

# A STUDY ON PSYCHOSOCIAL WELLBEING WITH ASSESSMENT AND INTERVENTION AMONGST MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN SALEM

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## Abstract

**Background and Objectives:** Autism is a complex neurobehavioral condition that includes impairments in social interaction, developmental language and communication skills combined with rigid, repetitive behaviors. To assess the level of stress among Mothers of autistic children aged 2-12 years in salem and to find out the association with the selected socio - demographic variables and stress among mothers of autistic children. **Methodology:** Mothers of children with Autism spectrum disorder presenting to Vinayaka missions kirupananda Variyar medical college and hospitals, in Salem. Mothers of children presenting with developmental delays, behavioural issues, speech delay and poor social communication skills who are diagnosed with Autism spectrum disorder by a Paediatrician or a psychiatrist using Diagnostic and Statistical manual of mental disorders fifth edition DSM-5 criteria. The study period was conducted between Feb 2024 to May 2024. **Results:** the most common age group for mothers are 31-35 years having 41% of study participants followed by 26-30 years of 38%. The most common age group of children was 2-4 years having 58% of total sample. Based on the Quartile Parental Stress, the mother's stress was categorized as Mild Stress – 1 -19.25, Moderate Stress – 19.26 – 26.9 and Severe Stress – Above 27. As per table 4 there was a significant association between age of child and parenting stress which suggests that the age increases the stress increases. ( $p < 0.05$ ), but it has no significant association with sex of the child ( $p > 0.05$ ). **Conclusion:** This study concluded that there are various factors like psychological, social, education, financial future concern will cause stress in parents of children with autism. The future concern is the major factor that creates more stress on parents.

**Keywords:** Autism, Psychosocial wellbeing, Stress, Intervention.

## INTRODUCTION

In 1908, the word autism was used by Eugen Bleuler to describe a subset of Schizophrenic patients who were especially withdrawn and self-absorbed<sup>1</sup>. In 1943, American child psychiatrist Leo Kanner publishes a paper describing 11 children who were intelligent but displayed a powerful desire for aloneness. He later named it as early infantile autism<sup>2</sup>. AS, previously known as pervasive developmental disorder is a lifelong condition that is characterized by impairments in communication, social interactions and responsiveness<sup>3</sup>. Autism is a complex neurobehavioral condition that includes impairments in social interaction, developmental language and communication skills combined with rigid, repetitive behaviors. Because of the range of symptoms, this condition is now called autism spectrum disorder (ASD). The term spectrum in autism spectrum disorder refers to the wide range of symptoms and severity. Autism the condition is the result of a neurological disorder that has an effect on normal brain function affecting development of the person's communication and

social interaction skills.<sup>4</sup> The symptoms of Autism may differ from individual to individual showing wide variety of combination of symptoms and behaviors which ranges from mild to severe. The males are more affected than females with a ratio of 4:1. The symptoms include spinning, loss of speech, poor eye contact, flapping hands or repetitive gestures, Repeating phrases or babble, heightened sensitivity or sensory aversion, inspecting toys rather than playing with them, playing alone, a lack of interest in pretend play, obsessive interests, unresponsive to his or her name, stereotyped behavior, loss of language or social skills, doesn't point or respond to pointing. The etiology of autism is multifactorial where the genetic and non genetic factors play a role. Autism may be syndromic or non syndromic.<sup>5</sup> The syndromic ASD is due to chromosomal abnormalities or mono genic alterations<sup>6</sup>. Few examples are Rett syndrome, MECP2 duplication syndrome, fragile X syndrome. The etiology of non syndromic ASD is still undefined but a collaboration of de novo mutations plus prenatal and postnatal, environmental factors are playing a role.

According to WHO(1993), approximately 75 to 85% of autistic individual are associated with development of mental retardation as a comorbid symptom. Parents with first child with autism, may have a chance of 2%-18% of second child with autism. There was a high parental stress and greater anxiety in parents caring for a child with autism<sup>7</sup>. There is evidence showed that there was increased anxiety, depression and financial difficulties among them. Parenting a child with autism puts a very high demand and hence makes it difficult to cope. Mothers play a major role in parenting a child that too if the child is autistic she is piled up with severe stress, so the researcher aims to understand the level of stress faced by mothers so that a negative cycle can be avoided and she can be taught coping strategies. There is a need of social support for the mother and governmental support by means of more accessible therapy centres to reduce the financial burden of the parents is essential to reduce the stress in parents of autistic children. Parental stress indicates more of support groups in general like developed countries for their betterment.

