Original Research Article

Quality of life in Caregivers of Children with Cerebral Palsy in Rivers State, Nigeria

Abstract

Introduction: Cerebral palsy (CP) is a common neurologic disorder which leads to physical disability in children. Children with CP require more care and attention from their care givers. Hence the quality of life (QoL) of the care givers can be adversely affected.

Aim: The aim of this study is to assess the QoL and its determinants among caregivers of children with CP in Port Harcourt, Nigeria.

Material& Method: Using a convenience sampling method, a hospital based cross-sectional descriptive study was carried out, participants were 96 caregivers of children on follow up for CP. The English Version of the World Health Organization Quality of Life-Bref (WHOQOL-Bref) was used to evaluate the QoL of the participants. A structured questionnaire was used to obtain socio-demographic characteristic of the participants and children with CP, while the patients hospital record was used to obtain the medical history of the patients. The functional disability level of the child was measured by the Gross Motor Function Classification System (GMFCS levels I-V) scale. Multiple regression analysis was carried out to determine the predictors of the care givers QoL on all four domains of the WHOQOL-Bref.

Result: The age of the participant ranged from 23 -58 years with a mean age of 37.67± 8.27 years. Seventy-eight (81.3%) were females, 77(80.0%) had secondary education and abovewhile 56 (58.3%) of the patients had co-morbidity. The care givers had lower level of QoL < 60 points in all domains except for Physical Health Domain which had mean point of 61.3.

The GMFCS level of the patients with CP and the marital status of the caregivers significantly determined the different domains of the caregivers QoL ($p \leq 0.05$). Age of care giver (p 0.00), presence of comorbidity (0.03) significantly predicted the psychological domain of the QoL of the care givers. In addition, the socioeconomic class significantly predicted the environment and psychological domains of the caregivers QoL. ($p < 0.05$)

Conclusion: The quality of life in caregivers of children with cerebral palsy is low. The predictors include GMFCS level of the patient, age of the care giver, marital status, presence of comorbidity and socioeconomic status.The treatment of CP should include strategies to enhance the health and quality of life of caregivers of children with the condition.

Keywords: Quality of life, caregiver, Cerebral Palsy, Port Harcourt

Introduction.

According to the World Health Organization, Quality of life (QoL) is defined “as the individual’s perception of their own position in specific cultural, social and environmental context, as well as in relation to personal goals, expectations, standards and interests.” [1].It is a person's subjective assessment of their general level of satisfaction and well-being in life, taking into account both the psychological, physical or other health-related areas. Understanding the factors that influence a person’s quality of life (QoL) can improve care, treatment, and recovery initiatives.[2]

Cerebral palsy (CP) describes a group of permanent disorders of movement and posture causing activity limitation that are attributed to nonprogressive disturbances that occur in the developing fetal or infant brain.[3] CP is the most common motor disability of childhood accounting for between 15% to 50% of neurological clinic presentations seen in developing countries.[4,5] The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviours. They are also prone to epilepsy and other secondary musculoskeletal problems which culminate in increased morbidity, increased hospital visits for follow up and rehabilitative care.[3]

The demands associated with caring for a child with CP can impact on the physical and mental health status on both the child and care giver especially as the child grows older.[3,6] The effect of these on the family result in losses in socio-economic, cultural and professional opportunities and create a vicious cycle which can worsen the overall wellbeing of the child living with CP.[7]

Studies have shown that the more time spent on child care, the higher the risk of burn out and mental illness among caregivers, particularly depression and anxiety especially among parents of children with CP of low degree functionality and high level of child dependence.[8]In addition, long-term care of children with impairments has been associated with social isolation, lack of medical attention, physical weakness and financial limitations.[9]

Numerous factors, such as the degree of the child's disability, stresses, social and environmental effects, and the amount of social support, have been found to affect the quality of life of care givers of children with CP.[2] As part of the wholistic approach to the management of children with chronic medical conditions such as CP , inclusion of measures to improve quality of life of care givers is now advocated including adequate social support for psychological wellbeing,[10] however the adoption and degree of implementation of these measures in health care delivery in developing countries is yet to be fully established.Given the challenges encountered in caring for children with cerebral palsy in a resource limited environment such as ours and the potential impact on the quality-of-life thereof, this study was conducted to assess the quality of life (QoL) and its determinants among caregivers of children with CP in Port Harcourt, Nigeria.

Materials and methods

This study was carried out in the Paediatric Neurology clinic in the Paediatric department, University of Port Harcourt Teaching Hospital. The Paediatric Neurology Clinic runs every Friday except on public holidays. All children with neurologic conditions who do not have acute conditions are referred to the clinic where they are seen and are followed up. The clinic serves the neighboring communities around the hospital and is also a referral hospital for public and private hospitals within and outside the state.

