INFLUENCE OF ILLNESS PERCEPTION AND KNOWLEDGE ON BURDEN OF CARE AMONG INFORMAL CAREGIVERS OF CHILDREN WITH SEIZURE DISORDERS IN ABEOKUTA

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ABSTRACT

Background: *Globally, there are about 50 million people living with seizure disorders, 60% of these are children. The prevalence of Children with Seizure Disorders (CSD) in Nigeria range form 8 – 13 per 1000. The burden of CSD is severe and challenging to Informal Caregivers (ICGs).Factors such as social support, religiosity and gender have been associated with Burden of Care (BoC) of CSD. However, there is a dearth of that which examined the relation between illness perception and knowledge on burden of care among informal caregivers of children with seizure disorders. This study, therefore, aimed at examining this relationship.*

Methods: *The Transactional Model of Stress and Coping guided the study. The design for this study was the cross-sectional survey. 265 ICGs were randomly selected from the register of Child and Adolescent patients attending the Neuropsychiatric Hospital, Abeokuta. The instruments used were BoC ($\alpha = 0.84$), Illness Perception ($\alpha = 0.78$), and Seizure Knowledge ($\alpha = 0.78$), Data were analysed using Multiple regression and One way Analysis at $p<0.05$ level of significance.*

Results: *The respondents' age was 33.80±8.03 years. The results indicate that caregivers with high level of illness perception scored significantly higher on burden of care than those with low level of illness perception among caregivers of children with seizure disorders $t(263) = -4.408$; $p<.01$). However, caregivers with high level of illness perception recorded a mean score of (54.56) and those with low level of illness perception recorded a mean score of (45.60).*

Conclusion: *It was concluded that burden of care among caregivers of children with seizure disorders were determined by illness perception and seizure knowledge.*

Key words: *Informal caregivers, Seizure disorders among children, Burden of care,*

INTRODUCTION

Epilepsy is a general term for conditions with recurring seizures that present as unusual electrical discharge in the brain. Such brain activity may lead to involuntary changes in the body sensation, movement, and behaviour. Epilepsy is a chronic non-communicable condition that has been identified as a worrisome serious public health problem impacting around 50 million people globally (WHO, 2012). It is most commonly diagnosed neurologic condition in children, impairing around 10.5 million children worldwide. (Guerrini, 2006). Its prevalence rate was reported by studies across Nigerian-based hospitals to range from 45.3–74.5% (Ogunlusi, Ogundeyi and Olowu, 2009; Iloeje and Paed, 1989; Izuora and Iloeje, 1989).

Children with seizure disorders depend on people, most commonly their family members, for care and support. Caregiving for this category of children could either be formal or informal. Formal caregivers are healthcare professionals such as physicians especially neurologist and psychiatrist, psychologists, trained nursing staff, occupational therapist, and other professionals who work in clinics, and residential facilities such as nursing homes. While informal caregivers are often family and relatives who continue to be the first, most dependable, and suitable source of care and help for the child, they also serve as a link to the formal caregivers.

The functions of informal caregivers include both direct and indirect activities depending on the stage and type of seizures. Informal caregivers' direct involvement in caregiving ranges from the delivery of personal care activities which include; assisting with grooming, putting on clothes, toileting, taking a bath and dressing, to the provision of supportive healthcare tasks such as supervision of medications. The indirect involvement of informal caregivers varies from searching for treatment centers for their loved ones and organizing their hospital visit to helping them in their everyday tasks such as cleaning, cooking, shopping (Noelker and Bass, 1994).

In their effort to fulfill these roles, some informal caregivers have to stop their work or reduce their working hours. This inherently produces ill-feelings such as resentment (towards tthe child? and isolation as well as financial challenges (Catherine, 1999). Informal caregiving also has other significant impacts on the carer's life such as; disruption of work routines and family roles, privacy violation, limiting their social and pleasurable activities, to mention but a few (Reinhard, Given, Petlick and Bemis, 2008). Caring for sick children who require specialised care owing to the nature of their condition may be a difficult task full of unexpected roles, extra responsibilities, and multiplied strain. The difficulty caused by these complicated duties was thus referred to as carers' burden or caregivers' strain.

