

Caring Under Strain: Elevated Parental Stress in Families of Children with Neurodevelopmental Disorders in an Urban Indian Setting

Gurpreet Kaur¹, Gopal Agrawal², Jayashankar Kaushik³, Manish Samnani⁴

1. Gurpreet Kaur (Corresponding Author)

Developmental Paediatrics, Iris Clinic, Gurugram, Haryana India

Orcid id:0000-0001-9188-2237

2. Gopal Agrawal

Department of Pediatrics and Neonatology Cloudnine Hospitals (Sector 47 & sector 14), Gurugram (Haryana), India

3. Jayashankar Kaushik

Department of Pediatrics, All India Institute of Medical Sciences, Guwahati, Assam, India

4. Manish Samnani, Pediatric Occupational Therapy, SOCH India, Gurugram, Haryana, India

Address for correspondence

Gurpreet Kaur

101B, First Floor, Supermart 2, DLF Phase 4,

Gurugram, Haryana, 122009, India

Email: gurpreet.virgo@gmail.com

Contact no. : +91-8800116593



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Abstract

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Keywords:

- Parental Stress
- Neurodevelopmental Disorders
- Parental Stress Scale (PSS).

Objective: To determine the Parental Stress Scale (PSS) score in parents whose children were diagnosed with neurodevelopmental disorders (NDDs) and compare it with the PSS score of parents of typically developing (TD) children.

Methods: This cross-sectional analytical study assessed parental stress levels using the 18-item Parental Stress Scale (PSS), a self-reported tool, with each item scored on a five-point Likert scale, total PSS score ranging from 18–90. Participants were recruited through convenience sampling from four institutions in Gurgaon. Parents of children with NDDs were enrolled from SOCH and Hope Brings Change, while parents of TD children participated from Iris Clinic and Cloudnine Hospitals. Each participant completed a demographic data form and PSS questionnaire.

Results: The study included 74 parents—39 with children having NDDs and 35 with TD children. Demographic profiles were almost similar between the groups (except parental employment and child gender). The mean PSS score was significantly higher in parents of children with NDDs (46.05 ± 8.86) compared to those with TD children (34.51 ± 7.70). The mean difference of $11.54 (\pm 1.93 \text{ SE}; 95\% \text{ CI: } 7.70\text{--}15.38)$ was statistically significant ($p < 0.001$).

Conclusion: Parents of children with NDDs experience significantly elevated stress levels compared to parents of TD children. This can negatively impact parental well-being and hinder the emotional and behavioral development of their child.

Introduction:

Parenting is defined as the process of raising and nurturing children, encompassing the provision of care, affection, and guidance necessary for their overall development^[1, 2]. It is a multifaceted and dynamic role, undertaken by an individual or family unit, that involves navigating diverse challenges while offering opportunities for substantial personal and relational fulfillment^[2].

Parental stress is a multifactorial construct arising from the perceived burden associated with fulfilling the roles and responsibilities of parenthood^[3,4]. While some degree of stress is a normative aspect of raising children, parents of children with neurodevelopmental differences often face significantly greater demands, encompassing physical, psychological, and emotional domains^[5]. Managing a wide spectrum of impairments frequently necessitates substantial investments of time, energy, and financial resources^[4,6]. Persistent exposure to such stressors can contribute to a self-perpetuating cycle of adverse outcomes, including heightened risk of parental depression, marital discord, compromised physical health, and diminished parenting efficacy^[7]. These factors may, in turn, exacerbate behavioral and emotional difficulties in the child, further intensifying parental stress^[8,9].

In India, parental stress in children with special needs is one of the lesser studied aspects of patient care^[10]. There is a lack of awareness about the role of the stress levels of parents on the behaviour of their children and the success of their therapies, even in institutes and centres providing therapies to children with Neurodevelopmental disorders (NDDs). With their constantly increasing burden, the NDDs in India are starting to be identified as a significant public health problem^[11-13]. With a large spectrum of severity, many of these conditions are only manageable (with difficulty) but have no cure till now. Hence, they cause a significant psychological distress to the parents and there is a dire need to understand the stress the caregivers go through. We hypothesize that parental stress levels are increased in families of children diagnosed

with NDDs. Therefore, intervention towards such children should not only focus on them but should pay attention to the family's mental health as well.

