

Evaluation of Participation Level of Adolescents with Cerebral Palsy

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ABSTRACT

Background: Adolescence is a time of rapid development in many facets of an individual's physiological, cognitive, and interpersonal traits, but it also comes with some complexities.

Aim: To evaluate the level of participation in different domains of life situations in adolescents with Cerebral Palsy.

Study design: Cross-sectional study.

Methodology: Study conducted in adolescents with Cerebral Palsy between age 10 – 19, with motor impairment level I, II and level III on GMFCS. Sample size was 84 participants. Questionnaire of Young People's Participation (QYPP) was used to evaluate participation in different activities and domains of life. **Statistical analysis:** Analysis of data was done by SPSS v.26.

Results: The highest percentage score was observed for Autonomy followed by Getting on with other people, Home life, Reception and Leisure and School or College life. The least percentage score was seen for two domains i.e., Work life and Preparing for the future. It was observed that participants in higher age category had higher score except school or college life domain but no significant difference was evident as per p-value.

Conclusion: It was concluded that overall frequency of participation levels proved inadequate in adolescents with CP in all the domains tested.

Keywords: Adolescents, Cerebral Palsy, Personal Autonomy and Social Participation.

INTRODUCTION

Cerebral palsy (CP) is a progressive functional and posture impairment. It causes non-progressive cognitive problems that impair movement and affect cognition, eyesight, recollection, behavior, and neural connections. It can cause pain disorders, hypotonia, hypertonia and impairment of movement, grasping, and many other physical disorders. Apart from children born with a severe case, Cerebral Palsy is regarded as non-malady¹.

Often these children with intellectual and physical disabilities are expected to live until adolescent's age. Their brain damage and disability are permanent. The cortex does not "heal" in almost the same manner that other systems of the body do. As a consequence, Cerebral Palsy will have mild to severe effect and will have a negative impact on a human's body. And in practical settings, things may either improve or deteriorate with aging in such cases.² Cerebral palsy is a prevalent neurological problem in infants, occurring around 2-2.5 out of every 1000 live births globally³.

Adolescence is a distinct phase of life that lies beyond adolescent years. It is a time of rapid progress in many facets of an individual's, psychological, and interpersonal traits, but it also has its own set of complexities. Children with disabilities, such as cerebral palsy, have challenges in their development and participation in adolescent lifestyle and situations. Some of these issues will continue to persist in the coming years. Subsequently, participating and interacting in society with others on an identical basis can be extremely problematic for teens with CP⁴.

Adolescence is a critical period of adjustment that lays the groundwork for later socialization. At this stage of development, social roles are very highly likely to transform, from being reliant on one's parents to, living on their own, getting a stable and respectable job, and maintaining some kind of long-term friendship or relationships. These deviations with growing age are often accompanied by growing societal and psychological demands. Adolescents with impairments may find integration and incorporation more difficult, leading to decreased adult participation. They are also severely hampered in aspects of job and marital partnerships⁵.

When it produced the International Code of Functioning, Impairment, and Health (ICF) in 2001, the World Health

Organization introduced the concept of "participation." It was defined as "involvement in real-life circumstances." Participation is perceived as a dynamic collaboration amid an individual and his/her environment. For participation and activity levels, the ICF defines the challenging dimension as "what one can do in a standardized environment", and the actual challenge in performance as "what one actually does in their current environment".⁷ Participation, may it be social or physical, and deciding the way of spending life is essential for every human being, which includes children and adolescents with or without disabilities. The ICF model defines participation as "involvement in life situations" but it is still being refined down to represent conceptualization and outcome measures.⁸ Participation, in general comprises of components like school life, family and friend circle activities, and commitment to job and leisure. Participation is very responsive to intervention and is a significant health outcome in researches related to interventional studies. Over the duration of last ten years, a significant increase has been noted in various rehabilitation interventions that address motor learning and re-learning capacities of children with CP. Some of these researches have named this intervention as functional therapy, but a detailed depiction of this is often lacking⁹.

