
PSYCHOLOGICAL WELL-BEING OF MOTHERS AND FATHERS OF CHILDREN DIAGNOSED WITH AUTISM

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Abstract: Autism is a complex behavioural and communication disorder. Autism can better be defined by DSM-V as Persistent deficit in social and communication and social interaction; Restrictive and repeated pattern of behaviour, interests or activities. On learning that child has been diagnosed with autism, parents (mothers and fathers) are collision the most. Autism is been associated with psychological problems of parents which affects all the phases of life. The present study examined the degree of autism and its effects on contextual variables on parents (mothers and fathers) of children diagnosed with autism. The study assessed the impact of autism, behavioural problems, parenting stress and coping strategies adopted by parents. The data was collected on 160 parents (N₁=100 mothers and N₂= 60 fathers) at least having one child diagnosed with autism. The results revealed that there is correlation between autism and behaviour problems, impact on parents parenting stress. The results revealed that mothers have been affected than fathers. 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, Psychological Well-being, Parenting Stress, Autism Impact, Coping Strategies.

Introduction: Autism is a multifaceted neurological disorder that affects brain functionality and majorly evident within first three of life. According to Centre of Disease Control (CDC, 2012) reports, 1 in 88 children diagnosed with autism: 1 in 54 boys and 1 in 252 girls (UNLV Centre for Autism Spectrum Disorder, 2012). Some autistic child might have relatively adequate verbal skills but may have suffered from adverse language impairment or have difficulty in initiating interaction. Children with autism does not involve in make believe play, and engage in self- stimulatory behaviours (CDC 2007). Autism is typically diagnosed in childhood and might have variety of symptoms that might be severe than that of others. These symptoms might consists of communication, behavioural disorder as well as minimal social skills (Weiss & Lunsy, 2011). The Diagnostics and Statistical Manual- V (DSM-V) represents accurate and medically and scientifically useful way of diagnosing individuals with autism-related disorders. Under the DSM-5 criteria, individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later.

Certain symptomatology can source to major social or occupational impairment or other important areas of functioning. The precise cause of autism stay behind indescribable, but progressively more is to be believed that both genetic and environmental plays a pivotal role. The manifestation of autism inside a family constantly brings out a challenges. Families with children with autism face many multifaceted challenges because of the behavioural issues associated with the disorder. Having a child with autism in the family may have adverse effect on family functioning, sibling relationship and family socialization (Greeff and Walt, 2010). On learning that child is autistic can lead to scattered emotions for the mother and father, coping with child's autism is very different with each other (Banach, Iudice, Conway & Couse, 2010). Parents reported strain and their psychological health (anxiety and depression) (Hastings, 2003). Problem behavior often associated with autism include social relatedness deficit, emotional functioning (Davis & Carter, 2008) or daily living skills (Estes, et al 2009), tantrum, self-injury, aggression (Dominick, et al., 2007; Hall & Graff, 2011).

Parents of children with developmental delays are at risk for increased level of psychological problem such as anxiety, distress, guilt, less satisfaction with life, hopelessness (Johnston et al, 2001; Abbeduto, et al, 2004; Murphy, et al, 2004). Primary caregivers reported lower marital adjustment, family cohesion with children diagnosed with autism, with more difficult behaviour of children results in conflicts within the family system. Coping strategies did not seem to be correlated with marital contentment (Higgins, et al 2005). Parents who understood their lives were not inhibited by their child’s disability and cope by focussing on family assimilation, assistance (Jones & Passey, 2006). Parents sought support from friends, casual support from other families and prescribed support from agencies and programs (Tway, 2007). The importance of providing and family centered to address the unique needs of families of children with developmental delayed children (Almars, 2010).

Methodology: This research is cross sectional research study of the social experience of parents of children with autism. The investigator purposively approached parents of children diagnosed with autism within the age of 3-16 years.

Sample: The researcher selected the sample from institutions providing intervention programs for the parents and rehabilitation services for the children. Parents of this population were contacted for the research study. The psychological tools were distributed to selected parents (mothers and fathers) asked to complete test in the presence of the investigator. After completion of forms, forms were collected from the parents (mothers and fathers) respectively.

