# **Original Article**

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# Burden in Caregivers of Adults With Epilepsy at A Tertiary Hospital in North Western Nigeria.

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# ABSTRACT

Epilepsy has a great impact on the lives of the patients and their caregivers. Caring for patients with epilepsy is challenging and associated with enormous burden. This cross-sectional study assessed the determinants of burden among 103 caregivers of persons with epilepsy attending Neurology clinic of Ahmadu Bello University Teaching Hospital (ABUTH) Zaria Nigeria. Ethical approval and informed consent were obtained from the Health Research Ethical Committee (HREC) of ABUTH and the participants respectively. Structured questionnaire, the Zarit Burden Interview (ZBI) and WHOQoL Bref instruments were interviewer administered to the caregivers and people with epilepsy (PWE) respectively. Data was analyzed using statistical package for social sciences (SPSS) version 21 and statistical significance was set at p value < 0.05. The mean and range ages of participants were 40.3  $\pm$ 12.8 and 51 (18-67) years respectively. More than half were female 56 (54.4%). The mean ZBI of caregivers and HRQoL of PWE were 45.0  $\pm$  16.7 and 65.2  $\pm$  16.4 respectively. Median duration and caregiving hours daily were 7 days and 8 hours respectively. Majority of caregivers, 96(93.2%) were either their first degree relatives or spouses. These caregivers reported little or no burden in 3 (2.9%), mild to moderate burden in 47 (45.6%), moderate to severe burden in 38 (36.9%) and severe burden in 15 (14.6%). Caregivers with lower monthly income and those with informal employment had significantly higher mean ZBI of 47.95, p = 0.006 and 49.87, p = 0.008 respectively. There was a significant negative correlation between burden of caregiving and health related quality of life (HRQoL) of persons with epilepsy (r = -0.355, p =0.0001). Equally, HRQoL was found to be a independent determinant of caregiving burden (t= -3.082, p = 0.003)

Conclusion: Majority of the caregivers were first degree relatives or spouses of the PWE, they **had** mild to moderate burden level and HRQoL of PWE was found to be an independent determinant of caregiving burden among them. Mitigating caregivers' burden will be essential in comprehensive epilepsy care.

Keywords: Burden, caregivers, epilepsy, Health related quality of life, determinants.

# How to cite this article

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# INTRODUCTION

pilepsy is one of the most common chronic non communicable disorders of the brain. It affects about 70 million people worldwide with high prevalence in sub-Saharan Africa.<sup>1, 2</sup>The overall prevalence estimate of epilepsy in Nigeria has been put at 8 per 1000 people.<sup>3</sup> This prevalence, which is associated with high burden varies slightly across the geopolitical zones of Nigeria and is 2.5 times higher in rural compared with urban communities.<sup>3</sup> The disease is characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (focal) or the entire body (generalized) and are sometimes accompanied by loss of consciousness and control of bowel or bladder function.<sup>4</sup> These seizure episodes result from abnormal excessive electrical discharges from different parts of the brain cells (neurons). Seizures can vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions. Seizures can also vary in frequency, from less than one per year to several per day<sup>4</sup>

Epilepsy was previously defined as at least two unprovoked seizures occurring >24 hours apart. The revised clinical practical definition considers a patient to have epilepsy after one unprovoked seizure in individuals who have other factors that are associated with a high likelihood of a persistently lowered seizure threshold and therefore a high recurrence risk.<sup>5</sup> Persons with epilepsy as a result of the unpredictability of the seizures and perceived stigma usually feel socially isolated with poor social adaptation and resultant low self-esteem<sup>6</sup> There could be stress on the family due to the illness and tendency to have higher rate of separation or divorce <sup>6</sup> Most patients with epilepsy therefore suffer social deprivation, discrimination and stigmatization in education, employment, housing, life opportunities and marital life amongst other components of daily living.7,8,9