Materials & Methods:

This institution-based cross-sectional analytical study was carried out in Gurgaon, Haryana, over a three-month period from August 2024 to November 2024, to assess and compare parental stress among parents of children diagnosed with Neurodevelopmental Disorders (NDDs) and those of typically developing (TD) children. Group 1 consisted of parents whose children were undergoing therapy at two key developmental centres: Soch India, known for its multidisciplinary interventions such as occupational therapy, speech therapy, applied behaviour analysis, and group therapy, and Hope Brings Change, the special education needs (SEN) wing of Windsor International School, which supports both enrolled and external children. For comparison, Group 2, parents of TD children were recruited from the outpatient departments (OPDs) of Iris Clinic and Cloudnine Hospital, Gurgaon, where children were being seen for minor ailments. The target population included parents of children (with NDDs or with TD) aged 2–9 years.

Sample size for comparison of two means was calculated based on data from previous similar studies used to measure parental stress in children with NDDs using the same tool, PSS^[14]. With a p value of <0.05, power of study 90% and the minimum detectable difference set to 5 points, the sample size calculated was 54 (27 in each group). A sample of at least 30 parents from each group was planned. Inclusion criteria ensured participants were parents of children aged 2–9 years and well versed with English. Parents undergoing psychiatric treatment were excluded from the study. The study tool used was the Parental Stress Scale (PSS), a freely available, self-reported 18-item questionnaire that assesses both positive and negative experiences of parenthood^[15]. Respondents are asked to agree or disagree with items in terms of their typical relationship with their child, to rate each item on a five-point likert scale. The possible scores on the scale can range from 18 to 90. Higher scores on

the scale indicate greater stress. Both mothers and fathers were individually allowed to participate, and in instances where both opted in, they filled separate questionnaires.

For data collection, convenience sampling was used. Parents meeting the inclusion criteria were briefed by institutional heads and, upon providing informed consent, completed a case record form (CRF) containing demographic information and the PSS questionnaire. A few open-ended questions were also added to the proforma to explore parental concerns and coping strategies. Participants dropped the filled forms into secure dropboxes at the respective centres, with optional disclosure of personal identity. Ethical considerations were thoroughly addressed. The protocol was approved by Genebandhu Independent Ethics Committee, New Delhi (ECG021/2024) and written permissions were obtained from all the participating centres. Participation was voluntary, anonymity was maintained, and it was assured that services provided to the children would remain unaffected regardless of participation. No personal identifiers were used in any stage of the analysis, and all collected data were kept confidential.

Statistical analysis:

Collected data was entered into the google sheets by the principal investigator. Analysis was done using Python 3.11 software. Categorical variables were compared using the chi-square or Fisher's exact test, while continuous variables were analyzed using either the Student's t-test or the Mann-Whitney U test, depending on data normality. A significance threshold of $p < 0.05$ was considered.

Results:

A total of 79 participants were initially enrolled, including 42 in Group 1 (parents of children with neurodevelopmental disorders) and 37 in Group 2 (parents of typically developing children). After excluding five participants—two incomplete responses, one pre-existing psychiatric condition in Group 1, and two with pre-existing psychiatric illness in Group 2—the final sample consisted of 74 participants (39 in Group 1 and 35 in Group 2) (See Figure 1). From amongst the 4 institutes that participated in the study, the highest number of participants were from Iris Clinic (22), followed by SOCH (20), Hope Brings Change (18), and Cloudnine Hospital (14), ensuring a diverse and balanced sample for comparison.

