

Original Article

Parental and Physical Therapists' Perspective on Physical Therapy Goals for Children with Cerebral Palsy

Rahila Suleman^{1*}, Ayesha Shaukat¹, Areej Tasnim², Rida Razaq Janjua¹, Irum Zahoor³, Memoona Zaryab⁴

¹Lecturer Physiotherapy, Islamabad College of Physiotherapy, Margalla Institute of Health sciences, Rawalpindi, Pakistan.

²Margalla Institute of Health sciences, Rawalpindi, Pakistan.

³Physical Therapist, Rawalpindi Institute of Cardiology, Rawalpindi, Pakistan.

⁴Riphah International University, Islamabad, Pakistan.

*Corresponding Author: Rahila Suleman, Lecturer Physiotherapy; Email: rahilasuleman59@gmail.com

Conflict of Interest: None.

Suleman R., et al. (2024). 4(1): DOI: <https://doi.org/10.61919/jhrr.v4i1.400>

ABSTRACT

Background: Cerebral palsy (CP) is a complex neurodevelopmental disorder that significantly impacts the quality of life of affected children and their families. Understanding the perspectives of parents and therapists regarding the goals and expectations for children with CP is crucial for effective treatment planning and implementation.

Objective: The objective of this study was to synthesize the experiences and challenges faced by parents of children aged three to six years diagnosed with CP, with a focus on the specialized physical and occupational therapy in a rehabilitation setting. The study also aimed to examine the perspectives of both therapists and parents about the establishment of treatment goals and the elements influencing the successful attainment of these goals.

Methods: This qualitative study involved structured interviews with a sample of 10 patients, their parents, and therapists experienced in treating children with CP. The recruitment was achieved through convenient sampling. Data collection and analysis spanned 8 months, adhering to ethical guidelines set by the ethical committee of Riphah International University. Analysis was conducted using SPSS version 25.

Results: Parents generally reported positive experiences in achieving set goals for their children's development. A divergence in preferences was noted between physicians, who emphasized normal or symmetrical movements, and parents, who often favored compensatory movement and adapted equipment. The study highlighted the importance of parental involvement, family dynamics, and the need for therapists to engage in discussions about these aspects. Financial constraints and increasing caregiving responsibilities were significant challenges faced by parents.

Conclusion: The study underscores the importance of understanding and respecting the perspectives of families in therapeutic settings. Establishing trusting relationships between families and therapists is crucial for effective treatment planning. This study contributes to the body of knowledge on family-centered approaches in managing CP, emphasizing the need for individualized treatment plans that align with family goals and circumstances.

Keywords: Cerebral Palsy, Family-Centered Therapy, Parental Perspectives, Therapeutic Goals, Qualitative Research, Child Rehabilitation.

INTRODUCTION

Cerebral palsy (CP), a neurodevelopmental disorder characterized by a lifelong deterioration beginning in infancy, presents a complex challenge in defining and managing its impact. Historically, the term "CP" has been difficult to pinpoint, leading to the adoption of a universally accepted definition revised in 1964, which emphasizes the disorder's impact on movement and posture abilities due to lesions or injuries in the developing brain (1,2). This definition, focusing primarily on motor impairments, has been foundational in understanding CP's broader consequences, including potential reductions in physical mobility and increased likelihood of cognitive, sensory, communication, epilepsy, and behavioral issues (3,4).

Understanding the epidemiology of CP is critical for formulating prevention strategies and estimating the necessary medical and supportive services for affected families. Data from cerebral palsy registries, particularly outside the United States, have provided

insights into prevalence patterns. For instance, an increase in CP incidence was observed in Sweden between the late 1960s and mid-1980s, with rates ranging from 1.3 to 2.5 per 1000 live births, particularly in infants with spastic or ataxic diplegia. In contrast, data from Western Australia showed a stable incidence of CP, while the Mersey region of the United Kingdom reported a higher prevalence, often in conjunction with malnutrition and other congenital anomalies like hydrocephaly and schizencephaly (7,8,9,10). Factors such as maternal illness, fever during pregnancy, genetic abnormalities, prenatal infections, and environmental triggers have been identified as increasing the risk of developing CP, with some studies suggesting preventative approaches such as administering magnesium sulfate post-childbirth (11).

The diagnosis of CP involves assessing neurodevelopmental outcomes and neuroimaging techniques, which are critical in determining the pathogenesis of CP in preterm and term infants (12,13). Conditions like choreoamnionitis have been linked to a significantly increased risk of CP in newborns, with a reliable diagnosis possible by the age of two years. The Gross Motor Function Classification System (GMFCS) has emerged as a reliable and valid prognostic tool in this context.