Epilepsy has a great impact on the lives of the patients and their caregivers because of the unpredictability of the seizures and stigma.<sup>10</sup> Therefore, caring for patients with epilepsy can be challenging and associated with enormous burden. Burden of care is a multi-factorial construct which includes emotional, psychological, physical and economic impact as well as related distressing feelings such as shame, embarrassment, anger, and feeling of guilt and self-blame.<sup>11, 12</sup> Burden could be described as either objective or subjective. Objective burden refers to changes in household routine, family or social relations, work, leisure and physical health while subjective burden consists of subjective distress among relatives, including impact on mental health<sup>13</sup>. A caregiver has been defined as the closest family member or friend who lived with the patient or as any person who spent a greater part of his or her life with patient, he/she would have witnessed seizures and taken active part in treatment (e.g. attended physician appointments as a companion and co-operated with the patient to achieve compliance with treatment)<sup>14</sup>. Caregiver burden refers to the perceived distress and impact on caregivers as a result of providing care.<sup>15</sup> Burden of caregiving experienced by relatives of patients with chronic illness like epilepsy can be enormous leading to impaired quality of life.<sup>16</sup>

Determinants of epilepsy burden in caregivers has been broadly categorized into patient, caregivers and care related factors.<sup>17</sup> The factors reported by previous researchers include: age of the patient, onset of seizure, seizure control, duration of antiepileptic drug (AED) use, gender and socioeconomic status of the caregiver.<sup>15,</sup> <sup>18-21</sup> Nuhu et al in Kaduna, Nigeria found that long duration of epilepsy, poor seizure control and living far away from treatment centre were all associated with high epilepsy burden on caregivers. <sup>14</sup>While Karakis and colleagues in their study at Massachussets, USA documented higher AED dose, lower patient's neuropsychological score, lower caregiver's education and time spent with patient to be associated with higher caregiver burden.<sup>13</sup> The present study sought to assess burden among caregivers of adult patients with epilepsy in order to elucidate the determinants of caregiving burden. The findings from this study will be relevant in providing a comprehensive care by clinicians to the patients with epilepsy and their caregivers. It will also be useful in decision making by administrators and policy makers.

J Biomed Res. Clin Pract | Vol 7 | No 1&2 | 2024



# METHODOLOGY

**Study Design and Setting**: This cross-sectional study assessed 103 caregivers of persons with epilepsy attending Neurology outpatient clinic of Ahmadu Bello University Teaching Hospital (ABUTH) Zaria, Kaduna State, Nigeria. This tertiary health care facility is a major referral centre for Neurological services from the three geo-political zones of Northern Nigeria including the Federal Capital Territory (FCT). Participants were enrolled for the study from September 2013 to September 2014.

**Ethical Issues**: Ethical approval for the study was obtained from the Health Research Ethical Committee of ABUTH while informed consent was obtained from all participants with strict confidentiality assured and maintained with the data obtained.

#### **Study Procedure:**

Participants were recruited purposively for the study if they were primary caregivers of PWE and at least 18 years old. Primary caregivers of PWE were defined as the main informal, unpaid individuals who provide care and assistance to manage the daily needs of persons diagnosed with epilepsy. Such persons are the main caregivers and attended clinic with the patient. They were excluded if they were less than 18 years old, had not witnessed patient's seizure, were financially compensated for caregiving or their patient had comorbid chronic medical or psychiatric illness. The recruited caregivers were required to complete a structured questionnaire containing demographics, questions related to caregiving such as relationship with the patient, family size, hours spent caregiving etc. The Zarit Burden Interview (ZBI) instrument was interviewer administered to the primary caregivers; while the World Health Organization (WHOQOL) Bref questionnaire was interviewer administered to the persons with epilepsy (PWE). ZBI assesses the burden on caregivers of individuals with chronic illnesses, and it reliability and validity has been established in North-West Nigeria.<sup>22</sup>

**Zarit Burden Instrument**: The Zarit Burden Interview (ZBI) was developed to measure subjective burden

among caregivers of adults with dementia. Items were generated based on clinical experience with caregivers and prior studies resulting in a 22-item self-report inventory that examines burden associated with functional/behavioural impairments and the home care situation. The items are worded subjectively, focusing on the affective response of the caregiver.

Each question is scored on a 5 point Likert scale ranging from score of 0 (never) to score of 4 (nearly always present). Total scores range from 0 (low burden) to 88 (high burden). Score values and interpretation are as follows: 0 to 20 means little or no burden; 21 to 40 means mild to moderate burden; 41 to 60 means moderate to severe burden and 61 to 88 means severe burden.<sup>23</sup>

#### WHOQOL Bref Instrument

The WHOQoL-BREF is a 26-item questionnaire made up of domains and facets. Domains are broad groupings of related facets. Each item of the WHOQOL-BREF is rated on a 5-point Likert type scale. Domain scores are scaled in a positive direction (i.e., higher scores denote higher HRQoL).<sup>24</sup>

**Data Analysis**: Data was analyzed using statistical package for social sciences (SPSS) software (version 21; IBM SPSS Statistics). Descriptive statistics was used to determine mean, median or inter quartile range (IQR), standard deviation, range, frequency and percentages. We also assessed for the relationship between burden of caregiving and categorical variables using independent samples t-test. Correlation analysis was done using Pearson's correlation, while the determinants of caregiving burden was assessed using multiple linear regression analysis. Statistical significance was set at p value less than 0.05.

