Research Article

Psychosocial Problems among Parents of Children with Cerebral Palsy in India

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Abstract

Cerebral palsy is the most common cause of motor impairment in children. Parents of children with this neurodevelopmental disorder often face numerous challenges similar to those experienced by other parents of children with disabilities. This study seeks to examine the social, emotional, financial, and institutional challenges faced by these parents.

Design: A Mixed research design involving Quantitative and Focus Group Discussions (FGDs) were used for this study. Setting: The study was carried out at the Department of Psychology & VG AIIPMR, Mumbai. In total, one hundred and one parents were selected to complete this study.

Outcome Measures: The study assessed the psychosocial challenges faced by parents of children with cerebral palsy (CP). It was found that around 85% of the parents of children with CP experienced psychosocial problems of moderate to extremely severe intensity. There was a significant difference between educated and non-educated parents of CP children concerning their psychosocial problems. Based on the mean scores, it is clear that non-educated parents of children with CP are facing more psychosocial problem (Mean = 37.85 than educated parents of children with CP (Mean = 32.63). there was a significant difference in the psychosocial problem among children with CP based on type. Based on the mean scores, it is clear that CP children having quadriplegia have high psychosocial problems (Mean = 38.64) than hemiplegia (Mean = 36.00), diplegia (Mean = 36.86) and monoplegia (Mean = 33.54). There was a significant difference in the psychosocial problem among children with CP based on parental education. Based on the mean scores, it is clear that CP children having illiterate parents have high psychosocial problems (Mean = 37.67) than parents with education up-to secondary level (Mean = 35.87) and parents with higher education (Mean = 33.38). There was a significant difference in the psychosocial problem among children with CP based on parental occupation. Based on the mean scores, it is clear that CP children having parents who are daily earner have high psychosocial problems (Mean = 39.12) than Govt. job (Mean = 32.89), private job (Mean = 38.58) and home maker (Mean = 35.28).

Based on thematic analysis, parents of children with disabilities face emotional distress, fragile hope, financial struggles, stigma, and disrupted social/work life, with caregiving responsibilities falling mainly on mothers. While family support provides resilience, systemic gaps in psychosocial and institutional support heighten their vulnerability across emotional, social, and economic domains.

Keywords: Cerebral Palsy, Psycho Social Problems India, Parenting Challenges, Disability Stigma, Special Needs, Inclusive Care, Healthcare Barriers.

Introduction

Cerebral palsy (CP), with a prevalence of 2.83 per 1000 children among the age group of 0 to 19 years, is one of the most common causes of disability in India [1]. A child with CP suffers from several problems such as spastic paralysis, cognitive impairment, chronic pain, speech and visual impairment, and gastrointestinal and feeding problems [2]. They also have several limitations in self-care functions such as feeding, dressing, bathing, and mobility. These limitations can result in requirements for long-term care that far exceed the usual needs of normal children [3]. The difficulties faced by children with CP result in their parents experiencing a higher level of stress [4] which has an adverse effect on their physical health and social well-being [5, 6]. Changes in healthcare systems and societal attitudes have resulted in most children staying at home in the care of family rather than in an institution. Moreover, in western countries, a greater emphasis is laid on family-centered care, wherein the focus of attention is the entire family, rather than just the child, and this has been found to be highly effective [7–8]. The family, together with service providers, is able to make informed decisions about the services and supports the child and family shall receive. In order to develop a family-centered care practice, it is imperative to understand and address the psychosocial problems experienced by the caregivers of the affected children. Several studies of this kind have been undertaken in western countries [5, 9, 10] but very few are reported in India. In a country like India there are significant differences between the environments of urban and rural areas. Our study seeks to explore the psychosocial problems experienced by the parents of children with CP. An improvement in understanding can allow us to further conduct studies in our region, to determine the extent of the problem, and develop systems to address issues that are uncovered.

Objectives

To determine the overall prevalence of psychosocial problems among parents of children with CP.

