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Stress and depression level of mothers of children with autism spectrum disorders

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Abstract
Mother has a universal image of motherliness. She has unconditional support, a figure of warmth, love and care for their children. The special child gets this unconditional support, love and care for his/her whole life. Besides the universal truth that mothers of children with autism are more prone to develop anxiety, depression and other psychological problems in comparison to children without autism. Hence researchers studied to find out the level of depression and stress mothers of children with autism. There were two major hypotheses was formulated i.e mothers of children with autism spectrum disorders will have significantly high levels of stress and Mothers of children with autism will have significantly high levels of depression. 68 mothers of children with autistic disorder with their level of autism ranged from mild to moderate and severe level. Hamilton rating scale for depression and Family Interview for Stress and Coping scale were used for data collection. Results were analyzed by inferential statistics and show that there was a significant presence of personal stress in mothers of children with autism. They also had altered social embarrassment and interpersonal problems. The mothers of children with autism have significant depressed mood, anxiety, somatic symptoms, as well as helplessness. Mothers of children with autism have mild depression and severe anxiety.

Keywords: Autism spectrum disorder, Depression and Special child mothers

Introduction
Autism and Pervasive Developmental Disorders are neuro developmental disorders characterized by patterns of delay and deviance in the development of social, communicative and cognitive skills. These conditions have their onset in the first 3 years of life, disrupt, developmental processes, and are often associated with mental retardation. These conditions differ from primary mental retardation and language and other specific developmental disorders in that the behavioural features and patterns of development are observed in multiple areas, are highly distinctive and are not simply a manifestation of developmental delay. (Volkmar *et al* 1997) [21].
The diagnosis of autism requires disturbances in each of three domains 1) social relatedness, 2) communication and plays and 3) restricted interests and activities. By definition, onset takes place before the age of 3 years (Volkmar *et al* 1997) [21]. Areas of social disturbances include marked impairment in nonverbal behaviours in social interaction, failure to develop peer relations as appropriate to developmental level, and lack of social or emotional reciprocity. Impairments in communication include either a delay or total lack of spoken language, or verbal communication. There is marked difficulty in the ability to sustain or initiate conversation. There is also stereotyped and repetitive language and a lack of appropriate social play. The category of restricted, repetitive and stereotyped behaviours, interests and activities include preoccupation with parts of objects.
ICD-10 criteria (World Health Organization, 1994) for Pervasive Developmental Disorders (F.84) is as follows: This group of disorders is characterized by qualitative abnormalities in reciprocal social interactions and pattern of communication, and by restricted, stereotyped, repetitive repertoire of interests and activities the conditions become manifest during the first five years of life.

Subdivision of Autism
PDDs include prototypic Childhood autism, Rett's syndrome, and Asperger's syndrome.

Childhood Autism
Childhood Autism (F.84.0) is defined by the presence of abnormal and impaired development that is manifested before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication and restricted, repetitive behaviour.

Rett's Syndrome
Rett's Syndrome (F.84.2) in most cases has an onset between 7 and 24 months of age. The most characteristic feature is a loss of purposive hand movements and acquired fine motor manipulative skills. This is accompanied by loss, partial loss or lack of development of language; distinctive stereotyped tortuous wringing or "hand-washing" movements, with the arm flexed in front of the chest or chin stereotypic wetting of the hands with

saliva; lack of proper chewing of food; often episodes of hyperventilation; almost always a failure to gain bowel and bladder control; often excessive drooling and protrusion of the tongue; and a loss of social engagement.

Asperger's Syndrome

Asperger's Syndrome (F.84.5) is a disorder of uncertain nosological validity, characterized by the same kind of qualitative abnormalities of reciprocal social interaction and typify autism, together with a restricted, stereotyped, repetitive repertoire of interest and activities. The disorder differs from autism primarily in that there is no general delay or retardation in language or cognitive development.

Mother as a facilitator in rearing Special child

Autism seriously affects multiple domains, making it a challenging disorder to understand and treat. The multiple developmental and behavioural problems associated with these conditions often require the care of multiple providers; coordination of services and advocacy for individuals and their families is important. We often hear of the mother's indispensable role in bringing up children. It is true and a mother is indispensable! She is after all the creator! The dependency of the child on the mother, and the implication of the mother in the life of the child, are expressed in artistic representations of the mother-child dyad that appear in many different cultural settings—most famously, in Western civilization. In the Indian setting, the mother has a universal image of motherliness. She is a figure of warmth, love and care. She has unconditional support for their children. The special child gets this unconditional support, love and care for his/her whole life.

