



Parenting Style and Parents' Level of Stress having Children with Autistic Spectrum Disorder (CWASD): A Study based on Northern India

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Abstract

The present study focuses on the type of parenting style used by the parents who were undergoing different level of stress when dealing with children with Autism Spectrum Disorder.

A total number 320 Parents of Children with Autism Spectrum Disorder (CWASD), from two major cities of northern India were purposely selected for the study. Out of which most of the respondents were mothers (75%) and only 25% respondents were fathers. Two questionnaires (Parenting style Dimension Questionnaire and Parenting Stress Index-Short form) and demographic details were used to obtain information. The finding of the result indicates that the mothers' tend to use more permissive form of parenting in comparison to the fathers. Authoritarian parenting style was used by parents with children having severe form autism spectrum disorder. Parents reported high level of stress when dealing with adolescence children as in comparison with pre- adolescence children and it was also seen that Permissive style of parenting was adopted when dealing with pre- adolescence children. The result also showed that most of the parents (81% in clinical range) were having high level of stress, hence proper counselling, therapy and training should be provided for parents for the most appropriate form of parenting style. The study will also provide suggestions for proper care and the most effective parenting style that should be adopted by them and also to provide appropriate coping strategies recognize to parents, especially mothers to combat their high level of stress. This study helps the parents to have a better understanding of the effective form of parenting, the effect of stress when dealing with children with Autism Spectrum Disorder.

Key Words: Parenting style; Level of stress; Autistic spectrum disorder (ASD); Children with autistic spectrum disorder (CWASD)

Introduction

Autism, and, more broadly, Autism Spectrum Disorder (ASD), is a condition characterized by impaired cognitive and social skills [1], along with a compromised immune function [2-5]. Autism was first described by psychiatrist Leo Kanner, MD, in 1943 as a behavioural disorder of children. Around the same time, Hans

Asperger was writing about children who had similar symptoms but no compromised speech. Many professionals and parents of autistic children have watched the number of autistic children rise to epidemic proportions while the toxic levels of ethyl mercury and other toxins persist in vaccines [6]. Autism has been classified by the disciplines of medicine as a psychiatric illness [7].

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■ Historical overview of autism in India

Autism is not uncommon in India [8-10]. There are no specific community-linked studies on prevalence or incidence of autism or ASD in India [11]. India is a country with a population of 1 billion people, of which 35% are children under the age of 14 [12].

Autism is rising alarmingly in India. Most recent estimates of 1 in 150 children in the United States having autism spectrum disorder, there are 2-3 million children with autism spectrum disorder in Indian [12]. According to Daley [13] due to the lack of research in the Indian context may reflect the fact, that some researchers have assumed that autism is rare in non-Western countries [14], or is 'an illness of modern civilization' [15].

In addition to recognition, the meaning attributed to a particular symptom is likely to vary. For example, a study of psychiatric disorders among children in South India found that parents did not initially report concerns about their children (it had never occurred to most parents that their children's troublesome ways were anything other than an accepted part of family life), until a researcher came along [16].

■ Impact of ASD on parents and families

Autism is unique in other developmental disorders, as it can create greater parental anxiety and tension than parents of non-disabled children [17]; other physical or learning disabilities; or with other developmental disabilities [18]. The effects of having a child with an ASD on parents and families are, like the disorder itself, multifaceted and pervasive. Approximately 85% of individuals with ASD present with cognitive and/or adaptive limitations that limit their ability to live independently, leading to the possibility that they will need some measure of care or assistance from their parents and families for the duration of their lives [19].

In Seltzer's [20] longitudinal study of parents of children with developmental disabilities, over 50% of parents aged 50 or older indicated that they still lived with their child, compared with a rate of 17% for typically developing children.

