



# ASSESSMENT OF HEALTH-RELATED QUALITY OF LIFE IN 13-18 YEAR OLDS WITH CEREBRAL PALSY USING CEREBRAL PALSY QUALITY OF LIFE TEENS PROXY REPORT BY CAREGIVER

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## Abstract

**AIM-** To assess the health-related quality of life of 13-18 years old with cerebral palsy in Mumbai and Navi Mumbai.

**OBJECTIVE-** To analyse various domains of quality of life of 13-18 year olds with cerebral palsy using cerebral palsy quality of life teens questionnaire proxy report.

**METHODOLOGY-** It is a cross sectional survey study using CPQOL teens questionnaire proxy report which will be filled by 60 caregivers of 13-18year old boys and girls with Cerebral Palsy who are able to walk with assistance upto GMFCS level 2 admitted to special schools and reside in Mumbai and Navi Mumbai. The caregivers will rate each question on a scale of 1-9 which will be recorded as per the questionnaire values for each number of likert scale and algebraic mean for each of the domains was calculated.

**RESULTS-** The CP-QOL Teens questionnaire proxy report revealed that on the basis of the scores of participants SOCIAL WELLBEING was the strongest domain while FEELINGS ABOUT FUNCTIONING was the weakest domain.

**CONCLUSION-** The study provides an brief discription of quality of life in 13-18year old with cerebral palsy in Mumbai and Navi Mumbai.

**KEYWORDS:** Cerebral Palsy, Quality of life.

## 1.INTRODUCTION

The term 'cerebral palsies' was first coined by William Osler. The most recent and widely used definition Cerebral Palsy is 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.<sup>[1]</sup> Sensation, perception, cognitive, communication, and behaviour abnormalities, epilepsy, and secondary musculoskeletal issues are frequently present in conjunction with the motor deficits of cerebral palsy. Usually, prenatal, perinatal, or postpartum circumstances that cause harm to a baby's growing brain are the cause of cerebral palsy. Cerebral palsy is a condition that affects many kids, but the exact reason is not always recognised. Preterm birth is the major risk factor (birth before 37 weeks of pregnancy). Other risk factors during the neonatal period (from birth to the first month of life) include prolonged hypoxia during birth, brain damage, strokes, or seizures, heart, blood vessel, airway, and lung disorders, prolonged mechanical ventilation, some infections, jaundice, and other neurological and genetical problems. Among the key indicators of functional outcome for children with CP, such as communication and gross motor ability, are the severity of the brain lesions, age of diagnosis, and the initial access to evidence-based intervention.

The Gold Standard for classifying motor function in kids with cerebral palsy is now the Gross Motor Function Classification System (GMFCS). The GMFCS is an ordinal classification that uses several descriptors depending on the age of the child.<sup>[9]</sup> The Gross Motor Function Classification System (GMFCS) is a multi-level categorization method that aids in describing different degrees of severity in cerebral palsy patients (CP). The GMFCS comprises five levels, with the lower levels denoting milder types of CP and the higher ones denoting growing severity. All varieties and degrees of cerebral palsy can be classified using the Gross Motor Function Classification System. It considers a person's age, functional capability, and voluntary movements in a range of situations.

**Gross motor function:** The GMFCS uses tests of gross motor abilities to measure the severity of a particular cerebral palsy case, as its name implies. Activities like standing, walking, sprinting, catching, and throwing fall under the category of gross motor abilities, which call for the utilisation of the body's major muscles. Gross motor abilities are frequently hampered by cerebral palsy as a result of impairment to brain regions required for balance, movement, and coordination. Leg control, mobility transition, dependency on assistive devices, and other relevant factors are all taken into account in this evaluation. **Performance:** The GMFCS assesses a person's ability to function independently in environments such as the home, school, and community in addition to their gross motor abilities. A more severe level of cerebral palsy is typically indicated if a kid requires significant assistance in any or all of these situations. It should be noted that this evaluation examines an individual's behaviour in real-world situations, not how they would act in an ideal situation. **Age:** The GMFCS also considers a person's age when determining their GMFCS level.<sup>[11]</sup>

Interventions are required to encourage and improve a child's and family's functioning and well-being in to prevent secondary musculoskeletal impairments and assist families in creating a successful life-course plan for their children (and themselves) in the midst of developmental differences.<sup>[12,13]</sup> Children with CP have a variety of demands that necessitate a thorough intervention programme due to the variability of CP in terms of aetiology, brain injury, severity of impairments, and co-occurring diseases. These initiatives also need to address a variety of medical, social, and cultural obstacles that are common in rural and isolated populations, especially in LMICs.<sup>[14]</sup>

Routine clinical evaluations might not take into account a person's treatment burden, functional limits, or requirement for disability adjustment, therefore health-related quality of life (HRQOL) is an important criterion to evaluate.<sup>[5]</sup> The evaluation of HRQOL is difficult since it requires for knowledge of a person's perspective, experiences with health-related problems, and sense of their level of coping and adjustment.

CPQoL-Teens assesses 9 domains 'general wellbeing and participation', 'communication and physical health', 'school wellbeing', 'social wellbeing', 'access to services', 'family health', 'feelings about functioning', 'pain and bother' and 'special equipment' a varied number of questions in each domain in 13 to 18-year-olds with CP. It has self-report and proxy-report versions and uses a nine-point Likert scale.<sup>[7]</sup>

The CPQoL-Teens has a reliability score of 0.89-0.96 which indicates a good reliability and has an adequate validity<sup>[8]</sup>

## METHODOLOGY

**Study Design-** Cross-sectional survey study

**Sampling Design-** Convenience sampling

**Sample Size-** 60

**Study Set-up-** Mumbai and Navi Mumbai

**Inclusion Criteria-**

- 1.Children under the age group of 13-18 years with cerebral palsy and their care-giver residing in Mumbai and Navi Mumbai.
2. Both Girls & Boys admitted to special school.
3. GMFCS LEVEL I & II

**Exclusion Criteria-**

1. Children not admitted to special schools.
2. Non consent participant.
3. GMFCS LEVEL III TO V

**Instrumentation-** CPQOL–Teens questionnaire proxy report version .

## PROCEDURE

An ethical approval was taken by the ethical committee of Lokmanya Tilak College of Physiotherapy.It was a cross-sectional survey study with convenience sampling.

