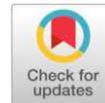


Original Research Article

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Parenting Stress of Children with Autism Spectrum Disorders

Gonal Amruta M¹, Pujar Lata¹, Muktamath Vinuta¹ and Kulkarni Uma²¹Department of Human Development and Family Studies, College of Community Science, University of Agricultural Sciences, Dharwad 580 005, Karnataka, India²Department of Food Science and Nutrition, College of Community Science, University of Agricultural Sciences, Dharwad 580 005, Karnataka, India**ABSTRACT**

Parents of children with Autism Spectrum Disorders (ASD) experience more stress than parents of children who are typically developing. Autism Spectrum Disorder (ASD) is a lifetime condition that involves persistent impairments in speech-language, social communication, and restricted and repetitive behaviors. Bringing up a child with autism can be challenging for parents due to the specific characteristics of autism. The present study was conducted to know parenting stress and associated factors. The study included 82 parents of children with ASD selected from different special schools and therapy centers located at Hubballi, Dharwad, and Bengaluru city. A personal information questionnaire, Parenting stress scale, and Indian scale for assessment of autism were used for data collection. The results showed a majority of the children belonged to moderate (44.00%) and severe (41.50%) categories of autism. The majority of the parents had clinical levels (75.00%) of parenting stress. The majority of the children had high problems in relationship and reciprocity (85.15%) followed by emotional responsiveness (78.05%), speech-language, and communication (65.85%). Child characteristics: younger age, being non-verbal, lack of speech-language and communication, lower cognitive abilities, and total Autism severity-induced parenting stress which can be reduced by providing intervention programs through speech therapies, cognitive behavior therapies, physical therapies etc. Parents should be supported by family members and society which help to reduce the stress caused by caring for an ASD child.

Keywords: Autism spectrum Disorders, Parenting Stress, Autism severity, Parenting stress, Autism Children, Autism Severity, Non-verbal, cognitive abilities, Adaptive behavior

Introduction

According to the American Psychiatric Association (22) Autism Spectrum Disorders (ASD) are neuro-developmental disorders characterized by deficits in social communication and interaction as well as restricted and repetitive behaviors and interests. In the key facts of the World Health Organization (22), it is mentioned that worldwide one in 100 children have ASD. Autism is three to four times more common in boys than in girls. The number of children diagnosed with ASD worldwide is on the rise. In India, cases of autism have been rising. It has been estimated that more than 2 million people might be affected by ASD in India (12). There are very few studies conducted on prevalence estimates of ASD in India. Hence the reality of ASD prevalence is still unidentified in India.

Caring for a child with ASD is especially stressful for parents due to the complexity of the symptoms (9). The need for constant care and supervision is a major stress factor for parents of children with a range of autism symptom severity (14). Fodstad *et al.* (7) reported autism symptoms and challenging behaviors such as social communication impairments and repetitive behaviors, poor cognitive and adaptive skills, and emotional and behavioral difficulties have been associated with increased

parental stress and physical and emotional aggression, destruction, and self-injury, tantrums, meltdowns, resistance, verbal or physical perseveration, tuning out, repetitive movements and unusual responses to sensory stimuli were the primary source of stress for parents. Parents are being judged and criticized for bad parenting which makes parents feel locked at home, as they fear taking their child out in public. And these symptoms make parents feel extremely isolated (21). From this point of view, the present study was undertaken to know parenting stress and associated factors.

Materials and Methods

The study was conducted in 2021-2022 and was a cross-sectional descriptive research. The population of the study was parents of children with ASD from Hubballi-Dharwad and Bengaluru city. In Hubballi-Dharwad, there were 5 special education schools/therapy centers. Thirty-eight therapy centers/special schools in Bengaluru were contacted out of which only nine special schools/therapy centers permitted research data collection. Each school/therapy center was individually visited, and permission to conduct the study was sought. Personal inquiries were made with parents of children with ASD to gauge their interest in taking part in the study. The parents of children with ASD between the ages of 3 and 12 were purposefully selected. 57 parents made up the Bangalore city sample and 25 were selected from Hubballi-Dharwad. There were a total of 82 people in the research's overall sample. A self-structured questionnaire was used to collect personal information of parents and children.

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The Parenting Stress Index (PSI) short form by Abidin (1995) was used to assess parenting stress. It consists of 36 items. The score anchored from strongly agree (5) to strongly disagree (1) with a five-point Likert scale. Based on the total stress score the respondents were classified as low (<55), normal (55-85), high (86-90), and clinically significant (>90) categories of parenting stress.