The presence of a child with CP in a family introduces additional challenges, often leading to altered family dynamics and increased stress levels, especially among caregivers. Studies, such as one conducted in Bangladesh, have highlighted the high stress levels among mothers of children with CP, underscoring the impact of the child's disability on family life, including behavioral and sleep issues (14). Victims of CP face functional difficulties related to their central nervous system, manifesting early in life and affecting daily activities, leading to distress not only for the children but also for parents and caregivers. School reports have indicated that children with CP, especially those with behavioral and intellectual issues, are at greater risk of victimization, peer rejection, and social isolation.

In terms of interventions, activity-based approaches have been found more effective in preventing functional limitations in children with CP compared to impairment-based methods (15). Antenatal prevention strategies include smoking cessation during pregnancy, screening and treatment for bacteriuria, antiplatelet administration to prevent preeclampsia, and caffeine therapy in preterm infants. Postnatal steroid use in premature infants has been linked to an increased risk of CP, suggesting a need for cautious use of such treatments. Magnesium sulfate administration has shown promise in improving neurodevelopmental outcomes in fetuses (16). This research aimed to examine how concepts of family-centered service, realistic goal setting, and quality of care are integrated into CP recovery programs. It focused on the perspectives of parents with CP children regarding goal setting and the importance of enabling parents to make their own decisions while highlighting the necessity of receiving support from therapists. The study's objective was to explore the experiences of parents with a CP child in relation to goals and goal setting, thereby contributing to a more nuanced understanding of the challenges and needs of families navigating the complexities of CP management.

MATERIAL AND METHODS

In this study, a qualitative research design was employed to gain in-depth insights into the experiences and perspectives of individuals affected by cerebral palsy. The focus was on conducting interviews with a carefully selected group of participants, which included both patients and their parents, as well as therapists specializing in cerebral palsy treatment. The research was conducted under the auspices of the National Institute of Rehabilitation and Medicine (NIRM) in Islamabad, which provided the necessary support for data collection.

Participant recruitment was achieved through convenient sampling techniques, ensuring a diverse range of perspectives. The study included 10 patients, both male and female, aged between 3 to 6 years and diagnosed with cerebral palsy. Parents of these children and therapists with a minimum of three years of experience in treating children with cerebral palsy were also included. This approach was guided by the principle of data saturation, prioritizing depth of understanding over a large sample size.

The ethical aspects of the study were stringently adhered to, in accordance with guidelines set by the ethical committee of Riphah International University. Prior to data collection, informed consent was obtained from all participants via telecommunication calls. This process emphasized confidentiality, respect for the participants' rights, and the voluntary nature of participation, including the right to withdraw from the study at any stage without any disadvantage or risk.

Data collection and analysis were conducted over a span of 8 months. The data collection process involved structured interviews, which were meticulously planned and executed to ensure comprehensive coverage of the research objectives. Thematic analysis was done. The quantitative part of data gathered were then subjected to thorough analysis using the SPSS version 25 software. This analytical approach was chosen for its robustness in handling qualitative data, allowing for an in-depth exploration of themes and patterns emerging from the interviews.

The methodology of the study was crafted to ensure credibility and reliability of the findings. The diverse participant selection, ethical considerations, and rigorous data analysis contributed to a comprehensive understanding of the experiences and challenges faced by individuals dealing with cerebral palsy, encompassing the perspectives of patients, their parents, and therapists.

RESULTS

Table 1 Distribution of Participants by Gender, Medical Diagnosis, and Gross Motor Function Classification System Levels

Variables	Descriptive Categories	Frequency (%)
Gender	Male	6 (60%)
	Female	4 (40%)
Medical Diagnosis	Spastic Hemiplegia	4 (40%)
	Athetoid Type of CP	1 (10%)
	Spastic Quadriplegia	3 (30%)
	Ataxic Type of CP	2 (20%)
Gross Motor Function Classification System	Level I	3 (30%)
	Level II	2 (20%)
	Level III	3 (30%)
	Level IV	1 (10%)
	Level V	1 (10%)

This table presents a detailed breakdown of the study's participants, categorized by gender, medical diagnosis, and their level on the Gross Motor Function Classification System (GMFCS). In terms of gender, 60% of the participants were male (6 out of 10), while 40% were female (4 out of 10). This distribution provides a balanced gender perspective in the study.

Regarding medical diagnosis, the majority of the participants, 40%, were diagnosed with Spastic Hemiplegia. This was followed by Spastic Quadriplegia, representing 30% of the participants. Those diagnosed with Ataxic Type of CP constituted 20%, and only 10% had Athetoid Type of CP. As for the Gross Motor Function Classification System, the levels of the participants were distributed as follows: 30% were at Level I, 20% at Level II, and another 30% at Level III. The remaining participants were less represented, with 10% at Level IV and 10% at Level V.

