



ORIGINAL ARTICLE

Stress level in parents of children with cerebral palsy.

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ABSTRACT... Objective: To evaluate the stress level in parents of children with cerebral palsy (CP) using parental stress scale (PSS). **Study Design:** Cross Sectional study. **Setting:** Department of Pediatric Medicine, National Institute of Child Health (NICH), Karachi, Pakistan. **Period:** July 2023 to December 2023. **Methods:** Parents of CP children of both gender and aged 1-12 years visiting outpatient department were analyzed. Demographic and clinical information of the CP children and their parents were noted. Parental stress level was evaluated using PSS. The scale's total possible scores range from 18 to 90, and a score of 51 or above was considered the cut-off value for parents experiencing psychological stress. **Results:** In a total of 149 children, 81 (54.4%) were female. The mean age and weight of the children were 3.92 ± 1.70 years. The mean parental stress scale score was 57.14 ± 9.97 (ranging between 30-80). There were 114 (76.5%) parents who were having high stress levels. Higher Gross Motor Function Classification System (GMFCH) grade ($p=0.013$), relation of parents as father ($p=0.006$), and relatively higher socio-economic status ($p=0.005$) were significantly associated with high levels of stress. Bivariate analysis revealed positive significant correlation of GMFCH grade with PSS scores ($r=0.232$, $p=0.004$). **Conclusion:** Very high prevalence of elevated stress levels (76.5%) was reported among parents of CP children. Factors such as GMFCS grade, parental role, and socioeconomic status contributed to high stress.

Key words: Cerebral Palsy, Parents, Psychological, Socio-economic Status, Stress.

INTRODUCTION

One of the main characteristics of cerebral palsy (CP) is the impaired development of gross motor function.¹ Children with CP are more likely to have chronic disabilities that leave them physically, intellectually, and socially isolated. Walking abilities and other issues like cognitive dysfunction, seizure condition, and visual and auditory impairments are all strongly associated.²

The commencement of a new life cycle and the addition of a new social role are both associated with the birth of a child.³ When a child has a disability, this incident takes on distinct qualities, creating an unexpected and sometimes anxiety-inducing circumstance.⁴ Being a parent of a child with a disability is much more difficult than other types of parenting.⁵ Many researchers have sought to pinpoint the socioeconomic, psychosocial, and demographic factors that are predictive of parenting stress levels.⁶ Caring for

children with CP presents challenges that are often underestimated. Parents also grapple with social exclusion, hindrances in participating in social activities, ostracization, and conflicts within both their families and society at large.⁷ In addition, the parents experience bodily stress like insomnia, musculoskeletal pain, and hypertension. As a result, it's critical to comprehend and solve the overlooked issue of carer burden.⁸ Ribeiro MF et al demonstrated the frequency of stress level in parents of children with CP as 45.3% respectively.⁹ There is limited agreement regarding the association between caregivers' physical and mental health deficits and the degree of motor inadequacy experienced by the child with CP, according to the research.¹⁰ This discordance shows that other factors, aside from those directly relating to the child and his or her impairment, may also have an impact on how well parents and children are able to adjust to one another.⁴

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High levels of parental stress have been linked to poorer mental health, a lower quality of life, and unhappiness with how parents of children with cerebral palsy view social support. It is not widely known how parental stress manifests in a normal Pakistani community. In order to comprehend the physical, psychosocial, financial, and other pressures faced by parents of CP children in Pakistan, this study attempted to perform a qualitative exploration. Also, the study's special goal is to pinpoint how parenting a child with a handicap intersects with gender, poverty, social stigma, and other social variables, as doing so is likely to make the parents' psycho-social stress worse. The objective of this study was to determine the stress level in parents of children with CP.

