

IMPACT OF AUTISM AND BEHAVIORAL PROBLEM ON PARENTING STRESS OF CHILDREN WITH AUTISM

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Abstract

Autism is a lifelong disorder which affects the social and communication behavioral pattern of children. Parents of children with autism are at higher level of distress. The present study objective investigates the impact of autism and behaviour problems on the parenting stress of mothers and fathers having a child with autism. Participants consists of 160 parents (mothers N=100 and fathers N=60) having a child with autism. Parents whose at least one child diagnosed with autism was considered for the study. Evidence of the study showed higher level of stress among mothers than that of fathers having a child with autism due to daily care during the care-giving responsibilities. Mothers and Fathers with children diagnosed with autism seemed to display a higher stress, probably for the combination of environmental factors and child's behavioral problem. These findings must be taken into version in policy making to endow with improved and more explicit supports and interventions for this group of disorder.

Keywords:Autism;Behavioral Problem;Emotional Problem;Impact of Autism;Parenting Stress.

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1. Introduction

Autism is a multifaceted set of behavioural problems categorized by the impairments of social interaction and communication conveyed by the repetitive behaviour. According to statistical report by Centres of Disease Control and Prevention, United States have around 1 in every 68 children suffers from autism(1). In India close to 15 million people suffer from autism at present. The exact causes are still being researched upon; however, the condition is seen as a heritable one having associations with genetic mutations as well as environmental factors. A few studies suggest that lack of oxygen supply to the foetus's developing brain may also trigger the condition. Children diagnosed with autism communicate verbally, non-verbally or a combination of both. Autism is associated with the brain's development and other functions around it. It affects the processing of information, development of skills and regulation of bodily actions and senses. Some of the latest studies suggest a sharp rise in global incidents of autism. Table 1 illustrates, DSM-5 categorized Autism as a pervasive developmental disorder. An individual diagnosed with autism may communicate verbally or nonverbally, they may follow(2):

Table 1. DSM-5 Autism Spectrum Disorder

A. PERSISTENT DEFICITS IN SOCIAL COMMUNICATION AND SOCIAL INTERACTION ACROSS CONTEXTS, NOT ACCOUNTED FOR BY GENERAL DEVELOPMENTAL DELAYS, AND MANIFEST BY 3 OF 3 SYMPTOMS:

A1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction.

- ✓ Abnormal social approach
- ✓ Failure of normal back and forth conversation
- ✓ Reduced sharing of interests; Reduced sharing of emotions/affect
- ✓ Lack of initiation of social interaction; Poor social imitation

A2. Deficits in nonverbal communicative behaviours used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures

✓ *Impairments in social use of eye contact; Impairment in the use and understanding of body postures; Impairment in the use and understanding of gestures*

✓ *Abnormal volume, pitch, intonation, rate, rhythm, stress, prosody or volume in speech; Abnormalities in use and understanding of affect*

✓ *Impairment in the use of facial expressions (may be limited or exaggerated)*

✓ *Lack of coordinated verbal and nonverbal communication; Lack of coordinated non-verbal communication*

A3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behaviour to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

✓ *Deficits in developing and maintaining relationships, appropriate to developmental level*

✓ *Difficulties adjusting behaviour to suit social contexts*

✓ *Difficulties in sharing imaginative play*

✓ *Difficulties in making friends*

✓ *Absence of interest in others*

B. RESTRICTED, REPETITIVE PATTERNS OF BEHAVIOR, INTERESTS, OR ACTIVITIES AS MANIFESTED BY AT LEAST 2 OF 4 SYMPTOMS:

B1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).

✓ *Stereotyped or repetitive speech*

✓ *Stereotyped or repetitive motor movements*

✓ *Stereotyped or repetitive use of objects*

B2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behaviour, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).

✓ *Adherence to routine*

✓ *Ritualized Patterns of Verbal and Nonverbal behaviour*

✓ *Excessive resistance to change*

✓ *Rigid thinking*

B3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

B4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

✓ High tolerance for pain

✓ Unusual visual exploration / activity

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

The autism spectrum ranges from low to high with some symptoms being more extreme than others and because of the wide range of manifestations, this disorder varies greatly. Autism Spectrum Disorder is typically diagnosed in children by the age of three where difficulties are recognized in the area of social interaction, language for communication and/or restricted, repetitive and stereotyped pattern of behavior (3). Several studies demonstrate a relationship between characteristic behaviours associated with autism and increased parental stress. Aggressive behaviors and public misconduct are especially distressing for mothers and fathers, who closely associate their parenting skills and self-worth with the behaviour of the child (4-5). These behaviours are frequently unpredictable and lead to feelings of inadequacy, disappointment, anger or embarrassment for parents. The behaviour of the child with autism affects parents on a shared and individual level. This often leads to increased stress anxiety, or depression along with feeling of isolation (6-7).

