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ORIGINAL ARTICLE

Comparative quality of life among parents of children with cerebral palsy and those with other neurological conditions

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ABSTRACT

BACKGROUND:

Parenting a child with cerebral palsy (CP) may differ between a mother and a father. Research comparing the quality of life (QoL) between mothers and fathers of children with CP is sparse.

OBJECTIVE:

This study aimed to compare the QoL of mothers and fathers of children with CP and the QoL of parents of children with other neurological conditions

METHODS:

A total of 168 participants were recruited into this study using the consecutive sampling technique. Parents' QoL was assessed with the World Health Organization Quality of Life BREF, and the functional ability of children with CP was assessed via the Gross Motor Function Classification System Expanded and Revised. The Mann-Whitney U test was used to compare the QoL between parents of children with CP and parents of children with other neurological conditions. The association between the functional ability of children with CP and the QoL of their parents was analysed using Spearman's correlation coefficient at $\alpha \leq 0.05$.

RESULTS:

A comparison between the QoL of fathers and mothers of children with CP revealed a statistically significant difference ($p \leq 0.01$; $p = 0.01$) in the physical health and psychological domains, respectively, with mothers having higher QoL in these domains. No correlation was found between the functional ability of children with CP and the QoL of their fathers or mothers.

CONCLUSION:

The outcome of this study suggests that mothers of children with CP have a better QoL in the physical and psychological domains than do fathers of children with CP.

KEYWORDS:

Cerebral palsy; Children; Fathers; Functional ability; Mothers; Parents; Quality of life

INTRODUCTION

Cerebral palsy (CP) is defined as a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances occurring in the developing foetal or infant brain [1, 2]. Motor disorders are often accompanied by disturbances in sensation, perception, cognition, communication, and behaviour; epilepsy; and secondary musculoskeletal problems. The average incidence of CP is estimated to range between 1.5 and 3.0 per 1000 live births; these values change among selected groups of patients, depending on various risk factors [3, 4]. However, the incidence among premature babies with birth weights less than 1,500 grams is reported to be more than 70 times greater than that among children with birth weights of 2,500 grams or more [5]. The prevalence is significantly greater in children born prematurely: 40–100 per 1000 live births for those born at less than 28 gestational weeks [4]. In many surveillance studies, low birth weight is often quoted rather than gestational age, as it is a more accurate measure. In other words, low birth weight often implies preterm birth [6, 7].

Cerebral palsy is the most common cause of motor disabilities in childhood. The resulting disability varies from mild to total dependence, and life expectancy is reduced, especially for those severely affected [8]. Life expectancy relates to the number of comorbidities; a significant proportion of those with severe comorbidities live to adulthood, and thus, CP places a lifelong burden of care on caregivers [9].

Caregiving for a child with CP comes with a considerable burden and stress that is greater than that required to take care of an apparently healthy child [10]. Like other chronic conditions, CP affects not only the child but also every other member of the child's family, especially the direct caregivers, usually the parents [11]. These caregivers feel socially isolated and experience physical stress, including sleep deprivation, musculoskeletal pain, and cardiovascular problems, in some extreme cases. A caregiver of a child with CP is one with the primary responsibility of encouraging the child to attain functional independence in their everyday activities [12]. This responsibility requires caregivers to sacrifice other aspects of their lives and well-being to have enough time to care for their children.

Quality of life (QoL) is a measure of the difference between the hopes and expectations of an individual and their present experiences, goals, potential, standards, and concerns [13]. Assessing the QoL of caregivers of children with neurological conditions such as CP provides insight into the challenges faced by caregivers while caring for these children [14]. As caring for children with CP (CWCP) is often a life-long commitment, it may affect the QoL of caregivers over time because these children need continuous special care, frequent medical check-ups, and physiotherapy management [15]. According to a study conducted in Nigeria, [16], the stress of caring for CWCP was identified as major of the nine factors highlighted to affect the psychosocial well-being of caregivers of CWCP.