Indian Scale for Assessment of Autism by the National Institute for the Mentally Handicapped (8) was used to assess the severity of autism rated on a 5-point Likert scale ranging from 1 (never) to 5 (always). It consists of 40 items, divided into six domains: Social Relationship and Reciprocity, Emotional Responsiveness, Speech - Language and Communication, Behaviour Patterns, Sensory Aspects, and Cognitive component. The severity of Autism was classified as normal (<70), mild (70-106), moderate (107-153), and severe (>153).

Descriptive and inferential statistics such as chi-square, correlation, and one-way ANOVA were employed to know the association, difference, and relationship between autism severity and parenting stress.

Results and Discussion

Table 1. Percentage distribution of ASD children N=82

Child characteristics	Category	Frequency (%)
Gender	Male	62 (75.60)
	Female	20 (24.40)
Age	3-6	48 (58.60)
	6-9	23 (28.00)
	9-12	11 (13.40)
Ordinal position	Firstborn	62 (75.61)
	Second born	16 (19.51)
	Later born	4 (4.88)
Verbal ability of the child	Nonverbal	37 (45.12)
	Says few words	31 (37.80)
	Speaks in phrases	14 (17.07)
Autism severity	Normal	-
	Mild	12 (14.50)
	Moderate	36 (44.00)
	Severe	34 (41.50)

The characteristics of the children such as gender, age, ordinal position verbal ability and autism severity are presented in Table 1. Among the sample selected for the study, 75.60 per cent of them were boys and 24.40 were girls. This finding is in line with DSM-5, which states that ASD is diagnosed four times more often in males than in females. It is evident from the results that, the age group of the children ranged between 3 to 12 years. Among them, 58.60 per cent of them belonged to 3-6 years, 28 percent in the 6-9 years and 13.40 percent of them belonged to 9-12 years. Regarding the ordinal position of the children, 75.61 per cent were first born, 19.51 per cent were second born and 4.88 percent were later born. A study stated that firstborn children had a higher increased risk of autism (4). Looking into the verbal ability of children nearly half (45.12%) of the autism children were non-verbal, followed by those who said few words (37.80%) and who spoke in phrases (17.07%). In support of this study, Young *et al.* (23) reported that 52 of the children (64.2 percent) had difficulties with speech. Of those in the selected group, only 8.8 percent had not developed language, while 16.3 percent had normal language. Consistent with a diagnosis of autistic disorder, communication problems were commonly reported. The results of Autism severity showed that the majority of the children belonged to moderate levels (44.00%) of autism that infer they had significant difficulties with communication and social interaction and their restricted, repetitive behaviors interfered with daily life. Severe (41.50%) level need a very substantial level of support from parents/others and children with mild (14.50%) level autism need a limited amount of support. Patra *et al.* (16) assessed the autism children using the Indian Scale for Assessment of Autism and found 12 cases in the moderate category and 23 in the severe category.

Figure 1 shows the distribution of autism children based on their level of autism severity. The majority of the children had high problems in relationship and reciprocity (85.15%) followed by emotional responsiveness (78.05%), speech, language, and communication (65.85%), sensory aspects (64.63%), behavior pattern (56.10%), cognitive component (42.68%).

