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Parental Stress and Coping Mechanisms in Indian Families of Children with Neurological and Neurodevelopmental disorders: A Mixed Methods Study

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Research Article

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ABSTRACT

● **Background:** Parents of children with neurological and neurodevelopmental disorders experience considerable psychological, social, and financial challenges. However, evidence integrating quantitative assessment of parental stress with qualitative exploration of caregiving experiences in the Indian context remains limited. This mixed-methods study evaluated parental stress, coping mechanisms, and lived experiences among Indian parents of children with neurological and neurodevelopmental disorders.

● **Methods:** A cross-sectional mixed-methods study was conducted over five months among 50 mothers of children with neurological and neurodevelopmental disorders attending a tertiary care teaching hospital. Quantitative data were collected using the Parental Stress Scale (PSS), the Coping Health Inventory for Parents (CHIP), and a structured sociodemographic questionnaire. Semi-structured interviews explored caregivers' lived experiences and coping strategies. Quantitative data were analyzed using descriptive statistics, correlation analysis, one-way ANOVA, and multiple linear regression, while qualitative data underwent thematic analysis.

● **Results:** The mean parental stress score was 49.06 ± 10.37, indicating substantial perceived stress. Parents of children with cerebral palsy and attention–deficit/hyperactivity disorder reported the highest stress levels, although differences across disorders were not statistically significant ($p=0.051$). CHIP II (maintaining social support, self–esteem, and psychological stability) demonstrated a significant inverse correlation with parental stress ($r = -0.427$, $p = 0.002$) and emerged as the strongest independent protective predictor in the final regression model ($\beta = -0.658$, $p < 0.001$), which explained 41.9% of the variance in stress. Higher socioeconomic status was independently associated with greater stress. Qualitative analysis identified six overarching themes: understanding the child's condition and diagnosis, daily life challenges and stress, coping mechanisms and support systems, healthcare experiences and resource utilization, impact on family life and work, and final reflections. Parents described emotional distress, financial burden, disruptions in family routines, and reliance on family support, spirituality, and peer networks to cope.

● **Conclusions:** Parental stress among Indian caregivers of children with neurological and neurodevelopmental disorders is substantial and multifactorial. Social support and psychological coping resources play a central protective role. Family-centered interventions that strengthen caregiver support, improve healthcare communication, and integrate psychosocial services into pediatric neurodevelopmental care may reduce caregiver burden and improve family well-being.

KEYWORDS: Parental stress, Coping strategies, Neurodevelopmental disorders, Neurological disorders, Caregivers, Social support, Mixed-methods study, India, Family functioning, Qualitative

BACKGROUND

Parenting children with neurological and neurodevelopmental disorders poses significant challenges for families, with studies consistently highlighting heightened levels of stress among parents [1,2,3]. In India, where cultural and socioeconomic factors intersect with caregiving responsibilities, understanding parental stress and coping mechanisms becomes paramount. Research underscores the profound impact on parental well-being and family dynamics, emphasizing the urgent need for tailored interventions and support systems [4]. This mixed-methods study aims to explore parental stress levels, coping strategies, and lived experiences among Indian parents, filling a critical gap in the literature and informing targeted interventions to better support these families.

REVIEW OF LITERATURE

Parental stress and coping mechanisms in families of children with neurological and neurodevelopmental disorders are critical areas of research due to the profound impact these conditions can have on family dynamics, parental well-being, and overall family functioning [1,5].

Studies found that parents of children with epilepsy reported significantly higher stress levels due to the unpredictability of seizures and the need for constant vigilance [6,7]. Davis NO et al. [4] highlighted that parents of children with Autism Spectrum Disorder (ASD) experience high levels of stress related to behavioral challenges and social stigma [4].

The burden of caring for a child with a neurological or neurodevelopmental disorder extends beyond emotional stress to encompass physical, social, and financial challenges. Parents often face difficulties in managing their child's symptoms and behaviors, which can lead to fatigue and physical strain [8,9,10,11]. Economic burden is also a significant factor, as highlighted by Liptak GS et al. [12] who noted substantial out-of-pocket expenses and loss of income due to caregiving responsibilities for children with cerebral palsy [12].

In the Indian context, cultural beliefs and practices play a significant role in shaping parental experiences and coping strategies [13,14]. Given the burden experienced by parents of children with neurological and neurodevelopmental disorders, there is a need for research to better understand their experiences and identify effective strategies for support. This mixed-methods study aims to address this gap by evaluating the level of parental stress and identifying coping mechanisms used by Indian parents, providing insights that can inform policy and practice in healthcare and social support systems.

OBJECTIVES

Primary Objectives

1. To evaluate the level of parental stress in families of children with neurological and neurodevelopmental disorders

2. To identify and categorize the coping mechanisms employed by these parents

Secondary Objectives

1. To conduct in-depth qualitative interviews with parents to understand their experiences, focusing on the challenges and strategies associated with raising a child with neurological or neurodevelopmental disorders

2. To determine various factors associated with parental stress and coping mechanisms.

METHODOLOGY

Type of Study: Mixed methods (Quantitative and Qualitative)

Study Design: Cross-sectional study

Period of Study: The study was conducted over a period of 5 months from date of approval.

Study Population: Parents of children diagnosed with neurological (cerebral palsy , hemiplegia, paraplegia, epilepsy) and neurodevelopmental disorders (Autism Spectrum Disorder (ASD), Attention-Deficit/ Hyperactivity Disorder (ADHD), Specific Learning Disorder, Intellectual disabilities, Global developmental delay)

Place of study: Paediatrics OPD, Paediatrics Palliative care OPD, Paediatrics ward

Inclusion Criteria:

- Parents of children diagnosed with the specified neurological and neurodevelopmental disorders

- Parents who provide consent and assent to participate in the study.

Exclusion Criteria:

- Parents of children with chronic medical conditions other than neurological and neurodevelopmental disorders

- parents who are not the primary caregivers of the child

- Parents who do not consent to participate in the study

- parents who have experienced a major life event (e.g., death of a spouse) within the past six months

Sample Size:

• Quantitative study:

To calculate sample size, prevalence was taken 2.9% based on Arora NK et al. [15]

Considering parameters as follows

Confidence level= 95%

Z score= 1.96

Estimated prevalence (p)= 0.029

Margin of error (e)=0.05

Using formula, $n= (Z^2 \times p \times (1-p))/ e^2$

Calculated minimum sample size (N)= 44

Considering the proportion to attrition (q) for follow up as 10% or 0.1,

Estimated minimum sample size (N^1) = N/(1-q) = 44/(1-0.1) = 49

• Qualitative study:

Data Saturation was the criterion for sample size in the qualitative study. Participants were selected until no new themes emerged from the interviews. Based on literature, 10-20 interviews are typically sufficient for saturation [16, 17, 18].

Sampling Method: Convenience sampling for quantitative study and Purposive sampling for qualitative interviews

Materials and Instruments:

- Quantitative study:

• Parental Stress Scale (PSS) [19]: PSS comprises 18 items that assess both positive and negative aspects of parenting, including parental satisfaction, emotional well-being, and perceived stress. Each item is rated on a 5-point Likert scale ranging from "strongly disagree" to "strongly agree". The PSS has been validated in various cultural contexts and is known for its reliability and ease of use, making it suitable for large-scale studies [19].