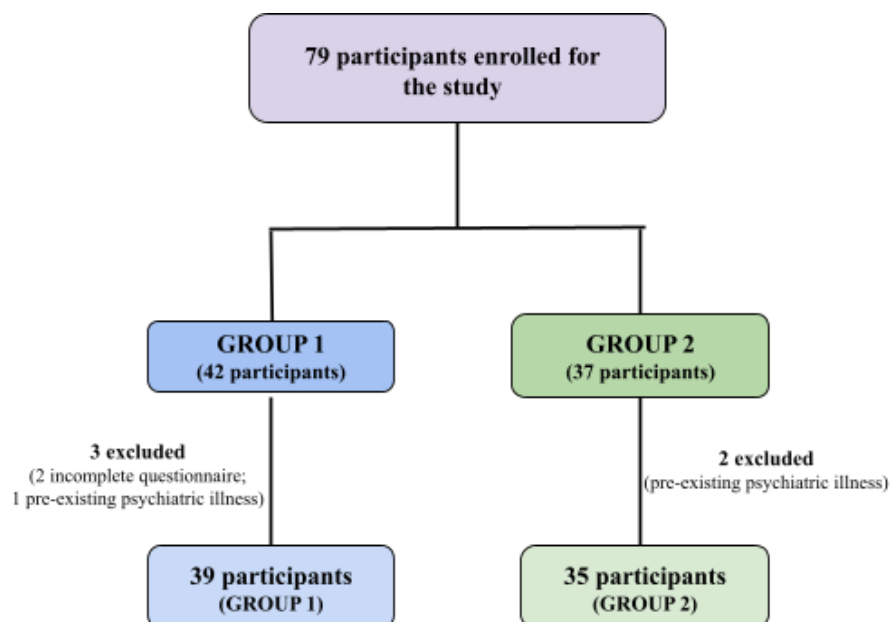


Figure1: ParticipantFlowinthe Study

Among the participants, the majority were mothers (82.43%) . There was no significant difference in gender distribution between the groups ($p=0.8$) (Table 1). The mean parental age was 37.23 years ($SD \pm 2.88$), with no significant difference between the groups ($p=0.1$). Most participants (79.73%) were employed, though a higher number of non-working parents were in group 1, which was statistically significant ($p=0.008$). The socioeconomic status was similar amongst both the groups ($p=0.4$) and 92.31% of the total participants belonged to the Upper Class as per the Kuppaswamy scale. Marital status was consistent across both groups,

with 95.95% married, and there was no significant difference in the family type (joint vs. nuclear; $p=0.5$). The median family size was 4 members in both groups, with no significant difference in the number of family members ($p=0.2$) or children ($p=0.4$). Overall, 91.89% of participants across both the groups reported no known family history of neurodevelopmental disorders (NDDs), and 86.49% reported no family history of psychiatric illness. There were no statistically significant differences between the groups in either of these family history variables.

Table 1: Sociodemographic characteristics of study population

Variable	Group1 (39)	Group2 (35)	P value
Parent Characteristics			
Age (years) (Mean ($\pm SD$))	36.79 (± 3.06)	37.71 (± 2.63)	0.173
Gender			
a) Male (father) (n%)	33 (84.6%)	28 (80%)	0.83
b) Female (mother)(n%)	6 (15.38%)	7 (20%)	
Marital Status			
a) Married (n%)	37 (94.8%)	34 (97.1 %)	1.0
b) Divorced(n%)	2 (5.12%)	1 (2.85%)	
Employment			
(a) Working (n%)	26 (66.6%)	33 (94.3%)	0.008
(b) Not working (n%)	13 (33.3%)	2 (5.7%)	
Kuppaswamy Class (n%)			
(a) Upper Class	36 (92.3%)	31 (88.6%)	0.401
(b) Upper Middle Class	2 (5.12%)	4 (11.4%)	
(c) Middle Class	0	0	
(d) Lower Middle Class	1 (2.56%)	0	
(e) Lower Class	0	0	

Type of Family			
(a) Joint Family (n%)	15 (38.4%)	10 (28.5%)	0.514
(b) Nuclear Family (n%)	24 (61.5%)	25 (71.4%)	
Number of Family Members (Median(IQR))	4 (2.5)	4 (1.5)	0.226
Family H/o Psychiatric Illness			
(a) Yes (n%)	6 (15.4%)	4 (11.4%)	0.876
(b) No (n%)	33 (84.6%)	31 (88.6%)	
Family h/o NDD			
(a) Yes (n%)	5 (12.8%)	1 (2.86%)	0.254
(b) No (n%)	34 (87.2%)	34 (97.1%)	
Child Characteristics			
Age (months) (Median $\pm$ IQR)	72 ($\pm$ 35.50)	72 ($\pm$ 48)	0.687
Gender			0.031
(a) Male (n%)	34 (87.2%)	22 (62.9%)	
(b) Female (n%)	5 (12.8%)	13 (37.1%)	

SD = Standard Deviation; IQR = Interquartile range; n = number of participants

Group 1 = parents of children diagnosed with Neurodevelopmental Disorders; Group 2 = parents of typically developing children

The children's age ranged from 2 to 9 years (24 to 108 months), with a mean of 74.35 months (Table 1). Both groups had similar age distribution ($p=0.6$), with 6–9 years being the most common age range. A significant difference was observed in child gender distribution ($p=0.03$), with more boys in group with neurodevelopmental disorders and more girls in the typically developing children's group.

