

Identification of Barriers and its influence on the Quality of Life in school going children with Cerebral Palsy: A Hypothesis

Avni Jain¹, Dinesh Chavhan¹

¹ Sancheti Institute college of Physiotherapy, Thube park, Shivajinagar Pune.

Institute at which research was conducted: Sancheti Institute College of Physiotherapy, Thube park, Shivajinagar Pune 411005, Maharashtra.

University Affiliation of Thesis: Maharashtra University of Health Sciences, Nashik

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Address of Correspondence

Dr. Avni Jain

Sancheti Institute College of Physiotherapy, 12, Thube Park, Shivaji Nagar, Pune - 411005, Maharashtra.

E-mail: jainavni24@gmail.com



Dr. Avni Jain



Dr. Dinesh Chavhan

Abstract

Background: Cerebral palsy is a group of permanent disorders of the development of movement and posture causing limitations in various aspects. Multisystem impairments are seen in these children. India has a prevalence of 2.95 CP children per 1000 children. These children face a lot of barriers in their ADLs. Also, these factors play an important role in deciding the quality of life of a child. Thus, schools form an important crossroad for a child outside his safe environment, in order to interact with others and environment, where he might face majority of his barriers. Thus, identifying them and seeing their impact on quality of life is of great importance.

Hypothesis: There will be an influence of barriers on the quality of life in school going children with Cerebral Palsy

Clinical importance: Identifying the barriers and its influence on quality of life will help the therapist plan a treatment protocol that is more patient oriented.

Future research: To study the impact of patient centered intervention strategies, whilst keeping in mind about the barriers, on the quality of life.

Keywords: Cerebral palsy, barriers, quality of life.

THESIS SUMMARY

Introduction

Cerebral palsy (CP) is a well-recognized neurodevelopmental condition beginning in early childhood and persisting throughout the lifespan. According to definition, Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems.[1] India is the second most populated country in the world and which is increasing and imposing a burden on the healthcare system. According the National Family health Survey (NFHS) 2015-16, 79% of childbirths took place in a health facility, while the rest were conducted in homes by untrained birth attendants. [2] Thus, seeing the figures it implies that the number of unsupervised obstetric deliveries in India is still huge resulting in obstetric complications and resulting in perinatal asphyxia. Also, there is an increasing survival rate of very low birth weight babies and premature

babies with improvement in neonatal care services in India. Both these factors, perinatal asphyxia and prematurity leads to major risk factor for cerebral palsy. The prevalence of cerebral palsy in India is same as global estimates. There is an average of 2.95 CP children per 1000 children.[3] In CP children, physiological factors, psychological factors, social factors and environmental factors all play a role in experiences of the participants in relation to physical activity, which helps to identify the barriers in the activity of daily living.[4] Also, it is said that environment plays an important role in improving the quality of life of a CP child or adolescent.[5] Environmental barriers also play an important role in deciding the level of participation from these children.[9] The children going to school also faces many physical and environment barriers which hinders their right to acquire education.[6] When these children interact with the community, his/her demands change. Therefore, schools should take into account the complexities associated with age, developmental stage and academic requirements of young people with cerebral palsy and plan physical activity programmes accordingly.[7] There is often a lack of disability friendly respite centres such as schools, which acts as a barrier to the caretaker for getting enough time to

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socialize or seek employment.[8]

Hypothesis

In a differently abled child, the presence of multiple barriers opens up opportunities for multiple points of entry to facilitate change. We cannot always change a child's functional abilities but we can enhance their participation by minimizing the gaps between the child's capabilities and the social and physical demands of the environment in which a child develops. [10] School going children with cerebral palsy face many barriers which burden their ability to acquire education. Often being different amongst others leads to low self-esteem, isolation and inactivity. All these factors play an important role in determining the Quality of Life of the child. There have been studies done to identify the barriers faced by children with cerebral palsy but there are very few studies amongst school going children with Cerebral Palsy. Also, there is a dearth of literature on how these barriers influence the Quality of life.