METHODS

This cross sectional study was conducted at the department of Pediatric Medicine, National Institute of Child Health (NICH), Karachi, Pakistan from July 2023 to December 2023. Considering expected proportion of stress among 45.3%⁹ parents of CP children with 95% confidence level and 8% margin or error, the sample size was calculated to be 149. By putting all the values, the sample size was calculated to be 149. Approval from "Institutional Ethical Review Board" was acquired (letter number IERB-36/2023, Dated: 23.11.2023). Inclusion criteria were parents of CP children of either gender and aged 1-12 years. Exclusion criteria were mothers who had more than one child with CP or those who had children with additional clinical disorders associated with CP. Mothers of children in level III of the GMFCS, an intermediate level that prevents a clear assessment of the motor abnormalities seen in individuals with CP were also excluded. CP was defined as a disorder of movement and posture that appears during infancy or early childhood resulting from damage to the brain. It was assessed by gross motor function classification system expanded and revised (GMFCS - E&R). Written as well as informed consent were sought from parents of all children.

All children visiting outpatient department of Pediatric Medicine, NICH and meeting the

inclusion and avoiding the exclusion criteria were included. Children with CP went through physical examination and information like age, weight were recorded. The camry analogue weighing scale was used to measure weight and the stadiometer and seca 212 head circumference tape was used to measure length and FOC respectively. Children were categorized into levels I through V based on the severity level of their cerebral palsy using the GMFCS. Moreover, information regarding educational level of parents and sociodemographic questionnaire included data regarding family income, birth history and comorbidities were noted. Socio-economic status was deemed as low, middle, or high as family monthly income below Rs. 30,000, between 30,000-60,000, and above Rs. 60,000, respectively.¹² Parental stress level was evaluated by using parental stress scale. The 18 items on the self-report measure cover both good and negative aspects of parenthood, such as emotional rewards and personal development as well as resource demands and limits. Regarding their typical relationship with their child, respondents either agree or disagree. A 5-point scale with the following options was used for rating: strongly disagree, disagree, uncertain, agree, and highly agree. The scale's total possible scores range from 18 to 90, and a score of 51 or above was considered the cut-off value for parents experiencing psychological stress.¹¹ All the above mentioned information was recorded on a pre-designed proforma.

A database was developed on IBM-SPSS Statistics version 26.0. Mean value and standard deviation (SD) or median along with interquartile range (IQR) as appropriate were calculated for quantitative variables like age, weight, length, FOC and mean parental stress scale. Normality of the data were assessed by using shapiro wilk test. Frequencies with percentages were presented for qualitative variables like parental residence (urban/rural), marital status (married/divorced/widow), employment status (employed/unemployed), socioeconomic status (upper/middle/lower), educational status (primary/secondary/matriculate/intermediate/graduate), gender of CP child (male/female), severity

of cerebral palsy of children with respect to GMFCS grades (I/II/III/IV/V). Effect modifiers were controlled through stratification and post-stratification chi square or Fisher's exact test (if frequency ≤ 5 in any cell) were applied. P-values of ≤ 0.05 was taken as significant.

RESULTS

In a total of 149 children, 81 (54.4%) were female. The mean age and weight of the children were 3.92 ± 1.70 years (ranging between 1-10 years) and 13.41 ± 6.38 kg (4-30 kg). The median GMFCH grade was 4 (4-5). The mean age of the parents was 36.35 ± 6.97 (ranging between. 23-52 years).

The Cronbach's alpha of the items considered

in the PSS was 0.84. The mean parental stress scale score was 57.14 ± 9.97 (ranging between 30-80). There were 114 (76.5%) parents who were having high stress levels. Higher GMFCH grade ($p=0.013$), relation of parents as father ($p=0.006$), and relatively higher socio-economic status ($p=0.005$) were significantly associated with high levels of stress (Table-I).

Bivariate analysis revealed positive significant correlation of GMFCH grade with PSS scores ($r=0.232$, $p=0.004$) whereas age of the children or parents were not having any significant correlation with PSS scores (Table-II). Figure-1 is showing linear regression analysis of GMFCH grades with PSS scores.

