

## Parental Perspectives on Quality of Life in Adolescents with Cerebral Palsy

Prabhu Prajakta, Sunila John, Rajashekhar Bellur

### ABSTRACT

**Background:** Quality of life (QoL) is an important outcome variable while evaluating intervention effectiveness during adolescence. Limited studies have addressed the issues that affect the QoL in adolescents with cerebral palsy. The present study explores the parent-reported QoL in adolescents with cerebral palsy. **Materials and Methods:** Using a cross-sectional study design, parental perspectives on QoL were investigated among 35 parents of adolescents with cerebral palsy, aged between 13 and 18 years. Performance on seven domains of QoL across age and gender were explored. **Results:** While the maximum QoL was seen in the domain of social well-being, the least QoL was noted for feelings about functioning. Across age, the early adolescence group (13–15 years) had a poorer quality of life in comparison to the late adolescence group (16–18 years). With respect to the gender, though females had a lower QoL scores, a statistically significant difference was observed only for the domain of general well-being and participation. **Conclusions:** From a parental perspective, the major issues of concern in adolescents with cerebral palsy were feelings about functioning, general well-being and participation, and access to services. This information will be useful when establishing management options or assessment protocols to improve their overall QoL.


**Key words:** Adolescents, cerebral palsy, parental perspectives, quality of life

**Key messages:**

*There are various issues that affect the QoL in adolescents with cerebral palsy. From a parental perspective, the major issues of concern in adolescents are feelings about functioning, general well-being and participation, and access to services.*

Cerebral palsy (CP) is one of the most common childhood conditions resulting in functional disability. It has been described as “a group of permanent disorders of the development of movement and posture, causing activity limitation, which is attributed to nonprogressive

disturbances that occurred in the developing fetal or infant brain”. The motor disorders of CP are often accompanied by disturbances of sensation, perception,

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cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems.<sup>[1]</sup> Management of children with CP, therefore, involves multidimensional treatment regimens.

QoL assessment is an important dimension that has gained worldwide importance over the last 20 years. It refers to an individual assessment of well-being across multiple domains of life. QoL is defined as the “value that an individual assigns to the duration of life as modified by impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy”.<sup>[2]</sup> These evaluations are useful as outcome measures, at different times, to capture the effects of interventions. The assessment of QoL in CP can be self-reported or parent-reported. The use of parent proxy QoL becomes essential in situations of children or adolescents with severe CP not being able to report their own QoL due to certain limitations such as cognitive immaturity and limited social experience. Recently, Das *et al.*<sup>[3]</sup> explored the primary caregiver perspectives in 50 Indian parents of children with CP between the age group of 4 to 12 years. Their findings revealed that in Hindi speaking children with CP; age and maternal education affected the QoL as compared to other demographic variables such as type of CP or gender. Arnaud *et al.*<sup>[4]</sup> through their study conducted in Europe among 818 children between 8 and 12 years of age revealed that parents with higher levels of stress often reported a poor QoL in all domains. The study further suggested that increased severity of the condition is not always associated with lower QoL.

Adolescence is a transition phase to adulthood, characterized by major changes in physical, cognitive, and social aspects. The issues and concerns that affect the QoL of adolescents are very different from those of children and cannot be generalized from findings of QoL in childhood or adulthood. It is highly possible that new impacts on their QoL take place and new domains of QoL emerge in adolescence.<sup>[5-7]</sup> Waters *et al.*<sup>[5]</sup> have suggested that adolescents with CP report poorer emotional and social health and that QoL is dependent on pain, mental health issues, general health condition, and how it affects activities at home. A decrease in life satisfaction during adolescence has also been reported in the literature.<sup>[6]</sup> The primary areas which have a large impact on the QoL of adolescents are their relationship with peers and friendships, self-image and appearance, and the importance of having a secure family and parental relationship.<sup>[5,6]</sup>

Parental reports provide a perspective on more functional and future-directed information. They also give insight into the associated factors that cause the

adolescents' QoL to be poorer, such as access to services, which is not frequently reported by adolescents but is a major contributor to their overall QoL. Rapp *et al.*<sup>[8]</sup> based on a longitudinal study among 551 adolescents with CP between 13 and 17 years of age, suggested that pain, psychological problems, and parental stress are suggestive of lower QoL as compared to the severity or sociodemographic variables. Another study has suggested that environmental barriers at home and school influence the QoL of adolescents with CP.<sup>[9]</sup> Most of the parents often feel dissatisfied with the service delivery of medical facilities.<sup>[10]</sup> The responsibility of caring for an adolescent with CP affects the parents' physical and social well-being, freedom, family well-being, and financial stability. However, in the Indian context, there are no published studies focusing on understanding parental perspectives on their adolescents' QoL. This necessitates the need to evaluate proxy reported QoL among children and adolescents with CP. Therefore, this study aimed to examine the parental perception of the QoL of adolescents with CP. The objectives of the study were to report the parents' perception of their adolescent's QoL by extracting domain-specific effects on QoL and to compare the parental perception of QoL in adolescents with CP across age groups and gender.

