

Neurological Disorders In Children: The Multidimensional Impact Of Caregiving On The Caregivers In Benin City, Nigeria

Caroline Edekie Ofovwe¹, Samuel Obateru Osasona², Gabriel Egberue Ofovwe³

1. Department of Mental Health, School of Medicine, University of Benin, Benin

2. Department of Medicine (Mental Health unit), Faculty of Clinical Sciences, Edo University, Iyamho

3. Department of Child Health, School of Medicine, University of Benin, Benin City

Corresponding Author

Name: Osasona S.O

Department of Medicine (Mental Health unit), Faculty of Clinical Sciences, Edo University

Email: samuelsosasona@gmail.com

Abstract

DOI: <https://doi.org/10.64052/qpqf2c73>

Background: Caregivers of children with chronic neurological disorders experience significant multidimensional strain associated with caregiving. A better understanding of the specific dimensions of caregiving impact will enhance, not only the child's treatment outcome but also the caregiver's well-being and quality of life. This study aimed to assess some specific dimensions of impact of caregiving; financial, socio-familial, personal strain and mastery; on the caregivers and determine their association with the socio-demographic and clinical variables of the caregivers and patients.

Methods: A cross-sectional analytical study was conducted among 136 caregivers of children with neurological disorders and their affected children at the consultant outpatient clinic, University of Benin Teaching Hospital (UBTH), Benin City. The Impact-on-Family Scale and a socio-demographic data sheet were used for data collection; statistical analysis was done using version 22 of SPSS at $P < 0.05$ level of statistical significance

Results: 51.5% of respondents reported high overall impact of caregiving; 35.3% reported high financial impact; 41.9% reported high social/familial impact; 38.2% reported high personal strain; and 36.0% reported high mastery. Bivariate (Chi2 and Pearson correlation) analyses showed that high impact of caregiving on the following dimensions had statistically significant association with the corresponding variables: Overall Impact/being married, $X^2=6.501$, $P=0.039$; Financial impact/diagnosis of seizure and Position of the affected child in the family, $X^2=6.464$, $P=0.039$ and $r=0.171$, $P=0.047$ respectively; Social/familial impact/duration of illness, $r=0.206$, $P=0.038$; Personal strain/duration of illness, $r=0.277$, $P=0.005$; and Mastery/level of education, $X^2=6.464$, $P=0.039$. Only a diagnosis of seizure disorder retained statistically significant association with high financial impact at the logistic analysis level but the odds was reduced compared with that of the reference category ('other' neurological disorders, such as Autistic disorder and congenital anomaly) ($P=.018$, OR=.272; 95% CI=.093-.799).

Conclusions: Caring for children with neurological disorders has a significant impact on multiple dimensions of the caregivers' lives and families. The need to reduce the burden of neurological disorders in children through preventive measures, prompt treatment and caregiver support is critical. It is recommended that hospital management or local health ministry implement neurological disorders management subsidies, Caregiver Support Group or social work integration for parents or caregivers of children with seizure disorder to mitigate their financial strain.

Keywords: Neurological Disorder, Children, Caregivers, Impact, Nigeria

Introduction

Neurological disorders (NDs) are diseases of the central and peripheral nervous systems which occur due to structural, biochemical or electrical abnormalities in the brain, spinal cord, cranial or peripheral nerves.¹ According to the World Health Organization (WHO), NDs are any diseases affecting the entirety of the nervous system² and are common in children in African countries^{3,4} including Nigeria.⁵ Neurological disorders in children (NDC), mostly have durations that are unpredictable⁶, but most cases run a chronic course⁵; that is, they may disturb the daily functions of the affected individual for at least three months out of a year⁵ or demand hospitalization for more than one month.⁷

Reports from many previous studies suggest that, cerebral palsy, seizure disorder, neonatal jaundice and speech impairment, are common neurological diagnoses in children^{8,9}, and implicated causative factors include: genetic factors, hypoxia, neonatal jaundice, infections, injuries and adverse perinatal events^{9,10,11}, trauma to the spinal cord and exposure to toxic chemicals^{9,10,11}; while risk factors may include: poverty, low level of education, cultural or traditional practices, absence of basic healthcare facilities and dearth of professionals.¹² NDC often manifest as muscle rigidity, incoordination, cognitive impairment and delayed developmental

milestone.¹¹

As far back as over a decade ago, Idro and his colleagues, reported that child neurological and neurodevelopmental disorders are prevalent in developing world, including Africa.¹³ The high prevalence rates reported by many previous studies^{3,5} seemed to be in keeping with that observation. However, reported prevalence rates in Africa, especially Nigeria are as varied as the number of studies; ranging from a low 1.4% in Port Harcourt, Nigeria¹⁴; 6.1% in Kenya¹⁵; 9.6% in Sagamu, Nigeria⁵ to a high 21% in Ibadan, Nigeria³ among children attending paediatric clinics in different tertiary health institutions. By implication, increasing rates of children with neurological disorders (CNDs), invariably, leads to a proportionate increase in the prevalence of their caregivers.