Table 2 Thematic Table

Main Themes	Description	Sub-Themes and Illustrative Quotes
1. Physical Changes of Cerebral Palsy Patient	Participants discussed the physical changes experienced due to CP and emphasized the importance of acknowledging improvements in quality of life.	(a) Movement: "Our goal is to see our child normal and it is very important because it is very painful to see the child in abnormal condition." (Mother of a 5-year-old girl, GMFCS level V)
		(b) Posture: "Main goal was that our child could at least fulfil his basic physical needs himself, but our child's condition is very worse and now we want that at least he can change his side/posture himself." (Father of a 3-year-old boy, GMFCS level V)
2. Social Changes (Community Based) of Cerebral Palsy Patient	Questions on social changes revealed insights into community acceptance and participation in social events.	(a) Acceptance by Community: "Our family and society are very sympathetic. Being Muslim and Pakistani, our society is very helpful and accepts our children wholeheartedly."
		(b) Attendance at Social Events: "I belong to a department and society where I often go to gatherings alone as well as with my children. Society supports in the best way it can. I have no complaint to society."
3. Family–Professional Partnership	The development of a partnership between family and professionals was explored for child recovery progress.	(a) Time to Develop Relationship: "With time and understanding, parents gained the self-confidence to appreciate their own input in decision-making."

Main Themes	Description	Sub-Themes and Illustrative Quotes
		(b) Shared Decision-Making: "Parents and therapists share responsibilities in decision-making, balancing guidance and input."
		(c) Open Communication: "Parents appreciated sharing reflections and constructive feedback and wanted to be asked about their expectations."
4. Therapist Perspective for CP Child	Therapists' perspectives on their role and relationship with CP patients and their families.	(a) Respect and Trust by Parents: "Do not give false hope to parents of patients, tell them clearly about the condition of the patient." (b) Therapist–Child Relationship: "Therapists understood the child’s most important problems and needs, and that the therapist had their child’s best interests at heart."

This table presents a thematic analysis of the qualitative data collected in the study. The main themes encompass the physical and social changes experienced by cerebral palsy patients, the development of family-professional partnerships, and the therapists' perspectives.

Theme 1 focuses on the physical changes due to CP, with two sub-themes: Movement, where parents express a desire to see their child in a normal condition, and Posture, emphasizing the goal for children to at least manage basic physical needs independently. Theme 2 addresses social changes, with sub-themes on community acceptance and participation in social events. This theme highlights the sympathetic and supportive attitude of the community towards families with CP children.

Theme 3 explores the family-professional partnership in the child's recovery process. Sub-themes include the development of relationships over time, shared decision-making between parents and therapists, and the importance of open communication.

Theme 4 presents the therapists' perspective, focusing on earning respect and trust from parents and understanding the child's needs and best interests.

Each theme and sub-theme is supported by illustrative quotes from the participants, providing a deeper understanding of the lived experiences of individuals dealing with cerebral palsy.