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. The maximum number of mothers were in the age group of 25-35 years and fathers were within 35-45 years. The average of children were within 3-5 years.

Findings of the Study: Autism Behaviour:

Table 1: Mean, Standard Deviation and value of “t” of Subscale data of Autism Behaviour

Domain/Subscale	Girls	Boys	t-value	p-value
	Mean±SD	Mean±SD		
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

Table 1 indicates that p<0.05 on the subscale social relationship where p<0.01 on the subscale of speech-language and communication. On comparison of the mean (M) score and standard Deviation (SD) of boys and girls having autism, it can be concluded that boys have acquired higher mean scores than girls on the subscale social relations (M=3.07, SD=1.18) and speech language and communication (M=3.30, SD=1.49). Table also depicts that the overall p<0.05. Since, the overall mean score of the subscale of degree of autism is greater in boys (M=18.80, SD=9.92) than that of the girls (M=16.73, SD=8.12) it can be concluded that boys were found to be more prone towards autism than girls. Brugha (2009) found that 1.8% of males surveyed had an ASD compared to 0.2% of females living in England. Lorna Wing, 1981

revealed that among people with autism, the prevalence was as many as 15 times in males compared to females. This suggests that, females are less likely to develop autism than that of the males.

Impact of Child's Autism on Families: 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. 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

Table 2: 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 2 indicate 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.

Parenting Stress and Autism: Parenting stress was computed of mothers and fathers of children diagnosed with autism. The result showed that the maximum number of mothers (48%) and fathers (50%) were within normal range of stress i.e. 16-80. The maximum number of mothers (29%) and fathers (26.66%) has been indexed in borderline stress which indicates that parents have been coping with stress on their own. Having a child with autism revealed that there was significant stress in parents of autistic children. Mothers expected more stress than fathers. The implication is that mothers of children with autism are prone to experience stress, thus requiring attention from mental health professionals (Sabiha and Sajid, 2005).

Table 3: Correlation Exhibiting Relationship between Child's Autism and Parental Stress

Domain of Parenting Stress Index	Mothers (N ₁ =100)	Fathers (N ₂ =60)
Child Domain Score	0.01**	0.01**
<i>Distractibility</i>	0.00**	0.02*
<i>Reinforce parents</i>	0.16 ^{NS}	0.54 ^{NS}
<i>Mood</i>	0.00**	0.28 ^{NS}
<i>Acceptability</i>	0.00**	0.04*
<i>Adaptability</i>	0.05*	0.05*
<i>Demandingness</i>	0.04*	0.02*
Parents Domain Score	0.01**	0.01**
<i>Competence</i>	0.01**	0.00**
<i>Attachment</i>	0.00**	0.04*
<i>Role Restrict</i>	0.07 ^{NS}	0.93 ^{NS}
<i>Depression</i>	0.00**	0.188 ^{NS}
<i>Relation Spouse</i>	0.00**	0.04*
<i>Isolation</i>	0.70 ^{NS}	0.76 ^{NS}
<i>Parent Health</i>	0.45 ^{NS}	0.80 ^{NS}
<i>Life Stress Score</i>	0.42 ^{NS}	0.71 ^{NS}
Total Raw Score	0.00**	0.00**

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

The result of Table 3 illustrates that on child domain $p < 0.01$ on distractibility, reinforce parents, mood, acceptability and adaptability and on parent domain $p < 0.05$ on depression and social isolation. On comparing the mean score on child domain mothers obtained higher scores on distractibility, reinforce parents, mood, acceptability and adaptability than fathers. Data analysed revealed that mothers were more stressed out whose children display several behaviors associated with attention deficits/hyperactivity disorder etc.

