



## ASSESSMENT OF QUALITY OF LIFE AMONG CHILDREN WITH NEUROLOGICAL DEFICIT IN SELECTED REHABILITATION CENTRES, KOLKATA

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### ABSTRACT

**Objective:** A descriptive survey was conducted on assessment of quality of life among children with neurological deficit in selected rehabilitation centres, Kolkata with the objectives to assess the quality of life among children with neurological deficit and to find out association between quality of life and selected demographic variables. Neurological deficit refers to cerebral palsy.

**Data sources:** Data is collected from two selected rehabilitation centres of Kolkata.

**Methodology:** A non experimental survey approach with descriptive survey design is adopted to collect the information from respondents. 103 children aged 8-18 years were selected through purposive sampling technique. Data related to demographic variables were collected through semi structured interview schedule and record analysis proforma. Kidscreen 52 questionnaire for parent proxy version was used to assess quality of life in 10 dimensions of cerebral palsy children.

**Findings:** Study findings revealed that children had poor quality of life in the dimension of physical wellbeing and autonomy, social support, school environment and financial resources whereas they had good quality of life in mood and emotion and self-perception dimension. They maintained average quality of life in the domain of parent relation and home life and maximum in social acceptance. A significant association was found between quality of life and initial age of treatment [ $\chi^2$  (1)= 4.2565] and associated problem including gross motor function level (GMFC) [ $\chi^2$  (2)= 10.1433], manual ability level (MACS) [ $\chi^2$  (2)= 28.148], limb distribution [ $\chi^2$  (2)= 11.9628] and intellectual functioning [ $\chi^2$  (1)= 16.8289] at 0.05 level of significance.

**Conclusion:** The study concluded that children were socially accepted and not bullied by other children which would be a positive direction toward improving the quality of life meaningful in the society. The result also concluded that early intervention can improve the quality of life by reducing associated problems in some extent.

**KEYWORDS :** Cerebral Palsy, quality of life, Kidscreen 52 questionnaire, GMFC, MACS

### Introduction

Disabled children are of great concern to a family as well as to the society. When disability is discussed, particularly in children, about a quarter of chronic childhood problems are neurological in origin. Cerebral palsy is the leading cause of chronic disability in children, making them physically and mentally handicapped and socially aloof. The worldwide incidence of CP is approximately 2 to 2.5 cases per 1000 live births. According to WHO estimation, nearly 15-20% of the total physically handicapped children suffer from Cerebral palsy (CP). However, being a developing country, the expected actual figure may be much higher than the probable figure.<sup>[1]</sup>

Quality of life (QOL) is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life.[7] On the individual level, the concept of health-related quality of life (HRQOL) includes physical and mental health perceptions and their correlates including health risks and conditions, functional status, social support, and socioeconomic status.<sup>[2]</sup> Measuring HRQOL will help to monitor progress in achieving the nation's health objectives. The 2005 national KIDSCREEN study was implemented following international KIDSCREEN protocol, using the standardized generic cross-cultural KIDSCREEN questionnaires.<sup>[3]</sup>

### Literature Review

Some studies have been conducted related to prevalence of neurological disorders causing neurological deficit. A cross sectional study conducted at Jammu and Kashmir revealed that cerebral palsy and epilepsy gave a crude prevalence rate less than 10 years of age group (Raina SK, Razdan S, Nanda R(2011)).<sup>[4]</sup>

Many national and international studies are conducted to determine quality of life. Balemans AC, Wely V, Becher JG, Dallmeijer AJ(2015) conducted a study to investigate the quality of life in CP children. 46 children (7-13 years) participated in this study and assessed by Kidscreen questionnaire. Results showed children's quality of life was affected in cerebral palsy.<sup>[5]</sup>

Lim MSY, Wong CP (2009) conducted a descriptive study aimed to look the impact of health-related quality of life (HRQL) of cerebral palsy in the lives of children in the age group of 3 to 10 years and their families. 27 children attending the Paediatric Rehabilitation Clinic at

University of Malaya Medical Centre were interviewed prospectively using the Lifestyle Assessment Questionnaire-Cerebral Palsy. Result showed 11.1 % children had severely affected quality of life, 25.9% had moderately affected quality of life and 37 % children reported mildly affected quality of life making an impression that Health-related quality of life quite depend on the impairment and disability due to cerebral palsy.<sup>[6]</sup>

Dickinson H et.al. (2007) conducted a cross-sectional study to describe quality of life of children with cerebral palsy and compare with quality of life of the general population. 500 children aged 8-12 years were randomly selected and reported their quality of life using KIDSCREEN tool. Result showed specific impairments were associated with poorer quality of life in the four other domains i.e. physical wellbeing, moods and emotions, autonomy, and poorer relationships with their parents.<sup>[7]</sup>

Arnaud C, et. al.(2008) conducted a descriptive study to determine the health related quality of life among children with cerebral palsy in the age group of 12 to 17 years in Europe. Quality of life was assessed through parent reports by using the KIDSCREEN questionnaire. Result showed that quality of life for children with cerebral palsy was associated strongly with impairment.<sup>[8]</sup>

### Objective

The objective of this study is to assess quality of life among children with neurological deficit and find out its association with selected demographic variables.