• Coping Health Inventory for Parents (CHIP) [20]: The CHIP consists of 45 items divided into three subscales: maintaining family integration, cooperation, and an optimistic definition of the situation; maintaining social support, self-esteem, and psychological stability; and understanding the medical situation through communication with other parents and consultation with the medical staff. Parents respond to each item on a 4-point Likert scale ranging from "not helpful" to "extremely helpful". The CHIP is a reliable and valid measure for assessing parental coping mechanisms and has been used extensively in research [20].

- Qualitative: Semi-structured interview guide- involves a set of predefined open-ended questions, but allows flexibility to explore responses in more depth through follow-up probes/prompts. This approach ensures both structured data and rich, detailed insights.

Quality Control:

Pilot testing of the Semi-structured interview guide and review by expert and external validity

Data Collection Procedure:

- Quantitative study:

1. According to inclusion and exclusion criteria, parents visiting Paediatrics OPD, Paediatrics Palliative care OPD, Psychiatry OPD, Paediatrics ward were invited to take part in study and only 1 reliable parent was selected from each family.

2. Procedure, purpose and nature of the study was explained to the parents and written informed consent was taken.

3. Parents completed a self-administered demographic questionnaire. Medical records of the children were reviewed to confirm the diagnosis and relevant medical history.

4. Parental Stress Scale (PSS) and Coping Health Inventory for Parents (CHIP) scales were administered to parents.

5. The forms were checked for completeness and accuracy of responses and interpretation of data was done

Qualitative study:

1. Participants were recruited from a pool of participants from quantitative study.

2. Parents were briefed about the qualitative nature of the study, and written consent was obtained. They were informed that interviews will be audio recorded.

3. Face-to-face interviews were conducted at a convenient time for the participants in the same hospital. Interviews were audio-recorded with participants' consent, and brief notes were taken.

4. Semi-structured interview guide was administered and participants were selected till data saturation occurred with no new theme emerging.

5. The interview recordings were transcribed verbatim and the transcripts were translated and also underwent back translation for verification.

6. Transcripts were then coded manually, and recurring themes were identified for thematic analysis

Statistical Analysis:

- Quantitative study: The collected data was entered in a Microsoft Excel spreadsheet, and for further analysis, IBM Statistical Package for Social Sciences (SPSS) was used. Descriptive statistics, correlation analysis and Multiple linear regression analysis was done

- Qualitative study: The qualitative data collected through semi-structured interviews was analyzed primarily following an deductive approach while incorporating inductive elements. Transcripts were read and re-read to ensure familiarity with the data. Initial observations and potential patterns were

noted before formal coding begins. NVivo software (Lumivero, version 15) (https://lumivero.com/products/nvivo/) [21], was used to facilitate manual coding and theme identification. In the coding process, each meaningful segment of text was assigned an initial code and codes were grouped into broader themes. To enhance trustworthiness and authenticity, following techniques were used: Data triangulation (Qualitative findings were compared with quantitative results), Include direct quotes from participants in the results.

Ethical Considerations:

The study was conducted after Institutional Ethics Committee (IEC) review and approval [Approval No.- EC/NEW/INST/2024/4293]. The study was conducted in accordance with ICH-GCP guidelines, the Declaration of Helsinki (October 2013), the ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants (2017) and the ICMR National Ethical Guidelines for Bio-Medical Research involving Children (2017). Informed written consent was obtained from study participants for this study and the procedure, purpose, nature and expected effects of the study was explained to them and all their questions were satisfactorily answered.

Subject's Safety and Protection:

There was no financial burden on the subjects' family for any of the tests performed for this study.

Confidentiality:

Unique codes for participants were used and data was secured in password protected device and study investigator had access.

RESULTS

Quantitative study

Participant Demographics

A total of 50 parents (mothers) participated in the study, with a mean age of 35.12 ± 6.56 years. The majority were married (84%), while a smaller proportion were widowed (8%) or divorced (4%). Spousal/partner support varied, with 20% reporting it as "very supportive," 50% as "supportive," 18% as "neutral," 8% as "less supportive," and 4% as "not supportive", as shown in Table 1.

Table 2 shows the mean age of children at the time of the study was 8.26 ± 4.39 years, with an average age at diagnosis of 3.59 ± 3.58 years. The most common neurological or neurodevelopmental disorders among children were autism spectrum disorder (ASD) (22%), seizure disorder (20%),

intellectual disability (20%), cerebral palsy (14%), developmental delay (12%), attention-deficit hyperactivity disorder (ADHD) (6%), and specific learning disability (SLD) (6%).

Regarding family structure, 70% of participants belonged to nuclear families, 24% to joint families, and 6% were single parents. The average number of family members was 5 ± 1.7. Based on the Kuppuswamy socioeconomic scale, 10% of families were classified as upper class, 52% as upper middle, 24% as lower middle, 10% as upper lower, and 4% as lower class as represented in Table 3.

Table 1: Characteristics of parents

Age (mean)		35.12 ± 6.56
Marital status	Married	42 (84%)
	Widowed	4 (8%)
	Divorced	2 (4%)
Spousal/ Partner support	Very supportive	10 (20%)
	Supportive	25 (50%)
	Neutral	9 (18%)
	Less supportive	4 (8%)
	Not supportive	2 (4%)

Table 2: Characteristics of Children

Age at present (mean)		8.26 ± 4.39
Age at diagnosis		3.59 ± 3.58
Neurological/Neurodevelopmental disorder	ASD	11 (22%)
	Seizure disorder	10 (20%)
	Intellectual disability	10 (20%)
	Cerebral palsy	7 (14%)

	Developmental delay	6 (12%)
	ADHD	3 (6%)
	SLD	3 (6%)

Table 3: Characteristics of family

Type of family	Nuclear	35 (70%)
	Joint	12 (24%)
	Single parent	3 (6%)
Number of members in family (mean)		5 ± 1.7
Kuppuswamy scale	Upper	5 (10%)
	Upper middle	26 (52%)
	Lower middle	12 (24%)
	Upper lower	5 (10%)
	Lower	2 (4%)

Scales Results

Table 4 shows the mean Parental Stress Scale (PSS) score among parents was 49.06 ± 10.37, with a range of 23 to 68. Coping Health Inventory for Parents (CHIP) total scores varied widely, with a mean of 76 ± 20.03. Among the subscales, CHIP I (Maintaining Family Integration, Cooperation & an Optimistic Definition of the Situation) had the highest mean score (38.42 ± 9.83), followed by CHIP II (Maintaining Social Support, Self Esteem & Psychological Stability) (23.44 ± 8.79) and CHIP III (Understanding the Health Care Situation Through Communication with Other Parents & Consultation with the Health Care Team) (13.68 ± 5.11).