Besides the issue of chronicity, NDC are often associated with long term morbidity, disability, functional limitation and dependence.⁸ Bajraszewski, reported that NDs are the major causes of disability in children. Consequently, caring for CNDs impose significant strain on the caregivers¹⁶. In Nigeria and other African countries, the primary caregivers of individuals with chronic illnesses are the family members, and in CNDs, the mothers are the caregivers in overwhelming majority of cases.⁶ The care demands of the affected child can negatively impact the caregiver physically,

psychologically and socio-economically. They suffer physical exhaustion, impaired quality of life, stress, depression, poor social support and distressing financial constraint.¹⁷ Thus, they have been referred to as the second victims of the disease to underscore the magnitude of stress they undergo.¹⁸ Operationally, “impact”, in this study, denotes the effects of a child's illness on the caregiver or family system and the theoretical framework is that changes occur in the family because of illness, forcing adaptations in the family environment.¹⁹ The authors conceptualized the impact of caregiving for CNDs in four dimensions based on Stein et al, model of multidimensional impact of caregiving on the family.¹⁹ Thus, four dimensions of impact: Financial, Social/familial, Personal strain, and Mastery were examined. The financial, social/familial and personal strain in negative sense, connote the strain imposed on the caregiver, while caregiver's mastery is a positive view of one's ability and ongoing behaviour during the caregiving process.²⁰ Empirical evidence indicates that caring for CNDs could cause profound financial stress; the caregiver or the entire family suffers financial disadvantages due to the care needs of the affected child.⁸ Undoubtedly, the financial impact could be worse in poor, developing countries like Nigeria due to limited resources.²¹ Financial impact or stress may arise from difficulty in balancing family and work, outright inability to participate in financially gainful jobs, employment loss, huge expenditure on transportation, medication, expensive investigations, and the need for multidisciplinary approach to management.⁸ The prevailing economic hardship in Nigeria as well as the poor insurance coverage could complicate the financial impact of caring for CNDs in the country. Significant restriction in the social and family life of caregivers is also an important dimension of impact. Neurological disorders in children have implications that extend beyond the affected child as the entire family structure and the social milieu of the primary caregivers are seriously impacted.⁶ The lack of, or little social support for the caregivers is, perhaps, a major social issue in Nigeria as the burden of caregiving is largely borne by the caregivers, especially the mother of the affected child.⁹ In previous qualitative studies, caregivers reported lack of adequate time to care for other members of the family, marital conflicts and arguments in decision making and other care-related matters,⁹ increased social isolation and prejudice.²² The impact of caregiving on the physical and mental health of caregivers constitute varying degrees of personal strain on them; they experience significant pain²³, chronic stress, somatic symptoms,²⁴ burnout, fatigue depression and anxiety.²² Mastery is a sense of control that one perceives over his/her life situation and, generally, it can reflect one's ability to cope with and adapt to challenging situations.²⁵ In the context of caregiving, mastery plays an important role in intervening in the process of stress. Empirical evidence indicates that low level of mastery could increase caregivers' burden and psychological disturbances while a high level could be associated with less stress and emotional consequences.²⁵ Despite the huge impact of caregiving on them, caregivers are often neglected; yet, their well-being is crucial to the success of treatment of the care recipients. This underscores the imperative of more

research to elucidate the dimensions of impact on them, with a view to providing the necessary support and interventions. Though many researchers within and outside Nigeria have examined the pattern of neurological disorders in children as well as the burden associated with caring for the affected children,^{5,11,12,19} literature is grossly inadequate on the impact of caregiving for CNDs in specific dimensions of caregivers' lives. The aims of this study, therefore, were to examine the multidimensional impact of caring for CNDs on the caregivers with specific focus on financial, socio/familial, personal strain and mastery, and to determine the socio-demographic and clinical variables that influence them. It is hoped that the findings will further enrich existing literature on this topic and guide relevant interventions.

Methods

Study Location and Design

The study was conducted at the outpatient paediatric neurology clinic of the University of Benin Teaching Hospital, an 850-bed-capacity tertiary health institution located in Benin-City, Edo-State, South-South zone, Nigeria. The paediatric neurology outpatient clinic is one of the many specialized outpatient clinics in the hospital and it receives referrals from the other units of the Child health department, the general practice clinic of the hospital, and other hospitals from within and outside Edo-State, including private health institutions. The clinic is run twice in a week by consultant paediatric neurologists, assisted by resident doctors in the unit. A cross sectional analytic design was adopted and data collection lasted from February to June 2023.

Study population

Caregivers of children (patients) diagnosed with neurological disorders who accompanied their children/wards to the hospital were recruited into the study and they provided information about the children.

Eligibility Criteria

Only primary caregivers of children aged 17 years and below with established neurological disorder, who had cared for the child for at least six months and consented to participate in the study were considered eligible to participate.

Sample size determination

The sample size for this study was calculated using single population proportion formula,
$$\frac{z^2 p q}{d^2}$$

where z = constant standard deviation usually set at 1.96 (at 95% Confidence level), p = estimated prevalence of social burden/impact of caregiving among caregivers of children with neurological disorders in a previous study (10%)⁸, $q = 1 - p$ and d = degree of accuracy set at 0.05.²⁶ The calculated minimum sample size in this study was 134. However, to compensate for anticipated questionnaire rejection due to incomplete data and to enhance the statistical power and reliability of the study, a 50% non-response rate was added to the calculated size bringing the total targeted sample size to 202.

