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Original Article

Burden and quality of life of informal caregivers of children with cerebral palsy

Sobrecarga e qualidade de vida de cuidadores informais de crianças com paralisia cerebral

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ABSTRACT

Objective: to analyze the caregiver burden and the quality of life of informal caregivers of children with cerebral palsy. **Methods:** the cross-sectional survey involved 109 caregivers of children with cerebral palsy recruited from physiotherapy clinic at a tertiary hospital. The quality of life and caregiver burden were assessed using the Personal Wellbeing Index Scale and the Modified Caregivers' Strain Index, respectively. Data were analysed using descriptive and inferential statistics. **Results:** the mean strain index and quality of life scores of the participants were 11.85 ± 5.72 and 64.68 ± 8.03 respectively. The majority (67.9%) of the caregivers had fair personal well-being, while about one-third (33.0%) had high caregiver's strain. Child's age (B=2.454; p<0.005) and caregivers' occupation (B= -2.547; p=0.001) were predictors of caregiver strain. **Conclusion:** caring for children with cerebral palsy imposed a substantial burden on the caregivers and child's age and caregivers' occupation were predictor variables.

Descriptors: Caregivers; Patient Care; Burnout, Psychological; Quality of Life; Cerebral Palsy.

RESUMO

Objetivo: analisar a sobrecarga e qualidade de vida de cuidadores informais de crianças com paralisia cerebral. **Métodos:** o estudo transversal envolveu 109 cuidadores recrutados em uma clínica de fisioterapia em um hospital terciário. A qualidade de vida e a sobrecarga foram avaliadas por meio do *Personal Wellbeing Index* e do *Modified Caregivers' Strain Index*, respectivamente. Os dados foram analisados de forma descritiva e inferencial. **Resultados:** as médias do índice de sobrecarga e dos escores de qualidade de vida foram 11,85 ± 5,72 e 64,68 ± 8,03, respectivamente. A maioria (67,9%) dos cuidadores apresentou bem-estar pessoal razoável, enquanto cerca de um terço (33,0%) apresentou alta sobrecarga. Idade da criança (B=2,454; p<0,005) e ocupação dos cuidadores (B= -2,547; p=0,001) foram preditores de tensão do cuidador. **Conclusão**: cuidar de crianças com paralisia cerebral impôs uma sobrecarga substancial aos cuidadores e a idade da criança e a ocupação dos cuidadores foram variáveis preditoras.

Descritores: Cuidadores; Assistência ao Paciente; Esgotamento Psicológico; Qualidade de Vida; Paralisia Cerebral.

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Introduction

Population based studies from around the world report that the prevalence estimates of cerebral palsy range from 1.5 to more than 4 per 1000 live births of a defined age range(1). However, in a recent clinical overview, the incidence of cerebral palsy is between 2 - 3 per 1,000 live births with common risk factors including prematurity, small for gestational age, multiple pregnancy and maternal genitourinary infections(2).

Caregiving is a normal part of being a parent but the care that children with cerebral palsy require can escalate the burden and stress on the caregiver(3). Living with a chronic condition like cerebral palsy not only affects the child but its effect can extend to other members of the child's family especially the caregiver, who often are the child's mother or father(4). Caregivers feel socially isolated and undergo physical stress, including lack of sleep, musculoskeletal aches and pains and hypertension. A caregiver of a child with cerebral palsy is one with the primary responsibility of encouraging a child to become independent in his or her daily activities(5), which requires sacrificing facets of his well-being to have enough time to care for the patients.

The quality of life is related to an individual's view of his/her place in life, in the context of the customs and value systems in which he/she lives, his goals, potential, standards and concerns(6). Measuring the quality of life of caregivers of children with chronic conditions provides insight into the challenges faced by these caregivers while caring for their children(7). As caregiving a child is often a life commitment, it may deteriorate health and health-related quality of life of informal caregivers. Families that have children with cerebral palsy need continuous special care, frequent medical check-ups and physiotherapy management(8). Similarly, a previous Nigerian study highlighted nine factors affecting the psychosocial well-being of carers of children with cerebral palsy, showing that stress of taking care of these children is a major factor(9). The provision of a high level of care required by a child can affect and impact the quality of life of the caregiver(5). For instance, caregiving may lead to decreased opportunities for socialization and formal employment, thus, informal caregivers are more often overwhelmed by the role.

