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Research Article

Emotional Distress In Family Caregivers Of Patients With Epilepsy And Its Negative Impact On Patients' Quality Of Life.

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Abstract

Background: The emotional distress that caregivers experience is not only detrimental to their own mental health but can also have far-reaching consequences on the patient's well-being and quality of life
Objectives: The objective of this study was to assess the anxiety and depression of caregivers of patients with epilepsy (PWE) and evaluate its effect on patient quality of life (QOL)
Method: One hundred and fourteen pairs of patients with epilepsy (PWE) and their caregivers were enrolled in our study through consecutive sampling at neurology clinic in a Tertiary health institution in Jos Nigeria. Quality of life in PWE was evaluated with the World Health Organization Quality of Life-BREF (WHOQOL-BREF) scale. Symptoms of anxiety and depression in caregivers were assessed with the Hospital Anxiety and Depression Scale (HADS). Frequency and chi square statistics were used as statistical analysis.
Results: Of the caregivers, 54 (47.4%) had anxiety symptoms (HADS scores > 7) and 45 (39.5%) had depression symptoms (HADS scores >7). Mean WHOQOL-BREF Transformed scores (0-100) for each domain were 55.54 ± 12.59 in physical, 55.73 ±17.44 in psychological, 51.20 ± 27.34 in social, and 59.79 ± 21.74 in environmental domain. Mean score for overall quality of life (QOL) was 55.56 ± 15.49. Caregiver anxiety was significantly associated (p=0.000) with poorer PWE QOL in 43 (82.7%) of care givers. Caregiver depression was significantly associated (p=0.000) with poorer PWE QOL in 35 (67.3%) of care givers.
Conclusion: caregivers of PWE are at high risk of experiencing anxiety and depression. Caregiver psychological status, especially anxiety was an independent predictor of poorer QOL for PWE. Therefore healthcare providers should take a holistic approach to managing epilepsy, considering not only the patient's health, but also the well-being of caregivers. This could include counseling, respite care, and other services to ease the emotional burden on caregivers.

Keywords : caregivers, anxiety, depresion, epilepsy, Quality of Life.

INTRODUCTION

Epilepsy, a chronic neurological disorder characterized by recurrent seizures, affects over 65 million people worldwide, with a significant proportion of them being adults. While much attention has been focused on the medical and clinical management of epilepsy, there is growing recognition of the critical role that family caregivers play in the lives of individuals with epilepsy. Family caregivers provide ongoing support, helping with daily activities, medication management, and monitoring seizures. However, care giving can be emotionally and physically demanding, often leading to emotional distress that can, in turn, impact both caregivers' well-being and the quality of life (QoL) of the patients they care for.

Emotional distress among caregivers has been defined as mood disturbances like anxiety, depression, feeling of loneliness, isolation, fearfulness and being easily bothered – all arising from providing care for a sick relative.1 Caregivers of patients with epilepsy (PWE) face unique challenges that can lead to high levels of emotional distress. These challenges often stem from the unpredictability of seizures, the constant need for vigilance, stigma associated with epilepsy, financial strain and the strain of managing both the medical and emotional aspects of the disorder.

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Family caregivers of patient with chronic illness like epilepsy, have often been described as forgotten patients and it was suggested that a caregiver's symptoms such as mood swings, fatigue, headaches, joint and muscle pains, marital and family conflicts, and financial problems may be a reflection of care giver stress in looking after a sick relative.2 Previous studies have shown that caregivers of patients with epilepsy are at high risks of experiencing depression and anxiety co-morbidity, even reaching up to 50%, and 58%, respectively.3,4,5

The World Health Organization (WHO) has defined Quality of life (QOL) as the individual's perception of their position in life in the context of culture and value system in which she or he lives in relation to her/ his goals, expectations, standards and concerns.6 Quality of life (QOL) is an important component in the clinical management of PWE.7 The emotional distress of caregivers significantly contributes to the decline in the quality of life for patients with epilepsy. Quality of life in individuals with epilepsy encompasses several dimensions, including physical health, mental health, social relationships, and general well-being. When caregivers are overwhelmed, the patient's quality of life is inevitably compromised.

