

Prevalence of Stress level among Mothers of Children with Autism

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DOI: <https://doi.org/10.52403/ijhsr.20250735>

ABSTRACT

Background: Parenting is a tough role and having a child with disabilities can make it more difficult as these children have impairment in physio- psycho- social development. Parents find it more stressful to accept the disability of their child. Parents who have a child with Autism have a chance of 2%-18% of having second child with Autism. There will be greater anxiety & stress in parents who are caring for autistic. Mothers play a major role in parenting a child that too if the child is autistic she experiences significant stress.

Materials & Methods: Ethical clearance was taken. Informed consent was obtained from the mothers. Parental Stress Scale (Reliability= 0.83) was filled by mothers through Google form.

Result: Data analysis was performed using Microsoft Excel version 2007. Out of 32 mothers about 52% of mothers with autistic children have been suffering from moderate amount of stress and about 45% of mothers with autistic children has severe stress only 3% of mothers have mild stress.

Conclusion: This study concludes that there is a prevalence of stress level in mothers of Autistic children.

Keywords: Prevalence, Stress, Mothers, Autism

INTRODUCTION

ASDs, or autism spectrum disorders, are a group of developmental problems that affect people for the rest of their lives. These conditions include Pervasive developmental disorder (PDD-NOS), Asperger's disorder, and autism spectrum disorder. Qualitative deficits in communication, reciprocal interaction with others, and the existence of restricted and repetitive behaviors or interests are indicators. [1]

In India, the prevalence of autism varies between 12 and 14 cases per 10,000 people, depending on whether the population is urban or rural. [1]

Autism is more commonly diagnosed in boys and is typically identified during early childhood. [2, 3]

The extremely challenging job of parenting becomes considerably more challenging when the child is on the autistic spectrum. The term "parenting stress" is not new; it refers in general to the anxiety and tension that arise from demanding circumstances. [4, 5]

But when the child in question has developmental problems, it takes on another significance. Parenting a child with autism requires constant attention and care, unlike parenting a typically developing child,

where the difficulties usually go away when the child enters adulthood.

This distinction is essential to understanding why parents of autistic children experience higher than average stress levels. This increased stress is a result of a child with autism's unique and intense needs in addition to the ongoing nature of their care. Furthermore, autism is not a uniform condition.

A variety of developmental problems, from minor to severe, are included in the disease and each has its own special set of difficulties.^[6]

Understanding this stress requires a knowledge of the etiology of ASD. Present research suggests that a mix of genetic and environmental variables may be responsible, while the exact etiology is yet unknown.^[7]

Diagnosis is a meticulous process that depends on the knowledge of qualified medical professionals who use a variety of techniques, such as examining a patient's medical history, monitoring them closely, and using evaluation tools designed specifically for autism spectrum disorders.^[8]

Through improving the child's capacity to communicate their needs, interventions such as the Picture Exchange Communication System (PECS) have proved essential in helping autistic children improve their communication skills and in turn reduce parental stress.^[9]

Parenting is further impacted by the severity of the child's condition, which can be evaluated with instruments such as the Childhood Autism Rating Scale.^[10]

Parenting a child with autism has an influence that goes beyond the day-to-day difficulties. In addition to the financial and professional demands, parents also struggle with concomitant psychological burdens like worry and sadness. Stress is an inevitable result for parents who are unable to manage the demands of their child's illness with their own coping mechanisms.

This stress is not just an experience that the person has; it is based on the Transactional Stress Theory, which clarifies the tension

that people feel when they are parenting in certain situations.^[11]

Being a parent of a kid with a developmental disability can be quite demanding, particularly for mothers who are responsible for providing extra care. Compared to mothers of typically developing children and mothers of children with intellectual disabilities without autism, mothers of children with autism are more likely to experience stress.^[12] Research has repeatedly demonstrated that psychological distress, which is marked by feelings of confusion, helplessness, frustration, grief, anger, and fear, is more common among parents of autistic children.^[12]

Mothers who are under stress tend to be poor parenting skills and have poor relationships with their kids. One important risk factor for child abuse and neglect is maternal stress. The child's physical health and well-being are negatively impacted by the mother's stress, which is strongly linked to more hostile, negative parenting.

It has been noted that while doctors and psychologists are naturally very concerned about the autistic child, they hardly ever seem to concentrate on the effects on the parents particularly the mother.^[13]

This study aims to explore the complex and persisting impacts of stress on mothers of children with autism. Through understanding the distinct obstacles faced by mothers, we may initiate the building of enhanced support networks and interventions to assist them in their parenting endeavors, resulting in advantages for both the mothers and their autistic children.

MATERIALS & METHODS

This was a cross-sectional study conducted in various pediatric physiotherapy clinics and private hospitals in Ahmedabad, Gujarat. A total of 32 mothers of children diagnosed with Autism were recruited based on predefined inclusion and exclusion criteria.

The study's target population for inclusion was mothers of children diagnosed with

Autism. Mothers with ages ranging from 20 to 50 years. The educational background was varied, ranging from primary education to doctoral-level qualifications. An essential requirement was that the parents should not have any medical or psychological conditions, as this could potentially alter the results of the study.