Measures

The questionnaire used for data collection in this study consisted of two sections:

Section A: A socio-demographic and clinical profile collection sheet; designed by the authors to collect information that are related to respondents' demographic profile.

Section B: The Impact-on-Family Scale, a formal standardized measure of the effects of chronic childhood illness on the caregiver/family, developed by Stein and his colleague.¹⁹ It's a 24-item scale consisting of four sub-scales: Financial, Social/familial, Personal strain, and Mastery with demonstrable internal consistency reliability. Cronbach's coefficient were, 0.72, 0.86, 0.81 and 0.60 respectively¹⁹. Its usefulness for cross-cultural comparison and application has been established.²⁷ In this study, the Cronbach's coefficient were 0.73, 0.79, 0.74 and 0.67 respectively. On each scale, respondents were asked to rate the items on 4-point Likert Scale to what degree the statements applied to them or the family (strongly agree to strongly disagree). The maximum obtainable scores were 16, 36, 24 and 20 on the Financial, Social/familial, Personal strain, and Mastery scales respectively; a total scale score was also generated as a measure of overall impact with a maximum score of 96. The higher the score on each subscale the greater the impact of the illness on that dimension of caregiving, while the total score indicates the level of overall impact of caregiving.

Mastery, is conceptualized as a positive coping resource, wherein caregiving is regarded as having a positive impact or adaptation on the caregiver whereas, Financial, Social/familial and Personal strains are adverse outcomes of caregiving. The term "Overall impact" as described by Stein and his colleague¹⁹ describes the summation of both categories of impact.

Operational definition of occupational skills

The International classification of occupational skill levels according to International Labour Organisation (ILO) was adapted in this study. The adapted version is a four-level classification of occupation groups; it's structure follows a grouping by education level and the skill levels were derived from corresponding both categories of the International Standard Classification of Occupations (ISCO-88 and ISCO-08) adopted in 1987 and 2008 respectively²⁸

Skill level 1: Elementary occupations- cleaners and helpers, refuse workers and other elementary workers

Skill level 2: Clerical support workers, service and sales workers, skilled agricultural, forestry and fishery workers, craft and related trades workers.

Skill level 3: professionals, Technicians and associate professionals.

Skill level 4: Legislators, senior officials and managers.

Ethical consideration

The study was conducted in accordance with the Helsinki declaration and the proposal was approved by the Health Research Ethics Committee of the University of Benin Teaching Hospital with a protocol number: ADM/E22/A/VOL.VII/483117171. All participating caregivers were informed that the study was confidential and anonymous, and that participation was voluntary. Verbal informed consent was obtained from all participants.

Procedure/data collection

Data collection was done by one of the investigators, assisted by resident doctors in paediatric neurology unit. On each clinic day, consecutive caregivers of children diagnosed with a neurological condition were approached after explaining the purpose of the study and following ethical protocols, consent was obtained from those who met the eligibility criteria. Thereafter, the study questionnaires were administered to the caregivers and retrieved immediately after

being filled. Some clinical information concerning the affected children were confidentially extracted from their case notes.

Statistical analysis

Retrieved questionnaires were checked for completeness and accuracy and data were entered into SPSS version 22, which was used to analyse the data as follows:

For the purposes of some statistical analyses such as Chi², categorical ranking of some socio-demographic and clinical variables were done, for example, scores on the IOFS were dichotomized at the mean score cut off, such that scores equal to and above the mean point ($\geq$) were classified as "high impact" and vice versa; frequency distribution and percentages were computed to describe the categorical variables; Chi-square test was performed to test the association of impact of care with some socio-demographic variables of the respondents and patients, as well as the clinical variables of the patients. Pearson correlation analysis was performed (assumption of normality for the use of parametric test was met by the data) to assess the relationship between impact of caregiving and some other continuous variables. Variables that had significant association with impact of caregiving in the bivariate analyses were simultaneously entered into multiple logistic regression model to determine independent predictors of impact of care, with impact as the dependent variable. Statistical level of significance was set at $P < 0.05$.

RESULTS

A total of 201 respondents (dyad of caregivers and their affected children) participated in the study having been considered eligible and consent given. However, 136 questionnaires were subjected to statistical analysis; 65 were excluded on account of incomplete data.

Caregivers' socio-demographic characteristics

One hundred and five (77.2%) of the respondents (caregivers) were patients' mother while 18(13.2%) were fathers, 109 (80.1%) were females, majority (83.1%) were Christians, and 112 (82.4%) were married. Their mean age was 38.30 ± 9.58 years. The highest proportion of the respondents (46.3%) belonged to occupational skill level 2 and 68 (50.0%) had tertiary level of education (Table 1).

Patients' socio-demographic characteristics

Eighty (58.8%) of the patients (children) were males while 56(41.2%) were females. Sixty seven (49.3%) were being managed for seizure disorders while 38(27.9%) were receiving treatment for cerebral palsy (Table I). Patients' ages ranged from 5 months to 17 years and the mean age was 5.59 ± 5.13 years.