### Methods

This descriptive survey study was conducted at two selected rehabilitation centres named National Institute of Mentally Handicapped (NIMH) Kolkata and Dr. B.C. Roy Post Graduate Institute of Pediatric Sciences, Kolkata. 103 children aged 8-18 years with neurological deficit were enrolled through purposive sampling technique in this study. Following are the inclusion criteria for respondents:

- Parents available at the time of data collection.
- Willing to participate in the study.
- Able to understand Bengali, Hindi, English.

Three different tools were used for the interview. Semi structured interview schedule was prepared to collect the socio-demographic data of children, record analysis proforma to find associated problems and Kidscreen 52 questionnaire (parent proxy version) to assess health related quality of life. 52 items grouped into 10 dimensions: Physical Well-being (5 items), psychological Wellbeing (6 items), moods and emotions (7 items), self-perception (5 items), Autonomy (5 items), Parent relations and Home life (6 items), Social support and peers (6 items), School environment (6 items), Social acceptance (Bullying) (3 items), and Financial resources (3 items). Responses are recorded by using 5 point likert scale mentioning the subheadings- 'never or poor' (1), 'seldom or fair'(2), 'quite often or good' (3), 'very often or very good' (4), 'always or extremely' (5). Scoring of Coding, scrutinizing and analysis were done after repeated consultation with statisticians and experts by calculating mean, mean percentage and frequency percentage. Pretesting of the tool and pilot study were done in a selected rehabilitation centres named MENTAID and Bodhayan respectively in Kolkata. Ethical permission was taken from institutional ethical committee. The final study conducted from 16.11.2015-12.12.2015.

**Findings**

103 children were selected in this study. The demographic characteristics, types of cerebral palsy, associated problems are shown in Table I.

**Table I Demographic characteristics of children with neurological deficit**

n=103

Demographic characteristics	Frequency	Percentage
Age (in years)		
8-12	53	51.46
13-18	50	48.54
Gender		
Boy	69	66.99
Girl	34	33.01
Birth order		
1 <sup>st</sup>	84	88.55
2 <sup>nd</sup>	8	7.77
>2 <sup>nd</sup>	11	10.68
Number of child		
Single child	62	60.19
>1 child	41	39.81
Religion		
Hinduism	64	62.14
Islam	39	37.86
Type of family		
Nuclear	59	5.28
Joint	44	42.72
Monthly family income(Rs/-)		
≤10,000/-	44	42.72
10,001-20,000/-	33	32.04
20,001-30,000/-	16	15.53
≥30,000/-	10	9.71
Initial age treatment		
<1 year	71	68.93
>1 year	32	31.07
Associated problem		
Limb distribution		
Hemiplegia	7	6.80
Diplegia	40	38.83
Quadriplegia	56	54.37
Gross Motor Function (GMFCS) level		
Stage I	Nil	-
Stage II	16	15.53
Stage III	31	30.10
Stage IV	34	33.01
Stage V	22	21.36
MACS level		
Stage I	Nil	-
Stage II	20	19.42
Stage III	36	34.95
Stage IV	42	40.78
Stage V	5	4.85
Intellectual functioning		
Normal	11	10.68
Learning disability	24	23.30
Mental retardation	68	66.02

**Findings related to quality of life**

The mean and percentage score are shown in Table II. Here, mean percentage of quality of life score was found maximum in social acceptance (90.81%), whereas minimum in financial resources dimensions (21.94%)

**Table II Mean and mean percentage of quality of life at various dimensions.**

n=103

Domains	Mean (mean percentage)
Physical wellbeing	8.56 (34.25)
Psychological wellbeing	17.49(58.32)
Moods and emotion	28.05 (80.17)
Self- perception	20.34 (81.40)
Autonomy	9.87 (39.50)
Parent relation and home life	19.27 (63.92)
Social support and peers	8.26 (27.54)
School environment	12.48 (41.62)
Social acceptance	13.62 (90.81)
Financial resources	3.29 (21.94)

In frequency percentage distribution it was found that maximum (78.06%) children were experiencing poor quality of life in physical wellbeing dimension, whereas maximum (60.03%) children were experiencing average quality of life in psychological wellbeing. Maximum children 72.12% and 61.36% were having good quality of life in moods and emotion and self-perception dimension respectively, whereas 67.77% and 90.61% children were experiencing poor quality of life in autonomy and social support dimension respectively. In the dimension of parent relation and home life, maximum children (50.65%) were having average quality of life whereas in school environment dimension 60.68% children were experiencing poor quality of life. In social acceptance dimension, maximum (91.26%) children experiencing average quality of life whereas in financial resources maximum (96.76%) children were experiencing poor quality.

