



Exploring The Levels of Social Participation In Individuals With Cerebral Palsy.

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Abstract

Cerebral Palsy refers to the broad classification of disorders that affects a person's ability to move and maintain balance or posture. This chronic disability restricts individual's participation in different domains of life. The aim of this review is to explore the levels of social participation in individuals with cerebral palsy. The Objective of this review is to determine psycho-social difficulties faced by individuals with Cerebral palsy in terms of communication, social exclusion, and behavioural issues. For data gathering electronic database includes Google scholar, and Research in Developmental Disabilities journals were used. All the papers used in this review are about various factors influencing social participation in individuals with cerebral palsy are between 2012-2022. The conclusion indicates that individuals with cerebral palsy face troubles in social participation in the society.

Keywords: Cerebral Palsy, Social Participation, Social Exclusion, Behavioural Issues.

INTRODUCTION

Children and adolescent with disabilities have dreams and aspiration as someone without the disabilities. They too hope for equal opportunities, health, respect, security and to become an integral part of the world community. The outcome of disability and the possibility of participation differs around the world. In technical terms, **Disability** refers to an impairment or condition which can be cognitive, developmental, intellectual, sensory or combination of these that significantly effects a person's personal, social, and occupational life. Throughout human history disability has been an aspect of discrimination and exclusion from the larger part of

the society. Societal norms, ignorance, disregard has isolated and increased their struggle for participation in the society.

Individuals with cerebral palsy don't have the opportunities to develop their cognitive, social, and interpersonal skills. Primary motor impairment, sensory and intellectual impairment, speech and language impairment, presence of epilepsy, psycho-emotional and psycho-social problems further tangles up the functionality of these individuals. With the given diverse spectrum of this condition, how the consequence of this impairment is influences one's social, personal, and occupational life has gathered interest in the last decade.

Basic concepts

Cerebral palsy

Cerebral palsy describes a group of 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. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception and/ or behaviour and/ or by a seizure disorder. It is a congenital disorder, that is, it is present since birth. Based on area of the brain affected being affected following movement disorders can occur-

- Stiff muscles also known as **Spasticity**
- Uncontrollable movement also known as **Dyskinesia**
- Poor balance and coordination also known as **Ataxia**

Spastic Cerebral Palsy is the one most common type of cerebral palsy, it accounts for about 80% of people with cerebral palsy. It is further described by which part of the body has been affected

- **Spastic diplegia/diparesis:** characterising feature is mainly muscle stiffness in legs with arms less affected or not affected at all. They mostly have difficulty in walking because of tight hips and leg muscles.
- **Spastic hemiplegia/hemiparesis:** characterising feature is, it mainly effects one side of the individual's body usually an arm or leg.

- **Spastic quadriplegia/quadriparesis:** It is a severe form of spastic cerebral palsy, in which all the four limbs, trunk and the face is affected.

Dyskinetic Cerebral Palsy is described by uncontrollable movements. Individuals with dyskinetic cerebral palsy have troubles controlling their motor movements resulting in problems with sitting and walking. At times if the face is affected it is hard for them to swallow or talk. It accounts for up to 5-6% of all cerebral palsy cases.

Ataxic Cerebral Palsy is explained by poor balance and coordination. Individuals with dyskinetic cerebral palsy are unsteady when they walk. They have troubles with quick movements.

Presence of symptoms of two or more cerebral palsy is termed as **mixed cerebral palsy**. Spastic-Dyskinetic cerebral palsy is most common in mixed cerebral palsy.

Social Participation

Social participation can be explained as “**a person’s involvement in activities that provide interaction with others in society or the community**” (Levasseur, Richard, Gauvin, & Ramond, 2010).

To help individuals with cerebral palsy to find jobs, spend leisure time, and continue their education and occupation in the society they live in, relations with various social institutions, and integration with society are important factors.

The World Health Organization (WHO) also focuses on social and physical participation as an important goal for all the people. The World Health Organization has defined areas of participation as knowledge learning and practice, general tasks and desires, communication, movement, self-care, interpersonal interaction, home and work habits, community life, social life, and citizenship.

Barriers in social participation:

There are certain barriers and limitations that restricts individuals with disability from participating in social activities.

People have stereotypes about individuals with cerebral palsy that their quality of life is poor because of their impairment. This generates a sense of sympathy toward these individuals.

There are stigmas, prejudices that reside within the society related to the ideas of disability. That is, these disabilities are personal tragedies, they are punishments of wrongdoing and other bizarre perceptions.