Participants fulfilling inclusion criteria were chosen purpose of the study will be explained instructions regarding the questionnaire were given and their consent was taken.All participants were given questionnaire through social media.

Step 1 - Participant were asked to score each question from 1-9 (1-very unhappy and 9- very happy) which will then be recoded as

- If person scored 1, recode to 0
- If person scored 2, recode to 12.5
- If person scored 3, recode to 25
- If person scored 4, recode to 37.5
- If person scored 5, recode to 50
- If person scored 6, recode to 62.5
- If person scored 7, recode to 75
- If person scored 8, recode to 87.5
- If person scored 9, recode to 100

Step 2- Then algebraic mean of item values is computed in each domain.

The data thus collected was statistically analyzed.

There are a few exceptions for 9 items that need to be reverse coded.

These include:

- concerned about having cerebral palsy?
- pain you/they have?
- level of pain you/they experience?
- level of discomfort you/they feel?
- ability to cope with pain?
- ability to control your/the8ir pain?

way pain gets in the way of your/their life?

way pain stops you from being yourself/themselves?

how pain takes you away from your/their everyday fun?

For these items:

- If person scored 1, recode to 100
- If person scored 2, recode to 87.5
- If person scored 3, recode to 75
- If person scored 4, recode to 62.5
- If person scored 5, recode to 50
- If person scored 6, recode to 37.5
- If person scored 7, recode to 25
- If person scored 8, recode to 12.5
- If person scored 9, recode to 0

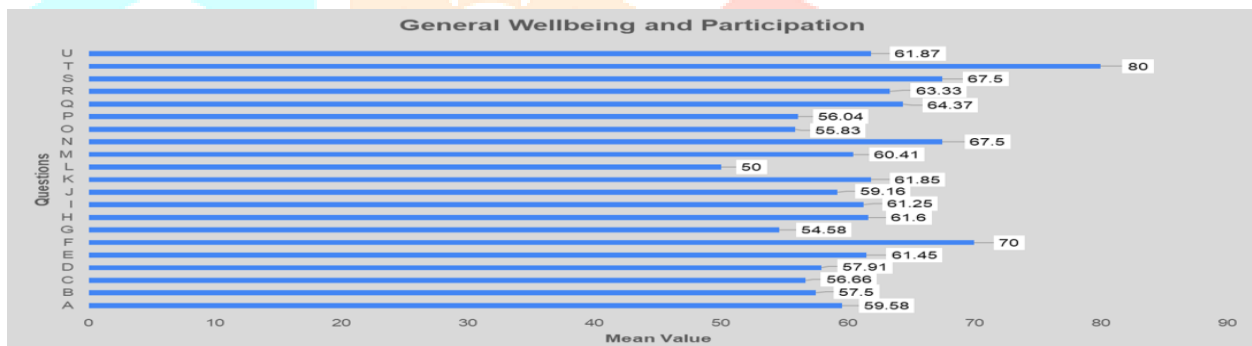
After recording the questions where segregated as per various domains, the mean value of each question and the mean value and standard deviation for each domain was calculated<sup>[7]</sup>

**DATA ANALYSIS AND RESULTS**

The data collected was statistically analyzed. Mean and SD were calculated using Microsoft Excel and interpretation was done.

**Table. No. 1 and Graph. No. 1- General Wellbeing and Participation. The table no. 1 represents questions in the domain with their alphabetical representation and mean value of each as well as the SD value of the domain.**

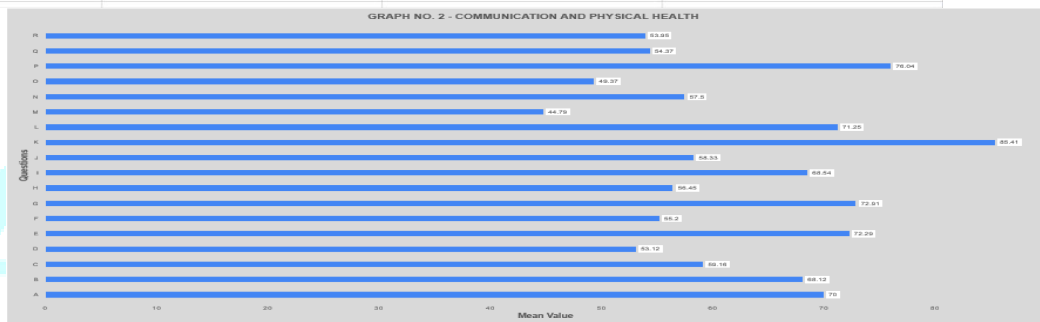
General Wellbeing and Participation			Standard deviation 16.51061095
Questions	Denoted as	Mean	
How do you think your teenager feels about their life in general?	A	59.58	
How do you think Your teenager FEELS about their life as a whole?	B	57.5	
How do you think your teenager FEELS about their quality of life?	C	56.66	
How do you think your teenager feels about the way they get along with other teenagers outside of school (not school friends)?	D	57.91	
How does your teenager FEELS about hanging out on their own?	E	61.45	
How does your teenager FEELS about hanging out with friends?	F	70	
How does your teenager FEELS about how they are accepted by other teenagers outside of school (not school friends)?	G	54.58	
How do you think your teenager feels about being able to do things they want to do (i.e their ability to do things, not whether they're allowed to)?	H	61.6	
How do you think your teenager feels about the way they 'have a go' and try new things?	I	61.25	
How do you think your teenager feels about themselves?	J	59.16	
How do you think your teenager feels about their positive attitude?	K	61.85	
How do you think your teenager feels about their future?	L	50	
How do you think your teenager feels about their opportunities in life?	M	60.41	
How do you think your teenager feels about their ability to participate in leisure and recreational activities?	N	67.5	
How do you think your teenager feels about their ability to participate in sporting	O	55.83	
How do you think your teenager feels about their ability to participate in social	P	56.04	
How do you think your teenager feels about their ability to participate in your community?	Q	64.37	
How do you think your teenager feels about the way they get around?	R	63.33	
How do you think your teenager feels about succeeding in things they want to be good at?	S	67.5	
How do you think your teenager feels about their ability to get around your neighborhood?	T	80	
How do you think your teenager feels about their ability to get from place to place?	U	61.87	