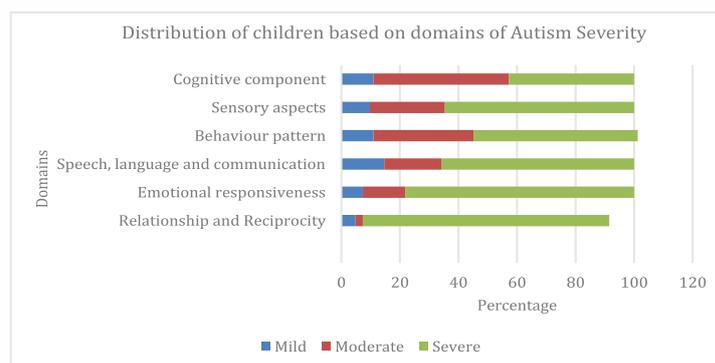


Figure 1. Distribution of children based on components of Autism Severity

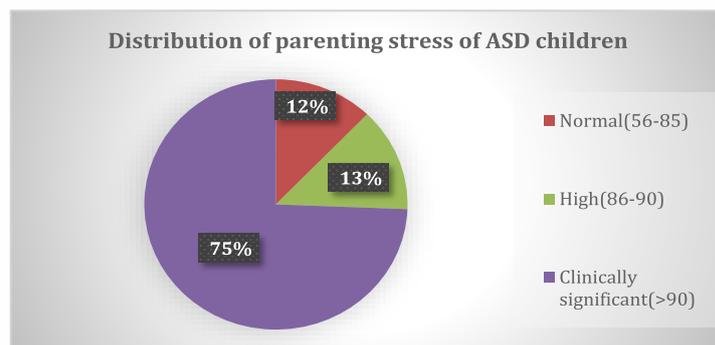


Figure 2. Distribution of parenting stress of ASD children

Parenting stress of parents was shown in Figure 2. It is shocking to know that the majority of the parents of children with autism had clinically significant (75.00%) levels of stress. Few of the parents had high (13.00%) and normal (12.00%) levels of stress. Similarly, Tripathi (23) reported most of the parents with children with ASD (81%) were in the clinical range of stress. Kayfitz *et al.* (10) also found that 26 percent of parents reported clinically significant stress levels. According to Kiami and Goodgold (11), parental stress of children with ASD has been found clinically significant levels in 77% of the cases.

Table 2. represents the association and comparison between child factors with parenting stress. The majority of the parents with male children had clinical (58.50%) levels of parenting stress followed by high (15.90%) and normal (4.90%) levels of stress. The results were the same for the female gender. There was no significant association or difference found between genders and parenting stress. The age of the children was found to have a significant association and difference with parenting stress. The majority of the parents who had children in the age group of 3-6 years had clinical parenting stress (70.80%) followed by high (18.80%) and normal (10.40%). The same trend followed in the 6-9 years and 9-12 years age groups. The majority of the parents of all the age group children fell under a clinical level of parenting stress. There was a significant difference found (ANOVA, F value 3.986) between parenting stress and the age of the children. Parenting stress of 3-6 years was higher than the other two age groups. Autism children's physical appearance looks very normal and the only difference can be seen in the behavior of children. During the age of 3-6 years, children get diagnosed with autism creating stress among the parents due to unawareness and less understanding about ASD. Baker *et al.* (3) reported that parenting stress remained relatively stable when children were 3, 4, and 5 years of age and that stress was related to both problem behaviors and having an

ASD diagnosis. A similar study by (19) found that higher levels of stress in parents were related to younger ages of children with ASD. The majority of the parents of first-born children were found to have a clinical (75.80%) level of parenting stress followed by high (12.90%) and normal (11.30%). There was no significant association or difference noticed between parenting stress and ordinal position.

The results for the verbal ability of the children and parenting stress denote that the majority of the children who say few words (75.00%) and nonverbal (73.90%) had a clinical range of parenting stress followed by high (16.70% and 13.00%) and normal (8.30% and 13.00%). The same trend follows for parents whose children speak in phrases. Dillenburger *et al.* (5) parents in his study reported that social-communication deficits caused major stress. Side and Kumar (17) also reported that autistic children being non-verbal was the major stressor for parents. There was a significant difference found between parenting stress and the verbal ability of autism children. It was imperative from F value (2.062) that parents whose children were non-verbal exhibited higher parenting stress. Majority of the parents whose children had severe levels of autism were found to have a clinical level (88.20%) of parenting stress followed by normal (8.80%) and high (2.90%) levels. The higher number of parents (63.90%) of children with moderate levels of autism severity were found to have clinical levels of parenting stress followed by high (27.80%) and normal (8.30%). A higher prevalence of clinically significant (66.70%) parenting stress was found among the parents of children with a mild level of autism and a normal level of 33.40 per cent. The association between parenting stress and autism severity was significant (chi-square value 16.586). The parenting stress was higher among parents of children with severe autism category (ANOVA F Value 4.726). Lai *et al.* (13) reported that the severity of autism symptoms was associated with higher parenting stress.

Table 2. Association and comparison between Autism children's characteristics and parenting stress among mothers