There is evidence that the level of caregiver burden affects caregiver QoL [17]. For example, caregiving may lead to decreased opportunities for socialization and formal employment; thus, informal caregivers are more often overwhelmed by the role. The provision of a high level of care required by a child can negatively impact the QoL of the caregiver [12]. As stated by Dezoti et al. [18], the quality of life of the caregiver of a child with CP depends on certain conditions, experiences, and activities that threaten the effort of the caregivers in achieving their purpose. These factors characterise caregiver strain. They include the characteristics of the patient, the responsibilities performed by the caregivers, the time spent in caregiving, and the characteristics of the caregivers themselves [19]. Another study [12] also showed that increased caregiver burden leads to a decrease in the QoL of caregivers of CWCP. Studies have compared the QoL of informal caregivers of CWCP with that of normal healthy children. However, few studies have compared the QoL of parents of CWCP with that of parents of children with other neurological conditions in the southwestern region of Nigeria, which necessitates this study. Therefore, the objective of this study was to compare the QoL of parents who are informal caregivers of CWCP with that of their counterparts who are caregivers of children with other neurological conditions.

METHODS

Design

This was a cross-sectional study utilizing an ex post facto research design. A total of 168 consenting biological parents (i.e. mothers and fathers) comprising 84 parents (42 mothers and 42 fathers) of CWCP and an equal number of parents of children with other neurological conditions (obstetric brachial plexus injury, sciatic nerve palsy, facial nerve palsy, Down syndrome and Guillain–Barré syndrome) were recruited using the consecutive sampling technique. Participants were recruited from the University College Hospital, Adeoyo Specialist Hospital, and Oni Memorial Children's Hospital, all in Ibadan, southwest Nigeria. These hospitals were selected because of a possible optimal representation of the population. The sample size for this study was determined using the formula of Charan and Biswas [20], with alpha set at 0.05. The sociodemographic features of the participants were recorded while the Gross Motor Function Classification System Expanded and Revised (GMFCS-E&R) was used to assess the functional ability of the children with CP, and the WHO Quality of Life BREF (WHOQoL-BREF) was used to assess the quality of life of all the parents.

Instruments

The GMFCS-E&R, an improvement on the original version of the gross motor function classification system (GMFCS), was developed by Palisano et al. [21] with the aim of incorporating aspects of the conceptual framework of the International Classification of Functioning, Disability and Health (ICF) into the classification system. The GMFCS-E&R, which can be administered by either a clinician or caregiver [22], is a five-level classification system that differentiates CWCP according to gross motor ability, limitations in gross motor function, the need for assistive technology, and wheeled mobility. Five age bands are identified: under 2 years, 2–4 years, 4–6 years, 6–12 years and 12–18 years, while the child's functional ability is categorized into five levels: level I– walks without limitations; level II– walks with limitations; level III– walks using a hand-held mobility device; level IV– mobility with limitations; potentially using powered mobility; and level V–transport in a manual wheelchair. The criterion to be classified into any of the levels hinges on the child meeting a set of age-appropriate functions or activities. The instrument has been reported to have excellent interrater reliability, with an intraclass correlation (ICC) of 0.96 [23]. It has also been reported to be a valid tool for assessing functional ability in CWCP [24, 25].

The WHOQOL-BREF is a self-administered report comprising 26 items. The first 2 items assess overall QoL and general health, whereas the remaining 24 items are grouped into four domains related to QoL, namely: physical health, psychological health, social relationships, and the environment. The domain raw scores range as follows: physical health (7--35), psychological health (6--30), social relationships (3--15), and the environment (8--40). The raw scores are transformed using the following formula:

Transformed scale: (Actual raw score − lowest possible raw score) ÷ Possible raw score range

The scores obtained are scaled positively so that higher scores denote better QoL and vice versa. The WHOQOL-BREF has good to excellent psychometric properties of reliability and is a sound, cross-culturally valid assessment of QoL [26]. It has internal consistency, with a Cronbach's alpha of >0.7 for its physical, psychological, and environmental domains and 0.68 for social relationships [26]. Both the English and Yoruba versions have been validated among the Nigerian population, as there was a significant correlation of participants' domain scores between their scores on the Yoruba version and those on its English version (r=0.695--0.859; p=0.000)[27].

Procedure for data collection

Ethical approval was sought and obtained from the University of Ibadan/University College Hospital Research Ethics Committee prior to the commencement of the study (UI/EC/17/0021). The purpose of the study was explained to participants, who were made to understand that participation in the study was voluntary and that they could decline if need be. Participants who were willing to participate were assured of the confidentiality of any information they supplied, and the informed consent form was administered to formally obtain their consent. Questionnaires were distributed by hand to consenting participants. A research assistant who was fluent in the

Yoruba language aided in the collection of data from participants who could speak Yoruba language only. Telephone interviews were conducted for participants who were not physically present, especially the fathers, at their convenient time. The GMFC E&R was administered by the researcher and their assistant to obtain the functional level of each child with CP.