An autism diagnosis can be perceived as a loss for the family; this in turn produces feelings of grief, stress and confusion. The initial autism diagnosis leaves parents confused and they may have a hard time accepting that the child they were anticipating is not the child they expected. This new transformation in their family impacts the relationships in the family, as feelings of fear and worry encompass the family system. Daily routines become much more complicated, family vacations become much harder to plan, and families find themselves no longer able to do some

of the things they were once able to do. Parents often experience stressful situations upon the initial diagnosis that relate to their child's behaviour, adapting to this new lifestyle and the complexity of finding access to the appropriate service useful to the family (8). Mothers and fathers reported more stress when having a child diagnosed with autism as opposed to parents who have children with Down Syndrome and parents of typically developing children (9). With the causes of autism still unknown, parents experience blame for their child's autism. Some fathers may blame the autism on their wives (10).

One of the main stressor for a parent is their child's inability to express their basic needs, community may not understand or be sensitive to the behaviour of the child, needs several services to assist in their care. This produces frustration for both the parent and the child. Extreme worry may also be present in parents as their child may be unable to report abuse or neglect in other settings. Parents experience worry and concern that their child be potentially harmed because often, they cannot communicate verbally and are highly vulnerable

(11). The influence of child's diagnosis, adaptive functioning and problem behaviour on parenting stress and psychological distress (anxiety/depression) (12). Some of this stress is likely related to the hallmark characteristics of autism, such as deficits in language, communication or social skills (13) and odd, repetitive or stereotypical behaviours. Other symptoms which are associated with autism include social relatedness deficits, emotional functioning or self-regulation.

Autism has been one of the disorders which are causing impairment in social behaviour in the child; the parents of these children have not remained unaffected. They suffer from day-to-day hardships sequentially to meet up the needs of their child. There has been critical gap in the scientific and public health literature in understanding the ways in which family of children with autism are affected by and manage the challenges of lifelong parenting. The present study investigates the impact of autism on the families of autistic children; to study the behavioural problems of children diagnosed with autism; to study the stress among parents with autistic children in the family.

2. Research Method

The researcher identified 120 mothers and 90 fathers of children diagnosed with autism. The study was performed in all the four zones of New Delhi on parents having a child with autism. The list of organisation working with children with autism and their parents were selected from the internet database. Parents of children with autism attaining special education from the organisation were selected as the subjects. Parents were contacted at the time of Parent Teacher Meetings. Out of these 120 mothers and 90 fathers who were asked to fill the form, only 100 mothers and 60 fathers returned completely filled forms. Hence, final sample size comprised of 100 mothers and 60 fathers. 100 children of these parents were also considered for the study.

2.1 Sampling

The investigation of the sample selection was done purposively to the parents/legal guardians of children with autism within the age group of 3-16 years.

2.2 Measures

The Impact Stress Index (Stein & Jossep, 2003; Stein & Riessman, 1980) is a 15-item scale reflecting economic burden, social and familial impact and subjective distress and contribute to a single factor reflecting perceived burden (14-15). *Behavioural Problem Emotional Problem* was assessed by Indian Scale for Assessment of Autism (ISAA) developed by the National Institute of Mentally Handicapped (NIMH) consists of 40 items rated on a 5-point scale ranging from 1 (never) to 5 (always). The 40 items of ISAA are divided under six domains: Social Relationship and Reciprocity; Emotional Responsiveness; Language and Communication; Behaviour Pattern; Sensory Aspects and Cognitive Impairment (16).

Parental Stress was assessed with Parental Stress Index (Abidin 1980) designed to potentially dysfunctional parent-child system. The index contains 120 items distributed among three subscales: Child Domain (distractibility, reinforce parents, mood, acceptability, adaptability and demandingness); Parent Domain (competence, attachment, role restrict, relation spouse, isolation and depression) and Life Stress covering family contextual issues as parental separation, loss of income and problem at work (17).