The quality of life of the caregiver of a child with cerebral palsy depend on certain conditions, experiences, and activities that threaten the effort of the caregivers in achieving their purpose(10). These factors characterize caregiver strain. Among these factors include the characteristics of the patient, the responsibilities performed, time spent in caregiving and the characteristics of the caregivers themselves(11). There is evidence to support the fact that the level of caregiver's burden determines their quality of life(12). A study also revealed that increased caregiver's burden leads to decrease in quality of life of cerebral palsy caregivers(5). However, there is little research done in the South-West region of Nigeria to determine the quality of life and burden of informal caregivers of the children with cerebral palsy, leading to the need for this study. Therefore, the objective of this study was to analyze the caregiver burden and the quality of life of informal caregivers of children with cerebral palsy.

Methods

A cross-sectional survey based on a questionnaire applied to caregivers of children with cerebral palsy, attending a Physiotherapy clinic in the Federal Medical Centre Abeokuta, between July 2016 to June 2019, was carried out. Participants were selected using a purposive sampling technique. Prior to selection, sample size was determine based on the formula n=40+8M where n = sample size and M = number of variables(13). In this study, the outcome variables are quality of life and modified caregiver index strain. The independent variables predicting the outcome variables were the following sociodemographic variables: age of caregiver and child, occupation, education, tribe and family type. At least, 88 participants would be required to achieve statistically significant association at $\alpha<0.05$ and a statistical power of 1- β ($\beta=0.20$), using regression analysis. The inclusion criteria include parents whose children have been diagnosed with cerebral palsy without any other neurological disorders such as difficulty seeing and hearing, intellectual disabilities and seizures. Also, the parents had to be able to express themselves in either English or Yoruba.

Personal Wellbeing Index Scale (PWI) was used to measure quality of life. The scale consists of 8 items. Each item corresponds to a quality of life domain, namely: standard of living, health, achieving in life, relationships, safety, community-connectedness, future security and spirituality. The measurement is made on an 11-point Likert scale ranging from zero to ten (zero means extremely dissatisfied and 10 means extremely satisfied). Higher scores reflect a higher level of satisfaction with each domain. The scale was linearly transformed to 0 – 100 point scale. The personal well-being was classified as poor (0 – 49 points), fair (50 – 69 points) and good (70 – 100 points). The PWI is considered a valid and reliable measure of life satisfaction for use in various population including Nigeria(14).

Modified Caregiver Strain Index (MCSI) was used to measure caregiver's burden. It consists of 13 items assessed on a three-point Likert scale ranging from zero to two (zero means no, 1 means yes, sometimes, and 2 means yes, on a regular basis). The higher the score, the higher the level of caregiver strain. The caregiver strain was classified as high (20 - 26), moderate (11 - 19) and low (0 - 10). The tool demonstrated good reliability and validity in various population including Nigeria(15).

Data were analysed using the Statistical Package for Social Science (SPSS) (IBM Inc., Chicago, Illinois, USA) version 25.0. Descriptive statistics of the mean, standard deviation, frequency tables and percentages were used to summarize the data. Kruskal-Wallis (with multiple pairwise post-hoc comparisons) and Mann Whitney U tests were used as appropriate for the comparison of PWI and MCSI scores across sociodemographic characteristics. Spearman rank correlation coefficient was used to test the relationship between PWI score, MCSI score and cerebral palsy history of participants.

Variables that showed significant associations with PWI and MCSI scores were entered into two separate multiple linear regression models (models 1 and 2) to examine factors that predict personal well-being and caregivers' strain. The level of significance was set at $p<0.05$.

Informal caregivers who met the inclusion criteria were recruited after their consent had been obtained. Trained interviewers (Physiotherapy Interns) obtained necessary information using structured forms, which included the socio-demographic characteristics of the participants. The lead author trained the interviewers, supervised and monitored data collection process. The PWI scale (written Format) and the MCSI index were administered once by the Physiotherapy Interns, however most of the literate caregivers were allowed to administer the MCSI by themselves. The estimated duration for the administration of all the instruments was 15 - 20 minutes. One of the authors entered the data into SPSS and run the analysis. Ethical approval was obtained from the Federal Medical Centre Health ethics committee (ethics committee approval number: Federal Medical Centre Abeokuta/470/Health Research Ethics Committee/09/2017).

Results

All 109 informal caregivers responded giving a 100.0% response rate. However, 10 participants did not complete the Modified Caregivers' Strain Index section of the questionnaire, hence responses of 99 participants regarding caregivers' strain were analysed.

