

Health-related Quality of Life in Children with Cerebral Palsy and Their Families

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Objective: To determine the health-related quality of life in children with cerebral palsy and their families.

Methods: One hundred children (3-10 years of age) receiving regular rehabilitation therapy for cerebral palsy for last 1 year at a Child Development Centre were enrolled and the Lifestyle assessment questionnaire – cerebral palsy was administered to the parents.

Results: 9% had good, 24% had mildly-affected, 37% had

moderately-affected and 30% had severely-affected health-related quality of life. The physical independence, mobility and social integration dimensions were much more severely affected than the clinical burden, economic burden and schooling dimensions.

Conclusion: Health-related quality of child is affected in most children with cerebral palsy.

Keywords: Cerebral Palsy, Quality of life, Questionnaire.

Quality of Life (QOL) has been defined by World Health Organization as an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relationship to their goals, expectations, standards and concerns [1]. The more specific concept of Health-related Quality of Life (HRQOL) has been defined to differentiate health from more general social and environmental issues [2].

HRQOL is especially relevant to conditions that are chronic and disabling such as cerebral palsy (CP) [3]. There is a paucity of published literature on HRQOL in children with CP, especially from the Indian subcontinent. The present study determined HRQOL using Lifestyle Assessment Questionnaire = Cerebral Palsy (LAQ-CP) [4].

METHODS

This study was carried out at Child Development Center (CDC) of a tertiary care centre located in New Delhi. Children in the age group of 3-10 years diagnosed with cerebral palsy, and receiving regular (at least 1 visit every 6 weeks) physical therapy/occupational therapy at CDC for last one year were enrolled. The exclusion criteria were non-availability of the primary caregiver, presence of other chronic illnesses not typically associated with cerebral palsy, and families having another child with cerebral palsy, autism, or intellectual disability.

After obtaining informed consent from the parents, a detailed history was taken and neurological examination was done. CP was classified based on the predominant tone. Patients with spastic CP were further classified based on the topography. The children were evaluated for accompanying impairments like seizures, hearing or vision impairments, cognitive deficits, feeding problems, contractures and behavioural problems. Developmental quotient/Intelligence quotient assessment and behaviour assessment was done by a clinical psychologist. The probable aetiology was determined as per the history and previous records.

The motor disability of the child was classified using Gross Motor Functional Classification System (GMFCS) into 5 levels (Children with level I have the most independent motor function and the child in level V have the least) [5].

LAQ-CP questionnaire evaluates the impact of disability in children with CP and their families. It has 46 items, organized into six dimensions: physical independence, mobility, clinical burden, schooling, economic burden, and social integration [6]. Based on scores in each item, dimensional scores and a final standard score, known as Lifestyle Assessment Score (LAS) is obtained. These are expressed as a percentage score. The classification of the HRQOL according to LAS is as follows: Good (<30%); mildly-affected (30-50%); moderately-affected (51-70%); and severely-

affected (>70%) [6].

Permission was taken from the authors of LAQ-CP to translate it into Hindi language. It was translated using back-translation method with necessary socio-cultural modifications.

The sample size was based on a previous study, in which mean (SD) LAS was 45 (19) [7]. To estimate similar LAS, with precision of 5% at 95% confidence level, 70 subjects were required. Data analysis was done using SPSS version 16.0. The study protocol was approved by the Institutional Ethics Committee.

RESULTS

One hundred children (64 males) were enrolled, the mean (95% CI) age was 61.0 (56.5,65.5) months. The socio-

TABLE I BASELINE CHARACTERISTICS OF THE STUDY POPULATION (N = 100)

Characteristics	n (%)
Urban household	86 (86)
<i>Socio economic status*</i>	
Upper class	2 (2)
Upper middle class	17 (17)
Lower middle class	32 (32)
Upper lower class	49 (49)
<i>Type of cerebral palsy</i>	
Spastic	83 (83)
Quadriplegia	32 (39)
Diplegia	35 (42)
Hemiplegia	15 (18)
Triplegia	1 (1)
Hypotonic	4 (4)
Ataxic	3 (3)
Choreoathetoid	1 (1)
Mixed: Spastic and athetoid	3 (3)
Mixed: Spastic and dystonic	6 (6)
<i>Probable etiology</i>	
Hypoxic-ischemic encephalopathy	40 (40)
Prematurity	26 (26)
Kernicterus	7 (7)
Congenital hydrocephalus	4 (4)
Post-meningitic sequelae	5 (5)
Brain tumor (Operated)	1 (1)
Head trauma	1 (1)
Not known	16 (16)