Several studies have also shown that caregiver psychological co-morbidities, depression and anxiety in particular, are significantly correlated with QOL in child and adolescent PWE.8,9,10 In view of the dearth of literature or studies focused on caregivers of patients with epilepsy, this study also aim at providing an insight into the problems facing the "hidden patients" and its impact on the people they cared for.

METHOD

Site

This is a descriptive cross-sectional study of patients with epilepsy and their family care givers attending Bingham University Teaching Hospital (BHUTH) in Jos, Nigeria. Bingham University Teaching Hospital formally known as ECWA Evangel Hospital is a missionary hospital established in February 1959. It is located in Jos North LGA. Jos is the capital city of Plateau State with a population of about 821,618 according to 2006 national census (National Bureau of Statistics, 2006). Most of the patients are within Plateau State and its neighboring states.

Sample

The sample comprise of 114 pairs of patients with epilepsy (PWE) and their caregivers, who were enrolled in our study through consecutive sampling at neurology clinic from December 2020 to December 2021. The inclusion criteria were clinical diagnosis of epilepsy, receiving treatment for at least six months and living together with the caregiver who is involved in monitoring adherence to medication and attending follow up clinic with the patient in the last six months. Care givers with a previous history of mental illness, those with co-morbid mental retardation and all those who decline consent were excluded from the study.

Procedure

Following approval from the ethical committee of BHUTH and permission to carry out the study from the Head of medicine department, consecutive out-patients with their care givers presenting at the neurology clinic of the hospital were approached, where an informed written consent were obtained from each of the respondents before conducting the interview. The respondents were interviewed using the following instruments;

1. ***Socio-demographic data collection sheet:*** this was designed for the purpose of this study. It was to elicit information such as age, gender, income, duration of illness and other related data.
2. ***Hospital Anxiety Depression Scale (HADS)***. This was developed to assess anxiety and depressive symptoms among non psychiatric patients in the hospital.11 The instrument had been validated in many countries including Nigeria.12-14 HADS has also been found useful in the assessment of psychiatric morbidity in the community. The instrument consists of seven items each for depression and anxiety. Scales are rated on a four point scale ranging from 0-3. A cut of point of 8 and above in either anxiety or depressive subscale indicates depression or anxiety.14
3. ***WHO Quality of life BREF:*** This is an abbreviated version of the WHOQoL-100.

Quality of life aims to measure the impact of disease and impairment on daily activities and behaviour and perceived health measures.15,16 Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.17 WHOQOL-BREF contains a total of 26 questions. One item from each of the 24 facets contained in the WHOQOL-100 and 2 items from the overall quality of life and general health facet.

Statistical analysis

Data was analyzed using the Statistical package of social sciences (SPSS) version 22.0 (SPSS 22) for Microsoft Window Software Package. Descriptive statistic was used to calculate for all continuous variables. Chi square test and student "t" test were used to test for associations. All statistical tests were carried out at 5% level of probability.

RESULTS

A total of One hundred and fourteen pairs of patients with epilepsy (PWE) and their caregivers were enrolled in our

study. From the total study participants, about 63(53.3%) pairs were females and almost half (43.9%) of the respondents were found in the age group between 20–40 years with the median age of 28 years old. More than half of the study participants (56.1%),had family size of more than five as well as those who live in urban area. Among the epileptic patients, more than two-third (65.8%) had duration of illness of more than one year.**Table 1**

Table 1. Distribution of participants by socio-demographic characteristics at Bingham University Teaching Hospital, Jos Nigeria, 2021 (n = 114).

