International Journal of Community Medicine and Public Health
Gulanikar AA et al. Int J Community Med Public Health. 2023 Jul;10(7):2457-2461
http://www.ijcmph.com
pISSN 2394-6032 | eISSN 2394-6040

DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20232036

Original Research Article

Environmental barriers to participation in children with cerebral palsy aged 5 to 12 years

Apurva A. Gulanikar, Amruta G. Ekbote*, Franny M. Nathani

Department of Physiotherapy, Sancheti Institute College of Physiotherapy, Pune, Maharashtra, India

Received: 20 April 2023
Revised: 06 June 2023
Accepted: 07 June 2023

***Correspondence:**
Dr. Amruta. G. Ekbote,
E-mail: amrutaekbote214@gmail.com

ABSTRACT

Background: Cerebral palsy is a group of permanent disorders of development in movement and posture causing various limitations. India has a prevalence of 2.95 CP children per 1000 children. Participation is important for overall development. Participation is influenced by factors around the child and family. Environmental factors include social support, accessibility, accommodation, and availability of facilities. There is dearth of literature about what environmental barriers prevent individuals with cerebral palsy from attaining participation in Indian surroundings. Thus, the aim was to find the environmental barriers faced to participation.
Methods: Parents of 30 children with CP from Pune participated in the study. Convenience sampling was used to onboard them. Ethical clearance, informed consent and assent were taken. They had to fill out the CHIEF questionnaire- Craig's hospital inventory of environmental factors and the therapist determined the GMFCS and MACS level of the child.
Results: Barriers to participation as reported by parents were 48.07% in the policies subscale, 23.47% in the physical/structural subscale, 4.55% in the school subscale, 34.29% in the attitude/support subscale and 37.86% in the services/assistance subscale.
Conclusions: The results showed barriers to participation were most common in the policies subscale and the services and assistance subscale. Policymakers and administrative heads in sectors across government, transport, and educational institutes need to take the requirements of children with cerebral palsy into consideration.

Keywords: Cerebral palsy, Children, Environmental barriers, GMFCS, MACS, Participation

INTRODUCTION

All children under the United Nations Convention of the rights of children, UNICEF have the right to development, survival, participation, and protection.[1] Children with disabilities are considered to be a vulnerable population group and thus require special support and protection.[2] However, it is necessary to understand that disabled children have the same aspirations as all children with hopes for health, security, respect, opportunities to learn skills, meaningful occupation, and the possibility of contributing to the lives of others which in other words is participation.[3]

According to the ICF given by WHO, environmental factors include the physical, social, and attitudinal environment in which a person lives and conducts his life. Environmental factors are classified as products and technology, natural environment and human-made changes to the environment, support and relationships, attitudes and service systems and policies.[4] Under ICF, Participation is defined as involvement in a life situation. Participation restrictions are difficulties an individual may experience while involved in life situations.[4] Thus the aim was to incorporate a biopsychosocial model while looking at environmental barriers.

Participating in activities of daily living and taking part in activities in society with other children and adolescents is important for an individual's growth. Through participation, children learn new skills, grow physically and mentally, and develop social networking skills that are crucial in the skillset to becoming adults.[5]

Cerebral palsy is a group of permanent disorders of development in movement and posture causing various limitations.[6] The degree of impairment seen in children with cerebral palsy varies greatly, from minimal affection to complete loss of motor control or communication.[7] These impairments are essentially non-progressive in nature but change with age.[8] They influence the participation of children with cerebral palsy in various contexts such as at home and in school.[9] The SCPE (surveillance for cerebral palsy in Europe) classifies CP into subtypes: spastic (bilateral and unilateral), dyskinetic (dystonic and choreoathetotic), and ataxic. A child with CP is classified according to the SCPE guidelines using the gross motor function classification system (GMFCS) and the bimanual fine motor function (BFMF) or the manual ability classification system (MACS).[8] India has a prevalence of 2.95 CP children per 1000 children.[10] Rehabilitation in children with Cerebral Palsy is a multidisciplinary rehab with the aim to improve functionality, control comorbidities, and pave the way to improve development of children with CP.[8]

The convention on the rights of persons with disabilities, under the United Nations organization, states in Article 31, the obligation of state parties to identify and eliminate the barriers faced by people with disabilities in exercising their rights.[11] Children with cerebral palsy end up not having the same opportunities as their non-disabled peers, which may be due to environmental factors and their effect on participation. Participation is a complex concept that gets influenced by personal and environmental factors related to the child and family.[12] The environment is a variable that can be potentially modified and hence acts as an important factor that can affect participation. Environmental factors will take into account social support, accessibility, accommodation, and availability of facilities. Children with cerebral palsy are known to face challenges in participation and the study aims to find out the environmental barriers to it.

