





Lived Experience of Individuals with Cerebral Palsy Regarding Harms and Social Interactions in the Marginalized City of Parand

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ABSTRACT

Objective: This study aimed to explore the lived experiences of individuals with cerebral palsy regarding the harms and social interactions they encounter in their daily lives.

Methods and Materials: Using a qualitative phenomenological approach, this research investigated the social and experiential challenges faced by individuals with cerebral palsy. The statistical population included 150 individuals with cerebral palsy, from which 15 participants (aged 30 to 45) were purposively selected from the Positive Life Center in Parand, Iran. Data were collected through in-depth semi-structured interviews that continued until theoretical saturation was reached. The interviews were audio-recorded, transcribed, and analyzed using Colaizzi's method. Ethical considerations were strictly observed throughout the process, including informed consent and assurance of confidentiality. The study focused on individuals who had lived with cerebral palsy since childhood and were currently married.

Findings: Analysis of the interviews led to the identification of 43 specific limitations categorized under eight overarching domains: (1) limitation in sharing social experiences, (2) limitation in employment and education, (3) limitation in social activities, (4) limitation in managing daily affairs, (5) limitation in cultural and psychological experiences, (6) limitation in health and treatment experiences, (7) limitation in the use of technology, and (8) limitation in independence and self-sufficiency. Participants reported substantial barriers in communication, social inclusion, accessibility, emotional well-being, and autonomy, all of which influenced their quality of life and social integration.

Conclusion: The findings underscore the complex, multidimensional challenges faced by individuals with cerebral palsy in their social environments. These results highlight the need for inclusive policy-making, targeted support services, accessible infrastructure, and awareness-building initiatives to enhance the social participation and quality of life for this population. Addressing these limitations is essential for promoting equity, reducing social isolation, and empowering individuals with cerebral palsy to lead independent and meaningful lives.

Keywords: Cerebral palsy, lived experience, social interaction, social harms, phenomenology.

1. Introduction

In recent decades, remarkable advances in medical science and modern technologies have created new possibilities for enhancing the quality of life for individuals with cerebral palsy. Despite these advances, individuals with cerebral palsy continue to face numerous challenges and barriers that significantly impact their social interactions and relationships (Jiang et al., 2024; Riquelme et al., 2024). Cerebral palsy, as a complex neurological disorder, affects not only motor functions and muscle coordination but also the daily life and social engagement of those affected (Delavar et al., 2019; Shilesh et al., 2023). Understanding the multifaceted challenges encountered by this population provides valuable insight into the development of effective support programs and social policies to promote their inclusion and participation in society (Babaei et al., 2014; Faccioli et al., 2023).

This study aims to explore the lived experiences of individuals with cerebral palsy by presenting contemporary approaches and strategies derived from their narratives. It seeks to foster a more compassionate and dynamic society by amplifying the voices of individuals with cerebral palsy. Beyond its contribution to academic understanding, the present research offers practical value in guiding the design of impactful social interventions. These individuals demonstrate admirable perseverance and resilience in confronting their daily challenges and actively seek solutions that enable them to lead meaningful and dignified lives (Baghdadi et al., 2020). In the face of physical limitations, they draw strength from their psychological resilience, highlighting the transformative power of will and faith in overcoming barriers (Delavar et al., 2019; Sierkov, 2024).

Additionally, this study seeks to cultivate empathy and respect among the general population by providing deeper awareness of the lived realities of individuals with cerebral palsy. Promoting societal understanding of their needs and experiences can contribute to building a culture that values diversity and encourages more inclusive social engagement (Otube & Karia, 2023; Vameghi et al., 2015). Consequently, conducting this study is not only a step toward supporting people with cerebral palsy but also a catalyst for enhancing social cohesion and cultural sensitivity. The lack of comprehensive research on this population may adversely affect various stakeholders, including individuals with cerebral palsy, their families and caregivers, and support organizations (Alizad et al., 2010; Pour Ahmadi et al., 2008).

