



Determination of the Quality of Life and the Factors Influencing it in Children with Cerebral Palsy

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INTRODUCTION

Cerebral palsy is a non-progressive neuromotor disorder of cerebral origin. It is defined as a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.⁽¹⁾ It is characterized by abnormal muscle tone, reflexes or motor development and coordination.

ETIOLOGY

Cerebral palsy occurs due to damage to the developing brain. The damage can occur during pregnancy, delivery or during the first month of life, or less commonly during early childhood.⁽²⁾ While in certain cases there is no identifiable cause, typical causes include problems in intrauterine development (e.g. exposure to radiation, infection), hypoxia of the brain, and birth trauma during labor and delivery, and complications around birth or during childhood.⁽³⁾ Risk factors include premature birth, being a twin, certain infections during pregnancy such as toxoplasmosis or rubella, exposure to methylmercury during pregnancy, a difficult delivery, and head trauma during the first few years of life, among others.⁽⁴⁾

REVIEW OF LITERATURE

Quality of life (QOL) assessments that are easily administered and which do not impose a great burden on the respondent are needed for use in large epidemiological surveys, clinical settings and clinical trials.

Quality of life has been studied from two major perspectives: objective and subjective. Objective measures focus on external, quantifiable conditions such as income levels, access to medical resources, and recreational opportunities. In contrast, subjective measures focus on internal evaluations of life circumstances (e.g. satisfaction judgments, emotions).

Self-reported quality of life of 8-12 year old children with cerebral palsy⁽⁶⁾ was done in Europe. The outcomes of this study showed that the self-mobility lowered the quality of life in these children. Pain was common in

many children and it also affected the quality of life negatively.

Pain characteristics and their association with the quality of life and self-concept in children with hemiplegic cerebral palsy⁽⁷⁾ was another study which showed that majority of the children with cerebral palsy had pain which was associated with the hemiplegic side. Pain lowered the quality of life for these children according to this study.

Determinants of child parent agreement in the quality of life with cerebral palsy⁽⁸⁾ Is a study which showed that parents rated their child's quality of life to be lower than the child in 32%-57% of the cases. The children rated their quality of life to be higher.

The PedsQL in paediatric cerebral palsy: reliability, validity, sensitivity of the generic core scales and cerebral palsy module⁽⁵⁾ is a study. This investigation determined the measurement properties of the Pediatric Quality of Life Inventory (PedsQL) 3.0 Cerebral Palsy (CP) Module. PedsQL 4.0 Generic Core Scales and 3.0 CP Module were administered to 245 families. The PedsQL 4.0 distinguished between healthy children and children with CP. Construct validity of the CP Module was supported.

Sensitivity of the PedsQL was demonstrated among children with different diagnostic categories and gross motor function.

Measuring health-related quality of life in young adolescents: Reliability and validity in the Norwegian version of the Pediatric Quality of Life InventoryTM 4.0 (PedsQL) generic core scales⁽⁹⁾. The conclusion of this study showed that the Norwegian PedsQL is a valid and reliable generic pediatric health-related Quality of Life measurement that can be recommended for self-reports and proxy-reports for children in the age groups ranging from 13–15 years.

The relationship between quality of life and functioning for children with cerebral palsy⁽¹⁰⁾ is a study that showed that this is the first study to examine the association



between functioning and QOL domains for children with CP using a CP-specific QOL questionnaire that was designed to measure well-being. Although many definitions of QOL refer to functioning, the results from this study demonstrated that QOL is associated with functioning, although the strength of the association depends on the QOL domain. Physical well-being domains of QOL are more strongly associated with functioning than psychosocial well-being domains. Hence, a child with poor functioning may report good social and emotional well-being.

AIM OF THE STUDY

The aim of the study is to determine and evaluate the quality of life and the factors influencing the quality of life in children with cerebral palsy.

OBJECTIVE

- To determine the quality of life in children with cerebral palsy (By using PedsQL 3.0 CP module).(5)
- To identify and evaluate the domains in which the Quality of life is high (daily activities, school activities, movement and balance, pain, fatigue, eating activities, speech and communication)
- To identify and evaluate the domains in which the Quality of life is poor.

INCLUSION CRITERIA

- Parents of children who are known case of cerebral palsy who are under 18 years of age, enrolled in Vidhya Sudha and Mithra.
- Parents/guardian willing to participate in this study with informed consent (in their known language)

EXCLUSION CRITERIA

- Parent/guardian who are not willing to take part in this study.

METHODOLOGY

SAMPLE SIZE -50

Schools mentioned in the inclusion criteria were visited after receiving the permission from their respective authorities. Parents of the children with cerebral palsy were informed about the study undertaken. Informed consent was obtained from the parents who were willing to take part in the study after clearly explaining to them about the nature of the study. Out of 25 children with cerebral palsy in Vidhya Sudha, 24 parents accepted to take part in the study and informed consent was obtained from them. Out of 35 in Mithra, parents of 26 children agreed to take part in this study. A total of 50 is the sample size.

