

## Depression and Anxiety in mothers of children with autism spectrum disorders and intellectual disabilities

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### ABSTRACT

**Background:** All parents always plan for perfect, healthy and normal babies. They never expect or think about children with disability. But if they confront with such situation in their lives, they face many emotional problems such as grief, loss, disbelief, guilt, rejection, helplessness, denial, shame, anxiety, anger and depression for a long period. Social stigma that itself attaches to the family and frustration and helplessness for not able to cure the condition leave parents sad and depressed

**Methodology:** The sample consisted of 60 mothers of children between ages 6 to 12 years; out of 60, 30 were mothers of children with autism spectrum disorder and 30 were mothers of children with intellectual disabilities. The data was collected from hospitals and special schools in Mumbai

**Results:** In the present study, it was found that depression and anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disability. The factors that lead to high depression and anxiety in mothers of children with ASD were behavioral issues in children like hyperactivity, aggressiveness, self-injurious behavior and stereotyped movements. They also have difficulties in their day to day life such as managing household chores plus looking after the child, financial problems and restricted social life.

**Conclusions:** The findings indicate that depression and anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disability. The results obtained are in line with hypotheses and past research.

**Keywords:** Depression, Anxiety, Autism Spectrum Disorder, Intellectual Disability, Parents.

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### INTRODUCTION

The birth of a disabled child evokes mixed feelings in the minds of the mother and rather both parents. Guilt, sadness, anger, anguish and non-acceptance are some of the emotions that are experienced. Mothers of children with intellectual disabilities have been proven to experience higher levels of stress and depression than their spouses [1]. It has been noted that mothers of autistic children show an increased anxiety with respect to the poor social relatedness, delayed speech development, hyperactivity, behavioural problems and lack of eye contact in their children [2].

A cross-sectional study compared the psychopathology in mothers of children with autism & mental retardation. When these groups were assessed on Beck Depression Inventory (BDI), it was found that a majority of mothers of children with autism had moderate to severe depression compared to the mothers of children with mental retardation who had more of mild to moderate depression. When assessed on State Trait Anxiety Inventory, results indicated that mothers of children with autism had significantly higher scores on both state anxiety and trait anxiety scales [3].

A study was conducted [4] to evaluate anxiety, depression, alexithymia, and general psychological symptoms in the mothers of children with autism in comparison with the mothers of children with mental retardation. Forty mothers of autistic children and 38 mothers of mentally retarded children were included in the study. Results indicated that there was no difference regarding anxiety and alexithymia between the two groups. But the psychopathology in the mothers of children with autism was more frequent than in those of children with mental retardation in all sub-scales of Symptom Distress Checklist (SCL-90). The mothers of children with autism experienced more psychological distress than those of mentally retarded children.

In a study to find out the level of depression and level of stress in mothers of children with mental retardation and autism and compare them, a sample of 50 children with mental retardation with their mothers and a sample of 50 children with autism and their mothers were selected for the purpose of the study. It was found that mothers of children with mental retardation and autism suffer from same level of stress although depression is higher in mothers of children with autism [5].

Olsson and Hwang investigated the prevalence and severity of parental depression in families of children with autism and with intellectual disability without autism. Parental Depression was assessed using the Beck Depression Inventory (BDI) in 216 families with children with autism and intellectual disability. The results indicated that Mothers of children with autism have higher depression scores than mothers of children with intellectual disability without autism [6].

### **Mothers of children with autism spectrum disorders**

A study aimed at evaluating presence of depression in a group of mothers of autism spectrum disorder (ASD) children in comparison with a group of mothers of normally developing children. Using short Beck inventory scale depression was significantly more among mothers of children with ASD than controls. The results indicated that autism is associated with burden and stress for mothers of the affected child. The demands placed by disability contribute to higher overall incidence of depression among mothers. Therefore, mothers of ASD children do need psychological interventions [7].

A semi-experimental study was performed to compare parenting related stress and depression symptoms in mothers of children with and without autism spectrum disorders. They found that mothers of children with an autism spectrum disorder generally report significantly higher levels of stress and depression than mothers of children without autism spectrum disorder [8].

A study assessed differences in parental reports of parenting stress, child behaviour problems, and dysphoria in 150 families who had children with autism, behaviour disorders, Down syndrome, or normal development. It was found that mothers of children with autism and behaviour disorders experienced statistically and clinically higher levels of dysphoria than mothers in the other two groups. In contrast, mothers of children with Down syndrome did not differ from mothers of nondisabled children on any of the measures [9].

In a review of literature, it was found that mothers of children with Down syndrome had the least impaired health and mothers of children with autism and particularly autism without intellectual impairment had the most impaired health [10]. A study was conducted to examine the relationship between stressors, social support, locus of control, coping styles, and negative outcome among parents of children with autism. Results indicated that parents of children with autism experienced more stress and were more susceptible to negative outcomes than parents of children with other disabilities [11].

