Original Article:
Social Participation in Children with Cerebral Palsy

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Abstract: Social participation is known to play a significant role in the maintenance of health and well-being. For a child, social participation is an important prerequisite for typical development, since children gather knowledge and develop social skills while interacting with other people. Children with cerebral palsy (CP) however experience limitations in their ability to participate in social activities due to the impairments associated with the damage to the brain. The impairments these children experience include motor, cognitive or a combination of both. We hypothesised that impairments in the motor abilities of a child lead to specific types of limitations in social participation of children with CP and hence the aim of the current study is to learn about the relationship between level of motor impairments and social participation in children with CP. A total of 80 participants in the age range of 6-12 years were recruited for this study. The Gross Motor Function Classification Scale (GMFCS) and Child Adolescent Scale of Participation (CASP) were administered to gain information about children’s levels of impairment and levels of social participation respectively. Results of the data analysis showed that children with CP had limited social participation in different contexts and activities in accordance with their level of severity of motor impairment.

Key Words: Cerebral palsy, Social participation, GMFCS, CASP, Motor impairment

Introduction:
Cerebral palsy (CP) is a developmental disorder of movement and posture, causing activity limitations, which are attributed to non-progressive disturbances that occur in the developing foetal or infant brain. (1) Over 25 lakh people in India including children are estimated to have CP, with the incidence rate being approximately 2-2.5 per live birth. (2) Children with CP have varying degrees of difficulties with movement, posture and mobility depending on the type and severity of their condition, as well as the area of the body affected. This mobility restriction is a major problem faced by children with CP that hinders movement from one place to another and exploration of the immediate environment. This restriction is due to impairments in motor control, muscle performance and musculoskeletal alignment. Children with CP exhibit different patterns of mobility based on their motor impairment and level of severity. (3) Such mobility restrictions further result in functional limitations. (4) Gross motor functions are found to be strongly associated with mobility and are also a predictor of self-care, mobility and social function. (5-6) Another Dutch population-based study (7) on children with spastic CP revealed that motor impairments (elevated muscle tone, spontaneous pathological postures, impaired trunk or head stability, ROM deficits of the extremities and spine deformities) are closely associated with gross motor function. Therefore, children with CP present with major limitations in mobility that has many functional implications. Social participation is one of the major components of the broader term, ‘participation’. (8) Though a clear demarcation between the terms participation and social participation has not been made, different professionals have been using the two terms interchangeably. (8-9) Social participation is a topic of on-going concern for occupational therapists. Social participation prepares individuals for a smooth transition from home environment to that of school and community. It also enables children’s participation in everyday occupations. (10) Social participation is defined as “the interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends.”

In addition, social participation includes involvement in a subset of activities that involve social situations with others. (12) Social participation occurs either in-person or through use of communication technology like phones, internet-mediation etc. The contexts in which social participation occurs include community, family, peers/friends. (13) Social participation is important in promoting child health, development and well-being. (14) Social participation depends on many factors including physical ability to move, to communicate, to understand, emotional stability and context of a social purpose. As the existing literature has demonstrated, mobility impairments in children with CP limit their opportunities to participate in social situations. In this regard, it remains unclear as to how mobility issues impact social participation.
in the Indian children with CP. This is also relevant as an affectation of social participation will result in problems in age appropriate occupational performance. Existing studies, however, have not analysed the relationship of the intensity of motor impairment to the various components of social participation. Therefore, this study aimed to understand the relation between severity of motor impairment in children with CP and their social participation.

Methods
Study design
A cross-sectional study design was used to understand the relationship between social participation and severity of motor impairment in children with CP.

Measures
Two tools, Child and Adolescent Scale of Participation (CASP) and Gross Motor Functional Classification Scale (GMFCS), were used in this study.

CASP is an ordinal scale developed by Gary Bedell, which measures social participation in different contexts and activities such as: home participation, community participation, school participation, and home and community living activities. This scale can be self-administered or interviewer-administered. In the current study, the interviewer-administered method was used to ensure uniformity in data collection. Scores were calculated in the following manner: sum of the scores of all items divided by the maximum possible score. This score is then multiplied by 100 to conform to a 100-point scale. CASP is a well-accepted scale which measures all components of social participation in different context like home participation, school participation, community participation and activities. (15-16)

GMFCS is a functional classification scale which helps to categorise children with CP based on their self-initiated movement, with particular emphasis on sitting and walking (mobility). (1) Based on the severity of motor impairment, this scale comprises of five levels, i.e., GMFCS I, II, III, IV & V. GMFCS I implies least severity while GMFCS V implies high severity in motor impairment. GMFCS was chosen for this study because it categorizes CP according to severity motor impairment in relation to the mobility. (17)

Participants
A convenience sampling approach was used to recruit participants. The participants were divided into two groups based on their GMFCS scores. Group 1 included children in GMFCS Levels I and II while Group 2 included children in GMFCS Levels III, IV and V. Sample size was 86, as calculated using the comparison of two mean formula. Inclusion criteria for participants were (1) children in the age group of 6-12 years diagnosed with cerebral palsy (2) children with IQ 70 and above. Exclusion criteria were children diagnosed with any other co-morbid conditions such as autism spectrum disorder, progressive degenerative disorder and intellectual disabilities (except mild intellectual disabilities).

