



ECOLOGICAL BARRIERS AND CHALLENGES AFFECTING THE SOCIOEMOTIONAL DEVELOPMENT OF CHILDREN WITH CEREBRAL PALSY: OPINION REVIEW

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ABSTRACT

Cerebral Palsy (CP) is a group of neuromotor disorders that affects 1 to 4 in every 1000 youth worldwide. Both physical and socioemotional challenges may arise due to physical ability, environmental context, and negative social attitudes around disability. In this article, elements of Urie Bronfenbrenner's 'Ecological Systems Theory' are used to explore the systems and contexts that children grow up in, with the purpose of demonstrating how these factors affect children's socioemotional development. Literature expanding on three major microsystems (the home environment, the school environment, and the medical environment) are examined, connecting individual challenges to broader systemic barriers. Within the home environment, factors such as caregiver well-being, community support, and sociocultural perceptions of CP are significantly related to socioemotional challenges. In the school environment, exclusionary behavior by both peers and teachers as well as need for CP-specific accommodation often lead to feelings of isolation and reduced participation. Finally, the medical environment poses systemic barriers in the form of financial and logistical challenges, stigma around disability, as well as inadequate support in the transition to adulthood. The presence of these barriers further emphasizes the importance of considering socioemotional challenges as an integral part of the experience of CP, and the need for further research and reform within the systems that produce these challenges.

INTRODUCTION

Cerebral Palsy (CP) is the most common neuromotor disorder among children, with a prevalence of approximately 1 to 4 in every 1000 youth worldwide (1). CP results from significant damage to one's central nervous system, resulting in challenges to a child's gross and fine motor skill development as well as their habitual physical activity levels (2,3). While much attention has been given to the physical consequences of CP, it is important to note that there are also many cognitive and emotional difficulties associated with the disorder. For example, Whitney et al.'s 2018 study surveying American children from 6 to 11 years of age found that having CP was correlated with an estimated 390% increase in the odds of acquiring a mental health disorder; these included anxiety and depression, even after accounting for physical ability (4). Given the impact of these associated mental disorders on patient quality of life, research has highlighted the importance of considering the socioemotional development of children with CP in conjunction with their physical development (5).

The complexity of this approach requires an emphasis on children's environmental contexts and highlights the need to adopt a holistic framework for analysis. Urie Bronfenbrenner's 'Ecological Systems Theory' can be used for this purpose, as it is tailored towards understanding how children influence and are influenced by their environmental and sociological contexts (6). Bronfenbrenner highlighted the impact of different systems, from microsystems (consisting of interpersonal relationships) to macrosystems (consisting of social attitudes and culture) on development (6,7). This article aims to examine the interplay between individual, community, and systemic factors and how they can affect the lives of children with CP as well as the support networks around them. Potential barriers will be identified

in three major microsystems and their macro connections: the home environment, the school environment, and the healthcare environment (6). It is important to note that this article does not contain an exhaustive list of all the systems and elements that can influence a child's life but rather expands on a select few of the major factors at play.

METHODS

Articles written or translated in English were reviewed. Databases including Pubmed, MEDLINE, and Cochrane were consulted. Literature and gray literature were also reviewed using search engines such as Google and Google Scholar. Searches included terms related to the experiences of children with CP with regards to familial support, teacher and peer interactions, and intervention accessibility in home, school, and medical environments. Studies, barriers, and key points were synthesized based on the reviewed articles.

THE HOME ENVIRONMENT - FAMILY, SUPPORT, AND COMMUNITY

Within the home environment, parents and caregivers are able to engage with their children in a manner that cultivates their autonomy and fosters positive attitudes and identities (8). This is a principle used in family-centered care, a rehabilitation approach widely used by healthcare providers that recognizes the positive role families can have on their child's development (9). Caregivers also play an integral role in supporting their children's social participation and development. Murphy et al.'s survey for parents of children from 5 to 18 years found a positive correlation between parents' efforts to improve socialization and child psychosocial and emotional health (10). It is important, then, that families be supportive of their children as they grow up.

While caregivers can have an overwhelmingly positive impact on their children's health and participation, potential for negative impact also exists. Within Bronfenbrenner's Ecological Model, community and friends interacting with family creates a mesosystem (6). It is through community that opportunities arise to support families and children (11). However, it has been suggested that caregivers experiencing high amounts of stress and low familial or community support can negatively affect a child's behavioral development (12). This may not be a unidirectional correlation, as it is also possible that behavioral problems can affect caregiver stress in return (13). In addition to this, a 2021 cross-sectional study examining 300 Chinese toddlers with CP revealed an association between anxiety amongst primary caregivers, increased child emotional dysregulation, and decreased child socioemotional competence (12). Given that caregivers do play a role in encouraging social participation, a close connection may exist between the mental and emotional wellness of a

child's caregiver and the child themselves.