Study design: The study is a cross sectional analytical study.

Study participants: Participants include 96 caregivers of children on follow up for cerebral palsy in the Paediatric neurology clinic of UPTH. Consent was obtained from all participants before the study.

Inclusion criteria: The caregiver must have cared and lived with the patient for at least one year and is the primary caregiver to be included in the study.

Exclusion criteria: Caregivers who had any form of chronic medical conditions were excluded from study.

A convenience sampling method was used, participants who fulfilled the inclusion criteria were enrolled consecutively from October 2022 to October 2023. A self-administered structured questionnaire was used to obtain socio-demographic characteristics of participants while the medical history of the patient was obtained from their medical records. The information obtained includes age, sex of both the care givers and that of the patients, presence of co morbidity in the patient. The Gross Motor Function classification system was used to assess the patient's functional capability. It was classified into levels 1- 5, a lower score indicates that the patient has a greater level of functional capability.[11]

The English version of WHO QOL-BREF was adopted for the study. The WHOQOL-Bref is 26 items, the initial first two questions are concerned with the general well-being and quality of life, whereas the other 24 are specific to each domain. These specific domains are 4 in number physical health, psychological, social relationships and Environment.[1]

The questions were graded on a 5- points Likert scales which were transformed to a 0-100 scale based on the domains specified according to the scoring guide. A WHOQOL- Bref cut-off score of 60 points was adopted for this study. This score was used in a previous study.[12] The score of 60 and above in any domain indicates a higher quality of life.

Socioeconomic class of patient

The socioeconomic class of the patient was determined by using the socioeconomic classification scheme as recommended by Ibadin et al[13], the level of education and occupation of parents were used to group the patients into six socioeconomic classes 1-6 which was further grouped into upper, middle and lower social class.

Data Analysis

Data was entered into an Excel spreadsheet and later transferred into Statistical package for Social Sciences (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, VERSION 25.0. Armonk, NY, IBM Corp.) for analysis. Descriptive statistics were used, quantitative variables were represented in frequency tables using simple proportions and percentages, and continuous data were presented as mean and standard deviation. Regression analysis was carried out to determine the factors that predicted the QoL of participants at the four different domains and a p-value of 0.05 or less was considered significant.

Result

Table 1 shows the socio- demographic characteristics of the care-givers. Theirages ranged from 23-58 years with a mean age of 37.67±8.27 year. Seventy-Eight (81.3%) of them were females, 67(69.8%) of the caregivers were married, 81(84.3%) were parents of the patients, and 69(71.9%) were employed.

Table II: shows socio demographic characteristics of children whose caregivers were part of the study. Their age ranged from 1 year to 13 years with mean age of 6.87± 4.22 years. Fifty-two (54.2%) were males, 20 of them (20.8%) belonged to the upper social class and 38(39.6%) of them had functional ability at level I using the GMFCS while 56(58.3%) had other co-morbidities.

Table III shows the mean quality life score for the participants. The mean quality of life score was found to be below 60 points in all the domains of the WHOQOL-BREF except for the physical health domain. This indicates that the study participants had a very low level of quality of life. The WHOQOL-Bref scores shows that the physical health domain (61.3%) and environmental domain (51.8) had the highest and lowest mean scores respectively.

Table IV Show the predictors of participants quality of life. All the quality-of-life domains had significant statistical variance except for the physical health domain; psychological R2= 0.34 (p 0.000); Social relationships R2=0.36(p 0.00), Environmental domain R2=0.25(p=0.000)

On evaluation of each domain, it revealed that only GMFCS of the patient (β=0.42, p 0.00) Significantly predicted the quality of life at the physical domain. The psychological domain was significantly predicted by the age of the caregiver (β=0.58, p 0.04) marital status of the participants (β 0.54, p 0.01), the presence of a comorbid state among the patient (β 0.26, p 0.03) and the socio-economic class (β 0.41, p 0.00).

Concerning the social domain, the significant predictors of participants quality of life include patients' socioeconomic status (β 0.32, p 0.01), GMFCS level of the patients (β -0.07, p 0.05).

The statistically significant predictors of the quality of life of the participants in the environment domain includes marital status of caregiver (β 0.43, p 0.00) and GMFCS levels (β-0.56, p 0.01).