To compare psychosocial problems between children with CP who are receiving formal education and those who are not.

To investigate whether psychosocial problem severity differ by type of CP (monoplegia, hemiplegia, diplegia, quadriplegia).
To assess the association between parents education level (illiterate / up to secondary / higher education) and children's psychosocial problems.
To determine whether parental occupation (house maker, daily earner, private job, govt. job) is associated with psychosocial problems and caregiver burden.

Hypotheses

H_{01}: There is no difference in psychosocial problem severity between educated and non-educated children with CP.
H_{02} Psychosocial problem scores do not differ across CP types
H_{03} There is no association between parents' educational level and psychosocial problem severity in children with CP.
H_{04}: Psychosocial problem severity and caregiver burden do not differ by parental occupation.

Methodology

Sample: The sample for the present study consisted of 101 parents of children with Cerebral Palsy (CP). These participants were selected from the All India Institute of Physical Medicine and Rehabilitation (AIIPMR), where they had brought their children for treatment. The study focused on parents as key informants since they play a crucial role in caregiving, and their psychosocial well-being is directly influenced by the challenges of raising a child with CP.

Sampling Technique

A purposive non-probability sampling technique was employed. This technique was considered appropriate because the study required participants who were directly relevant to the research objectives, i.e., parents of children diagnosed with CP.

Tool Used

To measure psychosocial problems, the Depression Anxiety Stress Scale (DASS-21) was administered. This standardized instrument consists of 21 items (7 items each for Depression, Anxiety, and Stress). It has been widely validated and is considered reliable for assessing the mental health status of individuals. In this study, it was used to determine the levels of psychosocial distress among the parents.

Research Design

The study adopted a mixed-method research design, combining both quantitative and qualitative approaches to provide a more comprehensive understanding of the issue. Quantitative Component The quantitative part of the study aimed to assess the prevalence and severity of psychosocial problems among parents of children with CP.

Statistical Techniques Applied:

Percentage analysis was used to determine the prevalence of mild, moderate, severe, and extremely severe levels of psychosocial distress.t-test was applied to examine gender-based differences and other group comparisons. Analysis of Variance (ANOVA) followed by Duncan's Multiple Range Test (DMRT) was carried out to determine significant differences across different parental demographic groups (such as occupation, education level, or schooling status of children).

Qualitative Component

In order to capture the lived experiences of parents, a thematic analysis was conducted.

Ethical Considerations

Confidentiality of responses was maintained, and participation was entirely voluntary.

Results

Objective-1: To determine the overall prevalence of psychosocial problems among parents of children with CP based on the DASS-21 total score.

Table-1: Prevalence of Psychosocial Problems among parents of Children with CP based on DASS- 21 Total Scores (N=101)

Lev el	Chil dre	Pe rce

	n No. of	nt ag e
Mil d	15	14. 85
Mo der ate	28	27. 72
Sev ere	38	37. 62
Extr em ely Sev ere	20	19. 80

Out of total 101 parents of children with CP assessed at All India Institute of Physical Medicine and Rehabilitation Mumbai, 15 (14.85%) were found to have mild psychosocial problems, 228(27.72%) had moderate problems, 38 (37.72%) reported severe problems and, 20 (19.80%) were in the extremely severe category. The results reveal that the largest portion of parent of children with cp fell into the severe range followed by moderate and extremely severe categories, while only a small friction reported mild psychosocial difficulties. Taken together, nearly 85% of the parents of children with cp experienced psychosocial problems of moderate to extremely severe intensity, indicating that psychosocial distress is highly prevalent among parents of children with CP those reported institution and requires urgent psychosocial support alongside medical and rehabilitation care.

Objective-2: To compare psychosocial problems between children with CP who are receiving formal education and those who are not.

H_{01}: There is no difference in psychosocial problem severity with between educated and non-educated children with CP.