Table I: Socio-Demographic Characteristics of Respondents

Variables	Frequency (n = 136)	Percentage (%)
Respondent's relationship with patient		
Mother	105	77.2
Father	18	13.2
Grandmother	6	4.4
Sister/Aunt	7	5.2
Respondent's Sex		
Male	27	19.9
Female	109	80.1
Religion		
Christianity	113	83.1
Islam	23	16.9

Marital Status		
Single	13	9.6
Married	112	82.3
Previously married	11	8.1
Family Type		
Monogamy	115	84.6
Polygamy	21	15.4
Occupation (n=123)		
Skill level 1	13	10.6
Skill level 2	57	46.3
Skill level 3	49	39.8
Skill level 4	4	3.3
Level of Education		
Primary	21	15.4
Secondary	47	34.6
Tertiary	68	50.0
Respondent's spouse's occupation Category (n=113)		
Skill level 1	1	0.9
Skill level 2	56	49.6
Skill level 3	47	41.6
Skill level 4	9	7.9
Respondent's spouse's level of Education (n=87)		
Primary	7	8.1
Secondary	31	35.6
Tertiary	49	56.3
Patients' Sex		
Male	80	58.8
Female	56	41.2
Patients' Diagnosis		
Seizure disorder	67	49.3
Cerebral palsy	38	27.9
Delayed development	22	16.2
*Others	9	6.6

*Others= Meningitis, cerebral malaria, Autistic disorder, congenital anomaly

Respondents' scores and impact of caregiving on the different dimensions

Respondents had an overall mean score of 60.15 ± 13.54 on the IOFS, and the mean scores on its subscales: financial, social/familial, personal strain and mastery were: 11.38 ± 2.83 ; 20.04 ± 5.96 ; 14.04 ± 4.68 and 15.19 ± 3.54 respectively. Regarding the impact of patient care on the respondent/family, 51.5% of the respondents experienced high overall impact. High financial impact, 35.3%; high social/familial impact, 41.9%; high personal strain, 38.2% and high mastery, 36.0% (Table II)

Table II: Frequency distribution of impact of caregiving (high or low) on the different dimensions of Impact

Variables	Frequency (n = 136)	Percentage (%)
Overall Impact of care		
Low impact	70	48.5
High impact	66	51.5
Financial impact of care		
Low impact	88	64.7
High impact	48	35.3
Familial Social impact		
Low impact	79	58.1
High impact	57	41.9
Personal Strain impact		
Low impact	84	61.8
High impact	52	38.2
Mastery impact		
Low	87	64.0
High	49	36.0

Association between impact of caregiving and socio-demographic/clinical variables

Chi² test showed that overall Impact had significant association with being married as married caregivers had the highest prevalence of 'high' overall impact (53.6%) compared to the other marital statuses and the difference was statistically significant (Chi² = 6.501, df=2, p=0.039).

Financial impact is significantly associated with clinical diagnosis (Chi² = 8.749, df =3, p = 0.033). On the Socio/familial dimension, no socio-demographic/clinical variable significantly differentiated caregivers with low impact from those that had high impact. Similarly caregivers with high or low impact on the personal strain dimension were not significantly differentiated by any socio-demographic variable.

A higher proportion of respondents with tertiary level of education compared with others, had high mastery of caregiving and the difference was statistically significant (Chi²=6.464, df=2, p=0.039) (Table III).

Table III: Summary of the Chi² test of association between socio-demographic variables and impact caregiving on the different dimensions

Variables	Overall Impact		Financial Impact		Social/Familial Impact		Personal Strain		Mastery	
	Chi ²	p	Chi ²	p	Chi ²	p	Chi ²	p	Chi ²	p
Occupation	0.722	0.868	0.548	0.908	4.977	0.173	1.012	0.798	2.212	0.530
Skill level 1										
Skill level 2										
Skill level 3										
Skill level 4										
Education	0.651	0.722	1.291	0.524	1.113	0.573	2.459	0.292	6.464	*0.039
Primary										
Secondary										
Tertiary*										
Caregiver's Sex	0.818	0.366	0.473	0.491	0.329	0.566	0.550	0.458	0.015	0.903
Male										
Female										
Religion	0.005	0.941	0.812	0.368	0.028	0.867	0.009	0.923	0.019	0.891
Christianity										
Islam										
Marital Status	6.501	*0.039	4.448	0.108	2.657	0.265	2.206	0.332	1.948	0.378
Single										
Married*										
Previously										
Married										
Type of Family	0.738	0.390	0.085	0.770	0.009	0.924	0.000	0.989	0.078	0.780
Monogamous										
Polygamous										
Patient's Sex	0.404	0.525	0.414	0.520	0.798	0.372	0.324	0.569	2.297	0.130
Male										
Female										
Diagnosis	5.268	0.153	8.749	*0.033	6.026	0.110	1.642	0.650	0.127	0.988
Seizure										
Disorder*										
Cerebral Palsy										
Delayed										
Development										
Others										

*Variables with significant association

Pearson correlation revealed that: Financial impact had weak, positive significant relationship with the position of the affected child in the family ($r = 0.171$, $p = 0.047$); Familial social impact had a positive significant correlation with the duration of illness ($r = 0.206$, $p = 0.038$) and Personal strain had a positive significant relationship, also with duration of illness ($r = 0.277$, $p = 0.005$) (Table IV). Thus, bivariate (Chi² and Pearson correlation) analyses showed that high impact of caregiving on the different dimensions had statistically significant association with the following corresponding variables: Overall Impact (Being married); Financial impact (Clinical diagnosis and Position of the affected child in the family); Familial/social impact (Duration of illness); Personal strain (duration of illness); and Mastery (level of education) (Tables III & IV).

