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Prevalence and correlates of generalized anxiety disorder and depression among caregivers of children and adolescents with seizure disorders

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ABSTRACT

Objective: The aim of this study was to assess the prevalence and correlates of anxiety and depression among caregivers of children with seizure disorders. **Methods:** Two hundred and two caregivers of children with seizure disorders were administered socio-demographic questionnaires at the Child and Adolescent Outpatient Clinic between October 2011 and March 2012. The Structured Clinical Interview for DSM – IV axis 1 Diagnosis (SCID) was used for diagnosis of Generalized Anxiety Disorder and Major Depression. **Results:** One hundred and forty six (72%) of the carers were females, with mothers of patients accounting for 66% of respondents. The prevalence of generalized anxiety among the respondents was 12%, while that of major depressive disorder was 50.5%. The socio-demographic characteristics of carers associated with psychiatric morbidity included older age range ($\chi^2=18.67$, $p=0.001$), being employed ($\chi^2=10.41$, $p=0.015$), longer duration of care ($\chi^2=18.07$, $p=0.001$) and being patients' mother ($\chi^2=10.17$, $p=0.032$). **Conclusion:** Depression and anxiety are common among caregivers of children with seizure disorders. Caregivers' socio-demographic characteristics and patients' clinical variables are associated with prevalence of anxiety and depression. These findings suggest the need to adopt a holistic approach to the detection of these disorders and developing adequate intervention for these caregivers.

KEY WORDS: Adolescents, anxiety, children, depression, seizure disorders

INTRODUCTION

Caregiving is a stressful experience that may severely affect the physical and psychological health of the caregiver [1]. For caregivers of children with seizure disorders, the job is enormous. They have to make a time commitment to cope with all the medical appointments, handle medication routines and deal with all the changes in their children's functioning. They may fear stigmatization from friends and neighbors, and may become overprotective and more restrictive than they ought to be. Caregivers may also become anxious, frustrated or depressed as they struggle to find adequate and appropriate support for the child. The psychological distress experienced by them can affect the quality of care provided for these children, which ultimately can affect the prognosis of these patients [2].

The presence of a child with epilepsy in the family affects the general well-being of the primary caregivers, typically the mothers, who may be emotionally overwhelmed by the child's illness. Anxiety, depression, feelings of rejection, low self-esteem, and guilt are reported among these mothers who are often concerned about

the children's epilepsy than the fathers [3,4]. Some caregivers gave up their employment, career and income to care for these children with seizure disorders. This may be accompanied by a feeling of depression, anxiety, helplessness, anger, guilt, and resentment. Although these caregivers care deeply about the children, it is as if their own needs and wishes go unnoticed [5].

Compared with families of healthy children, caregivers of children with epilepsy have been found to have significantly higher levels of depression and anxiety [6]. Mother is most often the primary caregiver of children, so it is reasonable to assume that mothers may have significantly higher levels of psychiatric morbidity, especially depression while caring for children with seizure disorders [7].

Seizure disorders affect young people and their families in ways that cannot be treated with medication alone. This is especially true of those who go through a long process before an accurate diagnosis is made and those who live with uncontrollable seizures for many years. The families are often left to grapple with emotional turmoil and social consequences of these serious

disorders on their own. They usually go through the lack of information, idiosyncrasies of the medical and social support systems and the overwhelming nature of the seizure disorders without much assistance[8].

A study in Nigeria showed that a third to half of caregivers of children with seizure suffer significant psychological distress and experience higher rates of mental ill health than the general population [9].

While extensive and detailed studies on anxiety and depression among caregivers of children and adolescents with seizure disorders have been carried out in other parts of the world, few have been done in Southwestern Nigeria. Since caregiving appears to accrue significant mental health risks, an understanding of the mechanisms through which it contributes to psychological distress among caregivers of children with epilepsy in a developing country setting is critical [10,11]. This study aimed to determine the prevalence and correlates of anxiety and depression among caregivers of children with seizure disorders attending the Child and Adolescent Clinic of a Neuropsychiatric Hospital in Southwestern Nigeria.

METHODOLOGY

This study was conducted between October 2011 and March 2012 at the Child and Adolescent Clinic of the Neuropsychiatric Hospital, Aro, Abeokuta, in Southwestern Nigeria. This is a Government owned Psychiatric Hospital established in 1954. The Child and Adolescent unit is run by three consultant children and adolescent psychiatrists and a neurologist, assisted by psychiatric nurses and other members of the healthcare team.

