

## Challenges of Raising A Child with Autism and Epilepsy: Stress and Coping Mechanisms Among Parents

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Most research on parental stress related to autism focuses on both parents in Western contexts. Parental mental well-being significantly impacts a child's quality of life. However, the unique traits of autism often pose added mental health challenges for parents. This study examined parental stress levels in relation to the child's age and the parent's gender. An online survey conducted in India used the Autism Parenting Stress Index and demographic details. Participants included 16 mothers and 9 fathers of children with epileptic autism across early childhood (3 months–5 years), middle childhood (6–12 years), and adolescence (13–18 years). Parents of children aged 6–12 reported the highest stress, possibly due to academic and social pressures. Fathers showed higher stress than mothers. Key stressors included epilepsy, self-harm, sleep issues, tantrums, and daily living challenges, impacting both parent and child well-being. This emotional strain can disrupt the overall well-being of family.

**Keywords:** Autism, Parental Stress, and Epilepsy.

Isolated in their world, children with autism appear in different and remote and are unable to form emotional bonds with others. Children with this baffling brain disorder can display a wide range of symptoms. Many are helpless to indulge other people's thoughts and requirements. Often, language and brainpower fail to develop fully, making interactions and social relationships difficult. Many children with autism engage in monotonous activities, such as rocking or banging their heads or rigidly following familiar prototypes in their daily habits. Some are glaringly sensitive to sound, touch, sight, or smell. Children with autism do not go behind the distinctive patterns of child growth. In some children, hints of future tribulations may be apparent from birth. In most cases, the harms become more conspicuous as the child slips beyond other children of the same age. Other children start well enough. Nevertheless, between 18 to 36 months old, they suddenly reject people acting strangely and lose language and social skills they had already acquired.

Parenting is a transforming incident in the life of parents that fetches bliss and pleasure as well as defies nuisance and demands. Being a parent indicates both a role as originality and impressionistic knowledge. In general, parenting is a transforming experience (Bornstein, 2015). Usually, it contributes to joy and satisfaction of significant meaning for people's lives; it also implies facing challenges and demands that imply less publicly recognized negative emotions such as frustrations, oppression, and fear (Kohler, 2016).

No parent is ever primed to be the parent of a special child with a particular educational need that affects a family. First, the characteristics of the disabled child help shape the family's reactions. The degree of problems in parents' experience is highly related to the child's care giving demands and the child's age. Second, the characteristics of the family influence the reaction. For example, size, cultural background, and socioeconomic status can

affect a family's adjustment to a disabled child. Third, the personal characteristics of each family member influence the family's reaction to a disability. Finally, a family's unique circumstances can affect their reactions to the disability. Parenting a special needs child involves much responsibility and many problems. Mostly, the mothers who spend time with the child are more stressed than the fathers (Soltanifar, 2015). Due to long waiting lists, it may take time to find out the examination for the child in the Health, Safety, and Environment (HSE) sector. Parenting a special needs child also causes frustration to the parents who have undergone several assessments and stay on the waiting list to get their child's prognosis. Children with special needs are being encountered by HSE, which suggests different types of intercession, remedies, clusters, and classes. Therapies with children who have ASD gain affirmative results, but it also depends on the level of Autism the child has and the complexities or needs they have. Lack of expert support, like therapies and intercessions, for ASD and their parents, plays a crucial role as it is another extreme irritation in their lives.

Stress is a part of day-by-day in human life. Most people experience stress on a daily basis. Exams, relationships, parenting, and work are only some of the triggers for stress response. Stress can affect individuals thinking, behaviour, confidence, and well-being. Stress can highly manipulate the quality of individuals' lives and how they function and behave from the everyday. The most common stress symptoms include loss of appetite, headache, low energy levels, sleeping problems, irritability, difficulty concentrating, and many others. Stress can affect individuals physically and mentally and provoke psychiatric and physical illness or depression (Woodman, 2018). It might affect the parents' capability to successfully raise their children and respond to their children's

needs. Occasionally, stress can shift to depression, which has more intense symptoms and lasts longer. Depression requires professional treatment and help; it does not go away by itself. Several parents also experience daily anxiety caused by their children's responsibility for their children and the additional needs their children might have. Parenting a typically developed child is a ubiquitous challenge; stress triggers many times, and it depends on many factors, such as relationships with the child, child's gender, and age. A child's personality and behavioural problems must consider disorders, disabilities, and many others. It is essential to consider if the child has any disorder or disability, as these are also possible stress triggers for parents. Many children have special needs, and their parents receive a more significant challenge (Woodman, 2015).

