

## CLINICAL STUDIES / ETUDES CLINIQUES

## QUALITY OF LIFE OF MOTHERS OF CHILDREN WITH CEREBRAL PALSY AND THEIR AGE-MATCHED CONTROLS

## QUALITÉ DE VIE DES MÈRES DES ENFANTS PRESENTANT UNE INFIRMITÉ MOTRICE CÉRÉBRALE AVEC UN CONTRÔLE D'ÂGE COMPARABLE

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**ABSTRACT****Background**

Caring for a child with cerebral palsy (CP) could negatively impact the quality of life (QoL) of the mothers who are usually the primary caregivers. Studies on the impact of caring for Nigerian children with cerebral palsy on the mothers' quality of life are not common hence the quality of life of mothers of children with cerebral palsy (MCCP) and age-matched mothers of typically developing children (MTDC) were compared in this study.

**Methods**

Eighty mothers (40 MCCP and 40 MTDC) participated in this cross-sectional survey. Participants in both groups had their quality of life assessed using the World Health Organization Quality of Life BREF (WHOQoL-BREF). Data were analyzed using independent t-test, Chi-square and Mann-Whitney U tests with alpha level set at 0.05.

**Results**

The two groups were not significantly different in their ages ( $p = 0.14$ ). The mean overall QoL score of the MCCP ( $62.83 \pm 17.83$ ) was significantly lower than that of the MTDC ( $68.87 \pm 8.51$ ) ( $U=590.0$ ;  $p=0.04$ ) just as scores for overall health perception ( $U=576.5$ ;  $p=0.03$ ). Religion, educational status and occupational status had no significant influence on the QoL scores of mothers of children with cerebral palsy.

**Conclusion**

Caring for a child with CP significantly impacted on the QOL and health of the mothers, irrespective of their socio-economic status. Measures to improve quality of life and health of mothers of children with cerebral palsy should be incorporated in the management of CP with emphasis on identified areas of need.

## INTRODUCTION

Cerebral palsy is the commonest physical disability in childhood yet in many cases the cause remains unknown [24]. Transporting a child with cerebral palsy to regularly scheduled physical therapy sessions can cause significant family stress [15]. This demanding responsibility can have an influence on physical and psychological health status [28] and tends to curb social, cultural, and professional opportunities [10]. 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 [20]. This is particularly so as the child ages and grows [7]. Eventually, this leads to a diminished quality of life (QoL) among such caregivers [4].

Living with a chronic condition not only affects the child but its effect can extend to other members of the child's family especially the caregiver, who often is the child's mother or father [3]. The QoL of a caregiver as it relates to health, psychological well-being, social networks and support, and the family dynamics can be negatively impacted when a significant amount of time is being committed to the care of a child with a chronic condition [13]. The commitment to long-term care for these children can significantly impact the QoL of the caregivers, who often are required to give round-the-clock care to meet the child's medical, physical and social needs [19]. This often requires them to sacrifice aspects of their own personal well-being in order to devote extended amounts of time to care for their children [7]. Therefore, an understanding of the ways in which a child's condition can affect the caregiver's own quality of life can enhance the treatment of the entire family [26].

Measuring the QoL of caregivers of children with chronic conditions provides insight into the challenges faced by these caregivers while caring for their children [6,7]. This is particularly important as the quality of care provided by a caregiver can be directly impacted by the caregiver's perceptions of his/her own QoL [22]. Several studies have examined the QoL of caregivers of children with cerebral palsy [7,8,12,21].

A significantly lower QoL have been reported in studies comparing caregivers of children with cerebral palsy (who were majorly or solely the mothers) compared to those caring for healthy children [8,12,21]. Eker and Tuzun [7] reported a similar finding in their study comparing QoL profile of mothers of children with cerebral palsy and mothers of children with minor health problems. This study [7] assessed physical well-being alone as a measure of QoL despite the fact that QoL includes all areas of a person's life such as social and emotional well-being, not just physical. A similar study showed that the psychological and physical health of caregivers were strongly influenced by the child's behaviour and care giving demands [23].

