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Original Article

Quality of life in children with cerebral palsy

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ABSTRACT

Cerebral palsy refers to a non-progressive brain disorder that affects the development of brain in developing infant and reduces the quality of life. Quality of life (QOL) is assessed using the CPQOL tool. **Objectives:** To assess the quality of life of children with CP. **Methods:** A cross-sectional study was conducted at the National Institute of Rehabilitation Medicine, Islamabad during Oct-2022 to Mar-2023. The sample was raised using slovin's formula and non-probability convenient sampling technique was used. Data were collected using standard CP-QOL tool. All types of CP diagnosed cases both gender, presence of a caregiver and an age range of 4 to 12 years were included. Patients with non-availability of a caregiver and presence of any other illness not associated with CP were excluded. **Results:** Out of 129 participants, 105 were included on the basis of inclusion and exclusion criteria. The mean ± SD of patients overall score came out to be 46.83 ±9.75. CPQOL score of males were 47.36±9.96 and of female was 46.19±9.56. CPQOL score of age 4-6years was 45.12±10.58, 7-9 years was 47.70±9.15 and 10-12 years was 49.21±8.54 while overall CPQOL score of children with diplegic CP was 48.38±9.11, hemiplegic CP was 48.66±7.74, quadriplegic CP was 37.92±11.16. **Conclusions:** study showed that among both genders, females had poor QoL than males. This study also concluded that quadriplegic children had poor QoL than any other types of cerebral palsy. The overall status of QoL of children having Cerebral Palsy was low.

INTRODUCTION

The prevalence of developmental impairments ranges from 16 to 20 per 1000 people globally. The prevalence of developmental impairments is becoming a serious problem for public health in nations like Pakistan [1]. The term "cerebral palsy" (CP) is used to represent a broad spectrum of symptoms that have many etiologies and change with age. William little, an orthopedic physician from England who first used the phrase "cerebral palsy." The description of cerebral palsy has undergone several changes over time. The motor disorder cerebral palsy (CP) affects a person's posture, muscle tone, and range of motion. Cerebral palsy (CP) affects males more frequently than women [2]. There are many different clinical presentations of cerebral palsy, which are grouped into different categories. Many people use the categorization Ingram and Hagberg suggested. Ingram's classification includes ataxia, dyskinesia, mixed types, bilateral hemiplegia (tetraplegia), hemiplegia, and diplegia. In Hagberg's categorization, ataxia, dyskinesia, and spasticity are all included. As stated by SCPE, cerebral palsy can be classified according to being spastic, dyskinetic, or ataxic [3, 4]. Spastic cerebral palsy is the most typical kind, which is largely brought on by cortical injury. Stiffness in the muscles and tight joints are common in people with spastic CP, which can make it painful and difficult for them to do daily tasks including sitting, moving, and walking. This type of CP comes in three different varieties. Spastic hemiplegic cerebral palsy which is limited to one side of the body, impairs the legs, arms, and hands. The condition, also known as unilateral CP, makes it difficult for the person to utilize the side that is afflicted. The type of CP that is most prevalent worldwide, spastic diplegia, predominantly affects the legs and is characterized by muscular rigidity. Quadriplegia with spasticity affects all four limbs. In children with CP, quadriplegia occurs in around 23% of cases, hemiplegia in 39%, and diplegia in 38% [2, 5]. After the spastic variant, athetoid or dyskinetic CP is the second most prevalent kind of CP. It is brought on by damage to the basal ganglia and frequently accompanied with significant mobility deficits, making therapy difficult. People who have this kind of CP display uncontrollable, repetitive, involuntary, and occasionally stereotyped motions. This group includes choreoathetosis and dystonia, two important disorders. Hypertonic-hypokinetic dystonia, or dystonic CP, is characterized by aberrant posture and elevated muscular tone. Contrarily, choreoathetotic CP, also known as hypotonic-hyperkinetic syndrome, is characterized by violent, uncontrolled, fast, and continuously changing movements [2, 5]. Because damage to the cerebellum causes a deficit or lack of movement coordination, ataxic CP is different from other types of CP. This subtype, which accounts for 5–10% of all instances of CP, is characterized by decreased muscular tone and poor hand-eye coordination. Bilateral or unilateral predominance are two possible symptoms of ataxic CP [4, 5]. A person is said to have a mixed kind of cerebral palsy (CP) if they exhibit traits from each of the three main categories of the condition [4, 6]. Cerebral palsy is often identified in the first two years of life using a combination of medical history, neuroimaging, and neurological and motor evaluation, according to studies by Novak *et al.,* [7]. Magnetic resonance imaging (MRI) and the Hammersmith Infant Neurological Examination are the two most reliable tests for detecting cerebral palsy in infants as young as 5 months of age, with MRI having a sensitivity rate of 86-89% and the HINE having a sensitivity rate of 90% [8, 9]. Functional categorization systems are used to standardize the evaluation of the therapeutic and support needs of persons with CP. Children ages 2 to 18 have their gross motor function measured using the Gros Motor Function Classification System (GMFCS) most notably the capacity to walk. GMFCS evaluates both spontaneous movement and movements aided by wheelchairs, crutches, canes, or walkers. The Manual Ability Classification System (MACS) measures how typically 4 to 18-year-old children utilize their hands and upper limbs [10, 11]. The measurement of quality of life (QOL) has drawn a lot of interest from the medical and health communities. One definition of QOL provided by the World Health Organization (WHO) is as follows: "An individual's opinion of their position in life in relation to their objectives, standards, requirements, and worries in the context of the culture in which they live" [12]. A crucial component of treating people with cerebral palsy is evaluating the patient's status of quality of life. Some tests that may be used to measure a child's quality of life (QOL) include PedsQL, KidSCREEN, Health-Related Quality of Life (HRQOL), and the Child Quality Questionnaire (CHQ). Children with cerebral palsy can be assessed for quality of life (QOL) by using a validated instrument, such as the Cerebral Palsy - Quality of Life (CP-QOL) questionnaire [13, 14]. Based on the International Classification of Function (ICF), the World Health Organization developed the CP-QOL questionnaire specifically for people with cerebral palsy [14]. The CPQOL questionnaire has two version for assessing the quality of life one version is designed for primary caregiver and other one is for children. The validity of CPQOL questionnaire has been established in many other countries [15, 16]. In this study, the purpose was to evaluate the quality of life in children with cerebral palsy in Pakistan, specifically in Islamabad.