Caregivers' burden, as defined by Zarit, Reever and Bach-Peterson (1980), is the degree to which caring tasks are seen to produce negative effect on all areas of a caregiver's life (social life, leisure, health, privacy, finances, sometimes marriages). The concept of burden is divided into two categories: subjective and objective burdens. The mental implications on the families, including the relatives' assessment of the situation and its perceived severity, are referred to as subjective burden. Objective burden, on the contrary, pertains to outwardly measurable distress experienced by close relatives, such as economic hardship, constriction to social relations, reduction in overall help and assistance received, maltreatment, interruptions of daily chores of caregivers and family members, as well as recreational time. Informal caregivers of children with seizure disorders constantly worry about the display of embarrassingly disruptive conduct, debilitating symptomology, self-harm, and feeling guilty of being responsible for the child disease conditions (Bioku, Ohaeri, Oluwaniyi, Olagunju, Chaimowitz and Olagunju, 2020).

Caregivers` knowledge about seizure disorders may determine their response and their coping strategies. Understanding informal caregivers` knowledge about seizure disorders is an important early step in improving their child's care. Several earlier studies in developing countries have shown that there is a strong belief that supernatural powers and spirits are the cause of seizure or epilepsy (Somasundaram, 2001; Kaculini, Tate-Loone, and Seifi. 2021). Successful treatment of seizure disorders in rural areas is largely influenced by the prevailing beliefs and attitudes. The major reasons for non-accessibility of treatment plus poor compliance with medication include; failure of informal caregivers to understand the nature of seizure disorders, their drug administration principles, and the side effects of medications. This inherent knowledge gap among informal caregivers might account for the high level of stigmatized attitude of caregivers, which in turn makes seizure disorder carry a high burden of social morbidity on their children.

Furthermore, informal caregivers' awareness and perceptions of their children's convulsions may be driven by their views on sickness and treatment. Illness cognitions are basic assumptions about sickness (Leventhal & Nerenz, 1985) and give an approach for dealing with and comprehending sickness. Health beliefs were demonstrated to impact therapy and preventative measures for a variety of diseases (Bebbington, 1995). As a result, it is possible that disease perception plays a role in the strain experienced by those providing informal care. This can have a major effect on care-seeking behaviour and compliance to prescribed interventions

(Barrowclough, King, Colville, Russell, Burns and Tarrier, 2001). Quite a lot of factors have been reported to have influenced the burden experienced by caregivers (Goncalves-Pereira, Xavier, van Wijngaarden, Papoila, Schene and Caldas-de-Almeida, 2013), including illness duration. How long informal caregivers have been involved in caring for a child with seizure disorders might determine the level of burden experienced by them. Studies among other samples of caregivers have yielded an inconclusive result about the nature of this relationship (Inogbo, Olotun, James, and Nna, 2017; Gulpak and Kocaoz 2014). Therefore, there is a need to reexamine this relationship as caregivers' illness perception and their level of knowledge could influenced their attitude towards treatment seeking behaviour as well as adherence to medication regimen.of their children thereby complicating the health status of their children as non medical treatment has been shown to lead to mental illness and other neurological complications. The aftermaths of this might be increase in burden of care.

Hypotheses

1. Illness perception and seizure knowledge will have significant inverse relationship with burden of care among caregivers of children with seizure disorders..

2. Caregivers with high level of illness perception will score significantly higher on the measures of burden than caregivers with low level of illness perception among caregivers of children with seizure disorders.

3. Caregivers with high level of seizure knowledge will score significantly lower on the measures of burden than caregivers with low level of seizure knowledge among caregivers of children with seizure disorders.

4 Illness perception, seizure knowledge, age, gender and educational level will jointly predict burden of care among caregivers of children with seizure disorders

METHOD

Research Design

A cross-sectional survey with an ex-post facto design is the study design of choice for this part of the research. The ex-post facto design was adopted because the study's main variable (burden of care) was already present in the individual before to the investigation. The participants were not manipulated in any way.

Population and Setting

The setting for this study was the Child and Adolescent Clinic at the Neuropsychiatric Hospital in Aro, Abeokuta, Nigeria, was the location for this study. This preference was based on the accessibility to the research participants in adequate number as specified in the study. The choice of this study setting was based on the popularity, proximity and accessibility of caregivers who bring their children for treatment.