# RESULT

#### Socio-demographic Characteristics of Caregivers:

The mean and range ages of participants were  $40.3\pm12.8$ and 51 (18-67) years respectively. There were 47(45.6%) males and 56 (54.4\%) females. Majority of the caregivers had formal education, 90 (87.4%) with most of them unmarried 76 (78.8%). Other details are shown in Table 1 below. Regarding the relationship between the caregivers and PWE, majority of them,

J Biomed Res. Clin Pract | Vol 7 | No 1&2 | 2024



96(93.2%) were either their first degree relatives or spouses. Their specific details showed that 30 (29.1%) were parents, 26 (25.2%) were siblings, 24 (23.3%) were spouses, 16 (15.5%) were children and 6 (5.9%) were other relatives such as cousin, niece, nephew and in-law while 1 (1.0%) was a friend as shown in Figure 1 below.



Figure 1: Relationship of Caregivers with Persons with Epilepsy

#### **Clinical Characteristics of Participants**

Female caregivers had non- significantly higher mean ZBI than male caregivers  $46.2 \pm 17.1$  and  $43.7 \pm 16.3$  respectively (p = 0.456) while the overall mean ZBI was  $45.0 \pm 16.7$  which was in the range of moderate to severe burden. The mean HRQoL of PWE was  $65.2 \pm 16.4$ . The median (IQR) duration of caregiving, hour caregiving daily and number of persons caring for the PWEs were 7 days, 8 hours and 3 persons respectively. The caregivers reported little or no burden in 3 (2.9%), mild to moderate burden in 47 (45.6%), moderate to severe burden in 38 (36.9%) and severe burden in 15 (14.6%) as in Figure 2. Burden of caregiving correlated significantly positively with employment status, r = 0.213, p = 0.005 and negatively with HRQoL of PWE, r = -0.355, p = 0.000.



# Relationship between Socio-Demographic, Clinical Factors and Burden of Caregiving

Caregivers with monthly income of less than 50,000 naira and those with informal employment had significantly higher mean ZBI of 47.95, p = 0.006 and 49.87, p = 0.008 respectively. However, there was no significant relationship between burden of caregiving and socio-demographic or clinical factors like gender, marital status, occupation, educational level of caregivers as well as patient's onset of illness, duration of illness, seizure type and seizure control (p > 0.05). Other details are shown in Tables 1 and 2 below. Further analysis using multiple linear regression showed patients' HRQoL to be a significant independent determinant of caregiving burden (t=-3.082, p=0.003; CI-0.562 to -0.121) as in Table 3 below.

Table 1: Relationship between Socio-Demographic Factors and Burden of Caregiving							
Variable	Frequency	Percentage	Mean	t- value	p-value		
Age	57	55.2	15 36	0.215			
18-40 Years	57	33.3	45.50	0.215	0.921		
>40 years	40	44.0	44.03		0.831		
Gender	47	15 (	42 70	-0.751			
Male	4/	45.6	45.70	-0.751	0.455		
Female	50	54.3	46.17		0.455		
Marital Status	27	26.2	46.02	0.328			
Married	21	20.2	40.05	0.520	0.744		
Unmarried	/6	/8.8	44.09		0.744		
Educational Level	12	12 (	52 60	1 777			
No Formal Education	13	12.6	33.09	1.///	0.007		
Had Formal Education	1 90	87.4	43.80		0.096		
Employment	56	54.2	41.00	-2 732			
Formal	50	54.3	41.00	-2.132	0.0004		
Informal	47	45./	49.8/		0.008*		
Monthly Income	69	((1	47.05	2.81			
< 50,000 Naira	68 25	66.1	47.95	2.01	0.00/*		
≥ 50,000 Naira	35	33.9	39.40		0.006*		
Relationship with Pat	ient		44.01	1.005			
Spouse or FDR	96	93.2	44.21	-1.095			
Others	1	6.8	56.42		0.314		
Family Size	=-		15.00	0 157			
1-10 Persons	73	70.7	45.09	-0.157			
>11 Persons	24	23.3	45.70		0.876		
Hours Spent Caregivi	ing			0.000			
1-6 Hours	63	61.2	44.11	-0.699			
>6 Hours	40	38.8	46.52		0.486		
<b>Residence Location</b>				0.2(2			
Within the City	69	66.9	44.75	- 0.263			
Jutside the City	34	33.1	45.64		0.793		