METHODS

A descriptive cross-sectional study was carried out over a 6-month period i.e., from October 2022 to March 2023 at the physiotherapy departments of National Institute of Rehabilitation Medicine. This was done after getting approvals from the Institutional Review Committee (IRC) /Ethical Review Board (ERB) of The University of Lahore and the Head of the Department of the University of Lahore Islamabad Campus (Ref. No: IRB-IIUI-FAHS/DPT/1022-1001). Consent was be taken from each participant. The study used a non-probability convenient sampling method to select 129 children with cerebral palsy age range from 4 to 12 years. The inclusion criteria involves diagnosed cases of all types of CP of either gender of age group ranging from 4 to 12 years along with the presence of caregiver at the time of questionnaire filling. Participants were excluded if the primary care giver was unavailable or if the kid was suffering from any other condition unrelated to CP. Sample was raised using slovin's formula i.e.,$\boldsymbol{n=N \div (1+Ne2)}$, Confident interval (CI): 95%, Margin of error (a-error):0.05 Where n= sample size, N= actual population, e= margin of error. Approximate CP patients in an OPD of NIRM was roughly around 192, n = 192/1+192(0.05)2, n =129. The CPQOL version 2 which was parent proxy version was used in the English language for this study. Demographics detail and history of child were recorded to determine type of CP. CP QOL questionnaire was administered to the parent. Patient proxy version (for parents of children age 4–12 years) comprising 66 items. The various domains assessed using this questionnaire were – social well-being and acceptance, functioning, participation and physical health, emotional well-being and self-esteem, access to services,

