

## Parental stress in dealing with girl children with autism spectrum disorders

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### ABSTRACT

Autism spectrum disorder among adolescence girls creates a lot of problems for their parents. The disability of adolescence girls affects them physically and emotionally and socially. The current study examined stress and well-being of parents with autism spectrum disorder. Parents of such children face more challenges in everyday living to cope with different stressful events. This study examined different causes of parental stress, real life stressful situation and its relationship with wellbeing of the children. The study has involved 80 parents have girl children with ASD. They completed three questionnaires, examining parent's stress level and status of wellbeing. Results revealed that parents have different reasons for stress, and they are different stress generating situations in daily life while they are dealing with their problematic children. These stresses are directly correlated with their and entire family's wellbeing. Perhaps some focused interventions may help parents to address these issues like sensitisation of parents to manage stressful situation, professional supports, creating more social interaction opportunities and linking with support services to improve wellbeing of the parents and children.

**Keywords:** Parental Stress, Autism Spectrum Disorder, Wellbeing of parents,

### INTRODUCTION

Parenting is a challenging task and having an autistic child may make things even more difficult. Parents can find their jobs highly stressful when coping with developmental concerns resulting in social, emotional, physical, and psychological problems since children with disabilities have impaired psychosocial development. Karsrt, j.s, & Van Hecke A V (2012) pointed that in tier studies,

in comparison to parents of children who are typically developing and those who have other developmental disorders, parents of children with ASD experience more mental and physical health issues and decreased parenting efficacy due to the pervasive and severe deficits that are frequently present in children with ASD. The difficulties connected with developmental needs of disabled children generate ambiguity, which many parents find difficult. Children with ASD may have complex needs that may require considerable financial, physical, and emotional investment. This may cause a lot of stress on the parents. Focusing on the autistic child may create challenges for other relationships. A study by Loomes, R., Hull, L., & Mandy, W. (2017) found the ASD prevalence is high among boys than girls. Many statistics indicating the same trend across the world. However, during adolescence, girls with ASD are at increased risk of not fitting in, feeling alienated from their age level peers and experiencing many protection issues.

More informed knowledge of the difficulties experienced by adolescent girls on the autism spectrum is essential to improve the provision of strategic and appropriate support. This is a major concern especially for the parents having girl children.

The present research tries to investigate the situation of the parents of girls with autism spectrum disorder. The presence of a differently able child is a problem for every member of the family, but it is of great significance for the parents of the child as parents traditionally plays the role of caregiver for a dependent child. The parents play this role in addition to various other responsibilities.

**AUTISM SPECTRUM DISORDER:**Autism spectrum disorder (ASD) is a lifelong severe developmental disorder affecting 1% of the population. It is characterized by general impairment in social interactions, stereotyped behaviours and restricted interests, repetitive and restrictive interests, problems with communication, and impaired social functioning. Autism Spectrum Disorder (ASD) or previously known as Pervasive Developmental Disorder. It's exhibited in early days of life with specific medical conditions and characteristics by social deformities, uneven behaviour patterns, repetitive and stereotyped interests, or activities (American Psychiatric Association, 2013).

**ISSUES WITH AUTISTIC GIRLS:** Parents have girls' child with ASD may experience difficulties as their daughters approach adolescence. The difficulties are undoubtedly different for men and women, and ladies with autism spectrum disorder (ASD) may deal with these difficulties differently than children with other special needs. Even in normal case many teenagers experience stress and anxiety due to their uncertainty about the physical changes that are occurring to their bodies and how to deal with those changes. Families are frequently ready to assist their daughters as they move through different developmental phases, such as kindergarten and primary school, but many girls find themselves unprepared as they move through adolescence and the period leading up to puberty. Adolescent autistic daughters' parents and themselves were substantially in agreement about the social difficulties the girls had on a daily basis. Most pertinent to the current study, parents and their daughters discussed how the girls felt alienated from society as a result of the confusing social "rules" that they found difficult to follow when they transitioned to secondary school and the related shifts in social expectations.

#### **CHALLENGES AMONG PARENTS:**

Significant stress and difficulties in providing care have been reported by parents and other caregivers of children with ASD. It is essential for parents, family members, and in particular the mother to care for and protect her child. If the child is autistic or has any other issues, the mother's role is increased even further. The management of the special need girl children's menstrual and personal hygiene needs is crucial. The family engaged faces a wide range of problems because of raising a child with autism. Autism is a disorder that is extremely difficult for the family. Specifically, parents are facing different kind of issues with related to finance, care and support, knowledge on care and support, lack of time, communication difficulties