Another study found higher levels of parenting stress and psychological distress in mothers of children with autism spectrum disorder (ASD) group compared to the developmental delay (DD) without autism group. Children's problem behaviour was associated with increased parenting stress and psychological distress in mothers in the ASD and DD groups [12].

A study was done to examine parenting stress and affective symptoms in parents of autistic children as compared to normally developing children. It was found that parents of autistic children reported higher levels of stress, depression, and anxiety than parents of normally developing children. Mothers of autistic children had a higher risk of depression and anxiety than that did parents of normally developing children. Also, mothers compared to fathers of autistic children were more vulnerable to depression [13].

McCabe studied the experiences of 78 parents (70 mothers, 8 fathers) of children with autism regarding their personal experiences and the experiences of their families in terms of having a child with autism. Results indicated increased stress, anxiety, and depression in mothers whereas the father tended to become less involved and somewhat more distant. McCabe also reported that having a child with autism significantly impacted the relationship between spouses in both positive and negative ways [14].

A study was conducted on symptoms of stress, depression and anxiety between parents of autistic children and parents of typically developing children. Findings suggested that parents of autistic children reported more symptom of stress, depression and anxiety than parents of clinically healthy children. Mothers of children with autism showed a significant difference in symptoms of stress, depression, and anxiety compared with fathers of children with autism [15].

Researchers studied the association between maternal quality of life and risk for depression in families of children with ASD. They found that higher autism symptomatology in the child was associated with an increased risk for maternal depression and a lower maternal quality of life [16].

Benson examined the relationship between coping and mental health outcomes in parents of children with autism. The study found that maternal use of avoidant coping (distraction and disengagement) was found to be associated with increased levels of maternal depression and anger [17].

### **Mothers of children with intellectual disabilities**

Researchers reported that the parents of children with mental disabilities registered high depression and anxiety scores and the majority met the criteria for possible clinical depression and anxiety [18].

Nisa, Safi, and Rizvi studied the relationship of different stressors with depression among mothers of children with mental retardation. The results of the study revealed that there is a significant positive correlation between daily care stress, family emotional stress, social stress, financial stress, and depression [19].

Mitchell and Hauser-Cram [20] investigated the utilization of and satisfaction with adolescent health care services reported by mothers of children with disabilities and their relation to maternal well-being. Regression analyses were conducted to test whether utilization and maternal satisfaction with care related to maternal depressive symptoms or parenting stress [20]. Mothers with higher family income reported both lower parenting stress and fewer depressive symptoms than those with lower income levels. Mothers who reported higher usage of medical services for their adolescent in this study also reported higher levels of depressive symptoms and greater parenting stress.

A study was conducted on psychological well-being among mothers of children with cerebral palsy. They found that anxious and depressed moods in mothers of children with cerebral palsy were inversely associated with generalized self-efficacy and anxious mood was inversely associated with children's sleeping difficulties [21].

The aim of the current study was to assess the levels of depression and anxiety in mothers of children with autism spectrum disorders and intellectual impairment and compare the same.

## **METHODOLOGY**

### **Participants**

The sample consisted of 60 mothers of children between ages 6 to 12 years; out of 60, 30 were mothers of children with autism spectrum disorder and 30 were mothers of children with intellectual disabilities. The data was collected from hospitals and special schools in Mumbai.

### **Design**

The proposed research is a survey design using questionnaires. It is a mixed study where open-ended questions were asked to mothers of children with autism spectrum disorder to understand their specific concerns.

### **Instruments**

1. Beck Depression Inventory (BDI) [22]
2. The Zung Self-Rating Anxiety scale (SAS) [23]

## Procedure

30 mothers of children with autism spectrum disorder and 30 mothers of children with intellectual disabilities were purposively selected from hospitals and special schools in Mumbai. The head of the psychiatry department in hospitals and the principals of the schools were contacted to provide information regarding the objective of the research, scales, principle of confidentiality and to seek their permission for the students to participate in the study. Once they agreed to allow the study to be carried out and the signed consent letters of the institute were acquired; the researcher arranged an appropriate date and time for administering the questionnaires. The data was collected using the survey method. Beck Depression Inventory (BDI) and The Zung Self-Rating Anxiety scale (SAS) were administered on each participant. The standardized instructions will be provided before the administration.

The mothers of children with developmental disabilities who were willing to participate in the study were provided with standardized instructions before the administration. They were explained the purpose and relevance of the study. After that these participants completed the paper and pencil questionnaire. After each participant was finished with the survey and the materials were collected, the participants were thanked for participating in the study. After the surveys were collected from the centres, data were scored, coded and entered into an excel spreadsheet. Data coding and entry were verified to minimize error. Verified data were then calculated on MS excel.