The Graph no. 1 represents data of the domain General Wellbeing and Participation . On Y axis we see alphabetical representation of all the questions in the domain and on X- axis we see the mean values for each question.

**Table. No. 2 and Graph no. 2 – Communication and Physical Health.** Table represents the all the questions in domain and the alphabetical representation with mean scores of each as well as the SD value of the domain.

Questions	Denoted as	Mean	Standard Deviation
How does your teenager FEELS about the way they get along with adults?	A	70	17.34241991
How does your teenager FEELS about how they are accepted by adults?	B	68.17	
How does your teenager FEELS about how they are accepted by people in general?	C	69.16	
How do you think your teenager feels about their ability to keep up academically with their peers (i.e. their school work)?	D	63.12	
How do you think your teenager feels about the way they communicate with people they know best (using any means of communication)?	E	72.29	
How do you think your teenager feels about the way they communicate with people they don't know well (using any means of communication)?	F	66.2	
How do you think your teenager feels about the way other people communicate with them?	G	72.81	
How do you think your teenager feels about the way they communicate with people using technology? (e.g. text messages, the internet)?	H	66.45	
How do you think your teenager feels about their overall health?	I	68.64	
How do you think your teenager feels about their physical health?	J	68.33	
How do you think your teenager feels about how they sleep?	K	66.41	
How do you think your teenager feels about the way they look?	L	71.25	
How do you think your teenager feels about the changes happening to their body to do with puberty?	M	44.79	
How do you think your teenager feels about being able to do things by themselves without relying on others?	N	67.6	
How do you think your teenager feels about what may happen to them later in life?	O	69.73	
How do you think your teenager feels about what they have achieved in life?	P	71.25	
How do you think your teenager feels about what plans for future?	Q	64.37	
Is your teenager concerned about having cerebral palsy?	R	63.95	



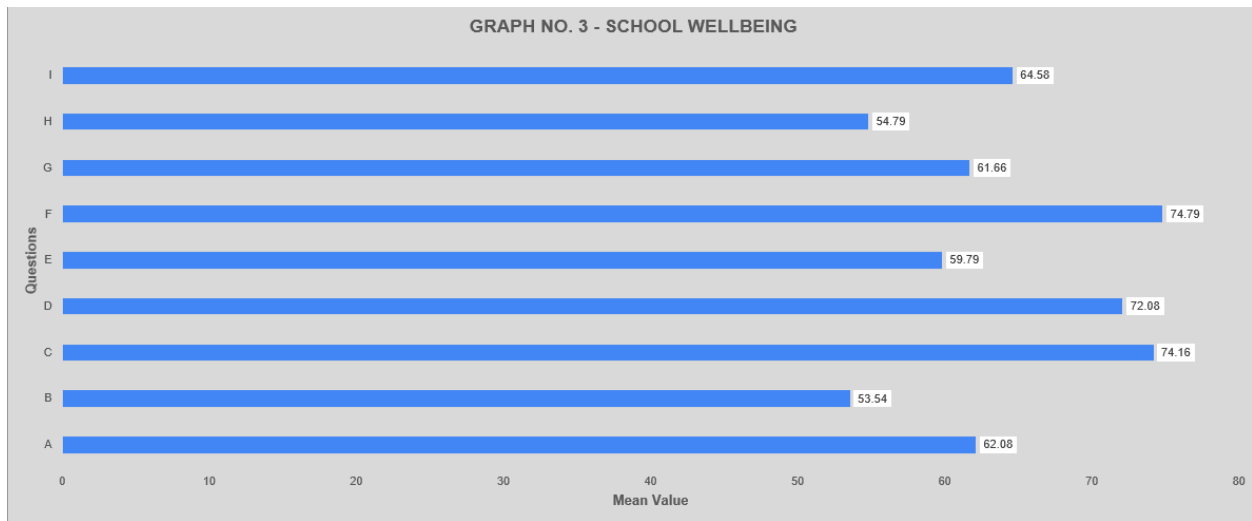
The Graph no. 2 represents data of the domain communication and Physical Health . On Y axis we see alphabetical representation of all the questions in the domain and on X- axis we see the mean values for each question

**Table No. 3 and Graph No. 3 – School Wellbeing.** The Table represents the questions in the domain and the alphabetical representation with mean scores of each as well as the SD value of the domain

