

Research Paper

Parenting Stress and Coping Strategies of Mothers with Autism Spectrum Disorder in Chennai District – A Descriptive Cross-Sectional Study

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ABSTRACT

A diagnosis of Autism Spectrum Disorder (ASD) has the potential to put in shock the entire family and can disrupt the functioning of the family thus affecting the family dynamics. It can create both physical and mental stress to parents having a psychological impact. The parents have to cope up with a lot of things including coming to terms or accepting the diagnosis, seeking guidance from experts, managing finance for therapy expenses, shuffling between therapies etc. The aim of this study was to assess stress and coping strategies among parents of children with autism spectrum disorder in Chennai district. **Methodology:** The study design constitutes a cross sectional study with descriptive data analysis. Targeted research audience consists of geographically urban domiciled parents of children with ASD aged between 3-12 years across all severity types. The research habitat focused on Private Clinical Centres, Chennai (Sample Size: 66). Purposive Sampling was used. Autism Parenting Stress Index (APSI). Family Crisis Oriented Personal Evaluation Scales (F-COPES) modified for the use of target population and subject sensitivity were used. **Results:** Parents of children with Autism showed approximately 80% prevalence of 'Often Creates Stress' to 'Very Stressful on a daily Basis' on the APSI. The results revealed that child's Aggressive behaviour and self injurious behaviour are the factor was most contributed to parenting stress in parents of children with autism, Coping strategy most used was evidenced as belief in a Higher Power along with passive acceptance of the issue by 65% of the study population. **Conclusion:** These findings suggest that parents' abilities to manage and reduce behavior problems is a critical target for interventions for young children with ASD in order to improve child functioning and decrease parenting-related stress.

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Received: January 18, 2022; Revision Received: June 26, 2022; Accepted: June 30, 2022

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Keywords: *Autism Spectrum disorder, Autism Parenting Stress Index, Family Crisis Oriented Personal Evaluation Scales*

Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges. (Centers for disease control and prevention) Psychological stress is defined as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p. 19).

The effect of having a child with autism in a family can generate severe psychological stressors. From the initial diagnosis to the continuous demanding everyday caretaker responsibilities, for some families, caretaking can be devastating. Parents of children diagnosed with autism encounter with the many obstacles associated with the disorder cause in more stress (Bilgin & Kucuk, 2010). The stressors include problems associated with the characteristics of the disorder, which include social skills, communication, and in diverse cases, behavioral difficulties. Parents, particularly mothers, are more liable to psychological and emotional problems due to the demanding day-to-day tasks of caring for a child with autism (Sawyer, et al. 2010)

Parents of children with ASD report more symptoms of anxiety and marital dissatisfaction than parents of children with other types of disabilities (Dunn, Burbine, Boers, & Dunn, 2001; Holroyd & McArthur, 1976; Konstantareas & Homatidis, 1989). In this view Coping involves psychological resources and coping strategies that help to eliminate, modify, or manage a stressful event or crisis (McCubbin & Patterson, 1983)

Parents of children with autism use a range of coping strategies and resources when encounter with parenting stress (Hall & Graff, 2011). Parents use both adaptive (e.g., cognitive reframing, seeking social support) and maladaptive (e.g., avoidance and disengagement) coping strategies with a tendency regarding adaptive coping approaches such as seeking social support and positive reinterpretation (Lai & Oei, 2014).

Parents of autism with disabilities suffer from stress, which invest them in demand to employ different strategies to cope. Several studies investigated the primary role of coping strategies employed by parents to manage these stresses, but conclusion of these studies did not add enough evidence about adequacy of these strategies in decreasing levels of stress in light of ASD, or rational in which parents choose specific coping strategy but not other. One may propose that parents' characteristics, and cultural differences may impede with their preference of strategies they used to cope.

The aim of this study was to assess stress and coping strategies among parents of children with autism spectrum disorder in Chennai district.

The objective of the study is

1. To assess condition- related stress among parents who have children in the ASD in Chennai district
2. To describe the coping strategies used by Mothers who have children with ASD in Chennai district.
3. To assess the relation between the stress level and the coping strategies

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4. To determine any association between stress & coping strategies on Socio demographic variable.

METHODOLOGY

It is a descriptive Cross-sectional study among **66 mothers** (where the Prevalence of 8.4%, 90% confidence interval, 5.5% marginal error) who have children with Autism spectrum disorder aged between 3-15 years across all severity types. The research habitat focused on private clinical Centers; Chennai & the convenient purposive sampling was used. The sample was selected based on the following Inclusion and exclusion criteria.