Table 1: Socio-demographic characteristics of the caregivers in the study

Variables	**Frequencies N=96**	**Percentages (%)**
Age group in years		
< 30	45	46.9
≥ 30	51	53.1
Mean age 37.67±8.27		
Sex		
Males	18	18.7
Females	78	81.3
Marital status		
Married	67	69.8
Single	16	16.7
Co-habiting	8	8.3
Others	5	5.2
Level of education		
None	7	7.3
Primary	12	12.5
Secondary	24	25
Tertiary	53	55.2
Relationship with the patient		
Mother	65	67.7
Father	16	16.7
Relative	11	11.4
Non related	4	4.2
Employment status		
Employed	69	71.9
Not employed	27	28.1

Table 2: Characteristics of patients whose caregivers Participated in the Study

Variable	**Frequency N=96**	**Percentages (%)**
Age in years		
≤ 2	14	14.6
3-5	34	35.4
6-8	20	20.8
≥ 9	28	29.2
Mean age 6.87±4.22		
Sex		
Males	52	54.2
Females	44	45.8
Socio economic status		
Upper	20	20.8
Middle	45	46.9
Lower	31	32.3
GMFCS-E&R levels		
Level 1	38	39.6
Level 2	32	33.3
Level 3	18	18.6
Level 4	4	4.2
Level 5	4	4.2
Presence of comorbidities		
Yes	56	58.3
No	40	41.7

Table III: WHOQOL-Bref scores for the different QoL domains

Quality of Life Domain	N	Mean	SD	Minimum	Medium	Maximum
Physical Health Domain	96	61.3	15.3	27.0	63.5	87.5
Psychological Domain	96	59.5	16.1	25.0	61.5	80.5
Social Relationships Domain	96	57.9	24.5	19.7	59.8	98.0
Environment Domain	96	51.8	16.2	23.9	50	80.5

Table IV: Predictors of the QoL in the four different domains using multiple regression analysis

WHOQOL-BREF	**N =96**	**R^2**	**B**	**P**
Physical Health		0.25		0.87
Age of care giver			-0.42	0.24
Sex of care giver			0.19	0.48
Marital status			-0.32	0.08
Socio economic class			0.48	0.09
GMFCS			0.42	0.00**
Presence of comorbidities			0.46	0.12
Employment status			-0.17	0.39
Age of the patient			-0.98	0.26
Psychological		0.34		0.00**
Age of care giver			0.58	0.00**
Sex of care giver			0.24	0.56
Marital status			0.54	0.01**
Socio economic class			0.41	0.00**
GMFCS-E&R levels			0.39	0.43
Presence of comorbidities			0.26	0.03**
Employment status			0.73	0.08
Age of the patient			0.25	0.31
Social Relationships		0.36		0.00**
Age of care giver			0.32	0.52
Sex of care giver			0.34	0.19
Marital status			0.32	0.01**
Socio economic class			-0.15	0.58
GMFCS levels			-0.07	0.05**
Presence of comorbidities			0.84	0.06
Employment status			0.14	0.56
Age of the patient			-0.56	0.80
Environment		0.25		0.00**
Age of care giver			0.38	0.57
Sex of care giver			-0.15	0.34
Marital status			0.57	0.06
Socio economic class			0.43	0.00**
GMFCS levels			-0.56	0.01**
Presence of comorbidities			0.34	0.18
Employment status			0.16	0.60
Age of the patient			-0.36	0.14

Discussion

The management of children with CP entails a multidisciplinary approach however, the child's family particularly the parents and caregiversremain at the center of the treatment team, and a child's challenges can be a significant source of stress for the family, affecting quality of life of the caregivers including their parents.[14] The quality of life of caregivers of children with cerebral palsy, according to the findings of our study is low. This finding is similar to earlier studies that had reported that caregivers/parents of children who have cerebral palsy and other chronic conditions had a much lower quality of life compared to parents of normal healthy children. [15-17] Although this present study is not a comparative study, it however highlights the burden of caring for a child with a chronic health condition like cerebral palsy. Children with cerebral palsy require varied forms of care because of the peculiar nature of their disorder with most of them relying on someone for their day to day living activities.[18]

Among the four domains of QoL, the participants in this study had a relatively greater QoL in the physical health domain and a much lower QoL in the psychological, social relationships and environmental domains. Several studies agree with this finding, [17,19,20] studies reported that, in comparison to parents or caregivers of healthy children, parents/caregivers of children with cerebral palsy frequently complained of significant and long-lasting stress, emotional and cognitive problems, in addition to several somatic problems over time. [17,19,20]

Similarly, in a study among mothers of children with cerebral palsy, it was reported that these mothers experienced psychological pressures, stress, and depression. They worry about the care and outcome of their child and hence, devote most of their waking hours to the child's nutritional needs, treatment, as well as the child’s rehabilitation which lead to a much lower quality of life across nearly all the domains. [17,21]

Borzoo et al [14] reported that the physical and psychologic QoL of mothers with children who have cerebral palsy was poor and that the financial cost of taking care of these children even made it worse. They reported that in contrast, mothers of healthy children had more free time and are more engaged in social activities, entertainment, and at their work place hence their QoL in the physical and psychologic domains were good. Similarly, Olsson & Hwang [22] reported that families with a child with disability were more likely to experience a higher level of psychological stress, anxiety and depression. [22]