The psychopathological aspect of parents' especially mothers' psychological problems

An understanding of how human beings cope with stressful situations represents an important dimension for understanding families with exceptional children. The Psychiatric Dictionary defines a defence mechanism as "how the organism protects itself against impulses and threats" (Hensie and Campbell 1970) [11]. Ross (1964) [18] explains that the use of projection by parents of exceptional children, by trusting blame for the child's condition onto sources outside the self, is a defence against unconscious guilt. The unconscious guilt may be related to realistic or less realistic factors that the parent believes are related to the child's handicap. It has been suggested that in looking for someone to blame, parents may blame each other, a grandparent, the school, or the teacher, although doctors make convenient scapegoats during the infants' years. Unconscious guilt at not spending more time with a child or not helping with academic subjects may be converted into blaming the teacher for a child's slow progress.

According to Ross (1964) [18] "Denial" is one of the more primitive defences against the threatening recognition of the discrepancy between the hoped-for healthy baby and the reality of the defective child. Parents will try to establish the myth that there is nothing wrong with the child and since this pretence serves to protect them from anxiety, they must try to maintain the myth against great odds. Parents' first exposure to rejection, is a harsh reality to confront, especially from one perceived to be intimately involved with human problems. Parents deny it not because they are mean or unfeeling, but because they have no way of dealing with the hurt and hopelessness they feel when they think of their child.

In many ways, a child represents to the parent an extension of himself… When the baby is born the mother's wish to be loved is partially transferred from her person to that of the baby. To the father, a normal child is often an affirmation, at least in part, of his sense of success. The capacity to produce unimpaired offspring is psychologically and culturally important for the parents' sense of personal adequacy.

Siman- Tov & Kaniel (2011) [20] studied that stress is defined as (perceived) threats or demands or constraints which undermine an individual's capacity to operate effectively. How parents react to their perceptions is critical, and the degree of stress experienced will depend on their appraisal of the stressful circumstance, the level of their ability to cope, and the availability of support.

Child behaviour difficulties may contribute to parental fatigue, which in turn may influence the use of ineffective coping strategies and increase stress. The significance of fatigue on maternal well-being was highlighted as an important area for consideration in families of children with ASD (Wood *et al* 2013) [22, 24].

The more immediate biological role of the mother in the birth process may endow the discrepancy between expectation and reality with greater psychological meaning for her than for her husband. Wunderlich (1977) [23] noted that the father's reactions are more reserved initially. He inclines toward such coping mechanisms as intellectualization, withdrawal, or sublimation. It is only when his ideas and plans for the future cannot be realized that his emotions will be strongly aroused.

Previous Studies related to stress and depression

Suzuki (2010) [19] investigated whether Japanese women's perceived marital social support affects their parenting self-efficacy directly or indirectly through their levels of parenting stress. Results showed that marital support, mother–in–law support, and friend support each lowered women's parenting stress, and the low stress, in turn, increased women's parenting self-efficacy; however, the indirect effects of mother-in-law support and friends' support on parenting self-efficacy only approached statistical significance. This study suggests that the criticism targeted to women from family and friends is detrimental to their psychological well-being, which in turn affects their parenting self-efficacy. Gupta and Kaur (2010) studied the stress among parents of children with intellectual disabilities. The result shows that most parents of children with intellectual did is abilities experience