Though with development of science and technology perception about cerebral palsy has changed significantly. Now, unlike generations before disability is understood as a social responsibility rather than a personal shortcoming. This helps in recognizing and rehabilitating individuals with disabilities effectively.

Another major barrier is lack of awareness within people. Various government policies are emerging as a tool to help individuals with cerebral palsy effectively become a part of the society without discrimination or stereotype.

These barriers affect an individual's life with cerebral palsy considerably.

Various rehabilitation techniques have been used and are being tested to make lives of individuals with cerebral palsy easier and help them become an integral part of the society.

Review of literature

Lopes, Thomas, Cardoso and Matsukura (2021) studied the perspective of adolescents with cerebral palsy and their mothers on social participation. The study was conducted on seven adolescents with cerebral palsy aged from 11 to 17 years old and their mothers from Sao Paulo, Brazil. Tools such as the Portuguese version of gross motors classification system (GMFCS) Family report questionnaire was used along with semi-structured interview. The data gathered from the interview was analysed with collective subject discourse technique (CSD). The study concluded that mothers believed their parenting practices contributes to the social participation of their children.

Gorp, Roebroek, Eck (2020) conducted research on childhood predictors of participation in domestic life and interpersonal relationships of young adults with cerebral palsy. The study was conducted on 67 young adults

with cerebral palsy having an age range between 21-27 years. To conduct the study tools such as Vineland adaptive behaviour scales (VABS) and life habits questionnaire were used. The statistic used for the study was Stepwise multiple linear regression. The results showed that lower manual ability, intellectual disability (ID), epilepsy and lower motor capacity decreased future participation in domestic life and/or interpersonal relationship. The research concluded that childhood factors account for around 79-90% of the variation in young adult participation in domestic life and interpersonal relationships of individuals with cerebral palsy.

Zulic, Hajkova and Jovanovic (2020) conducted a study on the factors relevant to social participation in primary school students with cerebral palsy in Republic of Serbia. The study was conducted on 75 students with cerebral palsy having an age range of 6 to 12 years. To conduct the study tools such as the school function assessment questionnaire, gross motors classification system (GMFCS) and manual ability classification system (MACS) scales were used. The statistics used for the study were T-test for independent samples, Pearson's correlation coefficient and the Mann-Whitney were used. The results indicated the importance of motor skills, intellectual and writing abilities of students with cerebral palsy as a significant predictor of social participation in school environments in the Republic of Serbia.

Remijn, Hoek, Satink, Swart and Sanden (2019) worked on the impact of difficulties with eating and drinking in adolescents and young adults in daily life. The study was conducted on ten participants with spastic cerebral palsy aged 15-23 years from Netherlands. Semi-structured interviews were used to recognize meaningful factors related to eating and drinking difficulties. The results were categorized into four categories 1) perceived eating and drinking difficulties 2) challenges in physical and social context 3) dealing with eating and drinking difficulties and 4) negative feelings about their eating and drinking. The study concluded that adolescent and young adults with cerebral palsy experience many restrictions in eating and drinking circumstances that leads to negative feeling and lower participation level.

Smith, Gorp, Wely (2019) conducted research on the participation in social roles of adolescents with cerebral palsy. The study was conducted on 45 adolescents with a mean age of 15 years. To conduct the research tool such as Gross Motor Function Classification System, Life habit questionnaire were used. The statistics used for this research was regression analysis. The results concluded dissociation between participation 47 accomplishment and satisfaction with participation among adolescents with cerebral palsy.

Amini, Saneii and Pashmdarfard (2018) conducted research on factors affecting social participation of Iranian children with cerebral palsy. The study was conducted on two-hundred seventy-four children with the age range of 6-12 years and their parents from Tehran, Iran. To conduct the study tools such the children participation assessment scale in activities outside of school- Parent version (CPAS-P), Manual ability classification system (MACS), Communication function classification system, eating drinking ability classification system, cognitive level assessment, gross motor function classification system, demographic questionnaire was used. The statistics used for study were correlation coefficient and chi-square due to the large no. of independent variable. Furthermore, multiple linear regression and stepwise linear regression was used to assess associations and correlations between the variable. The study concluded that personal and environmental factors contributed to the social participation of children with Cerebral Palsy. Personal factors included level of communication, ability to eat and drink, the gross motor function levels whereas environmental factors included residence, father's job, and mother's age.