In this part of life, the exact life circumstances that are most important to children and teens are virtually certainly going to suddenly change. The most essential life conditions for kids and teens will vary dramatically throughout regions and geographies. Additionally, agreeing on an uniform list of important performance qualities would indeed be a significant step forward in changing the lifestyles and interaction level of persons with disabilities¹⁰.

Individuals who suffer from various disabilities are becoming increasingly aware that they must be worried about something other than their symptoms and diagnosis, but also about the wider elements of what they're doing in terms of interaction as well as how they feel about overall life situations pertaining to quality of life. It is also critical that we already have ways for examining these concepts when selecting performance measures in medical and preclinical settings, none of which was intended expressly for teenagers¹¹. It was to evaluate the level of participation of adolescents aged between 10 to 19 years with Cerebral Palsy in their daily life situations within different domains, so that we can determine which area is lacking participation and where intervention is needed to improve the participation.

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The objective of the study was to evaluate the level of participation in different domains of life situations in adolescents with Cerebral Palsy.

METHODOLOGY

Study conducted at Rising Sun Institute for Special Children and Dimensions Institute, Lahore in adolescents with Cerebral Palsy between age 10 – 19, with motor impairment level I, II and level III on GMFCS. Sample size was 84 participants. Questionnaire of Young People’s Participation (QYPP) was used to evaluate participation in different activities and domains of life. Individuals with congenital diseases, muscular dystrophies and co-morbidities such as epilepsy, severe hearing and vision impairments, severe intellectual impairment & cognitive disorders such as autism, mental retardation were excluded.

The written consent was taken from each individual or their parents. A cross-sectional survey of the adolescents was done which was taken approximately 20 minutes to attempt, in order to evaluate the level of participation involving daily life domains such as home life, getting on with other people, school or college life, work life, recreation and leisure, autonomy, preparing for the future and extra information. The adolescents with Cerebral Palsy were assessed to check for their level of participation through seven domains with total division of forty - five multiple choice questions. If the individual cannot attempt due to any physical restriction, a parent or guardian was asked to perform the survey on his behalf. The content review resulted in content validity index of 93%. Known-groups validity was demonstrated by correlation with impairment severity. Test-retest reliability was satisfactory for all domains. Internal consistency varied between domains¹².

Statistical analysis: Analysis of data was done by SPSS v.26. The qualitative variables were evaluated as proportions (%). The evaluation of participation level was done by non-parametric testing, Likert type Questionnaire by measuring the frequency of participation in each domain and representing it graphically to see which domain is most neglected & which is most performed.

RESULTS

Mean age of study participants in this study was 15.79±2.14 years. The minimum age of a participant was 12 years and maximum age of participants was 19 years. In this study 47 (55.95%) participants were male and 37(44.05%) were female as shown in table-1. In this study, the mean score of the participants for home life domain was 5.96±5.25. Minimum and maximum score was 0 and 19. The Getting on with other people domain of Questionnaire of Young People’s Participation had eight questions. This domain score ranges between 0-48. In this study, the mean score of the participants for getting on with other people was 13.40±9.23.

Table-2 showed normality assessment of different domains score for study participants. As all domains p-value was <0.05 that

showed none of the domains scores were normally distributed or follow normal distribution. The highest percentage score was observed for Autonomy followed by getting on with other people, home life, reception and leisure and school or college life. The least percentage score was seen for two domains i.e., work life and preparing for the future as shown in figure-1.

Comparison of QYPP questionnaire each domain was carried out for male and female participants. Above table describes mean score in each domain for male and female participants separately. No statistically significant difference was seen between male and female for each domain as shown in table-3.

Comparison of QYPP questionnaire each domain was carried out for age of study participants. Age was divided into two groups i.e., participants aged 2-15 years and the other category was 16-19 years age participants. Above table describes mean score in each domain for both age categories separately. No statistically significant difference was seen in both age categories for each domain. However, it was observed that participants in higher age category had higher score except school or college life domain but no significant difference was evident as per p-value (Table 4).