All participants were women, 98.0% are the biological mothers of these children and the majority of them were older than 30 years (71.6%). Most were artisan or traders (80.7%) and had high school or graduate education (81.5%). Details of participants' sociodemographic characteristics are presented in Table 1. The mean PWI and MCSI scores of the participants were 64.68 ± 8.03% and 11.85 ± 5.72 respectively. About one-third (33.0%) of the participants reported a high level of caregiver strain, 16.5% reported moderate level of strain and 41.3% reported a low level of caregiver strain while 67.9% of them reported fair personal well-being (Table 1). Most of the children with cerebral palsy (64.2%) that were being cared for by the participants were males, their mean age was 1.84 ± 0.60 years and they have been diagnosed with cerebral palsy for 1.06 ± 0.23 years.

Table 1 – Sociodemographic characteristics of participants. Nigeria, 2019

Variable	n (%)	95% Confident interval
Age (years)		
21-30	31 (28.4)	20.2 – 37.9
31-40	55 (50.5)	40.7 - 60.2
>40	23 (21.1)	13.9 – 30.0
Education		
Primary	19 (17.4)	10.8 – 30.0
Secondary	47 (43.1)	33.7 – 52.9
Tertiary	43 (39.4)	30.2 – 49.3
Occupation		
Trader/artisans	88 (80.7)	72.1 – 87.7
Civil servant	21 (19.3)	12.3 – 27.9
Family type		
Monogamous	75 (68.8)	59.2 – 77.3
Polygamous	29 (26.6)	18.6 – 35.9
Others	5 (4.6)	1.5 – 10.4
Tribe		
Yoruba	92 (84.4)	76.2 – 90.6
Hausa	11 (10.1)	5.1 – 17.3
Others	6 (5.5)	2.0 – 11.6
Religion		
Christianity	67 (61.5)	51.7 – 70.6
Islam	42 (38.5)	29.4 – 48.3
Gender of child		
Male	70 (64.2)	54.5 – 73.2
Female	39 (35.8)	26.8 – 45.5

Table 2 shows the comparison informal caregivers' PWI and MSCI scores based on socio-demographic characteristics. Significant differences (p<0.05) were observed in PWI scores across the categories of education (p=0.001), family type (p=0.008) and tribe (p=0.005). The results of multiple pairwise comparisons of the Kruskal Wallis test further showed that participants with primary education had significantly higher median score than those with secondary and tertiary education. Participants with other family settings had significantly lower median PWI scores than those with monogamous and polygamous settings. Respondents from other tribes had significantly higher median PWI scores than the Yorubas and the Igbos.

Also, in Table 2, significant differences are found in MCSI scores across the categories of education (p=0.040), occupation (p=0.002) and tribe (p=0.006). Analysis of multiple pairwise comparisons further showed that participants with other qualifications had significantly higher median MCSI scores than those with primary, secondary and tertiary education. The trader and artisan group had significantly higher MCSI scores than the civil servants. Participants of Igbo ethnic ancestry had significantly higher MCSI scores than the Yorubas, Hausas and other tribes. The Yorubas also had significantly higher MCSI scores than the Hausas and other tribes.

The analysis of the relationships between PWI index, MCSI scores, and duration of cerebral palsy diagnosis indicated no significant correlation observed between PWI score, age of the child (p=0.579) and duration of cerebral palsy diagnosis (p=0.210). Age of the child showed significantly low correlation (r=0.358; p<0.001) with MCSI score, but there was no significant relationship between MCSI score and duration of cerebral palsy.

Multiple linear regression models for predictor factors of personal well-being (model 1) and caregiver strain (model 2) are presented in Table 3. The analysis of variance (ANOVA) for model 1 was significant (F=8.926, p<0.001) and the independent variables explained 26.0% of the variances of personal well-being.

Results from model 1 further revealed age (B=3.348; p=0.001), education (B= - 3.630; p<0.001), and family type (B= - 3.572; p=0.004) as significant predictors of personal well-being.

The ANOVA for model 2 was also significant (F=7.770, p<0.001), while the independent variables explained 25% of the variances of care giver strain. Results from model 2 further revealed occupation (B= -2.547; p=0.001) and age of child (B=2.454; p<0.005) as significant predictors of care giver strain.