Table 4: Scales results

Scales	Mean	Std. Dev	Minimum score	Maximum score
PSS	49.06	10.37	23	68
CHIP total	76	20.03	33	123
CHIP I	38.42	9.83	15	55
CHIP II	23.44	8.79	9	45
CHIP III	13.68	5.11	5	24

Group Comparisons

The mean PSS scores differed across various neurological and neurodevelopmental disorders and represented in Table 5. Parents of children with cerebral palsy (56.57 ± 9.62) and ADHD (55.67 ± 11.15) reported the highest stress levels, while those with children diagnosed with SLD (37.33 ± 12.66) had the lowest. Parents of children with ASD (50.45 ± 6.73) and intellectual disability (50.7 ± 8.29) also reported higher stress, whereas those with seizure disorder (44.8 ± 10.84) and developmental delay (44.67 ± 12.13) had comparatively lower stress levels.

A one-way ANOVA was conducted to compare parental stress (PSS scores) across different neurological and neurodevelopmental disorders. The result was marginally non-significant $F(6, 43) = 2.307$, $p = 0.051$. However, the effect size was large ($\eta^2 = 0.244$, 95% CI: 0 to 0.392) and moderate-to-large when adjusted for bias ($\omega^2 = 0.136$, 95% CI: 0 to 0.255), suggesting a meaningful impact of disorder type on parental stress. Post-hoc Tukey tests did not reveal any statistically significant pairwise differences (all p-values > 0.05;). These findings indicate that while the disorder type may influence parental stress, the differences between individual disorders did not reach statistical significance in this sample. Further studies with a larger sample size are needed to confirm these effects

Table 5: Descriptive Total PSS table for respective Neurological/Neurodevelopmental disorder

Neurological/Neurodevelopmental disorder	Mean	SD	p value
ASD	50.45	6.73	

Seizure disorder	44.8	10.84	0.051
Intellectual disability	50.7	8.29	
Cerebral palsy	56.57	9.62	
Developmental delay	44.67	12.13	
ADHD	55.67	11.15	
SLD	37.33	12.66	

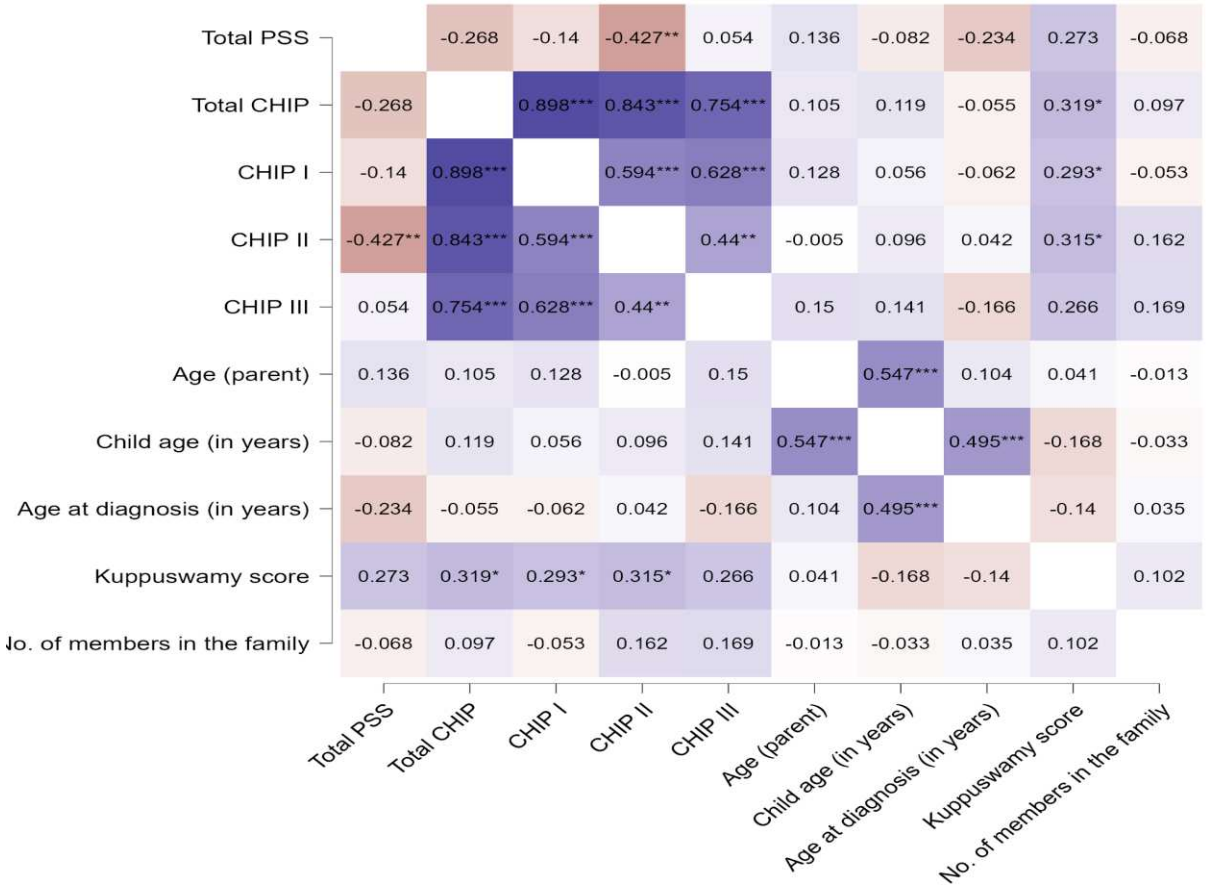
Correlation analysis

A Pearson correlation analysis was conducted to explore the bivariate relationships among parental stress (Total PSS) and several independent variables including coping scores and demographic factors. The Total PSS score demonstrated a moderate negative correlation with Total CHIP ($r = -0.268$, $p = 0.06$), which approached statistical significance. Notably, CHIP II was significantly and inversely correlated with Total PSS ($r = -0.427$, $p = 0.002$), suggesting that higher scores on the CHIP II subscale (reflecting social support and psychological stability) are associated with lower parental stress. In contrast, CHIP I ($r = -0.14$, $p = 0.334$) and CHIP III ($r = 0.054$, $p = 0.71$) did not exhibit significant correlations with stress levels.

Furthermore, demographic variables showed generally weak associations with parental stress. Parent's age ($r = 0.136$, $p = 0.346$), child's age ($r = -0.082$, $p = 0.569$), and age at diagnosis ($r = -0.234$, $p = 0.102$) were not significantly correlated with Total PSS. The Kuppuswamy socioeconomic score had a marginal positive correlation with stress ($r = 0.273$, $p = 0.055$), nearly reaching significance, whereas the number of family members was not significantly related ($r = -0.068$, $p = 0.639$).

These findings indicate that among the variables examined, aspects of coping—particularly those measured by CHIP II—play a more substantial role in relation to parental stress than do demographic factors. Figure 1 shows Heatmap for Pearson's Correlation, where Blue is positive and Red is negative.

Figure 1: Heatmap- Pearson's Correlation for respective variables



Multiple linear regression analysis

A multiple linear regression analysis was conducted to identify predictors of parental perceived stress (Total PSS) among caregivers of children. Model performance across successive iterations (M_0–M_8) is summarized in Table 7. Model M_5 demonstrated the optimal balance between explanatory power and parsimony, and was therefore selected as the final model.

Model Fit and Assumption Testing

Analysis of variance (ANOVA) demonstrated that all regression models were statistically significant ($p < 0.001$), confirming that the predictors jointly explained a significant proportion of variance in caregiver stress (Table 8).