#### **REVIEW OF LITERATURE**

Mount, Nicola & Dillon, Gayle. (2014). Parents faced multiple daily struggles as a result of the behaviours their child displayed. The pervasive nature of autism made constant demands on

parents' psychological and physical well-being, creating imbalances within relationships and family functioning. Receiving a diagnosis helped these parents accept autism as a part of their child, enabling them to work together and support each other. Many other studies pointed out that parents of children with autism differed from parents of typically developing children in social diversion coping. These challenges were different aspects of life parents as well as children in large. Most of the time parents are unable to meet the psychosocial needs of the children. Studies pointed that Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Vecili, M., & Lunsky, Y. (2012). psychological acceptance may be an important factor in coping for parents of young people with ASD, in line with the growing literature on positive coping as compared with problem-focused coping. Asmadialsa (2021) Psychological Well-being of Mothers with Autistic Children. This Study state that severe stress and depression are common phenomena among mothers of children with autism. As a consequence, adequate support becomes necessary in ensuring balanced mental health. Crowell, J. A., Keluskar, J., & Gorecki, A. (2019) parenting behaviour and the development of children with autism spectrum disorders (ASD) are neurodevelopmental diseases that are caused by a combination of hereditary and environmental factors. Symptoms of social communication deficiencies as well as limiting, repetitive behavioural patterns appear in the early stages of a child's development. While these issues are not caused by parents, they are caused by a lack of social connection. Parental stress can stifle parent-child connections, and parental stress can have negative transactional consequences. The growth of children Parental behaviour, like that of usually developing children, can boost development

#### **RATIONAL OF THE STUDY**

Among the several developmental disorders in children, Autism is the most common brain disorder. There are approximately 2 million children with autism spectrum disorder in India (according to the India scale assessment). Parents of children with autism play multiple roles in their life. Often, they are the first people who recognize a developmental problem. Autism disorders significantly impact daily lives of affected Individual and their parents. Autism is a complex situation for the parents. Most importantly parents of adolescence girls with ASD typically higher level of parenting stress. So, when adolescence girls with ASD experience physical, social and emotional changes in their life, it will affect parents for stressful life. Parents of children with autism cause significant stress for parents and disruption in family relationships. Parents of children with autism are at risk for increased levels of psychological problems such as depression, anxiety, distress, guilt, poor social and marital adjustment, less satisfaction with life, poor parent child interaction and hopelessness. Parents of such children face more challenges in everyday living to cope with different stressful events. They have to face more financial strain to provide necessary medical expenses, have to pay more attention to the child and parental demands increase which in turn enhance psychological strain and burden on parents. Consequently, it is difficult to assess the extent to which raising a child with autism affects parents. Parents are exhausted and confused about the best way to handles their girls with ASD behaviour.

#### **MATERIALS AND METHODS**

The purpose of this paper is to analyse and tried understanding challenges facing the parents with ASD girl children. The current study majorly addressing the following research questions (1) To

find out the parents 'concerns area about their adolescence girls with ASD and (2) To assess the level of stress of parents of adolescence girls with ASD.

This study conducted in Kozhikode district in Kerala. The parents of adolescence girls with autism spectrum disorder in Calicut district is taken as universe of this study. The investigators used multistage cluster sampling method in the research. For this study 80 samples from the different cluster were identified as a sample. Samples were proportionally selected from each cluster. Following variables were used to collect relevant information form identified respondents. For collecting socio-demographic data a structured questionnaire was used which includes information related as age, educational qualification and other basic profiles of the respondent. In addition to that following standard scales were used for assessing parental stress and

1. Autism parenting stress (APSI) scale prepared by Silva l.m.t and Schalock,M in 2012 used for collecting data to measure the stress of parents
2. Parental stress scale (PSS) prepared by Judy berry and Warren jones(1995) and used to assess father and mother worries about their child
3. Parental wellbeing scale (2020) by Roy McConky for used in assessment of parents feeling while take care of child with ASD

## RESULTS

**Table-1 : Demographic Profile of the respondents**

Particulars	n	Percentiles
<b>GENDER OF THE RESPONDENTS</b>		
Male	30	38.7%
Female	50	61.2%
<b>EDUCATIONAL QUALIFICATION</b>		
High School	22	27.5%
Higher Secondary	19	23.8%
Graduate	26	32.5%
Postgraduate	13	16.3%
<b>AGE OF GIRL WITH ASD</b>		
11-13 Years	13	16.3%
14-15 Years	34	42.5%
16- 17 Years	17	21.3%
18 -20 Years	16	20.0%

Among the respondents 61.25% of the respondents are female and 38.75% by the male respondents. Around 82% of the parents of autistic adolescent girls have education up to graduation level and another 18% have post-graduation. As per the table 1, 42% of the respondents say that their adolescent girls with ASD belong to 14-15 age groups, 21.3% of adolescent girls with ASD belong to 16-17 age groups, 16.3% of the girls are between 11-13 age category and remaining one belongs to 18 above age group.