Omura, Fuentes and Bjornson (2018) conducted research on the levels if participation and examine relationship of participation with quality of life in ambulatory children with cerebral palsy. The study was conducted on 128 ambulatory children with cerebral palsy. To conduct the study tools like Gross Motor Function Classification System levels- I-III, Pediatric quality of life inventory, assessment of life habits and Children's assessments of participation and Enjoyment and Assessment of Preschool Children's Participation were used. The results concluded that level of participation was associated with psychosocial quality of life. Moreover, it was reported that increasing age and decreased frequency of participation were negatively associated with all domains of quality of life.

Gorp, Wely, Dallmeijer et al. (2018) conducted a study to determine the long-term course of difficulties in participation of individuals with cerebral palsy without intellectual disability. The study was conducted on 151 individuals falling within the age range of 16- 20 years. To conduct the study assessment of life habits questionnaire and gross motor function classification system (GMFCS) were used. The results concluded that despite the high average participation levels, adolescents, and young adults with cerebral palsy faced difficulties in participation in housing and interpersonal relationship.

Finnvold (2017) conducted research on school segregation and social participation in Norwegian children with physical disabilities. The study was conducted on 491 children with disabilities. To conduct the study tools such

as survey questionnaire were used. The statistics used for the research was multiple logistic regression models.

The results indicated that showed that the more the individual is segregated from normal classroom education, the lower were their chances of seeing friends or participating in after-school formal group activities.

Mehraban, Hasani and Amini (2016) conducted a study to compare participation in school-aged cerebral palsy children and normal peer. The study was conducted on 30 children with cerebral palsy and 30 children without cerebral palsy. To conduct the study tools like children's assessment of participation and enjoyment (CAPE) was used. The results suggested significant differences between the two groups regarding the diversity, intensity, and overall participation.

Tan, Ketelaar, Slot, Becher et al. (2016) conducted a study on the factors contributing to longitudinal development of social participation in individuals with cerebral palsy. The study was conducted on Dutch population from rehabilitation centres of Netherlands between the age group of 1 to 24. To conduct the study tools such as Vineland Adaptive Behaviour Scale, Raven's coloured progressive matrices, Snijders-Oomen Nonverbal intelligence test, Surveillance of cerebral palsy in Europe- guidelines scale, Manual Ability Classification System (MACS), TNO-AZL Children's quality of life and short form health survey were used. The statistics used for the study was Descriptive statistics of factors per age cohort and were computed and compared by the means of one-way analysis of variance and independent sample t-test. The study concluded that children with epilepsy and speech impairment are at an increased risk for restricted social participation, also a trend was found that children attending special education are at risk to develop less favourably in social participation.

Lipscombe, Boyd, Andrea et al. (2016) conducted research to investigate whether early communication ability mediates the relationship between early motor ability and later social development in a cohort of children with cerebral palsy. The study was conducted 71 children with cerebral palsy out of which 43 were males. To conduct the study tools such as Gross motor function measure (GMFM), the Communication and Symbolic Behaviour Scales-Developmental Profile (CSBS-DP) Infant-Toddler Checklist and the Paediatric Evaluation of Disability Inventory (PEDI). The results concluded that early communication skills partially mediated the relationship between early motor ability and later social functioning in children with cerebral palsy.

Weber, Bolli, Heimgartner, Merlo, Zehnder and Katterer (2015) conducted a study on the behavioural and emotional problems in children and adults with cerebral palsy. The research is a two-centre cross-sectional

study and was conducted on 121 adults and 88 children with cerebral palsy. To conduct the study tools such as Vineland Adaptive Behaviour Scale- II(VABS), Child Behaviour Checklist (CBCL), Strengths and Difficulties Questionnaire (SDQ) were used. The result concluded that both groups reported same frequency of abnormality in social interactions and attention problems in CBCL and peer problems in SDQ which emphasised on the importance of early intervention.

Dang, Colver Marcelli, Parkes et al. (2015) conducted a study to explore the predictors of participation of adolescents with cerebral palsy. The study was conducted on 818 children aged 8-12, who were randomly selected from six European countries. To conduct the study tools such as Parenting stress index short form, strength and difficulties questionnaire and LIFE Habits questionnaire. The results concluded that participation of adolescents with cerebral palsy were predicted by factors related to the child and family.

Vos, Dallmeijer, Verhoef et al. (2014) conducted a study to determine the developmental trajectories of expressive (speech) and receptive (spoken and written language) communication by the type of motor disorder and intellectual disability in individuals with cerebral palsy. The study was conducted on 418 participants with cerebral palsy. To conduct the study tools such as Vineland Adaptive Behaviour Scale were used. The results indicated that the development of expressive and receptive communication was prominent in unilateral spastic cerebral palsy.