The final model (M_5) explained 41.9% of the variance in perceived stress (Adjusted $R^2 = 0.419$). The overall regression was statistically significant, $F(6,43) = 6.895$, $p < .001$, with a standard error of estimate of 7.905. There was no evidence of autocorrelation in residuals (Durbin–Watson = 2.191, $p = 0.591$). Visual inspection of the normal probability (Q–Q) plot and residual scatterplots confirmed normality, linearity, and homoscedasticity.

Predictors of Parental Stress

Among coping domains, CHIP II emerged as a strong independent predictor of caregiver stress (B = −0.776, SE = 0.151, β = −0.658, p < 0.001), indicating that greater use of this coping strategy was associated with significantly lower perceived stress. CHIP III showed a positive trend with stress (B = 0.450, SE = 0.251, β = 0.222), though this association did not reach statistical significance (p = 0.080). Socioeconomic status, measured using the Kuppuswamy score, was significantly associated with caregiver stress (B = 0.871, SE = 0.201, β = 0.562, p < 0.001), with higher socioeconomic scores corresponding to higher perceived stress levels. Caregivers who were divorced, separated, or widowed reported significantly higher stress compared to married caregivers (B = 8.09, SE = 3.96, β = 0.256, p = 0.047). Family structure also showed a near−significant association, with caregivers from joint families reporting lower stress compared to nuclear families (B = −7.21, SE = 3.65, β = −0.300, p = 0.055). The number of family members did not independently predict stress levels (p = 0.188).

Collinearity Diagnostics

Collinearity diagnostics revealed no evidence of multicollinearity in the final model. Tolerance values ranged from 0.506 to 0.777, and variance inflation factor (VIF) values ranged from 1.286 to 1.977, all well below commonly accepted thresholds, supporting the stability of regression estimates (Table 9).

Residual Diagnostics

Residual analysis supported the assumptions of regression (Table 10). Predicted values ranged from 28.188 to 58.469, while residuals were symmetrically distributed around zero (mean residual ≈ 0). Standardized residuals ranged from −1.94 to 2.05, remaining within acceptable limits (±3), indicating absence of influential outliers. The standard deviation of standardized residuals approximated unity (SD = 1.01), further confirming homoscedasticity and normality of residuals.

Final regression model:

Perceived stress = 40.568 − 0.776(CHIP II) + 0.450(CHIP III) + 8.090(Marital Status) − 7.208(Family Type) + 0.871(Kuppuswamy)

Table 7: Summary of regression models

	Durbin-Watson

Model	R	R^2	Adjusted R^2	RMSE	Autocorrelation	Statistic	p
M_0	0.719	0.518	0.378	8.182	-0.092	2.175	0.684
M_1	0.719	0.517	0.394	8.077	-0.094	2.18	0.687
M_2	0.718	0.515	0.406	7.994	-0.097	2.185	0.627
M_3	0.715	0.512	0.416	7.926	-0.079	2.153	0.708
M_4	0.711	0.505	0.423	7.88	-0.122	2.236	0.489
M_5	0.7	0.49	0.419	7.905	-0.1	2.191	0.591
M_6	0.685	0.469	0.409	7.976	-0.123	2.236	0.465
M_7	0.666	0.444	0.395	8.071	-0.17	2.338	0.267
M_8	0.64	0.41	0.371	8.226	-0.058	2.115	0.763

Table 8: ANOVA for regressions models

Model		Sum of Squares	df	Mean Square	F	p
M_0	**Regression**	2729.067	11	248.097	3.706	0.001
	Residual	2543.753	38	66.941		
	Total	5272.82	49			
M_1	**Regression**	2728.604	10	272.86	4.183	< .001
	Residual	2544.216	39	65.236		
	Total	5272.82	49			
M_2	**Regression**	2716.587	9	301.843	4.723	< .001
	Residual	2556.233	40	63.906		

	Total	5272.82	49			
M₃	**Regression**	2697.313	8	337.164	5.367	< .001
	Residual	2575.507	41	62.817		
	Total	5272.82	49			
M₄	**Regression**	2665.068	7	380.724	6.132	< .001
	Residual	2607.752	42	62.089		
	Total	5272.82	49			
M₅	**Regression**	2585.49	6	430.915	6.895	< .001
	Residual	2687.33	43	62.496		
	Total	5272.82	49			
M₆	**Regression**	2473.858	5	494.772	7.778	< .001
	Residual	2798.962	44	63.613		
	Total	5272.82	49			
M₇	**Regression**	2341.717	4	585.429	8.988	< .001
	Residual	2931.103	45	65.136		
	Total	5272.82	49			
M₈	**Regression**	2160.005	3	720.002	10.64	< .001
	Residual	3112.815	46	67.67		
	Total	5272.82	49			

Table 9: M5 (Model 5) regression- coefficient table

Model		Unstandardized	Standard Error	Standardized	t	p	95% CI		Collinearity Statistics	
							Lower	Upper	Tolerance	VIF
M_5	(Intercept)	40.568	6.338		6.401	< .001	27.787	53.349		
	CHIP II	-0.776	0.151	-0.658	-5.15	< .001	-1.08	-0.472	0.725	1.379
	CHIP III	0.45	0.251	0.222	1.796	0.08	-0.055	0.956	0.777	1.286
	No. of members in the family	1.265	0.946	0.205	1.336	0.188	-0.644	3.173	0.506	1.977
	Marital status	8.09	3.96	0.256	2.043	0.047	0.104	16.076	0.755	1.325
	Type of family	-7.208	3.651	-0.3	-1.974	0.055	-14.571	0.154	0.514	1.945
	Kuppuswamy score	0.871	0.201	0.562	4.342	< .001	0.467	1.276	0.708	1.412

Table 10: Residual statistics

	Minimum	Maximum	Mean	SD	N
Predicted Value	28.188	58.469	49.06	6.639	50
Residual	-15.244	14.812	-1.271×10^{-16}	7.97	50
Std. Predicted Value	-3.144	1.417	-2.263×10^{-16}	1	50
Std. Residual	-1.939	2.049	0.003	1.014	50