These studies conducted in diverse countries, are equivocal in reporting reduced QoL among caregivers of children with CP. However, many of the studies were limited in that they only looked at a few aspects of QoL instead of taking into account the variety of domains that make up QoL such as physical well-being, social well-being, and emotional well-being altogether. The studies that explored only the physical or mental health aspects of QoL also concluded that the QoL of the parents was reduced [7,16,21]. This study was hence designed to compare the QoL of mothers of children with cerebral palsy (MCCP) and that of age-matched mothers of typically developing children (MTDC) and investigate the influence of religious affiliation, occupational status and educational status on the QoL of the MCCP. We hypothesized that the QoL of MCCP will be significantly lower than that of MTDC.

## METHODS

The study was a cross-sectional descriptive survey of participants drawn from a consecutive sample of mothers of children with cerebral palsy who brought their children for physiotherapy in selected hospitals in Ibadan, Nigeria. Inclusion criteria included having not more than one child with cerebral palsy or any other disability and living with the child in the same house. They were age-matched with mothers of typically developing children, recruited from communities mainly serviced by each of the selected hospitals. Mothers in both groups had no prior history of psychological disorder or any chronic medical condition that could negatively impact on quality of life.

Ethical approval for the study was obtained from the local Ethics Committee (UI/IRC/06/0078) and the procedure and the rationale for the study explained to prospective participants. The informed consent of each participant was then sought and obtained. Data on age, educational level (categorized as pre-secondary/secondary and post-secondary) and occupation (categorized as skilled and unskilled) of the participants were collected using a researcher-designed data collection form. The QoL of the mothers of children with cerebral palsy and their counterparts with typically developing children were assessed using the WHOQoL-BREF, a 26-item version of the WHOQoL-100, which could be self-administered or interviewer-administered. The WHOQoL-BREF covers four domains (physical health, psychological, social relationships and environment) to give an overall QoL profile. The first two questions assess the participant's view of their overall QoL and their overall view of their health status. The scores for the WHOQoL-BREF are in a positive direction so that a higher score represents a higher QoL. The raw scores can be transformed through two methods, one of which gives scores on a scale of 1-5 and the second which gives scores on a 0-100 scale. It has an internal consistency with Cronbach's  $\alpha$  of  $>0.7$  for domains 1, 2 and 4 and 0.68 for domain 3 [17].

The questionnaire was self administered by participants who were able to read and write in English or the native Yoruba language while it was administered as an interview to those who lacked the ability to do so. Both English and Yoruba-translated versions of the instrument have been validated among Nigerians [1].

Data were summarised using descriptive statistics of mean and standard deviation. Independent t-test was used to compare the ages of MCCP and MTDC while Chi-square test was used to compare the distribution of participants in the two groups based on education, occupation and religion. Mann Whitney-U test was used to compare the groups' domain scores as well as the overall health perception and quality of life scores. All tests were conducted at  $\alpha = 0.05$ .

## RESULTS

Eighty mothers comprising 40 mothers of children with cerebral palsy (MCCP) and 40 mothers of typically developing children (MTDC) participated in this study. The ages of the MCCP ( $30.53 \pm 3.65$  years) and MTDC ( $29.33 \pm 3.55$  years) were not significantly different ( $p = 0.14$ ). There were significant differences in the distribution of MCCP and MTDC based on education ( $p = 0.01$ ) and occupation ( $p = 0.01$ ) but not on religion ( $0.22$ ) (Table 1). The mean overall QoL ( $p = 0.04$ ) and health perception ( $p = 0.03$ ) scores of the MCCP were significantly lower than that of the MTDC but there was no significant difference between the domain scores of the two groups (Table 2). Religion (Table 3), educational status (Table 4) and occupational status (Table 5) had no significant influence on MCCP's quality of life. Discussion The quality of life of mothers of children with cerebral palsy and their age-matched counterparts with typically developing children was compared in this study. The participants in the two groups were different in terms of their educational and occupational status but otherwise had comparable demographics. Similar to previous findings of reduced QoL in caregivers/mothers of children with cerebral palsy [7,8,12,21], the QoL of the MCCP in this study was significantly lower to that of the MTDC. Scores for MCCPs were also lower in all the domains of the WHOQoL-BREF, though not significantly. Unlike the present study however, some of the previous studies looked only at an aspect of QoL or considered overall QoL instead of taking into account the variety of components of QoL such as physical well-being, social well-being, and emotional well-being [4,7,8,21]. They all concluded that the QoL of parents with children with cerebral palsy was lower. The present study aligns with this finding when overall QoL is considered.