From the perspective of individuals with cerebral palsy, the absence of in-depth studies can contribute to societal misunderstanding of their needs and limitations, potentially leading to feelings of marginalization and hopelessness (Otube & Karia, 2023; Vameghi et al., 2015). Limited access to accurate information also places additional burdens on families and caregivers, who are in need of evidence-based guidance and support (Pour Ahmadi et al., 2008). Support and social service organizations, aiming to deliver adequate assistance, may implement ineffective programs in the absence of valid data, ultimately delaying improvements in the living conditions of this population (Babaei et al., 2014; Olusanya et al., 2022).

Furthermore, insufficient understanding of the specific needs and challenges of individuals with cerebral palsy can foster social discrimination and threaten equity. Encouraging active engagement with this population and deepening societal awareness of their lived conditions can reinforce the social fabric and have lasting impacts on human rights and cultural development (Scheinberg et al., 2006; Vameghi et al., 2015). People with physical disabilities often contend with dual struggles: overcoming physical limitations and achieving social acceptance (Baghdadi et al., 2020).

In educational contexts, the experiences of individuals with cerebral palsy are so varied that it is not feasible to apply a single theoretical framework. While some may be absent from school due to frequent medical appointments, hospitalizations, or extended rest at home, others may perform and learn comparably to their neurotypical peers without any special support (Delavar et al., 2019; Hoesi-Hansen et al., 2023). Given the essential need for targeted research in this area, the current study aims to represent the lived experiences of individuals with cerebral palsy regarding the harms and social interactions they face in daily life. Accordingly, the main research question is: What are the harms and social interactions that individuals with cerebral palsy encounter in their everyday lives?

2. Methods and Materials

Given the research problem, the present study employed a phenomenological approach, which is a qualitative research methodology. The statistical population included 150 male and female individuals with cerebral palsy. From this population, a sample of 15 individuals (both male and female), aged between 30 and 45 years, from the "Positive

Life Center" in the new city of Parand, were selected. Sampling was conducted purposively, which is a type of non-probability sampling, and in-depth interviews were used. Interviews continued until the point of theoretical saturation. The individuals studied had been living with this disability since childhood, and all participants were married.

In this qualitative research, data collection was conducted through the technique of in-depth interviews. The arrangement of interview sessions was as follows: due to the interactions between the researcher and the participants, initial coordination was carried out in person. The researcher orally explained the interview topic and its purpose to the participants. Then, a written summary of the study's aim and the core interview questions was provided to the participants. After one week, the researcher coordinated the time and location of the interview with the participants, either in person, via telephone, or using WhatsApp. Before conducting the interviews, the necessary ethical considerations were explained to the participants. After obtaining their consent, they were assured of their right to withdraw and the confidentiality of all personal information throughout the research process. All interviews were conducted at a predetermined time and in an appropriate setting. Each interview lasted between 40 and 130 minutes. Data were collected, recorded, and transcribed over a period of three months.

3. Findings and Results

The analysis and constant comparison of the data led to the identification of 43 limitations experienced by individuals with cerebral palsy, which were categorized under 8 broader domains. Each is discussed below.

Limitation in Sharing Social Experiences

Limitation in sharing social experiences is one of the most significant and complex challenges for individuals with cerebral palsy. This limitation may manifest in various dimensions.

Deficiency in physical communication: Individuals with cerebral palsy may have difficulties in controlling physical movements, which leads to incomplete or restricted physical communication. This can affect physical experiences such as touch or initiating gestures like handshakes.

Challenges in verbal communication: Speech impairments may hinder individuals with cerebral palsy from fully utilizing language for interaction. This may include difficulties in articulation, speech fluency, or even language comprehension.

Experiencing barriers in social spaces: Some social environments are not designed for easy and unobstructed access by individuals with cerebral palsy. This may include difficulties in entering restaurants, shops, or recreational venues.

Limitation in participation in events and activities: Individuals with cerebral palsy may be unable to fully engage in social events and activities such as festivals, weddings, or even family gatherings. This can result in feelings of social isolation.

Limitation in Employment and Education

Limitation in employment is one of the most crucial and impactful restrictions faced by individuals with cerebral palsy. This limitation can appear in several ways across different occupational domains.

