

Assessment of Quality of Life of Children with Cerebral Palsy

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ABSTRACT

Background: Children with cerebral palsy (CP) may have individual experiences and problems that restrict the participation in daily life activities. Quality of life (QOL) in children with CP needs to be quantified by CP-specific questionnaire. CP-QOL questionnaire is being used for this purpose. **Objective:** The aim of the study was to study the QOL of children with CP as asked by the caregivers of such children in south Indian population. **Methodology:** A cross-sectional and observational study including 121 participants (Parents/caregivers of children) with CP with age of 4–12 years was asked to complete the CPQOL questionnaire. The CPQOL questionnaire for primary caregivers is used to assess the QOL of children with CP. The study was conducted at the physiotherapy OPD of SRM Hospital, Kattankulathur and was completed after a period of 15 months started from May 2019 till August 2020. **Result:** The mean QOL score of 37.67 ± 4.57 was calculated using SPSS. **Conclusion:** The QOL of children with CP was compromised and the CP-QOL can be used to assess the QOL in children with CP.

Keywords: Cerebral palsy, CPQOL, Primary caregivers, Quality of life
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INTRODUCTION

Cerebral palsy (CP) is a group of condition that is characterized by chronic disorder of movement or postures; it is cortical in origin, manifests itself early in life, and is not the outcome of progressive disease which is collectively defined as “Developmental Disabilities.” CP is a syndrome with combination of motor, sensory, intellectual, language, perceptual, and behavioral problems. CP has a prevalence of 3/1000 live births. Worldwide CP has the incidence of one in 500 births. The impact of such children in the families is intense which greatly affects the quality of life (QOL) of such children. QOL of children with CP can be assessed using a validated tool such as CP-QOL questionnaire which helps in addressing the several domains of life both by children themselves and by the caregivers also. CP-QOL is a CP specified questionnaire designed in accordance with International Classification of Function and definition of QOL by the World Health Organization (Waters *et al.*, 2007).^[1] CP-QOL basically assesses the well-being of children with CP, rather than ill-being (Waters *et al.*, 2007).^[1] The common challenge faced by researchers in the field of cerebral palsy is the inability of most children to communicate themselves thus, the need to rely on the caregiver for information regarding the quality of life.^[2]

There are other QOL questionnaires for children such as Kid-KINDL, HRQOL^[3] and CHQ. For CP-QOL, there are two versions available, one for the children and the other for the primary caregivers. The validity and reliability have already been established in different countries using the questionnaire in several languages besides the English language.^[4] The primary caregiver version for ages 4–12-years-old has seven domains such as social well-being and acceptance, functioning, physical health, pain and impact of disability, participation, emotional well-being, access to services, and family health. The other version for self-report by children is available for children with ages 9–12 years old.^[4]

The present study provides insight on the quality of care received by children with CP in Southern geographical areas of India. As the geographical location can play a key role in type of care and facilities provided to these children and the extent to which facilities are available for such children in the community to look at a perspective for the health-care providers.

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A similar type of study was done in the Northern region of India in 2017 in 50 participants whose findings slightly varied from this study as the questionnaire was used in the local language of that area using the same questionnaire. The objective of this study was to assess the QOL and care received by the children with CP from their primary caregivers.

MATERIALS AND METHODS

A convenient sampling method was adopted to select 121 primary caregivers of children with CP with ages 4–12 years that were recruited as participants for this study. The sample size was calculated by the survey sample size calculator on the basis of prevalence of CP. The selection criterion was that the participants should be the primary caregiver of these children who at least spends 18 h with the child in a day. The study was conducted at Physiotherapy OPD, SRM Hospital, Kattankulathur. The child of these participants (primary caregivers) should be between the ages of 4 and 12 years. The participants themselves filled the

printed form of questionnaire in the presence of the author. The samples were taken from the physiotherapy, occupational therapy, and pediatric outpatient department during the period October 2017 to December 2018 with inclusion criteria being the primary caregivers of children with CP between 4 and 12 years of age. The questionnaire version 2 July 2013 was used in the English language for this study. Permission to use the questionnaire in English for Indian population was taken from the author. The language barrier was minimized for those who did not understand English well by translating the questionnaire by the same individual in a face to face interview. The same person interviewed all the caregivers to maintain the homogeneity of the data. The researcher did not intervene in between the interview sessions. Informed consent was taken from all the parents/caregivers and was explained about the questionnaire and its interpretation to be used for research before the beginning of the interview. The data analysis and interpretation were done using Statistical Package for the Social Sciences (SPSS) version 2.0 to obtain the mean scores of the different domains of the questionnaire.

RESULTS

In this study, information was collected from 121 caregivers using CP-QOL questionnaire. Among these children, 72 (59%) were male and were 49 (41%) female, who were aged into three categories of 4–years ($n = 72$ children), 7–9 years ($n = 38$ children), and 10–12 years ($n = 11$ children). They were categorized according to the Gross Motor Functional Classification Scale (GMFCS) levels in which there were $n = 71$ children in GMFCS level 2, $n = 24$ children in level 3, $n = 18$ children in level 4, and $n = 8$ children in level 5. The SPSS version 2.0 was used to analyze the data.