Santos, Pavao, Santiago (2013) conducted a study on the relationship with knee extensor torque and social participation on children with hemiplegic cerebral palsy. The study was conducted on seven spastic hemiplegic cerebral palsy patients and 18 typical children. The trunks, hips, knees, and ankle angles were measured by the means of kinematics evaluation. Social participation was assessed by Assessment of life Habits for children (LIFE-H) scale. The results showed that children with spastic hemiplegic CP have lower knee extensor torque in the affected limb and restriction in social participation in dimensions related with fine motor control and language skills when compared to their typical peers. It was therefore recommended that during rehabilitation processes, impairment in body functions and structures should be related with how much it affects a child's ability to perform functional activities.

Thomas, Shevell, Schmitz, Lach, Law conducted research to estimate the potential influence of adolescent characteristics and environmental factor as determinants of participation in activities for adolescents with cerebral palsy. The study was conducted on adolescents having an age range of 12-19 years with cerebral palsy.

To conduct the study tools such as Vineland Adaptive Behaviour Scale – II, Gross Motor Function Measure, Gross Motor Function Classification System, Manual Ability Classification System, questionnaire such as the Self-Perception Profile for Adolescents, Dimensions of Mastery Questionnaire, Strengths and Difficulties Questionnaire, Family Environment Scale, the European Child Environment Questionnaire were used. The study conclude that Adolescent's self-perception and behaviour were individually associated with participation in different activity domains but did not strongly predict participation within multivariate models.

Badia, Longo, Orgaz and Vela (2013) conducted research on the influence of participation in leisure activities on quality of life in Spanish children and adolescents with cerebral palsy. The study was conducted on a total of 206 children and adolescents with cerebral palsy recruited from Association caring for people with Cerebral palsy and related disabilities (ASPACE) along with their parents. To conduct the study tools such as Spanish version of Children's assessment of participation and enjoyment (CAPE), KIDSCREEN to measure quality of life, Gross Motor Function Classification System (GMFCS) and a demographic questionnaire for parents of caregiver were used. The statistics used for the study were descriptive statistics, hierarchical regression, and linear regression. The study concluded that participation in leisure activities had a positive effect on the quality of life of the Spanish children and adolescent with cerebral palsy.

Raghavendra, Newman, Grace, and Wood (2013) conducted a study on the effectiveness of a tailored Internet support intervention to increase the social participation of youth with disabilities. The study was conducted on 18 youth having an age range between 10- 18 years with cerebral palsy, physical disability and acquired brain injury. To conduct the study tools such as The Canadian Occupational Performance Measure (COPM) and Goal Attainment Scale (GAS) were used, interviews were also conducted to identify subjective changes. The statistics used for study was paired t-test. The results showed increase in performance and satisfaction with performance on identified goals concerning social networking. The study concluded that internet could be a viable method to facilitate social participation for youth with disability.

Shimmell, Gorter, Jackson (2013) conducted research on physical activity experiences of youth with cerebral palsy and their parents. The sample for the study was collected through purposive sampling approach. Children falling within the age range of 10-18 years were recruited for the study. To conduct the study tools such an Expanded and Revised Gross motor function classification system (GMFCS E&R) was used. For data analysis, content analysis approach was used. The results concluded youth with cerebral palsy experience personal and

environmental factors that act as facilitators and barriers to participation in PA. Secondly, limitations related to body structure and function might inhibit youths' ability or desire to be physically active.

Stewart, Lawless, Shimmell (2012) conducted a study on social participation of adolescents with cerebral palsy. The study was conducted on 10 youths with cerebral palsy within the age range 17-20 years from Ontario, Canada. To conduct the study tool such as gross motor function classification system (GMFCS) was used, and data was collected through interviews. The results concluded that adolescents with CP want to participate in social activities that are typical of their developmental age group, but they often experience more barriers, and need more supports, to participate.

Colver, Thyen, Arnaud (2012) conducted a study on participation of children with cerebral palsy (CP) varied with their environment. The study was conducted on children with the age range of 8-12 years with cerebral palsy in six European countries. To conduct the study tools such as Administration of Assessment of Life Habits and European Child Environment Questionnaires were used. The results indicated that the physical, social, and attitudinal environment of disabled children influences their participation in everyday activities and social roles.

Racine, Waknin, Thomas (2012) conducted research on behavioural difficulties in adolescent with cerebral palsy. The study was conducted on 160 adolescents along with their parents with cerebral palsy. To conduct the study tools such as strength and difficulties questionnaire was used. Subjects motor and cognitive abilities, as well as parental stress was also evaluated. The results indicated that behavioural difficulties are present in adolescent with cerebral palsy. Prosocial behaviours were related to better function whereas hyperactive symptoms were associated with greater limitations.

