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## Evaluating Quality of Life among Parents of Children living with Cerebral Palsy in Enugu State, Nigeria

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### Abstract

*The study examined the quality of life of parents of children living with cerebral palsy (CP) in Enugu State, Nigeria. 50 parents of children living with CP (25 mothers and 25 fathers) and 50 parents of healthy children (25 mothers and 25 fathers) were recruited for the study. The age of the participants ranges from 25 to 65 years, with a mean age of 45.44 years and standard deviation of 9.45 years. World Health Organization Quality of Life-BREF was employed for data collection. Cross-sectional survey design was adopted for the study while independent t-test was used to analyze the data. The result revealed a statistically significant difference on Quality of life between parents of children living with CP and their counterpart. It was recommended that government should establish a community based program that would improve the QOL of parents of children living with CP parents.*

**Keywords:** *Quality of Life, cerebral palsy, parents, mental retardation, life satisfaction.*

### Introduction

Quality of life (QoL) is the perception of one's status in life as defined by cultural features and social value (Yilmaz, Erkin & İzki, 2013). It is an individual's personal perspective of overall well-being and contentment in life, which includes both psychosocial and physical or health-related domains (Majnemer, Shevell, Law, Poulin, & Rosenbaum, 2008). According to Verdugo (2012), QOL consist of different domains such as emotional well-being, personal development, physical well-being, self-determination, interpersonal relations and material well-being. Many factors has been found to influence the quality of life of individuals' (parents) living with cerebral palsy, and these include child's level of disability, environmental and social influences, stressors, and level of social support (Chalipat, Malwade, Karambelkar, Agarkhedkar & Kannan, 2016). Hence, parents of children living with cerebral palsy are more vulnerable to emotional, social and psychological burden that affects their lives and well-being (Chalipat et al., 2016).

Cerebral palsy (CP) is a developmental disorder resulting from damage to the fetal or developing brain, leading to partial losses of motor and cognitive functioning (Shelly, Davis, Waters,

Mackinnon, Reddihough et al., 2008; Varni, Burwinkle, Sherman, Hanna, Berrin et al., 2005). Cerebral palsy is the most common form of chronic motor disability that starts in childhood (Belonwu, Gwarzo & Adeleke, 2009). Unlike other childhood neurodevelopmental disorders, cerebral palsy is a permanent disorder of movement and posture, causing activity limitations, which are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. This disorder often affects the child's sensation, perception, cognition, communication and behaviour, and in most case causing epilepsy or secondary musculoskeletal problems (Rosenbaum, Paneth, Leviton, Goldstein, Bax et al., 2007). Thus, cerebral palsy disability ranges from mild to severe effects on motor and cognitive functioning (Wippermann, 2013).

According to Diagnostic and Statistical Manual of Mental Disorders, cerebral palsy is classified based on the nature of movement disorder and the anatomic or topographic distribution of the motor abnormalities (APA. 2013). There are four main types of CP which are categorized as spasticity, ataxia, dystonia and athetosis cerebral palsy. Briefly, spasticity type is observed among children born prematurely, this manifest in form of an increase muscle tone (resistance to stretch). In ataxic cerebral palsy, there is a loss of orderly muscular coordination, so that movements are performed with abnormal force, rhythm, and accuracy. Dystonia is characterized by hypertonia and reduced activity while choreo-athetosis, have to do with irregular, spasmodic, involuntary movements of the limbs or facial muscles (O'Shea, 2008).

However, review report has shown that there is high prevalence rate of cerebral palsy cases in the low and middle income country such as spastic (41.7%), mixed (29.8%), hypotonic (21.9%) and dyskinetic (6.6%) (Belonwu et al., 2009). In Nigeria, Belonwu, Gwarzo and Adeleke (2009) reported 42.4% cases of cerebral palsy highlighting that birth asphyxia was the leading cause of cerebral palsy (45.7%), followed by neonatal jaundice (12.6%), seizure disorder (11.9%), meningitis (7.3%), prematurity (3.3%), encephalitis (2.6%), genetic disorder (1.3%), trauma (1.3%) and craniosynostosis ( 0.62%). Indeed, the report shows that there is lack of mental health attention to the raising issues of CP in Nigeria (Belonwu et al., 2009). Clinically, the diagnosis of cerebral palsy is typically based on observations or parent reports of attained motor milestones, such as sitting, pulling to stand, and walking, and evaluation of posture, deep tendon reflexes, and muscle tone. Particularly among infants born prematurely, neurological abnormalities, observed in the early months of life, may not be associated with motor impairment and may resolve during the first one or two years of life (O'Shea, 2008). Based on this assertion, Cerebral palsy causes a huge financial and physical stress to the family due to vague and unknown predicted outcomes of the disorder (Wippermann, 2013).