Questions	Denoted as	Mean
How do you think your teenager feels about the way they get along with other teenagers at school? (If they attend more than one school, please think about the school where they spend the most time).	A	62.08
How do you think your teenager feels about the way they are included by other students at their school?	B	53.54
How do you think your teenager feels about the way they get along with their teachers?	C	74.16
How do you think your teenager feels about how they are accepted by other students at school? (If they attend more than one school, please think about the school where they spend the most time).	D	72.08
How do you think your teenager feels about how they are accepted by the staff and teachers at their school?	E	53.73
How do you think your teenager feels about being treated the same as everyone else at their school?	F	74.73
How do you think your teenager feels about their ability to keep up physically with their peers?	G	61.66
How do you think your teenager feels about their ability to participate at school? (If they attend more than one school, please think about the school where they spend the most time).	H	54.73
How do you think your teenager feels about their ability to participate at school? (If they attend more than one school, please think about the school where they spend the most time).	I	64.58

Standard Deviation

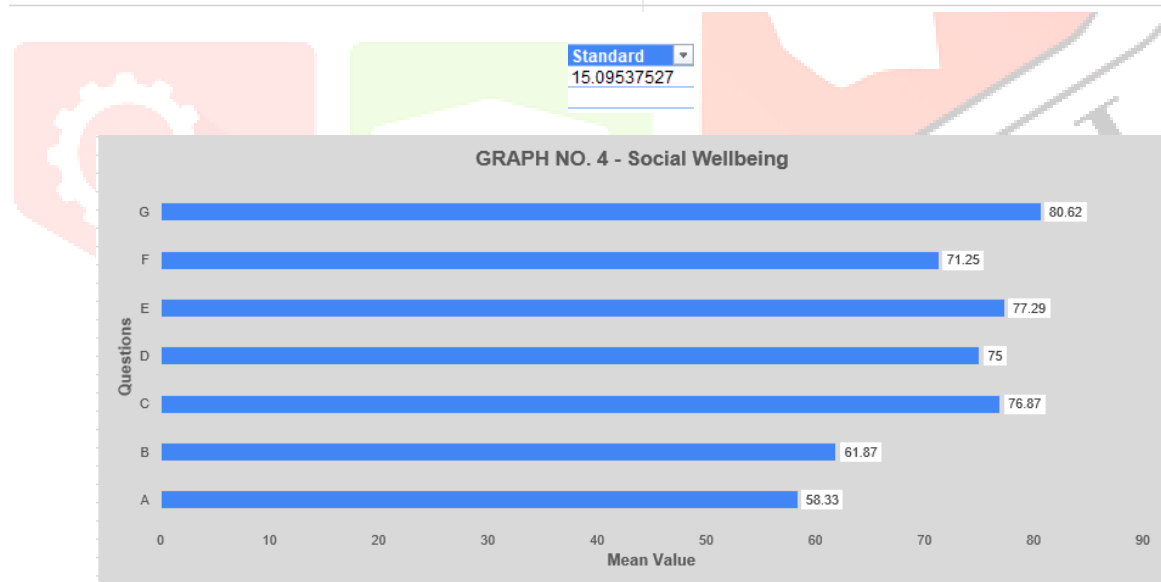
15.3839241



The Graph no. 3 represents data of the domain School Wellbeing. On Y axis we see alphabetical representation of all the questions in the domain and on X- axis we see the mean values for each question

Table No. 4 and Graph No. 4 – Social Well-being. The Table represents the questions in domain and the alphabetical representation with mean scores of each as well as the SD value of the domain.

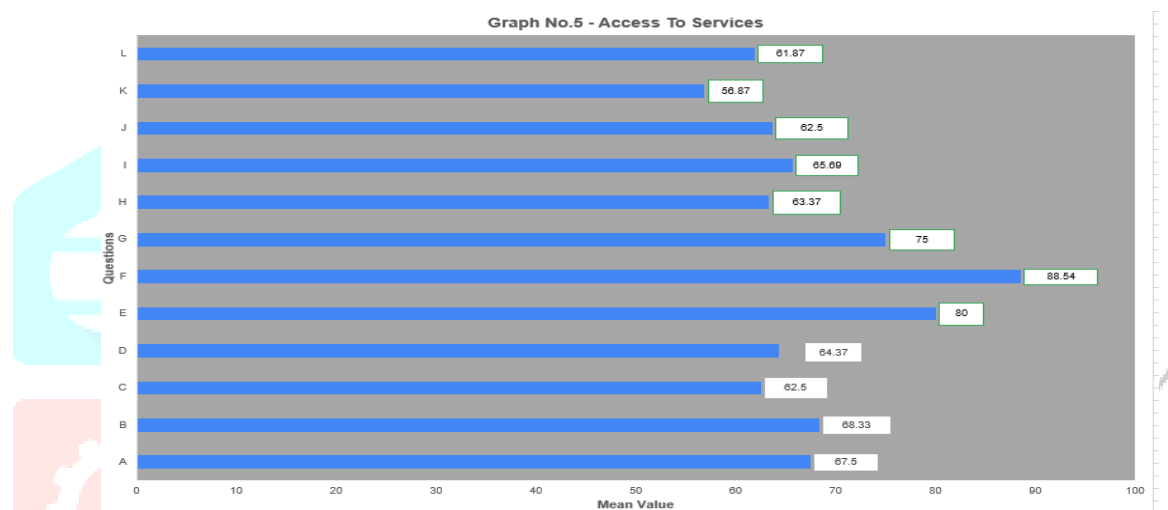
Questions	Denoted as	Mean
How do you think your teenager FEELS about how happy they are?	A	58.33
How does your teenager FEELS about the way they get along with people generally?	B	61.87
How do you think your teenager feels about the way they get along with you?	C	76.87
How do you think your teenager feels about the support they get from their family?	D	75
How do you think your teenager feels about the way they get along with their brothers and sisters?	E	77.29
How does your teenager FEELS about going on trips with family?	F	71.25
How does your teenager FEELS about how they are accepted by their family?	G	80.62



The Graph no. 4 represents data of the domain Social Wellbeing . On Y axis we see alphabetical representation of all the questions in the domain and on X- axis we see the mean values for each question.