Data analysis

The data were analysed with the Statistical Package for Social Sciences (SPSS) version 21. The participants' sociodemographic variables and questionnaire data were summarized using descriptive statistics such as frequency counts, percentages, means, and standard deviations. The Mann–Whitney U test was used to test the difference between the QoL of both parents of the CWCP and that of children with other neurological conditions. The Wilcoxon signed rank test was used to compare the QoL of mothers and fathers in each group, and Spearman's correlation coefficient was used to evaluate the association between the functional ability of the CWCP and the QoL of their parents at an alpha level of 0.05.

RESULTS

A total of 168 participants (42 mothers and fathers of CWCP and 42 mothers and fathers of children with other neurological conditions) participated in this study. The mean ages of mothers of CWCP (33.47±5.67) and mothers of children with other neurological conditions (32.0±5.4) were comparable. The mean age of fathers of children with other neurological conditions (37.54 ±5.60) was not significantly different from that of fathers of CWCP (37.9±5.80). A large proportion of fathers of both the CWCP group and those of children with other neurological conditions (78.6% and 85.7%, respectively) were absent at their child's appointment (Table 1). A total of 71.4% of CWCP were males; 29% and 36% of them were categorized into either level 4 or level 5 classifications of the GMFCS, respectively (Table 2).

Table 1. Demographic characteristics of all parents (N=168)

	PCWCP		PCWNC	
Attributes	**n**	**%**	**n**	**%**
Mothers' Highest Education				
Primary	4	9.5	2	4.8
Secondary	14	33.3	17	40.5
Tertiary	17	40.5	15	35.7
Postgraduate	7	16.7	8	19.0
Fathers' Highest Education				
Primary	6	14.3	5	11.9
Secondary	10	23.8	12	28.6
Tertiary	19	45.2	18	42.9
Postgraduate	7	16.7	7	16.7
Mothers' Occupation				
Gainfully employed	18	42.9	14	33.3
Self-employed	21	50.0	21	50.0
Unemployment	3	7.1	7	16.7
Fathers' Occupation				
Gainfully employed	24	57.1	19	45.2
Self-employed	18	42.9	23	54.8
Unemployed	0	0.0	0	0.0
Fathers Present	9	21.4	6	14.3
Fathers Absent	33	78.6	36	85.7

*PCWCP= parents of children with CP; PCWNC= parents of children with other neurological conditions

Table 2. Demographic and clinical characteristics of all the children (n=84)

	CWCP		Children with other neurological conditions	
Variable	**Frequency**	**%**	**Frequency**	**%**
Child's Gender				
Male	**30**	**71.4**	**25**	**59.5**
Female	**12**	**28.6**	**17**	**40.5**
Child's Age				
<1	**7**	**16.7**	**19**	**45.2**
1-5	**30**	**71.4**	**17**	**40.5**
6-10	**4**	**9.5**	**5**	**11.9**
11-15	**1**	**2.4**	**1**	**2.4**
Types of CP				
Spastic	**21**	**49**		
Athetoid	**11**	**27**		
Flaccid	**2**	**5**		
Ataxic	**1**	**2**		
Unspecified	**17**	**17**		
GMFCS Levels				
Level 1	**6**	**14**		
Level 2	**5**	**12**		
Level 3	**4**	**10**		
Level 4	**12**	**29**		
Level 5	**15**	**36**		
Children with other neurological Conditions				
Sciatic nerve palsy			**17**	**40.5**
Obstetric brachial plexus injury			**18**	**42.9**
Facial nerve palsy			**1**	**2.4**
Down's syndrome			**3**	**7.1**
Muscular dystrophy			**1**	**2.4**
Guillain–Barre syndrome			**1**	**2.4**
Spina bifida			**1**	**2.4**

The test of differences between the QoL of parents of CWCP and those of parents of children with other neurological conditions revealed no statistically significant differences in the majority of items of the WHOQOL-BREF between the two groups ($p>0.05$). However, the physical and psychological domains were significantly lower in mothers of CWCP than in mothers of children with other neurological conditions ($p<0.05$) (Table 3).