## METHODS AND METHODOLOGY

The research design selected for this study is cross sectional study done in Aurora child care in Salem. Done in Mothers of children with Autism spectrum disorder. Mothers of children presenting with Developmental delays, behavioural issues, speech delay and poor social communication skills who are diagnosed with Autism spectrum disorder by a Paediatrician or a psychiatrist using Diagnostic and Statistical manual of mental disorders fifth edition DSM-5 criteria. The study period was conducted between May 2023 to July 2023.

### Inclusion Criteria:

- Mothers of child diagnosed to be an autistic spectrum disorder more than 3 months' duration by an expert.
- Mothers of autistic children who were willing to participate in the study.

### Exclusion Criteria:

- Mothers who refused to participate in the study Mothers with comorbid physical illness
- Mothers already underwent training programme for coping stress.

Consecutive sampling technique suggest sample of 66 using, Marginal error : 5.5%, prevalence: 8.4% and confidence interval: 10% The study was conducted after obtaining approval from the ethical committee. The mothers were explained the purpose and the need of the study. They are assured that the details of the answers was used only for research purpose. Further they were ensured that their details would be kept confidentially.

## DATA ANALYSIS

The data was entered in Microsoft Excel and statistical analysis was done using SPSS 20 Version. Basic descriptive analysis was reported using frequencies/percentages and means with standard deviation wherever appropriate. Bivariate analyses were represented with chi-square tests.

## RESULTS

**Table 1: Frequency distribution of Age of Mother and Child in this study**

Mother's Age	Frequency	Percent
20-25 Years	7	10.6
26-30 Years	25	37.9
31-35 Years	27	40.9
36 - 40 Years	5	7.6
Above 40 Yeras	2	3.0
<b>Total</b>	<b>66</b>	<b>100.0</b>

As per table 1 the most common age group for mothers are 31-35 years having 41% of study participants followed by 26-30 years of 38%. The most common age group of children was 2-4 years having 58% of total sample. The distribution of gender was equal 33 boys and 33 girls. The parents of most of the children's were graduates 96%.

**Table 2: Frequency distribution of parenting stress in this study**

Parenting Stress	Frequency	Percent
Mild stress	17	25.8
Moderate stress	34	51.5
Severe Stress	15	22.7
<b>Total</b>	<b>66</b>	<b>100</b>

As per table 2 most of the mothers were having moderate stress (51.5%) followed by mild stress in 26% and severe stress in 23%.

**Table 3: Comparison of age of the mother and parenting stress among mother of autism children by Fisher Exact test**

Mother's Age	Parenting Stress			Total N (%)
	Mild Stress N (%)	Moderate Stress N (%)	Severe Stress N (%)	
<b>20-25 years</b>	01 (5.9)	04 (11.8)	02 (13.3)	07 (10.6)
<b>26-30 Years</b>	05 (29.4)	11 (32.4)	09 (60)	25 (37.9)
<b>31-35 Years</b>	08 (47.1)	16 (47.1)	03 (20)	27 (40.9)
<b>36 - 40 Years</b>	02 (11.8)	02 (5.9)	01 (6.7)	05 (7.6)
<b>Above 40 years</b>	01 (5.9)	01 (2.1)	0	02 (03)
<b>Total</b>	<b>17 (100)</b>	<b>34 (100)</b>	<b>15 (100)</b>	<b>66 (100)</b>
X <sup>2</sup> – Value :6.950, P value :- 0.523 (ns)				

As per table 3 no significant association was seen between age of mother and parenting stress. (p>0.05)