Table IV: Correlations among Impact subscales and caregivers'/patients' continuous variables

Variables	1	2	3	4	5	6	7	8	9	10
1 Overall Impact	1	.649**	.748**	.751**	.345**	.041	-.036	.189	.039	-.039
2 Financial Impact		1	.455**	.565**	.132	.171*	.025	.019	.074	.049
3 Familial/Social Impact			1	.589**	.195*	.055	-.008	.206*	.090	-.095
4 Personal Strain Impact				1	.103	.039	-.034	.277**	.047	.019
5 Mastery					1	.055	.063	-.029	.032	-.087
6 Position of affected child in the family						1	.664**	.157	.119	.045
7 Number of children in the family							1	.281**	.350**	.103
8 Duration of illness (years)								1	.513**	.119
9 Child's age									1	.229*
10 Caregiver's age										1

Figures = Pearson correlation (r).

** Correlation is significant at <0.01 level (2-tailed).

* Correlation is significant at <0.05 level (2-tailed).

Predictors of impact

Binary logistic regression analysis revealed that duration of illness and being married increased the odds of experiencing high overall impact of caregiving but the associations were not statistically significant. Similarly, duration of illness increased the odds of experiencing both familial/social and personal strain impacts but not to a statistically significant level. Although a diagnosis of seizure disorder retained statistically significant association with financial impact, the odds of experiencing it was reduced when compared with the reference category. (OR= .272; P = .018, 95% CI= .093-.799), contributing 11.5% to the variance in financial impact (Table V).

Table V: Logistic Regression for Predictors of impact of care

Variables	B (regression co-efficient)	p value	Odds ratio	95% C.I. for EXP(B)	
				Lower	Upper
Overall Impact					
Duration of illness	.064	.361	1.066	.929	1.223
Marital status					
Single	-.706	.501	.494	.063	3.853
Married	1.011	.164	2.748	.661	11.419
Constant	-1.028	.153	.358		
R ² (co-efficient of determination) = 9.8%					
Financial Impact					
Position of the child	.173	.185	1.189	.920	1.536
Diagnosis					
Seizure disorder	-1.301	.018	.272	.093	.799
Cerebral palsy	-.457	.440	.633	.199	2.018
Delayed development	.237	.818	1.267	.169	9.531
Constant	-.275	.612	.759		
R ² (co-efficient of determination) = 11.5%					
Familial Social Impact					
Duration of illness	.078	.245	1.081	.948	1.234
Constant	-.556	.054	.574		
R ² (co-efficient of determination) = 1.8%					
Personal Strain					
Duration of illness	.043	.522	1.044	.915	1.192
Constant	-.783	.008	.457		
R ² (co-efficient of determination) = 0.5%					

Discussion

This study examined the concept of impact of caregiving on the caregivers of children with neurological disorders with respect to the financial, social/familial, personal strain and mastery aspect of their lives.

Some of the demographic profiles of the caregivers and their affected children reflect the pattern in some previous studies. Similar to some previous reports⁵, the vast majority of the caregivers were the mothers of the affected children.^{5,6} This pattern is in keeping with the traditional African practice where mothers take on, substantially, the role of caring for other members of the family. The mean age of the children (5.59±5.13 years) was also similar to many previous reports^{5,8,12}, this suggests high vulnerability to neurological disorders in this age bracket, though the authors acknowledge that most of the disorders have an onset that predates this age; however, it is the age of high vulnerability to CNS infections and the manifestation of most neurodevelopmental conditions.⁵ Majority of the patients were males, a finding that was also in keeping with previous reports.^{5,6,8,12} It is noteworthy that seizure disorder and cerebral palsy were the two commonest disorders in the studied sample, similarly, other studies found that seizure disorder and cerebral palsy contribute significantly to the number of neurological disorders seen in paediatric units.^{5,8,9,12} While neurological disorders in children comprise many diagnostic entities, overwhelming prevalence of seizure disorder and cerebral palsy in many studies warrants particular attention to their possible etiological factors for the purposes of prevention.

More than one-third of the caregivers reported high impact of caregiving in all the dimensions of impact: financial, social/familial, personal strain and mastery, with almost half of them reporting high overall impact of caregiving. To the best of our knowledge, no previous researchers in Sub-Saharan Africa, had, in a single study, investigated the impact of caregiving on the four dimensions of impact as considered in this study, posing a limitation to the comparison of our findings with similar previous reports. However, many studies had reported huge toll of caring for children with neurological conditions on different/isolated aspects of the caregivers' lives or families^{11,12,19}. The findings of this study largely support those reports and mostly indicate that the impact of caregiving is huge on caregivers of CNDs.