Table 3. Comparison of individual quality of life domains between parents of children with cerebral palsy and children with other neurological conditions via the Mann–Whitney U Test (N=168)

	Mean Ranks			
	PCWCP	**PCWNC**	***U***	**p-value**
Fathers' QoL				
Physical Health	**45.9**	**39.0**	**735**	**0.18**
Psychological	**41.4**	**43.6**	**834**	**0.66**
Social Relationships	**38.7**	**46.2**	**725**	**0.16**
Environment	**38.2**	**46.8**	**701**	**0.10**
Mothers' QoL				
Physical Health	**37.2**	**47.8**	**658**	**0.04***
Psychological	**37.4**	**47.8**	**667**	**0.05***
Social Relationships	**38.0**	**47.0**	**693**	**0.09**
Environment	**40.1**	**44.9**	**780**	**0.37**

Comparison of QoL between mothers and fathers of CWCP showed a significant difference in the physical health and psychological domains (p<0.05). Mothers of CWCP had higher mean rank scores in these domains than the fathers of CWCP. On the other hand, when the QoL of mothers and fathers of children with other neurological conditions was compared, there was no significant difference in the QoL domains (Table 4). Furthermore, no correlation was found between the functional ability of CWCP and each of the QoL domains of their mothers and fathers (Table 5).

Table 4. Within-group comparison of the quality of life of mothers and fathers of children with cerebral palsy and those with noncerebral palsy using the Wilcoxon signed rank test.

	Mean Ranks **Mothers of CWCP**	**Fathers of CWCP**	**Z**	**p-value**
Quality of Life				
Physical Health	21.08	12.50	-4.12	0.00*
Psychological	20.73	14.04	-2.59	0.01*
Social Relationships	17.18	18.78	-0.38	0.70
Environment	17.67	15.0	-1.02	0.31
	Mothers of children with other neurological conditions	**Fathers of children with other neurological conditions**		
Physical Health	22.79	18.43	-0.31	0.76
Psychological	16.61	17.54	-0.63	0.53
Social Relationships	15.76	20.95	-1.02	0.30
Environment	19.50	16.00	-1.23	0.22

Table 5. Correlations between the quality of life of parents of children with cerebral palsy and the functional ability of children with cerebral palsy according to Spearman's correlation coefficient

	GMFCS Level rho	p value
Mothers' QoL		
Physical Health	-0.19	0.24
Psychological	0.20	0.19
Social Relationships	-0.06	0.72
Environment	0.28	0.08
Fathers' QoL		
Physical Health	0.000	0.99
Psychological	-0.004	0.98
Social Relationships	-0.17	0.28
Environment	0.13	0.42

DISCUSSION

Summary of key findings

Mothers of CWCP had poorer QoL in the physical and psychological domains when compared to mothers of children with other neurological conditions. Within group comparison, however, showed that mothers of CWCP fared better in the physical and psychological domains of QoL than fathers. Also, the functional ability of CWCP was not associated with the QoL of their parents.

Strengths and limitations of the study

This study takes into consideration the QoL of both parents actively involved in the care of CWCP, rather than focusing only on mothers as caregivers of these children. This is particularly important because the health of caregivers may determine the quality of care received by these children.

The impact of the severity of CP as a lifelong condition on parents may not be comparable to the impact of most of the other neurological conditions seen in this study, therefore posing a limitation. Also, the cross-sectional design used for this study may limit causal interpretations of the results obtained.

Comparison with previous studies on the topic

A total of 168 parents, comprising 42 mothers and 42 fathers of CWCP and an equal number and distribution by gender of parents of children with other neurological conditions, participated in this study. There was no age disparity between mothers of CWCP and mothers of children with other neurological conditions or between fathers in either group. This finding could be attributed to the fact that the parents of these children were still within their childbearing window. The present study revealed that a significant percentage of fathers in both groups were absent at their child's appointment. This discovery may be associated with a patriarchal society, such as Nigeria, where being a father means that the man is the breadwinner and that the woman is often left to care for the children and household needs. Therefore, tasks such as bringing a child to the hospital for medical attention automatically fall to the mother, while the father may be out at his source of livelihood to enable him to provide for his family [28]. Fathers' absence at their children's clinic appointments may also be attributed to their lack of support for the mothers of these children [29], as mothers may be blamed for the plight of their children.