Procedures
Institutional Ethics Committee approval was obtained to conduct the study. Thereafter, parents of children who met the selection criteria were approached with requests for participating in the study. Informed written consent was obtained from parents and children. The investigator then administered the GMFCS and CASP scales to all participants. Based on their GMFCS scores, the participants were classified into the groups; Group 1: Levels I and II and Group 2: Levels III, IV and V.

Data analysis
Numeric values of the questionnaire responses were tabulated individually and a total score for each participant was then calculated. Data were compiled and entered into Statistical Package for the Social Sciences (SPSS) version 17.0 for analysis. The independent variable was the level of motor impairment (GMFCS) while the dependent variable was social participation components (CASP).

First, descriptive statistics of mean, standard deviation and frequencies were calculated for all the variables. To ensure that the two groups were similar in terms of age and gender, analysis was conducted. An independent samples t test was conducted to compare the mean age of the two groups. Also, Chi square tests were done to analyse for any association between demographic variable (sex) and independent groups (GMFCS) with level of significance set at p<.05.

In order to determine differences between the two groups in their social participation a Multivariate Analysis (MANOVA) was conducted. To examine whether there are any differences in different sub component of social participation between the groups, a series of ANOVA was performed on different components of social participation scores across the two groups.

Results
Demographic Characteristics
Demographic characteristics of the participants are displayed in Table 1. A total of 86 participants were recruited in the age range of 6-12 years. There were 40 participants in group I (low severity) and 46 in group II (high severity). 46 males and 40 females were included in the study. Of the 86 participants, 67 were school-going.

To ensure comparability between the two groups in terms of age and gender, statistical tests were carried out. An independent t test indicated no significant difference in the age (in years) of group I (Mean=9.31, S.D=1.98) and group II (Mean=8.72, S.D=2.39); t (84) = 1.24, p = 0.218. The chi-square test revealed no association between GMFCS groups and gender (22 = 0.029, p =0.864).

A simple linear regression was calculated to predict Social Participation based on age. A significant regression was found (F (1, 84) =6.161, p=.015) with a R² of .068. For gender, a non-significant regression was found (F(1, 84)=.353, p=.554) with a R² of .004. This result revealed that age was found to be a predictor of social participation while gender was not found to play a significant role in predicting social participation.

Table 1: Demographic characteristics of the participants

<table>
<thead>
<tr>
<th>Demographic variables</th>
<th>Frequency (N)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>46</td>
<td>53.5</td>
</tr>
<tr>
<td>Female</td>
<td>40</td>
<td>46.5</td>
</tr>
<tr>
<td>CP Characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spastic quadriplegia</td>
<td>11</td>
<td>12.8</td>
</tr>
<tr>
<td>Spastic diplegia</td>
<td>63</td>
<td>73.3</td>
</tr>
<tr>
<td>Spastic hemiplegia</td>
<td>8</td>
<td>9.3</td>
</tr>
<tr>
<td>Dysskinetic</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td>Hypotonic</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td>Age in years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>15</td>
<td>17.4</td>
</tr>
<tr>
<td>7</td>
<td>13</td>
<td>15.1</td>
</tr>
<tr>
<td>8</td>
<td>13</td>
<td>15.1</td>
</tr>
<tr>
<td>9</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

Social participation of children with CP according to their motor impairment level
MANOVA was conducted to test mean differences between motor impairment (low level of severity and high level of severity) and total social participation scores. A statistically significant MANOVA effect was obtained, Pillai’s Trace = .606, F (4, 81) = 31.115, p < .005 with multivariate effect size of .564.

A series of follow up univariate tests were conducted with a Bonferroni adjustment of 0.0125 (0.05/4). The subsequent univariate tests on each of the four dependent variables, as
The present study was undertaken to study social participation components to determine the differences in Indian children with CP according to their motor impairment severity. This study revealed that there was a definite difference in social participation across different levels of severity of motor impairment. Not only was there an overall difference but also there was a difference in each component of social participation in accordance to different contexts. Various other factors may affect social participation but the study’s aim was to see the involvement of the motor component. This study gives a clear picture about social participation in different contexts and for different activities that children are expected to participate in at that age.

References

depicted in Table 2, showed a statistically significant difference (p < 0.0125) between the group means of all the social participation subcomponent scores. The effect size (partial ?2) – home and community activities, neighbourhood and community participation, school participation are .553, .504, .424 and .411 respectively.