Parental stress was measured using the Parental Stress Scale (PSS). The mean PSS score was significantly higher in the group 1 (46.05 ± 8.86) than in the group 2 (34.51 ± 7.70), with a mean difference of $11.54 (\pm 1.93 \text{ SE}; 95\% \text{ CI: } 7.70\text{--}15.38)$ ($p<0.001$) (Figure 2). This indicates a considerably higher stress burden among parents of children with NDDs compared to parents with TD children.

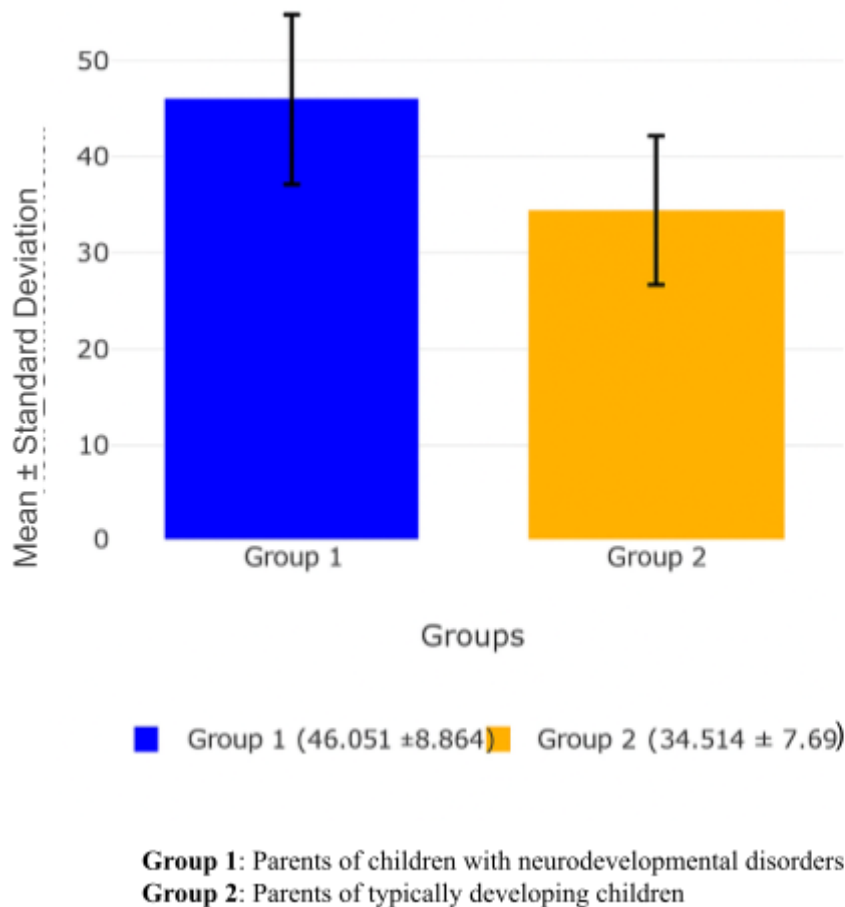


Figure 2: Error bar plot comparing the Parental Stress Scale (PSS) scores in parents of children with neuro developmental disorders and parents of typically developing children)

In terms of the diagnosis of the children with NDDs in group 1, 25 had autism spectrum disorder (ASD) as the sole diagnosis, while ASD with attention-deficit/hyperactivity disorder (ADHD), and global developmental delay were the other diagnoses. There was no significant difference in stress levels between parents of children with single vs. multiple diagnoses ($p=0.6$). Additionally, having siblings did not significantly impact parental stress ($p=0.5$). A weak, non-significant positive correlation was noted between child age and parental stress ($r=0.27$, $p=0.09$).