Inclusion Criteria

- Children diagnosed by psychiatrists with ASD
- Mother who provide care directly and attached to child with ASD

Exclusion Criteria

- Mother who didn't fill the questionnaire completely
- The researcher verbally described about the project to each mother individually and got informed concern from them. Mothers who concerned to take part in this study were asked to answer to the questionnaire. The questionnaire has questions from the following domains: socio demographic, Parental stress and coping strategies.

Data collection tools:

- **Autism parenting stress index (APSI):** The measure of parental stress was adapted from the Autism parenting stress index (APSI). It is a tool used to measure parental stress of young children with autism. It reflects the physical, social, and communication barriers imposed by the disability. As such, the items on this test fall into three categories: the core social disability, difficult-to-manage behavior, and physical issues. The test is designed to indicate how much stress parents are experiencing and what factors are causing this stress.
- **Family crisis orientated personal evaluation scales [F COPES]:** The measures of coping strategies was adapted from the Family crisis orientated personal evaluation scales consists of 30 items designed based on Likert's fivepoint scale (5= completely agree, 1 = completely disagree). The tool is featured with five aspects of seeking spiritual support, passive appraisal, acquiring social support, reframing, and mobilizing family to acquire and accept help. The score range of the tool is 30-150 and the higher the score the better the adaptation behavior of the family in stressful situations.

Translation: Both APSI & F- COPES was translated into Tamil by a Linguistic professor who is expert in both English and Tamil. Once the questionnaire was transliterated into the Tamil and that transliterated version was back-transliterated into English by another bilingual person expert. For comparison, the back transliterated was reviewed with the original English version. Some modifications in wording of the Tamil were suggested and accomplish with the help of the back translator, and an acceptable Tamil version was reached by the translators and researchers. This final modified Tamil version was believed that adequate in terms of a transliterated adaptation of the original English inventory. Face validity and content validity of the transliterated questionnaire were assessed.

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Statistical methods: Descriptive statistical analysis was used to measure the means, standard deviations, one-way Anova & Independent T test was used to compare the association between the groups. The Pearson Product moment correlation was used to find out the relationship between the two variable. A 5% alpha was adopted to minimize the possibility of Type II error due to multiple comparisons.

RESULT

A total of 66 mothers were participated in this study with the mean age of 30.71 years and standard deviation 3.66 and child mean age of 6.77 years and standard deviation of 3.13. The average monthly income of the participant’s family is INR 18340.90 & standard deviation is INR 14055.15

Table No. 1: Socio demographic of the Participants

Variables	Response	Frequency (%)
Child Age	2-5 years	28 (42.4%)
	5-10 years	27(40.9%)
	10-15 years	11(16.7%)
Mothers Age	25-30 years	39 (59.9%)
	30-35 years	22 (33.3%)
	35-40 years	5 (7.6%)
Mothers education	Primary	11 (16.7%)
	Secondary	31 (47.0%)
	Graduates	24 (36.4%)
Mother occupation	Home maker	52 (78.8%)
	Employer	14 (21.2 %)

The table below indicates high levels of stress with regards to comorbid physical characteristics, followed by comorbid behaviour, followed by core aspects.

With respect to each individual aspect, stress levels were found to be high for self-injurious behaviours and bowel problems (constituting 23% of severe stress)., acceptance of others (contributing 20% of severe stress), and communication (contributing 12% of severe stress).