Table 2 – Median differences in Personal Wellbeing Index and Modified Caregiver Strain Index scores in relation to sociodemographic characteristics of the participants. Nigeria, 2019

Variable	Personal Wellbeing Index Score			Modified Caregiver Strain Index Score		
	Median (LQ, UQ)	z/H-value	p-value	Median (LQ, UQ)	z/H-value	p-value
Age of caregiver (years)		24.314	< 0.001*		2.906	0.234
21-30	64.00 (60.00, 69.00)			14.00 (9.00, 17.00)		
31-40	63.00 (58.00, 66.00)			9.50 (6.00, 17.50)		
>40	72.00 (69.00, 77.00)			15.00 (11.00,17.00)		
Education		16.553	0.001*		8.308	0.040*
Primary	69.00 (69.00, 73.00)			11.00(6.00, 16.00)		
Secondary	64.00 (58.00, 72.00)			14.00 (7.25, 17.00)		
Tertiary	65.00 (58.00, 69.00)			12.00 (6.00, 17.00)		
Others	66.00 (66.00, 66.00)			19.00 (19.00,19.00)		
Occupation		1.498	0.134		-3.152	0.002*
Trader/artisans	65.00 (58.50, 69.00)			14.00 (8.00, 17.00)		
Civil servant	69.00 (63.00, 71.00)			6.50 (3.00, 15.00)		
Family type		9.596	0.008*		4.697	0.096
Monogamous	65.00 (60.00, 69.00)			15.00 (7.00, 17.00)		
Polygamous	69.00 (57.00, 70.00)			13.00 (7.00, 16.50)		
Others	47.00 (47.00, 60.00)			8.00 (3.00, 8.00)		
Tribe		13.021	0.005*		12.614	0.006*
Yoruba	65.00 (60.00, 69.00)			14.00 (7.25, 17.00)		
Hausa	69.00 (66.00, 72.00)			7.00 (0.00, 16.00)		
Igbo	56.00 (56.00, 56.00)			18.00 (18.00,18.00)		
Others	71.00 (71.00, 71.00)			6.00 (6.00, 6.00)		
Religion		0.571	0.578		1.357	0.175
Christianity	65.00 (60.00, 70.00)			6.25 (14.00, 16.00)		
Islam	66.00 (59.00, 69.00)			12.00 (7.00, 18.00)		
Gender of child		-0.826	0.409		0.944	0.345
Male	64.50 (58.00, 70.00)			15.00 (7.00, 17.00)		
Female	66.00 (61.00, 70.00)			10.00 (7.00, 16.00)		

*Significant at p<0.01; LQ: lower quartiles; UQ: upper quartiles

Table 3 – Multiple regression analysis for predictor factors of personal well-being and care giver strain. Nigeria, 2019

Variable	Constant	Standard error	Beta	T	p-value
Personal Wellbeing Index (model 1)					
(Constant)	73.807	4.043	-	18.255	<0.001
Age	3.348	0.976	0.293	3.431	0.001
Education	-3.630	0.911	-0.340	-3.983	<0.001
Family type	-3.572	1.196	-0.254	-2.988	0.004
Tribe	1.017	1.079	0.081	.942	0.348
(df= 4,108; F= 8.926; p<0.001, R^2 = 0.26)					
Modified Caregiver Strain Index (model 2)					
(Constant)	6.933	3.114	-	2.226	0.028
Education	1.269	.683	0.168	1.859	0.066
Tribe	-0.211	.839	-0.024	-0.251	0.802
Occupation	-2.547	.708	-0.347	-3.599	0.001
Age of child	2.454	.853	0.260	2.877	0.005
(df= 4,94; F= 7.770; p<0.001, R^2 = 0.25)					

*T = t-value; df: degrees of freedom; F: variation between sample means/variation within the samples

Discussion

The result of this study needs to be interpreted with caution because of inherent limitations. First, variables such as gross motor functional level, depression, and social support, which have been demonstrated to be strong predictors of quality of life and burden of care, and which would have given a holistic view of the strain and wellbeing of caregivers were not assessed. Second, participants were recruited from a single centre, which may not represent the population of informal caregivers in Nigeria.

Despite the limitations of the study, the findings have some clinical implications for rehabilitation professionals, caregivers and the government. Mothers/caregivers of children with cerebral palsy have health needs challenges imposed on them which must be addressed during rehabilitation. The child's health alone must not be focused on but also the health needs of caregivers that must be assessed and promptly attended. Therefore, there is the need for identification and implementation of models of care, which improve the quality of life of caregivers in addition to providing care to children with cerebral palsy. During rehabilitation emphasis must be laid on improving the child's independence as the improvement in functional level reduces burden, improve caregivers' quality of life, and outcomes(11,16). This may suggest the need for the provision of interventions, including the provision of assistive devices, such as wheelchairs to caregivers of children with cerebral palsy to enhance independence.