Like other developmental disorders, autism has no biological markers which make it extremely difficult for parents to accept the child's condition. Autism always is characterized by problems of social interaction, such as forming attachments and showing affection, this is why it

has been considered as one of the most complex developmental disorders. Being ambiguous, the diagnosis of and prognosis for autism is fraught with uncertainty that often placed lifelong burden on parents and siblings of children with ASD, which also present parents with ongoing grief and likely decreases optimism about their own future, as well as the future of their affected child.

■ Parenting style

Parenting children with autism can be highly stressful [21, 22]. Parenting is a complex activity whereas parenting style normal variations in parenting that revolves around issues of control [23]. In his study In of the research Noh and his colleagues [24] have reported that parenting is affected by the child's inability to adjust to changes in the social environment, child's behavior problems such as seeking attention, disobeying, acceptability and demandingness. The parents of these children are usually the prime care giver, and their level of interaction and the ability for them to cope with problems seen in these children is an important area of concern.

■ Parental reactions: "Why me?"

The Indian society views disability as a 'tragedy worse than death', it is not surprising that families may feel the desire to hide the diagnosis, or even the individual with disability, from the world in order to avoid societal censure and ridicule. Coming to terms with a diagnosis of disability in a child is never easy. Families almost always go through a process of grieving with emotions that may range from confusion, guilt, shock, frustration, anger, denial, anxiety, shame, resentment, inadequacy, depression, to the question "Why me?"

The diagnosis is one of autism the situation is even more complex in comparison to other disabilities, a child with autism might be physically normal and healthy at birth, and for the initial years parents may imagine they have a regular child. Some parents experience confusion and helplessness if their child is non-responsive or aloof, or if as often happens their child experiences a regression following a period of apparently typical development. Having received a diagnosis of autism, parents generally do not know what to do next in order to help their child. In some cases, they are overwhelmed by the prospect of a diagnosis with no referrals or recommendations whatsoever. In other

cases, they become frustrated when they seek out educational or social support and schools or professionals who can guide them with their child and find very little that is specific to autism, or are referred to agencies that have no space available for their children. Attempts to integrate their children in the broader society on their own can be taxing for parents.

Since many children with autism look 'normal', people unfamiliar with the disorder often mistake their tantrums and social inappropriateness as evidence of spoiling, or parents are viewed as uncaring and unable to handle their child. Due to the explosion of knowledge through the internet, parents come to learn the crucial importance of immediate intervention in long term prognosis of children with autism. Knowing this and yet not having the tools is extremely frustrating, and can increase a parent's sense of helplessness. Many enterprising parents are also able to access information, accept the limitations of the Indian situation, and do what they can to adapt different approaches to their own situation.

Parents of children with autism in India face a myriad of challenges, both as a result of the inherent hurdles of having a child with a disability and the impact of a society often impedes rather than promotes the integration and acceptance of children with disabilities into its midst. Recent studies have consistently reported that families with a child with disabilities can and in fact do have positive perceptions which lead to better quality of life for the family, and scope for maximizing the child's potential. Though precipitated by a specific event, formation of positive perceptions is usually a process, which can occur simultaneously or a long-time after the event [25]. In India, as in many countries, parents have led the movement for people with autism, and through their strength and determination, the prospects for children with autism are continually improving.

■ Stress undergone by parents of children with ASD

When a child is diagnosed as disabled, there is a change in the way society deals with that child, both formally through special institutions and informally in the way members of a society react to disabled children. Indeed, becoming a parent of any child calls for a role change that subjects new parents to many unique stresses that may constitute a crisis. The birth of an exceptional child adds a situational crisis, one that results from an unanticipated, traumatic event beyond

parents' control. When parents become aware of their child's exceptionality; they are inevitably shocked and painfully surprised. They must suddenly adjust to a new role as the parents of an exceptional child, and they must adjust their self-image to cope with new responsibilities and functions [26].