The questionnaires and socio demographic profile were prepared in Tamil and English. The domains included in the **PEDSQL 3.0 CP** are daily activities, school activities, movement and balance, pain and hurt, fatigue, eating activities and speech and communication. A 5 point rating scale (0-4) was used to document the responses to the survey.

Table 1.1 Rating Scale Descriptions

Scale Value	Description
0	Never
1	Almost Never
2	Sometimes
3	Often
4	Almost Always

Since a majority of parents were illiterate and the questionnaires were explained, questions were verbally conveyed to them and their responses were documented.

This process was completed in a period of 2 months (May – June2015). The data collected was then analyzed.

Table 1.2 SOCIODEMOGRAPHICS

Child	Age (in years)	Sex	Birth Weight	Did the child cry after birth	NICU admission	Knowledge of parent about cerebral palsy
1	16	M	1.9	Yes	No	Yes
2	5	M	1.75	Yes	No	No
3	2	F	2.7	No	No	No
4	2	M	2.3	No	Yes	No



5	2.8	M	1.4	Yes	Yes	No
6	13	F	3.4	No	Yes	No
7	10	M	4	Yes	No	Yes
8	18	M	2.5	No	No	No
9	15	F	2.5	Yes	Yes	Yes
10	9	F	2.7	No	No	No
11	18	M	2		No	No
12	8	M	3.75	No	No	No
13	17	F	2.5	Yes	No	No
14	15	F	2.2	Yes	Yes	No
15	18	F	3	No	Yes	No
16	18	M	3.25	Yes but Late	Yes	Yes
17	17	M	1.75	Yes but Late	Yes	Yes
18	12	M	3.75	Yes	No	No
19	18	M	2	Yes	No	No
20	14	M	2	No	Yes	No
21	18	M	2.1	No	No	No
22	10	F	3	Yes	No	No
23	2	F	2.3	No	Yes	Yes
24	4	F	3	Yes	No	Yes
25	8	M	2.5	Mother not aware	No	No
26	14	M	3.25	Yes	No	No
27	2	F	3.5	-	Yes	No
28	7	F	2.25	Cried Immediately after birth	No	No
29	4.5	M	1.38	Yes	Yes	No
30	7	F	2	No	Yes	Yes
31	3	F	1.62	Yes	Yes	No
32	3	F	2.8	No	Yes	No
33	3	M	1.3	Yes	Yes	No
34	5	F	2.5	Yes	No	No
35	6.5	M	2.5	Yes	No	No
36	5	M	1.6	Yes	Yes	Yes
37	2.5	M	3.25	Yes	No	No
38	4	M	3.4	After 1.5 hrs	Yes	No
39	6	M	2.5	Yes	Yes	No
40	5	M	3.3	Yes	No	No
41	6	F	3	Yes	No	No
42	3	F	1.08	Yes	Yes	No
43	6	M	2.3	Yes	No	No
44	5	M	2.5	Yes	No	No
45	6	M	2.2	Yes	No	No
46	16	F	3	No	No	No
47	14	F	2.25	No	Yes	No
48	4.5	F	3.5	Yes	No	No
49	7	M	2.4	No	Yes	No
50	14	M	3	Yes	yes	No

Table 1.3 Sex and Age Profile of the Sample

SEX	No. of Male	29	58%
	No. of Female	21	42%
	Total	50	
AGE	Mean Age	9.0	



	SD	5.6	
	Min Age	2	
	Max Age	18	
	Mode	18	

In the sample surveyed:

Low birth weight babies constituted 44% and those with an NICU admission equaled 46% of the total sample. Of

the population included in the study, only 18% of parents interviewed had knowledge about cerebral palsy.



DISCUSSION

The mean and standard deviation of the 7 domains analyzed as part of this study I documented in Table 1.4.

Table 1.4 Mean and Standard Deviation (SD) of the Domains

Domain	Mean	Standard Deviation
DAILY ACTIVITIES (Problems With)	2.6	1.3
SCHOOL ACTIVITIES (Problems with)	2.6	1.4
MOVEMENT AND BALANCE (problem with)	1.5	1.3
PAIN AND HURT (PROBLEMS WITH)	1.1	1.3
FATIGUE	1.2	1.0
EATING ACTIVITIES	1.8	1.3
SPEECH AND COMMUNICATION	1.2	1.2

Among the 7 domains that were studied, it was found that the domains which were affected most were

daily activities and school activities (among the ages 2-18).

Table 1.5 Mean and Standard Deviation (SD) for Sub Categories under Daily Activities

DAILY ACTIVITIES (Problems With)									
	Difficulty putting on shoes	Difficulty buttoning own shirt	Difficulty pulling shirt over head	Difficulty putting pants on when getting dressed	Difficulty brushing own hair	Difficulty getting into bathroom to use the toilet	Difficulty undressing to use the toilet	Difficulty getting in and out of the bathtub / shower	Difficulty brushing teeth
Mean	3.1	2.8	2.5	2.3	2.6	2.5	2.6	2.9	2.3
SD	1.5	1.7	1.7	1.6	1.6	1.7	1.7	1.5	1.7

Among the various factors studied under daily activities the factors that affect the quality of life for CP children the most include difficulty in putting on shoes (mean=3.1), difficulty in buttoning own shirt (mean=2.8) and difficulty with bathing(mean=2.9).