Characteristics		Number (%)	Stress		P-Value
			Low (n=35)	High (n=114)	
Children					
Gender	Male	68 (45.6%)	20 (57.1%)	61 (53.5%)	0.706
	Female	81 (54.4%)	15 (42.9%)	53 (46.5%)	
Age (years)	1-5	125 (83.9%)	32 (91.4%)	93 (81.6%)	0.166
	6-12	24 (16.1%)	3 (8.6%)	21 (18.4%)	
Residence	Rural	72 (48.3%)	12 (34.3%)	60 (52.6%)	0.057
	Urban	77 (51.7%)	23 (65.7%)	54 (47.4%)	
GMFCH Grade	I	3 (2.0%)	-	3 (2.6%)	0.013
	II	9 (6.0%)	6 (17.1%)	3 (2.6%)	
	III	22 (14.8%)	7 (20.0%)	15 (13.2%)	
	IV	77 (51.7%)	16 (45.7%)	61 (53.5%)	
	V	38 (25.5%)	6 (17.1%)	32 (28.1%)	
Parents					
Relation	Mother	115 (77.2%)	33 (94.3%)	82 (71.9%)	0.006
	Father	34 (22.8%)	2 (5.7%)	32 (28.1%)	
Age (years)	<35	51 (34.2%)	12 (34.3%)	39 (34.2%)	0.993
	≥ 35	98 (65.8%)	23 (65.7%)	75 (65.8%)	
Marital Status	Married	136 (91.3%)	31 (88.6%)	105 (92.1%)	0.669
	Divorced	8 (5.4%)	2 (5.7%)	6 (5.3%)	
	Widow	5 (3.4%)	2 (5.7%)	3 (2.6%)	
Employment status	Employed	69 (46.3%)	19 (54.3%)	50 (43.9%)	0.279
	Unemployed	80 (53.7%)	16 (45.7%)	64 (56.1%)	
Educational status	Illiterate	23 (15.4%)	2 (5.7%)	21 (18.4%)	0.254
	Primary	21 (14.1%)	5 (14.3%)	16 (14.0%)	
	Secondary	17 (11.4%)	5 (14.3%)	12 (10.5%)	
	Matriculation	47 (31.5%)	9 (25.7%)	38 (33.3%)	
	Intermediate	34 (22.8%)	11 (31.4%)	23 (20.2%)	
	Graduation or above	7 (4.7%)	3 (8.6%)	4 (3.5%)	
Socioeconomic status	Low	68 (45.6%)	17 (48.6%)	51 (44.7%)	0.005
	Middle	78 (52.3%)	15 (42.9%)	63 (55.3%)	
	Upper	3 (2.0%)	3 (8.6%)	-	

Table-I. Characteristics of study participants and their association with stress levels (N=149)

Variables	r	P-value
Age in years (child)	0.007	0.933
GMFCH grade	0.232	0.004
Age in years (parents)	0.006	0.944

Table-II. Correlation of PSS scores with study variables (n=149)

