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ORIGINAL ARTICLE

Perceived stress among caregivers of children with cerebral palsy.

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ABSTRACT… Objective: The study aims to ascertain the degree of felt stress among parents of cerebral palsy patients at HIT and POF Hospitals. **Study Design:** Cross-sectional. **Setting:** Department of **P**ediatrics, HIT & POF Hospitals. **Period:** February 2022 to May 2022. **Material & Methods:** The study was approved by IRB of HITEC-IMS under approval number HITEC-IRB-22-2021. Using the purposive sampling method, the study included CP children aged under 3 to 10 and caregivers who had experienced stress for three consecutive months. The total score was determined using Sheldon Cohen's perceived stress scale. Scores between 0 and 13 were classified as low perceived stress, 14 to 26 as moderate, and 27 to 40 as high felt stress. **Results:** Children with the spastic form of CP made up 50% of the population, while those with the dyskinetic ataxic and mix types made up 16%, 8%, and 5% of the total. 66 percent of the children were under 5, 22 percent were between the ages of 6 and 10, and just 12 percent were under 3. With level 4 on the second, the GMFCS level of 3 was the most prevalent. The parents' average age was 31±7.2. Respondents' average stress score was 18.03±8.8. **Conclusion:** Parents of CP children experience moderate to high levels of stress that are significantly influenced by the employment status of moms and family income. Parents must be stress-free in order to raise children with poor health.

Key words: Cerebral Palsy, Caregiver, CP Child, Perceived Stress Scale, Stress Scale.

INTRODUCTION

A chronic disorder called cerebral palsy (CP) is characterized by several functional restrictions brought on by deviations in the development of the central nervous system.[1] The primary limitation of CP is motor dysfunction, although the prevalence of sensory, cognitive, and social deficits significantly affects how severe the disability is.[2] The Gross Motor Function Classification System (GMFCS) classifies motor impairment severity into five levels, ranging from Level I, which denotes less motor impairment and corresponds to when the patient can walk without any restrictions, to Level V, which denotes severe motor impairment and the requirement for a wheelchair for mobility.[3] With an incidence of 2 to 3 cases per 1000 live births, cerebral palsy is the most prevalent chronic illness that causes impairment in children.[4] As a result, Children with CP are quite reliant on their caretakers. The majority of mothers look after Children with cerebral palsy.[5] These women frequently shoulder the responsibility of taking care of the household and the kid with CP in low- and middle-income environments.[6] The demands and conduct of the children have an impact on the parents' physical and mental health, especially the mother who is the primary caregiver.[5] When compared to the incidence of 5% in the general population, it was found that 36% of the 818 parents of children with cerebral palsy in the European research done in 2011 displayed high levels of parental stress.[7] High levels of stress were also seen among caregivers of children with cerebral palsy in research carried out in rural Bangladesh.[8] According to a qualitative study on psychosocial stress among caregivers of children with cerebral palsy conducted in India, the main problems were the caregiver's troubled social relationships, health issues, financial difficulties, worry about the child's future, and a need for more supportive services.[9] Similar pressures and harsh and unsupportive contact with society

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were revealed in an Iranian study.[10] In a Pakistani survey, the majority of parents reported feeling unsatisfied with their mental well-being, social connections, physical health, their child's growth, and their child's reliance.[11]

The study aims to investigate a previously understudied population, specifically caregivers of children with cerebral palsy attending HIT and POF Hospitals. By assessing the level of perceived stress among these caregivers, the study aims to identify potential areas for improvement in their mental health and suggest strategies to enhance the quality of caregiving for children with cerebral palsy. This research fills a gap in current knowledge by focusing on a specific population and highlighting the importance of addressing the mental health needs of caregivers in this field.

MATERIAL & METHODS

The study was approved by the Institutional Review Board of HITEC-IMS under approval number HITEC-IRB-22-2021. From February 2022 to May 2022, this cross-sectional study was carried out at the pediatrics department of HIT & POF Hospitals. The sample size was calculated using WHO sample size calculator. Following the purposive sampling, all patients meeting the criteria from February 2022 to April 2022, caregivers experiencing stress for three consecutive months, and CP children aged under 3 to 10 were enrolled in the study. The primary carers of Children with cerebral palsy were identified by pediatric outpatient department clinicians, who were also known as data collectors. The researcher recognized the primary caregiver and obtained verbal consent before filling out the data collecting Performa. The total score was determined using Sheldon Cohen's perceived stress scale. Scores between 0 and 13 were classified as low perceived stress, 14 to 26 as moderate perceived stress and 27 to 40 as high felt stress.[12] SPSS version 28 was used to analyze the data, and tables and charts were used to display the results.