**Table No. 5 and Graph No. 5 – Access to Services . The Table represents the questions in domain and the alphabetical representation with mean scores of each as well as the SD value of the domain.**

Questions	Denoted as	Mean
How do you feel about your teenager's access to treatment?	A	67.5
How do you feel about your teenager's access to physiotherapy?	B	68.33
How do you feel about your teenager's access to speech therapy?	C	62.5
How do you feel about your teenager's access to occupational therapy?	D	64.37
How do you feel about your teenager's access to specialised medical or surgical care?	E	80
How do you feel about your ability to get advice from a pediatrician?	F	88.54
How do you feel about your access to specialists services available in the community? (e.g. for employment, moving out of home)?	G	75
How do you feel about your access to respite care?	H	63.37
How do you feel about the amount of respite care yo	I	65.63
How do you feel about how easy it is to get respite care?	J	63.66
How do you feel about your teenager's access to community services and facilities (e.g after-school programs, holiday programs, community based groups such as Activities, Sports and Clubs)?	K	56.87
How do you feel about your teenager's access to extra help with learning at school?	L	61.87



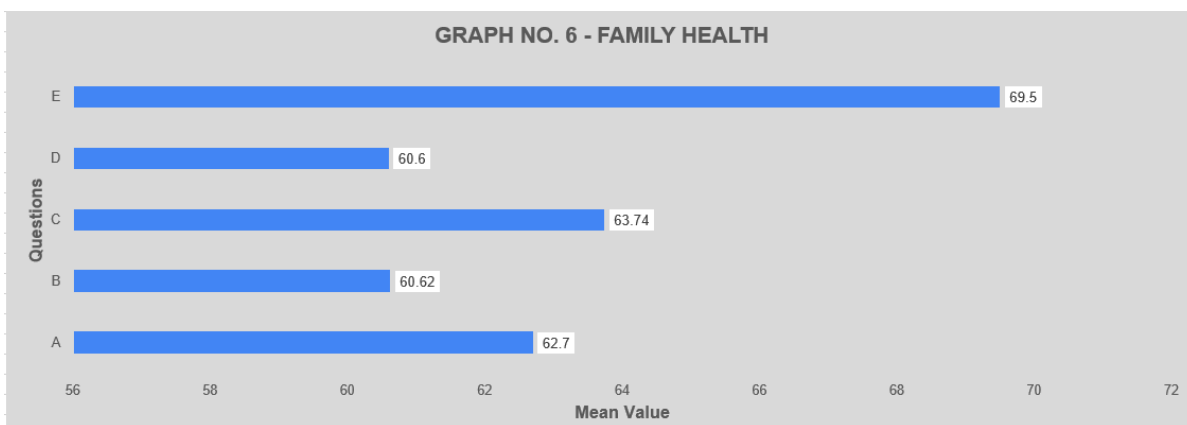
The Graph no. 5 represents data of the domain Access to Services. On Y axis we see alphabetical representation of all the questions in the domain and on X- axis we see the mean values for each question.

**Table No. 6 and Graph No. 6 – Family Health. The Table represents the questions in domain and the alphabetical representation with mean scores of each as well as the SD value of the domain.**

Questions	Denoted as	Mean
How happy are you?	A	62.7
How do you feel about your physical health?	B	60.62
How do you feel about your work situation ?	C	63.74
How do you feel about your family's financial situation?	D	60.6
How confident are you that you can report how your teenager feels?	E	69.5

Standard  
15.79388116



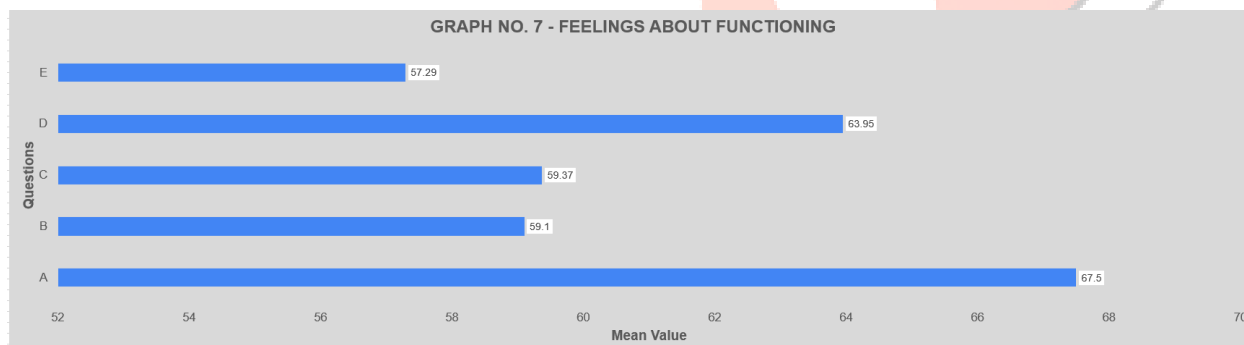


The Graph no. 6 represents data of the domain Family Health. On Y axis we see alphabetical representation of all the questions in the domain and on X- axis we see the mean values for each question.

Table No. 7 and Graph No. 7- Feelings about Functioning. The Table represents the questions in domain and the alphabetical representation with mean scores of each as well as the SD value of the domain.