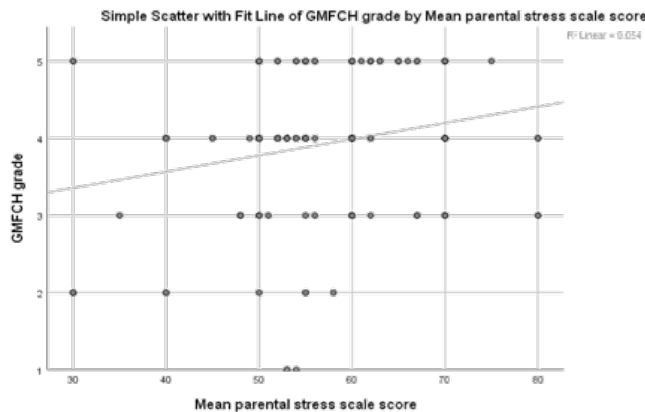


Figure-1. Linear Regression analysis of GMFCH grades and PSS scores

DISCUSSION

The present study aimed to evaluate the stress levels in parents of children with CP and identified factors associated with elevated stress levels. This study contributes to the existing literature by shedding light on the psychosocial challenges faced by parents in the context of raising children with CP. The findings revealed a substantial prevalence of high stress levels among parents, with 76.5% experiencing psychological stress, as indicated by an overall mean parental stress scale (PSS) score of 57.14 ± 9.97 . Proportion of parents experiencing high levels of stress (76.5%) in this study is much higher than what was noted by Lima et al from Brazil analyzing parental stress of caregivers with CP children as 46.2%.¹³ A study from Malaysia reported that 59% of mothers of CP children were having higher levels of psychological stress.¹¹ A study from Sri Lanka found that 56% of caregivers of CP children had psychological disorders.¹⁴ Local study by Siddiqua et al showed that 48% of caregivers of CP children had moderate to high levels of perceived stress.¹⁵ Our findings along with many others show that psychological stress among parents of CP child is a major issue affecting very high proportion of parents. The literature highlights that parents or caregivers of

children showing higher PSS scores are likely undergo a clinically significant level of parental stress, necessitating referral to professional care services and potential clinical monitoring.¹⁶ The consequences of enduring heightened and/or persistent parental stress can manifest in both short-term and long-term scenarios, commonly linked to adverse effects on psychological well-being, overall quality of life, and the availability of social support for parents.^{17,18} Elevated parental stress has the potential to negatively impact the quality of parent-child relationships, feelings of competence, and overall parental well-being.¹⁹

The observed correlation between higher GMFCS grade and increased parental stress ($p=0.013$) is consistent with previous research highlighting the impact of the severity of a child's disability on parental well-being.^{20,21} Parents of children with more severe motor impairments may face heightened stress due to increased caregiving demands and potential limitations in the child's functional abilities. The positive correlation between GMFCS grade and PSS scores ($r=0.232$, $p=0.004$) underscores the importance of considering the functional limitations imposed by CP when assessing parental stress. Understanding the specific challenges associated with different levels of motor impairment can inform tailored support programs for families.

Another noteworthy finding is the association between the parental role, specifically fathers, and elevated stress levels ($p=0.006$). This suggests a potential gender-specific role in coping with the challenges of raising a child with CP. While existing literature has often focused on maternal stress, our results emphasize the need to consider the unique experiences and stressors faced by fathers. Further research exploring the nuanced dynamics of parental stress in different cultural and familial contexts could provide valuable insights. The association between relatively higher socioeconomic status and increased parental stress ($p=0.005$) is intriguing and warrants careful consideration. While previous studies have reported mixed findings regarding the impact of socioeconomic status on parental stress, our results suggest a need for targeted interventions

and support mechanisms for families across diverse socioeconomic backgrounds.^{11,14}

Our research highlighted very high prevalence of elevated stress levels among parents of children with CP and identified factors such as GMFCS grade, parental role, and socioeconomic status that contributed to heightened stress. These findings emphasize the need for comprehensive, family-centered interventions that address the unique needs of parents and caregivers. Future research should explore the longitudinal impact of parental stress on the well-being of both parents and children, guiding the development of targeted support programs.

CONCLUSION

Very high prevalence of elevated stress levels (76.5%) was reported among parents of CP children. Factors such as GMFCS grade, parental role, and socioeconomic status contributed to high stress. By addressing these factors, healthcare professionals and policymakers can develop more effective strategies to alleviate parental stress and enhance the quality of life for both parents and children living with cerebral palsy.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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AUTHORSHIP AND CONTRIBUTION DECLARATION

No.	Author(s) Full Name	Contribution to the paper	Author(s) Signature
1	Saneeda Bibi	Acquisition and analysis of data, Drafting, Final approval.	
2	Muhammad Ashfaq	Concept and design, Critical revisions, Final approval.	
3	Jawed Akbar Dars	Interpretation of data, Critical revisions, Final approval.	
4	Syed Habib Ahmed	Interpretation of data, Critical revisions Final approval.	
5	Aijaz Ahmed	Interpretation of data, Critical revisions Final approval.	