Figure 2: Residuals vs. Predicted

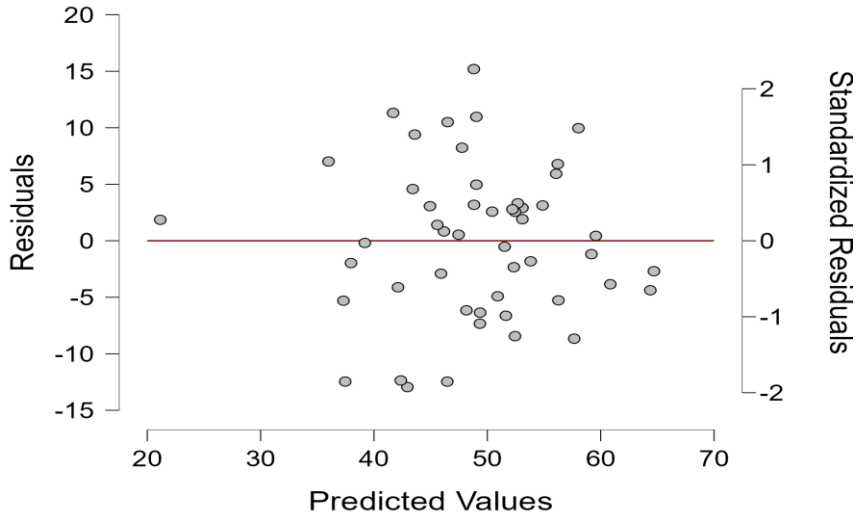
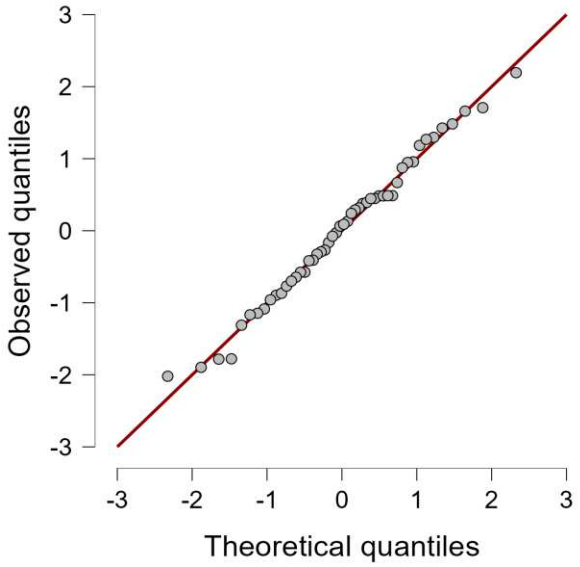


Figure 3: Q-Q Plot Standardized Residuals



Qualitative study

Analysis of the interview data revealed six primary themes- 1. Understanding child condition & diagnosis, 2. Daily life challenges & stress, 3. Coping mechanisms & support systems, 4. Healthcare experience & resource utilization, 5. Impact of family life & work, 6. Final reflections, as represented in Table 11.

Table 11: Themes and Codes of Qualitative interviews

Themes	Sub-themes	Number of Files Coded	Number of Coding References
1. Understanding child condition & diagnosis	1.1 Diagnostic Journey	8	18
	1.2 Emotional and Cognitive Reactions to Diagnosis	8	13
2. Daily life challenges & stress	2.1 Daily routine	6	6
	2.2 Specific day challenges	5	6
	2.3 Emotional and Physical Strain	9	9
	2.4 Impact on Family Dynamics	8	11
3. Coping mechanisms & support systems	3.1 Personal Coping Strategies	9	12
	3.2 Reliance on Social and Family Support	6	7
	3.3 Cultural and Religious Influences on Coping	8	9
4. Healthcare experience & resource utilization	4.1 Experiences with Healthcare Access and Quality	8	9
	4.2 Adequacy of Informational Resources	9	9
	4.3 Financial impact	10	15
5. Impact of family life & work	5.1 Alterations in Family Routines	4	4
	5.2 Social life	6	7
	5.3 Relationship with siblings	5	7
	5.4 Work-Life balance	6	6
6. Final reflections	6.1 Gaps in healthcare	2	2
	6.2 Advice to other parents	6	9

1. Understanding child condition & diagnosis

1.1 Diagnostic Journey

"I found out about his condition when he was two years old. We didn't know what this condition was. The first time he had an episode, foam started coming out of his mouth, and his entire body stiffened. We both panicked because we had never seen anything like this before."

"When I gave birth, my baby did not cry. After that, for four months, he did not turn over at all. Wherever we placed him, he remained there without any movement. It was only after four months that's when I realized something was different about him…"

1.2 Emotional and Cognitive Reactions to Diagnosis

"I felt sad obviously. He is our first child and we took all the care yet we didn't understand why this happened."

"My child was not like other children. That realization itself was painful. It hurt."

2. Daily life challenges & stress

2.1 Daily routine

"Everything revolves around my child—from waking him up, feeding him, taking him for therapy, and managing his daily routine."

"It's not just about handling the child; we have to manage everything. Our whole day revolves around completing tasks."

2.2 Specific day challenges

"Sometimes, when he gets angry, he becomes difficult to manage. When he gets aggressive, we try to calm him down by taking him outside or distracting him."

"Doctors say giving medicines to him on time is important and 2-3 times a day physiotherapy is necessary…"

2.3 Emotional and Physical Strain

"I feel completely drained. I even had to start taking medication because of mental stress."

"I don't even take care of my own health anymore. I don't pay attention to myself. My focus is entirely on my child."

2.4 Impact on Family Dynamics

“There was a lot of tension. But we both wife and husband live in harmony, never listen to anybody.. Rest all we don't give much attention.”

“We have come closer; no one has distanced themselves...”

"my family members say, ‘You take care of him yourself, don't expect anything from us.’ ”

3. Coping mechanisms & support systems

3.1 Personal Coping Strategies

“When I feel overwhelmed, I cry for a while, release my emotions, then calm down and move on.”

“I constantly speak with my child and sometimes I listen to devotional chants or prayers. It helps bring some peace to my mind.”

"Nothing much, just seeing my child happy makes me feel relaxed and often I also practice my sewing hobby which makes me feel less stressed.”

“I just listen to songs sometimes on my mobile.”

3.2 Reliance on Social and Family Support

“Sometimes, neighbors or relatives might be there to help. But if I need emotional support, I turn to my parents”

“whenever our stress increases,we talk with friends,family members and they help us lighten our burden”

“Yes, after a few months, we joined a group in this hospital when we used to come here for follow ups in a unit where there were many parents like us and we used to interact.”

3.3 Cultural and Religious Influences on Coping

“Some people believe that such children are gifts from God, they belong to the divine.”

"In my family, people don’t usually observe fasts. But yes we go to temples and pray. We trust God. I don’t know what will happen, only God knows. I have faith that God will make things better.”

4. Healthcare experience & resource utilization

4.1 Experiences with Healthcare Access and Quality

> “The doctors here are good; they listen to us and explain everything and make us feel comfortable.”
>
> "Since my child doesn’t have any major physical issues, I mainly need to take him to different places for mental health support.”
>
> “Treatment is not fully understood yet. If the treatment were better, things would have been different.”

4.2 Adequacy of Informational Resources

> "We have had tests done multiple times, but we don’t fully understand what’s happening. We don’t get clear information.”
>
> “When I go for therapy sessions, the doctors explain what needs to be done at home. They provide guidance on what should be done to help my child improve.”

4.3 Financial impact

> “We spent roughly 7 to 8 lakhs. We had to take loans and sell jewelry. It’s been very difficult.”
>
> "We have to buy some medicines from outside, but that's the main expense. Otherwise, there aren’t many extra costs—just travel expenses.”
>
> “We manage within our means. However, some medicines are expensive when bought from private pharmacies.”

5. Impact of family life & work

5.1 Alterations in Family Routines

> “I still do my daily household chores, cooking, and everything else while also managing him.”

5.2 Social life

> “We don’t go out much anymore. Whenever we take him anywhere, he often soils himself. People get annoyed.”