This study is based on the hypothesis that there will be an influence of barriers on the quality of life in school going children with Cerebral Palsy. To meet this purpose an observational analytical study will be performed, the approval of which will be obtained from the institutional review board. The samples will be collected from tertiary care centres or from special and integrated schools. A purposive sampling technique would be used to collect data from school going children with cerebral palsy between 9-12 years of age of GMFCS score I and II. Children with moderate to severe disability of IQ levels, will not be included in the study. The data collection, assessment and analysis shall be done as per the STROBE statement guidelines. The impact of disability or the barriers will be measured through the lifestyle assessment questionnaire for CP children, which would be answered by the parents. Other than this for measuring the Quality of life (QOL), Cerebral palsy Quality of Life scale (CPQOL) will be taken. Later, correlation between barriers and QOL will be done using Pearson's correlation coefficient and the effects of barriers will be analysed through regression analysis by SPSS software.

Discussion

Children with CP are prone to have a sedentary lifestyle. Also, the activity levels of children with CP reduces compared to the healthy subjects. The activity and participation levels also change within different GMFCS levels. These children have lower walking activity levels compared to healthy children. Similarly, these children have lower participation levels in schools. In a study, positive correlation was found between impairments, activity limitations and participation of the ICF model. Ko et al evaluated children according to ICF-CY found that there was a decline in body function, activity, learning and application of knowledge, communication and environmental factors. Akmer Mutlu et al, found similar results. Previous studies have shown that increasing the child's participation is one of the most important goals of treatment. However, evaluation of activity and participation in clinical settings may provide an unrealistic image of capabilities in daily life, as this setting is isolated from environmental and personal factors.[11] A significant

difference was observed in the quality of life between the school aged children with cerebral palsy who can ambulate and normal children who can ambulate.[12] School going children with CP has restrictions related to environment factors and personal barriers. Health is a factor that affects happiness subjectively. Pain and physical limitations usually interfere with daily activities and affects or lowers the quality of life.[13] The Korean Institute for Health and Social Affairs reported that 31.2% of disabled children stated that they received discrimination during admission or transfer to elementary schools. In addition, 50.3% of disabled children responded that they have been socially discriminated by similar aged students.[14] Knowledge of the factors that influence participation from the perspectives of the children and their parents provides information that can be used to design services and supports to enhance participation. The benefits of physical activity are universal for all children and might have downstream impacts on the adult lives of children who are inactive. This is equally true for children with disabilities. However, for most children with disabilities, being physically active must be integrated in their daily lives. Addressing identified barriers and facilitators to physical activity from the perspectives of children and adolescents with CP and their parents may have the potential to offset the decline in health and function observed in children with disabilities as they move through adolescence and into adulthood. The facilitators and barriers identified provide important theoretical insights into why children and adolescents may or may not choose to participate in formalized physical activity programs.[15] Thus, a more objective outcome measures to evaluate the child's activity and participation in environment is needed. Lifestyle assessment questionnaire for CP gives information of the descriptive profile of the child in various domains such as physical independence, mobility, clinical burden, schooling, economic burden and social integration. Other than this CP-QOL gives an idea about how the child feels about various domains like social well-being and acceptance, feelings about functioning, participation and physical health, emotional well-being and self-esteem and pain and impact of disability. So, this study aims at identifying the different barriers and its influence on the quality of life in school going children.

Clinical Implication

Identifying the barriers in school going children with CP will help the therapist to get a better understanding of the hurdles faced by the child and be able to plan a treatment protocol focussed more on the child's independence. Quality of life is one of the important aspects through which one attains a better standard of living thus a therapist can work on barriers by modifications in the environment or at personal level and improve the quality of life. Also, the scales used that is LAQ-CP and CPQOL are easy to administer and give an objective measure to check for improvement.

Future direction

Intervention strategies can be designed based on the impact of barriers on the quality of life giving the therapist a guide to form a treatment

protocol which is more patient centered. Modification strategies can be given to the school administration for providing a sense of ease to these children and improving their quality of life. Post intervention data can be collected to see the influence of changes in the QOL. Also, QOL pre and post intervention can be assessed of the parent and child, and can check the influence of it over one another. The same study can be performed for a different set of population eg: ADHD, Downs syndrome etc.

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Declaration of patient consent : The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient's parents have given their consent for patient images and other clinical information to be reported in the journal. The patient's parents understand that his names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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