**Table 4: Comparison of age of the Child and parenting stress among mother of autism children by Fisher Exact test**

Age of the Child	Parenting Stress			
	Mild Stress N (%)	Moderate Stress N (%)	Severe Stress N (%)	Total N (%)
2- 4 Years	02 (11.8)	23 (67.6)	13 (86.7)	38 (57.6)
5 -7 Years	09 (52.9)	07 (20.6)	01 (6.7)	17 (25.8)
8 - 10 Years	03 (17.6)	02 (5.9)	01 (6.7)	06 (9.1)
Above 10 years	03 (17.6)	02 (5.9)	0	05 (7.6)
<b>Total</b>	<b>17 (100)</b>	<b>34 (100)</b>	<b>15 (100)</b>	<b>66 (100)</b>
<b>X<sup>2</sup> – Value :21.82, P value :- 0.000***</b>				

As per table 4 there was a significant association between age of child and parenting stress which suggests that the age increases the stress increases. ( $p < 0.05$ ). But it has no significant association with sex of the child ( $p > 0.05$ ).

**Table 5: Comparison of Education, Occupation and Income of the parents and parenting stress among mother of autism children by Fisher Exact test**

Variables	Parenting Stress			
	Mild Stress N (%)	Moderate Stress N (%)	Severe Stress N (%)	p-value
Education of parents	17	34	15	0.21
Occupation of the parents	17	34	15	0.89
Income of the parents	17	34	15	0.88

As per table 5 all variables like education, occupation and income of parents along with religion shows no significant association with parenting stress ( $p > 0.05$ ).

**Table 6: Comparison of number of children’s and parenting stress among mother of autism children by Chi -Square test**

Number of children’s	Parenting Stress			
	Mild Stress N (%)	Moderate Stress N (%)	Severe Stress N (%)	Total N (%)
01	07 (41.2)	20 (58.8)	12 (59.1)	39 (59.1)
02	10 (58.8)	14 (41.2)	03 (40.9)	27 (40.9)
<b>Total</b>	<b>17 (100)</b>	<b>34 (100)</b>	<b>15 (100)</b>	<b>66 (100)</b>
<b>X<sup>2</sup> – Value :4.971, P value :- 0.04***</b>				

As per table 6 the number children shows a significant association with parenting stress among mother of autism child.

**Table 7: Comparison of Availability of support system and parenting stress among mother of autism children by Chi –Square test**

Availability of support system	Parenting Stress			
	Mild Stress N (%)	Moderate Stress N (%)	Severe Stress N (%)	Total N (%)
No support	01 (5.9)	03 (8.8)	06 (40)	10 (15.2)
Relatives	15 (88.2)	29 (85.3)	08 (53.3)	52 (78.8)
Social support	01 (5.9)	02 (5.9)	01 (6.7)	04 (06.1)
<b>Total</b>	<b>17 (100)</b>	<b>34 (100)</b>	<b>15 (100)</b>	<b>66 (100)</b>
<b>X<sup>2</sup> – Value :9.596, P value :- 0.04***</b>				

As per table 7 when the mothers of autistic child has support the stress was less and it was significant. ( $p < 0.05$ )

**Table 8: Comparison of Type of family and parenting stress among mother of autism children by Chi -Square test**

Type of family	Parenting Stress			
	Mild Stress N (%)	Moderate Stress N (%)	Severe Stress N (%)	Total N (%)
<b>Nuclear Family</b>	08 (47.1)	14 (41.2)	02 (13.3)	24 (36.4)
<b>Joint Family</b>	09 (52.9)	20 (58.8)	13 (86.7)	42 (63.6)
<b>Total</b>	<b>17 (100)</b>	<b>34 (100)</b>	<b>15 (100)</b>	<b>66 (100)</b>

**X<sup>2</sup> – Value :4.639, P value :- 0.05\*\*\***

As per table 8 most of the mother belonged to joint family and it was seen that there was a significant association with the type of family and parenting stress.

