

# Impact Of Economic Burden on Stress in Caregivers Of Children With Cerebral Palsy: Correlational Study

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## ABSTRACT

Cerebral Palsy (CP) is one of the most common cause of childhood disability in India, with a global prevalence ranging from 1.5 to 4 per 1000 live births or children and it poses a significant economic burden on families, the health care system and the general economy. Children with CP rely heavily on their caregivers and this responsibility can lower the caregiver's quality of life, leading to frequent stress and sadness. Along with diminished earning potential, caregivers face additional social and financial responsibilities, exacerbating stress levels. Despite this, there is a lack of published literature on the relationship between economic burden and parental stress. Thus, this study aims to explore the correlation between parental stress and the economic burden among the caregivers of children with cerebral palsy. A total of 40 diagnosed Cerebral palsy cases consisting of both males and females, aged 1 to 12 years were included in the study. The economic burden on caregivers of children with cerebral palsy was evaluated using a standard performa that accounted for both direct and indirect healthcare costs. Additionally, parental stress was measured using the Parental Stress Index - Short Form (PSI-SF). The time frame for the study was 5 months. There was a highly positive correlation between the economic burden and parental stress ( $r=0.876$ ,  $p<0.01$ ). The study concluded that the rising economic burden was associated with an increase in stress levels among the caregivers of the cerebral palsy children.

**Keywords:** Cerebral Palsy, Economic burden, Direct healthcare cost, Indirect healthcare cost, Parental stress.

## I. INTRODUCTION

Cerebral Palsy (CP) is one of a group of permanent disorders related to the development in movement and posture causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.<sup>1</sup> One of the leading causes of childhood disability in India is cerebral palsy and major studies throughout the world have shown that 1.5- 4 per 1000 live births or children are affected with cerebral palsy.<sup>2,3</sup>

In CP, the dependence of children on their care-givers is greater and in low- and middle-income settings, mothers often face the dual burden of caring for the family and earning a livelihood, looking after a child with CP. These responsibilities reduce the caregiver's quality of life, leading to frequent experiences of stress and depression.<sup>2</sup>

Cerebral palsy and the conditions associated with it are expensive for families, healthcare & society.<sup>4</sup> Families still bears the brunt of pediatric disability costs unfairly; in 2020 annual median total economic burden borne by the parents/caregivers per child was estimated as RM52,540.00 (~USD12,515.03).<sup>5</sup> Along with a decline in earning potential, there are additional social and financial responsibilities, which can exacerbate the stress levels.<sup>2</sup> There is lack of published literature which indicates the relation between economic burden and the parental stress, thus the aim of the present study was to find the relationship between the parental stress and economic burden in caregivers of the cerebral palsy child.

## II. MATERIALS AND METHODS

This observational study was conducted from February 2024 to June 2024. A total of 40 diagnosed Cerebral palsy cases consisting of both males and females, aged between 1 to 12 years were included in the study. Subjects who were non-cooperative or had any other serious comorbid illness were excluded from the study. Stress among caregivers of cerebral palsy child was measured using the Parental Stress Index - Short Form (PSI-SF), which demonstrated high internal consistency ( $\alpha = 0.91$ ).<sup>6</sup> The economic burden on caregivers was evaluated using a standard performa that included both direct and indirect healthcare costs. The costs associated with specialist visits, hospital stays, physical therapy, medications, and hospital stays accounted for the direct healthcare costs. Additionally, the indirect healthcare cost consisted of transportation expenses and the loss of labor productivity. The data was collected at the end of each month during the duration of 5 months.

### III. RESULTS

1. **Demographical Details-** There were total 40 subjects included in the study. Their demographic profile is described in Table 1.

**Table 1: Distribution of socio-demographic factors of the subjects.**

Socio-demographic factors		N=40	%
Gender	Female	17	43%
	Male	23	57%
Type of CP	Spastic	30	75%
	Ataxic	4	10%
	Mixed	6	15%