stress, physical and mental stress are significantly correlated, gender differences in stress experienced occur only in the mental area, and parents have higher mental stress scores as compared to physical stress. Chancel *et al* (2010) studied the prevalence of depression among caregivers of children with autism in Thailand. Results indicated that 26% of the participants demonstrated depressive disorders, of which 14.8% and 11.1% met diagnostic criteria for major depressive disorder and dysthymic disorder respectively. The prevalence of clinical depression is higher among caregivers of children with autism in the general population. Ou Wet (2010) studied the mental health of mothers of children with autism. The results indicated that the SCL-90 of obsessive-compulsive symptoms, depression, anxiety and paranoia in the fathers of autistic children were significantly higher than those in the fathers of healthy children. The SCL-90 scores of obsessive-compulsive psychotic symptoms, interpersonal sensitivity, depression, anxiety, paranoia, psychotic symptoms, hostility and sleep/diet were significantly higher in the mothers of autistic children than those in the mothers of healthy children. The mothers presented higher scores in interpersonal sensitivity, anxiety and psychotic symptoms than the fathers. Dabrowsky & Pisula (2011) studied the parenting stress and coping styles in mothers and fathers of preschool children with Autism and Down syndrome. The results indicated a higher level of stress in parents of children with autism. Mothers of children with autism scored higher than fathers in parental stress. Emotion-oriented coping was the predictor for parental stress in the samples of parents of children with autism and Down syndrome, and task-oriented coping was the predictor of parental stress in the sample of parents of typically developing children. The results strongly supported earlier findings on parenting stress in parents of children with autism. They also shed interesting light on the relationship between coping styles and parental stress. Rezendes *et al* (2011) [16] studied the Parents of children with autism spectrum disorders (ASDs) have been shown to experience increases in stress, depression, and anxiety, which are also associated with child behaviour problems related to ASDs. Literature-examining potential mechanisms that underlie the relationship between child behaviour problems and parental anxiety/depression in this population are scarce. The current study sought to examine the roles of parenting stress and parenting self-efficacy as mediators between child behaviour problems and parental anxiety/depression. Using a sample of 134 mothers, these potential mediators were tested. Hypotheses were supported, indicating that parenting stress mediated the relationship between child behaviour problems and decreased parenting self-efficacy, and decreased parenting self-efficacy in turn partially mediated the relationship between parenting stress and increased depression/anxiety. Baker *et al* (2011) found on their research on families of individuals with autism has tended to focus on child-driven effects utilizing models of stress and coping. The mother reported on family adaptability, the mother-child relationship, their depressive symptoms, and the behaviour problems of their children at Wave I, and these factors were used to predict maternal depression and child behaviour problems 3years later. It is well recognized that parents of children with autism spectrum disorder (ASD) often experience clinically significant levels of stress and depression. Bathurst (2013) [3], found that the child's behavioural and emotional impairments predicted the parent's overall levels of distress (i.e., stress/tension, anxiety, and depression), but not stress associated with parenting. Instead, the child's social impairment severity was found to predict parenting-specific stress. Wood *et al* (2013) [22, 24], showed that child behaviour difficulties may contribute to parental fatigue, which in turn may influence the use of ineffective coping strategies and increased stress. The significance of fatigue on maternal wellbeing was highlighted as an important area for consideration in families of children with ASD.

The above studies showed that mothers of children with autism are more prone to develop anxiety, depression and other psychological problems in comparison to children without autism.

Research Problem

"To study the stress and depression level of mothers of children with Autism Spectrum Disorder."

Objectives of Study

The objectives of the present study areas follows:

- To assess the level of stress in the mothers of children with autistic spectrum disorders.
- Toassessthelevelofdepressioninthemothersofchildrenwithautismspectrumdisorders.

Hypotheses

The following hypotheses were formulated for the study.

1. Mothers of children with autism spectrum disorders will have a significantly high level of stress.
2. Mothers of children with autism will have a significantly high level of depression

Sample

The sample of the present study consisted of 68 mothers of children with autistic disorder who volunteered to participate in the study. These children were chosen from cities of Aurangabad, Akola, Jalna and Nagpur of Maharashtra in India, such as Special School and Multidisciplinary Clinic. These children were diagnosed as having autism by using CARS. Their level of autism ranged from mild to moderate (50), and severe was 18. Among these children 43 were male and 25 were females. Their age range between 1 to 15 years. 25 children were 1 to 5 years, 37 were 1-10 years and 6were between 11 to 15 years.

Criteria for sample selection

Two criteria, *viz* inclusion and exclusion criterion were used for the selection of the sample. The inclusion criteria used were:

- Mothers whose children fulfilled the criteria for autism spectrum disorders as per ICD-10 and were below the age of 15 years.
- Mothers of autistic children who were free from any major physical, mental and neurological illness.
- Mothers who were willing to participate in therapy. The exclusion criteria used were**:**
- Mothers whose Autistic children had severe &profound mental retardation
- Had severe neurological complications
- Wereabove15 years of age.