RESULTS

SPSS 28 was used to enter and evaluate data from 50 parents. Children with the spastic form of CP made up 50% of the population, while those with the dyskinetic ataxic and mix types made up 16%, 8%, and 5% of the total. Sixty six percent of the children were under 5, 22 percent were between the ages of 6 and 10, and just 12 percent were under 3. 34 percent of the children were female, with 66 percent being male. With level 4 on the second, the GMFCS level of 3 was the most prevalent. 38 percent of dads and 62% of mothers took part in the survey. The average age was 31 ± 7.2. Respondents' average stress score was 18.03 ± 8.8. Table-I shows the information from the recruited participants' profiles. The majority of respondents were educated, with roughly 32% having intermediate or higher degrees. The majority of respondents said their households had less than four Children. More than 70% of the participants reported having a family income of under 50,000 rupees.

Figure-1 demonstrates how the stress levels of the responding parents were classified. According to the data, moderate stress levels were experienced by 52% of respondents, followed by low-stress levels by 18%. Thirty percent of the individuals received high-stress scores.

Table-II demonstrates the relationships between PSS and other research factors. It was shown that the age of the kid influences PSS; as the child gets younger, the parents experience greater stress, and the ratio falls as the child gets older. (Figure-2). At moderate and high levels, the parents of children with spastic CP experienced increased stress. (Figure-3)

Parents who are between the ages of 30 and 40 experience a lot of stress. (Figure-4). The gender of the caregiver revealed that moms of children with cerebral palsy experience higher levels of stress. (Figure-5). Mothers who are working are under higher stress.

DISCUSSION

Previous studies have shown a mismatch between perceptions of environmental demands and personal resources as the cause of parental stress.[6]

Variables	N (%)
Age of CP Child	
3-5 Year	33 (66.0%)
6-10 Year	11 (22.0%)
<3	6 (12.0%)
Type of Cp	
Spastic	25 (50%)
Dyskinetic	12 (24%)
Ataxic	8 (16%)
mix	5 (10%)
Gender of CPC Child	
Male	32 (64%)
Female	18 (36%)
GMFCS	
Level 1	8 (16%)
Level 2	9 (18%)
Level 3	15 (30%)
Level 4	13 (26%)
Level 5	5 (10%)
Age of Care Giver	
20-30	12 (24%)
31-40	18 (36%)
41-60	20 (40%)
Gender of Care Giver	
Male	19 (38%)
Female	31 (62%)
Education of Care Giver	
Illiterate	4 (8%)
Intermediate	30 (60%)
More than Intermediate	16 (32%)

Table-I.

Variable	PSS	
	P	Phi
Age of CP Child	>0.05	0.2
Type of CP	>0.05	0.3
Gender of CP child	>0.05	0.08
Age of caregiver	<0.05	0.09
Gender of Caregiver	<0.05	0.09
Education of Caregiver	>0.05	0.4