Additionally, higher levels of stress were reported when mothers of children with autism felt less control over their situation, with perception of parenting mediating that relationship [27]. Higher levels of stress were reported when mothers of children with autism felt less control over their situation, with perception of parenting mediating that relationship [28]. These studies revealed that the presence of a child with a disability or illness is stressful for parents especially mothers, but very few studies have explored the relationship between stress and the way mothers' of children with autism cope with the fact of disability in their child. Satisfactory accurate data about the specific prevalence or even the criteria used to diagnose autism spectrum disorder in India is currently unavailable. Thus its summarizes the literature on the "lived experience" of parents of children with ASD and places these experiences in relation to models describing interactions between parenting stress, parenting behaviors, child behaviors and parenting style. Although research till this date has revealed that some parental factors, such as parental stress might be associated with the functional improvement of children with ASD, few studies have systemically described approaches to parenting and parental perceptions of what in their parenting practice helps their children.

To fill this gap in the literature, this study aims to focus on the type of Parenting style or technique used by the parents who are undergoing different level of stress in dealing with their Autistic Children. The main aim of this study is to help to reduce the behavioural problems that are undergone by the Autistic children through parents.

Objectives

1. To find out the Level of ASD in children with ASD.
2. To assess the level of stress undergone by parents with children with ASD.
3. To find out the Parenting style of the parents with children with ASD.

Research Methodology

■ Area of the study

The study was conducted in two major cities (Delhi and Dehradun) of Northern India. These two cities were identified on the basis of their services through Autistic schools and organization. A total no. of 10 Autistic schools and organization were purposely selected for the study.

■ Sample

320 parents with children with Autism Spectrum Disorder were purposely selected from 10 different Autistic schools and organization of Delhi and Dehradun city of Northern India for the purpose of the study. The sample was identified through Organizations which had children who were diagnosed with Autism Spectrum Disorder (age range of 5-22 years) and were undergoing therapy and treatment in these Organizations. Parents of the above children were requested to participate in the study. Purposive Sampling method was used for sample selection.

■ Sample stratification

10 organizations from two major cities Delhi and Dehradun of Northern India were randomly selected for the purpose of the study. Out of which 5 Autistic schools and organization were of Delhi and 5 Autistic schools and organization were of Dehradun city of India were randomly identified for the purpose of the study. All the parents who were willing and whose children were diagnosed with Autism Spectrum Disorder by the Organizations were taken into consideration.

■ Sampling procedure

The Organizations which were curtailing to the needs of Autism Spectrum Disorder were first listed and then randomly approached for administration of the test. The parents, who had children suffering from Autism spectrum Disorder, were then selected within the organizations were asked to participate. Once participants read and agreed to the consent form they answered the demographic data and the three different questionnaires, out of which few were administered directly by the researcher and the rest was administered online through a web link, which was given to the parents who were not able to reach the organizations. The three questionnaires which were administered were the following:

1. Parenting Style Dimension Questionnaire (PSDQ) [28].

2. Parenting Stress Scale [29].

■ Statistical plan

Quantitative method was used for the statistical analysis and interpretation of results. For the computation of data Frequency, Percentage mean, SD and Independent sample T-test of analysis of variance was applied using SPSS (Statistical Packages of Social Sciences).

Result and Discussion

■ Demographic profile of the respondents

The findings of (Table 1), shows that out of 320 parents, 75% of the parents were mothers of autistic children (N=240) and 25 % of the respondents were fathers of autistic children (N=80). Research tells us that parents of disabled children are particularly vulnerable to stress. High levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children [30]. In their article Gupta and Singhal [25], report studies recognising families that have been successful in developing positive perceptions regarding raising a child with disability. It has been reported that families with a child with disability can and in fact do have positive perceptions which leads to a better quality of life for the family, and scope for maximising the child's potential.