Study Tools: Based on the nature and scope of the study, the following research instruments were used to collect the data. All standardized scales were used in the study.

Socio-demographic datasheet: The socio-demographic information of the sample was collected, using a data sheet prepared by the investigator. It included information such as name, age, education, socio-economic status and other important information about the family.

Hamilton rating scale for depression (HARS): Max Hamilton developed this rating scalein 1960 for assessing the severity of depressive symptoms. Since its development in1960 by Dr Max. Hamilton of the University of Leeds, England, the scale has been widely used in clinical practice and has become a standard in pharmaceutical trials. The Hamilton Depression Rating Scale (HAM-D) has proven useful for many years as a way of determining a patient's level of depression before, during, and after treatment.
Itcontainsthe24items related to depressed mood, feeling of guilt, suicide, insomnia, work and activities, retardation, agitation, anxiety, psychic, somatic symptoms, gastrointestinal, somatic general, Hypochondriasis, loss of weight, insight, Diurnal variation, depersonalization and derealization, paranoid symptom, OCD, helplessness, hopeless, worthlessness. It generally takes15-20 minutes to complete the interview and score the results. Eight items are score don a5-point scale, ranging from 0=not present to4 = severe. There are total cut off scores such as0-7 = Normal, 8-13 = Mild Depression,14-18=ModerateDepression,19-22=Severe Depression, >23=Very Severe Depression. Nine are scored from0-2. Inter-rater reliability for the total score ranges from 0.87to0.95. The validity of the scale appears high.

Family Interview for Stress and Coping (FISC): This Scale was developed for the project in NIMHANS, under the leadership of Dr Satish Girimaji in 1993.Though it is used for the assessment of stress and coping in families with children having mental retardation, this scale was used for assessing stress and coping of mothers of autistic children since most of the areas in the subscales were found applicable even for autism. It has two major sections: The first section has 11 subscales, and the second section has 9 areas, which are used to assess the stress and modulators/modifiers of parents of children with mental retardation. There are sub scales in both are as such as extrain puts for care, decreased leisure time, neglect of others, disturbing behaviour, personal distress, marital problems, other inter personal problems, effect on siblings and other family worries, altered social life, social embarrassment, financial implications. Other sub-scale such as awareness about mental retardation, misconception about mental retardation, expectations from child, attitude towards the child as apers on and family member, attitude towards management, rearing practices-general, rearing practices-specific, social support, global/overall adaptation. A four-point rating scale with scoring instructions is provided for each subscale. The sub-scales on stress are rated on a 5-point scale (no- or minimal stress to very high level) and those in section IIareratedona4-point scale (most favorable to most unfavorable). Three measures of reliability were calculated. Cronbach's Alpha, measures of internal consistency calculated for the whole sample separately for section I and section II was 0.9 and 0.67 respectively. Inter-rate reliability of 3 raters for families was computed. The intra-class correlation coefficient (ICC)for any single rater was0.81and the average reliability for all 3 rates was 0.93, indicating good inter-rater reliability. Test-retest reliability was calculated at intake and again after a mean duration of 4.5 months (N-110). Pearson's 'r' for section I was 0.71 ($p<.01$) and section II was 0.36 ($p<.01$) indicating moderate to high test-retest reliability. The criterion or concurrent validity, as measured as Pearsons 'r' between section I and QRS-SF score for 157 families at intake was 0.63 ($p<.01$), indicating moderate criterion or concurrent validity. Pearsons 'r' between section I total score and section II total score was found to be 0.51($p<.001$), indicating a moderate degree of evidence for construct validity.

Procedure

The investigator personally contacted the participants in the selected centre. They were briefed about the nature of the study and its relevance and effect on psychotherapeutic intervention. The consent for participation in the study was obtained and only mothers who volunteered were included in the study. They were assured of the confidentiality of their performance on the test and also assured that the written report of the results would be given to them individually after completion of the study. After establishing rapport with the subjects and an initial interview was conducted and socio-demographic data was obtained from the subjects (mothers). Children were assessed and diagnosed with ASD. Each mother was personally interviewed at the centre at a convenient time. There search instruments selected for the study. FISC and HARS were then administered to the sample according to a time convenient to the subjects. The tests were administered in three sessions, and times ranged from 45min. to one hour per session. The pre-assessment lasted for about one and a half to two years period.