METHODS

Participants and procedure

A convenience sample of 30 parents of children with Cerebral Palsy aged between 5 to 12 years who have resided in Pune district for at least a year were a part of the study. Participants were recruited from physical therapy setups in private hospitals, government hospitals, and rural setups in Pune, with their consent to get a proper cross-section of the population. Ethical clearance was taken from the Institutional Ethical Committee of Sancheti Institute College of Physiotherapy before starting the research project. The study was conducted from October 2022 to March 2023. An informed consent and assent form were signed by all participants. Children of GMFCS levels- I to V and MACS levels- I to V and all subtypes of CP were included in the study. Motor function and manual ability of the child were determined according to the GMFCS E and R tool and MACS tool respectively. Participants had to fill out the Craig's hospital inventory of environmental factors (CHIEF) scale.

Instruments

The CHIEF scale is developed by disability experts to assess the impact of environmental factors on people with disabilities.[13] There are five subscales: policies, physical and structural access, work and school domains, attitudes and support, equipment, services, and assistance in the 25 items long-form scale.[13] The participant rates the frequency with which their child encounters the environmental barriers (daily =4, weekly =3, monthly =2, less than monthly =1, or never =0). and then they are asked if their child considers that barrier to be a big problem =2 or a little problem =1. A score of each subscale was calculated as the mean of frequency-magnitude product score across items of the subscale and a total score was calculated as the mean of frequency magnitude product score across all items. The total scale score of ICC reliability was 0.926.13 It has good test-retest reliability and internal consistency. It also has evidence of construct validity for children with physical disabilities. Gross motor function is determined via (GMFCS- E and R).[14] The tool is used to classify and describe the abilities of children and youth with cerebral palsy aged 0-18 years old. The GMFCS E and R contain five age groups, those being under 2 years, 2-4 years, 4-6 years, 6-12 years, and 12-18 years of age. Interrater reliability was 0.84.[14] The GMFCS classifies the severity of motor impairment of children with CP into five levels. The higher the level more is the motor affection seen. The manual ability classification system (MACS) is used to understand hand function for children with cerebral palsy of different ages (4-18 years) in daily activities.[15] The interrater reliability has an ICC value of 0.97.[15] Children in level one had minor limitations, while children in level five have major limitations in handling objects compared to typically developing children. The GMFCS and MACS levels of children were determined by the same physical therapist with the help of caregivers and observation of the child as needed. Statistical analysis was done using Microsoft Excel 2007. Descriptive statistical methods including mean and percentage were used.

RESULTS

Both genders were included in the study- male and female. Out of 30 participants, there were 20 and 10 male and female children respectively. Types of cerebral palsy included in the study- 8 hemiplegic CP, 18 spastic diplegic CP, 2 spastic quadriplegic CP, 1 quadriplegic

dystonia, 1 hypotonic CP. The participants' mean age was 7.8±2.44 years. The sample distribution across gross motor functioning of the participant is seen in Figure 1.

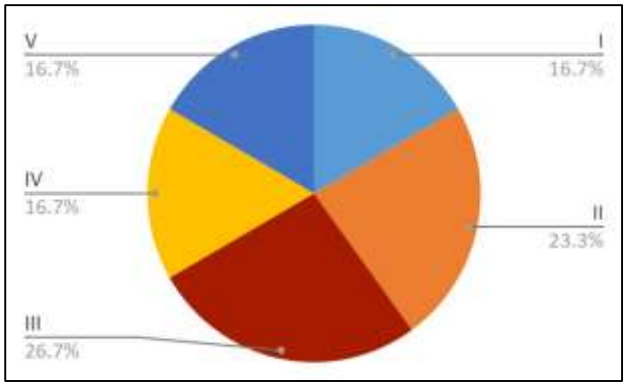

Figure 1: Distribution of participants according to GMFCS levels.