The findings of (Table 2), shows the age range of the children suffering from Autistic Spectrum disorder was between 5-22 yrs of age. The findings of the table presents that out 320 children with ASD, most of them (65.6%), were in the pre-adolescence and 34.4% of them were adolescent. This higher prevalence could be partially attributed to better assessment procedures or better understanding of autism and pervasive developmental disorders and of the heterogeneity of behaviours of individual with autism. Additionally, many children are receiving diagnosis at earlier ages. While in the past, children typically were diagnosed around the age of 5 years when they entered school [31], there is now a great deal of knowledge about how to service preschool-age children. Consequently, children as young as 2 to 3 years, who exhibit behaviour associated with a diagnosis can qualify for early intervention services. This alarming rise in the number of children, clearly calls for additional services to meet the needs of these children and their families.

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The findings of (Table 3), shows the frequencies of the level of autism in children with autism. The findings presents that out 320 children with ASD, most of them (71.9%), were having severe form ASD and 28.1% of them were having mild/moderate form of ASD.

The findings of (Table 4), shows the frequencies of the level of stress that is undergone by the parents of the autistic children, out of 320 parents, only 3.1% parents were in normal range. The findings further revealed that most of the parents (81.3%), were having high level of Stress and 15.6% parents were in the risk range.

The findings of (Table 5), present analysis of variance on the basis of gender. The findings of the table indicate that for Permissive Parenting (one of the dimensions of parenting style), F value is 5.54, which is significant at 0.02 level, that suggests that females reported more permissive style in comparisons to males. Jarymke et al. [32] also showed that the parents of children with autism spectrum disorder (ASD) face specific challenges in parenting. In his study he compared parenting behaviours among mothers of children and adolescents with and examined associations between child behaviour problems and parenting behaviour. Results showed that mothers of children with ASD reported significantly lower scores on Rules and Discipline and higher scores on Positive Parenting, Stimulating the Development, and Adapting the Environment, which shows that the mothers of children tend use more of permissive parenting style when they are dealing with their children with Autism. In an article by Shaun [33], it was also seen that mothers of children with autism were more likely to report adjusting their environment or their communication to suit their child's needs and were more intimately involved in problem-solving for their kids.

The findings of the result also indicated for the level of stress F-value is 6.16 which is significant at .03 level, suggest that mother of children with ASD reported more stress in comparison to their fathers. According to Gray [34] mothers were much more likely to claim that their child's autism had severely affected their emotional well-being. Gray [35] also found mothers to be more stigmatised by their child's disorder.

The findings of (Table 6), present analysis of variance on the basis of Level of Autism and parenting Style. The findings of the table indicates that for Authoritarian Parenting (one of the dimensions of parenting style), F value is

Table 1. Gender profile of the parents of children with ASD.

	Parents	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Father	80	25.0	25.0	25.0
	Mother	240	75.0	75.0	100.0
	Total	320	100.0	100.0	

Table 2. Age of the children with ASD.

	Category of Autism Spectrum Disorder	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Pre-adolescence(Below-11 yrs)	210	65.6	65.6	65.6
	Adolescence (11 yrs and above)	110	34.4	34.4	100.0
	Total	320	100.0	100.0	

Table 3. Level of autism in children with ASD.

	Level of Autism	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Mild/Moderate	90	28.1	28.1	28.1
	Severe	230	71.9	71.9	100.0
	Total	320	100.0	100.0	

Table 4. Level of stress undergone by parents of children with ASD.

	Level of Stress	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	59-94 (Risk Range)	60	18.8	18.8	18.8
	Above 94 (Clinical Range)	260	81.3	81.3	100.0
	Total	320	100.0	100.0	

Table 5. ANOVA on the basis of gender of parents and their parenting style.