This study design was cross-sectional, and respondents were recruited through a convenient sampling method. The sample size for this study was determined using the formula for calculating minimum sample size and 39% prevalence of depression reported by a previous study in Nigeria [12]. The calculated sample size was 202. For the purpose of this study, a caregiver was operationally defined as someone who through family relationship or friendship provides unpaid care by looking after an individual with a disability or chronic illness [13]. The caregivers must have shared the same living arrangement with the patients for at least 6 months and must be involved in monitoring or assisting with self-care functions such as dressing, bathing, and procuring medications. Caregivers with a previous history of anxiety, depression or any other psychiatric diagnosis before caring for these children were excluded. Patients with a diagnosis of seizure disorder made by psychiatrists or neurologist, with electroencephalography confirmation of the seizure type were included. Patients with history of febrile convulsion or any other axis I psychiatric diagnosis was excluded. Furthermore, children with a history suggestive of a chronic physical illness such as asthma and sickle cell disease were excluded.

The researchers designed a questionnaire to obtain socio-demographic characteristics of the caregivers (such as age, gender, employment status) and socio-demographic and clinical

variables of the patients (such as age, gender, type of seizures, and frequency of seizure). The generalized anxiety and major depressive disorder module of the Structured Clinical Interview Schedule for Axis I DSM IV disorder (SCID) was used to diagnose generalized anxiety and major depressive disorders.

The Research and Ethical Committee of the hospital gave approval for the study. Caregivers of patients that met the inclusion criteria were identified and informed about nature and purpose of the study. Each eligible caregiver was approached and written informed consent was obtained. The patients and their caregivers who met the inclusion criteria were selected consecutively from the outpatient clinic until the required sample size was reached. Anonymity and confidentiality was assured as no name was included in the questionnaires, rather serial numbering of questionnaires was used. Caregivers who were diagnosed were educated on their mental health status and counseled on the need for treatment

The Statistical Package for Social Sciences Version 16 was used to analyze the data. The association between socio-demographic variables, depression and anxiety was examined using Chi-square test. The level of significance was set at <0.05.

RESULTS

The instruments were administered to 202 caregivers of children and adolescent with seizure disorders. Two of the eligible caregivers did not complete the interview in the study, giving a response rate of 99%.

The caregivers comprised 144 females (72%) and 56 (28%) males, with a mean age (\pm SD) of 42.90 years (\pm 1.04). Majority of the caregivers were married (84.5%), and employed (84.5%). Mothers constituted 66% of the carers, while 25% of the carers were fathers.

The majority (80%) spent more than 35 h a week providing care and most (64%) have spent up to 5 years in the caregiving role [Table 1].

The patients comprised 130 males and 70 females, representing 65% and 35% of the sample, respectively. The mean age of the patients was 12.32 years (\pm 4.09). Most of them had generalized tonic-clonic seizure (65%), had been ill for <5 years (65%) and had 5 or more episodes of seizures (91.5%) before they commenced treatment in the hospital [Table 2].

Of the 200 caregivers interviewed 24 (12%) met the diagnostic criteria for generalized anxiety disorders, and 101 (50.5%) for major depressive disorders.

Psychiatric morbidity among the carers was significantly associated with older age, longer duration of care and with being patients' mother. Psychiatric morbidity was more likely in caregivers who were employed compared to those not employed or those who were retired. There were no significant relationships between psychiatric morbidity and caregivers'

Table 1: Socio-demographic characteristics of carers

Characteristics	n (%)
Age (years)	
22-30	26 (13.0)
31-40	65 (32.5)
41-50	69 (34.5)
51 and above	40 (20.0)
Mean (SD)	42.9 (±1.04)
Gender	
Male	56 (28.0)
Female	144 (72.0)
Marital status	
Single	13 (6.5)
Married	169 (84.5)
Divorced/separated	13 (6.5)
Widowed	5 (2.5)
Highest educational	
No formal	74 (37.0)
Primary	44 (22.0)
Secondary	49 (24.5)
Tertiary	33 (16.5)
Ethnicity	
Yoruba	182 (91.0)
Hausa	10 (5.0)
IGBO	8 (4.0)
Religion	
Christianity	120 (60.0)
Islam	80 (40.0)
Employment status	
Employed	169 (84.5)
Unemployed	20 (10.0)
Retired	4 (2.0)
Students	7 (3.5)
Duration of care (years)	
≤5	128 (64.0)
6-10	42 (21.0)
≥11	30 (15.0)
Hours spent caring per week (h)	
<35	40 (20.0)
≥35	160 (80.0)
Relationship to patient	
Mother	132 (66.0)
Father	50 (25.0)
Others ^b	18 (9.0)

N=200, ^aare uncles, grandparents

socio-demographic variables such as gender, marital status, or educational status [Table 3].