Research has demonstrated that raising a child with chronic disability (cerebral palsy) can be very stressful and task demanding (Chalipat et al., 2016). Children with CP may suffer from several problems such as spastic paralysis, cognitive impairment, chronic pain, speech and visual

impairment, and gastrointestinal and feeding problems (Odding, Roebroek & Stam, 2006). They also experience difficulties in their basic self functioning like feeding, dressing, toileting and mobility. Thus, cerebral palsy may affect parents or caregivers in different ways depending on coping mechanisms, support systems, age and level of functioning of the child and so on (Wippermann, 2013). For example, a child with cerebral palsy may require constant care, frequent medical examinations, continuous physical and educational-rehabilitation therapy etc. In other words, mental health challenges associated with CP significantly influence the psychological state of the family (parents or caregivers) by causing them to adjust in a particular way (Bumin, Günal & Tükel, 2008).

However, Fonseca, Nazare and Canavarro (2012), proposed that children with CP require increased intensity of care, which may become a burden for parents and influence their physical and mental health (Fonseca et al., 2012; Glasscock, 2000). Taking care of children with CP has impact on physical, psychological and social aspects of the quality of life of caregiver (Chalipat et al., 2016). As opined by Jone and Passey (2005), parents of children with CP are posed with higher risk of having psychological challenges in compared to parents of children without disabilities. In addition, parents may be unprepared or in equipped to handle the developmental condition due to financial constraint and lack of time or poor service care. Against this background, this study evaluates the quality of life of parents of children with CP in Nigeria.

Romeo, Cioni, Distefano, Battaglia, Costanzo, Ricci, Sanctis et al. (2010), examined the quality of life (QOL) of parents of children with cerebral palsy (CP) and the possible effect of behaviour problems on their QOL. One-hundred children with CP, aged between 4 and 10 years, and both their parents were included in the study. Both parents completed the WHOQOL-BREF, to assess their QOL. A sample of 60 parents of healthy children was used as control group. The primary caregiver also completed the child behaviour checklist (CBCL). Parents of children with CP showed lower scores on physical and psychological domains than the control group on QOL.

Ström, Kreuter and Rosberg (2012), investigated QOL in parents/caretakers of children with cerebral palsy in the province of Kampong Cham, Cambodia. Forty parents/caretakers of children with cerebral palsy aged 1–13 years (F19/M21) participated in the study. The study utilised Comprehensive Quality of life Scale A5 (ComQOL-A5) questionnaire. Results point out three major domains where quality of life is unsatisfactory: health, material well-being and emotional well-being. Of these areas, QOL in the health domain demonstrates the lowest scores.

In Turkey, Yilmaz, Erkin & İzki (2013), explored the health-related quality of life (HRQoL) in mothers of children with cerebral palsy (CP). Participants comprised 137 mothers of children with spastic-type CP, and controls comprised 140 mothers with healthy children. Functional levels of children with CP were evaluated using Gross Motor Function Classification System (GMFCS). HRQoL of mothers with CP children and control groups was assessed with 36-Item

Short-Form Health Survey (SF-36) and depression levels with Beck Depression Inventory (BDI). Results revealed that social function, mental health, role limitation emotional, and vitality as subscale of mental component of SF-36 were found to be lower in CP children's mothers than controls. BDI scores were higher in CP children's mothers than controls. Among mothers with CP children, a negative correlation was detected between BDI scores and all subscale scores of SF-36 and age rate of mothers and physical function, bodily pain, and physical component scale scores, among subscales of SF-36.

Several empirical literatures in this area have been predominantly focused on the western countries/culture (Yilmaz, Erkin & İzki, 2013). Despite the high prevalent of CP in our society, it is unfortunate that only few studies have attempted to explore the quality of life of parents of children with this disability (Akinyemi, Owoaje, Popoola & Ilesanmi, 2012). Based on this assumption, the present study wants to provide answer to the following statement;

- Will there be a difference on quality of life of parents of children living with CP and parents of healthy children.

### **Hypothesis**

There will be a significant difference on quality of life of parents of children living with CP and parents of healthy children.

### **Method**

#### **Setting of the study**

The study took place in the therapeutic day care inclusive school located in Abakpa Nike, Enugu state, Nigeria.