Findings of non-significant difference between the groups in individual QoL domains however suggest that while the impact of CP on a caregiver/mother may not be so severe on individual domains of QoL, the additive domain effect impacts more severely on the mothers' health and undermine their quality of life. It was also noted that differences in scores for MCCP and MTDC in the physical health, social relations and environmental health domains were approaching statistical significance. It seems that these were the more affected domains for the MCCP. Clinicians managing their care-recipients ought to pay keener attention specifically to these areas so as not to jeopardize the quality of care these recipients receive.

The QoL domain mean scores of MCCP are rather modest and comparable to that of MTDC. It seems that several factors other than the presence of a disability can affect caregiving for any child. Associating the severity of disability and burden of care with quality of life in mothers of children with cerebral palsy do not make for comparison in mothers of children with typically developing children who do not have such factors to contend with. In our study the influence, presence or otherwise of these factors was not assessed and may account for the findings. Interestingly, studies had shown that the degree of stress experienced by parents of children with cerebral palsy is not related to the level of their child's degree of functioning, but is rather affected by their access to resources and support and the nature of the family environment [9,21]. It could be that the MCCP in this study similarly had access to resources and supports as the MTDC. It could also be that the mothers being aware of the possible outcomes, long-term nature and prognosis of cerebral palsy once diagnosed, had developed coping strategies that limit the impact of their care-giving on their quality of life [25].

Another factor that may have influenced the QoL of the MCCP is family support through the extended family system. This plays a role in alleviating the stress and burden of caring for children with disabilities in our environment. The modest overall QoL and domain scores for the MCCP may have been helped by the family support that is often available. One may naturally expect that the higher the level of emotional support that a caregiver receives, the lower is the probability of QoL impairment. Caregivers report that they receive emotional support from their spouse, other family members, friends or members of the community [11].

The QoL of the MCCP was not influenced by their religious affiliations. This may be indicative of the possibility that any act of religiosity could positively influence QoL. Religiosity and spirituality help to bring about a positive perception of and reaction to caregiving stress [18] and these positive effects have been identified as contributing to the caregiver's sense of well-being and coping [2]. According to Morano and King [18], caregivers who are religious have lower incidence of depression because of the stress-buffering effect of religious involvement. The MCCP in our study undoubtedly practice one form of religion or the other which might have encouraged them to have a positive outlook on life in spite of their children's condition. Religion encourages optimism (faith) and optimistic individuals have been reported to cope more effectively with stressful life events [14].

The QoL of the MCCP was not significantly influenced by the level of education of the mothers of children with cerebral palsy in this study. This is similar to earlier findings of no association between the health-related QoL of mothers of children with cerebral palsy and their educational status [29]. However, health-related QoL was negatively correlated with the educational status of mothers in the study of Ones et al [21] while Lawako and Soares [16] identified level of education as a predictor of QoL in caregivers of children with chronic conditions; caregivers with university-level education reporting lowest QoL. Our findings suggest that educational status of the mothers have no effect on their ability to cope with the demands of their roles as caregivers. Ability to cope with stress and optimism about life may be more related to individuals' inherent traits and dispositions rather than educational status.

### **LIMITATIONS**

The small sample size may constitute a limitation as to the generalizability of findings from this study, thus the findings need to be interpreted with caution. Another possible limitation may arise from the fact that the study did not explore the relationship or influence of variables such as social support, age of child and mother, severity of disability as well as socioeconomic status which had been reported to affect quality of life. However, the absence of a child without disability in the control group may make assessment of some of these variables among them unrealistic. Future studies should compare the quality of life of mothers of children with cerebral palsy with that of mothers of children with other forms of disability. Studies exploring the quality of life of mothers of children with cerebral palsy of different levels of severity and in different age groups could also provide insight into the impact of cerebral palsy on the quality of life of primary caregivers.