Table-II

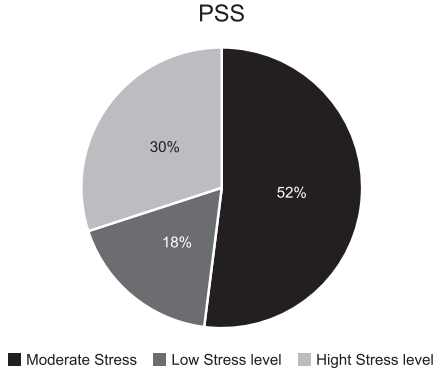

Figure-1

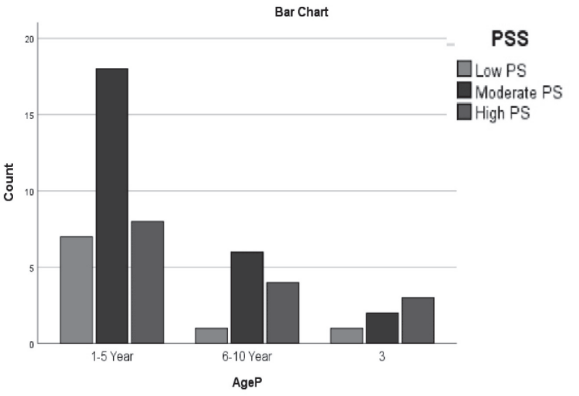

Figure-2

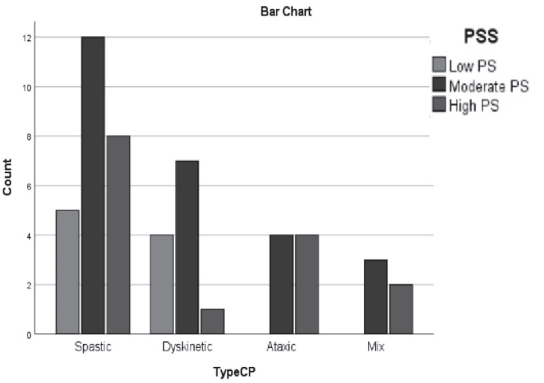

Figure-3

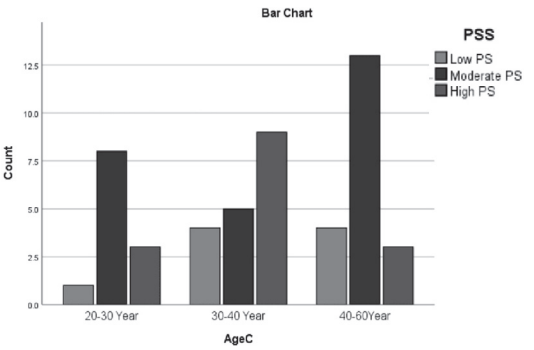

Figure-4

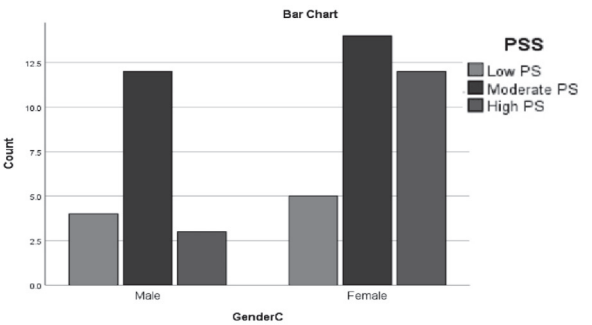

Figure-5

In addition, earlier research has shown that stress is perceived differently by mothers and dads.[13] The greatest range of the perceived stress total score in our study was approximately 41, and its mean score was 18.03 ± 8.8. This tendency showed a higher frequency among both parents. According to a categorical breakdown of the overall perceived stress score, 18% fell into the low-stress group, 52% fell into the moderate category, and 32% fell into the high category. Another research that found moms to be more stressed than fathers is a strong supporter of this conclusion.[14]

A review of the literature found that the bulk of the research was undertaken to examine stress levels among parents of normal children, whereas relatively few studies had examined perceived stress among parents of children with special needs. In contrast to the parenting stress experienced by the father, it was discovered that the frequency of interaction with children was associated with the mother's parenting stress.[15] According to our study, parents had a good education (intermediate or higher), yet despite this, their perceived stress levels were high, indicating that they had trouble managing expectations and resources. Mothers' employment positions and family finances may be the primary determinants of their inability to cope. Another significant cause for increased parental stress in this situation may be the overall number of children in the household. Other research has also confirmed this result.[16] Parental stress may be exacerbated by compromised economic conditions, and our study's findings indicate that the majority of respondents earned less than 50,000 rupees per annum. Another study that connected access to socioeconomic resources and financial hardship to a stress assessment provides substantial support for this outcome.[17] The dual obligations of providing for one's family and being actively involved in their upbringing are emphasized in modern fatherhood conventions. According to the findings of the current qualitative study, working-class fathers find it challenging to fulfill the requirements of good parenting. Additionally, this may worsen due to workplace rigidity and employment insecurity.[15]

Despite the recent rise in understanding, spirituality and religion continue to play a significant role in how society views intellectual impairment, portraying it as either parental neglect or retribution.[18] Some went so far as to say that they had been blamed for their child's illness. They did, however, concur that, before their kid was impacted, they also saw having a child with ID as a tragedy or a punishment.[19] Joint family configurations can sometimes make people feel more stressed than they are. Our analysis suggests that joint families had higher test scores, but the multivariable model revealed that this is not statistically significant. The research has several limitations First and foremost, because the study was cross-sectional, we are unable to establish a link between the aforementioned characteristics and parents' perceptions of stress. Second, because the individuals were readily chosen from two private hospitals the sample size taken from the target demographic may not be representative. However, the study does add the significant conclusion that stress permeates most households, and a community-level study with a larger sample size would offer a more in-depth understanding of stress levels among parents. In addition, although it was not examined in this study, grandparents' roles may be another significant cultural component that influences stress among parents. According to the literature, grandparents are a probable source of support for many parents, offering emotional, monetary, and practical aid.[20]

CONCLUSION

Parents of CP children experience moderate to high levels of stress that are significantly influenced by the employment status of moms and family income. Parents must be stress-free in order to raise children with poor health.

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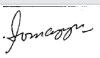
AUTHORSHIP AND CONTRIBUTION DECLARATION

No.	Author(s) Full Name	Contribution to the paper	Author(s) Signature
1	Somayya Siddiqa	Study design, Study concept, Data collection.	
2	Syed M. Ali Haider	Manuscript writing, Data analysis.	
3	Bushra Babar	Data collection.	
4	Nazir Ahmed Malik	Data collection.	
5	Sumaiyya Javed	Data collection.	
6	Aqsa Naheed	Manuscript writing.