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Stress factors in parents of children with Autism spectrum disorder

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Abstract

Autism Spectrum Disorder (ASD) is a lifetime condition that involves persistent impairments in language, social skills and daily life activities. Difficulties in child-rearing, which are present from early ages put strong pressure on parenting. Bringing up a child with autism can be challenging for parents due to the severity of autism. The present study was conducted to know stress factors in parents of children with autism. Study included 82% of children with Autism Spectrum Disorders selected from different special schools and therapy centres located at Hubballi, Dharwad and Bengaluru cities during the year 2021-2022. Self-structured questionnaire and Parenting stress scale by Abidin, were used for data collection. Results revealed that majority of the mothers and fathers were in the age group of 30-40, studied till graduation and fathers were professionals and mothers were housewives. Majority of the parents had clinically significant (74.40%) levels of stress. Occupation and marital status were only the two factors which showed significant association with parenting stress. Parents in the age group (30-40 years) and education graduation had influence on parenting stress. The identification and understanding of the factors that contribute to parenting stress is necessary to address the psychological needs of parents to manage their mental health.

Keywords: Autism, autism spectrum disorders, parenting stress, children

Introduction

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder characterized by persistent difficulties in communication and social interaction and stereotyped patterns of behavior and interests (American Psychiatric Association, 2022) [2]. It is estimated that worldwide one in 160 children has an ASD (WHO report, 2022) [3]. Autism spectrum disorder is also three to four times more common in boys than girls. The number of children diagnosed with ASD worldwide is on the rise.

Parenting is a transforming experience for the life of parents that brings joy and satisfaction as well as challenges and demands. Becoming a parent is generally imagined to be a happy and natural life event. Parents dream about their child's future and they try to fulfill their unaccomplished wishes through their children. But when they find out that their child is having disability such as Autism Spectrum Disorder it brings overwhelming emotions of shock, disbelief, anxiety, fear, despair and stress. Parental stress is a distinct type of stress that arises when a parent's perception of the demands of parenting outstrip his or her resources. The dominant view for describing parental stress delineates from three major source domains characteristics, stressors for parents: child parent characteristics situational/demographic-life Stress (Abidin, 1995) [1]. Given the gravity of demands and responsibilities in parenting, parents of children with ASD report higher levels of stress than parents of normally developing children (Smith, 2009) [18].

Parents of children with Autism Spectrum Disorders (ASD) experience more parenting stress and mental health problems than parents of children with other disabilities (Rezendes *et al.* 2011) ^[16]. Parenting stress is a specific form of stress arising from parenting-related challenges and a relative lack of perceived resources to adapt to the demands of those challenges (Deckard, 2004) ^[6]. Increased parenting stress has been shown to contribute to negative physical and mental health outcomes for caregivers and children. Caring for a child with a developmental disability is a well-documented risk factor for parenting stress (Neece *et al.* 2012) ^[13]. In this view present study was conducted to know the parental factors contributing to parenting stress.

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Materials and Methods

A cross-sectional descriptive research was carried out during the year 2021-2022. The population of the study were parents of children with ASD from Hubballi-Dharwad and Bengaluru city. There were 5 special education schools/therapy centres at Hubballi-Dharwad city. Thirty eight therapy centers/special schools in Bengaluru, out of which only nine special schools/therapy centers and permission for data collection. Each school/therapy centre was individually visited, and took permission to conduct the research study. 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 selected purposefully. A total of 57 parents from Bangalore city 25 parents selected from Hubballi-Dharwad. Totally 82 parents constituted study sample.

Self-structured questionnaire was used to collect personal information of parents and children. Parenting Stress Index (PSI) short form by Abidin (1995) [1] was used to assess the parenting stress. It consists of 36 items and Score on five point likert from strongly agree (5) to strongly disagree (1). Based on the total stress score the respondents were categorized as low (<55), normal (55-85), high (86-90) and clinically significant (>90) levels of parenting stress.

Table 1: Parental characteristics of ASD children N=82

S. No.	Charact eristics	Category	Mother	Father
1.	Age		F (%)	F (%)
		20-30	36(43.90)	Ī
		30-40	42(51.22)	67(81.70)
		40-50	4(4.88)	10(12.20)
2.	Educatio n	Profession or Honors	34(41.46)	
		Graduate	35(42.68)	20(24.39)
		Intermediate or Diploma	13(15.85)	19(23.17)
		High School certificate		-
		Middle school certificate		-
		Primary school certificate		-
		Illiterate		-
	Occupati on	Legislators, senior officials and	04(4.88)	28(34.15)
		Managers	` ′	` ′
		Professionals	22(26.83)	45(54.88)
		Technical and Associate	_	3(3.66)
3.		professionals		
		Clerks	-	3(3.66)
		Skilled workers and Shop and	_	3(3.66)
		Market sales workers		
		Skilled Agricultural and Fishery	_	-
		Workers		
		Craft and Related Trade workers	-	-
		Plant and Machine operators and	-	-
		assemblers	5.6460 3 00	
		Elementary occupation/Housewife	56(68.29)	-
		Unemployed	-	-
١.	Marital status	Married	77(93.90)	-
4.		Separated/Divorced	5(6.10)	-
		Widow	-	-

