A questionnaire based study of the quality of life of children with cerebral palsy aged 4–12 years

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ABSTRACT

Background: Cerebral palsy (CP) is an umbrella term used to describe a group of non-progressive, but often changing motor impairment syndromes due to heterogeneous causes. **Aim:** The primary objective was to study the quality of life (QOL) of children aged 4–12 years with CP. The secondary objectives were to determine the correlation between QOL and demographic and clinical aspects. **Materials and Methods:** CP QOL-child, an Australia based questionnaire was translated and culturally adapted to 45 items. The questionnaire was then retranslated into English to ensure content and concepts were maintained. 50 parent-child dyads were interviewed after training of the primary interviewer. The statistical analysis of the data was done using statistical package for the social sciences software using t-test and Spearman correlation test. **Results:** The mean QOL score was within the "happy" range (66.38±10.38). The highest score was in "participation" and lowest in "special equipment." Negative correlation was found in age with caregiver's health ("your health") and socioeconomic (SE) status with "others." There was a positive correlation of paternal literacy with "communication," "special equipment," and "your health," and "negative correlation of the number of siblings with others." There was a negative correlation of gross motor classification system classes with "health" and manual ability classification system classes with mean QOL scores, "participation" and "health." **Conclusions:** Increased access to special equipment is likely to help in improving QOL. There should be adequate support for the physical and mental health of parents and caregivers as well. Furthermore, caregivers must be educated and must be made aware of the disease. Comorbid conditions other than the primary disorder should not be ignored.

Key words: *Cerebral palsy, Quality of life, Children, 4–12 years, Questionnaire*

Cerebral palsy (CP) is an umbrella term used to describe a group of non-progressive, but often changing motor impairment syndromes (primarily of movement and posture), due to heterogeneous causes [1]. It is associated with cognitive and sensory impairment, language perceptual deficits, behavioral problems, and attention deficits. Coexistent conditions such as epilepsy, malnutrition, growth retardation, and gastroenterological disorders add to the pre-existing neuro-developmental morbidity [2]. The data are inadequate in India, but it is estimated that over 2.5 million children in India suffer from CP, making this disease a huge health problem [3].

Quality of life (QOL) has been defined by world health organization as "an individual's perception of their position in life in context to their culture and value systems and in relation to their goals, expectations, standards, and concerns". Questionnaires have been developed that quantitatively measure the impact of the disability on either the patient's or primary caregiver's perceptions. It also helps in the assessment as to how existing interventions are helpful in improving the life of the individual. These benefit patient care by widening the parameters of the benefit of therapy, indicating better supportive measures, helping in prognostication and decision-making and resource allocation in health-care policymaking. Some of these questionnaires are generic for all children with a disability such as pediatric evaluation of disability inventory and KIDSCREEN while some are specific for CP such as CPQOL and child health questionnaire (CHQ) [4].

CP-QOL child questionnaire is an Australian based questionnaire that evaluates certain aspects of QOL according to specific age ranges. It is available for various age ranges, children aged 4–12 years (parent proxy version) and 9–12 years (self-report version). The validation study of the tool was conducted in the Royal Children's Hospital, Melbourne in which primary caregivers of 4–12 years and 9–12 years age group were recruited to determine the psychometric properties of both versions of CP-QOL. The validity of CP-QOL was supported by correlations between CP-QOL-child scales with the CHQ, KIDSCREEN, and gross motor classification system (GMFCS) [5].

Most of the studies pertaining to the QOL of children with CP originate from developed countries. The profile of Indian children with CP differs from their counterparts from the developed countries; hence, naturally, the QOL would differ too. Differences in underlying etiology, decreased awareness of parents and treating physicians about the role of early intervention, limited accessibility to these services, financial constraints, negative societal attitude and social stigma associated with disability, and adversely affect the QOL [6-8]. Hence, observations relating to the QOL of children with CP may not be applicable in developing countries like India, and therefore, we planned this study. The primary objective was to study the QOL of children aged 4–12 years with CP. Secondary objectives were to determine the correlation between QOL and demographic and clinical aspects.