On an individual level, it has been suggested that parental well-being is related to the physical ability of their child with CP. In a couple cross-sectional studies, parents of children who experienced more severe forms of CP indicated that they felt greater amounts of stress on average (14,15). Again, this may present greater risk for children's behavioral development (12). One theory states that increased caregiving demands associated with greater physical limitations put more strain on caregivers, worsening stress and mental health (14). However, this theory has been disputed by other researchers who have argued that a child's family context and the presence of support systems carry greater weight than purely physical ability when considering child and caregiver socioemotional outcomes (12,16). Regardless, it is likely that parental and child mental health are not exclusively affected by physical ability.

Social views and systems centered around deficits associated with CP can also contribute to parents' experiences caring for their children. A systematic review by Smith and Blamires reported that some mothers felt isolated from and marginalized by family, friends, and communities (17). From an accessibility standpoint, a lack of universally inclusive spaces in the community can restrict family participation, and from a cultural perspective, shame and stigma around disability can lead to social isolation (17,18). This represents another barrier that influences microsystems and mesosystems, reducing a child's opportunities for physical and socioemotional development. Additionally, it is important to address the reality that gender-based discrepancies often exist in both the provision of care and the adoption of a caregiving role. Mothers often struggle to meet additional CP-related needs within a patriarchal society that sets their role as the primary caregiver (17). This was identified in a study that employed a feminist biographical approach, which emphasized the importance of gender-conscious thinking when examining how health and educational systems impact the lives of individuals with CP (19). With this factor in mind, multiple personal, relational, and cultural challenges create greater pressure for the parents of children with CP, which has the potential to impact children's development and participation.

THE SCHOOL ENVIRONMENT - TEACHERS, FRIENDS, PARTICIPATION

Schools are environments where microsystems involving stakeholders such as parents can interact with mesosystems and macrosystems involving public policy. This unique intersection plays a role in a child's socioemotional development. Children spend a considerable amount of time interacting with the school system and schools are an important avenue through which children learn knowledge, gain skills, and develop relationships between both peers and mentors that shape

the development of their identity and aid in future pursuits (20). However, this process is not always positive, especially in the context of CP. Negative societal attitudes and stigma towards children with disabilities can indirectly or directly influence how schools interact with children with CP in both supportive and isolatory manners. On a macro level, it's important to recognize that many institutions are fundamentally designed in ways that cater towards the typical majority. This can pose many challenges for children with CP, who often lie outside of this majority in many institutions. A cross-sectional study from the 2016 National Survey of Children's Health found that children with CP have greater difficulty forming friendships and greater rates of victimization by bullies than typically developing children (21). Furthermore, literature suggests that greater difficulty with friendships and greater rates of bullying lead to lower levels of physical activity in children with CP (21).

Social exclusion is largely implicated in both bullying and decreased participation in all aspects of the school environment. A qualitative study by Lindsay and McPherson shows that children with CP often have negative experiences with school due to social exclusion, with this exclusion occurring at three different levels: institutional, teacher, and peer (22). Institutional exclusion is mainly caused by the presence or absence of accommodations. As a result of the absence of accommodations, children with CP are often excluded from participation in many school activities, especially those involving physical activity (22). However, even the presence of accommodations can lead to further exclusion, as they can highlight differences in physical ability and lead to a feeling of isolation from typically developing children (23). The literature shows that if institutional exclusion is present, teacher and peer exclusion are more likely to occur (22). Teacher exclusion primarily occurs when teachers lack adequate knowledge about CP. This lack of knowledge can cause children with CP to be excluded from activities, such as gym class or recess, out of a well-intentioned but misguided fear for their safety (22). More broadly, this focus on a child's limitations instead of their abilities is very harmful to socioemotional development (21). In terms of peer exclusion, two different types of peer exclusion were reported in the literature: implicit exclusion and explicit exclusion. Implicit exclusion occurs when children with CP were excluded as a result of peers' lack of understanding surrounding disability. Explicit exclusion, on the other hand, occurs when peers intentionally bully children with CP verbally and even physically (22). Children with CP often express feelings of isolation due to being unable to receive support for their experiences with exclusion and bullying; this often leads to feelings of shame and negative self-concept (22). These findings highlight how the school environment can often be a difficult place for children with CP.

However, it is important to highlight that not all experiences with the school environment are negative.