A high financial impact reported by more than one-third of the caregivers in this study, agreed with reported financial implication of caregiving by previous authors^{8,21}. This finding is explainable from the perspective that financial disadvantages could arise due to the care needs of the affected child⁸, and the huge expenditure associated with treatment, especially in the context of pervasive poor socio-economic status in developing countries like Nigeria. Similarly, about one-third of the caregivers experienced high impact of caregiving on their social and family functions. In keeping with this finding, some previous researchers reported significant restriction in the social and family life of caregivers,⁶ lack of adequate time to care for other members of the family⁹ as well as discrimination and prejudice²². These findings buttress earlier assertions that the impact of neurological disorder in children extends beyond the child and disturbs the entire social structure of the family.⁶ The high personal strain impact on the caregivers is also substantial and worthy of note; more than one-third of them experienced high personal strain. Raina and his colleague reported that caring for a child with long term ND could impact on the physical and mental health of the caregivers causing severe personal strain.²³ Consequently, their overall well-being is being undermined. Although, this study did not assess family and social support available to the caregivers, it would appear that, a lack of adequate social support, a major issue which has been reported in both Nigeria and beyond,^{6,9,23} is fundamental to the high impact of caregiving on the multiple dimensions. The burden of caregiving is largely born by the parents, especially the mother of the affected child with little support from the government⁹, non-governmental organizations or individuals. This may also explain why as much as half of the caregivers experienced high overall and personal strain impacts. While this study focused on the impact of caregiving, future research should incorporate a validated Social Support Scale to determine if the lack of formal support networks is the primary driver of the high personal strain observed.

On a positive note, however, a little above one-third of the caregivers experienced mastery; that is, an individual's perceived global sense of control over life situations and not being fatalistic²⁹. It is possible that in the course of caring for the affected child, some caregivers developed a sense of control and capacity to adapt and cope with the challenges of caregiving. Studies have suggested the protective effect of mastery against psychological stressors of caregiving by intervening in the stress process^{30,31}. Chan and his colleagues reported that a high level of mastery could be associated with less stress and emotional consequences.²⁵

The correlates of high impact of caregiving as found in this study included: being married, a diagnosis of seizure disorder, the position of the affected child in the family, duration of illness and high level of education. A significant relationship between overall impact and being married is understandable from the perspective that marriage alone comes with substantial family responsibility on

many fronts; caring for a child with chronic neurological disorder in the context of existing marital responsibilities might create significant high overall impact on the family, especially the primary caregiver. However, further research is needed to determine if this finding reflects marital strain arising from the shared burden of a child's illness or simply the increased household complexity faced by married couples. A diagnosis of seizure disorder was found to be associated with high financial impact. Besides its chronic nature, seizure is often characterized by relapses and recurrent hospitalization leading to huge expenses on treatment, investigations, transportation and caregiver's repeated absenteeism from work. This finding corroborates previous research findings^{8,17,21}. High social/familial impact as well as high personal strain had significant associations with duration of illness. Recent advances in the diagnosis and management of neurological disorder has probably reduced associated mortality, however morbidity and disability may persist for variable length of time and caregiving has to be sustained. Consequently, caregiving is, invariably, long lasting and tasking leading to prolong psychosocial challenges and physical exhaustion related to social/familial and personal strain impacts. Early detection, prompt initiation of expert treatment may go a long way in shortening the duration of some types of NDs in children and ameliorate associated impacts.

A significant relationship between mastery and high level of education is noteworthy. Education, formal or informal, often comes with increased awareness, enlightenment and knowledge. It presents the caregivers with the opportunity to have a better understanding of the illness, and the essentials of caregiving. Vadivelan and his colleagues opined that education increases caregivers' knowledge about options for caregiving⁶. Often, this may translate to enhanced capacity to adapt and cope with inevitable challenges of caregiving. Thus, targeted education interventions for mastery, may have potential benefits by influencing caregiving outcome through caregivers' mastery.

Though the above variables had significant relationship with the corresponding dimensions of caregiving at the bivariate level of statistical analysis, their significance disappeared after adjusting for potential confounders in the logistic regression analysis. However, caring for children with seizure disorder retained statistically significant relationship with high financial impact but the odds was reduced compared with the reference category (autistic disorder/congenital anomaly).

Summary and recommendations

In conclusion, this study has shown that caring for a child with a neurological disorder impacts substantially on multiple dimensions of the caregiver's life; large proportions of the caregivers, more than one-third, experienced perceived high financial, social/familial, personal strain and mastery impact while half of them experienced high overall impact. These findings, prominently, underscored the need to reduce the burden of neurological disorders in children and caring for them. To this end, cardinal recommendations include, firstly, preventive measures through public enlightenment and education, as well as good antenatal and immediate childhood care to reduce the prevalence of NDC. Secondly, early diagnosis and prompt treatment; although, many categories of neurological disorders in children may not be curable, they are largely treatable and the affected child can be helped to live a near normal life, thereby reducing the burden of caregiving. Thirdly, due recognition of the challenges of caregivers and implementation of measures to support them through concerted efforts by relevant stakeholders. It is noteworthy that almost half of the patients in this study had a diagnosis of seizure disorder and caring for them had statistically significant association with high financial impact. Thus, it is recommended that hospital management or local health ministry

implement seizure management subsidies, Caregiver Support Group or social work integration for parents or caregivers of the children with seizure disorder to mitigate their financial strain.