Table No. 2 Autism Parenting Stress index Score

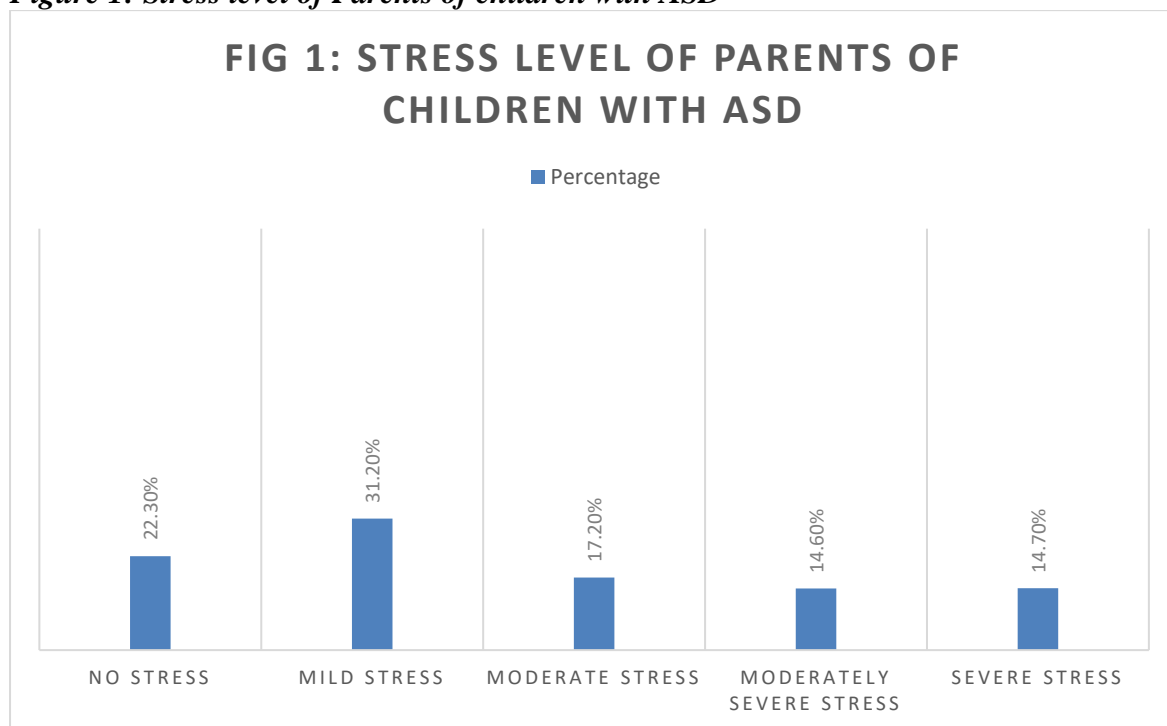
	No Stress (%)	Mild (%)	Moderate (%)	Moderately severe (%)	Severe (%)
Core Aspects					
Social development	27.3	47	10.6	4.5	10.6
Communication	18.2	25.8	25.8	18.2	12.1
Not Feeling close to the child	31.8	28.8	18.2	12.1	9.1
Acceptance by other	15.2	30.3	10.6	24.2	19.7
Future independence	34.8	27.3	19.7	9.1	9.1
Co morbid behaviour					
Temper tantrum	18.2	34.8	16.7	16.7	13.6
Aggressive behaviour	24.2	30.3	12.1	16.7	16.7

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Self-injurious behaviour	24.2	19.7	16.7	16.7	22.7
Difficulty in making transition	25.8	28.8	15.2	16.7	13.6
Co morbid physical characteristics					
Bowel problem	25.8	18.2	24.2	9.1	22.7
Toilet training	27.3	24.2	19.7	16.7	12.1
Sleep Problem	30.3	24.2	16.7	7.6	21.2
Child diet	25.8	18.2	24.2	9.1	22.7

Among the 66 Participants, 22% of mothers stated having no stress, 31% stated having mild stress, 17 % stated having moderate stress and 15 % stated having moderately severe & Severe stress.

Figure 1: Stress level of Parents of children with ASD



When analysing various coping strategies used by mothers it was found that the most used coping strategy was Seeking Spiritual Support (SSS) which has the highest median value (3.2500), followed by Passive Appraisal (PA) (3.2000), Mobilizing Family to Acquire Social Support (MFA) and Reframing (3.000) and the least being Acquired Social Support (ASS) (2.9444).

Table No. 3: Median score for F- COPES Score

Domains	25th Percentile	Median	75th Percentile
Acquired Social Support	2.5556	2.9444	3.3333
Reframing	2.5000	3.0000	3.3750
Seeking Spiritual Support	2.5000	3.2500	3.7500
Mobilizing Family to Acquire Social Support	2.5000	3.0000	3.5000
Passive Appraisal	2.8000	3.2000	3.4500

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Table No. 4: F COPEs Score

Domains	Mean	Std. Deviation	Minimum	Maximum
Total F COPEs Score	90.5758	9.09448	74.00	118.00
Sub scales				
ASS	27.0455	5.15433	15.00	37.00
Reframing	23.5606	5.18616	14.00	35.00
SSS	12.3636	3.15076	5.00	18.00
MFA	11.6970	2.92454	6.00	18.00
PA	15.9091	2.64125	11.00	22.00