“No, we don’t get time for that.We don’t go out because our child gets ill”

5.3 Relationship with siblings

“His elder brother feels like you give less attention to me and more towards him. Even if not needed, you look more towards him”

"...their bond is very loving. Sometimes, children feel jealous, but since my son is still young, he doesn’t mind much.”

5.4 Work-Life balance

“I miss about 15 days of work a month and have to work 12 hours a day. It’s exhausting.”

“I can’t work as much as before. When she was younger, it was easier, but now that she’s growing, it has become more difficult.”

6. Final reflections

6.1 Gaps in healthcare

“Early diagnosis would be helpful. If we had known earlier, we could have started intervention sooner. Delayed diagnosis creates additional mental and emotional stress.”

“There isn’t much awareness. We only got to know things by going through this.”

6.2 Advice to other parents

“Every parent has their own struggles. Some have two children with similar conditions, and they still manage. So, I tell myself that I can manage too.”

“To manage stress, some people listen to devotional songs, others listen to music, or simply sit in peace and think positively. These things help to relax.”

“Take good care of your child, ensure they eat well, and follow proper treatment. Also, caregivers must look after their own health.”

Figure 4 shows Hierarchy Chart of Themes by coding references chart visually represents the major themes and sub-themes identified in the interviews, sized according to the number of coding references. Larger areas indicate themes that parents discussed most frequently. Figure 5 shows Word Cloud of Frequently Mentioned Terms. This word cloud displays the most common words appearing in the interview transcripts, with larger text size reflecting higher frequency.

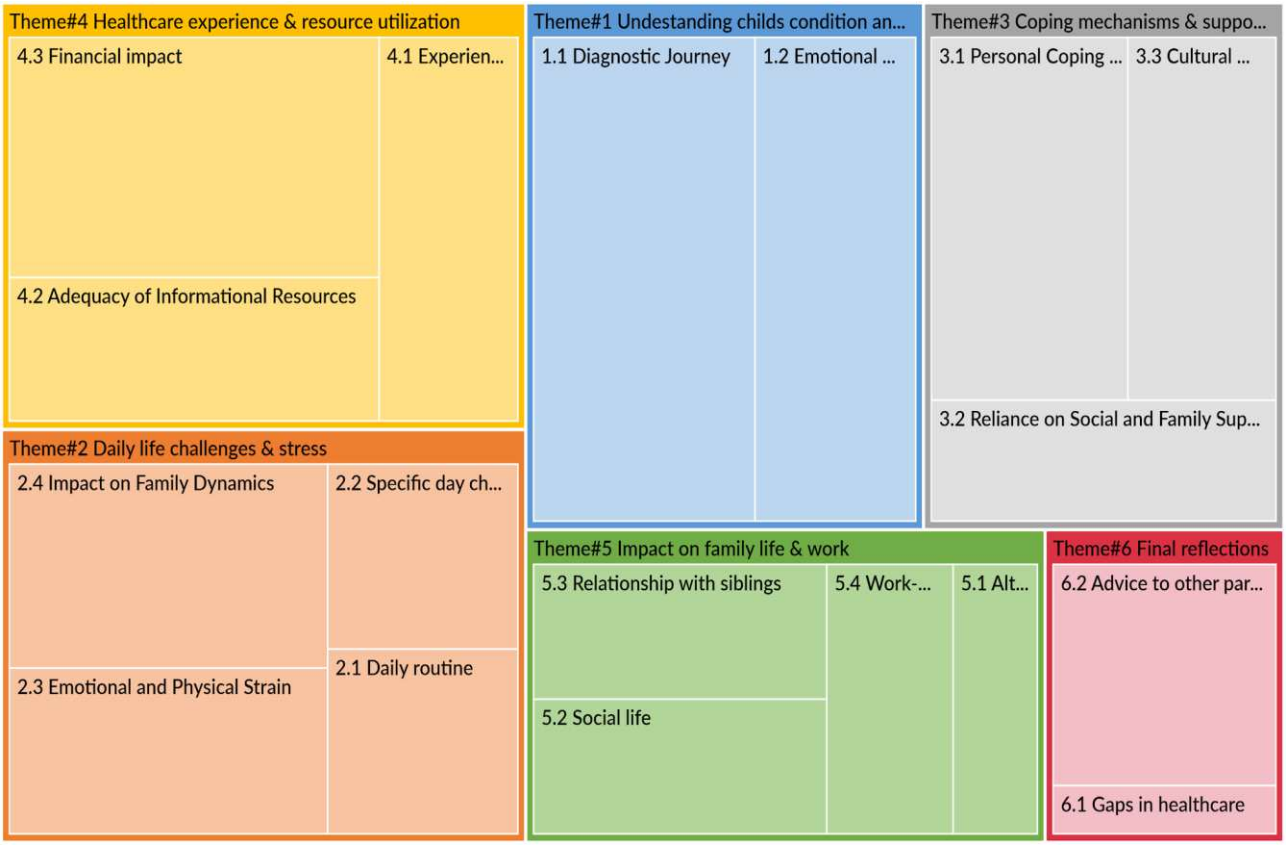


Figure 4: Hierarchy Chart of Themes by coding references chart

DISCUSSION

Quantitative study

The present study examined psychosocial and demographic predictors of perceived parental stress among caregivers of children with chronic neurological and neurodevelopmental conditions. Parental stress was examined among 50 caregivers of children with neurological and neurodevelopmental disorders in India and explored the role of coping strategies and demographic factors in influencing stress levels. The demographic profile—characterized by a mean parental age of 35.12 ± 6.56 years, predominantly married status, and a nuclear family structure.

Using a multiple regression approach, the final model explained approximately 42% of the variance in parental stress, indicating that coping strategies, socioeconomic status, and family structure play a

substantial role in shaping caregiver stress experiences. These findings contribute to the growing literature emphasizing the multifactorial nature of parental stress in pediatric chronic illness.

Coping Pattern II (CHIP II)

Among all predictors, Coping Pattern II (CHIP II)—maintaining social support, self-esteem, and psychological stability—emerged as the strongest and most consistent predictor of parental stress. Higher CHIP II scores were associated with significantly lower stress levels across all regression models. CHIP II encompasses behaviors such as seeking emotional support, preserving personal identity, and managing psychological tension, which are widely recognized as protective coping mechanisms in caregiving contexts [22].

This finding is consistent with prior studies demonstrating that emotional coping and perceived social support buffer stress in parents of children with chronic conditions [23]. Social support has been shown to mitigate caregiver burden by reducing emotional exhaustion, enhancing resilience, and improving psychological well-being [24, 25]. Similarly, preservation of self-esteem and psychological stability has been linked to lower levels of anxiety, depression, and perceived stress among caregivers [26, 27]. The present findings reinforce the central role of emotion-focused and support-based coping in protecting parents from chronic stress.

Coping Pattern III (CHIP III)

In the present study, higher scores on Coping Pattern III (CHIP III)—which reflects parents' engagement with healthcare professionals and other parents to better understand the child's illness—were associated with higher perceived stress. Although healthcare communication is generally considered an adaptive coping strategy, this finding may reflect the greater illness severity and caregiving burden among parents who engage more intensively with the healthcare system. Studies have shown that frequent medical consultations, continuous treatment monitoring, and ongoing decision-making demands can increase emotional strain and caregiver burden [28, 29, 30].