MATERIALS AND METHODS

A cross-sectional observational study was conducted in the pediatrics department of a tertiary level hospital over 2 months after obtaining approval from the Institutional Ethical Committee. Children aged 4–12 years with diagnosed CP were enrolled on an opportunity basis until a pre-decided convenient sample size of 50 was achieved. Those whose primary caregivers were unavailable or refused participation were excluded. After taking informed consent, the interviewer recorded demographic and clinical details. This included European classification and functional ability measurement by GMFCS and manual ability classification system (MACS). This was followed by administration of the CP-QOL child questionnaire. The concept of CP-QOL child questionnaire was introduced to the parent before administration.

The principal investigator was trained in interviewing methods and administered the questionnaire in a small sample of parents before commencing the study. All responses were documented irrespective of literacy level. Those items that were not applicable, in a particular patient, were marked as NA. Options of parental rating responses ranged from very unhappy to very happy which corresponded to a Likert scale of 1–9. These were then converted into the following scores; 1=0, 2=12.5, 3=25, 4=37.5, 5=50, 6=62.5, 7=75, 8=87.5, and 9=100.

Each question of the provided questionnaire starts with the phrase "how do you think your child feels about." The items were distributed over eight QOL domains; family and friends, participation, communication, health, use of special equipment, pain and bother, access to services, and health of the primary caregiver. The meaning of each domain has been summarized in Annexure 1. It comprises 66 open and close-ended structured questions that are administered to the caregiver. It takes 15–20 min for administration.

Development of the Hindi Version of CP-QOL

The questionnaire was translated in Hindi and then re-translated into English to ensure that the content and concept of the original retained items were maintained. On pre-testing in a small group of the intended target population, it was observed that some items were culturally inappropriate in the intended social milieu, i.e., relating to respite care. In addition, difficulties in comprehension arose in items that had overlapping content, i.e., "how do you think your child feels about how they are accepted by adults" and "how they are accepted by people in general." Considering these factors, the questionnaire was modified for the purpose of this study. Some items were combined and some were removed. The total number of questions was 45 distributed over 10 domains. The modified version was administered in 10 parents and was easily understood.

Individual Performa's with unique identification numbers were maintained. Statistical package for the social sciences software latest version was used. Mean QOL was calculated for the overall sample, every demographic or clinical group considered. Independent t-test was used to compare the means of various groups. Correlations were calculated using Spearman's correlation test.

RESULTS

Fifty-eight eligible children were recruited wherein 50 children between 4 and 12 years with CP were selected as the study population. The study group comprised 31 males (62%) and 19 females (38%). The mean age was 6.5±2.3 years. A total of 37 (74%) children were in 4–8 years age group and 13 (26%) in 8–12 years age group. According to the modified Kuppuswamy SE classification, 2 (4%) children belonged to upper SE strata, 6 (12%) to the upper middle strata, 18 (36%) to the middle/lower SE status, 23 (46%) to lower middle/lower, and 1(2%) to lower strata. 12 (24%) children were a single child, 23 (46%) had 1 sibling, and 15 (30%) had >1 sibling. Table 1 depicts the distribution of maternal and paternal literacy levels.

Distribution of comorbid conditions was as follows; epilepsy (24, 48%), visual problems (17, 34%), hearing impairment (7, 14%), difficulties in chewing/swallowing (23, 46%), microcephaly (32, 64%), stunting (29, 58%), and wasting (20, 40%).

The European classification categorizes CP as spastic bilateral CP (32, 64%), spastic unilateral CP (13, 26%), dystonic CP (0%), choreoathetoid CP (2, 4%), ataxic CP (0%), and non-classifiable CP (3, 6%). The distribution of the functional ability of the study population as measured by the GMFCS and MACS is given in Table 2.

The mean QOL score (n=50) was 66.38±10.38. Domain wise distribution of scores is given in Table 3.

In 4–8 years age group, the mean QOL score was 65.9±10.5, whereas it was 67.7±10.2 for 8–12 years age group. There was no significant difference in overall mean QOL scores or mean scores of individual domains according to age. A negative correlation was found between age and "your health" domain ($p<0.05$). The mean score was 66.6±11.48 in males and 66.6±8.6 in females. There was no significant difference in mean QOL scores or mean scores of individual domains according to gender. No correlation of gender with mean QOL scores or with mean scores of individual domains was found.