Similarly, the children included in the study were between the ages of 3 and 15, encompassing both male and female genders. These children had varying degrees of mild to severe autism and they had a variety of verbal to non-verbal communication abilities. Children with any other physical or mental illness were excluded from the study. The exclusion criteria specifically ruled out parents of children with autism who also had co-morbid disabilities.

This was done to make sure that the stress being measured was only associated with raising an autistic child and was not increased by other circumstances. A comparative cross-sectional approach was used to acquire the data.

The purpose of this method was to provide a picture of the current state of parental stress levels through evaluation of data at a specific moment in time.

Parents' stress levels were assessed using a standardized tool known as the Parental Stress Scale (PSS). This tool has been validated in multiple research and is well known for its effectiveness in measuring parental stress. Its standardization ensured the reliability and validity of the collected data.

Mothers of children with autism were asked to provide information in two areas:

- The age and gender of children with Autism

- Information about mothers (name, age, number of children, age of mother when she delivered this child, education, occupation, and type of family)

The 18-item self-report scale covers both good and negative aspects of parenting, including the demands and constraints of resources as well as the emotional benefits and personal growth.

Five-point rating system: Strongly disagree, Disagree, Undecided, Agree, and Strongly agree.

The scale allows for a total score ranging between 18 and 90.

The measured amount of parental stress increases with increasing score. ^[14]

RESULT

The mother's age distribution showed a concentration in the 30–40 age group, which constituted 40.4% of the participants, followed by the 20–30 age group at 12.5% and the 40-50 age group at 40.6%. This indicates that a larger proportion of the participants were in middle adulthood.

The child's age distribution concentration was highest in the 7-10 years age group, which constituted 43.8%, the 3-6 years age group at 28.1%, and the 11–15-year age group at 25.1%. 90.6% of the boys and only 9.4% of the girls.

The educational background of the participants varied, with the largest group holding bachelor degrees 74.8%, followed by masters degrees 9.3%, intermediates 6.3%, matrices 6.2%, and undergraduates 3.1%. The participants appear to have a wide range of educational backgrounds, based on the diversity of their educational levels. In terms of type of family, 43.8% had a joint family and 56.3% had a nuclear family. (Table 1)

Table 1 Participant Demographics

Demographic variables	Category	Percentage (%)
Age of mother	20-30 years	12.5%
	30-40 years	40.4%
	40-50 years	40.6%
Age of child	3-6 years	28.1%
	7-10 years	43.8%
	11-15 years	25.1%

Gender of child	Boys	90.6%
	Girls	9.4%
Education of mother	Undergraduate	3.1%
	Matric	6.2%
	Intermediates	6.3%
	Bachelor degree	74.8%
	Master degree	9.3%
Type of Family	Joint family	43.8%
	Nuclear family	56.3%

There was a range of opinions about happiness in the parental role. While 43.8% agreed that they were happy as parents, 27.1% disagreed and 18.1% strongly disagreed. A small portion, 6.9%, strongly agreed, and 4.2% were unsure or neutral in their response.

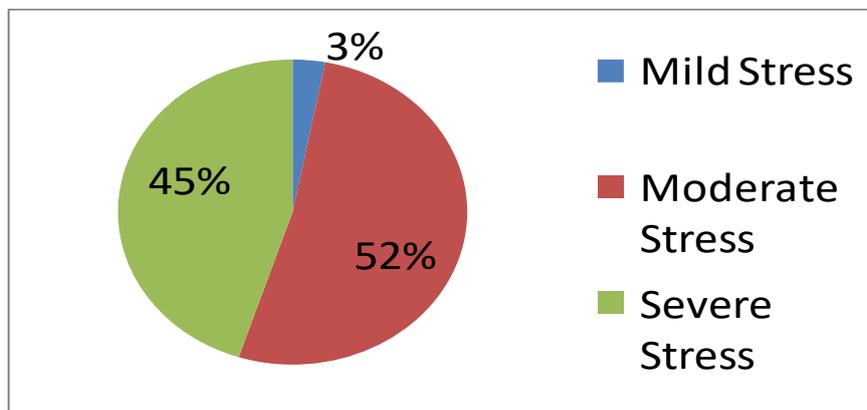
51.4% of individuals agreed, compared to 21.5% who disagreed and 12.5% who strongly disagreed, when asked if they were providing enough for their children if necessary.

A segment of participants 10.4% were undecided and a minority 4.2% strongly agreed with the statement. Concerning the time and energy invested in caring for their children, a majority 52.1% agreed that they were investing adequate time and energy, while 18.1% disagreed and 8.3% strongly disagreed. A significant percentage 9.7% strongly agreed with the statement, while 11.8% were still unsure.

When participants were queried about doing enough for their children, a slight majority 52.8% agreed, 18.8% disagreed, and 9.7% strongly disagreed. A smaller proportion 6.3% was undecided, and 12.5% strongly agreed with the statement. Children are a

source of affection, according to 64.6% of respondents who agreed and 9.2% strongly agreed. This was a strong positive response. However, 15.3% disagreed, and 6.9% strongly disagreed. On this matter only 4.2% were undecided.