Data Analysis: Theempiricaldataobtainedweresubjectedtoquantitativeanalysisusing descriptive and inferential statistics. The details of the analysis and the results are present.

Results and Discussion

The main variables included in the study were stress, coping behaviour, depression, psychological symptoms and parent-child interaction. The results obtained on these separate variables are discussed as follows:

Stress

A stress scale was used to assess the level of stress in the subjects.

Table 1: shows the percentage, mean and SD of stress (n-68)

Severity level of stress	Stress%
Mild/low	2.9
Moderate	14.7
Severe	67.6
Very severe/high	14.7
Mean & SD	27.60 &5.707

Results of the present study as seen in table 3 show that the mothers of children with autism were severely stressed (67.6%). The mean of the sample is found to be 27.60 and SD 5.707.

This finding is congruent with the result obtained by Durate (2006) [7], Guillermo (*et al*, 2006) [9], and Alhomaidan (2013) [1] reported that having a child with autism was a burden and stress form other seven after adjusting for the child's social skills and demographic background and they also have poor or fair mental health as compared to mothers in the general population. The demands placed by the disability contribute to a higher overall incidence of depression and anxiety among parents/caregivers.

The results obtained by the present study confirm the hypothesis is set up that mothers of autistic children have a high level of stress.

Dimensions of stress
(Variable: Stress)

Table 2: shows the mean and SD on various dimensions of stress during pre-intervention on Family Interview for Stress and Coping (FISC)

Dimensions	N	Mean	Std. Deviation
Extra inputs for care	68	3.06	.770
Decreased leisure time	68	3.06	.751
Neglect of others	68	2.68	.584
Disturbed Behavior	68	2.88	.873
Personal Distress	68	3.26	.803
Marital Problems	68	0.97	1.106
Other IP problems	68	2.57	.951
Effecton Sibs, another family	68	2.37	.945
Altered Social Life	68	2.90	.831
Social embarrassment	68	2.76	.883
Financial Implications	68	1.12	1.140
FAS Total	68	27.60	5.707

Table 2 shows the percentage of stress in the various dimensions of FISC. Results indicate that in the present study mothers have personal distress (mean:3.26), neglect of others (mean: 2.68), need extra inputs for care (mean: 3.06) and decreased leisure time (mean:3.06) in pre-assessment scores. Results also show that mothers have other interpersonal problems (mean: 2.57), effects on family (mean: 2.37), altered social life (mean:2.90), and social embarrassment (mean:2.76).

Results of the above tables indicate that mothers of children with autism had personal distress, and due to special children were unable to spare leisure time and also neglected other family members. Other factors also prominently shown in the results table were that they also had altered social life, felt social embarrassment and interpersonal problems. All these dimensions caused stress in the respondents.

Koegel *et al*, (1992) [13] mothers of children with autism have been found to have a characteristic stress profile. This profile suggests that concerns over child dependency and limited family opportunities were the primary contributors to maternal stress. Fathers and mothers both expressed concerns about their child's future, their child's independence and acceptance in the community. (Moes *et al*, 1992; Rodrigueetal; 1990).

Among the stressful experiences, according to Uskun, *et al* (2010) [8], and Firth, *et al* (2013),it was found that the parents gave the highest points to 'attitudes of society towards disabled people, 'having limited free time' and

'financial problems' (Top three situations).The child's behavioural and emotional impairments predicted the parents' overall levels of distress (i.e. stress/ tension, anxiety, and depression), but not the stress associated with parenting. Instead, the child's social impairment severity was found to predict parenting-specific stress. The above research studies prove the hypothesis set up for the study.

Depression

HARS was used to assess the depression in the subjects.