76% percentage of parents rated putting on shoes as a difficulty (i.e. the parents scored 3 or 4 in the questionnaire which signifies that the believed that the children had problems with putting on shoes often or almost always). In fact 70% of the parents said they have problem almost always with this factor. **52%** of the

parents responded that their children almost always have problems with buttoning their shirt.

Among the various factors in school actives, the mean for difficulty in drawing/writing with pen or pencil is 2.1 and the total percentage of the children who almost always have a problem with this factor is **30%**. The mean for the children having difficulty with using scissors or materials for art and craft is 2.8 and the total percentage of children who experience this difficulty is **52%**.

Table 1.6 Mean and Standard Deviation (SD) for Sub Categories under School Activities

SCHOOL ACTIVITIES (Problems with)				
	Difficulty writing or drawing with pen or pencil	Difficulty using scissors	Difficulty using a keyboard on the computer	Difficulty using a mouse for the computer
Mean	2.1	2.8	2.9	2.9
SD	1.6	1.7	1.5	1.5

The domains that were perceived to have the least impact amongst the population studied were pain/ hurt and speech/communication. The mean and standard

deviation for the sub categories under these domains have been documented in Table 1.7 and 1.8.



Table 1.7 Mean and Standard Deviation (SD) for Sub Categories under Pain and Hurt

PAIN AND HURT (PROBLEMS WITH)				
	Aches in joints and/or muscles	Having a lot of pain	Trouble sleeping because of pain or aching in joints and / or muscles	Muscles getting stiff and/or sore
Mean	1.3	1.3	0.7	1.1
SD	1.5	1.5	1.4	1.5

Table 1.8 Mean and Standard Deviation (SD) for Sub Categories under Speech and Communication

SPEECH AND COMMUNICATION				
	Difficulty telling family what he/ she wants	Difficulty telling others what he/ she wants	Difficulty with family understanding his/ her words	Difficulty with others understanding his/ her words
Mean	1.7	1.8	0.9	1.9
SD	1.7	1.6	0.9	1.6

Mann-Whitney Test: The Mann-Whitney test was conducted to test the significance of sex as well as 2 age groups (Group 1= toddlers(2-4years) and Group 2=others(5-18years)).

The Mean Rank for the sexes was reported as in Table 1.9 below. Sex did not seem to have a significant impact

on the domains explored, i.e. the factors impacting quality of life in CP children had the same impact on both sexes. The p value was insignificant when it was calculated between males and females for the different domains.

Table 1.9 Mean Rank by Sex

Domain	Males (29) Mean rank	Females (21) Mean rank
Movement and balance	26.16	22.18
Pain and hurt	22.67	28.38
Fatigue	27.24	20.32

Table 1.10 Mean Rank by Group 1 and Group 2

Domain	Group 1 Mean rank	Group 2 Mean rank
Movement and balance	16.75	26.54
Pain and hurt	29.50	23.85
Fatigue	23.75	24.70

Analysis showed that the p value for the movement and balance scale is **0.048** which is significant. This implied that for the parameter Movement and Balance there was a difference between the responses received by the two groups – Group 1 and Group 2, i.e., toddlers and others. The p value for the other domains was insignificant.

Finally, the overall quality of life for CP children was analyzed based on all the scored received for all the factors. This was performed for the whole group 2-18 ages. For this the 5 point scale was transformed to calculate the overall quality of life against a factor of 100.

0=100

1=75
2=50
3=25
4=0

The overall mean was found to be 53.6 which indicated that the quality of life for CP children in the sample considered was neither good nor poor and it was average according to the parent proxy.

CONCLUSION

This study is based on the parent proxy report of quality of life in children with cerebral palsy. According to this study the domains which were affected most were daily activities and school activities.



The domains affected least were pain, hurt and speech and communication. The reason for these domains to be affected less could be due to the fact that all these children are enrolled in special schools and are receiving physiotherapy, speech therapy and occupational therapy.

The affected domains however indicate that though these children are in special schools they need more training regarding the day to day activities to help them achieve their best possible outcomes.

There was no significant variation among males and females in these domains. However when the analyses was done by dividing the data according to toddlers and ages 5-18 the p value was significant for the movement and balance domain indicating that there is a difference in the difficulty rating for movement and balance in the different age groups.

The overall quality of life in these children is average according to the parent proxy report. The percent of low birth weight babies among this population is 44% which could be a risk factor for cerebral palsy⁽⁴⁾.

This study has also thrown light on the fact that only 18% of the parents knew about cerebral palsy vaguely. The remaining 82% had no idea/awareness about cerebral palsy.

This gives a strong need to have more awareness campaigns about cerebral palsy so that, the earlier the children are diagnosed, the earlier they can be enrolled in special schools and stimulation programs can be started as soon as possible which will improve their quality of life.

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