Table-1: Demographic distribution of characteristics among participants

Gender	Frequency	Percent
Male	47	55.95%
Female	37	44.05%
Parameters	Mean ± SD	
Age	15.79 ± 2.14 years	
Home Life Domain	5.96 ± 5.25	
Getting on with other people	13.40±9.23.	
School or college life Domain	5.68±4.88	
Work Life Domain	2.28±3.04.	
Recreation and leisure	19.21±13.13	
Autonomy Domain	5.13±4.59	
Preparing for future Domain	3.84±5.70	

Table-2: Normality assessment of questionnaire of young people participation

Domain	Shapiro-Wilk	p-value	Normality
Home Life	0.914	0.000	Not normally distributed
Getting on with other people	0.951	0.003	Not normally distributed
School or college life	0.921	0.000	Not normally distributed
Work life	0.773	0.000	Not normally distributed
Recreation and Leisure	0.947	0.002	Not normally distributed
Autonomy	0.896	0.000	Not normally distributed
Preparing for the future	0.717	0.000	Not normally distributed

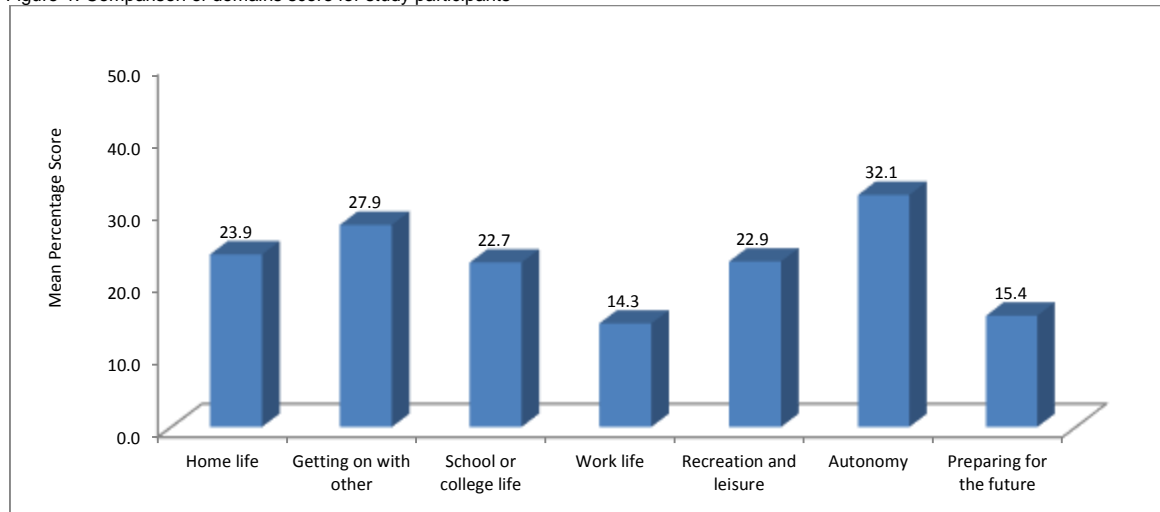
Table-3: Comparison of Questionnaire of Young People’s Participation Domains score in relation to Gender

Domains	Male		Female		p-value ^(a)
	Mean±SD	Median (IQR)	Mean±SD	Median (IQR)	
Home Life	6.14±4.88	6.00(7.0)	5.72±5.75	4.00(9.00)	0.499
Getting on with others	13.31±8.71	12.40(14.20)	13.52±9.97	11.80(16.70)	0.864
School or college life	5.59±4.87	5.75(6.41)	5.78±4.95	4.58(7.59)	0.831
Work life	2.32±3.42	0.00(4.00)	2.24±2.52	1.00(4.40)	0.550
Recreation and Leisure	19.50±13.81	20.00(18.00)	18.85±12.38	18.00(16.50)	0.889
Autonomy	5.07±4.41	4.00(6.33)	5.20±4.87	3.33(8.50)	0.903
Preparing for the future	3.90±5.98	0.00(3.67)	3.77±5.41	0.00(9.00)	0.739