Questions	Denoted as	Mean
How do you think your teenager feels about the way they use their arms and hands?	A	67.5
How do you think your teenager feels about the way they use their legs?	B	59.1
How do you think your teenager feels about their ability to dress himself/herself?	C	59.37
How do you think your teenager feels about their ability to eat and drink?	D	63.95
How do you think your teenager feels about their ability to use toilet by themselves ?	E	57.29

Standard  
18.41483097



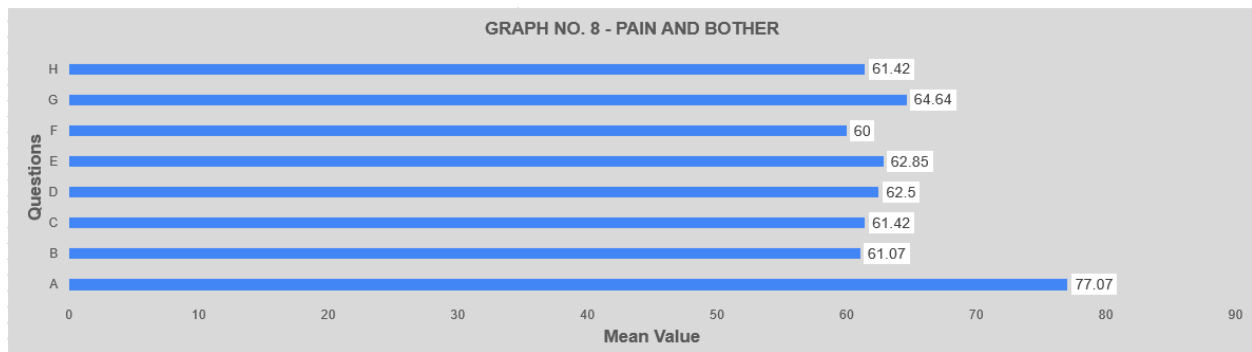
The Graph no. 7 represents data of the domain Feelings about Functioning. On Y axis we see alphabetical representation of all the questions in the domain and on X- axis we see the mean values for each question.

Table No. 8 and Graph No. 8 – Pain and Bother. The Table no. 8 represents the questions in Pain and Bother domain and the alphabetical representation with mean scores of each as well as the SD value of the domain.

Questions	Denoted as	Mean
How do you feel about how much pain does your teenager have?	A	77.07
How do you feel about the level of pain they experience?	B	61.07
How do you feel about the level of discomfort they feel ?	C	61.42
How do you feel about their ability to cope up with pain ?	D	62.5
How do you feel about their ability to control pain?	E	62.85
How do you feel about the way that pains gets in the way of their life?	F	60
How do you feel about the way pain stops them from being themselves?	G	64.64
How do you feel about how pain takes away from their everyday fun?	H	61.42

Standard Deviation  
16.62872938

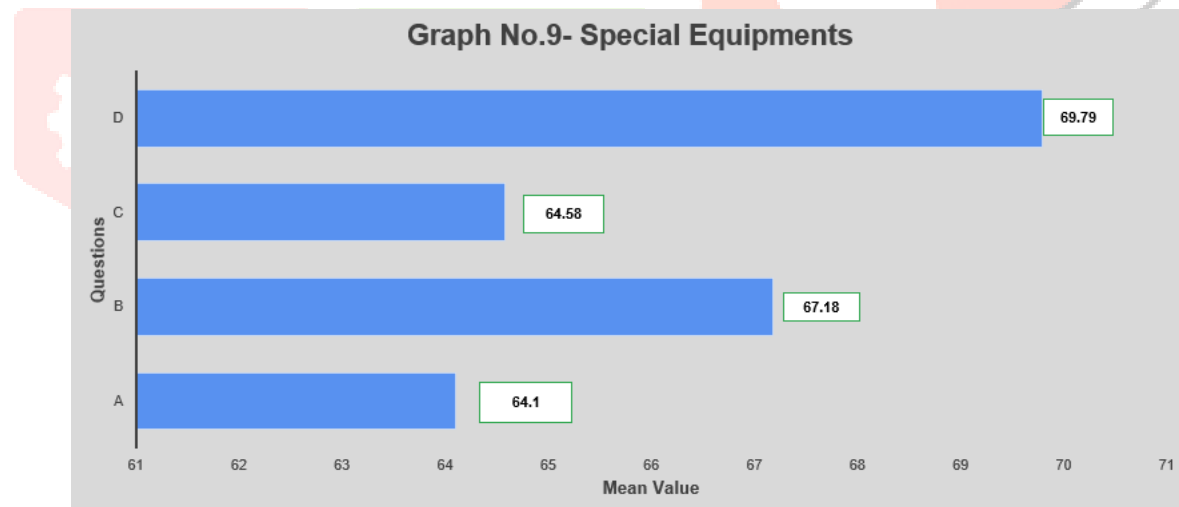




The Graph no. 8 represents data of the domain Pain and Bother. On Y axis we see alphabetical representation of all the questions in the domain and on X- axis we see the mean values for each question.

Table No. 9 and Graph no. 9 – Special Equipments. The Table no. 8 represents the questions in Pain and Bother domain and the alphabetical representation with mean scores of each as well as the SD value of the domain.