Table No. 5 Correlation Between Stress score and Coping strategy

		Total F COPEs	ASS	Reframing	SSS	MFA	PA
Total Stress score	Pearson Correlation	-.138	-.112	-.290*	.116	.058	.108
	Sig. (2-tailed)	.267	.370	.018*	.352	.642	.386
	N	66	66	66	66	66	66
Core aspects	Pearson Correlation	.033	-.004	-.076	.195	-.044	.087
	Sig. (2-tailed)	.791	.976	.545	.116	.725	.488
	N	66	66	66	66	66	66
Co Morbid behavior	Pearson Correlation	-.118	-.083	-.293*	.120	.017	.168
	Sig. (2-tailed)	.344	.506	.017*	.339	.893	.177
	N	66	66	66	66	66	66
Co Morbid physical	Pearson Correlation	-.248*	-.198	-.291*	-.048	.153	-.009
	Sig. (2-tailed)	.044	.111	.018	.701	.219	.943
	N	66	66	66	66	66	66

*P value >0.05

Pearson product-moment correlation coefficient was computed to assess the relationship between the various coping strategies and the stress scores

Findings suggest,

1. Negative correlation between the Stress score and Reframing where, $r = -0.290$, $n = 66$, $p = 0.018$. Overall, there was a weak negative correlation between Stress score and Reframing Coping Strategies.
2. Negative correlation between Co morbid behaviour and Reframing where, $r = -0.293$, $n = 66$, $p = 0.017$. Overall, there was a weak negative correlation between Co morbid behaviour stress and Reframing Coping Strategies.
3. Negative correlation between the Co Morbid physical and Total F Copes Score where, $r = -0.248$, $n = 66$, $p = 0.04$. Overall, there was a weak negative correlation between Co Morbid physical characteristics and Total F COPE Score.
4. Negative correlation between the Co Morbid physical and Reframing where, $r = -0.291$, $n = 66$, $p = 0.018$. Overall, there was a weak negative correlation between Co Morbid physical and Reframing Coping Strategies.

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Effect of Socio demographic variable on stress & Coping strategies

- a. A one-way, between subject's ANOVA was conducted to compare the effect of Mother education on Coping strategy. There was a significant effect of Mother education and Total F COPEs Score [$F(2, 66) = 5.187, p = 0.008$]. using the Bonferroni test indicated that the mean score for the Graduates ($M = 94.54, SD = 9.09$) was significantly higher than the Primary educated mothers ($M = 84.54, SD = 4.22$). However, the Secondary educated mothers ($M = 89.93, SD = 8.43$) did not significantly differ from the Graduates & Primary educated mothers. Taken together, these results suggest that mothers who have high levels of education have a better coping skill.
- b. A one-way, between subject's ANOVA was conducted to compare the effect of Mother education on the Coping strategy Acquired Social Support. There was a significant effect of Mother education and Acquired Social Support [$F(2, 66) = 5.236, p = 0.008$]. Post hoc comparisons using the Bonferroni test indicated that the mean score for the Graduates ($M = 29.63, SD = 5.60$) was significantly different than the Secondary educated mothers ($M = 26.18, SD = 4.69$) and Primary educated mothers ($M = 24.45, SD = 3.41$). However, the Secondary educated mother did not significantly differ from the Primary educated mothers. Taken together, these results suggest that mothers who have high levels of education are better in Acquiring Social Support.
- c. There is no significant difference between child age on Stress score and coping Strategies
- d. A one-way, between subject's ANOVA was conducted to compare the effect of Mother age on the coping strategy, Seeking Spiritual Support. There was a significant effect on Mother age and Seeking Spiritual Support [$F(2, 66) = 3.865, p = 0.02$]. Post hoc comparisons using the Bonferroni test indicated that the mean score for the mothers between the age of 31-35 ($M = 13.77, SD = 2.87$) was significantly higher than the mothers between the age of 25 – 30 ($M = 11.53, SD = 3.14$) However, the mothers between the age of 36-40 did not significantly differ from the 31-35 and 25-30 age groups.
- e. An independent-samples t-test was conducted to compare mother's occupation and the coping strategy, Mobilizing Family to Acquire Social Support. There was a significant difference between mothers who were employed ($M = 13.35, SD = 3.20$) and mothers who were home-makers ($M = 11.25, SD = 2.70$); $t(65) = -2.487, p = 0.16$. These results suggest that the mothers who were employed more coping strategies on Mobilizing Family to Acquire Social Support.
- f. Pearson product-moment correlation coefficient was computed to assess the relationship between the Monthly income and the Coping strategy, Seeking Spiritual support. There was a positive correlation between monthly income and Seeking Spiritual Support where, $r = 0.25, n = 66, p = 0.036$. Overall, there was a weak positive correlation between Monthly income and Seeking Spiritual support.