The CWCP in this study were mostly males, which could be an indication that more families with male children accessed physiotherapy care at the venues of this study. This trend may be a result of the importance placed on the male child in this setting or that the male gender is at greater risk of CP than their female counterparts are. Research, in conjunction with these findings, shows that CP is more prevalent in males than in females [30-32]. A greater percentage of the children in this study were classified within levels 4 and 5 of the

GMFCS. This may have been a reflection of the functional ability of the children who visited the study centres.

A comparison between mothers in both groups revealed significantly different scores in the physical and psychological domains of the WHOQOL-BREF. Poor physical health in mothers of CWCP may be due to the heavy physical activity of caregiving, as techniques such as lifting and carrying, moving, cleaning, feeding the child, and performing home programmes may lead to aches and pains in these mothers [29]. Caregivers of CWCP have been shown to experience physical stress, a lack of sleep, musculoskeletal aches and pains [29]. The psychological burden experienced by mothers may be related to the fact that CP is a condition that requires long-term and lifelong care. It may further be associated with feelings of guilt, self-blame, or possible emotional and/or domestic violence experienced by spouses [29]. Uncertainty regarding the future of a child with CP may also pose a psychological burden on their mothers. Physical and psychological strain may also result from the functional ability of the child, as mothers of children in the GMFCS level IV have been shown to experience more caregiver stress/burden than mothers of children in other GMFCS classifications do [14, 33-34]. It has been established in the literature that mothers of children with developmental challenges have poorer health than mothers of typically developing children do [35].

The test of differences between fathers and mothers of the CWCP revealed a significant difference in the physical and psychological domains of the QoL measure. Mothers were shown to have higher mean scores in these domains than their spouses did. This result may be because mothers may have adopted coping mechanisms to help them adjust to caring for a child with CP. The lack of difference in the QoL domains of parents of children with other neurological conditions could be because both parties equally share in their plight. In the same vein, there was no correlation between the functional ability of CWCP and parents' QoL. This may imply that the child's functional ability does not have any effect on parents' QoL. This may hinge on parents in this study accepting their child's condition and, as a result, expressing positive attitudes towards it. Studies have shown a positive correlation between caregiver burden and the severity of CP [33, 36, 37]. The findings from this study also agree with Tuna et al[38] who stated that there was no association between the functional ability of a child with CP and their caregivers' health because, "once a catastrophic event occurs, its severity seems to have minor importance". In another study,[39] an improved QoL of caregivers was attributed to strong governmental and family support despite the poor functional ability of the CWCP. The difference between the present study and previous studies could be that the complexity of the child's health (other health challenges experienced by the child), the general mental health of the caregivers, parenting stress, individual coping patterns, environmental family life and social support[40, 41] are better indicators of caregiver health than the severity of motor function. The QoL of mothers, although not significantly different, was observed to increase in the physical health and social relationships domains (rho = -0.19 and rho = -0.06, respectively) as the severity of CP decreased. This could be because with less severe CP, mothers are able to carry out activities of daily living fully without being overwhelmed with caregiving, and it could also allow adequate time to form and enjoy personal relationships.

Interpretation of findings

The QoL of both mothers and fathers of CWCP is affected by providing care for them. However, fathers showed poorer QoL in the physical health and psychological domains than mothers did.

Implications of findings

The quality of life of fathers of children with cerebral palsy is also affected by their child's condition. Although interventions such as support groups and psychoeducation[42] are usually benefitted by mothers of CWCP, future interventions should consider including both mothers and fathers of the children.

CONCLUSION

The psychological and physical health quality of life domains were poorer in mothers of CWCP than in mothers of children with other neurological conditions. However, there was no difference between the QoL of parents of CWCP and parents of children with other neurological conditions in the other quality of life domains. On the contrary, mothers of CWCP ranked higher in the physical and psychological domains of quality of life than fathers of CWCP, and there was no association between the functional ability of CWCP and their parents' QoL.

CONFLICT OF INTEREST

All authors declare that they have no competing interests (financial and non-financial) concerning the study to disclose.

AUTHORS CONTRIBUTION

Mrs. Samuel-Udofia Cindy Goda conceived, designed the study, participated in the data collection process, analysed data, and wrote the manuscript. Mr. Zaki Desmond Aondowase wrote the manuscript, reviewed and provided feedback. Mr. Alabi Oluwasegun conceived the study, provided critical revisions, and feedback. All authors have approved the version of the manuscript to be published.

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