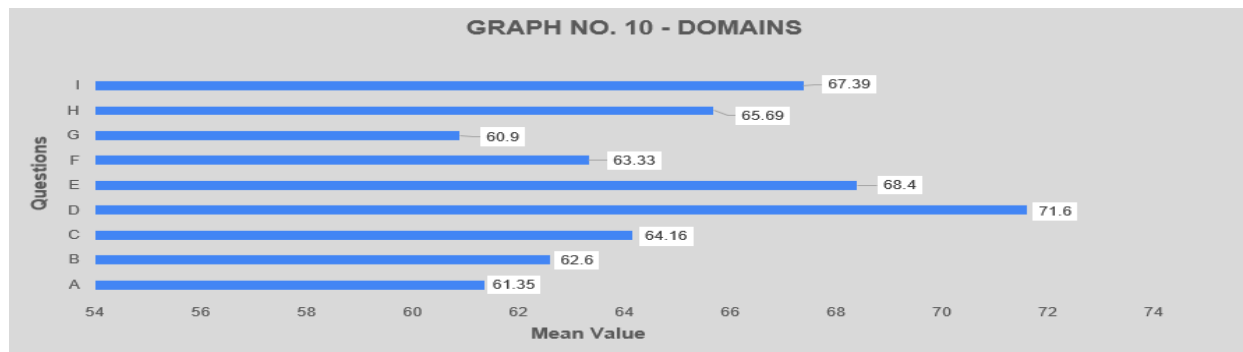
Questions	Denoted as	Mean
How do you think your teenager feels about the special equipment they have at home? (e.g special seating, standing frames, wheelchairs, walkers, AFOs, visual aids, hearing aids, communication aids)	A	64.1
How do you think your teenager feels about the special equipment they have at school? (e.g notelakers, special seating, standing frames, wheelchairs, walkers, laptops, visual aids, hearing aids, communication aids)	B	67.18
How do you think your teenager feels about the special equipment that is available in the community (ramps, escalators, wheelchair access)?	C	64.58
How do you think your teenager feels about their access to special services available in the community (e.g. for employment, moving out of home)?	D	69.79



The Graph no. 9 represents data of the domain Special Equipments . On Y axis we see alphabetical representation of all the questions in the domain and on X- axis we see the mean values for each question.

**Table No. 10 and Graph No. 10 – Domains.** Table represents names of all domains with their alphabetical representation and mean as well as standard deviation value for each domain.

Table No.10 - Domains			
Name of Domains	Denoted as	Mean Value	SD values
General Wellbeing and Participation	A	61.35	16.51061095
Communication and Physical Health	B	62.6	17.34241991
School Wellbeing	C	64.16	15.3839241
Social Wellbeing	D	71.6	15.09537527
Access to Services	E	68.4	16.71532674
Family Health	F	63.33	15.79388116
Feelings about Functioning	G	60.9	18.41483097
Pain and Bother	H	65.69	16.62872938
Special Equipments	I	67.39	12.46485383



The Graph no. 10 represents all the domains with their mean values. On y- axis are the alphabetical representation of the domains and on X-axis are the mean values of each.

A total of 97 people including special school and private therapy centres were approached. Out of which 7 schools did not have children in that age group and 4 did not give the consent for data collection. 11 private clinics did not have children with cerebral palsy in that age group and 6 denied to share the information details. 9 of the participants who had agreed did not submit the forms . Therefore all these were excluded. 60 participants whose children with cerebral palsy were completing all the points of the inclusion criteria were included in the study. The were explained the study purpose and what is expected from them and the questionnaire was sent to them via social media platform. On the basis of their scores we found Feelings about Functioning to be the weakest domain with lowest mean value and Social Well-being to be the strongest domain with highest mean value according to the CPQOL teens questionnaire proxy report.

## DISCUSSION

The study assessed health related quality of life of 60 children including both boys and girls with Cerebral Palsy between 13-18 years who come within GMFCS levels 1 and 2 and reside in Mumbai and Navi Mumbai according to various questions under 9 different domains of CPQOL – Teens questionnaire proxy report which was answered by their primary caregivers. The participants rated each question on a scale of 1 very unhappy to 9 very happy . These scores were then recorded as per the manual of the scale following which the question were segregated domain wise and the mean for each question as well as for each particular domain was calculated and SD for each domain was calculated. The maximum marked scores for each question is taken from the master chart as marked by participants.

**Domain 1- General Wellbeing and Participation is represented in table no. 1 and graph no. 1.**

In this domain “How does your teenager feel about their future? “Was seen to have a mean score of 50 maximum responses had scored it 5 that is neither happy not sad on a scale of 1 -9 followed by How does your teenager feel about how they are accepted by other teenagers? (not school friends) with a mean score of 54.58 on the other hand the highest mean score of 80 was for the question How does your teenager feel about their ability to get along with their neighbours which had maximum scores as 8 i. e happy on a scale of 1-9 . Remaining questions have a range of 56-70 on mean scores.

**Domain 2- Communication And Physical Health is represented in table no. 2 and graph no. 2**

How does your teenager feel about what may happen to them later in life? Was a question with lowest mean score of 44.7 where maximum people rated it as 4 that is unhappy in 1-9. The question is your child concerned about having cerebral palsy had maximum of 5 on a scale of 1 Not at all concerned to 9 very Concerned. The highest mean score was found to be for “How does your teenager feel about how they sleep?” 85.4 and followed by 76.04 for the question “How do you think your teenager FEELS about what they have achieved in their life? Maximum scoring it as 6 on 1-9 Other questions range with mean scores between 49.3to 72.9.

**Domain 3 – School Wellbeing is represented in table no.3 and graph no. 3.**

“How do you think your teenager FEELS about how they are accepted by other students at school was rated 5 by most of the parents and has a mean score of 53.3. The Question “How do you think your teenager FEELS about the way they are treated the same as everyone in school? and How do you think your teenager FEELS about the way they get along with their teachers? “Were seen to have mean score of 74 maximum participants reported these questions as 7 i.e. happy on 1-9.