Table 1. Shows the paternal characteristics like age, education, occupation and monthly income. Majority (81.70%) of the fathers were belonged to 30-40 years age group, 12.20 percent of them were in 40-50 age group and 6.10 percent of them in 20-30 age group. With regard to education of the fathers 52.44 percent of fathers studied professional or honors degree, 24.39 percent of them were

graduates and 23.17 percent of them studied till intermediate or diploma. None of the fathers were illiterate. Occupation of the fathers indicates that 54.88 percent of them were professionals,34.15 percent of them were Legislators, senior officials and Managers and 6.66 percent of them were Technical and Associate professionals, 3.66 percent of the fathers were Clerks and Skilled workers and Shop and Market sales Workers. With respect to marital status of parents,93.90 percent of them were married and 6.10 percent of separated or divorced. With regard to the maternal age majority of them belonged to 30-40 (51.22%) age group followed by 20-30 (43.90%) and 40-50 (4.88%). In terms of maternal education, majority (42.68%) of them completed graduation and 41.46 percent of them were professional graduates and 15.85 percent of them were studied till Diploma or intermediate. Looking into the maternal occupation, majority (68.29%) of mothers were housewives, 26.83 percent of them were working as professionals and only 4.88 percent of them were working as legislators, senior officials and managers.

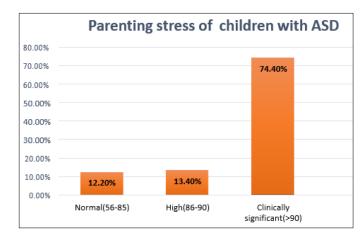


Fig 1: Distribution of Parenting stress among parents of children with ASD children

Parenting stress of parents are shown in the Figure 1. It is shocking to know that majority of the parents of children with autism clinically significant (74.40%) stress. Few of the parents had high (13.40%) and normal (12.20%) levels of stress. The reasons could be that ASD is neurodevelopmental disorder where children with autism had deficits in social communication, restricted and repetitive behaviour which makes challenge for parents to take care and adopt to the demands of autistic children. The interaction and bonding with child, understanding child needs and challenging behaviour creates stress among parents. According to Kiami and Good gold (2017) [9], parental stress of children with ASD has been found clinically significant levels in 77% of the cases.

Table 2. indicates the association and difference between parenting stress with parental factors. The parental characteristics which were considered were age, education, occupation, marital status, parental needs, parenting satisfaction. Among the parents in the age group of 30-40 years, majority (70.10%) of parents were in clinical level of parenting stress, followed by high (14.90%) and normal (14.90%) level of parenting stress. In the age group of 40 years and above, cent percent of the parents had clinical level of parenting stress. In the age group of 20-30 years, majority of the parents had clinical level of parenting stress with (80.00%) and few (20%) had high level of parenting stress.

The value of chi-square indicated non- significant association between parenting stress and age of the parents. The mean difference indicates that parents in the age group of 30-40(141.70) years had higher parenting stress than other two groups. There was a significant difference found between the parenting stress and age group with (F value 3.225). Because the condition of autism got confirmed when the parents were in the age group of 30-40 years, younger mothers may find it more difficult to deal with the demands of raising a child with ASD. The continued need and demand of children might create pressure and tension on parents to raise the autism children. So parents were trying to learn about what autism is, searching for therapy centres and accessing effective treatments for their autism child. To support the present results, Koegel et al. (1992) [10] revealed that mothers of autism children who were 30 years and younger than 30 years showed higher levels of stress. Similarly Duarte et al. (2005) [7] reported that mothers in the age of below 30 years shown higher levels of stress than mothers older than 31 years old. Because younger mothers find it more difficult to deal with the demands of raising a child with ASD child.

It was observed from the Table 2 that, 77.10 percent of the parents with education till graduation had clinical level of parenting stress followed by high and normal stress with (11.40%). Majority (74.40%) of the parents who studied professional or degree had clinical level of parenting stress followed by high (14.70%) and normal (11.80%). The same trend was followed in the parents who studied intermediate or diploma course. There was no significant association found between parenting stress and education of the parents. The mean scores of parenting stress of parents with different level of education did not show any significant difference. The

parenting stress of parents who studied till graduation had more parenting stress compared to other two groups. In the study by Nomaguchi and Johnson (2016) [14] opined that highly educated parents may find it difficult to adjust to the new parental role and greater investment in a career. Caring for the autism child increased their stress levels. Contradictory studies reported that parents with lower education reported higher stress. Stress significantly correlated with lower educational levels of the parents (Samadi and McConkey, 2014 and Phetrasuwan and Miles, 2009) [17, 15].