**Table-2 : Areas of Stress**

Particulars	Not Stressful	Sometimes	Often	Very Stressful	I can't Cope
Parental Stress on Social Development of the Children	6.3%	15.0%	13.8%	37.5%	27.5%
Child's Ability to Communicate	6.3%	16.3%	16.3%	33.8%	27.5%
Behavior of the child	11.3%	25.0%	22.5%	17.5%	23.8%
Concern of Child's Future	2.5%	15.0%	10.0%	42.5%	30.0%

The respondent parents were asked about their perception on their child’s social development ‘37.50% of the respondents have experienced very stressful. 27.50% of respondents have agreed that they can’t cope with the situation. Around 15% have some time experience stress and 13.75% have experienced often stress. Parents were also asked about stress in communicating with their children. 32.5% of respondents often and sometimes experience difficulties and 33.75% of the respondents have been very stressed due to communication barriers .27.5% experience so stressful life in their daily life and can’t cope with the situation The table-2 also indicates the parents' stress in dealing with the aggressive behaviour of adolescent girls with ASD in their daily routines. Children’s behaviour is another concern area for parents and here 25 % of respondents sometimes create stress, while another 17.5% of parents have experienced a very stressful life. 23.75% have been so stressful and sometimes they feel can ‘t overcome the situations. While discussing in concern on Child’s Future. Overall, more than two third of respondents are facing stressful experiences. The above table shows that more than 42.5% of respondents have very stressed about their concern for their future child living independently. Parents area of concern regarding their children are different, however most of the parents are concerned about their children’s future.

**Table-3 : Stressful Situations of parents in Daily life**

Particulars	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
Stressful due to embarrassing behaviour of child”	3.8%	11.3%	13.8%	42.5%	28.8%
Stressful due to overwhelmed by the responsibility of being parents	5.0%	25.0%	3.8%	43.8%	22.5%
Stressful on hardship during daughter’s periods	2.5%	7.5%	15.0%	43.8%	31.3%
Stress level of financial burden	6.3%	10.0%	15.0%	60.0%	8.8%

The table -3 shows that 42.5% of respondents strongly agree that the behaviour of a child is often embarrassing and stressful for them.11.3% and 3.8% of respondents agree and strongly disagree with the statement. While the respondents were asked about “exhausted with their responsibilities” 43.75% parents are agreeing that overwhelmed by the responsibility of being parents with ASD, whereas 25 % respondents have not felt that the overwhelmed by the responsible parents and 5% of the parents strongly disagree the statement. The study found that 31.3% of parents strongly agreed that they face hardship during menarche of their girl children, while 43.8% of parents agree with the statement. Similarly, another major stress area of the

parents was their financial situation around 60% respondents have agreed that having girls with ASD makes an additional financial burden for them.

**Table-4 : Correlation of parental Stress and Parental Wellbeing**

Particulars	Mean	N	Std. Deviation	Std. Error Mean
Parental stress	35.6375	80	7.65100	.85541 1.49810
Pair 1	23.0000	80	13.39941	
Parental wellbeing	t-8.408	Df-79	(2 tailed) 0.000	

The level of Significance Selected as .05. p- value is .000

From the above table it is very clear that the strength of association between the and that the correlation coefficient is very highly significantly different from Zero. The p value is less than .05 so it is understood that there is significant association between parental stress and wellbeing.

**DISCUSSIONS AND SUGGESTIONS**

According to the obtained results of the research, among the respondents 61.25% of the respondents are female and 82% of the parents of autistic adolescent girls have education up to graduation level and another 18% have post-graduation. Parental stress and theirsocio-economic background areinterrelated. Many studies have emphasized Pickard, K. E., & Ingersoll, B. R. (2015). the role of socioeconomic status in shaping parents’ ability to access services for their child with autism spectrum disorder. Low socioeconomic status parents are aware of their child’s basic autism spectrum disorder needs. Hence the support service should more focus on the people in the low strata, so the children the ASD will get better services at local level. In the current study most of the respondents are females. Mothers have crucial role especially the mother for caring, nurturing, practicing, protecting her child and if the child is having any kind of problems.Tehee, E., Honan, R. and Hevey, D. (2009), When compared with fathers, mothers were significantly more stressed, more involved, and reported higher levels of stress and coping related to caregiving.

Around 37 percent of parents reported that they are “very stressful” on their children’s social development and another 33% said that they are worried ab\*out their children’s ability to communicate with in and outside family. However around 42.5% of the parents identified as very stressful whit regards to their children’s future. Overall, more then one forth of the respondents are informed that they can’t cope with their stress situation. It means that despite general support services to children, parents metal health also should focus. Rivard, M. et al. (2014) stress levels of both parents were associated with their child’s age, intellectual quotient, severity of autistic symptoms, and adaptive behaviours.

Parents are stressful in different circumstances. Around 60% of parents are stressful because of additional financial burden they have due to special need in their household. Parents are also stressful with their responsibilities.Anderson, D., Dumont, S., Jacobs, P., &Azzaria, L. (2007).

There is evidence in the literature that parents with disabled children suffer financial difficulties, and that it can be challenging for most parents to meet their special children's requirements. Findings in this study show that parental Stress and Parental Wellbeing are positively correlated. High level of the stress affect parents social and psychological wellbeing of the parents. Opportunities for more social interaction and early intervention in the psychological issues of the parents may help to manage stress level of the parents.

## CONCLUSION

Parental stress is a reality among parents have children with autism spectrum disorder. The reason for the stress is different and it is ultimately it is adversely affecting the wellbeing of the parent's and entire household. Managing parental stress is important because this will ensure better care and support for children with disability. Parents should be sensitised on different aspects to manage stress, care and support services for their girl children's needs.

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