Consistent with the findings of this study, several studies have reported a better physical QoL among parents of children with cerebral palsy. [23,24] For instance, Okurowska-Zawada et al[23] asserts that about 50% of the parents were satisfied with their physical health and thought that their QoL was good. They reported that these parents may have adjusted to their circumstances and embraced them. They also reported that these families exhibited greater level of resilience, which minimized the adverse outcomes.[23] Lee et al [24] also reported a better physical QoL compared to the mental health-related QoL and opined that higher physical health related QoL was significantly correlated with longer child disability durations and less chronic conditions among mothers.

Studies have shown that chronic diseases and other problems that pose a risk to health are linked to QoL. These illnesses can lower a mother’s/ caregiver’s mean QoL score in relation to her child's overall health, and physical discomfort. [18,25] Thus, it is possible that the need to constantly provide special care for children with CP contributed to the poor QoL noted in the psychological, social relationships and environment domain among the participants in this study.

This present study found that the environmental domain of caregivers' QoL was most affected having the lowest mean score with respect to other domains. This is comparable with reports by Bello et al[26] who asserted that the reason for the lower QoL score in the domain could be due to the caregivers' potential limitations on their freedom of movement as a result of the child's high need for assistance with their activities of everyday living, thus affecting the caregiver's general health.

Finding from this study showed that socioeconomic status, marital status, the age of the caregivers, presence of co morbidity among the CP patient's as well as their functional ability level were the significant predictors of caregiver's quality of life.

Our research indicates that socioeconomic class predicts almost all the facets of Quality of Life of caregivers. This is confirmed by another study with comparable findings [27]. Numerous studies have indicated that a person's socioeconomic situation directly affects their quality of life.[27-29] This is due to the fact that having a higher socioeconomic status typically translates into being able to gain access to better medical care, career opportunities, as well as having more income and wealth. Higher socioeconomic level is also associated with more stable living conditions, such as having access to a clean and safe place to reside, reliable transportation, and other basic necessities. All of these factors may result in better physical and mental health outcomes, greater interpersonal relationships, involvement in the community, and a greater sense of personal satisfaction.[30]

Quality of life appears to be more strongly associated to marital status as seen in this study, this is similar to earlier studies. [31,32] Mannell & Dupuis [31] opined that being married offers social assistance and companionship, which improves life satisfaction and, that married persons enjoy greater financial contentment and health, both of which have been linked with a better coping mechanism and better QoL. Similarly, the finding of this study agrees with Ahmed et al[32] who reported that living with a husband significantly determined the QoL of a mother whose child has CP. This is because the woman and her husband will receive both physical and emotional support from the other family members which helps them devote more time to their special care needs children and reduce emotional stress.[32]

Unlike the age of the child with CP that was not a predictor of caregiver's QoL, the age of the caregiver and presence of a comorbidity was a significant predictor of the psychological domain. This finding agrees with Kalay et al[33] It is possible that with a secondary disorder there will be need for more clinic visits, higher cost of health care, less leisure time. And with advance age in the caregiver, it becomes more difficult to cope with the child with CP.

Although, the finding of this study showed that the GMFCS level of the patients was a significant predictor of caregivers QoL in nearly all the domains. This is contrary to several other previous studies. [26,34,35] In this present study with 73% of the patients in GMFCS levels I and II, it is expected that they should have better ambulatory function and therefore should not be a significant predictor of the caregivers QoL. However, it is possible that despite their level of mobility they still require constant supervision and special care. Also, notwithstanding their ambulatory level, there are still buildings or places they may not be able to access hence may need assistance. For example, gaining access to a building that lacks facilities suitable for those with disabilities, a situation that is common in our setting and thus may require the caregiver carrying the child.This can have an unfavorable impact on the caregiver's quality of life.

Conclusion

This study has shown that the quality of life in caregivers of children with cerebral palsy is low.The predictors include age and marital status of the care giver, patients' level of function, presence of comorbidity and socioeconomic status.Proper functioning of the caregiverincreases the possibility of creating conditions needed for the optimum growth and development of the child with a chronic condition like cerebral palsy.

From this finding it is recommended that

1. In order to properly care for and rehabilitate a child with cerebral palsy, it is imperative to evaluate and enhance the QoL of the caregivers.
2. Social care support services should be included in government initiatives to improve the QoL for caregivers of children with CP.

Consent: Every participant that took part in the study gave their informed consent.

Ethical approval: Ethical approval was gotten from the Human Research Ethics Committee (HREC) of University of Port Harcourt Teaching Hospital.

Competing interests: The authors states that there are no conflicting interests.

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