Barriers to job opportunities: Individuals with cerebral palsy may encounter difficulties accessing suitable job opportunities that align with their abilities and skills. Some jobs require specific physical capabilities that may be inaccessible to them.

Limitations in performing daily job tasks: Tasks such as commuting, using tools and equipment, or self-care may be challenging for individuals with cerebral palsy.

Barriers to professional advancement: Due to motor impairments, individuals with cerebral palsy may face constraints in career progression, which can reduce opportunities for promotion and access to professional training.

Discrimination and inequity in the workplace: Some individuals with cerebral palsy may experience discrimination in professional environments, including unequal promotion opportunities, lack of proper facilities, and discouragement from participating in team activities.

Difficulties accessing educational resources: These individuals may face barriers in accessing textbooks, digital resources, or other educational tools that could otherwise support their learning.

Insufficient availability of special facilities: Individuals with cerebral palsy require accommodations such as ramps, accessible hallways, and assistive infrastructure in educational settings. The absence of such accommodations can significantly hinder their educational experiences.

Limitation in Social Activities

Limitation in social activities is a significant challenge for individuals with cerebral palsy and can emerge in various aspects.

Difficulties participating in festivals and events: These individuals may face barriers in attending festivals, concerts,

exhibitions, and public events due to accessibility issues at venues.

Limitation in sports participation: Many sports require coordinated and free movement, which may be difficult for individuals with cerebral palsy, making participation in team sports and recreational activities challenging.

Communication difficulties: Individuals may encounter issues in engaging with others, including problems with verbal communication or initiating physical interaction, such as handshakes or proper posture.

Barriers to attending family ceremonies: Family events may pose challenges such as inaccessible locations or inadequate facilities.

Challenges in group activities: Participating in group-based activities such as art classes, music groups, or theater may be difficult, leading to feelings of exclusion and social withdrawal.

Limitation in Managing Daily Affairs

Managing daily tasks is among the most critical challenges for individuals with cerebral palsy, affecting several aspects of their everyday life.

Difficulties with mobility: Individuals may face movement challenges that prevent them from navigating various environments with ease, thereby impacting their ability to complete daily responsibilities.

Self-care limitations: Basic activities such as bathing, dressing, and maintaining personal hygiene may be difficult, requiring assistance from others.

Problems accessing objects and tools: Due to limitations in hand and finger movement, accessing everyday items such as books, writing instruments, or kitchenware may be difficult, complicating routine tasks.

Time management difficulties: Performing tasks may take longer due to movement constraints, making time management particularly challenging.

Difficulties in managing finances: Accessing financial services such as banks or service centers may be difficult, affecting their ability to independently manage financial and tax-related responsibilities.

Limitation in Cultural and Psychological Experiences

Cultural and psychological experiences are significantly impacted in individuals with cerebral palsy.

Religious and spiritual experiences: Accessing religious centers or participating in faith-based activities may be difficult, potentially affecting their spiritual well-being.

Emotional and psychological challenges: Due to limitations in mobility and social interactions, individuals may experience loneliness, depression, or anxiety.

Barriers to psychological services: Access to mental health services can be limited, hindering their ability to receive necessary counseling and therapy.

Limitation in Health and Medical Experiences

Health and treatment-related limitations are fundamental challenges that affect many aspects of daily life for individuals with cerebral palsy.

Restricted access to healthcare: These individuals may face difficulties in obtaining medical services, including reaching physicians, acquiring medications or necessary medical devices, and receiving therapies such as physiotherapy.

Limitations in participating in health programs: Engaging in physical therapy, nutritional plans, or other treatment protocols may be hindered by motor limitations or fatigue.

Limitation in Technology Use

Technology-related limitations are significant barriers for individuals with cerebral palsy in their daily lives.

Restricted access to electronic devices: Individuals may face challenges in using computers, mobile phones, or tablets, limiting their ability to engage with modern technologies.

Barriers to internet access: Difficulties accessing the internet can restrict online communication, news consumption, online learning, and access to educational resources.

Challenges in using communication technologies: Using communication tools such as mobile phones and messaging services may be difficult, limiting their ability to stay connected and participate in digital environments.