Patient related variables significantly associated with psychiatric morbidity among carers include long duration of illness, frequency and duration of seizures in the last 4 weeks preceding interview and occurrence of seizure in less than a week prior to the interview. Table 4 shows the relationship between psychiatric morbidity among carers and other socio-demographic/clinical characteristics in patients.

DISCUSSION

Most of the carers in this study were females (72%), with mothers of the patients accounting for 66%. Similar female preponderance has been noted in several other studies among caregivers done within and outside Nigeria. A study among caregivers of children with mental illness in Lagos, Nigeria

Table 2: Socio-demographic and clinical variables of children (patients)

Variables	n (%)
Age (years)	
3-7	33 (16.5)
8-12	62 (31.0)
13-18	105 (52.5)
Mean (SD)	12.34 (±4.16)
Gender	
Male	130 (65.0)
Female	70 (35.0)
Duration of illness (years)	
≤5	130 (65.0)
6-10	38 (19.0)
≥11	32 (16.0)
Types of seizure	
Generalized tonic-clonic seizures	130 (65.0)
Complex partial seizures	62 (31.0)
Others	8 (4.0)
Frequency of seizure before medication (monthly)	
≤4 episodes	17 (8.5)
≥5 episodes	183 (91.5)
Frequency of seizure 4 weeks prior to interview	
≤4 episodes	181 (90.5)
≥5 episodes	19 (9.5)
Duration of last seizure episode (min)	
1-3	123 (61.5)
4-6	55 (27.5)
≥7	22 (11.0)
Last episode of seizure (weeks)	
<1	74 (37.0)
1-4	31 (15.5)
≥5	95 (47.5)

reported that 80.5% of the caregivers were females with 74% of them being patients' mothers [14]. Another study reported that the majority of caregivers were females with mothers constituting about 50%. The authors posited that the cultural belief that men should work, and in most cases they are breadwinners, may have entrusted the responsibility of caring for the sick to the women [15]. A study among carers in America opined that women provided the majority of the informal care to children, spouses, friends and neighbors, and they play many roles while care giving. They act as care managers, decision makers, advocates and provide linkages with health care facilities [16]. Women are usually more closely and emotionally involved in care giving, and are traditionally expected to be involved with household work than men; thus bringing them into more contact with the patients [17].

The male preponderance among children with seizure disorders found in this study has been reported by other studies [18,19]. This may be due to the finding that the prevalence of seizure disorders is more common among male children. Some reasons suggested for this include: Males are more likely to suffer from obstetric complications, intra-uterine growth abnormalities, and post-natal injuries [20].

Generalized tonic-clonic seizures were the most common types of seizures reported in this study (65%). Aronu and Ojinnaka have reported that regarding the clinical description of seizures the three most common seizure types were generalized tonic-

Table 3: Relationship between socio-demographic characteristics of carers and psychiatric morbidity

Variables	Psychiatric morbidity				
	Yes (%)	No (%)	χ^2	Df	P value
Age (years)					
21-30	4 (15.4)	22 (84.6)	14.80	3	0.002
31-40	36 (55.4)	29 (44.6)			
41-50	38 (55.1)	31 (44.9)			
>50	23 (57.5)	17 (42.5)			
Gender					
Male	23 (41.1)	33 (58.9)	2.76	1	0.096
Female	78 (54.2)	66 (45.8)			
Marital status					
Single	3 (23.1)	10 (76.9)	5.77	3	0.123
Married	87 (51.5)	82 (48.5)			
Divorced/separated	7 (53.8)	6 (46.2)			
Widowed	4 (80.0)	1 (20.0)			
Educational status					
No formal	45 (60.8)	29 (39.2)	5.35	3	0.148
Primary	18 (40.9)	26 (59.1)			
Secondary	23 (46.9)	26 (53.1)			
Tertiary	15 (45.5)	18 (54.5)			
Ethnicity					
Yoruba	89 (48.9)	93 (51.1)	1.83	3	0.401
Hausa	7 (70.0)	3 (30.0)			
Igbo	5 (57.1)	3 (42.8)			
Religion					
Christianity	58 (48.7)	62 (51.3)	0.48	2	0.488
Islam	43 (53.8)	37 (46.2)			
Employment status					
Employed	94 (54.4)	75 (45.6)	10.41	3	0.015
Unemployed	5 (35.0)	13 (65.0)			
Retired	2 (50.0)	4 (50.0)			
Student	7 (100.0)				
Duration of care (years)					
≤5	52 (40.6)	76 (59.4)	8.36	2	0.015
6-10	26 (61.9)	16 (38.1)			
≥11	13 (76.7)	17 (23.3)			
Hours spent caring/week					
≤35	20 (50.0)	20 (50.0)	0.05	1	0.944
>35	81 (50.6)	79 (49.4)			
Relationship to patient					
Father	23 (46.0)	27 (54.0)	6.98	2	0.030
Mother	74 (56.7)	58 (43.3)			
Others	4 (22.2)	14 (77.8)			