The therapeutic day care center was founded in January 1979 by Mrs. Hildegard Maria Ebigo, nee Raab from Fremdingen in Bavaria, Germany. The institution was aimed to assist children with intellectual disabilities, learning disabilities, multiple handicaps and severe emotional disturbance.

### **Participants**

One hundred participants were adopted for this study. The participants comprised of 50 parents of children with cerebral palsy (CP) (25 mothers and 25 fathers) and 50 parents of healthy children (25 mothers and 25 fathers). They were sampled from parents of children attending Therapeutic Day care inclusive nursery and primary school Abakpa, Enugu State, using a purposive sampling technique. The participants were between the ages of 25-65 years, with a mean age of 45.44 years and standard deviation of 9.45. The inclusion criterion for participation in this study is that participant must have at least SSCE qualification.

### **Instruments**

World Health Organization Quality of Life-BREF (WHOQOL-BREF-) was adopted in this study. The scale measures four domains of quality of life such as physical health, psychological

(mental) health, social relationship and relationship with features in the environment as a function of quality of life. The WHOQOL-BREF has 26 items rated on a Likert-type response format ranging from 1- Never and 5 - Always. Scores were scaled in a positive direction (i.e. higher scores denote higher quality of life). The scoring of negatively phrased questions (3, 4 and 26) were reversed (1=5, 2=4, 3=3, 4=2, 5=1) thus transforming them to positively phrased questions. Scores less than 78, were categorised as poor QoL while scores equal to and above 78 were categorised as good QOL. However, higher score on the WHOQOL-BREF, indicate a better the quality of life. A good reliability coefficient has been reported by Majnemer, Shevell, Law, Poulin and Rosenbaum (2008) while the present study reported a Cronbach's alpha of .93 across the scale.

### **Procedure**

An inform consent was obtained from the parents before the distribution of the questionnaires. During the 40th year anniversary of the school parents were communicated about the study and assured about the confidentiality level of information that will be obtained from them. They were made to understand the voluntary nature of their participation. After which, on the day of parents teachers association meeting, the questionnaire were randomly distributed to them and was returned to researchers immediately after responding to it. However, for parents of healthy children, an introductory letter was given to the school management of Liberty School Abakpa. Data were collected during the teachers-parents meeting at the beginning of the academic session. The researcher observed that from the 110 copies of the questionnaire distributed to the participants, 10 copies were not properly filled due to cancellation and was discarded. Thus, 100 of the questionnaire that were correctly filled were used for data analysis.

### **Design/Statistics**

Cross sectional survey design was adopted for this study. On statistics, independent t-test was used to analyze the data. SSPS version 23 was employed to manage the data.

## Results

**Table 1: Socio-demographic variables of the respondents**

Variables	Frequency (n = 100)	Percent (100%)
<b>Age groups</b>		
25-35 years	45	45%
36 - 45 years	32	32%
46 - 55 years	14	14%
56 - 65 years	9	9%
<b>Sex</b>		
Male	50	50%
Female	50	50%
<b>Marital Status</b>		
Single parent	25	25%
Currently married	53	53%
Separated	14	14%
Widowed	8	8%
<b>Religion</b>		
Catholic	54	54%
Anglican	27	27%
Penticoaster	13	13%
Others	6	6%
<b>Level of Education</b>		
SSCE	12	12%
Undergraduate	3	3%
Hnd/Ond	26	26%
Bsc	37	37%
Msc	17	17%
Phd	5	5%

Table 1 above showed the frequency distribution of the respondents of the study. Majority of the respondents were between 25- 35 years (45%); followed by 36-45 years (32%); 46-55 years (14%) and 56-65 years (9%). Equal percentage of women (50%) and men (50%) were reported. The respondents' religious information showed that the highest proportion were Catholic (54%); followed by Anglicans (27%); Penticoaster (13%) and others (those who do not belong to no particular) religion were 6%. Marital status information revealed that 53% of the respondents were currently married; 25% were single parents; 14% were separated and 8% were widowed.

Education information indicated that 37% of the respondents have B.SC degree; while 26% have HND/OND; 17% MSC degree; 12% SSCE; 5% PHD and 3% Undergraduates.