Table-2: Showing the Mean Difference of the Psychosocial Problems Scores Based on Education of the Child

Variable	**E d u c a t i o n**					
Psychosocia l Problems	Y e s					
	N o					

** Significant at 0.01 level of confidence (2- Tailed)*

From table 2, the obtained t-value for psychosocial problem scores of educated and non-educated children with CP is 4.33, which is significant at 0.01 level ($p<0.01$). Hence, the above-stated H_{02} is rejected at a 1% significance

level. It is concluded that there is a significant difference between educated and non-educated parents of CP children concerning their psychosocial problems. Based on the mean scores, it is clear that non-educated parents of children with cp are facing more psychosocial problem (Mean = 37.85 than educated parents of children with CP (Mean = 32.63).

Objective-3: To investigate whether psychosocial problem severity differ by type of CP (monoplegia, hemiplegia, diplegia, and quadriplegia).

H_0: Psychosocial problem scores do not differ across CP types.

Table-3: Showing the Mean Difference of the Psychosocial Problems Scores Based on Type of Cerebral Palsy

Variable	**CP Type**					
Psychosocial Problems	Monoplegia					
	Hemiplegia					
	Diplegia					
	Quadrip					

	legia					

** Significant at 0.05 level of confidence (2- Tailed)*

From table 3, the obtained 'F'-value for psychosocial problem scores of children with cerebral palsy based on type (monoplegia, hemiplegia, diplegia and quadriplegia) is found to be 2.97, which is significant at 0.05 level ($p<0.05$). Hence, the above-stated hypothesis H_{04} is rejected at a 0.05 level of significance. It is concluded that there is a significant difference in the psychosocial problem among children with CP based on type. Based on the mean scores, it is clear that CP children having quadriplegia have high psychosocial problems (Mean = 38.64) than hemiplegia (Mean = 36.00), diplegia (Mean = 36.86) and monoplegia (Mean = 33.54).
Based on Duncan's Multiple Range Test (DMRT), it is clear that psychosocial problems of CP children having quadriplegia differ significantly from children having monoplegia. However, CP children having hemiplegia and diplegia did not differ significantly from monoplegia and quadriplegia forming an intermediate category.

Objective-4: To assess the association between parents education level (illiterate / up to secondary / higher education) and children's psychosocial problems.
H_0: There is no association between parents' educational level and psychosocial problem severity in children with CP.

Table-4: Showing the Mean Difference of the Psychosocial Problems Scores Based on Type of Parental Education

Variable	**Parental Education**					**P-value**
Psychosocial	Illiterate					.026
	Up					

Problems	to Sec.					
	Higher Edu.					

** Significant at 0.05 level of confidence (2- Tailed)*

From table 4, the obtained 'F'-value for psychosocial problem scores of children with cerebral palsy based on parental education (illiterate, up-to school education and higher education) is found to be 3.80, which is significant at 0.01 level ($p<0.01$). Hence, the above- stated hypothesisH_{05} is rejected at a 0.01 level of significance. It is concluded that there is a significant difference in the psychosocial problem among children with CP based on parental education. Based on the mean scores, it is clear that CP children having illiterate parents have high psychosocial problems (Mean = 37.67) than parents with education up-to secondary level (Mean = 35.87) and parents with higher education (Mean = 33.38).

Based on Duncan's Multiple Range Test (DMRT), it is clear that psychosocial problems of CP children having illiterate parents differ significantly from children having parents with higher education. However, CP children having parental qualification up-to secondary education did not differ significantly from either group, suggesting an intermediate position.

Objective-5: To determine whether parental occupation (house maker, daily earner, private job, govt. job) is associated with psychosocial problems and caregiver burden.

H_{04}: Psychosocial problem severity and caregiver burden do not differ by parental occupation.