Variable	Category	Frequency	Percentage (%)
Care giver information			
Sex	Male	51	44.7
	female	63	55.3
Age in years	<20	37	32.5
	20-40	49	43.0
	>40	28	24.5
Formal education	Yes	61	53.5
	No	53	46.5
Family size	≤5	50	43.9
	>5	64	56.1
Financial support	Yes	51	44.7
	No	63	55.3
Relationship	Parent	41	36.0
	Spouse	44	38.6
	Child	24	21.1
	Sibling	3	2.6
	Others	2	1.8
Place of residence	Rural	54	47.4
	Urban	60	52.6
Employmen status	Employed	59	51.8
	Unemployed	55	48.2
Patients information			
Sex	Male	52	45.6
	Female	62	54.4
Age	<20	37	32.5
	20-40	50	43.9
	>40	27	24.6
Duration of illness	≤1 year	39	34.2
	>1 year	75	65.8
Employment status	Employed	52	45.6
	Unemployed	62	54.4

In **Table 2**; out of the 114 caregivers, almost half, 54 (47.4%) had anxiety symptoms (HADS scores > 7) and less than half,s 45 (39.5%) had depression symptoms (HADS scores >7).

Table 2. HADS Scores of caregivers

Caregivers	Frequency	Percent (%)
With anxiety	54	47.4
Normal	60	52.6
Total	114	100
With depression	45	39.5
Normal	69	60.5
Total	114	100

Table 3 showed distribution of WHOQOL BREF domains of the respondents, thus mean WHOQOL-BREF Transformed scores (0-100) for each domain were 55.54 ± 12.59 in physical, 55.73 ±17.44 in psychological, 51.20 ± 27.34 in social, and 59.79 ± 21.74 in environmental domain. Mean score for overall quality of life (QOL) was 55.56 ± 15.49. In this study, more than half (53.5%) of the study participants had poor quality of life in the social domain, and relatively low scores of poor quality of life were seen in the environmental domain which was 48(42.1%) However, the other two domains (physical and psychological domains) had similar frequency distribution of poor quality of life which accounts for 43(37.7%)

Table 3. Distribution of WHOQOL BREF domains of the respondents at Bingham University Teaching Hospital, Jos Nigeria, 2021 (n = 114).

Variable	Mean ± SD	Poor QOL frequency	Good QOL frequency
Physical domain	55.54 ± 12.59	43 (37.7%)	71 (62.3%)
Psychological domain	55.73 ±17.44	43 (37.7%)	71 (62.3%)
Social domain	51.20 ± 27.34	61 (53.5%)	53 (46.5%)
Environmental domain	59.79 ± 21.74	48 (42.1%)	66 (57.9%)

Table 4 shows the relationship between HADS scores of caregivers and quality of life of epileptic patients; the result revealed that among caregivers with anxiety symptoms, more than two-third 43 (82.7%) of their patients with epilepsy(PWE) had poor quality of life (QOL). Care giver anxiety was significantly associated (p=0.000) with poorer PWE QOL. Likewise among caregivers with depression, nearly two-third 35 (67.3%) of their PWE had poor quality of life. This care giver depression was also significantly associated (p=0.000) with poorer PWE QOL.

Table 4. Relationship between HADS scores of caregivers and quality of life of epileptic patients.

Variables	Anxiety status		Statistics	Depression status		Statistics
Physical Domain	With anxiety	Normal		With Depression	Normal	
Poor	26 (60.5%)	17(39.5%)	P=0.035	26 (60.5%)	17(39.5%)	P=0.001
Good	28 (39.4%)	43(60.6%)		19 (26.8%)	52(73.2%)	
Psychological domain						
Poor	33(76.7%)	10(23.3%)	P=0.000	31 (72.1%)	12(27.9%)	P=0.000
Good	21 (29.6%)	50(70.4%)		14 (19.7%)	57(80.3%)	
Social Domain						
Poor	41(67.2%)	20(32.8%)	P=0.000	33 (54.1%)	28(45.9%)	P=0.001
Good	13(24.5%)	40(75.5%)		12 (22.6%)	41(77.4%)	
Environmental domain						
Poor	36 (75.0%)	12(25.0%)	P=0.000	32 (66.7%)	16(33.3%)	P=0.000
Good	18 (27.3%)	48(72.7%)		13 (19.7%)	53(80.3%)	
Overall quality of life						
Poor	43(82.7%)	9(17.3%)	P=0.000	35 (67.3%)	17(32.7%)	P=0.000
Good	11(17.7%)	51(82.3%)		10 (16.1%)	52(83.9%)	