3. Result and Analysis

3.1 Socio-demographic Characteristics and Child's Autism

In the preliminary analyses of the study socio-demographic profile of parents of children with autism were studied. The data collected regarding the characteristics represented that 80 per cent were boys and 20 per cent were girls diagnosed with autism. The average age of boys was 6.91 (SD=3.72). The average age of girls was 5.85 (SD=2.7). The maximum number of fathers were within the age group of 35-45 years. The average age of fathers was 36.91 years (SD=4.96). The maximum number of mothers were within the age group of 25-35 years. The average age of mothers was 34.25 (SD=5.08). Chi-Square analyses in (Table 2) indicated that there was no significant association between the socio-demographic profile and child's autism.

Table 2. Association between Socio-demographic of Parents and Child's Autism

Socio-demographic Profile and Child's Autism	Chi-Square	p-value
Father's Age and Child's Autism	4.33	0.36 ^{NS}
Mother's Age and Child's Autism	1.07	0.89 ^{NS}
Father's Education and Child's Autism	12.75	0.23 ^{NS}
Mother's Education and Child's Autism	5.15	0.52 ^{NS}

NS=Non-Significant

3.2 Behavioral Problem in Children with Autism

As for the severity levels of autistic behavior problems, 52.5% (n=42) boys, 60% (n=12) girl and 42.5% (n=34), 40% (n=8) presented mild to moderate autistic behavior, and 5% (n=4) boys presented severe autistic behavior problems. A sample of 60 Arab children were studied, result revealed that 32 boys were diagnosed with autism in contrast to 21 girls (18). Comparison of the mean scores among subscale assessing difficulties in the ISAA revealed higher mean scores of boys in the domains of social relationship, emotional responsiveness, behavior pattern (Table 3).

Table 3. Mean, Standard Deviation and value of 't' of Subscale data of degree of Autism

Domain/Subscale	Girls Mean±SD	Boys Mean±SD	t-value	p-value
Social Relationship	2.86±1.27	3.07±1.18	1.98	0.04*
Emotional Responsiveness	2.45±1.29	2.67±1.21	0.93	0.17 ^{NS}
Speech-Language and Communication	2.53±1.32	3.30±1.49	2.97	0.01**
Behavior Pattern	2.36±1.13	2.55±1.27	1.18	0.12 ^{NS}
Sensory Aspect	2.30±1.45	2.48±1.35	0.64	0.52 ^{NS}
Cognitive Component	2.37±1.30	2.31±1.22	0.59	0.55 ^{NS}
Overall Score	16.73±8.12	18.80±9.92	2.12	0.03*

* $p < 0.05$, ** $p < 0.01$, NS=Non Significant

In an epidemiological study the data revealed the prevalence was as many as 15 times in males than that of females suggesting that females are less likely to develop autism than that of the males (19). In an another study opposing the findings showed that the females not the males showed significantly more extra problems (low intellectual level, behavior problems). The data recommended that in the absence of extra intellectual or behavioral problems, girls are less likely than boys to meet diagnostic criteria at equally high levels of autistic traits (20).

3.3 Impact of Autism on Parents

There are always unanticipated effects when a new child arrives into the family but none with such an exceptional impact as the birth of a child with disabilities. When a number of a family is diagnosed with a serious disability like autism, there are many changes that happen within the family. Table 4 illustrates the level of impact of child's autism on mothers and fathers.

The result presented in the table shows that mothers 87% (n=100) and fathers 80% (n=60) assessed with moderate level impact of autism, and mothers 8% (n=100) and fathers 13.33 (n=60) were severely impacted of child's autism (Fig 1).