clonic seizures (54.5%), complex partial seizures (19.2%), and simple partial seizures (10.3%)[9].

The prevalence of anxiety and depression was 12% and 50.5%, respectively among caregivers in this study. This is similar to 51.6% in Indiana in a study among carers of children with a seizure disorder. The mother’s depressive symptoms negatively impacted the child’s health-related quality of life, but the effects in that study were moderated by the amount of family resources and mediated by how well the family functions and the extent of family demands [21].

In a study among Mexican American, it was reported that 40% of caregivers of children with seizure disorders met the cut-off point for depression. The authors opined that younger caregiver’s age (contrary to findings from this study), lower levels of caregivers education and lower levels of patients functioning all contributed significantly to morbidity among caregivers [22].

Table 4: Relationship between patients’ (children) socio-demographic and clinical characteristics and caregivers’ psychiatric morbidity

Variables	Carers’ psychiatric morbidity				
	Yes (%)	No (%)	χ^2	df	P value
Age (years)					
3-7	14 (42.4)	19 (57.6)	0.996	2	0.608
8-12	32 (51.6)	30 (48.4)			
13-18	55 (52.4)	50 (47.6)			
Gender					
Male	67 (51.1)	63 (48.9)	0.16	1	0.689
Female	34 (48.6)	36 (51.4)			
Duration of illness (years)					
≤5	52 (40.0)	78 (60.0)	16.97	2	<0.0001
6-10	25 (65.8)	13 (34.2)			
≥11	24 (75.0)	8 (25.0)			
Types of seizures					
GTC*	67 (51.5)	63 (48.5)	0.38	2	0.826
CPS**	30 (48.4)	32 (51.6)			
Others#	4 (50.0)	4 (50.0)			
Frequency before medication (monthly)					
≤4 episodes	7 (41.2)	10 (58.8)	0.65	1	0.422
≥5 episodes	94 (51.4)	89 (48.6)			
Frequency in the 4 weeks prior to interview					
≤4 episodes	86 (47.5)	95 (52.5)	5.60	1	0.018
≥5 episodes	15 (78.9)	4 (19.1)			
Duration of last seizure episode (minutes) prior to interview					
1-3	43 (35.0)	80 (65.0)	30.79	2	<0.0001
4-6	38 (69.1)	17 (30.9)			
≥7	19 (86.4)	3 (13.6)			
Last seizure episode (weeks) prior to the interview					
<1	62 (83.8)	12 (16.2)	70.77	2	<0.0001
1-4	18 (58.1)	13 (41.9)			
≥5	21 (22.1)	74 (77.9)			

*Generalized tonic-clonic, **Complex partial, #Others like simple partial

Psychological health is the area of the family caregiver’s daily life that is most affected by providing care. Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their non-caregiving peers. When compared to the general population, primary caregivers are more frequently depressed and anxious, and are more likely to use psychotropic medications, and exhibit more symptoms of psychological distress, although the use of medication by caregivers was not explored in this study [23-25].

When caregivers suffer from excessive burden and high rates of depressive symptoms, the potential impact to the family, patient, employer and society can be high. Research has shown that depression is a costly disorder if it goes untreated. People with depression have been found to use 2 to 4 times more health care than people without mental illness [24]. The real costs of depression, however, are the indirect costs associated with disability and lost productivity at work when depression is not recognized or treated. It was reported that, given that two-thirds of caregivers are in the workforce, juggling caregiving, employment, and other family responsibilities, the costly impact to employers and business can be staggering [26]. It was found in the United States that lost productivity of caregiving

employees (due to many factors, including depression) may cost the nation's employers as much as \$29 billion annually [27].

Depression further depletes the caregiver's own resources, increasing care costs for both caregiver and care recipient, including earlier institutionalization of the patient.

When caregivers feel depressed and overwhelmed by their caregiving tasks, they are more likely to suffer burnout and may make the often agonizing decision to place their loved ones in a nursing home [28].