Limitation in Independence and Self-Sufficiency

Mobility limitations: Individuals with cerebral palsy may face challenges in moving from place to place, which can result in reduced independence and personal freedom.

Self-care limitations: Activities such as personal hygiene, dressing, and self-maintenance may be difficult and require external support.

4. Discussion and Conclusion

The results of this study revealed 43 distinct limitations experienced by individuals with cerebral palsy, categorized into eight broader domains: limitation in sharing social experiences, limitation in employment and education, limitation in social activities, limitation in managing daily affairs, limitation in cultural and psychological experiences, limitation in health and treatment experiences, limitation in

the use of technology, and limitation in independence and self-sufficiency. Each of these domains reflects complex and interrelated challenges that not only affect the individual's quality of life but also hinder their full social integration. The findings demonstrated that participants frequently encountered obstacles in verbal and physical communication, limited access to educational and professional opportunities, exclusion from community events, difficulty managing daily routines, psychological distress due to isolation, insufficient access to healthcare and therapeutic services, barriers in accessing digital resources, and a reduced sense of autonomy.

The limitation in sharing social experiences—identified as one of the most significant constraints—aligns with findings from Riquelme et al., who highlighted the interconnectedness between proprioceptive challenges and reduced social responsiveness in children with cerebral palsy, suggesting that sensory-motor impairments can impede effective social communication and emotional attunement (Riquelme et al., 2024). Similarly, Otube and Karia emphasized that communication disorders, whether expressive or receptive, are central barriers that prevent individuals with cerebral palsy from engaging in typical peer interactions, often resulting in social exclusion (Otube & Karia, 2023). Moreover, Sierkov noted that insufficient physical rehabilitation support further diminishes these individuals' ability to participate in shared social spaces, reinforcing a cycle of isolation (Sierkov, 2024).

The results related to limitations in employment and education confirm the structural and attitudinal barriers reported in previous studies. Babaei et al. found that individuals with cerebral palsy often lack access to vocational training and inclusive educational environments, contributing to high unemployment rates and restricted professional advancement (Babaei et al., 2014). This is supported by the findings of Olusanya et al., who revealed a global gap in inclusive service provision for young individuals with developmental disabilities, particularly in employment and academic systems (Olusanya et al., 2022). Furthermore, Alizad et al. emphasized the role of family functioning in supporting or hindering educational engagement among individuals with cerebral palsy, suggesting that a supportive family system can partially compensate for institutional limitations (Alizad et al., 2010).

Regarding social activities, the results demonstrated that individuals with cerebral palsy often face physical and environmental barriers that hinder participation in group events, sports, and public gatherings. These findings align

with Yahagi et al.'s research, which indicated that individuals with severe motor impairments are less likely to engage in recreational activities due to both physiological limitations and the inaccessibility of facilities (Yahagi et al., 2024). Additionally, Jiang et al.'s bibliometric analysis underscored the persistent underrepresentation of social integration issues in the research agenda surrounding cerebral palsy, further highlighting the importance of studies that address these limitations (Jiang et al., 2024). These challenges in social participation also have psychological ramifications, as individuals reported heightened feelings of loneliness and detachment from their communities.

Limitations in managing daily affairs, as reported by participants, ranged from mobility constraints to difficulty handling personal and financial tasks. These challenges echo the findings of Delavar et al., who emphasized the need for adaptive equipment and environmental adjustments to facilitate independent living for individuals with cerebral palsy (Delavar et al., 2019). Pour Ahmadi et al. also highlighted how co-occurring conditions, such as epilepsy, can exacerbate challenges in daily functioning, underscoring the multidimensional nature of disability in this population (Pour Ahmadi et al., 2008). Vameghi et al. further demonstrated that neurofeedback interventions targeting cognitive and motor functioning can improve attention and self-regulation, potentially reducing dependency on caregivers for routine tasks (Vameghi et al., 2015).