Sampling Technique

Cochran's (1963) formula was used to determine the sample size for this study. A total of two hundred and sixty-six (266) participants were selected using a simple random sampling technique. A list of participants that met the inclusion criteria of maintaining a living quarters with the care recipient for at least 6 months prior to the study and has had a child under the age of 18 was compiled from the medical record department. Participants with odd serial numbers from the list were selected until the desired 266 sample size was obtained. The frequency distribution results showed that out of the two hundred and sixty six (266) participants who completed the questionnaires, one participant's responses was not enough to be included in the final data analysis. Therefore, a total of 265 participants were used in the final analysis. Of these, 229 were Yoruba (86.4%), 24 were Igbo (9.1%), and 7 were Hausa (2.6%) while 5 were from other ethnic groups (1.9%). 200 (75.5%) of these participants were female while 65 were males (24.5%). 12.5% of the respondents did not attend school (33), 22.3% had first school leaving certificate (59), 30.9% (82) had senior secondary certificate of education (SSCE) and 12.8% (34)acquired national certificate of education / ordinary national diploma (NCE/OND), 16.6% (44) had higher national diploma or bachelor of science degree (HND/BSc while 4.9% possess a postgraduate degree (13). 15.1% of the respondents who participated in this study work as office assistants (40) , 38.9% were traders (103), 13.2% were teachers (35), 0.8% were poultry workers (2), 10.9% were civil servants (29), 6.8% were farmers (18), 2.3% were bankers (6), 0.8% were attendants (2), 1.1% were drivers (3), 0.8% were self-employed (2), 0.8% were technicians (2), 4.2% were artisans (11), 1.1% were engineers (3), 1.5% were nursing officers (4) while 1.9% were students (5)

Measuring Instruments

Section A: Caregivers Socio-Demographic Variable Questionnaire

This was designed and used by the researcher to receive data on the carers' socio-demographic characteristics, which include gender, age, religion, marital status, academic credentials, relation to the client, and mean spent hours with the patient.

Section B: Zarit Burden Interview

The Zarit Burden Interview was a 22-item inventory that measure caregiver burden. The 22 items were negatively phrased questions or comments with a 5-point Likert answer scale ranging from 0 to 4. The score ranges from 0 to 4, with the summation being the highest. All items have a score range of 0 to 88, with higher scores suggesting greater burden (21–40: mild-to-moderate burden, 41–60: moderate-to-extreme burden, 61–88: severe burden). It has a Cronbach's alpha of 0.82 to 0.93 for internal accuracy and 0.88 for test-retest reliability. In this study, the reliability was reported to have a Cronbach's alpha of 0.84 and divergent validity when correlated with the seizure knowledge scale ($r=0.54$, $p < .05$)..

Section D: Caregivers' Illness Perceptions Questionnaire –Brief (IPQ-Brief)

This scale contains eight items as well as an additional component that looks at the causal factors. Except for the ninth item, which looked at the causal factors, the other eight items on the scale had a Likert-type rating range of 0 to 10. The scores for Items 3, 4, and 7 are reversed and added to the scores for Items 1, 2, 5, 6, and 8. A higher score indicates that the individual is more concerned about the illness. In this analysis, the scale had a Cronbach's alpha 0.78 and the concurrent validity of r .32, $p < .05$ when correlated with the neuroticism scale. There was a significant positive relationship between illness percept and neuroticism scale.

3.2.6.5 Section F: Caregivers' Seizure knowledge scale.

The Caregiver Seizure Knowledge scale was developed by the researcher to measure caregivers' knowledge about seizure disorder in Nigeria. It consists of 7 items that are score on a 5-point Likert format ranging from 1= strongly disagreed, 2= disagreed, 3=undecided, 4=agreed to 5=strongly agreed. Item 1, 4 and 7 were reversely scored. A high score on the scale indicates high knowledge about seizure disorder. The instrument recorded a Cronbach alpha of 0.78 and convergence validity of 0.37 when correlated with 34 items relating to medical aspects of epilepsy adapted from the Epilepsy knowledge questionnaire developed by Jarvie, Espie, Brodie (1993).

Data Collection Procedure

Permission was obtained from ethical committee of the hospital. One caregiver per child was screened for eligibility based on the inclusion criteria. A list of all eligible participants was compiled from the medical record department comprising of seven hundred and forty (740) of which participants with odd serial numbers on the list were selected. Caregivers who refused to participate were allowed without any form of victimization and another caregiver was selected from the sample frame based on their number to replace them until the sample size was completed. Each selected caregiver was then approached at the time of their clinic visit or called to invite them for the study after the researcher had obtained their informed consent. They were requested to pick a date convenient for them within the stipulated time frame of 4 months (August to November 2017). The questionnaires were given to them to fill. The Yoruba version of the questionnaires was administered to the respondents that requested to have their own in the Yoruba language while the English version was administered to respondents who requested their own in the English language. All the questionnaires administered were collated and subjected to data cleansing of which one (1) of the respondents was discovered not to have provided sufficient information worthy of analyzing. Therefore, this individual was excluded from the analysis

Statistical Analysis and Data Management

Data obtained was analysed using the Statistical Package for the Social Sciences (SPSS). Descriptive statistics such as frequency, mean, standard deviation, and variance were conducted to describe the participants' information. Hypotheses were tested using multiple regressions, ANOVA and T-test for the independent samples. The reliability analysis of the study instruments were examined and reported as local reliability for future reference.