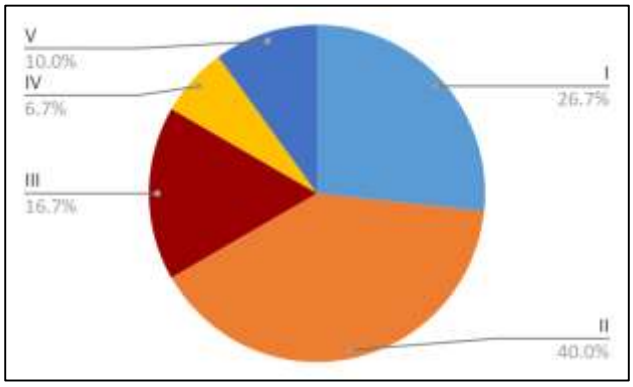

Figure 2: Distribution of participants according to MACS levels.

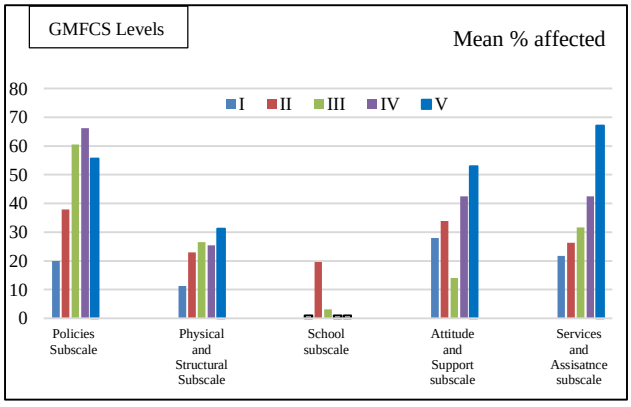

Figure 3: Comparative analysis of the motor affection of the child with environmental barriers.

Analysis of the CHIEF score with GMFCS levels shows GMFCS levels I and V face maximum barriers in the services and assistance subscale. GMFCS levels II, III, and IV face maximum barriers in the policies subscale. According to it, 48.07% in the policies subscale, 23.47% in the physical and structural subscale,5.15% in the school subscale, 34.29% in the attitude and support subscale, and 37.86% in the services and assistance subscale.

Similarly, the distribution of the sample according to manual abilities is shown in Figure 2. It is important to mention that out of the sample population, 53.33% do not attend school due to lack of proper educational opportunities and hence did not qualify to fill the school subscale in the CHIEF questionnaire. Barriers to participation as reported by parents using the CHIEF questionnaire were 48.64% in the policies subscale, 23.75% in the physical and structural subscale, 5.41% in the school subscale, 32.25% in the attitude and support subscale and 36.48% in the services and assistance subscale. Comparative analysis of the motor affection and manual ability of the child with environmental barriers faced was done with GMFCS level, MACS level, and mean% affection in CHIEF score subscales. The results can be seen in Figures 3 and 4.

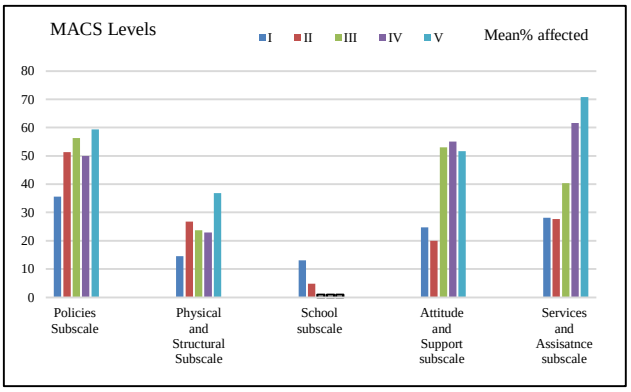

Figure 4: Comparative analysis of the manual affection of the child with environmental barriers.

Analysis of the CHIEF score with MACS levels shows GMFCS levels IV and V face maximum barriers in the services and assistance subscale. GMFCS levels I, II, and III face maximum barriers in the policies subscale. According to it, 50.49% in the policies subscale, 24.95% in the physical and structural subscale, 3.57% in the school subscale, 40.87% in the attitude and support subscale, and 45.72% in the services and assistance subscale.