DISCUSSION

The goal of this study was to evaluate stress and coping mechanisms among moms of children with Autism Spectrum Disorder in Chennai. Self-administrative questionnaires, such as the Autism Parenting Stress Index (APSI), were used to determine parental stress across various domains and levels of stress, and family crisis oriented personal evaluation scales (F-COPES) were used to determine the coping strategies used by the mothers to cope with the stress and their level of dependence on those coping strategies.

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In the domains of co-morbid behaviours, specifically in the element of self-injurious behaviour, and co-morbid physical difficulties, particularly in the aspects of bowel problems and child diet, mothers reported the highest degree of stress. As a result, self-injurious behaviour, bowel difficulties, and child diet were the top three worries for moms, followed by acceptance of others and communication with the child.

This finding is consistent with the findings of earlier studies that looked into the relationship between autistic children's behaviour and parental stress levels (Tomanik et al., 2004; Donenberg & Baker, 1993; Frey et al., 1989; Norton & Drew, 1994).

When their children were more irritable, socially withdrawn, self-injurious, unable to take care of themselves, and unable to communicate or connect with others, mothers of children with autism reported the most stress.

Although several research indicated "challenging behaviours" as a main source of stress, only one of those studies focused on these behaviours and highlighted physical and emotional violence, destruction, and self-injury as behaviours related with them (Fodstad, Rojahn, & Matthew, 2012). Additional obstacles include tantrums and meltdowns (Ludlow et al., 2011; Myers, Mackintosh, & Goin-Kochel, 2009), and resistance (Ludlow et al., 2011; Myers, Mackintosh, & Goin-Kochel, 2009). (Bearss, Johnson, Handen, Smith, & Scahill, 2013), The findings of this study are in line with those of other investigations.

Another concern is disrupted sleep, which causes chronic tiredness in the parent and exacerbates behavioural issues in the child. The ongoing need for vigilance and care (Giallo, Wood, Jellett, & Porter, 2013; Moss & Howlin, 2009; Montes & Halterman, 2007; Silva Schalock, 2012), the child's tantrums, and the social consequences of the child's problematic behaviours can all seem endless and stressful (Ludlow et al., 2011; Myers, Mackintosh, & Goin-Kochel, 2009). When added to an already challenging daily routine, managing a child's diet, nutrition, and weight is a particular struggle for parents of children with ASD (Curtin, Jojic, & Bandini, 2014).

When analysing various coping strategies used by mothers, it was found that the most used coping strategy was seeking spiritual support, followed by passive appraisal, mobilizing the family to acquire social support and reframing, and the least used being acquiring social support. And also, we found out that There was a weak negative correlation between stress score and reframing coping strategies and also weak negative correlation between comorbid physical characteristics and Total F copes scores.

Mothers who have high levels of education have better coping skills and also, they are better at acquiring social support. Mothers who used more coping strategies to mobilise their family to obtain social support.

Among the coping mechanisms adopted by moms of autistic children, seeking spiritual support and passive appraisal were shown to be the most common. Gallagher & Whiteley (2012) observed that parents of children with ASD used much more coping methods than parents of typically developing children (e.g., emotional support, positive reframing, planning, humour, acceptance, and religion). Parents of children with ASD, on the other hand, utilised fewer social support-seeking tactics than parents of typical children, according to Pisula & Kossakowska (2016).

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Acknowledgement

The author appreciates all those who participated in the study and helped to facilitate the research process.

Conflict of Interest

The author(s) declared no conflict of interest.

How to cite this article: Karuppanan A., Ramamoorthy A. K., Ananathakrishnan P. & Swaminathan A. (2022). Parenting Stress and Coping Strategies of Mothers with Autism Spectrum Disorder in Chennai District – A Descriptive Cross-Sectional Study. *International Journal of Indian Psychology*, 10(2), 868-876. DIP:18.01.088.20221002, DOI:10.25215/1002.088