Table-5: Showing the Mean Difference of the Psychosocial Problems Scores Based on Type of Parental Occupation

Variable	**Parental Occupati**					

	on					
Psychosocial Problems	Home Maker					
	Daily Earner					
	Private Job					
	Govt. Job					

*** Significant at 0.01 level of confidence (2- Tailed)*

From table 5, the obtained 'F'-value for psychosocial problem scores of children with cerebral palsy based on parental occupation (home maker, daily earner, private job and Govt. job is found to be 7.28, which is significant at 0.01 level ($p<0.01$). Hence, the above-stated hypothesis H_{07} is rejected at a 0.01 level of significance. It is concluded that there is a significant difference in the psychosocial problem among children with CP based on parental occupation. Based on the mean scores, it is clear that CP children having parents who are daily earner have high psychosocial problems (Mean = 39.12) than Govt. job (Mean = 32.89), private job (Mean = 38.58) and home maker (Mean = 35.28).

Based on Duncan's Multiple Range Test (DMRT), it is clear that psychosocial problems of CP children having

parents who are daily wager differ significantly from children having parents with Govt. job. However, CP children having parents who are home maker and with private job did not differ significantly from children having parents with Govt. job and who are daily wager forming an intermediate category.

Findings

1.About 85% parents of children with CP experienced psychosocial problems of moderate to extremely severe intensity, indicating that psychosocial distress is highly prevalent among parents of children with CP those reported institution and requires urgent psychosocial support alongside medical and rehabilitation care.
2.There is a significant difference between school going and non-enrolled CP children concerning their psychosocial problems. Based on the mean scores, it is clear that non-educated children are facing more psychosocial problems.
3.There is a significant difference in the psychosocial problem among children with CP based on type. Moreover, Based on Duncan's Multiple Range Test (DMRT), it is clear that psychosocial problems of CP children having quadriplegia differ significantly from children having monoplegia. However, CP children having hemiplegia and diplegia did not differ significantly from monoplegia and quadriplegia forming an intermediate category.
4.There is a significant difference in the psychosocial problem among children with CP based on parental education. Based on Duncan's Multiple Range Test (DMRT), it is clear that psychosocial problems of CP children having illiterate parents differ significantly from children having parents with higher education. However, CP children having parental qualification up-to secondary education did not differ significantly from either group, suggesting an intermediate position.
5.There is a significant difference in the psychosocial problem among children with CP based on parental Occupation. Based on Duncan's Multiple Range Test (DMRT), it is clear that psychosocial problems of CP children having parents who are daily wager differ significantly from children having parents with Govt. job. However, CP children having parents who are home maker and with private job did not differ significantly from children having parents with Govt. job and who are daily wager forming an intermediate category.

Elaborated Thematic Analysis of Parents' Experiences with Children Having Cerebral Palsy

1. Parental Emotional Response

The emotional landscape of caregiving was dominated by anger, sadness, exhaustion, and helplessness. Parents often broke down in tears as a way to release the emotional weight. For some, the strain manifested in frustration during daily care routines.

- *"When I try to feed my child, he is not cooperative because of his condition, so I become aggressive and think about not feeding him."*
- *"Often, I end up crying to deal with it all."*

Interpretation: Parents lack structured coping mechanisms, with crying serving as both a cathartic release and an indicator of psychological distress. Emotional strain sometimes spilled into caregiving interactions, producing guilt and frustration. This highlights the urgent need for psychosocial support and counseling services to help caregivers manage stress constructively.

2. Hopes and Worries for the Future

Parents' narratives revolved around a fragile optimism: the dream of their children walking, talking, and going to school like their peers. Alongside this hope, however, were deep anxieties about long-term dependency and questions of survival.

- *"My child should walk and talk like other children."*
- *"Today I am alive, but if I am not alive, who will take care of my child?"*

Interpretation: Parents' hopes were tightly bound to therapy outcomes, reflecting a belief that medical intervention could restore normalcy. Yet, beneath this hope lay existential worries about mortality and the child's lifelong dependence. This duality illustrates a psychological tension between resilience and vulnerability, where optimism serves as a survival strategy but is constantly undermined by fear.