FDR = First degree relative; \* = Significant

J Biomed Res. Clin Pract | Vol 7 | No 1&2 | 2024

Table 2: Relationship between Clinical Factors and Burden of Caregiving									
Variable	Frequency	Percentage	Mean	t- value	p-value				
Seizure type									
Generalized	52	50.5	44.15	-0.527	0.586				
Focal	51	49.5	45.96						
Age at onset									
1-20 Years	52	55.3	44.30						
≥20 Years	51	44,7	45.80	-0.452	0.652				
<b>Duration of Illness</b>									
1-15 Years	85.4	85.4	45.67						
>16 Years	14.6	14.6	41.40	1.264	0.217				
Seizure Control									
Controlled	43	41.7	47.51						
Uncontrolled	60	58.3	43.28	1.271	0.207				

Table 3: Multiple Linear Regression Analysis of Determinants of Caregivers Burden

Model	Unstandardized Coefficients		Standardized Coefficients	Т	Sig.
	В	Std. Error	Beta		
(Constant)	72.326	20.983		3.447	.001
Age	.017	.186	.013	.092	.927
Sex	-2.234	4.194	066	533	.596
Marital status	2.584	4.534	.081	.570	.570
Family size	046	.799	012	057	.955
Location of residence	774	1.766	047	438	.662
Duration of caregiving	.280	.316	.152	.886	.378
Number of persons giving care	664	.912	083	728	.469
Duration of illness	-16.070	8.636	325	-1.861	.066
Hours spent caregiving daily	1.445	3.912	.042	.369	.713
Family size	.498	7.766	.013	.064	.949
HRQoL of Patients	342	.111	330	-3.082	.003*
Seizure classification	5.255	3.659	.155	1.436	.155
Seizure control prior month	-3.406	3.817	100	892	.375
Age at onset of seizure	056	.112	057	500	.618
Employment status	6.147	3.929	.181	1.565	.122

HRQoL = Health related quality of life; \* = Significant

# DISCUSSION

This study examined caregiving burden among caregivers of adult PWE and found moderate to severe burden level. Our finding is in contrast to previous researches that reported mild to moderate level of burden. <sup>13,17,25,26</sup> This reported mean ZBI of 45.0 is higher than the mean scores of 20.02, 29.93 and 36.43 respectively found in those studies. <sup>13,17,25</sup> The higher level of caregiving burden found in our study may be explained by clinical factors like seizure control and socio-economic factors like monthly income and employment status which were noticed to be significantly related. Some previous studies have reported the moderating

effect of uncontrolled seizures on caregiving burden.<sup>19, 27</sup>In this study about 58.3% of the PWE being cared for by our cohorts have uncontrolled seizures. A study among caregivers of children with epilepsy in Nepal had documented poorly controlled seizure as one of the determinants of burden in them.<sup>27</sup> Penovich et al had reported the impact of seizure clusters of PWE on caregiving burden.<sup>19</sup> In their study, about 58.0% of caregivers reported a major to moderate negative effect of seizure clusters of PWE on them. It especially affected their mood, vacation, travel, hobbies or social activities and job. When asked to describe how they feel when their patient experiences seizures, caregivers reported that they felt stressed, helpless, scared and overwhelmed.<sup>19</sup>

Caregivers with lower income of less than 50,000.00 naira monthly and those with informal employment like artisans, traders etc. were found to have higher mean ZBI scores. This finding is congruent with previous researches.<sup>17,26</sup>This is not unexpected as either under- or unemployed caregivers subsequently have low income, hence caring for their patient with a chronic disease like epilepsy requires high financial demand that would pose a heavy burden on them. In a similar study by Nuhu et al, unemployment was noted to be a major factor responsible for a high caregiver burden.<sup>14</sup> The study showed that majority of the participants were lowincome earners with an average income of less than 140 dollars per month and a good number of the caregivers had higher burden<sup>14</sup>. Another reason for high epilepsy burden among these caregivers with low-income may be attributable to their inability to sustain the purchase of quality and effective anti-epileptic drugs for seizure control of their patients.