Another qualitative study by Taylor et al. demonstrates that children with CP were able to have positive experiences with school when instilled with a sense of belonging in the classroom setting (23). This clearly indicates the importance of ensuring that children with CP are included in all aspects of the school environment and provided ample opportunity to develop meaningful relationships with their peers. This can take the form of learning alongside their peers, as well as a focus on their abilities instead of limitations (23). Children with CP have stated that knowledgeable and informed teachers and educational assistants make a meaningful impact on their learning, participation, relationships, and sense of community (23). However, literature shows that teachers often feel unsupported and unequipped in this area, highlighting the importance of providing advanced educator training and resources (23-25). Communication between health care professions, teachers, parents, and students - both with and without CP - was also found to be of high importance in fostering a positive school environment (23,26). All of the above studies highlight the importance of an inclusive school environment for children with CP and how microsystem-level factors of the ecological model can impact the physical and socioemotional development and well-being of children with CP.

THE MEDICAL ENVIRONMENT - COST, EDUCATION, ACCESSIBILITY

Children growing up with CP interact more frequently and intensely with the healthcare system, which can have significant socioemotional ramifications. This is compounded by the fact that there are often significant barriers to the fulfillment of their increased healthcare needs. Geographical access plays a significant role in the lives of many individuals with CP, as seen by the absence of wheelchair-friendly infrastructure in the transportation system or even the increased distances that caregivers must regularly navigate to bring their child to appointments (27). This is especially salient for rural areas, which often lack specialized pediatric neurology centers or clinics required to treat children with CP. A study conducted in 2021 on the out-of-pocket costs of accessing healthcare for individuals in rural areas in British Columbia established an average transport cost of \$856, with the average distance traveled being 1966 km (28). Interviews with participants also revealed that in some cases, this cost as well as the cost of lost wages led to a hesitancy or outright refusal to access specialized medical care (28). At a systems level, support for these monetary and time costs remain scarce; only 14% of participants indicated that they received any form of financial support through the government or an external organization (28). A 2020 study on the financial cost of CP in Canada estimated that out-of-pocket expenses are approximately \$4,212 per year for individuals with CP, compared to an estimated \$84 for those without CP (29). This is most significant in the context of lower household incomes, exacerbating the already high time

requirements caregivers must devote to transporting and supporting their child with CP at appointments (28). Furthermore, qualitative interviews with parents found that the healthcare system often does not adequately educate caregivers about the nature of CP, which may cause misperceptions of either the healthcare system or their care needs (27,30,31). This is particularly important in the context of CP with comorbidities that may impact communication such as deafness, as well as in the context of cultural beliefs and practices that may result in further stigmatization (32).

Additionally, navigating healthcare systems can be difficult for patients with CP when combined with societal stigma associated with neurodisability (27). Given the interrelation between physical therapy and enjoyment of physical activity for many children with CP, it should be noted that the above barriers may ultimately have impacts at an ecological level. For example, an inability to access care that would improve a child's range of motion or physical ability may result in a lower level of physical ability and typically a corresponding decrease in perceived self-efficacy (32). This may prove to be a driver of physical discomfort, leading to increased risk of self-consciousness (33,34). It may also lead to decreased participation in physical activities, despite focused interviews with children showing a general willingness and desire to participate (33,34).

Finally, a key area of the medical environment that significantly impacts socioemotional development pertains to the transition from pediatric to adult-oriented health systems. An interview of 14 children with CP in Canada revealed significant points of tension that children often encounter as they navigate or prepare for transition into adult care (35). Children often become acquainted with the pediatric medical systems, establishing trust with healthcare professionals (36). As a result, fear and apprehension is often noted amongst children with CP when thinking about a future transition out of this familiar system. One participant in the above study felt this was centered around uncertainty about seeking care for symptoms of CP, such as pain, while others noted the contribution of feeling uninformed or unsupported by the medical system in their worries (35). At the micro level, children with CP build strong and longitudinal bonds with specialist physicians and pediatricians as a by-product of their close involvement with their health (37). While this is incredibly beneficial in the context of pediatric care, the seemingly abrupt termination of these bonds at the age of 18 can lead to feelings of sadness and abandonment in leaving the pediatric system (35). From an ecological perspective, it's clear how structural factors in the medical system — such as the sharp delineation between childhood and adulthood — contribute to socioemotional challenges for children with CP.

CONCLUSION

It is clear that, due to the complex interplay of factors ranging from family to broader societal attitudes, the barriers to typical socioemotional development in the context of CP should not be considered in isolation. These factors are critical to the design and implementation of new health and educational supports for individuals with CP, with full consideration of their downstream implications in another context. For example, a novel assistive technology device may bring additional physical mobility, but it may also impose a financial burden on caregivers or cause social isolation within the school setting. While CP is primarily a physical disorder, the reaction to this disorder at all ecological levels presents a unique set of challenges that can influence socioemotional development as well as physical development beyond the limitations of CP. It is often the case that the root cause of a barrier within one system lies within the purview of another, emphasizing the importance of interdisciplinary and holistic care for individuals with CP. Further research is required to better understand the nature of these interactions, and how they ultimately intertwine to create the landscape that children with CP and their caregivers must navigate today.

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