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pain and impact of disability, and family health. Scoring of the items involved 2 steps as per the CP QOL child questionnaire. All the items in various domains have a 1–9 point rating scale where 1 = very unhappy and 9 = very happy. A few items like pain, where this rating is not appropriate, the scale is 1 = not upset, 9 = very upset. All QOL score were converted to a scale from 0 to 100, i.e., 1 = 0, 2 = 12.5, and 3 = 25. The algebraic means of item values were computed for each domain. The survey was scored in accordance with the standard guidelines, and the necessary statistical analysis was completed [17, 18]. Data were analyzed using SPSS version 25.0. Using the Shapiro-Wilk test, the obtained demographic and outcome measures were evaluated for normality. All descriptive were stated in terms of mean and standard deviation because the data had a normal distribution. Cronbach's alpha was used to determine the internal consistency of the CP-QOL scores of all seven domains. All QOL scores were recoded using SPSS i.e.,1=0, 2=12.5, 3=25, 4=37.5, 5=50, 6=62.5, 7=75, 8=87.5 and 9=100. Items that are in 5 points were recoded as 1 = 0, 2 = 25, 3 = 50, 4 = 75, and 5 = 100.

RESULTS

Out of total 129, 105 participants met the inclusion and exclusion criteria. So, all the results are formulated on 105 participants. Among the total participant, 45.7% (48) were female and 54.3% (57) were male. Mean age of study population was 7.22±2.279. Out of 105 participants, 46 (43.8%) were in age range 4-6years, 41 (39.0%) in age range 7- 9years, 18 (17.1%) in age range 10-12years. 65(61.9%) participants were diagnosed as CP at the time of birth to within 1 year, 35(33.3%) were diagnosed at the age of 2-3years, 5 (4.8%) were diagnosed at the age of 4-5 years. Out of 105 participants 50 (47.6%) were diplegic, 24 (22.9%) were hemiplegic, 17 (16.2%) were quadriplegic, 5(4.8%) were ataxic, 3(2.9%) were athetoid, 6(5.7%) were of mixed type. Most of participant were of diplegic type. Social well-being and acceptance have mean 50.93±15.87. Participation and physical health have mean 37.69±16.85. Feeling about functioning has mean 42.60±16.09. Emotional well-being and self-esteem have mean of 48.51±15.15. Access to services has mean 25.91±14.25. Pain and impact of disability has mean 40.26±13.28. Family health has mean 81.93±10.07 mean and SD. The patients overall score is 46.83±9.75 (Table 1).

Table 1: Mean and SD of all the seven domains of CPQOL with minimum and maximum scores along with internal consistency.

CPQOL Domains	Min	Max	Mean ± SD	Cronbach's α
Social well-being and acceptance	20.83	86.46	50.93 ± 15.87	0.805
Participation and physical health	0.00	87.50	37.69 ± 16.85	0.796
Feeling about functioning	2.08	97.92	42.60± 16.09	0.797
Emotional well-being and self esteem	2.08	79.17	48.51± 15.15	0.818
Access to services	0.00	65.63	25.91± 14.25	0.854
Pain and impact of disability	0.00	83.33	40.26± 13.28	0.836
Family health	45.00	95.00	81.93 ± 10.07	0.872
Overall Score	19.94	68.68	46.83 ± 9.75	0.790

CPQOL score of males is 47.36±9.96 and of female is 46.19±9.56 (Table 2).

Table 2: CPQOL score among male and female

Gender statistics	N (n =105)	CPQOL Mean ±SD
Male	57	47.36±9.96
Female	48	46.19±9.56

CPQOL score of age 4-6years is 45.12±10.58, 7-9 years is 47.70±9.15 and 10-12 years is 49.21±8.54. Overall CPQOL score of children with diplegic CP is 48.38±9.11, hemiplegic CP is 48.66±7.74, quadriplegic CP is 37.92±11.16, Ataxic CP is 46.94±8.35, athetoid CP is 54.84±6.37 and CPQOL score of mixed types of CP is 47.70±8.31 (Table 3).