3. Acceptance

Parents expressed acceptance of their child's condition, though this acceptance was often accompanied by hope for eventual improvement. Acceptance, therefore, was not resignation but a practical adaptation infused with optimism.

- *"Yes, we have accepted the child with this condition."*
- *"Yes, we've come to terms with the child's situation completely."*

Interpretation: Acceptance functioned on multiple levels: emotional (acknowledging the diagnosis), practical (adjusting routines), and conditional (accepting while anticipating recovery). It reflects parents' resilience but also underscores how acceptance is shaped by cultural and social expectations of progress.

4. Family and Marital Support

Support from husbands, parents, and extended families provided an important buffer. Mothers, however, remained the primary caregivers, shouldering the day-to-day responsibilities, while fathers contributed mainly through income and treatment-related sacrifices. Marital relationships were reported as stable and even strengthened through shared struggles.

- *"My husband supports me a lot. My family and relatives make me feel that I should take proper care and attention towards the child."*
- *"Our bonds with one another remain strong and positive."*

Interpretation: Families act as a protective factor against complete caregiver burnout. Yet the gendered nature of care means mothers disproportionately carry the physical and emotional labor, reflecting cultural expectations of maternal sacrifice. While marriages remain intact, this imbalance places women at higher risk of long-term emotional fatigue.

5. Financial Struggles

Economic hardship was universal. With most fathers employed as daily wage laborers, treatment required frequent absences from work, reducing income. Parents relied heavily on relatives for financial support and lacked access to formal government or NGO assistance.

- "*We have not received any support from any trust, and we are not aware of these assistance schemes."*
- *"Husband works as a daily laborer and often misses work to bring the child for sessions."*

Interpretation: Financial precarity compounds the stress of caregiving, forcing families into cycles of borrowing and instability. The absence of institutional support reflects systemic gaps, leaving parents economically vulnerable while also responsible for high-cost, long-term treatment needs.

6. Social Perception and Stigma

Parents reported their children being viewed differently, with subtle but painful forms of exclusion. Community members often avoided interaction, reinforcing feelings of isolation. Some parents tried to dismiss these judgments, focusing instead on therapy.

- "*People use to see in different ways because of the condition of the child. Sometimes they do not sit with me and do not allow me to participate in daily living."*
- *"People look at my child in an odd way since he can't walk yet."*

Interpretation: Stigma operates both overtly (exclusion from community participation) and subtly (strange looks, avoidance). Parents often respond with protective denial, focusing on therapy to shield themselves emotionally. Yet, stigma reinforces social isolation, compounding the already heavy caregiving burden.

7. Impact on Social Life

Therapy routines and the child's condition restricted parents' participation in social gatherings and daily interactions. Parents withdrew from community life, prioritizing treatment over leisure or relationships.

- *"I am not going to attend any functions because of the ongoing treatment of my child. I cannot go anywhere."*
- *"I've withdrawn from every gathering and event, constrained by the demands of the child's therapy which leave no room for outings."*

Interpretation: The caregiving role reshapes parents' identities, isolating them from normal social roles and activities. This self-imposed withdrawal, while practical, deepens loneliness and removes an important coping resource: social support.

8. Impact on Work Life

The treatment schedule disrupted fathers' employment, leading to frequent absenteeism. Since most worked as daily wage laborers, even a single day off meant lost income. Mothers, fully occupied with caregiving, were not able to pursue employment.

- *"The father has to take time off from his job for the treatment."*
- *"Working daily wages, my husband regularly forgoes shifts to accompany us for therapy."*

Interpretation: Work-life disruptions show how child disability directly intersects with economic vulnerability. Treatment, though essential, destabilizes livelihoods, creating a cycle of poverty and reinforcing the family's dependence on uncertain informal support systems.