RESULTS

Hypothesis One

Illness perception and seizure knowledge will have significant inverse relationship with burden of care among caregivers of children with seizure disorders. The hypothesis was analyzed with zero order correlation statistics and the result is presented in table 1.

Table 1 Zero-order correlation showing the relationship between illness perception and knowledge of seizure on caregiver burden

	Mean	S.D	1	2	3
Caregiver burden	**22.30**	**11.16**	**-**	**.41****	**-.32****
Illness perception	**52.12**	**14.93**		**-**	**-.33***
Knowledge of seizure	**9.80**	**4.08**			**-**

**. Correlation is significant at the 0.01 level (1-tailed).

The result shows that there was a significant positive relationship between illness perception and caregiver burden (r=.41, p<0.05). The result implies that an increase in illness perception will significantly increase caregiver burden. However, there was a significant negative relationship between knowledge of seizure and caregiver burden (r=-.32, p<0.05). The result shows that an increase in the knowledge of seizure will significantly decrease perception of threat thereby reducing caregiver burden.

Hypothesis Two

Caregivers with high level of illness perception will score significantly higher on the measures of burden than caregivers with low level of illness perception among caregivers of children with seizure disorder. The hypothesis was tested with t-test for the independent samples and result is presented.

Table 2: Summary of t-test for the independent samples showing the influence level of Illness perception on burden of care

	Illness Perception	N	Mean	S.D	**df**		**T**
Burden Of Care	High	125	54.56	9.38	263	-4.408	.01
	Low	140	45.60	7.31			

Table 2 results indicate that caregivers with high level of illness perception scored significantly higher on burden of care than those with low level of illness perception among caregivers of children with seizure disorders t(263) = -4.408; p<.01). However, caregivers with high level of illness perception recorded a mean score of (54.56) and those with low level of illness perception recorded a mean score of (45.60). This result implies that there is significant different in level of illness perception among caregivers of children with seizure disorders. Hence, the hypothesis was supported.

Hypothesis Three

Caregivers with high level of seizure knowledge will score significantly lower on the measures of burden than caregivers with low level of seizure knowledge among caregivers of children with seizure disorders

Table 3: Summary of t-test for the independent samples showing the influence level of seizure knowledge on burden of care

	Seizure knowledge	N	Mean	S.D	**df**	**T**	
Burden of care	High	90	33.01	3.42	263	-5.107	.01
	Low	175	67.20	12.01			

Table 3 results reveal that caregivers with high level of seizure knowledge scored significantly lower on burden of care than those with low level of seizure knowledge among caregivers of children with seizure disorders t(263) = -5.107; p<.01). However, caregivers with high level of seizure knowledge recorded a mean score of (33.01) caregivers with low level of seizure knowledge recorded a mean score of (67.20). This result suggests that there is significant difference in level of seizure knowledge among caregivers of children with seizure disorders. Hence, the result confirmed the stated hypothesis and it is accepted in this study.

Hypothesis Four

Illness perception, seizure knowledge, age, gender and educational level will jointly predict burden of care among caregivers of children with seizure disorders. This hypothesis was tested using multiple regressions and the results are presented on table 4:

Table 4: Summary of Multiple Regressions showing the Influence of illness perception, age gender and educational level **on burden of care.**

Predictors	β	T	p	R	R^2	F	P
Gender	-.15	-3.12	<.05	.78	.44	53.72	< .05
Age	.02	.15	> .05				
Seizure knowledge	-.21	-5.12	<.05				
Illness perception	.43	11.30	<.05				
Educational level	-.03	-.51	>.05				

The results in table 4 showed that illness perception, seizure knowledge, age, gender and educational level jointly predicted burden of care among caregivers of children with seizure disorder, F(261) = 53.72, R^2 = .539; p < .05). This implies that illness perception, age, gender and educational level jointly accounted for about 44% variance in burden of care while the remaining 56% could be attributed to other variables not considered in this study. However, the analysis of the independent predictions indicated that illness perception (β = .43; t =11.30; p<.05), seizure knowledge (β = -.21; t = -5.12; p<.05) and gender (β = -.15; t = -3.12; p<.05); predicted significant independent influence on burden of care among caregivers of children with seizure disorders. Therefore, the stated hypothesis is supported by the result obtained and it is accepted in this study.

