and average monthly income.

Level of burden	Average income per month in Naira				Total
	20000-50,000	51000-100000	101,000 – 150000	> 150000	
No burden	12	5	2	2	21
Mild burden	28	6	3	1	38
Moderate burden	13	7	1	1	22
Severe burden	21	4	6	0	32
Total 112	74	22	12	4	

$X^2= 7.59 P < 0.05$

*One Naira = 360 dollars

Table IV shows a cross tabulation between the burden of care and the average cost of procurement of antiepileptic drugs per month. More than a third 38(33.9%) of the caregivers spend between 5000 to 7000 monthly to procure antiepileptic medications. Caregivers who spend more money to procure AED

have a high burden compared to those who spend less. There is a significant relationship between the average costs of antiepileptic drugs per month with the level of burden. ($X^2=72.59 P < 0.05$)

Table 1V: Relationship between level of burden and average cost of antiepileptic drugs per month

Level of burden	Average cost of antiepileptic drugs/ month				Total
	< 2000	2000-4000	5000-7000	>7000	
No burden	6	10	2	2	20
Mild burden	0	16	6	2	24
Moderate burden	0	2	6	16	24
Severe burden	4	2	24	14	44
Total	10	30	38	34	112

$X^2= 72.59 P <0.0$

Table V shows the majority of the respondents 76(67.9%) are caring for children who have been on antiepileptic drugs for period of between one to three years. Of the caregivers whose children have been on AED for four to six years 8/15 (53%) experience high burden compared to 6/21(28.6%) caregivers in the less than one year on antiepileptic drug category who experience severe burden. There is a significant relationship between level of burden experienced by caregivers and the duration of the child on AED. ($X^2= 36.85 P <0.05$)

Table V: Relationship between level of burden and duration on antiepileptic drugs

Level of burden	Duration on antiepileptic drugs			
	< 1 year	1- 3 years	4- 6 years	Total
No burden	12	8	0	20
Mild burden	3	32	3	38
Moderate burden	0	18	4	22
Severe burden	6	18	8	32
Total	21	76	15	112

$X^2= 36.85 P <0.05$

Eighty eight (78.6.3%) of the respondents are caregivers of children living with epilepsy without comorbidities. Twenty (17.9%) had children with cerebral palsy(CP), three(2.7%) had those with microcephaly and one(0.89%) with attention deficit hyperactivity disorder. Of the 20 caregivers with CP children, 18 had higher burden (moderate and severe) while only two had lower burden. Similarly, two of the three patients with microcephaly had higher burden. There is statistical significant relationship between burdens of care and the presence or absence of comorbidity. ($X^2= 16.5, P<0.05$)

Table VI: Relationship between level of burden and comorbidities

Level of burden	comorbidities				
	Nil	cerebral palsy	microcephaly	ADHD	Total
No burden	19	0	1	0	20
Mild burden	27	2	0	0	29
Moderate burden	19	10	1	0	30
Severe burden	23	8	1	1	34
Total	88	20	3	1	112

$X^2= 16.5 P <0.0$

Discussion

The study showed that about a 48.2% of the caregivers experience high burden (moderate and severe) which is comparable to 52% high burden recorded in a similar study by Folorunsho et al in Northern Nigeria. . The care givers above 40 years have higher compared to those in lower age group. This is probably because advanced age is more likely to be associated with increase strain thereby increasing the burden of the caregiver. Low social class of the caregivers was also seen from the study to be associated with high burden. This is expected as caregivers in this category have low level of education and are either under- or unemployed with low income, hence caring for children with a chronic disease requiring high financial demand would have a heavy burden on them. In a related study by Folorunsho et al unemployment was found to be a major factor responsible for a high burden by caregivers.

The study showed that majority of the respondents are low income earners with an average income of less than 140 dollar per month and a good number of the respondents in this category had higher burden. Previous studies have shown that epilepsy burden is higher among poor and low income earner and this is attributable to inability to sustain the procurement of quality and effective drugs for the control of epilepsy. Also stigma against children living with epilepsy and caregivers is known to be common among low income and poor people. This could further add to the burden of epilepsy and may in part explain why those with low income experience higher burden compared to those with higher income.[17]

The study showed that the longer the duration on antiepileptic drugs the higher the burden being experienced by the caregivers. This is in consonance with earlier studies in Nigeria on adults patients on AED where those who have been on AED for more than 5 years' experience significantly higher burden compared to those with shorter duration.[16] Studies have shown that longer duration on antiepileptic drugs increases the economic burden on the patients or caregiver[18] which invariably will increase the burden on caregivers.

The key driver of the cost of managing epilepsy is the cost of procurement of effective antiepileptic drugs.[19]The study showed a proportional increase in the burden of care as the average cost of procurement per month of AED increases. Given the low socioeconomic status, poor income of the majority of the caregivers in this study and the out of pocket procurement of medications, one is not surprised at the high level of burden amongst those who spend more money monthly to buy AED.

The presence of comorbidities in a patient is known to increase the burden of care of caregivers. This is partly due to increase cost of care of the patient and also the possibility of an unfavorable outcome as a result of the associated comorbidities. [16,20] Our observation in the study showed that caregiver whose children have cerebral palsy and ADHD have higher burden compared to those without comorbidities.

Conclusion

In conclusion caregivers of children with epilepsy in a developing country experience burden mainly from cost of managing epilepsy and comorbidities. Efforts should be made towards prevention of comorbidities and provision of subsidised drugs to reduce the burden of care experienced by them.

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