## MATERIALS AND METHODS

A cross-sectional study design was opted for, and 35 parents of adolescents with CP were included in the study. Ethical approval was obtained from the Institutional Research Committee. The data was collected from both the parents of adolescents with CP coming to the rehabilitation unit of a tertiary hospital in Karnataka. As per the participant selection criteria, using convenience sampling, only parents of adolescents aged between 13 and 18 years and with any type of CP, with Kannada as their mother tongue, and belonging to any socioeconomic background were considered for the study. However, parents with a low level of education or schooling of fewer than 4 years and having adolescents with multiple disabilities were excluded from the study.

The parent-reported QoL was assessed using the Cerebral Palsy Quality of Life Questionnaire – Teen v2.0 (CPQOL – Teen), parent proxy version (for adolescents aged between 13 and 18 years)<sup>[11]</sup> after obtaining the permission from the authors. This tool is a condition-specific questionnaire to measure the QoL in adolescents with CP. It comprises 88 items that include questions about family and friends, school, participation, communication, health, special equipment, pain and bother, access to services, and a few questions about themselves (parents). The questions are categorized into seven domains: general well-being

and acceptance, communication and physical health, school well-being, social well-being, access to services, family health, and feelings about functioning. The tool, originally developed in English, was translated into Kannada language using a forward-backward translation procedure by four native speakers of Kannada.

Informed consent was sought for administering the questionnaire, from the parents of the children, prior to the study. Demographic details, encompassing adolescent's age, gender, the severity of impairment using gross motor functioning classification system,<sup>[12]</sup> type of CP, parental level of education, occupation, and socioeconomic status using Kuppuswamy's socioeconomic scale: Revised Income for 2014,<sup>[13]</sup> were obtained from the parents.

Parents were informed that questions asked to him/her are regarding their adolescent's life, such as his/her family, friends, health, and school. Each question begins with, "how do you think your teenager FEELS about." A visual analog scale of 9 points was presented to the parent to get the response, in which: 1 = very unhappy and 9 = very happy. They were asked to circle the option whichever they feel for each of the items. The responses of each participant were numerically coded for further analysis. Each of the questionnaires was also numerically coded to maintain confidentiality.

Descriptive statistics was used to summarize the performance of seven domains of QoL across age and gender. The mean values of each domain were utilized to compare the domains, and the domain with high scores was identified. An independent *t*-test was performed to find if there is any significant difference across gender and age groups. Statistical analysis was carried out using SPSS version 15, with a confidence interval of 95%.

## RESULTS

A total of 35 adolescents (24 males and 11 females) between 13 and 18 years of age were included in the study, as indicated in Table 1. They were divided into two groups, 13–15 years (early adolescence) and 16–18 years (late adolescence). Twenty-four participants (68.6%) were included in the early adolescence group and 11 (31.4%) in the late adolescence group. The early adolescence group comprised of 15 males (62.5%) and 9 (37.5%) females. The mean (SD) age of the group was 13.95 (0.69) years. The late adolescence group included 9 males (81.81%) and 2 females (18.18%). The mean (SD) age of the late adolescence group was 16.36 (1.12) years. The overall mean (SD) age of the participants was 14.82 (1.50) years. The mean age of male and female participants was 14.79 (1.44) and 14.90 (1.70) years, respectively.

**Table 1: Demographic characteristics of study participants (n=35)**

	Age	
	Early adolescence n=24 n (%)	Late adolescence n=11 n (%)
Gender		
Male	15 (62.5%)	9 (81.81%)
Female	9 (37.5%)	2 (18.18%)
GMFCS		
Level I	0 (0)	0 (0)
Level II	5 (20.83)	4 (36.36)
Level III	9 (37.5)	4 (36.36)
Level IV	8 (33.33)	3 (27.27)
Level V	2 (8.33)	0
Socioeconomic Status		
Class 1	3 (12.5)	2 (18.18)
Class 2	4 (16.66)	2 (18.18)
Class 3	1 (4.16)	3 (27.27)
Class 4	16 (66.66)	4 (36.36)
Class 5	0 (0)	0 (0)

GMFCS – Gross Motor Functioning Classification System

## Domain-specific overall performance

The study explored the parental perception of their adolescent's QoL across seven domains. As indicated in Table 2, across the domains, the mean scores were noted to be the highest for social well-being (71.38 [15.21]), with the lowest score on the domain of feelings about functioning (48.50 [24.75]). There was a statistically significant difference between the early adolescence group and the late adolescence group across all the domains except on social well-being.