### **CONCLUSION**

The quality of life of mothers of children with cerebral palsy and that of mothers of typically developing children was compared in this study. Though, the MCCP had significantly lower scores in the overall quality of life and health perception, their lowered scores were not significantly different to that of the MTDC in all the domains of WHOQoL-BREF. This could be because of the social support from the extended family system in our environment and the possibility that the MCCP had developed positive coping strategies. However, since mothers of children with cerebral palsy had consistently lower quality of life than their counterparts with typically developing children, measures to improve quality of life should be implemented for mothers of children with cerebral palsy.

### **Key Messages**

- The quality of life of mothers of children with cerebral palsy, though comparable in individual domains, is generally lower than that of mothers of typically developing children.
- The negative impact of caring for a child with cerebral palsy is more on the health perception and overall quality of life of the mothers.
- Measures to improve the health status and quality of life of mothers of children with cerebral palsy should routinely be provided in the course of care of these children.

**Conflit d'intérêt : Aucun**

**Table 1: comparison of socio-demographic characteristics of the participants**

Variable	Category	MCCP (n)	MCCP (%)	MTDC (n)	MTDC (%)	$\chi^2$	p
Education	Pre-Secondary	20	50	8	20	7.91	0.01*
	Post-Secondary	20	50	32	80		
Occupation	Skilled	14	35	25	62.5	6.05	0.01*
	Unskilled	26	65	15	37.5		
Religion	Christianity	26	65	31	77.5	1.53	0.22
	Islam	14	35	9	22.5		
Mean Age (years)		30.53±3.65		29.33±3.55		1.49	0.14

Key:

MCCP: Mothers of Children with Cerebral Palsy.

MTDC: Mothers of Typically Developing Children

\*Indicates significant difference at  $\alpha = 0.05$ **Table 2: comparison of quality of life of mothers of children with cerebral palsy and mothers of typically developing children**

Variable	MCCP (n = 40)	MTDC (n = 40)	U	p-value
Physical Health	61.45±17.10	69.55±10.20	624.5	0.09
Psychological Health	57.55±13.39	61.55±8.71	664.5	0.18
Social Relationship	69.43±20.04	76.50±9.69	619.0	0.08
Environment	62.88±17.31	68.97±7.81	618.0	0.08
Health Perception	59.55±17.89	65.55±8.73	576.5	0.03*
Overall QOL	62.83±17.83	68.87±8.51	590.0	0.04*

Key:

MCCP - Mothers of Children with Cerebral Palsy

MTDC - Mothers of Typically Developing Children

\* = significant difference at  $\alpha = 0.05$ **Table 3: influence of religion on quality of life of mothers of children with cerebral palsy**

Variable	Christianity (Mean Rank)	Islam (Mean Rank)	U- value	p-value
Physical Health	41.72	37.48	586.00	0.45
Psychological Health	41.28	38.57	611.00	0.63
Social Relationship	42.79	34.83	525.00	0.16
Environment	42.48	35.59	542.50	0.22
Health Perception	42.01	36.75	569.50	0.32
Overall QOL	41.45	38.15	601.50	0.52

**Table 4: influence of educational status on quality of life of mothers of children with cerebral palsy**

<i>Variable</i>	<i>PrS (Mean Rank)</i>	<i>PtS (Mean Rank)</i>	<i>U-value</i>	<i>p-value</i>
Physical Health	34.79	43.58	568.00	0.10
Psychological Health	40.93	40.27	716.00	0.90
Social Relationship	35.86	43.00	598.00	0.18
Environment	36.45	42.68	614.50	0.24
Health Perception	37.71	42.00	650.00	0.39
Overall QOL	39.77	40.89	707.50	0.82

Key:

PrS - Pre-secondary Level

PtS - Post-Secondary Level

**Table 5: influence of occupational status on quality of life of mothers of children with cerebral palsy**

<i>Variable</i>	<i>Skilled Occupation (Mean Rank)</i>	<i>Unskilled occupation (Mean Rank)</i>	<i>U-value</i>	<i>p</i>
Physical Health	44.35	36.84	649.5	0.14
Psychological Health	40.06	40.91	782.5	0.87
Social Relationship	41.10	39.93	776.0	0.82
Environment	40.32	40.67	792.5	0.95
Health Perception	40.14	40.84	785.5	0.88
Overall QoL	40.32	40.67	792.5	0.94

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