Table 2: Differences in the sub components of social participation scores of low level of severity and high level of severity group as obtained on a series of Follow up Univariate Tests

<table>
<thead>
<tr>
<th>Social Participation</th>
<th>Low severity group (n=40)</th>
<th>High severity group (n=46)</th>
<th>F</th>
<th>P</th>
<th>Partial eta squares</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home participation</td>
<td>Mean(S.D)</td>
<td>Mean(S.D)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>95.51 (5.4)</td>
<td>73.45 (17.5)</td>
<td>58.61</td>
<td>.00*</td>
<td>.411</td>
</tr>
<tr>
<td>Neighbourhood &amp; community participation</td>
<td>91.82 (7.5)</td>
<td>61.82 (19.2)</td>
<td>85.22</td>
<td>.00*</td>
<td>.504</td>
</tr>
<tr>
<td>School Participation</td>
<td>91.37 (5.1)</td>
<td>42.60 (38.92)</td>
<td>61.73</td>
<td>.00*</td>
<td>.424</td>
</tr>
<tr>
<td>Home and Community activity</td>
<td>80.25 (14.71)</td>
<td>42.93 (18.63)</td>
<td>103.94</td>
<td>.00*</td>
<td>.553</td>
</tr>
</tbody>
</table>

Note: *p < 0.0125

Discussion
The findings of this study revealed that there were differences between the two groups for each component of social participation with the individuals in the lower level of severity (Group I) consistently scoring higher on the CASP. It implied that children with higher levels of motor impairment had decreased social participation as compared to children with lower levels of motor impairment in all sub components of social participation. Based on CASP, home participation was considered to include social, play or leisure activities with family members or friends at home; family chores, responsibilities and decisions at home; self-care activities; moving about in and around the home and communicating with others at home. It was found that social participation was less in the home context. This could be explained by the amount of family support provided for their everyday activities at home. This may occur as parents feel guilty that their child has chronic health issues and they feel responsible for this. (18) Thus parents do all the activities for children like brushing, combing, eating, taking the child from one room to the other etc. Therefore, this finding is consistent with the available literature. (18)

Going to school is a major activity of children in the 6-12 year age group. Based on the CASP, school participation includes educational (academic) activities with other students in classroom at school; social, play and recreational activities with other students; moving around in school; using educational materials and equipment that are available to other students in the class room; communicating with other students and adults at school. In schools, children with disability get continuous attention from adults mainly teachers and school assistants, even during unstructured activities like recess or lunch break. Adult involvement in school context constrains participation with peer group. (19) In the current study there was significant difference in school participation of children with CP with respect to their level of severity of motor impairment. This result is in accordance with existing research that that children with CP participate less in school context. (20)

Neighbourhood and community participation is the participation in activities outside the home. In the CASP, this includes the following activities in the neighbourhood and community: social, play, or leisure activities; structured events and community activities; moving around in and around the community; social, play, or leisure activities; structured events and community activities; moving around in and around the community; social, play, or leisure activities; structured events and community activities; moving around in and around the community. The social model of disability focuses on environment (attitudinal, social and physical environment) for participation. (14) Environment can facilitate or constrain an individual’s participation. (14) In India, the physical environment is not disabled-friendly. Persons with disability face multiple architectural barriers when accessing community facilities especially in rural south India. (21) They are unable to access neighbourhoods, parks and cinema halls. Transportation was another major barrier to access other community places. Due to their mobility issues, children with CP in the higher severity group had more difficulties with neighbourhood and community participation. The findings of the current study suggest that physical architectural barriers could be the reason for less community and neighbourhood participation in children with CP varying across the different levels of severity of motor impairment.

Home and community activities included in this study were household activities; shopping and managing money; managing daily schedule; using transportation to get around in the community; work activities and responsibilities. Household and community activities require lots of mobility for participation, but children with CP have difficulties with mobility. This may be the primary reason that social participation is affected in home and community activities in children with CP. The findings are in accordance with findings of other studies suggesting that children with CP participated differently in different activities (frequency and intensity) according to their motor impairments. (22-23) There was a significantly decreased frequency of participation in community activities like games, sports activities and cultural events. (24) The findings of the present study are contrary to the findings of a previous study, that children with CP participate proportionally more in home activities compared to their peer group. (25) This study (25) included participants in an adolescent age group and utilised the CAPE scale in contrast to the CASP in the present study. As the CAPE measures social participation differently and the current study had relatively younger participants, these factors might explain the difference in the findings.

Strengths, Limitations and Recommendations
The present study is an initiative towards exploring social participation in different contexts for children with CP with motor impairment. Thus, one of the strengths of this study is the way that multiple contexts are used to define participation rather than only a single context. One of the limitations of the present study is that personal factors and environment factors were not considered in the evaluation. Hence, the present study recommends that further studies about social participation include measures of physical and societal factors which contribute to social participation.

Conclusion
The present study was undertaken to study social participation components to determine the differences in Indian children with CP according to their motor impairment severity. This study revealed that there was a definite difference in social participation across different levels of severity of motor impairment. Not only was there an overall difference but also there was a difference in each component of social participation in accordance to different contexts. Various other factors may affect social participation but the study’s aim was to see the involvement of the motor component. This study gives a clear picture about social participation in different contexts and for different activities that children are expected to participate in at that age.