Epilepsy has been associated with poor HRQoL with several factors shown to be attributable to it. Determinants documented previously included demographic factors like marital status and monthly income and psychosocial factors like stigma, depression and social support.<sup>28</sup> From the current study HRQoL of PWE correlated negatively with caregiving burden and was also found to be a significant independent determinant of caregiving burden. Some previous studies that focused on the relationship between HRQoL and burden among caregivers had reported similar trend.<sup>13,29</sup>

Our study also demonstrated higher level of caregiving burden among female caregivers than their male counterparts. This finding has been corroborated by Lai and colleagues in their study in Malaya Malaysia.<sup>17</sup> More proportion of the study participants (54.4%) were female. Similar demographic characteristics have been reported by previous researchers.<sup>6,7,12,13</sup> The preponderance of female caregivers found in our study could be attributable to the cultural belief that men are bread-winners of the family and hence should work to provide financially for the family while the women take the responsibility of caregiving such as attending hospital with their sick family members. In addition, polygamous nature of most marriages in the study environment makes it mandatory for most mothers to provide care for their children and as such absolving fathers of caregiving responsibility.

It is noteworthy that in the current study about 93.2% of the caregivers were either spouses or first degree relatives of PWE. This shows enormous social support which has been reported to be essential for optimal care of PWE. A previous study had documented social support as the main determinant of HRQoL.<sup>30</sup> Social support is defined as the perception that an individual is a member of a network in which one can give and receive help, affection and obligation<sup>31</sup> It is "the commitment, caring advice, and aid provided in personal relationship", which is thought to buffer the negative impact of stressful events, ongoing life strains and chronic health conditions like epilepsy.<sup>32</sup> Also, in our cohort 23.3% of the caregivers were spouses. It has been opined that intimate relationship like marriage as a source of social support is thought to improve a person's ability to cope with stressful life events due to mutual assistance of the couple, thereby enhancing their individual capacity and has positive effect on mood.<sup>33</sup>

Majority, 61.2% of caregivers reportedly spent 1-6 hours of caregiving daily, with 38.8% spending more than 6 hours. The median (IQR) hour caregiving daily was 8 hours. There was no significant association between caregiving hour daily and burden of caregiving. This is in contrast to the study by Lai et al that demonstrated 11 hours of caregiving daily which equally correlated positively with caregiving burden.<sup>13</sup> A previous study had documented some forms of caregiving activities to include rendering assistance during seizure, reminding patient to take their anti-epileptic medications, accompanying patient to the hospital, accompanying patient in going out and assisting in some activities of daily living.<sup>28</sup>

This study showed that the 33.1% of caregivers who reside outside the city had higher mean ZBI and which aligns with a previous study by Nuhu et al in Kaduna.<sup>7</sup> This implies that caregivers living outside Zaria had higher caregiving burden. Living outside Zaria will

J Biomed Res. Clin Pract | Vol 7 | No 1&2 | 2024

imply living far from this health facility which will impose more financial burden on caregivers due to the cost of transportation. Some patients may travel from other states or rural areas and will be required to come a day before to be able to meet up with their clinic appointment and as such may need to bear the additional cost of accommodation thereby worsening their already poor financial situation and increase the overall burden. This shows the need for the availability of easily accessible and effective health care services for PWE.

#### Strengths and limitations

This study has elucidated some determinants of caregiving burden in caregivers of PWE which can be targeted to provide evidence based and wholistic care to them. There is the possibility of recall bias due to the self-reporting nature of this study. However, self-report scales are commonly used and cost-effective for both diagnostic and outcome assessments.

# CONCLUSION

Majority of the caregivers were first degree relatives or spouses of the PWE, they had mild to moderate burden level and HRQoL of PWE was found to be an independent determinant of caregiving burden among them. There is the need to focus attention on improving the QoL in PWE so as to mitigate caregivers' burden.

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# **Conflict of Interest**

The authors declare no conflict of interest.

# **Authors' Contributions**

'Author EUI' designed the study, wrote the protocol, involved in data collection, performed the statistical analysis, wrote the final version of the manuscript. Author 'ITI' wrote the first draft of the manuscript 'Author ORO' revised the manuscript to give it intellectual content. All authors read and approved the final manuscript.

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J Biomed Res. Clin Pract | Vol 7 | No 1&2 | 2024

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