**Table 2: Mean, Standard Deviation of parents of children with cerebral palsy and healthy children**

Quality of life	GROUPS	N	Mean	Std. Deviation
Physical Health	Parents of healthy children	50	38.1600	25.11960
	Parents of cerebral palsy children	50	30.3400	5.35518
Psychological	Parents of healthy children	50	35.6200	25.90634
	Parents of cp children	50	27.6200	7.71664
Social relationships	Parents of healthy children	50	26.5000	27.61858
	Parents of cp children	50	17.9000	2.37547
Environment	Parents of healthy children	50	42.9600	23.98976
	Parents of cp children	50	35.7600	5.97806

The inspection from the table above showed that in the four domains of quality of life such as physical health, parents of healthy children ( $M= 38.16$ ;  $SD=25.12$ ) reported more physical health than parents of children with cerebral palsy ( $M= 30.34$ ;  $SD=5.36$ ). On psychological health, parents of healthy children ( $M= 35.62$ ;  $SD=25.91$ ) reported more psychological functioning than parents of children with cerebral palsy ( $M= 27.62$ ;  $SD=7.72$ ). Likewise, on social relationships, parents of healthy children ( $M= 26.50$ ;  $SD=27.62$ ) reported more social functioning than parents of children with cerebral palsy ( $M= 17.90$ ;  $SD=2.38$ ). Finally, parents of healthy children ( $M= 42.96$ ;  $SD=23.99$ ) reported more environmental well-being than parents of children with cerebral palsy ( $M= 35.76$ ;  $SD=5.98$ ).



**Table 2:** Independent t-test on QOL of parents of children with cerebral palsy and children with normal development

Quality of life	M	SD	T-test	Df	Sig.
Physical Health	30.44	5.37	2.153	98	.034
Psychological Health	27.57	7.77	2.093		.039
Social relationships	17.75	2.36	2.194		.031
Environment	35.63	6.32	2.059		.044

The result revealed that a statistical significantly difference between parents of children with cerebral palsy and parents of healthy children on quality of life domains, physical health at  $t(2, 98) = 2.15, p < .05$ ; psychological functioning  $t(2, 98) = 2.09, p < .05$ , social relationship  $t(2, 98) = 2.19, p < .05$ ; and environment health  $t(2, 98) = 2.06, p < .05$  level of significance. This means that parents of children living with cerebral palsy experience low quality of life than their counterparts. Thus, hypothesis of the study was accepted.

## Discussion

The goal of the present study is to examine the quality of life (QOL) in parents of children living with cerebral palsy and parents of healthy children. Based on the objective of the study, a hypothesis was tested.

The hypothesis which stated that there will be a significant difference on quality of life of parents of children living with CP and parents of healthy children was accepted. The result of this finding clearly show that parents of children with cerebral palsy reported more low QOL than parents of healthy children. This finding is in agreement with Brown et al. (2006) study that demonstrated that parents of children with normal development have a better quality of life than parents of children with cerebral palsy in all domains of quality of life. It is in tandem with Romeo et al. (2010), parents of children with CP showed lower scores on physical and psychological domains than the control group on QOL.

Also, Ström et al. (2012), found that out of the three major domains where quality of life is unsatisfactory: health, material well-being and emotional well-being domains demonstrated the lowest scores. Also, other studies have found a profile of differences in all QOL domains between these groups of parents (Juhásová, 2015). In addition to reduced QOL, parents of children with cerebral palsy report higher levels of depression and anxiety (Gallagher et al., 2008). Furthermore, Kazmi, Perveen, Karamat & Khan (2014) reported a lower quality of life of mothers of children with cerebral palsy and the more frequent depression in mothers than in fathers. IASSIDD (2014) stated that mothers of children with cerebral palsy are the ones who report increased level of stress and poorer physical and mental health.

## **Limitations of the Study**

One major limitation of this study is the sample size. Due to the nature of the study, the sample was drawn from a relative small inclusion school which may not be a true representative of the study population. Thus, there should be cautious in generalizing the result of the findings for all parents in Nigeria.

## **Recommendations**

This study recommends that government and policy makers should establish a community based program that would improve QOL of parents of children living with CP in Nigeria. The need for such program is to provide supports for families of children with these disabilities through the establishment of possible interventions and coping strategies. Also, it is recommended that parents should be sensitized on the causes of Cerebral palsy in order to reduce its prevalence in Nigeria. Since, studies have proven that parents of children with CP often feel a sense of hopelessness and helplessness, as well as a sense of failure and guilt; there is need for further research in this area.

Support services for parents of children with these disabilities should be established across the country, so that the parents in all parts of Nigeria have necessary information, advice and support. Furthermore, mothers should be a priority for support provision. Mothers should also have some benefits regarding their employment status in the sense of flexible working hours.

## **Conclusion**

This research examined quality of life of parents of children living with CP and their counterpart in Enugu state, Nigeria. Based on the findings, the study concluded that parents of children with CP experience low quality of life characterized by depression, anxiety, and poor psychological well-being as compared to their counterpart with normal developed children.

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