Variables	Gender				F-Ratio	Level of significance
	Male		Female			
	Mean	S.D	Mean	S.D		
Authoritative	55.13	6.43	54.49	7.20	0.014	0.905
Authoritarian	23.01	6.32	25.92	8.70	1.738	0.197
Permissive	11.07	1.66	12.40	4.09	5.54	0.025*
Level of Stress	10.75	.463	13.83	0.380	6.16	0.034*

P<0.05*, 0.01**, 0.001***

26.87, which is significant at .045 level , that suggests that for children with severe ASD (Autism Spectrum Disorder) reported more of Authoritarian type of parenting style in comparison to children with mild/moderate form of Autism Spectrum Disorder. Hadi et al. [36] showed that when authoritarian and authoritative parenting styles were used by the parents with children with ASD, it led to a decrease in behavioural problems and an increase in pro-social behaviours. The concerns of parents of children with autism may increase with the severity of the impairments [37]. Parents in this study too have high level stress due to which parents of children with autism might be more susceptible to display authoritarian parenting styles instead of an authoritative style that is

Table 6. ANOVA on the basis of level of autism and parenting style.

Variables	Level of Autism				F-Ratio	Level of significance
	Mild/Moderate		Severe			
	Mean	S.D	Mean	S.D		
Authoritative	53.11	7.93	55.25	6.57	0.265	0.611
Authoritarian	20.89	5.77	26.87	8.45	4.33	0.045*
Permissive	10.22	2.87	12.79	3.73	0.923	0.344
Level of Stress	11.77	0.440	12.83	0.387	3.50	0.054*

P<0.05*, 0.01**, 0.001 ***

Table 7. ANOVA on the basis of age of the children and parenting style.

Variables	Age of the Child				F	Level of significance
	Pre-Adolescence		Adolescence			
	Mean	Standard Deviation	Mean	Standard Deviation		
Authoritative	54.47	6.67	54.97	7.68	0.261	0.613
Authoritarian	25.36	8.38	24.87	8.14	0.006	0.940
Permissive	12.46	4.17	11.31	2.36	3.92	0.053*
Level of Stress	1.71	0.46	2.00	0.000	45.83	0.000***

P<0.05*, 0.01**, 0.001***

characterized by high demandingness and high responsiveness [23]. These studies show that authoritarian parenting style is used when stress is high due to the severity of the child with autism.

The findings of the result also indicated that for the level of stress and level of autism, the F value (3.50) is significant at 0.05 level, which suggest and level of ASD severity was found significantly related with level of stress as shown in the above table that parents whose children were having severe level of ASD reported more stress in comparison to the parents whose children were having low/moderate level of ASD. It is true, that the more severe the child’s symptoms, the greater will be the degree of parental stress [18]. Furthermore, the more the negative characteristics a child has, the more socially isolated the family will be [38], and more the feelings of stigmatisation that they will experience.

The findings of (Table 7), present analysis of variance on the basis of the age of the children with Autism spectrum Disorder. The findings of the table indicates that for stress level of parents , the F value is 45.83, which is significant at .000 level , that suggests that for parents the level of stress was higher when dealing with Adolescence children as in comparison with pre- adolescence children. Bristol and Schopler [39] also found that family impacts increase in severity as the child reaches adolescence, primarily attributable

to the realization of the permanency of the child’s handicaps and the emergence of deep worries about the child’s future and the services that will be needed. Parental stress during adolescence is a persistent theme in clinical and empirical reports [21]. Parents of children with autism experience elevated levels of distress. Their parenting stresses appear to increase and intensify after the child reaches adolescence.

Findings of this table also suggested that for permissive parenting (one of the dimension of parenting style), F value is 3.91, which is significant at 0.05 level, that suggests that Permissive style of parenting was adopted when dealing with Pre-Adolescence children (Below-11 years).

Findings of this table further suggested that for the level of stress the F- value 45.83, significant at .001 level, which indicates that parents whose children with ASD were in adolescent group reported high level of stress than the parents whose children with ASD were in pre-adolescence age group. It is also found that children as young as 2 to 3 years, who exhibit behaviour associated with a diagnosis can qualify for early intervention services, while in the past, children typically were diagnosed around the age of 5 years when they entered school [31], there is now a great deal of knowledge about how to service preschool-age children. Epidemiological reports also suggest that the number of children who are receiving diagnosis of autism and ASD is rising [40].