Autism spectrum disorder (ASD) is a multifaceted permanent and premature neurodevelopmental muddle characterized by persistent scarcity in social interaction and communication in the compound scaffold and limited and tedious patterns in behaviours, interests, and activities. In light of these characteristics, mothers and fathers of children with ASD face unique challenges and demands of parenting (Reichman, 2008), which may affect parenting functioning (Giannotti, 2021). Incredibly, there were more challenging issues for a parent with epileptic autism compared to a parent of autism.

#### **Objectives:**

The main objective of the research is to explore the stress level of a parent of children with autism spectrum disorder based on the age of the children and the sex of the parent. Moreover, it explores the connection between epilepsy and stress levels, problems faced by parents who get stressed, and its impact on the child.

## Hypotheses

- H1: There may be a difference on parental stress levels based on the age group of children with autism spectrum disorder (ASD).
- H2: There may be a difference in parental stress levels based autistic condition.
- H0: There is no difference in stress levels between fathers and mothers of children with ASD.

## Method

### Participants and Procedure

The sample comprised 25 parents from 16 mothers and nine fathers of Early childhood (3 months' baby to age 5), middle childhood (ages 6 - 12), and adolescents (ages 13 - 18) with autism who submitted the responses. The survey was conducted through social media in 7 days, and an Autism Parental Stress Index questionnaire and demographic data were given. The researcher clarified the doubts-related questionnaire through calls and messages. Questions of the demographic data are name, age, sex of the child, and parent. Epilepsy duration, issues faced by parenting stress, and its impact on the child. Since we were interested in samples from around the world, we did not request their location. Within the period, 74 parents responded. On that, only 25 parents have epileptic autistic children.

### Measures

*Autism Parenting Stress Index* (APSI) measures the stress level of parents with autism spectrum children (Silva et al., 2012,). This tool consists of 13 items, namely child's social development; child's ability to communicate; tantrum; aggressive behaviour towards siblings or peers; self-injurious behaviour; difficulty in making transitions from one activity to another; sleep problems; child's diet; bowel problems; potty

training; not feeling close to a child; concern for the future of child being accepted by others; and concern for the future of child living independently. These 13 items are grouped into 3, such as social difficulties (items 1, 2, 11, 12 & 13), behaviour difficulties (items 3, 4, 5 & 6), and physical difficulties (items 7, 8, 9 & 10).

## Analytical Discussion

The study utilized descriptive statistics to analyse parental responses, offering an overview of trends and proportions in the data. Percentages were calculated to quantify the prevalence of stress factors among parents of children with Autism Spectrum Disorder (ASD), with epilepsy. The inclusion of comment boxes enriched the quantitative findings, adding qualitative insights that made the study more engaging and reflective of real-world parental experiences.

### 1. Social Difficulties as a Major Stressor (58%)

A significant portion (58%) of parents identified social challenges as the most distressing aspect of raising a child with autism. These included: Communication barriers: Many children with ASD struggle with expressive and receptive communication, which frustrates both the child and parent. Lack of peer interaction: Parents often expressed concern about their child's inability to form friendships or engage in group activities. Fear of future independence: A common concern was whether the child would be able to live independently or integrate into society as they grow older. This highlights how social functioning, more than medical or behavioural symptoms, can dominate the emotional burden of caregiving. The stigma around autism and lack of inclusive community support may further amplify these concerns.

## 2. Physical Challenges (31%)

About one-third (31%) of respondents reported physical stressors, including: Sleep disturbances: Common in children with autism, irregular sleep patterns can severely impact parental rest and functioning. Dietary issues: Many children with ASD have restrictive eating habits or sensitivities, requiring constant meal planning and nutritional monitoring. These concerns contribute to chronic fatigue and emotional exhaustion among caregivers, often affecting their physical health and job performance.

## 3. Behavioural Issues (11%)

Although less frequently reported (11%), behavioural challenges such as tantrums, aggression, or self-injurious behaviour were still significant sources of stress. These behaviours can lead to: Social isolation (avoiding public spaces), Strained family relationships, Guilt or helplessness in managing outbursts. The lower percentage may reflect underreporting due to normalization of these behaviours or parents developing coping strategies over time.

## 4. Age-Related Stress: Middle Childhood (6–12 years)

The study found that parents of children aged 6 to 12 experienced the highest stress levels. This period, known as middle childhood, involves: Entry into formal schooling, Heightened academic expectations, Increased awareness of social norms and peer pressure. These new demands can highlight the developmental gap between autistic children and their peers, causing parents to feel overwhelmed and worried about the future.