DISCUSSION

The present study used CHIEF score to analyze parent-reported environmental barriers faced by children with cerebral palsy.

Going into details of each subscale, 61.66% face difficulties due to a lack of programs and services specific to the needs of children with cerebral palsy. The lack of government policies with a wider spectrum of inclusivity and feasibility in obtaining benefits is preventing participation in 60% of the sample population. Followed by a lack of educational opportunities (57.91%), and transportation issues (50%). Most children with cerebral palsy face mobility issues, thus increasing difficulty in participation. The lack of accessories and modifications in public transport systems makes it difficult for them to travel across public domains.

Nobakht et al in a similar study found that most barriers were faced in the services and assistance subscale and the policies subscale.[9] This study used the CHIEF score to find environmental barriers. Thus, the findings of the current study are aligned with those demonstrated in this study conducted in 2013. It states that environmental barriers are similar in both these geographical areas. The environmental barriers faced by children with cerebral palsy in Tehran are analogous to that in Pune.

Sahoo et al found that participation is reduced more in home setups vs community setups.[16] This is contrary to the current study where maximum barriers to participation were found in community setups. However, both studies suggest that Indian surroundings are not disabled-friendly. It also goes to say that physical architectural barriers and poor transportation facilities could be a reason for reduced participation in community settings.

Further, the current study suggested that the current policies and rules of businesses and organizations are proving to be barriers in 49.58% of the sample population. The unavailability of proper and specific covers for medical, physiotherapy, and adaptive equipment costs is proving to be a barrier preventing children from participating. Most children with cerebral palsy experience prejudice and discrimination, which ends up having a negative effect on participation as faced by 47.08% of the population. This behavior can be seen in family members, peers, people in authority positions, and community dwellers. Other people's attitude toward children with cerebral palsy is reported as a barrier to participation by 40.41% of the sample population. Architectural designs and layouts of public places cause multiple difficulties while participating (42.08%).

These findings are supported by evidence from a qualitative study by Longo et al which states that friends are a vital part of community life while growing up, and a feeling of not being included with them can cause negative effects on participation.[17] Communities should promote strategies that strengthen links between children with and without disabilities and thus improve attitudes and support.[12]

The lack of educational opportunities and institutions in the community for these children proves to be a severe barrier. Out of the sample population, 53.33% do not attend school due to a lack of proper educational opportunities and hence did not qualify to fill the school subscale in the CHIEF questionnaire. This states that the lower affection seen in the school subscale could be a false negative.

Low scores could be due to a lack of exposure to that environment and not just due to a lack of barriers in school setups. Thus, there is a need for better educational opportunities and more exposure to the said environment before commenting on its barriers.

According to Limaye, despite government and institutional policies, children with disabilities are amongst the most disadvantaged in terms of physical access to schools and completion of elementary education, as their needs do not get met efficiently.[18] The current study also puts forth that there is a severe dearth of educational opportunities amongst other environmental barriers for children with cerebral palsy.

Thus, this study highlighted that there are environmental barriers to participation. To improve participation in children with cerebral palsy it is necessary to tackle these environmental barriers and try to modify them policy makers and administrative heads in sectors across government, transport, and educational institutions need to consider the requirements of children with cerebral palsy to enhance their participation and improve the quality of life. There is a need to improve awareness about cerebral palsy and work on inclusivity in schools and community areas.

This being said, environmental factors change with changes in communities, people, and geographical conditions.[4] Thus, it is necessary to understand that barriers faced are subjective in their nature. We are aware of the lacunae in this research. Firstly, we acknowledge the discrepancy caused by the vernacularity of languages, which is the result of people being widespread over regions in Maharashtra and their diverse educational backgrounds.

Secondly, the intellectual levels of the children were not taken into consideration, thus there can be variation in the barrier perception of parents because of it.

CONCLUSION

This study concludes that maximum affection is seen in the policies subscale and then in the services and assistance subscale. GMFCS levels I and V face maximum barriers in the services and assistance subscale. GMFCS levels II, III and IV face maximum barriers in the policies subscale. MACS levels I, II and III face maximum barriers in the policies subscale while MACS levels IV and V face more barriers in the services and assistance subscale. To be more specific, organizational and government policies and lack of availability of education, training, community programs, and transport services are major barriers faced.