**Findings related to association between quality of life and selected sample characteristics.**

A significant association was found between quality of life and initial age of treatment [ $\chi^2(1)=4.2565$ ,  $\chi^2df(1)=3.84$   $p<0.05$ ], Gross motor function (GMFC) [ $\chi^2(2)=10.1433$ ,  $\chi^2df(2)=5.99$   $p<0.05$ ], Manual ability (MACS) [ $\chi^2(2)=28.148$ ,  $\chi^2df(2)=5.99$   $p<0.05$ ], intellectual functioning [ $\chi^2(1)=16.8289$ ,  $\chi^2df(1)=3.84$   $p<0.05$ ], limb distribution [ $\chi^2(3) = 11.9628$ ,  $\chi^2df(2)=5.99$   $p<0.05$ ]. No significant statistical association was found between the quality of life and age, religion, family type and monthly family income.

**Discussion**

Colver A Rapp M, Eisemann N, Thyen U, Dickinson HO (2014) conducted a cross sectional longitudinal study to examine the variation of impairment in adolescent (13-17years) with cerebral palsy. Result showed that individual and societal attitude is strongly affected of quality of life of adolescent with cerebral palsy.<sup>[8]</sup>

An another descriptive study conducted to determine the health related quality of life among children with cerebral palsy in the age group of 12 to 17 years in Europe. Quality of life was assessed through parent reports by using the Kidscreen questionnaire. Result showed that depending on the areas of life, the most severely impaired children (in terms of motor functioning or intellectual ability) did not always have the poorest quality of life. Result also showed that quality of life for children with cerebral palsy was associated strongly with impairment (Arnaud C et. al., 2008).<sup>[9]</sup>

Shelly A et.al. (2008) conducted a study to examine the association between functioning and quality of life domains for children with cerebral palsy using Cerebral Palsy Quality of Life Questionnaire for children. It was seen that all domains of quality of life were significantly associated with functioning level. Results also showed that children with cerebral palsy have the potential to report a high psychosocial quality of life score even if they have poor functioning.<sup>[10]</sup>

**Conclusion**

On the basis of the findings it was concluded that children were socially accepted and not bullied by other children which would be a

positive direction toward improving the quality of life meaningful in the society. Findings gave an inference that children had poor quality of life in some aspects of life like in physical wellbeing, autonomy, social support, school environment, financial resources. But it also found that they maintained average and good quality of life in psychological wellbeing, moods and emotion, self- perception, parent relation and home life indicating a positive sign.

Present study also revealed that quality of life of children with neurological deficit was strongly associated with associated impairment. The result also provided useful information regarding treatment modality making a conclusion that quality of life could be improved by initiating the treatment techniques in early age of children with neurological deficit.

## Reference

1. Dominick KL, Ahern FM, Gold CH, Heller DA. Relationship of health related quality of life to health care utilization and mortality among older adults. *Aging Clin Exp Res* 2002;14(6):499-508.
2. The WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL). Development and psychometric properties. *Soc Sci Med* 1998;46:1569-85.
3. Keenaghan C, Kilroe J. Study on the Quality of Life Tool KIDSCREEN for children and adolescents in Ireland: Results of the KIDSCREEN National Survey 2005. The National Children's Strategy Research Series 2008 Feb. Available from: [www.omc.gov.ie](http://www.omc.gov.ie). Accessed January 16, 2016.
4. Raina SK, Razdan S, Nanda R. Prevalence of neurological disorders in children less than 10 years of age in Jammu and Kashmir. *Pediatr Neurosci* 2011 Jul-Dec; 6(2): 103-105.
5. Balemans AC, Vanweley L, Becher JG, Sieberer RU. Longitudinal study related quality of life in children with CP. *American physical therapy association* Mar 2015;24(3):996-1005.
6. Lim MSY, Wong CP. Impact of cerebral palsy on the quality of life in patients and their families. *Neurology Asia* 2009;14:27-33.
7. Dobhal M, Juneja M, Jain R, Sairam S, Thiagarajan D. Health-related Quality of Life in Children with Cerebral Palsy and Their Families. New Delhi, India, 2013. Accessed January 9, 2016.
8. Colver A F, Rapp M, Eisemann N, Thyen U, Dickinson HO. Self -reported QoL of adolescent with cerebral palsy. *INT J PED Oct* 2014;38:p.705-716.
9. Arnaud C, White- Koning M, Michelsen SI, Parkes J, Parkinson K, Thyen U. Parent reported quality of life of children with cerebral palsy in Europe. *Pediatrics* Jan, 2008; 121 (1): 54-64
10. Shelly A, Davis E, Waters E, Mackinnon A, Reddihough D, Boyd R, Reid S, Graham HK. The relationship between quality of life and functioning for children with cerebral palsy. *Developmental Medicine and Child Neurology* 2008; 50(3):199-203