**Table 9: Comparison of Cost of the treatment and parenting stress among mothers of autism children by Chi -Square test**

Cost of the treatment	Parenting Stress			
	Mild Stress N (%)	Moderate Stress N (%)	Severe Stress N (%)	Total N (%)
<b>Low Cost</b>	12 (70.6)	03 (8.8)	0	15 (22.7)
<b>Moderate Cost</b>	03 (17.6)	08 (23.5)	01 (6.7)	12 (18.2)
<b>High Cost</b>	02 (11.8)	23 (67.6)	14 (93.3)	39 (59.1)
<b>Total</b>	<b>17 (100)</b>	<b>34 (100)</b>	<b>15 (100)</b>	<b>66 (100)</b>

**X<sup>2</sup> – Value : 34.908, P value :- 0.000\*\*\***

As per table 9 there was significant association with the cost of treatment compared with parenting stress. (p<0.05)

## DISCUSSION

Advanced parental age is an important risk factor for autism spectrum disorder (ASD), a neurodevelopmental condition with a complex and not well-defined etiology. Girard et al found that the prevailing hypothesis is that the increased rate of de novo mutations with advanced paternal age leads to the observed increased risk of ASD<sup>8</sup>. In our study we also found that frequency distribution of Age of Mother was between 31-35 years.

Autism shows unusual pattern of development from beginning in infancy or toddler years<sup>9,10</sup>. Several studies showed that the condition was diagnosed between 2-3 years and may extend upto 5 years or late adolescence<sup>11,12</sup>. A recent study found that autism was diagnosed at age of 2 years<sup>13</sup>. The present study showed that the child diagnosed with autism was found between the age group of 2-4 years. Special child care faced by the parents of children with disabilities results in parental stress and disruption in family relationship<sup>14</sup>. There are several evidences that showed the parents faced various challenges and the ways in which they deal with the nature of child's disability<sup>15</sup>.

In many studies they found that the mother of children with chronic illness or disabling conditions produced higher rates of depressive symptoms and feelings of increased psychological distress<sup>16</sup>. In our study, we found that the parents experienced 51.5% of moderate stress and 22.7% of severe stress.

Gray et al found the mothers of children with autism experienced more stress than their father. This may be due to males suppress their emotions. The mothers have primary responsibility for child care and are subjected to challenges associated with



their disability<sup>17</sup>. In our study we found that the mothers of male children is affected by severe stress of about (60%).

In some studies, the results showed that the child with ASD status and level of externalizing behavior problems are associated with parental stress<sup>18</sup>. In our study, we found that age of children (5-7 years) are highly associated with elevated parental stress. A child with autism represents a increased source of stress on parents especially to mothers. Parents of these children undergo chronic psychosomatic pressure and this pressure may be increased due to several factors. Stress of rearing a child with autism can be overwhelming for parents.

In our study we found that the availability of social support system may reduce the stress of the mother,s with autism child to about 6.7%. Al-Kandari et al noted that with Social support and a significant support from the family reduces the stress of the mothers of the children with Autism<sup>19</sup>.

Similarly, in our study, we found that, in the permissive type of family the mother of the Autism children experiences mild stress than in authoritarian type of family. Yeo and Lu found treatment costs contributed 15% of the variance in psychological distress for Malaysian mothers compared to only 3% for Chinese mothers.

Treatment cost was considered to be an important factor that contributed to the difficulties and distress especially among Malaysian mothers, as it was speculated that Malaysian families are further challenged by having to support schooling needs for multiple children, in comparison to the Chinese, single-child families<sup>20</sup>.

In our study, we noted that the low cost of treatment for the autism children reduces the stress for the mother than the treatment with high cost. Negative emotions like sadness, rejected, anxiety, anger, self-blame, shame, and stress after a child was diagnosed with autism, but with the support of various stakeholders such as the family and the husband, as well as increased knowledge of the mother in the understanding of this developmental disorder, the mother is able to accept the limitations in child.

## CONCLUSION

The present study showed that the parent of child with autism represents a dynamic and complex process. This study concluded that there are various factors like psychological, social, education, financial future concern will cause stress in parents of children with autism. The future concern is the major factor that creates more stress on parents. The psychomotor functions of the parents are affected more in rearing a child with autism. It is also concluded that there is a considerable amount of stress among parents of children with autism.

Results of this study showed the mothers of these children are more stressed. Rearing a child with autism was a life challenging experience. This study found a guide to another important region of research and that is to find out those factors which can be helpful to decrease parental stress. There must be additional investigation concerning impact of developmental disabilities on parents as well as their psychological health problems, which will have clinical significance pro therapeutic intervention amid susceptible parents and families.

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