Summary of Themes and Sub-themes from Cerebral Palsy Study

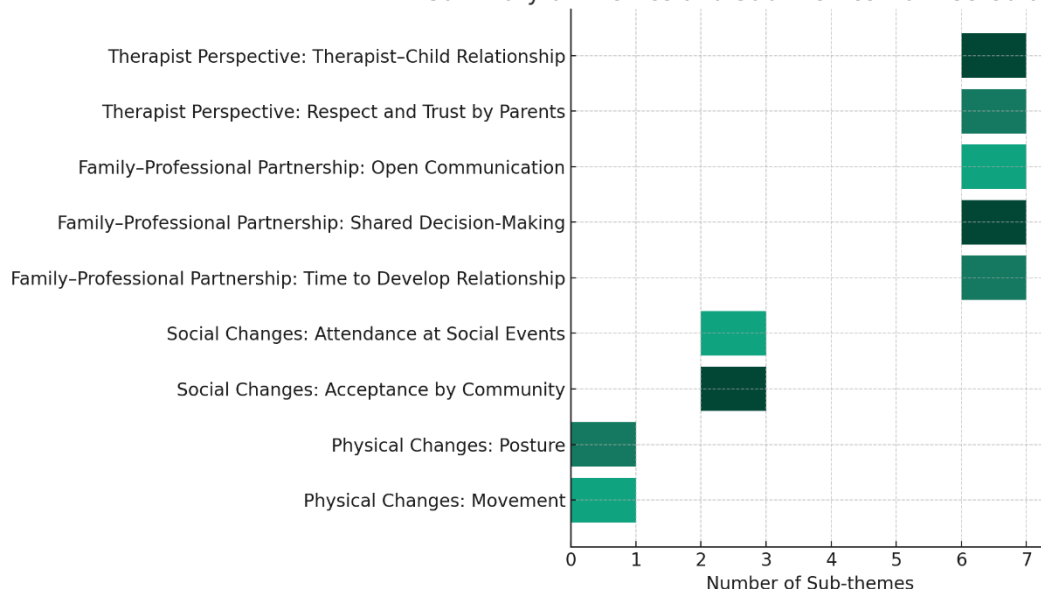


Figure 1 Thematic Summary

DISCUSSION

In this study, we aimed to synthesize the experiences and challenges faced by parents of children aged three to six years diagnosed with cerebral palsy (CP), focusing particularly on their perspectives regarding the objectives and expectations set in a specialized physical and occupational therapy setting. The study revealed that parents generally reported positive experiences in achieving their goals for their children's development (17, 18). A notable finding was the divergence in the preferences of physicians and parents

concerning the children's movements. Physicians typically emphasized achieving normal or symmetrical movements, while parents often preferred compensatory movement strategies and adapted equipment, prioritizing tangible outcomes over conventional mobility approaches.

This preference aligns with the social model of disability, which views disability as a matter concerning both the individual and the community. This perspective was evident in the parents' inclination towards integrating their children into leisure activities and their desire for support, affirming the importance of parental involvement in the long-term welfare of CP children (19, 20). Narratives from caregivers, in this regard, provided valuable insights into addressing the diverse needs of families, underscoring the necessity for therapists to engage in extensive discussions about family dynamics and support.

The study also highlighted additional challenges faced by parents, including financial constraints and increasing caregiving responsibilities over time. These challenges often compounded the stress and guilt within the family structure, especially when there was insufficient understanding of family dynamics or lack of communal support centered around the children. The importance of establishing reliable connections with the family was emphasized, particularly in aligning proposed solutions with the parents' views, interests, goals, and lifestyle (19, 20).

From a therapeutic standpoint, the study shed light on the influence of therapists' own perspectives about disability and goals related to mobility. It is crucial for therapists to understand and respect the perspectives and values of families, as these significantly influence treatment decisions. The absence of concrete research guiding therapeutic decision-making, coupled with varying goals and aspirations of parents, highlights the need for establishing trusting relationships with families. Such relationships facilitate open and honest discussions of personal perspectives, values, and priorities, ultimately aiming to develop a versatile therapeutic approach that caters to the specific needs of children and families throughout their lifespan (21).

One limitation of the study was its inability to include perspectives from family members who declined to participate, potentially skewing the results. The study's qualitative nature limits the generalizability of its findings to all families with CP children. However, it provides valuable insights into the perspectives of participating families, a common objective in qualitative research inquiries (22, 23). Further research could benefit from incorporating therapy observations and comprehensive interviews with parents, adolescents, and therapists to gain a deeper understanding of the strategies used in goal setting.

CONCLUSION

In conclusion, the study demonstrated that positive parental experiences with their child's intervention led to increased time dedicated to the child, broader community engagement, opportunities to share experiences with other parents, improved goal-setting skills, and enhanced ability to monitor progress. The need for establishing trustworthy relationships with children was emphasized, highlighting the importance of open discussions about the appropriate level of involvement in goal setting, family values, and specific circumstances. Future research should focus on exploring these aspects in greater depth to enrich our understanding of family dynamics and therapeutic approaches in the context of CP.

REFERENCES

1. Omer A, Moghadam BA, Shadmehr A, Hafeez T, Azfar H, Arif M, et al. Effects of Kinesio Taping and Modified Constraint-Induced Movement Therapy on Upper Extremity Function, Quality of Life, and Spasticity in Individuals Recovering from Stroke. *Journal of Health and Rehabilitation Research*. 2024;4(1):167-72.
2. Tahir M, Tehzeeb K, Javaid F, Khan UA, Ayyaz A, Usama M. EFFECTS OF ROUTINE PHYSICAL THERAPY WITH AND WITHOUT HIGH INTENSITY INTERVAL TRAINING ON BALANCE, QUALITY OF LIFE AND FUNCTION IN PARKINSON'S DISEASE PATIENTS. *Journal of Population Therapeutics and Clinical Pharmacology*. 2023;30(19):483-90.
3. Safdar Z, Asghar M, Tahir M. Level of Quality of Life among Post Stroke Patients; A Cross Sectional Survey. *Journal of Health and Rehabilitation Research*. 2023;3(2):299-304.
4. Asghar M, Safdar Z, Tahir M. Quality of life and functional Outcomes among Burn Patients: A Cross Sectional Survey. *Journal of Health and Rehabilitation Research*. 2023;3(2):293-8.
5. Tahir M, Maqsood M, Azhar N, Safdar Z, Amin U, Waheed TS. Association of Knee Pain in Long Standing and Sitting among University Teachers: Association of Knee Pain in University Teachers. *The Healer Journal of Physiotherapy and Rehabilitation Sciences*. 2023;3(1):314-21.
6. Khan MT, Shareef F, Farooq U, Tahir A. Impact of Facility Characteristics on Patient Safety, Patient Experience, and Service Availability for Procedures in Hospitals. *Pakistan Journal of Rehabilitation*. 2022;11(1):136-44.