Table 4: Mean, Standard Deviation and 't' values on the domains of Parenting Stress

Parenting Stress Index Domains	Mothers (N ₁ =100)	Fathers (N ₂ =60)	P value
Child Domain Score	130±19.24	129.98±15.60	0.96
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}
Parent Domain Score	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}
Social Isolation	18.16±3.13	17.13±3.32	0.05*
Parent Health	13.01±2.54	11.91±2.18	0.00**
Life Stress Score	15.33±10.17	15.23±9.98	0.95 ^{NS}
Overall Score	302.43±21.33	287±17.54	0.00**

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

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 that there is a significant difference between mothers and fathers stress. This implies that mothers experience more parenting stress as compared to fathers. Mothers are more stressed out whose children display several behavior associated with attention deficit/ hyperactivity disorder because when confronting their children they experience low energy level. It makes parenting task more difficult by virtue of child's inability to adjust to the changes in his/her physical and social environment. On obtaining mean scores on parent domain, it can be observed that mothers have obtained higher score on competence (M=40.97, SD=7.02); role restrict (M=21.26, SD=4.18); depression (M=27.03, SD=3.48); social isolation (M=18.16, SD=3.13) and parent health (M=13.01, SD=2.54) than fathers. This implies that mothers experience more parenting stress as compared to fathers.

The complicatedness parents experience in finishing specific care-giving tasks, behavior problems during care-giving errands and level of child disorder respectively were considerable predictors of level of parent 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 (Plant and Sanders, 2007). Fathers noticed the child's effect on family members' opportunities to satisfy their own needs and an overall family activity (Baker-Ericzen et al. 2005).

Family Functioning of Families (Cohesion and Adaptability) of Children with Autism: The descriptive statistics of the F-COPES illustrates the mean score of the mothers was 89.89 (SD=12.76). In reviewing the results of this study, the two most frequently utilized coping strategies were seeking social support (M = 28.10) and reframing (M = 27.65). Passive Appraisal (M=14) was the least utilized. However,

if one looks at the frequencies and percentages for each individual item rather than the subscales as a whole, the most strongly agreed with item was Item 30: "Having faith in God or a higher power" (n = 84), Seeking information/advice from the family doctor (n = 100). The most disagreed was "If we wait long enough the problem will go away" (n = 32).

Table 5: Coefficient of Correlation between Stress and Ways of Coping as Experienced by Mothers

Variables	r	p
Stress and Social Support	0.186	0.36*
Stress and Reframing	0.10	0.32
Stress and Spiritual Support	-0.12	0.23
Stress and Mobilizing Family	0.06	0.55*
Stress and Passive Appraisal	-0.15	0.13

**significant at $p < 0.05$

With regard to the use of coping strategies, social support have been correlated to the stress mothers face having a child with autism. Most of these coping strategies are very direct by nature necessitating the mother to play a very active role in dealing with the stressful situation. This however might have been difficult to adopt by them owing to the non-assertive nature of Indian women. Seeking social support ($r(df=100) = 0.195, p < 0.05$); Reframing ($r(df=100) = 0.32, p < 0.05$); Spiritual Support ($r(df=100) = 0.23, p < 0.05$); Mobilizing Family ($r(df=100) = 0.55, p < 0.05$). Mothers of children with autism have been found to use this coping strategy more. To cope with the stress of having a special child, mothers of these children have more often tried to seek informational support, tangible support and emotional support than mothers of normal children. Seeking social support is positively correlated to the stress mother face having a child with autism. Mothers of children with autism have been found to use this coping strategy more frequently than mothers of normal children. Taanila, Syrjälä, Kokkonen, & Järvelin (2002), who studied the coping of parents with physically or intellectually disabled children and found that social support was one of the strategies most frequently used. The high level of social support for the mothers in this sample is a positive finding because mothers of children with autism who perceive more social support experience less somatic problems and depressive symptoms (Gill & Harris, 1991; Gray & Holden, 1992).

The findings of the study found that the stress and positive appraisal in not significantly correlated to each other. The study was limited by the fact that gender of the child was not taken into account nor were fathers and siblings included. Hence future studies should explore these factors also.

Conclusion: The results of this study indicate clearly the need for designing an intervention program for mothers of children with autism which should be implemented in special schools for these children. There is a strong need for employing a counsellor/psychologist in such schools who should work with the mothers as well as the special child and help them deal with the stressors encountered during the daily care of the child. 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's hope and dreams get affected. Mental Health Professionals and institutions should provide mutual help which involves the use of educational workshops, social support with or without professional help. Empowerment programs such as coping skills training, stress management, optimistic thoughts and self-help support groups should be arranged in order to 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 about the steps can be taken into consideration while performing task at home. Session can be arranged among parents who are facing same problems with their children in order to gain better understanding about child's behavioural 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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