Table 1: Distribution of maternal and paternal literacy levels

Literacy levels	Maternal, n (%)	Paternal*, n (%)
Illiterate	20 (40)	3 (6.4)
Class 1–Class 10	21 (42)	27 (57.4)
Class 10 and above	9 (18)	17 (36.2)

*Three values missing due to death of the parent

Table 4 represents the SE status, no significant difference between mean QOL scores or between individual domain mean scores were found. A significant negative correlation was seen between SE status categories and the mean score of "others."

Table 2: Distribution of functional ability categories of study population measured by GMFCS and MACS

GMFCS Category	Description	n (%)
I	Walks without assistance; limited advanced motor skills	6 (12)
II	Walks without assistance; limited advanced walking	11 (22)
III	Walks with assistive walking device	3 (6)
IV	Self-mobility with a transporter	3 (6)
V	Self-mobility with a transporter/ severely limited	27 (54)
MACS Category	**Description**	**n (%)**
I	Handles objects easily and successfully	6 (12)
II	Handles most objects but with somewhat reduced quality and/or speed of achievement	12 (24)
III	Handles objects with difficulty; needs help to prepare and/or modify activities	4 (8)
IV	Handles a limited selection of easily managed objects in adaptation situations	14 (28)
V	Does not handle objects and has severely limited ability to perform even simple action	14 (28)

GMFCS: Gross motor functional classification scale, MACS: Manual ability classification system

Table 3: Domain wise distribution of the mean scores (SD and CI) of CPQOL

CP-QOL domain	Interpretation of derived scores 0–37.5 unhappy; 37.5–62.5 ambivalent; 62.5–100 happy	
	Mean±SD	95% CI
Family and friends	75.93±12.18	72.47−79.39
Participation	81.33±27.14	73.62−89.05
Communication	57.50±15.38	53.13−61.87
Health	57.01±14.96	52.76−61.26
Activities of daily living	76.90±15.13	71.03−82.76
Special equipment	44.44±35.75	30.30−58.59
Bother	75.21±30.64	66.50−83.92
Others	64.38±25.08	57.25−71.50
Access to services	59.44±24.88	51.97−66.92
your health	62.10±14.39	58.01−66.19

SD: Standard deviation, CI: Confidence interval, CPQOL: Cerebral palsy quality of life

Table 4: Mean QOL scores of SES classes

SES	QOL score (Mean±SD)
Upper	68.80±7.10
Upper middle	68.80±8.04
Middle/lower middle	62.77±12.57
Lower middle/lower	68.27±9.21
<Lower	68.61

SD: Standard deviation, QOL: Quality of life, SES: Socioeconomic status

The maternal QOL mean scores in the illiterate group, Class 1–Class 10 and Class 10 and above were 67.01±9.59, 65.5±12.11, and 67.01±8.56, respectively. In contrast, the paternal QOL mean scores in the illiterate group, Class 1–Class 10 and Class 10 and above were 62.5±3.61,65.9±10.61, and 68.41±10.53, respectively. There was no significant difference in the mean QOL scores between the groups of maternal literacy or paternal literacy. There was no significant difference in individual domain mean scores according to maternal literacy or paternal literacy.

There was no significant correlation of maternal literacy with mean QOL or individual domain mean scores. However, there was a significant correlation of paternal literacy with "communication" ($p<0.05$), "special equipment" ($p<0.05$), and "your health" ($p<0.01$). Fig. 1 represents mean QOL scores in different groups of maternal and paternal literacy.

In single child group, the mean QOL score was 67.2±9, 2 children group 63.8±11.1, and in >2 children group it was 67.4±6.9. There was no significant difference between the mean QOL scores or mean scores of individual domains according to the number of siblings. The significant negative correlation of the number of siblings with "others" domain was noted ($p<0.05$).

Mean QOL scores of the categories of European classification are shown in Fig. 2. No significant difference between the mean QOL or between individual domain means scores as well as with European classification. Fig. 3 represents the mean QOL of different categories of GMFCS. There was no significant difference between the mean QOL of different classes or between individual domain mean scores. GMFCS categories were negatively correlated ($p<0.01$) with "health" and positively correlated with "bother" ($p<0.05$).