Implication of findings to clinical practice and policy making

A preventive approach to reducing the burden of caregiving is to emphasize and ensure early and regular antenatal care by pregnant women and facilities put in place for their safe delivery. Also, delivery of specialized and effective medical care to CNDs depends on the availability of consultant paediatric neurologists. There is a need to train, recruit and retain more paediatric neurologists especially at a time when many professionals seek greener pastures abroad. Furthermore, improved effort is required on the part of the government to put in place modern and advanced technological innovations for early diagnosis and adequate treatment of NDC.

Policies that will guarantee substantial social support, from governmental and non-governmental organizations, should be enacted to alleviate caregivers' stress. Similarly, treatment subsidy and financial support for caregivers as well as adequate health insurance coverage should be considered and enacted by policy makers

Finally, the role of knowledge is critical; thus, education, enlightenment and training of caregivers of CNDs will enhance their mastery and should enjoy policy consideration.

Limitations

This study is limited by its cross-sectional design, and scope in terms of sample size and single centre nature. Also, the low Chronbach's Alpha coefficient obtained for the Mastery subscale of the IMPACT questionnaire, possible introduction of selection bias due to the consecutive sampling technique adopted and the low explanatory power of regression models are limitation factors. Authors also acknowledge the arbitrariness of using the mean as the cut-off for dichotomization of variables because the Impact-on-Family Scale is a continuous scale. In the light of these limitations, a cautious generalization of findings is necessary. A larger scope, multicenter replication of the study, which will include other well-known determinants of caregivers' burden, which were outside the scope of this study, such as mental health status, health insurance (potential residual confounders) and so forth is suggested in future study. Despite the limitations, the study has enhanced our understanding of a very important subject which, up until now, has been missing prominently in literature.

Acknowledgement

The authors wish to thank the authority of the study institution for granting the permission to conduct this study, other consultant paediatric neurologists whose patients participated in the study, the resident doctors who assisted in data collection and the respondents.

Financial support and sponsorship: Research was self-sponsored

Conflict of interest: No conflict of interest was declared by any of the authors

Authors' contribution: COO conceived the study while all three authors contributed significantly to every aspect of the work from literature search, initial draft, statistical analysis, interpretation of the results and review of the final draft and all consented to the publication of the work in the Nigerian Journal of Family Practice.

REFERENCES

1. Faroogui T, Faroogui AA. Trace Amine and their relevance to neurological disorders: a commentary (chapter 17) In Trace Amines and neurological disorders. Academic press, Columbus, 2016; pages 257-268. <https://doi.org/10-1016/8978-0-12-803603-700017-3>. Accessed September19, 2024.