Consistent with the transactional model of stress and coping proposed by Lazarus and Folkman [31], coping strategies do not uniformly reduce stress; their effect depends on the intensity of caregiving demands and contextual appraisal [31, 32]. Thus, CHIP III in this study likely represents increased caregiving intensity rather than maladaptive coping, underscoring the need for parallel psychological support alongside medical care.

Socioeconomic Status

Socioeconomic status, measured using the Kuppuswamy scale, was independently associated with higher parental stress. Although socioeconomic advantage is often assumed to be protective, evidence

indicates that higher socioeconomic status may be linked to increased self-efficacy and expectations regarding caregiving roles, child outcomes, and access to optimal treatments [33, 34]. Parents from higher socioeconomic strata may experience greater decisional burden, role conflict, and psychological pressure to optimize their child's health outcomes, which may contribute to elevated stress levels.

Marital Status

In the present study, marital status was a significant predictor of parental stress, with divorced, separated, or widowed caregivers experiencing higher stress compared to married caregivers. This finding is consistent with existing literature indicating poorer psychological outcomes among single caregivers of children with neurodevelopmental disorders.

Dereje et al.[35] reported that divorced or widowed caregivers had significantly lower psychological and social quality-of-life scores, which was attributed to increased emotional vulnerability, lower self-esteem, and higher levels of anxiety and depression [35]. Similarly, Chu et al.[36] found that separated, divorced, or widowed caregivers exhibited higher depressive symptoms than those who were married or cohabiting, highlighting the protective role of spousal support [36].

Indian studies also support these findings. Upadhyay [37] demonstrated significantly higher stress levels among single-parent caregivers due to emotional, financial, and social challenges following spousal loss [37]. Likewise, Gonal and Pujar [38] observed greater parenting stress among divorced parents of children with autism spectrum disorder, largely due to the absence of spousal support and increased caregiving burden [38].

Family Structure

Family structure also demonstrated a meaningful, though borderline, association with stress. In collectivist sociocultural contexts, joint families often distribute caregiving responsibilities across multiple members, provide emotional reassurance, and offer practical and financial support, thereby buffering the daily burden of caring for a child with developmental or chronic health needs [39, 40]. Lohar et al. [41] observed significantly greater stress among parents from nuclear families compared to joint families in a tertiary mental health setting ($p < 0.01$) [41]. Similarly, Yousefzai HA [42] reported higher psychological distress among parents of children with intellectual disabilities in nuclear households, attributing this to limited caregiving assistance and reduced social support [42]. Studies further suggest that joint family systems promote work-sharing and economic stability, which reduce mental strain and improve overall well-being [40, 43, 44]. Consistent with these findings, the direction of association in our study suggests that the availability of extended family support may mitigate parental stress, whereas nuclear family arrangements may increase caregiver role overload.

Although the association approached borderline statistical significance, its clinical relevance underscores the importance of strengthening social and community support for families lacking extended household networks.

Qualitative study

The qualitative component of the present study provides a deeper understanding of the lived experiences of caregivers for children with neurological and neurodevelopmental disorders and complements the quantitative findings by contextualizing parental stress within everyday realities. Six interrelated themes emerged, collectively highlighting that caregiving stress is shaped not only by the child's medical condition but also by emotional responses, social support, healthcare systems, and socioeconomic pressures.

The first theme, "Understanding the Child's Condition and Diagnosis," reflects the emotionally charged and often uncertain pathway toward diagnosis. Many parents described shock, denial, confusion, and fear upon recognizing early developmental abnormalities such as delayed crying at birth, seizures, or delayed milestones. The diagnostic period was frequently associated with anxiety stemming from limited information and unclear prognostic expectations. These experiences are consistent with earlier studies showing that the time surrounding diagnosis represents one of the most psychologically distressing stages for parents of children with developmental disabilities and parents often experience feelings analogous to grief and loss during this phase [45, 46, 47]. Our findings therefore underscore the importance of structured counseling, early screening, and empathetic communication by healthcare professionals to mitigate distress at this critical stage.

The second theme, "Daily Life Challenges and Stress," illustrates how caregiving responsibilities permeate all aspects of daily life. Parents reported constant supervision, behavioral management difficulties and persistent physical exhaustion, often describing their routines as being entirely centered around the child's needs. Such sustained caregiving demands disrupted household functioning and reduced opportunities for rest or recreation. These observations align with the caregiving burden model described by Raina et al. [48], who demonstrated that parents of children with chronic disabilities experience significantly greater psychological strain and poorer health outcomes than parents of typically developing children. A meta-analysis by Singer GH [49], further confirmed higher rates of stress and depressive symptoms among mothers of children with developmental disorders. The convergence of our findings with these studies suggests that caregiving-related strain is both chronic and cumulative.

The theme “Coping Mechanisms and Support Systems” highlights the adaptive strategies employed by families to manage stress. Parents described both emotion-focused coping (crying, acceptance, prayer and spiritual practices) and problem-focused approaches (seeking information and engaging in meaningful activities). Social and familial support, particularly from spouses and extended family members, emerged as a crucial protective factor. In the Indian sociocultural context, religious faith and devotional practices were frequently cited as important sources of strength and resilience. These findings are theoretically supported by Lazarus and Folkman’s stress–coping framework [50,51] and empirically by Hastings and Taunt [52], who noted that positive coping and perceived social support are strongly associated with better parental adjustment. Peer and Hillman [53] similarly emphasized that strong support networks enhance resilience and buffer caregiver stress. Thus, strengthening both formal and informal support systems may represent an important target for intervention [53].

The fourth theme, “Healthcare Experience and Resource Utilization,” revealed heterogeneous interactions with healthcare services. While some parents expressed satisfaction with empathetic and communicative providers, others reported inadequate guidance, fragmented services and considerable financial burden. These findings echo prior research demonstrating that family-centered communication and continuity of care are critical determinants of caregiver satisfaction and psychological well-being [54, 55]. In low- and middle-income settings, out-of-pocket healthcare expenditures may further compound stress and delay care-seeking, emphasizing the need for accessible and coordinated services.

The fifth theme, “Impact on Family Life and Work,” underscores the broader social and occupational consequences of caregiving. Participants reported reduced social engagement, strained family dynamics, altered sibling relationships, and compromised employment or career opportunities. Many mothers described sacrificing personal and professional aspirations to meet caregiving demands. Similar spillover effects have been documented in earlier studies, where parents of children with disabilities experienced greater marital strain, social isolation, and decreased workforce participation [56,57,58]. These systemic disruptions illustrate that parental stress extends beyond the individual to affect overall family functioning and socioeconomic stability.

Finally, the theme “Reflections and Recommendations” captured parents’ resilience and constructive outlooks. Despite substantial challenges, many caregivers demonstrated adaptive acceptance and expressed a desire to help other families navigate similar journeys. Calls for earlier diagnosis, improved awareness, and better institutional support highlight a collective need for systemic change. This resilience is consistent with other studies which reported evidence of post-traumatic growth and strength among families of children with developmental disabilities [59, 60, 61]. Such findings suggest that supportive environments can foster empowerment alongside coping.