Fig. 4 shows the mean QOL in different categories of MACS. No significant difference in the mean QOL scores or individual domain means scores of categories of MACS was found. There was, however, a negative correlation of mean QOL scores, "participation" and "health" scores with MACS classes. Children who had no chewing problems scored better on "family and friends," "others," "access to services" and those who had no swallowing problems had higher scores in "health," "bother," and "others." People not stunted had higher scores in "special equipment" and "bother." Children without microcephaly had higher scores in "special equipment" and "others."

DISCUSSION

From the study results, which were contrary to our expectations, it was observed that the QOL scores were not low. The response of the study population as a group is positive toward their child's QOL suggestive by the overall mean QOL scores falling in the "happy" range (66.38±10.38). The highest score was noted in participation and the lowest in special equipment. The domains, which scored positive >62.5, were "family and friends," "participation," "ADL," "bother," and "others." All the others scored in the ambivalent

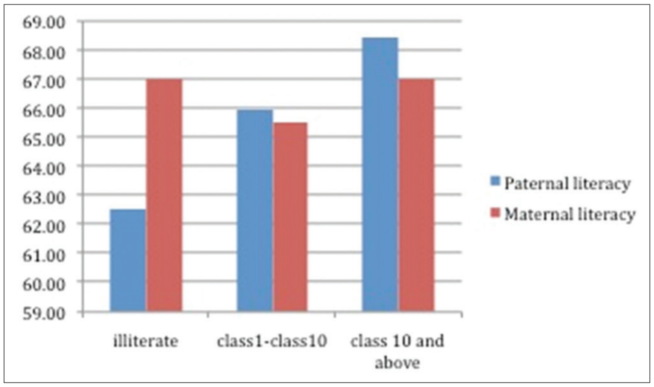

Figure 1: Mean quality of life scores in different groups of maternal and paternal literacy

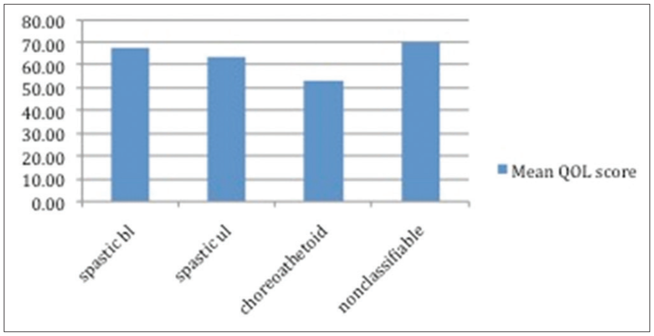

Figure 2: Mean quality of life scores of different categories of cerebral palsy based on the European classification

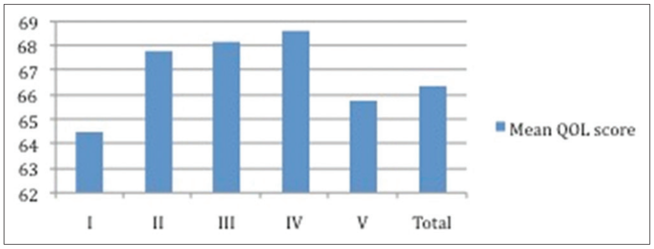

Figure 3: Mean quality of life scores of different categories of gross motor classification system

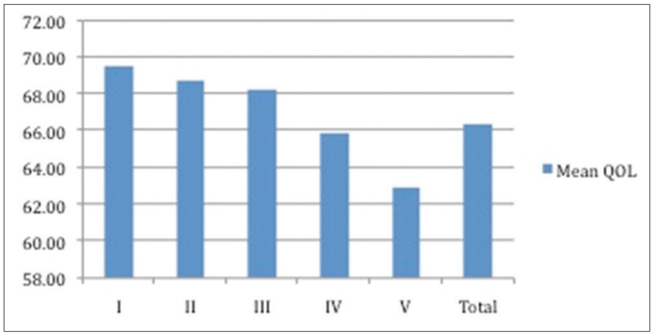

Figure 4: Mean quality of life scores of different categories of manual ability classification system

range. No domain scored in the "unhappy" range. These findings imply that despite the study population having a large number of children with GMFCS V and MACS V indicating severe functional impairment, the parents felt that their QOL was not unhappy. This may be because they are resilient or that they are unaware of the type of QOL that a child with a disability can live in more socially advantaged populations. The fact that "special equipment" scored the lowest may also reflect the concreteness of the feeling which parents with disabled children are largely aware of in contrast to the items of the more conceptual domains like feelings related to social acceptance.