Conclusion

The thematic analysis across all six parents reveals a deeply interconnected set of challenges:

- Emotional distress is a constant reality, expressed through crying, frustration, and helplessness.
- Hopes for recovery sustain parents' commitment to therapy but coexist with fears of abandonment and long-term dependency.
- Acceptance is not passive but conditional, shaped by expectations of eventual improvement.
- Family support provides emotional cushioning, but caregiving roles are heavily gendered, leaving mothers disproportionately burdened.
- Financial struggles and lack of institutional aid place families in precarious positions, amplifying stress.
- Stigma and social withdrawal limit participation in community life, depriving families of social support.
- Work disruptions reinforce economic vulnerability, tying the child's condition to ongoing financial instability.

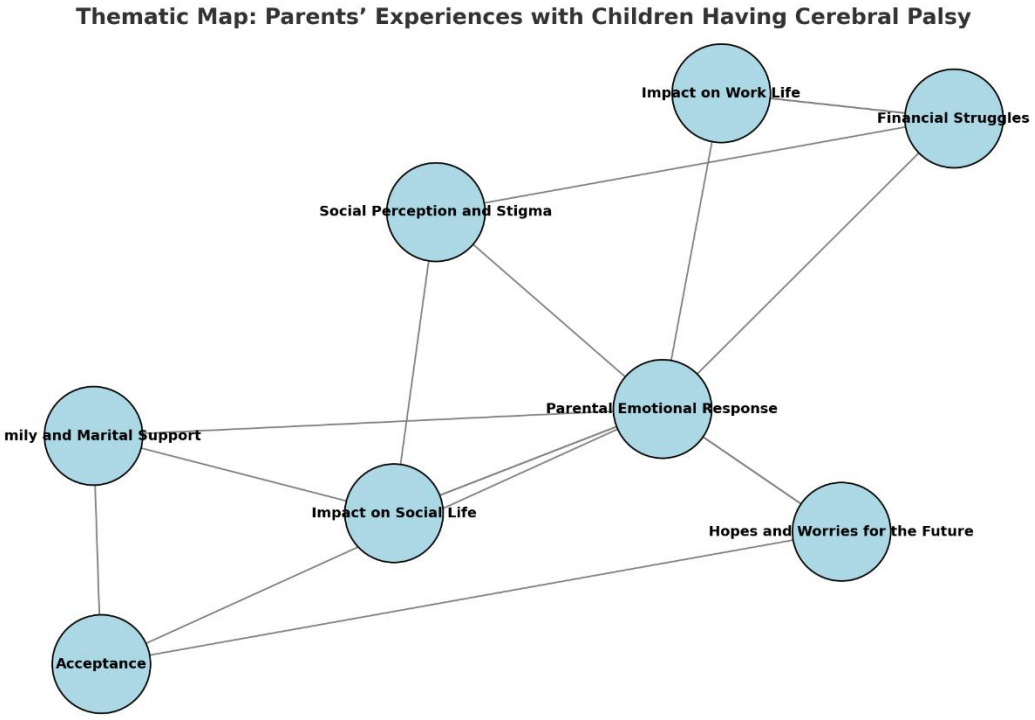


Fig: Thematic map showing how the themes interconnect. This map shows how all themes are part of a cycle of stress, hope, and resilience in the lives of parents caring for children with cerebral palsy.

- Emotional responses are shaped by financial struggles, social stigma, and work-life disruptions.
- Family support acts as a protective factor, linked with emotional stability and acceptance.
- Financial strain directly influences both work-life disruptions and emotional stress.
- Social stigma feeds into social withdrawal, which further impacts emotional wellbeing.