ACKNOWLEDGEMENTS

I would like to thank Dr. Saloni Raje, MS, PT, for her encouragement. I am grateful to Dr. Dinesh Chavan (PT), Dr. Manish Ray (PT) and Mr. Nitin Chavan for helping me to recruit subjects for the study. I thank Dr. Rachana Dabadghav (PT) for always making time to solve my doubts and queries about statistical know-how; and all the participants of the research study.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

REFERENCES

1. Convention on the rights of the child text. UNICEF. https://www.unicef.org/child-rights-convention. Accessed on 12 May 2022.
2. Huus K, Schlebusch L, Ramaahlo M, Samuels A, Berglund IG, Dada S. Barriers and facilitators to participation for children and adolescents with disabilities in low-and middle- income countries- a scoping review. Afr J Disabil. 2021;10:1-10.
3. McConachie H, Colver AF, Forsyth RJ, Jarvis SN, Parkinson KN. Participation of disabled children: how should it be characterised and measured? Disabil Rehabil. 2006;28(18):1157-64.
4. World Health Organization. International Classification of Functioning, Disability, and Health: Children and Youth Version: ICF-CY. 2007. Available from: https://apps.who.int/iris/handle/10665/43737. Accessed on 12 May 2022.
5. Anaby D, Law M, Coster W, Bedell G, Khetani M, Avery L, et al. The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. Arch Phys Med Rehabil. 2014;95(5):908-17.
6. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl. 2007;109(suppl 109):8-14.
7. Jonsson U, Eek MN, Sunnerhagen KS, Himmelmann K. Cerebral palsy prevalence, subtypes, and associated impairments: a population-based comparison study of adults and children. Develop Med Child Neurol. 2019;61(10):1162-7.
8. Sadowska M, Sarecka-Hujar B, Kopyta I. Cerebral palsy: current opinions on definition, epidemiology, risk factors, classification and treatment options. Neuropsychiatr Dis Treat. 2020:1505-18.
9. Nobakht Z, Rassafiani M, Rezasoltani P, Sahaf R, Yazdani F. Environmental barriers to social participation of children with cerebral palsy in Tehran. Iran Rehabil J. 2013;11(1):40-5.
10. Chauhan A, Singh M, Jaiswal N, Agarwal A, Sahu JK, Singh M. Prevalence of cerebral palsy in Indian children: a systematic review and meta-analysis. Indian J Pediatr. 2019;86:1124-30.
11. Convention on the rights of persons with disabilities and optional protocol. United Nations. Available from: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf. Accessed on 12 May 2022.
12. Anaby D, Law M, Coster W, Bedell G, Khetani M, Avery L, et al. The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. Arch Phys Med Rehabil. 2014;95(5):908-17.
13. Craig Hospital Inventory of Environmental Factors. Available from: https://craighospital.org/uploads/CraigHospital.ChiefManual.pdf. Accessed on 12 May 2022.
14. Bodkin AW, Robinson C, Perales FP. Reliability and validity of the gross motor function classification system for cerebral palsy. Pediatr Phys Ther. 2003;15(4):247-52.
15. Eliasson AC, Krumlinde-Sundholm L, Rösblad B, Beckung E, Arner M, Öhrvall AM, et al. The Manual ability classification system (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. Develop Med Child Neurol. 2006;48(7):549-54.
16. Sahoo R, Rege S, Rao S. Social participation in children with cerebral palsy. Online J Health Allied Scs. 2017;16(4):5.
17. Longo E, Regalado IC, Galvão ER, Ferreira HN, Badia M, Baz BO. I Want to play: children with cerebral palsy talk about their experiences on barriers and facilitators to participation in leisure activities. Pediatr Phys Ther. 2020;32(3):190-200.
18. Limaye S. Factors Influencing the accessibility of education for children with disabilities in India. Glob Educ Rev. 2016;3(3):43-56.

Cite this article as: Gulanikar AA, Ekbote AG, Nathani FM. Environmental barriers to participation in children with cerebral palsy aged 5 to 12 years. Int J Community Med Public Health 2023;10:2457-61.