2. World Health Organization (WHO). What are neurological disorders? Available from <https://www.who.int/new-room/q-a-detail/what-are-neurological-disorders>. Accessed September 19, 2024.
3. Lagunju IA, Dkaforoo OO. An analysis of disorders seen at the Pediatric Neurology Clinic, University College Hospital, Ibadan, Nigeria. *West Afr Med*. 2009; 28(1): 38-42. <https://doi.org/10.4314/wajm.v28i1.48424>.
4. Burton KJ, Allen S. A review of neurological disorders presenting at a paediatric neurology clinic and response to anticonvulsant therapy in Gambia children. *An Trop Paediatr*. 2003; 23(2): 139-43. <https://doi.org/10.1179/027249303235002215>.
5. Akodu OS, Ogunlesi TA, Adekanmbi AF, Gbadebo FA. Neurological diseases at the paediatric Neurology Clinic in a semi-urban Nigeria tertiary hospital. *Sudan J paediatric* 2022; 22(1): 83-89. Doi: 10.24911/SJP.106-1688689565.
6. Vedivelan K, Sekar P, Shri Sruth S, Gopichandran V. Burden of Caregivers of children with cerebral palsy: an intersectional analysis of gender, poverty, stigma and public policy. *BMC Public Health* 2020; 20:645 available online <https://doi.org/10.1186/s12889-020-08808-0>
7. Osuntokun BO. The pattern of neurological illness in tropical Africa. Experience at Ibadan, Nigeria. *J Neurol Sci*. 1971; 12(4): 417-42. [https://doi.org/10.1016/0022-510x\(71\)90110-9](https://doi.org/10.1016/0022-510x(71)90110-9)
8. Lawal H, Anyebe EE, Obiako OR, Garbo S.N. Socio-economic challenges of parents of children with neurological disorders; A hospital -based study in North-West, Nigeria. *Academic Journals* 2014; 6(4): 58-66 doi:10.5897/IJNM2014.0122.
9. Adejoh SO, Adebayo K, Osazuwa p, et al. Neurological disorders: perceived causes, effects and coping strategies among caregivers in Lagos, Nigeria. *Journal of Social Issues in Non-Communicable Conditions & Disability* 2023; 2(1): 119-132.
10. Abuga JA, Kariuki SM, Abubakar A, Nyundo C, Kinyanjui SM, Van Hensbroek MB, Newton CR. Neurological Impairment and disability in children in rural Kenya. *Developmental Medicine & child Neurology* 2021, 64: 347-356.
11. Kumar G, Sharma V, Kumar A. Clinical Profile of Paediatric neurology disorders: a study from a semi-urban medical college in northwestern India. *Cureus* 2022; 14(10). e30359. doi:10.7759/cureus.30359.
12. Ifezuike CC, Okeke. KN, Onubogu CU, Echendu ST, Odita AO, Agu NV, Joseph E, Onah SK. Pattern of Neurological Disorder among children presenting at the Neurology unit of a Tertiary Hospital, Awka. *Open Journal of Endocrine and Metabolic Diseases* 2023; 13:53-62. Dio: 10.4236/ojemd.2023.134006.
13. Idro B, Kakooza- Mwesige A, Balyejjussa S, Mirembe G, Mugasha C, Tugumisirize J, Byarugaba J. Severe Neurological Sequelae and Behaviour problems after Cerebral Malaria in Uganda. *Child BMC Research notes* 2010; 3:104 Available at <http://www.biomedcentral.com>.
14. Awoala WB, Chinweoku OU. Pattern and predisposing factors of neurological disorders in a neurology out-patient clinic in Port-Harcourt, Nigeria. *Med. Res. Chronicles [internet]* 2019; 6(4): 2018-2. <https://medrech.com/index.php/medrech/article/view/391>.
15. Mung'ala OV, Meehan R, Njuguna P, Mturi N, Alock KJ, Newton C. Prevalence and risk factors of neurological disability and impairment in children living in rural Kenya. *Int J of epidemiology* 2006 academic. Oup.com assessed October 3, 2024.
16. Bajraszewski E, Came R, Kennedy R, Lanigan A, Ong K, Randall M, Reddihough D, Touzel B. *Cerebral palsy: An information Guide for parents*, 5th edition. Melbourne: The Royal Children's Hospital 2008.
17. Kozłowska K, Sawchuk T, Waugh JL, Helgeland H, Baker J, Scher S, Fobcan A.D. changing the culture of care for children and adolescents with functional neurological disorders. *Epilepsy & Behaviour Reports*, 16, 2021, 100486, ISSN 2589-9864. <https://doi.org/10.1016/j.ebr.2021-100486>.
18. Ahanotu CJ, Ibikunle PO, Hammed AI. Burden of Caregiving, social Support and quality of life of informal caregivers of patients with cerebral palsy. *Turk J Kin* 2018; 4(2); 58-64 www.dergipark.gov.tr/turkjkin.
19. Stein REK, Riessman CK. The Development of an Impact-on-Family Scale: Preliminary Findings. *Medical Care* 1980; XVIII(4): 465-472.
20. Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A. Measuring Caregiving appraisal. *J. Gerontol* 1989; 44 (3): 61-71 doi: 10.1093/geronj/44.3.p61.
21. Obembe OB, Adeyemo S, Ogun OC, Ijarogbe G.T. The relationship between coping styles and depression among caregivers of children with cerebral palsy in Nigeria, West Africa. *Arch. Clin. Psychiatry* 2019; 46(6): 145-150. <https://doi.org/10.1590/0101-60830000000215>.
22. Caicedo C. Families with Special Needs Children: Family Health, Functioning and Care Burden. *J AM Psychiatry Nurses Assoc* 2014; 20: 398-407 Doi:10.117/1078390314561326. [PMID; 2543 8686].
23. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, Swinton M, Zhu B, Wood E. The health and well-being of caregivers of children with cerebral palsy. *Paediatrics* 2005; 115:626-636.
24. Brehaut JC, Kohen DE, Raina P, Walter SD, Russell DJ, Swinton M, O'Donnell M, Rosenbaum P. The heart of primary caregivers of children with cerebral palsy. How does it compare with that of other Canadian Caregivers? *Paediatrics*, 2004; 114(2): 182-91
25. Chan EY, Glass G, Chua KC, Ali N, Lim WS. Relationship between mastery and caregiving competence in protecting against burden, anxiety and depression among caregivers of frail old adults. *J Nutr Health Aging* 2018; 22(10): 1238-45 doi: 10.1007/s/2603-018-1098-1.
26. Araoye OM. *Research Methodology with statistics for Health and Social Sciences* 2nd Edition, Nathadax, Ilorin, 2004, 118.
27. Kolk AM, Schipper JL, Hanewald GJ, Casari EF, Fantino AG. The Impact-on-Family Scale: A Test of Invariance Across

- Culture. *Journal of Paediatric Psychology* 200; 25 (5): 323-329.
28. [Ilostat.ilo.org/methods/concepts-and-definitions/classification-occupation/?](https://ilostat.ilo.org/methods/concepts-and-definitions/classification-occupation/) Retrieved September 19, 2024.
29. Pearlin LI, Bierman A. Current issues and Future direction in research into the stress process. In: Aneshensel CS, Phelan JC, Bierman A, editors. *Handbook of the sociology of Mental Health*. Dordrecht: Springer Netherlands; 2013. Pp. 325-340.
30. Chan E-Yuee, Glass G, Chua K-C, Ali N, Lim W-S. Relationship between Mastery and caregiving competence in protecting against Burden, Anxiety and Depression among caregivers of frail older adults. *J Nutr Health Aging* 2018; 22 (10): 1238-1248. Doi: 10.1007/s12603-018-1098-1.
31. Mausbach BT, Roekpe SK, Chattillion EA, Harmell AL, Moore R, Romero-Moreno R, Bowie C, Grant I. Multiple mediators of the relations between caregiving stress and depressive symptoms. *Aging and Mental Health* 2012; 16: 27-38.