## 5. Epilepsy as a Compounding Factor

The presence of epilepsy a neurological condition common in some individuals with ASD was reported to further intensify stress. Although seizure duration varied, the average

recorded was 36 seconds, which can feel alarmingly long and traumatic for a caregiver. Managing epilepsy alongside autism requires: Constant medical supervision, Emergency preparedness, Medication side effects management. Parents expressed heightened fear over sudden seizures and the unpredictability of their child's condition, increasing their psychological burden.

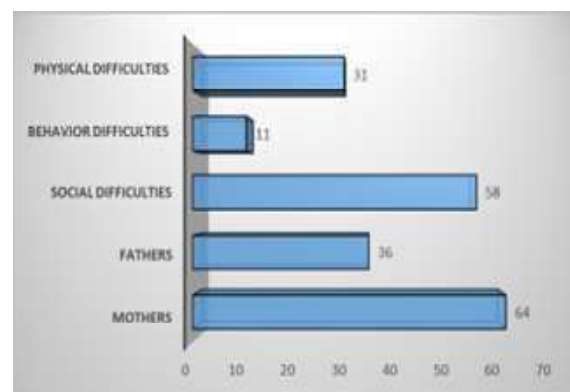


Figure 1 showing the graphical representation of parental stress and demographic data in percentage

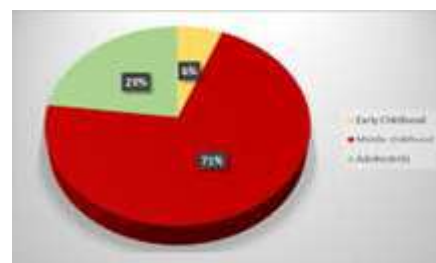


Figure 2 showing the graphical representation of parental stress in percentage on the level of age of the children with autism

Therefore, Hypotheses 1 and 2 were accepted, and the null hypothesis ( $H_0$ ) was rejected, as the study found significant differences in parental stress levels based on the child's age group, the severity of autistic traits, and the gender of the parent. Specifically, fathers and mothers of children with ASD experienced differing levels of stress. These findings align with previous

research. For instance, (Van der Veek, 2025) reported strong correlations between parental stress and both mental and physical health, highlighting the reciprocal nature of stress within families. Similarly, (Strauss, 2022) found that greater parenting self-efficacy helps mitigate the negative effects of behavioural challenges on parental stress. (Operto, 2019) emphasized the ongoing stress experienced by parents managing a child with epilepsy. Additionally, (Pardo-Salamanca, 2024) underscored the influence of child behavioural characteristics and the critical role of social support in shaping parental stress levels.

### **Conclusion**

The findings emphasize the critical need for targeted interventions to mitigate parental stress. Programs designed to enhance children's social skills and communication abilities could help alleviate some of the primary concerns of parents. Additionally, comprehensive support systems addressing both the medical and behavioural aspects of autism and epilepsy are crucial. Providing mental health resources for parents, such as counselling and stress management workshops, could enhance their emotional well-being and coping mechanisms.

These insights highlight the necessity of structured support systems to address the various stressors parents face while raising children with autism and epilepsy. The study concluded that parents experience heightened stress levels during their child's middle childhood years. Furthermore, it was observed that fathers tend to experience more stress than mothers, particularly concerning factors such as epilepsy, self-injurious behaviour, sleep disturbances, independent living challenges, and tantrums. As a result, parents often express their frustration toward their children, neighbours, and colleagues.

The research also indicates that parental stress directly impacts the mental health and daily routines of children with autism. Therefore, future studies should focus on strategies to reduce parental stress by enhancing the quality of life for individuals with autism. A significant number of parents have suggested that research should explore ways to alleviate their stress through training programs for children with autism. While many existing studies focus on training parents to manage stress, there is a growing need to investigate the effectiveness of child-focused training in reducing parental stress levels.

### **Recommendation**

**Targeted Interventions for Social Development:** Efforts should be directed toward improving children's social skills and communication abilities. This can be achieved through customized social skills training programs and peer interaction workshops, helping to alleviate parental concerns about their child's social acceptance and future independence. **Enhanced Support for Parents of Children in Middle Childhood:** Research indicates that parents of children aged 6 to 12 require additional assistance. Collaborative efforts among schools, healthcare professionals, and community programs should focus on providing resources such as counselling, stress management workshops, and parental support groups tailored to this age group. **Specialized Approaches for Epilepsy Management:** Since epilepsy adds to parental stress, integrating medical and behavioural interventions can offer more comprehensive support. Programs that address both epilepsy management and autism care simultaneously may prove more effective in alleviating the overall burden on families. **Mental Health Support for Parents:** Ensuring the emotional well-being of parents is essential. Providing access to mental health services, including therapy sessions

and stress-relief activities, can help them better manage their responsibilities and enhance their overall quality of life.

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