In developed countries, several psychometric properties were correlated with the QOL, and there was an association between functional disability to the QOL. It was found that higher functional disability showed a correlation to poorer QOL. Few others found a relationship of QOL to psychometric properties [9-11]. Several studies exploring the cultural adaptations and translations of the CPQOL tool have been conducted in nations such as China, Brazil, and Poland [12-16].

Some authors in the Indian setup have explored the relationship between factors of disability and the QOL in children with CP. A study conducted by Chatterjee and Aneja using translation of PedsQL found lower QOL in children with higher disability (GMFCS IV), and in those who were quadriplegics versus the diplegics [17]. In a study at a district hospital, Das *et al*. found that age and maternal education had a significant bearing on the QOL of the children [18].

"Your health" domain being negatively correlated with age suggests that the parents of older children may feel more tired and unhappy with their health due to not being able to take care of themselves as increasing age brings in more difficulties in handling the child with CP. The fact that SE status categories were negatively correlated with mean scores of "others" shows that the underprivileged groups felt that their children were in more pain, discomfort and were overall unhappy than the privileged groups. The positive attitude regarding "communication," "special equipment," and "your health" that was observed in the fathers educated till Class 10 and above may reflect that they probably understand the disease better after counseling from the treating doctors. The negative correlation of the number of siblings with "others" may indicate an increase in unhappiness, pain, and discomfort of the child with more siblings due to the parents' divided attention, care, and resources.

In GMFCS, the severely disabled children felt negative about their health, which was obvious. However, the positive correlation of GMFCS with "bother" suggests the lack of expression often found with higher motor disabilities that would make it difficult for parents to understand the feelings of their children. MACS was negatively correlated with "participation" and "health"; that is higher manual disabilities made it difficult for the children to participate in various activities and also was associated with the feeling of unhappiness toward their health. Some domains of QOL scored less in children with treatable physical comorbidities such as chewing and swallowing problems, stunting, and microcephaly that implies that if these aspects are taken care of during intervention, QOL can improve. Unfortunately, when a child with a disability is presented to the hospital, both parents and doctors are so focused on the primary neurological manifestations that these aspects are often overlooked and not addressed appropriately. In contrast to developed countries, the QOL of our children was lower, especially in domains like access to services [4].

The limitation of this study was that many questions such as relating to "respite care" and "special equipment" could not be responded to due to unavailability in the Indian settings. A question that was particularly difficult to understand was when parents were asked how their child feels (especially the younger ones).

CONCLUSIONS

Despite a largely positive QOL, there is a felt need among caregivers and children for special equipment that may enhance function and mobility. There should be adequate support to take care of the health of parents and caregivers of CP patients. Furthermore, education and awareness of the caregivers could increase reported QOL by giving them a perspective. A child with CP needs to be evaluated holistically so that rectifiable issues such as nutritional deficiencies and malnutrition can be detected and treated appropriately that will enhance the QOL.

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ANNEXURE

Annexure 1: Brief outline of the domains in the questionnaire

Family and friends	Questions about their interaction and feelings with family and friends
Participation	Questions about feelings of being able to participate at school and home
Communication	Questions about feelings of being able to communicate
Health	Questions about feelings, about their health
Activities of daily living	Questions about feelings related to how they are able to carry out their daily tasks such as bathing, eating, and dressing
Special equipment	Questions about the use and availability of special equipment in school and home
Bother	Questions about feel bothered due to not being able to go to school, being handled by others, hospital visits, etc.
Others	Questions about pain, restlessness, overall happiness.
Access to services	Questions about the caregiver's feelings about access to services such as treatment and specialist care
Your health	Questions about the caregiver's health