Previous studies have identified poor quality of life among caregivers of children with cerebral palsy (in the area of communication, worries, emotional functioning and daily activity as well as physical, psychological, social relationships, and environment domains including physical and mental health) compared with caring for healthy children or children with minor ill-health(3-4,8). Children with cerebral palsy presented with more disabilities compared with healthy children(16) and may be more dependent on the caregivers and thus, impact caregivers' quality of life. A recent meta-analysis of the caregiver health effects of caring for young children with developmental disabilities has shown that general health, physical health and depressive symptoms were significantly affected(17). Some of the children with cerebral palsy may be technology-dependent coupled with the stress of caring may result in poor quality of life of caregivers(18). These findings underscore the need not to focus on the health of children with cerebral palsy only but also of their caregivers as well during rehabilitation.

Most caregivers (98.9%) in the present study are the biological mothers. Mothers always consider 24/7 care of their child's care a top priority(19). The mother-child bond may make them go extra miles without considering their own health and thus, impacts their quality of life. It has been reported that long-term caregiving may lead to lower/poorer health-related quality of life(20). It is also likely that mothers did not see caregiving to a child with cerebral palsy as a burden because they have accepted them as a gift from God. However, none of the caregivers' sociodemographic characteristics predicted their quality of life.

The MCSI was used to measure the levels of strain and impact on the parents/caregivers. About one-third of the sample had high caregiver's strain. Our results were similar to previous studies, which reported a significant burden or strain among caregivers/mothers of children with cerebral palsy(18,20). These strains are expected as the older children presented more functional/developmental disabilities and depend on caregivers for their daily activities or care. Generally, functional level of a child predicts the burden of care with increase burden as function reduces(16). Other sociodemographic variable found to predict the burden of care, in the present study, was occupation of the mothers/caregivers. Work adjustments are usually undertaken by mothers of children with cerebral palsy to give more attention needed(9). This may call for an effort to identify working-class mothers during rehabilitation to provide necessary support for them.

Though, a similar study from Africa which also used the MCSI (measure of caregivers' burden) as in this study, reported no significant association between sociodemographic data (such as the child's age, the severity of cerebral palsy, caregivers' age, and caregivers' relationship with child and caregivers' educational status) and burden of care. Many studies reported predictors of the burden of care among caregivers such as physical strain, inconvenience, disrupted personal plans, social isolation, work adjustments, family adjustments and financial strain. Thus, physical, economic and psychosocial burdens are enormous among caregivers of children with cerebral palsy(9). Children with cerebral palsy required more attention than healthy children and constitute more burden on the caregivers. An increase in the burden of care with the increase in informal care hour given had been reported(20). Given that about 50.0% of participants reported moderate/high strain caring for children with cerebral palsy, there is a great need to constantly assess caregivers' burden during rehabilitation to detect those who need a form of support early. This is imperative as the burden of care impacts quality of life of caregivers(5).

Follow-up tests on the effects of demographic variables on the burden of care and quality of life were shown that only the age of the child correlates significantly with the burden of care. This was further confirmed by multiple linear regression. With an increase in age, the burden of care increases. However, the degree of disability or functional level of a child with cerebral palsy, the number of informal care hours provided in a week, signs of potential clinical depression, being dependent in the performance of activities of daily living, impairments in cognition, self-efficacy, male gender and older age have been reported as predictors of burden of care(11,20).

There are substantial physical, economic and psychosocial burdens encountered by caregivers of children with cerebral palsy. Therefore, social support for caregivers is needed. The benefits of social support in moderating the relationship between caregiver's burden and quality of life have been reported(5). Thus, social support contributes to alleviating the negative consequences of stress and burden of the caregiver in caring for a child. There is still a long way to go between providing financial assistance or support to caregivers of children with cerebral palsy by the government and reducing their burden facilitating access to healthcare.

Also, caregivers need the knowledge and skills relevant to the care they are providing for the children with cerebral palsy. Therefore, informal caregivers need to be educated about the cerebral palsy, disability, managing stress, coping with depression and anxiety and how to develop proper caregiving techniques(5).

Conclusion

Caring for children with cerebral palsy impacted caregivers' quality of life and imposed a substantial burden on the caregivers. The impacted caregivers' quality of life was predicted by caregivers' occupation, age and family type while burden was predicted by child's age and caregivers' occupation. Therefore, a child's age should be taken into consideration when providing support for caregivers.

Collaborations

Davis AO, and Orekoya K participated in conception and design, drafting the manuscript, and revising the manuscript critically for important intellectual content. Olagbegi OM collaborated in data analysis and to writing of methods and results of the manuscript. Oyewole OO participated in analysis and interpretation of data, drafting the manuscript or revising it critically for important intellectual content. Adekunle M, Adepoju M, and Soetan O contributed in data collection, data interpretation and design. All authors give final approval of the version to be published.

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