Overall, the qualitative findings reinforce that parental stress is multidimensional, arising from the intersection of emotional, caregiving, socioeconomic, and healthcare-related factors. Interventions should therefore adopt a holistic, family-centered approach incorporating psychological counseling, structured caregiver education, peer support groups, and improved healthcare communication. Addressing these broader determinants may substantially enhance caregiver well-being and ultimately improve outcomes for children with neurological and neurodevelopmental disorders.

CONCLUSION

This mixed-methods study of Indian parents caring for children with neurological and neurodevelopmental disorders demonstrates that parental stress in this population is substantial and multifactorial. The final regression model explained approximately 42% of the variance in perceived stress and identified four independent predictors: coping through social support, self-esteem, and psychological stability (CHIP II), which was strongly protective; higher socioeconomic status, which was paradoxically associated with greater stress; unmarried status, which elevated stress relative to married caregivers; and nuclear family structure, which showed a borderline association with higher stress compared to joint families. The qualitative findings contextualized these patterns, revealing that stress emerges not from a single source but from the convergence of diagnostic uncertainty, relentless caregiving demands, financial strain, fragmented healthcare experiences, and disruptions to family and occupational life. Mothers drew on a combination of emotion-focused coping, spousal and extended-family support, and culturally rooted religious and spiritual practices to navigate these demands, and emotional and social coping resources — rather than demographic or economic factors alone — emerged as the most consistent buffer against stress across both study components. Taken together, these findings suggest that interventions to reduce parental stress in this population should prioritize the strengthening of social support networks, the preservation of caregiver psychological stability and self-identity, and the provision of family-centered healthcare communication, with particular attention to single caregivers, those in nuclear family structures, and those navigating higher-expectation caregiving contexts. Addressing caregiver well-being should therefore be regarded as an integral, rather than peripheral, component of pediatric neurodevelopmental care in India.

LIMITATIONS

Certain limitations should be considered when interpreting these findings. The final sample comprised 50 caregivers, all of whom were mothers; although this reflects the predominantly maternal caregiving pattern observed in Indian clinical settings, it precludes any conclusions about paternal stress and coping and limits the generalizability of findings to fathers or other primary caregivers. While the sample size met the a priori estimate, the study remained underpowered for subgroup analyses across the seven disorder categories, with some groups containing as few as three

participants; this likely contributed to the borderline non-significant ANOVA across disorders despite a moderate-to-large effect size. The cross-sectional design further precludes causal inference, and the directionality between coping strategies and perceived stress cannot be established — an important consideration for CHIP III, where greater healthcare engagement may be a consequence, rather than a cause, of higher caregiving burden. Convenience sampling from a single tertiary-care center also introduces selection bias, as families able to access specialized paediatric and palliative services may differ systematically from those in primary care or rural settings.

Clinical severity of the child's condition was not quantified using severity indices. The counterintuitive association between higher socioeconomic status and greater stress should therefore be interpreted cautiously, as higher-SES families may access tertiary care more readily, recognize developmental deficits earlier, or face greater role-expectation pressures, which were directly measured. The multiple linear regression employed an iterative model-selection strategy; while the final model was selected based on optimal adjusted R^2 and parsimony, such stepwise approaches can inflate Type I error in small samples and should be regarded as exploratory rather than confirmatory, and no adjustment for multiple comparisons was applied in the correlation analyses.

FUTURE PERSPECTIVES

The limitations outlined above directly shape priorities for future research. Longitudinal cohort designs are needed to disentangle the temporal relationship between coping strategies and perceived stress and to characterize how parental stress evolves across key transition points such as initial diagnosis, school entry, adolescence, and transition to adult care; a prospective design would also help clarify whether CHIP III represents an adaptive response to caregiving intensity or a marker of unmet psychological need. Multi-center studies with larger and more diverse samples — including fathers, grandparents, and other primary caregivers, and participants recruited from primary care and rural settings — are essential to establish the generalizability of these findings across the heterogeneous Indian caregiving landscape, and future work should also stratify or match samples by standardized indices of disease severity so that the independent contributions of condition type, severity, and family context can be distinguished.

Intervention trials should target the most modifiable predictor identified in this study, namely coping through social support, self-esteem, and psychological stability. Randomized evaluations of peer-led parent support groups, structured psychoeducation programs, mindfulness-based stress reduction, and culturally adapted cognitive-behavioral interventions are warranted, particularly for single caregivers and those in nuclear family configurations identified here as higher-risk subgroups. Hospital-based peer support networks, such as the one described spontaneously by participants in this study, merit formal evaluation as low-cost, scalable interventions.

Health systems research is also needed to evaluate the counterintuitive association between higher socioeconomic status and greater parental stress, and mechanistic studies exploring role-expectation pressures, decisional burden, and the psychological costs of navigating multiple therapy providers would help determine whether this finding reflects a genuine phenomenon or a methodological artifact. Finally, policy-oriented research should examine the economic impact of caregiving on Indian families, the reach of existing entitlements, and the feasibility of integrating caregiver mental health screening and support into routine pediatric neurology and palliative care pathways. The substantial out-of-pocket expenditures described by participants, including the sale of assets to finance care, underscore an urgent need for systems-level financial protection for families of children with neurodevelopmental conditions and highlight caregiver well-being as a legitimate target of public health policy rather than a private family concern.

DECLARATIONS

ABBREVIATIONS

PSS: Parental Stress Scale, CHIP: Coping Health Inventory for Parents

ETHICAL APPROVAL AND CONSENT TO PARTICIPATE

The study was conducted after Institutional Clinical Ethics Committee - Biomedical Health Research (ICEC-BHR) review and approval [Approval No.- EC/NEW/INST/2024/4293] and the institute was Rajiv Gandhi Medical College and Chhatrapati Shivaji Maharaj Hospital, Thane, India. The study was conducted in accordance with ICH-GCP guidelines, the Declaration of Helsinki (October 2013), the ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants (2017) and the ICMR National Ethical Guidelines for Bio-Medical Research involving Children (2017). Informed written consent was obtained from study participants for this study and the procedure, purpose, nature and expected effects of the study was explained to them and all their questions were satisfactorily answered.

CONSENT FOR PUBLICATION

Not Applicable

AVAILABILITY OF DATA AND MATERIALS

The datasets generated and analyzed during the current study are not publicly available due to institutional policy, but are available from the corresponding author on reasonable request after approval from the institute.

COMPETING INTERESTS

The authors declare that they have no competing interests.

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AUTHORS' CONTRIBUTIONS

Dr. Yuvraj Rananajay Singh: concept, data collection, data evaluation, statistical analysis, writing the manuscript

Dr Sunil Junagade: concept, data collection, data evaluation, supervision, writing the manuscript and monitoring

Dr. Alkesh Patil: planning, monitoring of data collection, manuscript evaluation

Ruchi Niranjan Patil: planning, monitoring of data collection, manuscript evaluation

Ganesh Gupta: data collection

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Vivek Pamula: data collection

Jaahnavi Sunkara: data collection

Shivam Dubey: data collection

Sumedha Gupta: data collection

Piyusha Vyavahare: data collection

Sumeet Bangar: data collection

All authors read and approved the final manuscript.

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