Table 3: CPQOL score of age categories and different types of CP

Age Category	N (n=105)	CPQOL Mean ±SD
4years-6years	46	45.12±10.58
7years-9years	41	47.70±9.15
10years-12years	18	49.21±8.54
Type of CP	**N (n=105)**	**CPQOL Mean ±SD**
Diplegia	50	48.38±9.11
Hemiplegia	24	48.66±7.74
Quadriplegia	17	37.92±11.16
Ataxic	5	46.94±8.35
Athetoid	3	54.84±6.37
Mixed	6	47.70±8.31

DISCUSSION

Bjornson and McLaughlin created the CPQOL questionnaire as a specific scale to determine the QOL [19]. The quality of life in children with CP is impacted on a permanent basis. It is made according to how well the parents comprehend the illness. Compared to typically developing kids, CP children suffer from decreased quality of life (QOL). Because activities of daily living are reduced, this increases the caregiver's workload. In Islamabad, we thus attempted to assess the quality of life for children who had CP. CP-QOL is a reliable questionnaire that was used in many studies. We tried to evaluate the overall quality of life of children with cerebral palsy that is 46.83±9.75. A study carried out in India by Vadivelan by using the same tool i.e., CP-QOL questionnaire. In this study, the overall CPQOL score was 37.67 ±4.57. We used the CP-QOL questionnaire to collect data from 105 caregivers of CP children for our study. There were 48 (45.7%) girls and 57 (54.3%) boys with mean age of 105 children is 7.22±2.279 and overall CPQOL mean score is 46.83±9.75 while in other study that is conducted in India there were 72 (59%) were male and were 49 (41%) females and 121 children with CP were 6.85± 2.43 years old on average. In our study, access to services, participation, physical health, pain, and the impact of disability were all significantly more impaired than other domains, whereas the domains of pain, access to services, and family health were severely compromised when compared to other domains [20]. In a study carried out in Indonesian Children with the use of Peds-QL having age group of 2-18 years. There were 52 subjects while most of them were male 67.30% and females were 32.70%.They divide them into three Half of the children were between the ages of 2 and 4 years, and only a small percentage were between the ages of 13 and 18. The children were divided into categories of age (toddlers, 2years to 4 years; young children, 5 years to7 years; youngsters, 8 years to 12 years; and teens, 13 years to18 years),having a mean and standard deviation of age 6.31±4.08.In this study among the domains the most compromised was domain of daily activities having a mean and SD of 16.66±30.10 while in our study the most compromised domain was access to services having a mean and SD of 25.91±14.25.In this study they interpret the QOL as those having A mean score of 70 or more was considered good, while a score of 70 or lower was considered poor. Based on this study 76.90% children had a poor QOL and 23.10 % children have good QOL. In our study the overall score was 46.83±9.75. The differences are because they had used different questionnaire [2]. Another study conducted in Bangladesh by M.M. Islam by using questionnaire LAQ-CP .100 CP children's data were collected having age group of 3-12 years that are grouped into age 3-8 years had mean and SD 48(48%) and age 8-12 years had mean and SD 52(52%). Most of the children were male i.e., 66% similarly in our study most of children were also male i.e., 54.3%. In this study children were classified into mild, moderate and severe according to the questionnaire. According to this study 40% of children were severely affected and had reduced QOL [21]. This study has a major limitation that study was conducted at only one setting of Islamabad due to approval issues and less prevalence of the disease. We recommend future researchers to conduct at large spectrum research.

CONCLUSIONS

This study showed that out of seven domains access to services, physical health and participation and pain and impact of disability were highly compromised than other domains. Among gender, females had poor status of quality of life than males. This study also showed that Quadriplegic children had poor quality of life than all other types of cerebral palsy. The overall quality of life in children with Cerebral Palsy was compromised.

Authors Contribution

Conceptualization: SH, AZ
Methodology: HW, FZ
Formal Analysis: IA, MC
Writing-review and editing: SH, AZ, MC, HW, FZ

All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

The authors declare no conflict of interest.

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