7. Makki ARK, Tahir M, Amin U, Tabassum MMB, Kamran M, Tahir F. Mechanism of Meniscal Injury and its Impact on Performance in Athletes: Meniscal Injury in Athletes. *The Healer Journal of Physiotherapy and Rehabilitation Sciences*. 2022;2(3):232-7.
8. Malik J, Farooq U, Tahir M, Ayyaz A, Khalid Makki AR. Impact of Attending Online Classes on Mental Health Among University Students During COVID-19 Pandemic in Lahore: Impact of Online Classes in Covid-19. *The Healer Journal of Physiotherapy and Rehabilitation Sciences*. 2022;2(2):162-9.
9. Tahir A, Fatima A, Khan MT. Association of depression in patients with fibromyalgia syndrome. *Pakistan Journal of Rehabilitation*. 2022;11(1):174-83.
10. Tahir M, Tariq F, Saeed HW, Nauman M, Usman M, Ali S. Impact of Air Pollution on Respiratory Health of Traffic Wardens in Lahore: Air Pollution and Respiratory Health. *The Healer Journal of Physiotherapy and Rehabilitation Sciences*. 2023;3(7):703-9.
11. Wiart L, Ray L, Darrah J, Magill-Evans JJD, rehabilitation. Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. 2010;32(3):248-58.
12. Kruijssen-Terpstra AJ, Verschuren O, Ketelaar M, Riedijk L, Gorter JW, Jongmans MJ, et al. Parents' experiences and needs regarding physical and occupational therapy for their young children with cerebral palsy. 2016;53:314-22.
13. Kruijssen-Terpstra AJ, Ketelaar M, Boeije H, Jongmans MJ, Gorter JW, Verheijden J, et al. Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review. 2014;40(6):787-96.
14. Aydin R, Nur HJTJoPM, Dergisi RTFTvR. Family-centered approach in the management of children with cerebral palsy. 2012;58.
15. Anttila H, Autti-Rämö I, Suoranta J, Mäkelä M, Malmivaara AJBp. Effectiveness of physical therapy interventions for children with cerebral palsy: a systematic review. 2008;8(1):1-10.
16. Egilson STJSJoCS. Parent perspectives of therapy services for their children with physical disabilities. 2011;25(2):277-84.
17. Gunel MJAOett. Rehabilitation of children with cerebral palsy from a physiotherapist's perspective. 2009;43(2):173-80.
18. Brandão MB, Oliveira RH, Mancini MCJBoPT. Functional priorities reported by parents of children with cerebral palsy: contribution to the pediatric rehabilitation process. 2015;18:563-71.
19. Gibson B, Teachman G, Wright V, Fehlings D, Young N, McKeever PJCc, health, et al. Children's and parents' beliefs regarding the value of walking: rehabilitation implications for children with cerebral palsy. 2012;38(1):61-9.
20. O'Neil ME, Fragala-Pinkham MA, Westcott SL, Martin K, Chiarello LA, Valvano J, et al. Physical therapy clinical management recommendations for children with cerebral palsy-spastic diplegia: achieving functional mobility outcomes. 2006;18(1):49-72.
21. Hinojosa JJTOTJoR. How mothers of preschool children with cerebral palsy perceive occupational and physical therapists and their influence on family life. 1990;10(3):144-62.
22. Peplow UC, Carpenter CJP, pediatrics oti. Perceptions of parents of children with cerebral palsy about the relevance of, and adherence to, exercise programs: a qualitative study. 2013;33(3):285-99.
23. Ketelaar M, Vermeer A, Hart Ht, van Petegem-van Beek E, Helders PJJPt. Effects of a functional therapy program on motor abilities of children with cerebral palsy. 2001;81(9):1534-45.