DISCUSSION

The preponderance of urban residence among the participants can be explained by the location of the study area. Females constituted the majority of the caregivers in this study. This is in keeping with the tradition of the area where female relatives constitute the majority of caregivers. A similar observation was made by an earlier study in this environment involving patient-caregiver pairs.18 Emotional distress was found to be very high among these caregivers. This is similar to the findings of other studies among caregivers of patients with epilepsy in other part of the world.3,4,19,20 Reason for this high emotional distress could stem from the unpredictability of seizures, the constant need for vigilance, stigma and the strain of managing both the medical and emotional aspects of the disorder.

The result of this study was revealed that 42.8% of the respondents had poor quality of life. This finding is comparable to the studies done on the quality of life of people with epilepsy in Kenya (49%), and Addis Ababa Ethiopian (45.8%).21,22 This might be due to the fact that caregivers who are emotionally distressed may be less able to provide the necessary support, potentially leading to poorer health outcomes, greater challenges in managing epilepsy, and reduced overall well-being for

the patient. The other possible justification for this similarity might be the combination of limited healthcare resources; lack of awareness, social stigma, cultural beliefs, and socioeconomic challenges contributes to the poor quality of life of respondents in these developing countries.

The finding of this study was higher than the studies which were conducted in Taiwan (33.29%), Brazil (31.27%), and Colombia (30%) in which most of the respondents had a good quality of life.23-26 This difference might be due to better healthcare systems, availability of medications, social support, and overall socioeconomic conditions contribute to a higher quality of life for respondents in these developed countries, in contrast, these factors are often less accessible in developing countries, like ours (Nigeria) leading to poorer management of the condition and a lower quality of life for patients.

In the current study, the poor quality of life in the social domain (53.5%) was higher than in physical domain (37.7%), psychological domain (37.7%), and environmental domain (42.1%). Where as a study which was conducted in Ethiopia had higher poor quality of life in the physical domains (45.3%), psychological domain (45.3%), and environmental domain (49.8%) than in the social domain (38.6%).21

This difference in this domain might be, in the current study, lack of social support, isolation, or poor relationships, stigma and discrimination, financial constraint, cultural or societal expectations might have not been well addressed by a health care provider. On the other hand chronic illnesses or disabilities, access to resources and healthcare, environmental factors, and socioeconomic influences might not have been properly addressed in Ethiopia.

The present study revealed that the quality of life of patients with epilepsy was significantly associated with care giver emotional distress. In this study, clinical factors such as anxiety and depression in care givers had significantly associated with poor quality of life of patients with epilepsy. Those care givers who had anxiety were about four times more likely to have their patients with poor quality of life than those care givers who had no anxiety. Care givers who had depression were more than three times more likely to have their patients with poor quality of life than those who had no depression. This result was consistent with the studies which were done in Ethiopia, China and Serbia. 21,27,28

The possible reason why anxiety and depression in care givers are associated with poor quality of life in patients with epilepsy could be due to emotional and physical exhaustion, in which they may struggle to provide care, reassurance and stability, which are crucial for a patient's well-being, leading to decreased ability to provide consistent and effective care for the patient. Secondly depressed or anxious caregivers may have difficulty managing the patient's medication schedules or ensuring adherence to treatment plans, or might not seek timely medical help or effectively communicate symptoms and treatment concerns to healthcare professionals, leading to poorer epilepsy management. Furthermore emotional distress in caregivers, particularly depression and anxiety, is associated with a higher prevalence of depression and anxiety in the patients themselves. These co morbid conditions further diminish the patient's ability to cope with the challenges of living with epilepsy and can lead to a downward spiral in overall quality of life.29

CONCLUSION

Caregivers of people with epilepsy face significant psychological challenges, which can, in turn, affect both their own well-being and the quality of life of the patient. Addressing these challenges through support, education, and mental health care is essential for improving the quality of life for both caregivers and patients

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Conflict of interests

The authors have declared that no competing interests exist

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