Discussion:

This institution-based cross-sectional analytical study aimed to assess stress levels in parents of

children diagnosed with neurodevelopmental disorders (NDDs) and compare them with those in parents of typically developing (TD) children. While most participants completed the PSS (Parental Stress Scale) questionnaire without difficulty, a few found certain items ambiguous, underscoring the need for culturally sensitive adaptations.

The study confirms significantly higher stress levels among parents of children with NDDs. Mean PSS scores were significantly higher in the NDD group (46.05 ± 8.86) compared to the TD group (34.51 ± 7.70), with a mean difference of 11.54 ($p < 0.001$). This aligns with global literature indicating consistently elevated parental stress in families of children with NDDs [9, 14, 16 - 19].

The stress burden was comparable across parents of children with single or multiple NDD diagnoses, reflecting the shared challenges posed by developmental impairments regardless of subtype. Although a weak, statistically insignificant trend suggested stress may increase with the child's age, parents described persistent high stress throughout the lifespan—linked to evolving challenges such as securing education, navigating adolescence, and uncertainty about future care. This finding is consistent with previous studies showing that the stress experienced by parents of children with developmental delays can be chronic, although there is marked individual variation in its trajectory over time^[20-22]. Like in previous studies, the parents of neurodivergent children who participated in our study, most frequently expressed anxiety about their child's future, including independence, healthcare, and employment prospects, with little alleviation even when siblings were present^[6,9,23-25]. Some parents mentioned the use of coping strategies like meditation, yoga, exercise, and leisure activities—but these seem to provide a temporary respite from caregiving responsibilities and distraction from their constant worries.

This study is among the few to examine stress levels across parents of children with any type of neurodevelopmental disorder. Key strengths of this study include its cross-sectional comparative design and the use of an anonymous, self-administered Parental Stress Scale, facilitating candid responses. The addition of open-ended questions further enriched the data by capturing parents' perspectives and concerns in depth.

However, participants in our study were recruited from private organizations and were predominantly from higher-income families, which may limit the generalizability of findings to the broader population. Stress levels in this group may differ from those of lower-income parents who face added challenges such as financial strain and limited access to resources. Furthermore, only the accompanying parent was included, and

involving both parents could have provided a more comprehensive perspective.

Parental stress in families of neurodivergent children remains an underexplored area in developmental pediatrics, particularly in Northern India. Limited research and awareness in this field have led to healthcare systems focusing largely on the child's treatment while overlooking the psychological needs of parents. The present findings confirm that parental stress is both high and pervasive across different neurodevelopmental disorders and persists throughout the child's developmental stages, with uncertainties regarding education, independence, and healthcare as key contributors. A holistic approach is therefore essential—one that integrates structured psychological support for caregivers as a core component of multidisciplinary management. Counseling at the time of diagnosis, stress management programs, and relaxation-based interventions at therapy centers could substantially improve parental well-being. In addition, fostering societal empathy, promoting inclusivity for neurodivergent individuals, and developing policies to ensure long-term security for children with NDDs will help reduce parental stress and strengthen family resilience.

Conclusion:

Parents of children with neurodevelopmental disorders experience significantly higher levels of stress compared to parents of typically developing children. The elevated stress appears to be consistent across different neurodevelopmental diagnoses and persists throughout various developmental stages. Concerns regarding the child's future, independence, education, and healthcare contribute substantially to caregiver burden. These findings highlight the importance of incorporating routine psychological assessment and support for caregivers into multidisciplinary care programs. Addressing parental well-being may improve both family resilience and outcomes for children with neurodevelopmental disorders.

What does this study add?

- Confirms the high levels of parental stress and highlights the universality of stress across different types and severities of Neurodevelopmental disorders (NDDs).
- Underscores the chronic nature of parental stress across the child's developmental stages, with future uncertainties (education, independence, healthcare) as key contributors.
- Draws attention to a gap in current care models, advocating for the inclusion of structured psychological support for parents as a core part of therapy for children with NDDs.

CONFLICT OF INTEREST: The authors declare that they have no conflict of interest.

ETHICAL APPROVAL: Ethical clearance was obtained from the Genebandhu Independent Ethics Committee, New Delhi. Ref No: ECG021/2024

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