**Domain 4 – Social well-being is represented in table no. 4 and graph no. 4**

Where the least mean score of was found to be for the question “How happy they are? “ Most of them scored the question 6 on 1-9. Following the question “How they get along with people in general? “With a mean score of 61.8 and max participants rating this scale as 6 on a scale of 1 to 9. The Question “How they get along with their family?” was having a mean score of 80.6 and a rating of 7 by most participants.

**Domain 5 – Access to Services the questions and their mean score are represented in table no. 5 and graph no. 5**

It was noticed that 45 out of 60 participants had access to respite care and 15 did not the highest mean score was count for the question “How do you feel about your teenager ability to get advice from their pediatrician? and access to specialised medical and surgical care? “With mean score of 88 and 80 respectively. Access to community services and facilities was the lowest with a mean score of 56 and maximum participants rated it as 6 on a scale of 1- Very Unhappy to 9 – Very Happy. Possibly due to less awareness of schemes and special facilities that are provided. Access to other treatment services range from means scores of 67, access to physiotherapy services is 68.3, occupational therapy 63.7, speech therapy 64.3 maximum rated as 7 i.e. Happy by most participants. The question How does your teenager FEELS about their access to speech therapy was not answered by 6 participants as those did not need speech therapy.

**Domain 6 – Family health has five questions enlisted in table no. 6 with their mean scores and represented on graph no. 6**

The question how do you feel about your physical health? and about your family’s financial situation? were rated as 6 and 5 on a scale of 1 – Very unhappy and 9 - very happy by most of the participants. Having a mean score of 60.6. The question with the highest mean score is 69.5 was “How competent are you that you can rate how you teenager feels?” Where maximum participants rated 6 on a scale of 1 to 9 where 1 – not at all confident and 9 – Very confident.

**Domain 7 – Feelings about Functioning is represented in table no. 7 and graph no. 7**

The lowest mean score was found to be 57.29 further question “Your teenagers ability to use the toilet by themselves?” Which was followed by the question “Your teenagers ability to use their legs?” With a mean score of 59.1 the highest was found to be having a mean score of 67.5 for the question “Their ability to use their hands?” Where most participants rated it as 7 i.e. Happy on the scale of 1 to 9 where 1 – Very unhappy and 9 – Very Happy. Other questions ranged between means scores of 57 to 63.9.

**Domain 8 – Pain and Bother is represented in table no. 8 and graph no. 8**

The question “How much pain does your teenager have?” was rated the highest i.e. 1 by 25 of the participants on a scale of 1 to 9 where 1 – no pain at all and 9 - too much of pain and remaining rated it as less than equal to 4. The question” How do you think your teenager feel about the way pain gets in the way of their everyday life?” 35 participants rated it as less than equal to 6 on a scale of 1-9 where 1 is not upset and 9 very Upset which shows the hinderance in the life of teenagers due to pain.

**Domain 9 – Special Equipment the question and the mean scores are represented in table no. 9 and graph no. 9.**

The least mean score was found for the question How does you teenager FEELS about the special equipment they have at home? Is found to have mean score 64.1 rated as less than equal to 7 by 52 participants and 7 did not have or used any special equipment at home. The question about having special equipment at school was rated as more than equal to 4 on a scale of 1 -9 where 1 is very unhappy and 9 is very happy by 56 participants and 4 did not have or used special equipment at school. For the question How do you think your teenager FEELS about the special equipment in their community? In which 6 did not have special equipment in their community and the remaining answered them as 4to 7 on a scale of 1 -9. The highest mean score of 67.9 was found for the question access to special service in community and most participants rated it as 6 on a scale of 1 very unhappy to 9 very Happy.

**Analysis of each domain of CPQOL -TEEN proxy questionnaire is shown in table No. 10 and graph no. 10 with their mean scores.**

It was noted that the domain with highest mean score was Social Wellbeing which shows that they get along well with their parents, siblings and people in general. They are happy and feel accepted by by the people around them whom they know which will help them to have a positive outlook towards life despite the difficulty they face due to impairments as social acceptance plays a big role in the life of people. Followed by this were domains Access to Services with 68.4, Special Equipment with 67.3 and Pain and Bother with 65.5 mean scores respectively This shows positive effects of all the services like physiotherapy, occupational therapy, speech therapy, access to respite care and availability and access to special equipment and services available in school and in community with the help of private and government hospital, clinic, schools in health care and education sectors.

The mean scores of domains are further seen to be decreasing in the order School Wellbeing with a mean score of 64.1, Family Health 63.3 Communication and Physical Health 62.2 and General Wellbeing and Participation 61.35 which is seen inspite of so many special school the children still feel that they are not included by other children and cannot perform as good as them physically and academically.

These children also find it difficult to communicate with the people they don't know. All of this seems to affect their confidence at large, the ones who understand and are concerned about having cerebral palsy are worried and upset about their future and what may happen to them later in life. Which is probably why we find "Feelings about Functioning domain with lowest mean score of 60.9 compared to the other domains. As according to most participants their teenagers are unhappy with their ability to dress themselves and to use the toilet for which they are dependent. Also unhappy for their ability to use their legs which is why they are dependent on assistive devices. On the other hand better scores are seen for their ability to use their arms and hands and their ability to eat and drink independently.

## CONCLUSION

This study provides an important overview of the quality of life of 13-18 year olds with cerebral Palsy in cities like Mumbai and Navi Mumbai as it shows the weakest and the strongest domain according to the CPQOL teens questionnaire proxy report.

Therefore we can conclude that there is still a lot of awareness about the meaning and importance of health related quality of life and improvement in intervention planning and accessibility to these resources is needed to make the children with cerebral palsy independent and to help them live a better life.

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