N=82

Characteristics	Category	Parenting stress				Modified χ^2	Mean \pm SD	F/t value
		Normal	High	Clinically significant	Total			
Gender	Male	6(7.30)	8(9.80)	48(58.50)	62(100.00)	1.648 ^{NS}	126.75 \pm 24.71	0.399 ^{NS}
	Female	4(4.90)	3(3.70)	13(15.90)	20(100.00)		124.24 \pm 28.54	
	Total	10(12.20)	11(13.40)	61(74.40)	82(100.00)			
Age (Years)	3-6	5(10.40)	9(18.80)	34(70.80)	48(100.00)	12.024*	121.79 \pm 28.14	3.986*
	6-9	4(17.40)	1(4.30)	18(78.30)	23(100.00)		125.65 \pm 24.79	
	9-12	1(1.20)	1(10.00)	9(90.00)	11(100.00)		140.30 \pm 23.99	
	Total	10(12.20)	11(13.40)	61(74.40)	82(100.00)		125.13 \pm 27.12	
Ordinal position	Firstborn	7(11.30)	8(12.90)	47(75.80)	62(100)	2.655 ^{NS}	124.38 \pm 25.81	0.863 ^{NS}
	Middle born	3(18.80)	3(18.80)	10(62.50)	16(100.00)		122.68 \pm 32.68	
	Third born	-	-	4(100.00)	4(100.00)		142.50 \pm 23.27	
	Total	10(12.20)	11(13.40)	61(74.40)	82(100.00)		125.13 \pm 27.12	
Verbal ability	Nonverbal	6(13.00)	6(13.00)	34(73.90)	46(100)	0.945 ^{NS}	125.34 \pm 27.53	2.062*
	Says few words	2(8.30)	4(16.70)	18(75.00)	24(100.00)		123.75 \pm 24.48	
	Speaks in phrases	2(16.70)	1(8.30)	9(75.00)	12(100.00)		127.08 \pm 32.44	
	Total	10(12.20)	11(13.40)	61(74.40)	82(100.00)		125.13 \pm 27.12	
Autism severity	Mild	4(33.30)	-	8(66.70)	12(100.00)	16.586*	118.83 \pm 29.50	4.726*
	Moderate	3(8.30)	10(27.80)	23(63.90)	36(100.00)		117.36 \pm 25.23	
	Severe	3(8.80)	1(2.90)	30(88.20)	34(100.00)		135.58 \pm 25.44	
	Total	10(12.20)	11(13.40)	61(74.40)	82(100.00)		125.13 \pm 27.12	

Table 3: The relationship between domains of autism severity and parenting stress

Domains of Autism severity	Parenting stress
Speech-language and communication	.299(**)
Relationship and reciprocity	.162
Emotional responsiveness	.084
Behavioral patterns	.053
Sensory aspects	.160
Cognitive component	.266(*)
Autism severity	.247(*)

**Significant at the 0.01 level

*Significant at the 0.05 level

The relationship between autism severity and parenting stress is presented in Table 3. The results indicate that there was a significant positive correlation found between domains of autism severity such as speech language and communication, the cognitive component, and overall autism severity with parenting stress. As the problems of speech language and communication increased parental stress also increased. Communication is the key to any relationship. Parents get stressed when their child lack the abilities of speech and communication. Parents expect children to communicate and respond to them with speech and language. Dillenburge *et al.* (5) found that parents with autistic children felt deficits in their child's social and communication skills, and lack of cognitive abilities were the root causes for most of their difficulties. Lack of Communication is a significant feature of ASD children. The cognitive impairments typically exhibited by ASD children include difficulties in predicting others' behavior based on their thoughts and feelings and problems regulating and controlling their behavior, combined with an aptitude for detecting parts of objects or small details. Miranda *et al.* (15) found a significant association between higher levels of parental stress and the increase in the core symptomatology of ASD which emphasized a strong correlation between the severity of autism symptoms and parental stress.

The study on parental stress is of great importance because it helps to understand the sources of parenting stress. The present study mainly focused on child factors such as age, gender, ordinal position, and autism severity which are contributing to parenting stress. There is no 'cure' for autism and still no medicines or surgeries that can 'cure' autism. But there are other ways to manage the ASD children's symptoms severity and help the children to learn the skills necessary to lead a life like normal people without much dependency. Autism children can substantially be benefitted from speech therapy, occupational therapy, cognitive behavior therapy, physical therapy, sensory integration therapy, social skills training, and life skills training, etc. It is also most important to support the parents at familial and societal levels. Parents also need intervention which helps reduce the stress raised in caring for an ASD child. Parents are central to every aspect of children's development, and thus a better understanding of their knowledge, attitudes, challenges, and coping strategies toward raising children with ASD holds significance. Programs that focused on acceptance, commitment, coping, and stress reduction (18) resulted in changes in parents' approaches to managing their child's care and their stress. Integration of interventions to facilitate problem-based coping technique hold the potential to mediate stress (6) and the risk for stress-related health issues, such as anger, confusion, guilt, denial, isolation, and depression (24). "Parent education programs that teach parents naturalistic strategies to increase their child's communication have been shown to result in decreased levels of parent stress and depression" (3).

The general public should be given awareness and education on ASD and provide a positive and supportive environment for parents as well as ASD children.

Future Scope of the Study

- Determinants of stress in parents of children with autism spectrum disorders
- Association between child behavioral problems and parenting stress in autism spectrum disorders
- Parenting stress and coping strategies of parents of Autism children
- Mindfulness based Intervention to reduce parenting stress of children with Autism Spectrum Disorders

Conflict of interest

We the authors of the article "Parenting stress of children with Autism Spectrum Disorders" declare that there is not any conflict of interest or unfair advantage related to this work.

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