Exactly 50% of participants agreed with the statement that having children had given them an optimistic outlook on the future, compared to 16.7% who disagreed and 11.1% who strongly disagreed. A segment of participants 12.5% were undecided, and 9.7% strongly agreed with the statement. Overall, these results present a complex picture of the experiences and perceptions of parents of children with autism spectrum disorder, encompassing aspects of gender, age, education, parental status, and different aspects of their attitudes towards their children and their responsibilities as parents. Data analysis was performed regarding the stress levels among mothers of children with autism. The result was carried out using Microsoft Excel 2007. Out of a total mother's 52% moderate level of stress, 45% severe level of stress, and 3% mild level of stress. (Figure 1)



(Figure 1: Stress level among mothers of autistic children)

DISCUSSION

The discussion of this study focuses on the significant stress experienced by mothers of children with autism.

The Parental Stress Scale (PSS) results indicated that there is a moderate, severe, and mild level of stress among mothers of children with autism.

The fact that the parents reported feeling exhausted and stressed about the huge responsibility of raising a child with a disability could be the cause of this outcome.

This is consistent with earlier studies that have shown mothers of autistic children to be more stressed than mothers of neurotypical children.^[15]

A study done by Mrs. D. Shanthakumari showed that out of 100 samples, about 59% of mothers with autistic children have been suffering from a moderate amount of stress, and about 41% of mothers with autistic children have severe stress. It shows that none of them has a mild level of stress.^[16]

Ji Wang et al. conclude that mothers of ASD children experience a high level of parenting stress, which is also related to high levels of depression and anxiety.^[17]

This outcome might be the result of the parent's reported feelings of exhaustion and stress brought on by the enormous amount of responsibility involved in raising a child with a disability. This conclusion aligned with previous research findings (Picci et al., 2015^[18]; Woodman & Hauser, 2013^[19]; Wang, Michaels, & Day, 2011^[20]) indicating elevated stress levels among parents of autistic children.

Based on the previously reviewed literature, it can be concluded that the high levels of stress were caused by parents experiencing ongoing crisis and feeling inadequate to manage behavioral and developmental issues in their child with a disability. Additionally, parents may also be experiencing feelings of exclusion and rejection from their communities. (Mount & Dillon, 2014)^[21]

Parents who have children diagnosed with ASD also experience feelings of loss since

their hopes for a healthy child fade and their reality falls short of their expectations. Karst and Hecke (2012)^[22] observed that parenting a child with autism spectrum disorder (ASD) can lower a parent's sense of effectiveness and overall quality of life. It also tends to heighten stress levels and contribute to physical and mental health challenges, as well as difficulties within the family and marital relationships.

According to Silva & Schalock (2012)^[23], the family may experience a great deal of stress due to co-morbid health conditions, trouble managing challenging behaviors, and poor social communications.

Hayes and Watson conducted a comprehensive meta-analysis to evaluate the literature on stress in parents of autistic children (2013)^[24]. The average effect size was 1.58, suggesting that parenting stress levels are significantly and greatly impacted by having an autistic child.

Fleishmann (2014)^[25] states that parents often experience shock, depression, and difficulty accepting their child's ASD diagnosis.

Research on coping mechanisms employed by parents of autistic children revealed that information seeking, avoidance, and denial were generally the most popular coping mechanisms.

Parents vary in how they handle the diagnosis and emotional challenges, but they all agree that having a strong social support system is essential to managing. (Altiere & Von Kluge, 2009)^[26]

On the other hand, Gallagher and Whiteley (2012)^[27] found that parents of children with ASD used a wider range of coping strategies significantly more often than parents of typically developing children. These strategies included emotional support, positive reframing, planning, humor, acceptance, and religious practices.

In contrast, Pisula found that parents of children with ASD used fewer strategies for obtaining social support than parents of typical children. (2016)^[28]

The limitation of the study is that the sample size does not capture the full spectrum of experiences among all parents of children with autism.

Future research could be improved by including a larger and more diverse group of participants. Furthermore, it is more difficult to track variations in stress levels over time due to the cross-sectional design of the study. Understanding the changing nature of maternal stress in the context of Autism would benefit greatly from longitudinal research.

CONCLUSION

This study concludes that there is significant stress among mothers of children with autism. This highlights the need for mental health professionals to provide children suffering from ASD and their parents with appropriate care. Tailored approaches designed to offer coping skills, psychological support, and practical support could significantly lessen the stress on these families, improving both the quality of care they give to children with ASD and their overall psychological well-being. Improving the quality of social support may also assist mothers in managing the stress associated with their child's condition.

Declaration by Authors

Ethical Approval: Approved

Acknowledgement: Authors would like to thank all the participants for their valuable time and support.

Source of Funding: None

Conflict of Interest: The authors declare no conflict of interest.

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- How to cite this article: Malvi Soni, Mansee Desai. Prevalence of stress level among mothers of children with autism. *Int J Health Sci Res*. 2025; 15(7):282-288. DOI: <https://doi.org/10.52403/ijhsr.20250735>