The percentage distribution of parents who were unemployed or housewives had clinical stress level with (78.60%) followed by high with (16.10%) and very few parents had in normal stress level with (5.40%). The parents who completed professionals degree had clinical level of parenting stress (63.60%) percent followed by normal stress level (27.30%) and high level (9.10%). Three fourth of the parents who were legislators, senior officials and managers had clinical level and one fourth of the parents had normal level of parenting stress. The chi-square value (15.556) indicated there was a significant association was between parenting stress with occupation of parents. However no significant difference was found between parenting stress with occupation. Cidav (2012) [5] revealed that autism children parents got less time in taking care of the child and they worry more about the child's future. Parents of children with autism earned less and worked fewer hours than people whose children had other health problems or no medical problems. Families may struggle to pay for therapies that were not covered by health insurance or provided by schools.

Table 2: Association and comparison between parental characteristics and parenting stress N=82

Characteristics	Category	Parenting stress				Modified χ2	Mean ± SD	F value
Characteristics		Normal	High	Clinically significant	Total	(p-value)	Mean ± SD	r value
	20-30	0	1(20.00)	4(80.00)	5(100.00)	4.921 NS	127.00 ± 27.20	3.255 *
Age	30-40	10(14.90)	10(14.90)	47(70.10)	67(100.00)		141.70 ± 10.45	
	40 and above	0	0	10(100.00)	10(100.00)		122.52 ± 28.17	
	Profession or Honors	4(11.80)	5(14.70)	25(73.50)	34(100.00)	0.399 NS	121.26 ± 25.03	1.056 NS
Education	Graduate	4(11.40)	4(11.40)	27(77.10)	35(100.00)		130.17 ± 28.75	
	Intermediate or Diploma	2(15.40)	2(15.40)	9(69.20)	13(100.00		121.69 ± 27.75	
	Housewife	3(5.40)	9(16.10)	44(78.60)	56(100.00)	15.556**	128.16 ± 25.51	-
Occupation of mothers	Professional	6(27.30)	2(9.10)	14(63.60)	22(100.00)		118.40 ± 29.88	
	Legislators	1(25.00)	-	3(75.00)	4(100.00)		136.33 ± 6.65	
Marital status	Married	10(12.65)	11(13.92)	58(73.41)	79(100.00)	- 14 162↑ 1	125.31± 25.91	1.021NS
iviaiital status	Separated/Divorced	-	-	3(100.00)	3(100.00)		144.86 ± 17.61	1.021113

Figures in parenthesis indicate percentages * - Significant at 5% level ** - Significant at 1% level NS: Non significant

It was observed from the table that majority of married parents of autism children had clinical level of parenting stress with 75.32 percent followed by normal with 12.98 percent and high with 11.68 percent. In the case of separated or divorced parents, 60 percent of them were in clinical range of parenting stress and 40 percent of them were in high level of parenting stress. There was significant association found between parenting stress and marital status of parents with chi- square value 14.162. But there was no significant difference found between parenting stress of married and separated/divorced parents. Majority of the parents were married and together, only few parents were single parents. There was a significant association seen between marital status and parenting stress. Single parents (divorced) experienced more parenting stress compared to married and

together couples. Because divorced parents didn't had any spousal support in caring for the child and had perform multiple roles. Johnson and Simpson (2013) [8] revealed the vulnerability of single mothers due to unmet expectations about support from relatives and neighbors with child care, household repairs, chores and the amount of time their child missed school. A study conducted by Koydemir-Ozde *et al.* (2010) [11] reported that some parents revealed that their marriage became strained, sometimes to the point of divorce. Reasons for the strain included loss of time spent together due to the high demands of taking care of the child, disagreements regarding parenting and blaming each other for the disorder.

Conclusion

Parenting stress indicated that majority of them had clinically

significant (74.40%) levels of stress. Occupation and marital status were only the two factors which showed significant association with parenting stress. Parents in the age group of 30-40 years and graduates had high level of parenting stress. Education and marital status did not influence parenting stress of ASD children. To reduce the parenting stress, parents has to get thorough knowledge on Autism when their child get diagnosed and the early intervention must be given to ASD children. Counselling and intervention program helps to reduce the stress in parents. The identification and understanding of the factors that contribute to parenting stress is necessary to effectively address the psychological needs of parents aspart of any intervention program.

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