Suggestions / Recommendations

1. Integration of Psychosocial Support with Medical and Rehabilitation Care Since nearly 85% of parents reported moderate to extremely severe levels of psychosocial problems, it is strongly recommended that psychosocial interventions such as counseling, stress-reduction programs, and peer-support groups be made a routine part of rehabilitation services. Multidisciplinary teams should include psychologists, social workers, and counselors to ensure that parents receive emotional support alongside medical and physiotherapy care.
2. Promotion of Inclusive Education and Enrolment of Children with CP The finding that parents of non-enrolled children face greater psychosocial problems highlights the importance of inclusive education initiatives. Special schools, resource centers, and integration of children with CP into mainstream schools with necessary aids should be strengthened. Sensitization programs for parents should also be conducted to encourage school enrolment, as education reduces both the child's dependence and parental stress.
3. Condition-Specific Support Programs Parents of children with quadriplegia were found to experience significantly higher psychosocial distress. Hence, specialized rehabilitation packages and respite care services should be designed for families of children with severe forms of CP. Training workshops can be conducted for parents to

manage daily care challenges more effectively, thereby reducing their emotional burden.

4. Parent Education and Awareness Initiatives The study found that parents with higher education levels reported fewer psychosocial problems compared to illiterate parents. Therefore, awareness campaigns, parent education workshops, and community-based training programs in simple local languages should be organized. These programs should cover home-based therapy, stress management, and available welfare schemes, empowering parents with practical knowledge and coping skills.

5. Economic and Occupational Support for Parents Parents who are daily wage earners were observed to have significantly higher psychosocial problems compared to those in government jobs. This indicates the need for financial support systems and flexible employment policies for caregivers. Possible measures include: • Monthly allowances or subsidies for low-income families with children with CP. • Caregiver leave and flexible work policies for working parents. • NGO and government collaboration to provide income-generating opportunities for affected families.

6. Adoption of Family-Centered Rehabilitation Models The findings collectively suggest that psychosocial problems are influenced by multiple factors, including the child's condition, parental education, and occupation. Rehabilitation services should therefore adopt a family-centered model, focusing not only on the child but also on the caregiver's emotional, social, and economic well-being.

7. Policy and Community-Level Recommendations • Policymakers should develop national guidelines for psychosocial support of caregivers of children with CP. • Community awareness programs should be launched to reduce stigma and promote social inclusion. • Community-based rehabilitation (CBR) services should be strengthened, especially in rural and underserved areas, to provide accessible and holistic support.

REFERENCES

1. Banerjee TK, Hazra A, Biswas A, Ray J, Roy T, Raut DK, et al. Neurological disorders in children and adolescents. Indian J Pediatr. 2009;76(2):139-146.

2. Odding E, Roebroeck ME, Stam HJ. The epidemiology of cerebral palsy: incidence, impairments and risk factors. Disabil Rehabil. 2006;28(4):183-191.

3. Breslau N, Staruch KS, Mortimer EA. Psychological distress in mothers of disabled children. Am J Dis Child. 1982;136(8):682-686.

4. Parkes J, McCullough N, Madden A, McCahey E. The health of children with cerebral palsy and stress in their parents. J Adv Nurs. 2009;65(11):2311-2323.

5. Davis E, Shelly A, Waters E, Boyd R, Cook K, Davern M. The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. Child Care Health Dev. 2010;36(1):63-73

6. Parkes J, Caravale B, Marcelli M, Franco F, Colver A. Parenting stress and children with cerebral palsy: a European cross-sectional survey. Dev Med Child Neurol. 2011;53(9):815-821.

7. Kazak AE. Families of chronically ill children: a systems and social-ecological model of adaptation and challenge. J Consult Clin Psychol. 1989;57(1):25.

8. King S, Teplicky R, King G, Rosenbaum P. Family-centered service for children with cerebral palsy and their families: a review of the literature. Semin Pediatr Neurol. 2004;11(1):78-86.

9. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics. 2005;115(6):e626-e636.

10. Ketelaar M, Volman MJM, Gorter JW, Vermeer A. Stress in parents of children with cerebral palsy: what sources of stress are we talking about? Child Care Health Dev. 2008;34(6):825-829.

11. Nimbalkar S, Raithatha S, Shah R, Panchal DA. A qualitative study of psychosocial problems among parents of children with cerebral palsy attending two tertiary care hospitals in western India. Int Sch Res Notices. 2014;2014(1):769619.