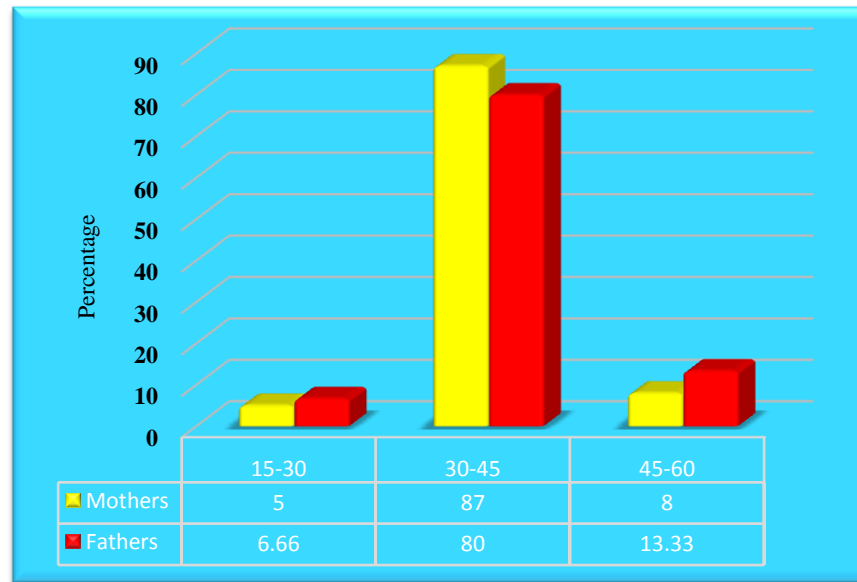


Fig 1 Percentage Distribution of Mothers and Fathers on Impact Level

Families raising a child with a disability face challenge that put demands on their resources and change their execution as a family unit. This can hinder with customary routines, such as shopping or holidays; child needs extra attention from the parents. Mothers and fathers have responded differently to how they have been impacted by the child's diagnosis with autism. Table 4 illustrates the correlation between the child's autism and impact level.

Table 4. Correlation between the Child's Autism and Impact Level

	'r' value	p value
Autism & Impact on Mothers	.48	0.00**
Autism & Impact on Fathers	.28	.03*

* $p < 0.05$, ** $p < 0.01$

The result of Table 4 indicates that there has been moderately positive correlation between the autism and its impact on mothers but weak correlation on fathers. This implies that mothers

are impacted more than fathers having a child with autism. Many family members have reported feelings of loneliness, social isolation or distance from friends and neighbours, relatives and their communities. Another reason for the disruption of social relations may be seen in the friends, neighbours' and relatives' feelings of discomfort and lack of knowledge about appropriate ways to interact with the child with autism (21).

3.4 Parenting Stress of Children with Autism

Parenting a child with autism always tend to pose additional stress on mothers and fathers. Problematic behavior, hyperactivity, destructiveness, thinking about child's future, social isolation, lack of community understanding etc are certain attributes which contributes to parental stress. There have been numerous other factors too contributing to stress as challenges in communication and learning due to issues related to emotional expression and language impairment. The parental stress of mothers and fathers of autistic children in Table 5 illustrates that mothers 48% (n=100) and fathers 50% (n=60) were within normal range of stress. Equal percentage of mothers and fathers has been indexed with clinically significant stress level considering them for the referral and/or professional services. Mothers experience more stress than fathers requiring special attention from mental health professionals (22).

Table 5 Frequency and Percentage Distribution of Mothers and Fathers on Stress Index

Percentile Range	Category	Mothers (N ₁ =100)	Fathers (N ₂ =60)
16-80	Normal Range	48 (48)	30 (50)
80-84	Borderline Stress	29 (29)	16 (26.66)
84-99+	Clinically Significant	23 (23)	14 (23.33)

Correlation was computed to assess the relationship between child's autism and stress among mothers and fathers. Table 6 shows that in mothers on child domain (distractibility, mood, acceptability, adaptability and demandingness) and on parent domain (competence, attachment, depression and relation spouse) found to be significant. In fathers, on parent domain (competence,

attachement and relation spouse) and on child domain (distractibility, acceptability, adaptability and demandingness) were found to be significant.

Table 6 Correlation Exhibiting Relationship between Child's Autism and Parental Stress

Domain	Mothers (N ₁ =100)		Fathers (N ₂ =60)	
	r value	p value	r value	p value
A. Child Domain	0.31	0.01**	0.33	0.01**
Distractibility	0.29	0.00**	0.29	0.02*
Reinforce Parents	0.14	0.16 ^{NS}	0.08	0.54 ^{NS}
Mood	0.43	0.00**	0.14	0.28 ^{NS}
Acceptability	0.26	0.00**	0.26	0.04*
Adaptability	0.19	0.05*	0.25	0.05*
Demandingness	0.19	0.04*	0.29	0.02*
B. Parents Domain	0.25	0.01**	0.32	0.01**
Competence	0.24	0.01**	0.36	0.00**
Attachment	0.35	0.00**	0.26	0.04*
Role Restrict	0.17	0.07 ^{NS}	-0.01	0.93 ^{NS}
Depression	0.36	0.00**	0.172	0.188 ^{NS}
Relation Spouse	0.45	0.00**	0.26	0.04*
Isolation	0.03	0.70 ^{NS}	-0.039	0.76 ^{NS}
Parents Health	0.07	0.45 ^{NS}	-0.032	0.80 ^{NS}
C. Life Stress	-0.08	0.42 ^{NS}	0.049	0.71 ^{NS}
Total Raw Score	0.62	0.00**	0.40	0.00**

* $p < 0.05$, $p < 0.01$, NS=Non-Significant

The total raw score was found to be significant among fathers and mothers. Complicated parents experienced in finishing specific care-giving tasks, behavior problems during the care-giving errands and level of child disorder respectively were considerable predictors of level of parents' stress. There is no uncertainty that bringing up a child with autism may also be significant challenge to fathers. However, the knowledge of how parents experience problems related with the child's developmental deficits is still limited (23).