2. **Economic Burden-**

**Table 2: Representation of Healthcare cost.**

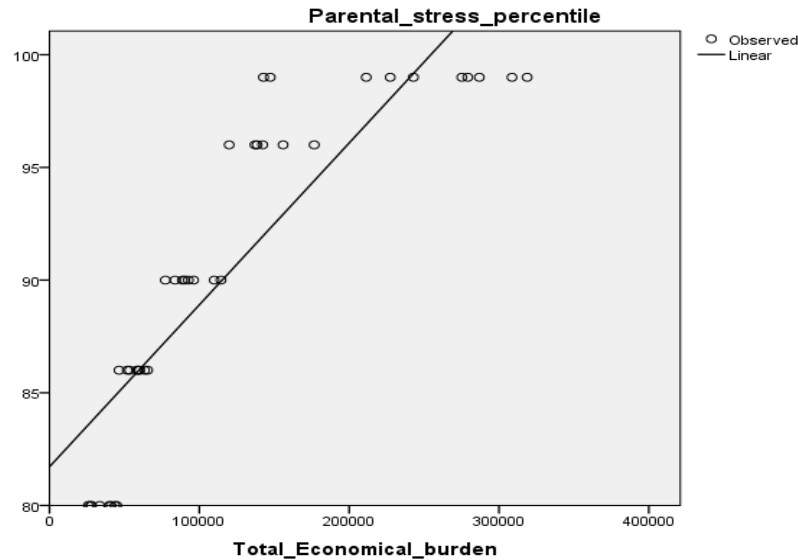
Parameter	Total Cost	Average cost per subject for 5 months	Average cost per subject for 1 month
Direct healthcare cost	₹3191680/-	₹79792/-	₹15958.4/-
Indirect healthcare cost	₹1615250/-	₹40381.25/-	₹8076.25/-
Total healthcare cost	₹48,06,930/-	₹1,20,173.25/-	₹24,034/-

Table 2: Shows the total and average cost per subject for 5 and 1 month.

**Table 3: Representation of Correlation between Economic burden and Parental stress.**

Karl pearson correlation	P- value
0.876	.<0.01

Table 3: Depicts the value of r was found to be 0.876 which reflects that there is a highly positive correlation between the Economic burden and the Parental stress.



**Figure 1: Depiction of Correlation between Economic Burden and Parental Stress.**

#### IV. DISCUSSION

This study focused on the economic burden and parental stress experienced by parents of children with cerebral palsy. Various parameters were evaluated, encompassing both direct and indirect healthcare costs. Parental stress was measured using the Parental Stress Index – Short Form (PSI-SF).

A study conducted by Oladunni Opeyemi et al. (2024)<sup>7</sup> investigated the socio-economic difficulties faced by parents of children with cerebral palsy, emphasizing the demanding nature of caregiving and its substantial impact on social interactions and financial stability. These findings align with the current research, which also found that caring for children with cerebral palsy is highly challenging and incurs considerable economic costs. Parents often dedicate significant time and effort to caregiving, potentially sacrificing employment opportunities to prioritize their child's well-being.

With this economic burden another aspect that is being equally important and is neglected in these cases is the parental stress. The parents had faced a considerable amount of psychological, social stress and they found themselves to be isolated from the society.

A study by Marian Sankombo (2023)<sup>8</sup> investigated the impact of cerebral palsy on parents and families, revealed that having a child with CP can be a significant source of stress, with serious implications for family finances and social life. Similarly, in our current study, we found that parents experience high levels of stress and their social lives are negatively affected due to the demanding care required by their child.

Monalisa Pattnaik et al. (2022)<sup>9</sup> conducted study on the psycho-socioeconomic challenges faced by low-income families raising a child with cerebral palsy. The study found that financial constraints had put these families into the poverty and majority of them had psycho social issues. The present study similarly demonstrates a strong positive correlation ( $r=0.876$ ) between economic burden and stress levels indicating that as financial pressures increase, so does parental stress.

Parents must be stress-free in order to raise children with poor health. To enhance the patient's quality of life, it is crucial to alleviate the stress experienced by parents. Due to a lack of awareness and knowledge, parameters like special education and insurance had no associated costs, indicating that no one had opted for life or accidental insurance, and no child received special education. However, the Indian government has introduced several affordable insurance schemes for societal welfare. These include Pradhan Mantri Jeevan Jyoti Bima Yojana, Pradhan Mantri Suraksha Bima Yojana, Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PMJAY), Rashtriya Bal Swasthya Karyakram (RBSK), and Sarva Shiksha Abhiyan. The current study emphasize on the education of the parents regarding several cost-effective government schemes that they can use to manage their child's care more effectively.

## V. LIMITATIONS

Present study consisted of few limitations. One potential limitation of the study is that study period was less and the sample size was small, confined to a particular geographical area. The findings were also not according to the types of Cerebral palsy.

## VI. CONCLUSION

The study concludes that the rising economic burden was associated with an increase in stress levels among the parents of the cerebral palsy children.

**Conflict of Interest-** Nil.

**Acknowledgment-** The authors sincerely thank all the caregivers who took part in this study and openly shared their experiences.

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