Across gender, as indicated in Table 3, there was a statistically significant difference between males (60.06 [17]) and females (46.96 [15.44]) only for the domain of general well-being and participation.

## DISCUSSION

In the present study, maximum QoL was seen in the social well-being domain while the least QoL was found to be in the domain of feelings about functioning. It was noted that regardless of the motor deficits and communication difficulties exhibited by these adolescents, their parents reported a better QoL related to social aspects. This better score in social well-being can be attributed to the family relationship and public outlook in the Indian scenario. Most often, the adolescents live with their family and are surrounded by family members, resulting in close family bonding. Earlier studies<sup>[14,15]</sup> have reported that maintaining good relationships with family and friends is crucial for higher QoL. Adolescents need to feel that their CP does not prevent them from being accepted and valued by their families. Similarly, the public outlook towards specially-abled children is fast improving.<sup>[16]</sup> The masses

**Table 2: Domain-specific overall performance and performance across early and late adolescence groups**

Domains	Early adolescence mean (SD)	Late adolescence mean (SD)	Overall mean (SD)	t statistic, p value
General Well-being and Participation	48.58 (13.90)	72.02 (13.19)	55.95 (17.43)	t (33)=-4.7, p<0.01
Communication and Physical Health	51.79 (12.76)	76.70 (13.04)	59.62 (17.26)	t (33)=-5.32, p<0.01
Social Well-being	68.94 (15.13)	76.68 (14.66)	71.38 (15.21)	t (33)=-1.41, p>0.01
School Well-being	58.45 (14.80)	78.03 (12.52)	64.60 (16.72)	t (33)=-0.38, p<0.01
Access to Services	49.46 (13.28)	72.47 (13.78)	56.69 (17.11)	t (33)=-4.70, p<0.01
Family Health	49.09 (21.23)	77.27 (14.66)	57.95 (23.32)	t (33)=-3.97, p<0.01
Feelings about Functioning	38.33 (22.03)	70.68 (13.32)	48.50 (24.75)	t (33)=-4.48, p<0.01

**Table 3: Domain wise performance across gender**

Domains	Male mean (SD)	Female mean (SD)	t statistic, p value
General Well-being and Participation	60.06 (17.00)	46.96 (15.44)	t (33)=2.17, p=0.037
Communication and Physical Health	62.63 (17.97)	53.05 (14.16)	t (33)=1.55, p=0.129
Social Well-being	73.26 (15.04)	67.27 (15.49)	t (33)=1.08, p=0.28
School Well-being	66.33 (18.09)	60.83 (13.23)	t (33)=0.90, p=0.37
Access to Services	59.88 (17.77)	49.74 (13.84)	t (33)=1.66, p=0.10
Family Health	62.23 (22.22)	48.60 (23.94)	t (33)=1.64, p=0.10
Feelings about Functioning	51.35 (23.87)	42.27 (26.65)	t (33)=1.00, p=0.32

now recognize the needs of the specially-abled and extend their support to them amicably. In the present study also, most of the parents reported that the adolescents were well involved in the family and home environment and got along well with their brothers and sisters. Thus, a feeling of belonging was seen among the study participants.

In the present study, apart from social well-being, the domain of school well-being showed relatively better QoL in comparison to other domains. Supporting evidence from Davis *et al.*<sup>[17]</sup> parent-reported study indicates that adolescents enjoy school, it being an active and enriching environment helping them to feel being a part of the community. Our finding can also be attributed to the fact that all participants were going to a regular school and enjoyed good peer relationships. Taking this into account, the parents reporting a better QoL for adolescents with respect to the school well-being domain is justified.

In comparison to social and school well-being, poorer QoL was reported for the communication domain. On similar lines, Davis *et al.*<sup>[17]</sup> reported that parents of adolescents with limited communication reported the frustration they and their children often felt. Similar findings obtained from the current study can be related to the difficulty that parents face in comprehending the adolescent's needs and requirements.

The study findings also revealed a poor QoL with respect to parent-reported physical health. Brehaut *et al.*<sup>[18]</sup> reported that caregivers tend to be more depressed if their child has poorer health and, in turn, report a poor QoL for their adolescent. Correlation between maternal

depression and parent-proxy reported health has also been reported in the literature.<sup>[19,20]</sup> This, along with increased familial tension and pressure, could be one of the contributing factors for the poor QoL reported in the present study.