Cultural and psychological limitations were another core theme identified in this study. Participants reported difficulty accessing religious spaces, engaging in communal spiritual practices, and receiving psychological support. These experiences mirror the findings of Baghdadi et al., who noted that emotional and psychological burdens are often intensified by social stigma and limited psychosocial support networks (Baghdadi et al., 2020). Faccioli et al.'s systematic review of rehabilitation strategies emphasized the necessity of holistic care that integrates psychological and spiritual well-being into the treatment framework for cerebral palsy (Faccioli et al., 2023). Additionally, Hoei-Hansen et al. stressed the need for early and sustained intervention programs that address not just motor outcomes but also emotional development and quality of life (Hoei-Hansen et al., 2023).

Health and treatment-related limitations were also prominently reported. Participants described restricted access to medical professionals, limited availability of medication and physiotherapy, and difficulty participating in structured health programs. These barriers are consistent

with the findings of Scheinberg et al., who found that even well-established pharmacological interventions such as baclofen are underutilized due to systemic gaps in service delivery and monitoring (Scheinberg et al., 2006). Shilesh et al. further demonstrated that effective physical therapy interventions remain inaccessible for many due to economic and logistical challenges, despite their proven efficacy in improving mobility and quality of life (Shilesh et al., 2023). These systemic healthcare barriers underscore the importance of inclusive policies and infrastructure tailored to the unique needs of this population.

Technology-related limitations emerged as a newer but equally critical theme. Many participants expressed difficulty accessing and using modern communication tools and digital platforms. These limitations hindered not only their social communication but also their ability to participate in educational and professional activities. These findings are consistent with recent literature emphasizing the digital divide affecting individuals with disabilities. Otube and Karia pointed out that without assistive technologies and accessible interfaces, digital inclusion remains a distant goal for individuals with cerebral palsy (Otube & Karia, 2023). Similarly, Olusanya et al. called for urgent investments in inclusive digital health infrastructure to bridge this gap (Olusanya et al., 2022).

Lastly, limitations in independence and self-sufficiency were central to the participants' narratives. Challenges in mobility and self-care compromised their autonomy and increased reliance on family or caregivers. These outcomes are supported by the findings of Alizad et al., who highlighted that autonomy is directly related to the severity and type of cerebral palsy, and that greater support is needed to foster self-efficacy in daily living tasks (Alizad et al., 2010). Faccioli et al. advocated for intervention programs that promote independence through skill-based training and environmental modifications (Faccioli et al., 2023).

5. Limitations & Suggestions

This study, despite its contributions, has certain limitations. First, the sample size was limited to 15 participants, all residing in one marginalized urban area, which may restrict the generalizability of the findings. The phenomenological design, while rich in detail, also introduces a degree of subjectivity inherent in qualitative interpretation. Additionally, all participants were adults with a childhood-onset diagnosis and were currently married, which may not reflect the experiences of adolescents, single

individuals, or those with recent diagnoses. The absence of caregiver or clinician perspectives further narrows the contextual understanding of the challenges faced by individuals with cerebral palsy.

Future research should aim to incorporate larger and more diverse samples, including individuals from rural and affluent urban areas to capture a broader range of experiences. Longitudinal studies could provide insight into how these limitations evolve over the life span and in response to different interventions. Including multiple stakeholder perspectives—such as family members, caregivers, educators, and healthcare providers—could also enrich the findings and help triangulate data. Moreover, future studies could focus on the intersection of cerebral palsy with other conditions such as autism or sensory impairments to explore compounded challenges in social and functional domains.

Practitioners and policymakers should prioritize the development of inclusive environments that facilitate participation for individuals with cerebral palsy across all aspects of life. This includes ensuring physical accessibility in public spaces, providing assistive technologies in schools and workplaces, and integrating mental health services into rehabilitation programs. Community-based interventions should be designed to promote social integration, while educational institutions must offer individualized supports and accommodations. Finally, digital literacy and access should be improved through subsidized tools and user-friendly platforms, allowing individuals with cerebral palsy to fully engage with modern society.

Authors' Contributions

Authors contributed equally to this article.

Declaration

In order to correct and improve the academic writing of our paper, we have used the language model ChatGPT.

Transparency Statement

Data are available for research purposes upon reasonable request to the corresponding author.

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Declaration of Interest

The authors report no conflict of interest.

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Ethical Considerations

The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants.

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