Discussion

The first finding revealed that burden of care increases illness perception of caregivers while it was observed that caregivers who were high on seizure knowledge reported low level of burden in this current study. This means that an increase in the knowledge of seizure will significantly decrease perception of threat thereby reducing caregiver burden. When caregivers have sufficient information about management of child's illness, their initial perceived threat about the illness is lower thereby putting them in advantageous position to better manage their children. This finding is in line with the common-sense model which explains the dynamics of interaction among the variables controlling health behaviours in response to threats. This model view illness perception as a direct influence on one's coping strategies which in this case is the caregivers' knowledge of seizure thereby determine the level of burden a caregiver might experience (Leventhal, Philips and Burns, 2016). According to the transactional model of stress and coping, carers primarily feel burdened because they believe their coping abilities such as knowledge are inadequate to fulfil the present needs of care giving.

The finding also revealed that caregivers with high level of illness perception will score significantly higher on the measures of burden than caregivers with low level of illness perception among caregivers of children with seizure disorders. When caregivers perceived their child's seizure as being threatening, they are suddenly overwhelmed with fear and anxiety associated with the illness thereby living them trapped and not knowing what to do. This condition hinders their ability to seek help for their children thereby worsening the health out of their children which increase the burden of care. This finding showed that there is a significant different in level of illness perception among caregivers included in the present study. This result supports the transactional theory in that person's perceptions about sickness, encompassing both the perceived actuality of the health threat and emotional reactions to that threat. The current finding indicated that caregivers with high level of illness perception significantly higher on burden of care than those with low level of illness perception among caregivers of children with seizure disorders The current finding is in keeping with Elsheriff, Behilak and Abdelraof (2020) studied that found a significant positive relation between illness perception and burden of care.

More so, findings also investigated whether caregivers with high level of knowledge about seizure disorders will score significantly lower on the measures of burden of care than those with low level of seizure knowledge. The result shows that caregivers with high level of knowledge were significant different in level of burden experienced when compared to those with low level of knowledge among caregivers included in the current study. This finding is in line,with Anab, Onyango, and Mwenda (2018) who observed that careers of individuals with schizophrenia's knowledge and attitude had an impact on the burden of care. Likewise, a related study reported caregivers' lower educational status as a predictor of higher burden of care (Inogbo, Olotu, James, &Nna, 2017). From a theoretical perspective, these findings are in keeping with the conservation of resources theory which proposed knowledge as one of the coping resources that help in the attainment of other resources (Stevan, 1989). Thus, it may be suggested that caregivers' knowledge about seizure disorders reduces their anxiety about their child's illness as well as lowers their perception of seizure disorders as being threatening. This may act as a catalyst to building their resilience and ability to cope with stress arising from their care giving roles.

Finally, finding also examined illness perception, seizure knowledge, gender, age and educational level as a significant joint predictor of burden of care among caregivers of children with seizure disorders. The result shows that illness perception, seizure knowledge, age, gender and educational level jointly predict burden of care. However, further analysis of the independent predictions indicated that illness perception, seizure knowledge, and gender predicted significant independent influence on burden of care among caregivers of children with seizure disorders included in the current study. This means that the level of burden experience is determined by the biological made of being male or female. This finding was in line with Roser, Jesus, Maria & Nuria (2018) who reported higher burden among female caregivers than male.

Similarly, carers' understanding of seizure condition was found to have a negative impact on the degree of hardship they experienced. This means that the higher the degree of burden experienced by caregivers, the lower the level of knowledge. This finding is in line with that of Anab, Onyango, and Mwenda (2018) who observed that careers of individuals with schizophrenia's knowledge and attitude had an impact on the burden of care. From a theoretical perspective, these findings are in keeping with the conservation of resources theory which proposed knowledge as one of the coping resources that help in the attainment of other resources (Stevan, 1989).

In the same vein, caregivers' illness perception played a pivotal role in burden of care. This study found that an increase in caregiver's perception of threat will directly increase the level of burden experienced by them. This result concurs with the observation of Dempster (2011) who reported a significant influence of illness perception on the burden of care among caregivers of cancer patients. Besides, the result of this study is in support of Osei (2015) who examined the role of illness perception in caregiver burden among family members and found a significant positive relationship between perceiving illness and caregiver's burden. An explanation may be offered for this observation in that caregivers' understanding of the seizure disorder in terms of its cause and treatment goes a long way in determining their desire to seek and adhere to treatment. In this line of reasoning, treatment is likely to reduce seizure episodes thereby lowering the burden experienced among caregivers of children with seizure disorders.

Conclusion

In conclusion, based on the findings of the present study, there was a significant influence of illness perception and seizure knowledge on burden of care among caregivers of children with seizure disorders. Therefore, future research should broaden the scope of this study by looking at other psychosocial variables such as caregivers' personality , child illness characteristics, and stigma in addition to the variables used in this study to see if they have an impact on caregiver burden among children with seizure disorders.

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