■ Major findings

- Most of the parents with children with Autism spectrum disorder (81%) were in the clinical range of stress, which is alarming and that more counselling needs to be given to these parents.
- Level of severity was found significantly related with level of stress which suggests that parents whose children were having severe ASD reported more stress in comparison to the parents whose children were having low/moderate level of ASD (F value 3.50, significant at 0.05 levels).
- Most of the mothers of children with Autism Spectrum Disorder reported Permissive Parenting (one of the dimensions of parenting style), in comparison to the father’s (F=5.54, Significant at 0.002 level).
- Most the parents reported Authoritarian Parenting Style (one of the dimensions of

parenting style) when dealing with children with severe form of ASD ($F=26.87$, which is significant at 0.04 level).

- Most of the parents showed high level of stress, when dealing with Adolescent children in comparison to Pre- Adolescent children ($F=45.83$, which is significant at 0.000 level).
- Most of the parents used Permissive parenting style (one of the dimension of parenting style), when dealing with Pre-adolescent children, ($F=3.91$, which is almost significant at 0.05 level)

Conclusion

Autism is a disorder affecting cognitive and social skills that has severe implications on the ability of the affected individual to lead a productive and independent life. The alarming increase in the incidence of ASD in the last decade suggests that, while genetic factors are contributory, environmental triggers must also play a decisive role. It can be concluded from this study that permissive style of parenting is used more in pre-adolescent children and that mothers tend to use more of this form of parenting than fathers. The authoritarian form of parenting was adopted by the parents when the children had severe form of Autism. It also can be concluded that the level of stress was higher when the parents were interacting with adolescents. Thus the current study will help future researchers to recognize and understand the problems, the parenting style and the level of stress that parent's undergone while interacting with Autistic Children. Children with Autistic Spectrum Disorder (ASD), face with a variety of behavioural problems (For Ex: Temper tantrums), under which different parents tend to perceive and react in different ways, of which one of the reason being stress. Parenting style may also vary in different families, due to which certain negative behaviours may also be induced unknowingly, which may become rigid with time, if it is not recognized and proper interventions are not provided for the change in parent's behaviour.

Currently, the needs of children with autism in India are not being met in either the regular or special education systems. Children with autism are frequently refused admission in these special schools because officials protest that they are not equipped to handle these children. With a significant part of the population lying below the poverty line, the focus for the families is

understandably on meeting the needs for daily sustenance. With low awareness levels and high levels of stigmatisation, there is an increased need for public education programmes.

Even within this framework, most of the work being done in autism focuses on the child and facilitates the improvement in the child. However, not much is done in the Indian context focusing on a parent's difficulties and struggles and how a parent can cope with them most effectively. Even less is known about the levels of parental involvement in the whole process. An individual with autism and their families need positive support from the system and need to know that they are respected as individuals and as human beings.

Hence this study will also will provide suggestions for proper care and the most effective parenting style that should be adopted by them and also to provide appropriate coping strategies recognize to parents, especially mothers to combat their high level of stress. This study helps the parents to have a better understanding of the effective form of parenting, the effect of stress when dealing with children with Autism Spectrum Disorder.

Recommendations

In a country like India, where the awareness about autism is still emerging, and the availability of services is in rather short supply, there is a great need to develop effective service providers, willing to deal with the individual, the family and society in general and as a whole. A variety of research has shown that the most effective form of parenting when dealing with ASD is Authoritative parenting, and the study shows that mothers tend use more of permissive form of parenting which may have an adverse effect on the behavioural problems of children with ASD.

Hence proper training and intervention can be provided to parents to use more effective form of parenting when interacting with children with ASD. Most of the parents have high level of stress, especially mothers, hence they need to have proper counselling so that they can overcome the stress that they are undergoing and learn proper coping strategies.

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