* According to Kuppaswamy classification.

demographic characteristics, types of CP, and probable etiology are shown in **Table I**. Most of the patients had associated co-morbidities: 31 (31%) had seizure disorder, 37 (37%) had squint, 6 (6%) had cortical blindness, 2 (2%) had hearing impairment, 81 (81%) had global developmental delay/intellectual disability (26 mild, 19 moderate, 18 severe and 18 profound), 18 (18%) had behavior problems, 42 (42%) had drooling or other feeding problems, and 4 (4%) patients had contractures. The GMFCS level of patients was as follows: level I-18 (18%), level II-12 (12%), level III-12 (12%), level IV-28 (28%) and level V-30 (30%).

The mean dimensional scores are shown in **Table II**. Nine (9%) patients had good, 24 (24%) had mildly-affected, 37 (37%) had moderately-affected, and 30 (30%) had severely affected HR-QoL.

LAS was significantly higher in boys as compared to girls [59.4 (16.7) vs. 50.4 (19.0), $P=0.01$]. No association was found between LAS and socioeconomic status of the patient. LAS was significantly more in subjects with quadriplegic CP, seizure disorder, visual problems, cognitive deficits and feeding problems (data not shown). The Pearson's correlation coefficient of LAS and the GMFCS levels was 0.907 ($P<0.001$).

DISCUSSION

In the present study, HRQOL was moderately to severely affected in two-third of children with CP, and their families. The physical independence, mobility and social integration dimensions of HRQOL were much more severely affected than the clinical burden, economic burden and schooling dimensions. Higher LAS in children with quadriplegic CP was expected as they have significant activity limitation and associated co-morbidities like epilepsy and cognitive deficits [7].

A study from Malaysia [8] using the same questionnaire reported good HRQOL in the majority, and only 11.1% having severely-affected HRQOL. The better

TABLE II MEAN DIMENSIONAL SCORES OBTAINED IN LAQ-CP

Dimensions	Mean score (95% CI)
Physical independence	62.6 (57.2- 68.0)
Mobility	59.1 (54.3-63.9)
Clinical Burden	18.5 (17.0-20.0)
Schooling	28.9 (25.7-32.1)
Economic burden	33.7 (31.1-36.3)
Social integration	47.6 (44.6-50.6)
Combined	56.6 (53.0-60.2)

WHAT THIS STUDY ADDS

- Health related Quality of Life is significantly affected in majority of children with cerebral palsy and their families.

QOL in this study could have been due to difference in severity, psychosocial factors and availability of the health care services. Other studies done worldwide show that HRQOL is adversely affected in children with CP; however, majority of these studies have used generic QOL measures like 'Child Health Questionnaire' (CHQ) and 'Pediatric Quality of Life Inventory' (PedQL). Varni, *et al.* [9] compared HRQOL across ten chronic disease clusters and 33 disease categories/severities, using PedsQL. Patients with CP self-reported the most impaired HRQOL across all disease categories [9]. Studies done using CHQ have also shown significant impairment in most of the domains, especially so in physical function and parental impact domain [10-14].

LAQ-CP has limitations of not addressing some of the domains of QOL, as it specifically measures the impact of disability on the life of children with cerebral palsy and their families. Being a single-center study, and including a uniform population of children receiving regular therapy, findings may not be representative of the general population. Our study relied on parental report, due to lack of a self-report version of the questionnaire; accurate measurement of HRQOL may have been compromised.

To conclude, HRQOL is significantly affected in majority of children with cerebral palsy. Measurement of HRQOL should be used with other forms of assessment, to indicate areas in which a person is most affected and help the practitioner in making appropriate decisions for patient care.

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