Kang, Palisano, King, Chiarello, Orlin, Polansky (2011) conducted research to explore whether social participation with friends differ among youths with Cerebral palsy based on their self-perceived competence as friend. The study was conducted on a total of 135 youth with cerebral palsy having an age range of 13-21 years. To conduct the study tools such as fulfilment in social roles and children's assessment of participation and enjoyment were used. The statistics used for the study were Kruskal-Wallis one-way analyses of variance,

Mann-Whitney U-test and Kolmogorov-Smirnov test. The study concluded a positive link between social participation and self-perceived competence that is youths with higher self-competence as a friend did the greatest no. of activities and participated most often with friends.

Kolman, Glanzman, Prosser (2018) conducted a study on the factors that predict overall health and quality of life and social participation in non- ambulatory individuals with cerebral palsy. The study was conducted on parents and guardians of non-ambulatory children, adolescent and young adult with cerebral palsy recruited from cerebral palsy clinic of a pediatric academic hospital. To conduct the study cerebral palsy child questionnaire were used. The statistics used in the study was univariate analyses. The results concluded that factors associated with comfort, communication and social interaction appears to predict overall quality of life.

METHODOLOGY

The aim of this review paper is to explore the levels of social participation in individuals with cerebral palsy. The literatures included in the review have described various aspects affecting social participation in individuals with cerebral palsy. Case study, single case design and single subject design were excluded due to the high risk of bias in this design. The Electronic Databases such as Medlin, PubMed, Google Scholar, Science direct, Tandfonline, Wiley library, NCBI, NLM and Scielo Brazil were used. Various Journal were used such as Research in Developmental disability, Developmental Medicine and Child neurology, International Journal of Language and Communication Disorders, Disability, and Rehabilitation, Iranian Journal of Child Neurology. The literatures mentioned in the paper are between 2012-2022.

DISCUSSION

The purpose of this study was to explore the levels of social participation in individuals with cerebral palsy. The given literatures indicated that, while there is an expanding research base on cerebral palsy and medical interventions, social participations remain limited.

Diverse samples are used in various literatures, but commonalities were found regarding the tests, questionnaire and manuals used. Gross Motors Classification System, Vineland adaptive behavioural scale, LIFE-H questionnaire are few of the tools.

Despite the limited no. several important findings emerged while conducting this review.

In this study major literatures are regarding the restriction in school participation, leisure activity participation. Firstly, it was significantly implied that intellectual disability (ID), lower manual ability and epilepsy restricted individuals with cerebral palsy from social participation. Early communication skills mediated the relationship between early motor ability and social participation.

Secondly, due to the difficulties in eating and drinking, young adults with cerebral palsy experience peer pressure which further leads to negative feeling and lower participation level. It has been seen that positive peer influence facilitate better levels of social participation. Thirdly, positive psychosocial quality of life contributed notably to the frequency of participation in children with cerebral palsy. Lastly, segregation of individuals with cerebral palsy and discrimination against them restricts their social participation.

It has been observed that both personal and environmental factors are responsible for lack of social participation in individuals with cerebral palsy. Various intervention techniques are being still tested to help individuals with cerebral palsy.

One of the most used therapies in rehabilitation of individuals with cerebral palsy is occupational therapy.

Occupational therapy is a part of health care system which helps an individual with social, cognitive, and sensory impairments. In cerebral palsy, occupational therapy helps the individual with their daily life activities and social participation.

Few examples of the everyday tasks given to individuals are, turning a doorknob, putting away toys after play, painting, drawing, and colouring, inserting and twisting a key to unlock/ lock a door, flipping through the pages of a book

Occupational therapy assists individuals with cerebral palsy with their daily activities in life and help them gain a certain amount of independence.

CONCLUSION

The aim of this review paper is to explore the levels of social participation in individuals with cerebral palsy. The Objective of this study is to determine psycho-social difficulties faced by individuals with Cerebral palsy in terms of communication, social exclusion, and behavioural issues. The literatures reviewed in this paper indicated that lower manual ability, intellectual disability restrict social participation of individuals with cerebral palsy along with social exclusion, isolation, and discrimination.

More research can be conducted to understand the social difficulties an individual faces with cerebral palsy. Further development of rehabilitation techniques for individuals with cerebral palsy is also important to focus on their psycho-social development.

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