Socio-demographic characteristics of carers having significant relationship with psychiatric morbidity identified in this study included: Older age of the carers, being employed, longer duration of care, and being patients mother. These findings are similar to other studies that reported that the risks for carers' psychiatric morbidity are related to gender, age, health status, ethnic and cultural affiliation, lack of social support, as well as certain other characteristics related to the caregiver [29].

A significant relationship was noted in this study between increasing age of carers and psychiatric morbidity. As these carers get older, it could become increasingly difficult for them to perform tasks they do with relative ease when they were younger.

Furthermore, age-associated impairments in physical competence make the provision of care more difficult for older caregivers [30]. Positive association was reported between age and caregiver burden in Whites, but a negative association for African Americans, suggesting that older African Americans are less likely to experience caregiving as physically burdensome [31]. Similarly, a negative association of age and burden in African American caregivers, but no significant association in Whites was found [31].

Although some studies have reported a significant association between gender and psychiatric morbidity among caregivers, this was not replicated in this study. Also being female was not significantly associated with psychiatric morbidity in this study, but being the patient's mother was. Mothers in societies are more likely to be thrust into the caregiving role than fathers. Mothers who are carers are also more likely to be 'hands-on', that is, they tend to do everything themselves rather than delegate to others. Fathers as carers tend to have more of a 'managerial' style that allows them to distance themselves from the stressful situation to some degree by delegating tasks [32].

Longer duration of care was significantly associated with depression in this study, this supports earlier findings that longer duration of care is associated with depressive symptoms among carers in Spain [33]. This may be due to the hopelessness for a cure to the seizure disorders the carers may be confronted with, it may also be related to the feelings of guilt experienced by the carers in their caregiving role.

Being employed was also significantly associated with psychiatric morbidity in this study. This may be due to the stress of having to combine daily employment with caring for a sick child at

home. There is also the possibility of threat of job loss due to absenteeism from work, and this may provoke psychological distress.

Other characteristics of carers such as marital status, educational status, ethnicity, religion, and hours spent caring were not significantly associated with psychiatric morbidity among carers.

The age and gender of the patients did not show a significant association with psychiatric morbidity in the carers. Patients' clinical variables that was associated with psychiatric morbidity in the carers included: Longer duration of illness, frequency of seizures 4 weeks prior to the interview, longer duration of each seizure episode, and last seizure episode prior to the interview. Carers of patient with long duration of illness, long seizure episodes and with poor seizure control experienced more psychiatric morbidity. These findings are in keeping with that of Ukpong which reported that caregivers experienced a high level of burden and psychiatric morbidity while caring for their children, and this was significantly associated with caring for younger patients, who were unemployed, had longer duration of illness, had a family history of epilepsy and short seizure-free periods [34].

This study was hospital-based and conducted in only one town in a single state within the country. Thus, the findings of this study may not be generalizable to the general population in different parts of the country. A further limitation to this study was that some caregivers may have vulnerability to anxiety and depression (e.g., family history of mood disorder) even prior to caring for these patients with a seizure disorder.

This study is perhaps the first to employ a well-standardized, internationally accepted semi-structured diagnostic instrument to examine specific psychiatric morbidity among carers of children in the recently established Child and Adolescent Unit of the hospital, and so provides a background data for further researches in the unit.

CONCLUSION

Caring for patients, especially children with a seizure disorder is really challenging, and it is associated with enormous burden, and psychiatric morbidity in the carers.

Half of all the carers in this study had psychiatric morbidity. Characteristics of the carers associated with psychiatric morbidity included: Older age, being employed, longer duration of care, and being patients' mother.

The patients' socio-demographic characteristics like age and gender were not significantly associated with psychiatric morbidity in the carers. Duration of illness, poor seizure control, longer duration of seizure, and frequency of seizures 4 weeks prior to the interview were the clinical characteristics of patients that are associated with psychiatric morbidity in the carers.

Since mental ill-health among the caregivers can adversely affect the quality of care they provide for these children, it is

imperative to ameliorate some of the burden experienced by these caregivers and provide psychological intervention to them.

It is imperative for the hospital to set up a policy of offering psychological support to caregivers of children with seizure disorders attending the Child and Adolescent Clinic. This psychological intervention can be provided in group settings when these carers attend the hospital for the patients' follow-up care. There is also need to introduce or reinforce hospital-based support groups for caregivers of these children. These will help them in sharing their challenges and coping with the burden they experienced.

Further studies involving larger sample sizes and multi-centered in nature are required to assess the relationship of specific psychiatric disorders and caregiving.

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