Table 4: Comparison of Questionnaire of Young People’s Participation Domains score in relation to Age

Domains	12-15 Years			16-19 Years			p-value ^(a)
	Mean±SD	Median (IQR)	Mean (IQR)	Mean±SD	Median (IQR)	Mean (IQR)	
Home Life	5.71±5.27	5.00	9.00	6.17±5.29	6.50	9.00	0.597
Getting on with others	13.36±9.76	12.70	17.30	13.44±8.88	12.10	14.05	0.946
School or college life	6.25±5.17	5.25	6.98	5.20±4.62	5.71	7.33	0.419
Work life	2.18±3.12	0.00	4.80	2.36±3.00	1.00	4.00	0.551
Recreation and Leisure	17.57±11.76	17.00	15.25	20.56±14.15	19.50	18.50	0.352
Autonomy	4.44±4.75	2.16	7.08	5.69±4.43	4.33	6.33	0.075
Preparing for the future	2.47±4.73	0.00	2.00	4.97±6.22	2.33	9.63	0.075

Figure-1: Comparison of domains score for study participants



DISCUSSION

Previous research has found that children and young adults with Cerebral palsy had lower desirability and level of involvement, but they are quite satisfied. Youngsters with disability and other constraints placed engage in fewer vocational activities than normal children, which may have implications for career advancement, athletics, and acceptance across friendship groups, connection bonding, understanding, and freedom.¹³ This study supports current study result that shows very low participation for preparing for the future among participants.

According to earlier study, teens with CP indulge in a diverse variety of recreational activities, notable amusement and outreach programs. Excluding proficiency sessions, programme participation was associated with enhanced physical function as well as improved socialization, communication, and simple everyday competencies. Current study result showed the highest percentage score for Autonomy followed by getting on with other people, home life, reception and leisure and school or college life. The least percentage score was seen for two domains i.e., work life and preparing for the future.¹⁴

Teenagers with learning disabilities have less influence over their daily house and enjoy less time with family than typical adolescents. During the period, teenagers with learning disabilities played video games just as much as adolescents in the general population. Teenagers with modest disabilities participated in a variety of activities at the very same rate as teenagers in basic categories. There was some geographical variation¹⁵.

Other factors that can contribute to lack of participation in our participants is pain in infancy which predicted lower adolescent participation in all categories. Adolescent depression symptoms suggested a lack of teenage involvement in all aspects of the social responsibilities. Parental participation in infancy affects teen involvement in medical cleanliness, communication, and collaborations¹⁶.

Youngsters with impairments rarely participated in a variety of functional tasks in their employment settings if they can find jobs¹⁷. Our current study also proves that there is a relatively low level of engagement in future planning among study participants.

Previous research reveals that adolescents with cognitive disability engage in lesser recreational activities than their peers; these interests are more sedentary, limited, and without variation. Demographics, ethnicity, physical constraints, family values and performance, aspiration, and economic and environmental support for families are all factors that influence the type of leisure participation.⁴ Current study show no statistically significant difference was seen between male and female for each domain. No statistically significant difference was seen in both age categories for each domain. However, it was observed that participants in higher age category had higher score except school

or college life domain but no significant difference was evident as per p-value.

Previous research indicated that knowledge of difficulties, as well as unavailability of public resources for the development of people with disabilities, had an influence on the participation of children and young people with cerebral palsy¹⁸.

Limitations: Single centre study with small sample size and financial constrains.

CONCLUSION

It was concluded that children and adolescents with CP engaged in a limited number of recreational activities in general, with the greatest percentage mark for autonomy, followed by getting along with others, home life, leisure and recreation, and school or college life. The two areas with the lowest percentage score were work life and planning for the future. But the overall frequency of participation levels proved inadequate in adolescents with CP in all the domains tested.

Authors' Contribution: **UJ&MF:** Conceptualized the study, analyzed the data, and formulated the initial draft, **SM &BR:** Proofread the draft

WL: Contributed to the analysis of data

Conflict of interest: None

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