The correlation of GMFCS levels and overall QOL scores along with Cronbach's alpha of the seven domains of the questionnaire is shown in [Table 1]. Cronbach's alpha with a value of >0.7 is considered to be an indicator of reliability and internal consistency. For the social well-being and acceptance, the Cronbach's alpha was (0.96), functioning (0.97), participation (0.93), physical health (0.85), emotional well-being (0.80), access to services (0.88), and (0.74) for pain, impact of disability, and family health. These results showed less correlation among pain, impact of disability and family health, access to services, and emotional well-being when compared to other domains of the questionnaire. This difference is may be due to limited awareness among the caregivers about rehabilitative services in India.

The correlation of QOL scores with GMFCS levels and the demographic details of the children is depicted in Table 2. Gross motor function (GMF) scores were compared to QOL scores which did not reveal any significant difference ($P = 0.59$). The overall QOL score of 37.67 ± 4.57 was computed. The gender difference was noted in the samples which may be due to more number of male samples as compared to the females whereas the age of the children does not affect the QOL score much. In this study, it is found that the QOL does not get affected much by age but can be affected due to gender.

DISCUSSION

Questionnaires are an important research tool in identifying the need for assessing the QOL of children with different disabilities worldwide. The CP-QOL, a CP-specific tool for assessing QOL in children with CP, is a valid and reliable tool used in many studies

Table 1: Depicts the mean scores and standard deviation of various parameters of CPQOL questionnaire

Parameters	QOL score (mean±SD)	Crobach's alpha
Overall QOL score	37.67±4.57	
Social wellbeing and acceptance	33.44±3.31	0.96
Functioning	31.84±0.81	0.97
Participation	34.37±1.30	0.93
Physical health	32.40±0.85	0.85
Emotional well-being	68.00±25.9	0.80
Access to services	39.40±9.33	0.88
Pain, impact of disability, and family health	40.12±10.55	0.74

CPQOL: Cerebral palsy quality of life, QOL: Quality of life

Table 2: Depicts the mean score and standard deviations according to the GMFCS levels, gender, and age

Parameters	QOL score (mean±SD)	P
Overall score	37.67±4.57	
GMF score		
GMF-2 ($n=71$)	36.51±3.51	0.59
GMF-3 ($n=24$)	40.4±4.66	
GMF-4 ($n=18$)	42.02±6.59	
GMF-5 ($n=8$)	31.75±22.22	
Sex		
Male ($n=78$)	37.27±0.32	0.013
Female ($n=49$)	42.32±7.46	
Age (years)		
4–6 ($n=72$)	37.44±12.52	4–6 versus 7–9, $P=0.581$
7–9 ($n=38$)	39.95±4.74	7–9 versus 10–12, $P=0.9161$
10–12 ($n=11$)	39.64±1.65	10–12 versus 4–6, $P=0.774$
Total	39.01±1.36	

GMFCS: Gross motor functional classification scale, QOL: Quality of life,

GMF: Gross motor function

in the different part of the world. CP is a life prolonged condition impacting the life of the children and their parents. The QOL is, therefore, needed to be assessed as in this study, it was attempted to calculate it on the basis of overall QOL score of 37.67 ± 4.57 .

The CP-QOL questionnaire has two forms: Primary caregiver-proxy parent report for children aged between 4 and 12 years and a self-report for children aged 9–12 years. The scoring was done as per instructions. The average mean was also calculated as an overall QOL score and score for each domain individually.^[5]

The validity and reliability have already been established in different countries using the questionnaire in several languages besides the English language.^[4] The primary caregiver version has seven domains such as social well-being and acceptance, functioning, physical health, pain and impact of disability, participation, emotional well-being, access to services, and family health.^[4]

In some of the studies carried out in Malaysian children with the use of Lifestyle Assessment Questionnaire to find the QOL of children with CP, which classified the children into mild, moderate, and severely affected children. Hence, every questionnaire has its own aspects of assessing a condition or disease which could not be generalized.^[6]

In a study, it was found that the parent report lower QOL than the children themselves in all domains of QOL measured. However, the parents reported improved QOL in psychosocial domains as compared to the children report which suggests that impairment severity has more influence on QOL.^[7]

A similar type of study in Northern India was conducted using the same CP-QOL questionnaire in the Hindi language for better

understanding of the caregivers that showed that there was no significant difference in the gender but there was a significant difference in parental education and age.^[6] A study in Iran assessed the association between GMF and the QOL domains for children with CP using the same questionnaire. They reported that an increase in GMF in children with CP has a considerable effect on their QOL.^[6]

The QOL score obtained from the study was much affected by the pain, impact of disability, and family health domain of the questionnaire. The gender difference between the samples also led to a statistical difference in this study. When comparing the overall QOL with that of demographic data such as sex, age, and type of GMF levels, the results did not vary much although to generalize the result more samples should be included in further studies.

The language barrier for some caregivers could be marked as the limitation of this study as some of the caregivers were not well educated. Another limitation was a small sample size that led to the result to be interpreted with caution and could not be generalized to the population as a whole.

CONCLUSION

The QOL among CP children was found to be compromised. The CP-QOL for primary caregivers can be used to find the QOL of Indian children by the use of this validated tool in the English language. Although more studies with large sample size should be conducted which should compare the type of CP, other associated medical conditions, parent's education and awareness about CP, and the duration or the time period, they are receiving the rehabilitative services.

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