Table 3: shows the percentage, and mean SD of depression obtained on HARS during the pre-intervention (n-68)

Severity level of depression	Depression%
Mild/low	17.6
Moderate	48.5
Severe	26.5
Very severe/high	7.4
Mean & SD	11.69 & 4.413

The above table shows the percentage of depression as a whole. The mean of the sample was found to be 11.69 and SD4.413.The subjects had a moderate level of depression (48.5). This is contrary to the hypothesis set up that subjects would have a high level of depression

Table 4: shows the mean, SD on various dimensions of depression

Variables	N	Mean	Std.Deviation
Depressed Mood	68	1.60	.602
Feeling Guilt	68	.82	.668
Suicide	68	.21	.475
Insomnia early	68	.49	.560
Insomnia middle	68	.06	.237
Insomnia late	68	.07	.263
Work& Activities	68	.35	.567
Retardation	68	.07	.263
Agitation	68	.74	.661
Anxiety psychic	68	1.46	.742
Anxiety Somatic	68	1.21	.764
Somatic Symptoms Gastrointestinal	68	.88	.744
Somatic symptoms general	68	.96	.742
Genital symptoms	68	.07	.263
Hypochondriasis	68	.04	.207
Loss of weight	68	.15	.396
Insight	68	.00	.000

Table 5

Variables	N	Mean	Std. Deviation
Diurnal variation	68	.01	.121
Depersonalization & Derealization	68	.01	.121
Paranoid symptoms	68	.01	.121
Obsessional &compulsive symptoms	68	.03	.170
Helplessness	68	1.31	.580
Hopelessness	68	.72	.619
Worthlessness	68	.44	.529
HRS Total	68	11.69	4.413

In the present study, results indicate that mothers of children with autism spectrum disorders had a moderate level of depression. Table 4 shows the percentage of depression on various dimensions of depression. Mothers had depressed mood (mean:1.60), anxiety psychic (mean:1.46), somatic anxiety mild (mean:1.21), somatic symptoms general &gastro (mean:.96,.88), helplessness (mean: 1.31), hopelessness (mean:.72). There were no significant symptoms of suicide, retardation, work & activities and worthlessness, also no symptoms of obsession & compulsions, paranoid and psychotic symptoms.

The above table indicates that mothers of children with autism had severely depressed moods and severe anxiety (psychic, somatic). Mothers were also affected by severe helplessness. There were no significant symptoms of suicide, work & activities, retardation, worthlessness, obsession &compulsion, and psychotic symptoms.

Chancel *et all* (2010) studied the prevalence of depression among care givers of children with autism in Thailand. Results indicated that 26% of the participants demonstrated depressive disorders, of which 14.8% and 11.1% met diagnostic criteria for major depressive disorder and dysthymic disorder respectively. The prevalence of clinical depression is higher among caregivers of children with autism in the general population. All the above studies confirm the findings of the present study and the hypothesis set up that mothers of autistic children have significant depression.

Results

The data were analyzed by using descriptive and inferential statistics. The specific statistical techniques used were mean, standard deviation, percentage, parameter test like 't-test and non-parameter test like Chi-square.

Stress (Family Assessment Scale)

There was significant parental stress among mothers of children with autism.

There was also a significant presence of personal stress (3.26) in mothers of children with autism. There is a significant presence of a decrease in leisure time, neglect of others, disturbed behaviour of the child and financial implications. Subjects had personal distress and due to their special child were unable to spare leisure time and also neglected other family members. They also had altered social embarrassment and interpersonal problems.

Depression

The mothers of children with autism have significant depressed mood (mean:1.60), anxiety (mean:1.46), somatic symptoms, as well as helplessness (mean:1.31,). Mothers of children with autism have mild depression and severe anxiety (psychic, somatic & gastro). Mothers are also affected by severe helplessness, guilt and insomnia early. Hypothesis II stated that mothers of children with autism would have a significant level of depression. This proves that the hypothesis is confirmed.

Conclusion

1. Mothers of children with autism have personal distress, and due to special child unable to spare leisure time and also neglect other family members. They also have altered social life, and feel social embarrassment and interpersonal problems.
2. The result also indicates that subjects show depression and interpersonal sensitivity.
3. In the present research it was also found that there were significant symptoms on subscales of the Hamilton Rating Scale such as depressed mood, feeling of guilt, insomnia, anxiety, somatic symptoms general and gastro-intestinal among mothers of children with autism. All hypotheses set up were found to be true.

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