The present study findings showed a poor QoL in the domain of family health. According to Davis *et al.*,<sup>[17]</sup> financial support is essential for childcare and rehabilitation. The financial stability to meet the child's needs had a major impact on QoL related to family health. Along with the above-mentioned factors, Magill-Evans *et al.*<sup>[21]</sup> reported that if the relationship of the adolescent with his/her sibling was poor, the parents reported the QoL as lower. This may be one of the factors contributing to the poor QoL observed in the present study.

In the current study, 57.14% of the parents were from a poor socioeconomic class. A poor financial condition in the family increases the level of parental stress, which could have affected the parent-report of QoL negatively. Further, a lower QoL score was observed for the domain of availability of services required for the adolescent and their access to these services. This could be explained by the fact that a lack of access to services added extra pressure on the parents while taking care of their adolescents. Darrah *et al.*<sup>[22]</sup> reported that families experience dissatisfaction and frustration with service delivery in the areas of health, education, work, recreation, housing, and transportation. In the Indian scenario, in rural areas, there is evident difficulty in accessing the required interventional and rehabilitative services. People with disabilities encounter a range of barriers when they attempt to access healthcare.



These include unaffordable costs, limited availability of therapy services, and lack of support groups. In the Indian context, the high cost involved for the services and lack of services was reported to be a common barrier that hinders rehabilitation.<sup>[23]</sup> This would have also contributed to the lower parent-reported QoL in the current study.

In the present study, poor QoL for the domain of general well-being and participation can be attributed to various factors, including parents' physical and mental health, personality, coping, optimism, and self-esteem. An additional factor that could lead the parents to report a poor QoL in this domain may be their tendency to infer negative conclusions just purely based on the physical, observable behaviors. Previous authors had suggested that parents report more impairment with reference to general well-being.<sup>[24,25]</sup> The reason for this could be that during adolescence, children do not tend to share their feelings and emotions with their parents quite often. Hence, parents have little access to emotions and feelings their adolescent has when the transition from childhood to adolescence happens. A restriction in the physical mobility of an adolescent renders them inefficient to carry out their daily activities, with increased dependency on others. The parents of adolescents with CP in this study were often burdened with the added responsibility of helping the adolescent carry out self-care activities and other daily needs such as toileting and dressing up. Apart from this, the parents also had the additional responsibility of taking care of household matters and other children in the family. This could be a possible explanation for the findings in our study.

On comparison of performance on QoL across early and late adolescence groups, it was consistently seen that parents of early adolescents reported a poorer QoL in domains encompassing the adolescent's general well-being, communication abilities, academic and schooling related activities, social participation, and familial involvement and support. These are contrary to the findings of Giannakopoulos *et al.*,<sup>[26]</sup> who reported that late adolescents have poorer QoL than younger adolescents. However, the current study findings are supported by Shikako-Thomas *et al.*,<sup>[14]</sup> who explained it as an adaptation that occurs in the family of the adolescent with CP because it is a congenital disorder. Parents develop a series of adaptive strategies and adapt their plans and expectations. As adolescents grow older, they learn to cope with the disorder and are much less dependent on the parents for their daily functioning. This might be one of the potential reasons why parents reported a better QoL for the late adolescence group.

On comparison of performance on QoL domains across genders, a strong relationship between the genders and QoL was observed. Without any domain as an exception, parents of female adolescents reported poor QoL in comparison to the males. Among all domains of life, female adolescents seem to have the poorest QoL with respect to mobility and independent functioning. In the Indian scenario, the reason for a poor parental report of QoL among female adolescents with CP may be that as a whole, especially in rural India, females have a lower social status in the community and are considered as an added responsibility.<sup>[27]</sup> In addition to this, the presence of a lifelong disorder like CP restricts the ability to carry out daily functions, heightens the caregiver's stress towards future planning and worsens the general perception of the community.

## CONCLUSION

Overall, the present study outlines the parental perspectives on QoL in adolescents with CP in the Indian scenario. It also provides information regarding QoL from a functional perspective. However, parent-reported QoL could not be used as a substitute for self-reported QoL, as it provides only complementary information about an overall view of the adolescent's QoL. One of the major limitations of the study is the lack of validation of the developed tool. Further, stress levels and overall mental health of the parents and adolescents were not measured. Owing to the limited sample size, a detailed analysis could not be done to evaluate the domain-specific effects of the gross motor function classification system level and socioeconomic status. Future research focussing on the comparison between self-report (after assessing their intellectual capacity) and parent-report of QoL on larger sample size, including different types of CP, is warranted. In addition, studies can be conducted in the Indian context to identify the effects of parental stress and mental health on parent-reported QoL in adolescents with CP and to analyze the psychometric properties (reliability and validity) of the Kannada version of the questionnaire.

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## Conflicts of interest

There are no conflicts of interest.

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