In order to investigate if there exists significant difference between mothers and fathers on domain of parenting stress, student 't' test was calculated.

Table 7. Mean, Standard Deviation and 't' values on the domains of Parenting Stress

Sub-Domain	Mothers (N ₁ =100)	Fathers (N ₂ =60)	p value
Child Domain	130±19.24	129.88±15.60	0.96 ^{NS}
Distractibility	30.65±3.93	28.56±5.17	0.00**
Reinforce Parents	15.61±3.61	12.29±2.94	0.00**
Mood	20.44±3.94	11.98±2.67	0.00**
Acceptability	30.76±5.69	20.66±4.83	0.00**
Adaptability	40.10±8.16	30.98±6.29	0.00**
Demandingness	22.04±4.66	22.73±5.16	0.38 ^{NS}
Parents Domain	157.76±12.77	156.85±13.95	0.67 ^{NS}
Competence	40.97±7.02	39.28±9.30	0.19 ^{NS}
Attachment	20.8±3.32	20.7±3.51	0.85 ^{NS}
Role Restrict	21.26±4.18	20.93±4.89	0.00**
Depression	27.03±3.48	25.93±3.44	0.05*
Relation Spouse	19.53±4.23	19.56±4.36	0.96 ^{NS}
Isolation	18.16±3.13	17.13±3.32	0.05*
Parents Health	13.01±2.54	11.91±2.18	0.00**
Life Stress	15.33±10.17	15.23±9.98	0.95 ^{NS}
Overall Raw Score	302.43±21.33	287±17.54	0.00**

** $p < 0.001$, * $p < 0.05$, NS=Non-significant

Table 7 illustrates that $p < 0.01$ on child domains (distractibility, reinforce parents, mood, acceptability and adaptability) as well as on parent domain (rolerestrict and parents' health). $p < 0.05$ on parent domain (depression and socialisolation).

On comparing mean score on child domain, it can be observed that mothers have obtained higher score on distractibility ($M=30.65$, $SD=3.93$); reinforce parents($M=15.61$, $SD=3.61$); mood ($M=20.44$, $SD=3.94$); acceptability ($M=30.76$, $SD=5.69$)and adaptability ($M=40.10$, $SD=8.16$) than fathers. Hence, it can be concluded thatthere is a significant difference between mothers and fathers stress. This implies thatmothers experience more parenting stress as compared to fathers.Mothers are more stressed out whose children display several behaviour associated with attention deficit/ hyperactivity disorder because when confrontingtheir children, they experience low energy level. It makes parenting task more difficultby virtue of child's inability to adjust to the changes in his/her physical and socialenvironment.

Overall mean score comparison shows that mothers ($M=302.43$, $SD=21.33$) is higher than the mean scoreof father ($M=287$, $SD=17.5$). Since, the overall mean scores is greater among mothersthan of fathers.This implies that mothers experience more parenting stress as compared to fathers. In parent domain, mothers experienced significant stress in terms of both theparenting role and their own psychic pain relating to issues of rejection and neglect.They find it complicated to organise the psychic and physical energy needed to fulfil parenting responsibility.

4. Conclusion

The impact of autism is more profound in mothers than in fathers. Parental stress is higher in mothers than fathers of children with autism. Their life'shope and dreams get affected. Mental Health Professionals and institutions should provide mutual help which involves the use of educational workshops, social support with orwithout professional help.Empowerment programs such as coping skills training, stress management,optimistic thoughts and self-help support groups should be arranged in orderto release parents' stress.Conduct workshops or seminars for children with autism and their parents and siblings collectively in order to provide them with equipped knowledge aboutthe steps can be taken into consideration while performing task at home.Session can be arranged among parents who are facing same problems withtheir children

in order to gain better understanding about child's behavioral problem and what steps can be taken to cope with child's condition. Therapists should provide detailed knowledge to parents of children with autism about various measures can be taken at home environment in order to enhance the Child's behavioral and speech and language problems. Counseling sessions or talks for family members of children with autism through regular meetings is of great importance.

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