## RESULTS

The result of the collected data was quantitatively and qualitatively analyzed. There was one independent variable- mothers of children with developmental disabilities. There were two levels of independent variable, i.e. mothers of children with autism spectrum disorder and mothers of children with intellectual disabilities. The two dependent variables were depression and anxiety. Also thematic analysis, as a part of qualitative study was done on 10 mothers of children with ASD.

**Table 1: Descriptive statistics of the variables**

Variables	Mothers of children with ASD		Mothers of children with ID	
	Mean	SD	Mean	SD
Anxiety	31.96	7.83	27.16	5.16
Depression	11.13	5.6	5.63	3.29

The descriptive statistics of the entire data revealed that the mean value for the anxiety in mothers of children with ASD was 31.96 with standard deviation of 7.83. On the other hand, the mean value for the anxiety in mothers of children with ID was 27.16 with standard deviation of 5.16.

The statistical results of depression scores, of the overall data showed that the mean was 11.13 and standard deviation was 5.6 in mothers of children with ASD. In mothers of children with ID, the mean was 5.63 and standard deviation was 3.29. The inferential statistics used is independent t-test since it is the robust statistics. The analysis of the data was carried out using MS excel. Before performing t-test, normality and homogeneity were checked. Skewness and kurtosis values were examined on the total population to check the normality of dependent variables. Results revealed that for the scores of anxiety in ASD group, the statistics was 61.34 for Skewness and -0.09 for Kurtosis. In mothers of children with ID, for the scores of anxiety in, the statistics was 26.69 for Skewness and 0.002 for Kurtosis. These values remain in between the range of -1 and +1, which is an acceptable range for the normality range for t-test.

The value of Skewness and kurtosis for depression in mothers of children with ASD were 31.36 and -0.57 respectively. In mothers of children with ID, the value of Skewness and kurtosis for depression were 10.86 and 0.34 respectively. Since these values remain in between the range of -1 and +1, it is an acceptable range for the normality range for t-test.

**Table 2: t-test for anxiety in mothers of children with ASD and ID**

Variables	Value of t	Df	Significance (one-tailed)
Anxiety in mothers of children with ASD and ID	-2.80	50	0.0036

The obtained t value for anxiety in mothers of children with ASD and ID is -2.80 and the degree of freedom is 50. The obtained value is significant at 0.05 level of significance.

**Table 3: t-test for depression in mothers of children with ASD and ID**

Variables	Value of t	Df	Significance (one-tailed)
Depression in mothers of children with ASD and ID	-4.63	47	0.0015

## DISCUSSION

The first hypothesis was that depression is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disabilities. The statistical result obtained was in line with the hypothesis and also in line with previous studies.

In a cross-sectional study, it was found that a majority of mothers of children with autism had moderate to severe depression compared to the mothers of children with mental retardation who had more of mild to moderate depression [3].

Olsson & Hwang investigated the prevalence and severity of parental depression in families of children with autism and with intellectual disability without autism. The results indicated that mothers of children with autism have higher depression scores than mothers of children with intellectual disability without autism [6].

Another study was conducted with the aim of considering anxiety, depression and any other general symptoms of mental illness of mothers of autistic children and comparing them with mothers of children with mental retardation. Rate of lack of depression in mothers of children with autism was 27.5% but for mothers of children with mental retardation it was 55.3%. It was also found that mothers of autistic children have experienced more psychological pain and discomfort than mothers of children with mental retardation. The second hypothesis was anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disabilities. The statistical result found was in line with the first hypothesis and also in line with past studies [4].

According to a study on the incidence and contributing factors in anxiety, depression and stress in parents of a child with autism spectrum disorder (ASD), nearly half of the participants were severely anxious and nearly two thirds were clinically depressed. Factors that emerged as significant in differentiating between parents with high versus low levels of anxiety and depression included access to family support, parents' estimation of family caregivers' expertise in dealing with the behavioural difficulties of a child with ASD, and parent [24].

Amanda Gane [25] explored mothers' experience of having a child diagnosed with an autism spectrum disorder. Ten mothers with children between the ages of five and nineteen were interviewed face to face regarding their experiences of caring for a child with an ASD. They described feelings of anxiety, despair, guilt and anger. Participants reported frustrations regarding their treatment by health care professionals and school systems. In addition, they spoke of the multitude of roles they had to play and relayed stories of loss in different areas of their lives as a result of mothering a child diagnosed with an ASD [25].

Ludlow, Skelly and Rohleder [26] interviewed 20 parents of children with ASD and explored their experiences, challenges faced, and what has helped them to cope. Their children's difficulties with social interactions, was a problem consistently raised by several of the parents (11 out of 20). Their children who were diagnosed with autism found it difficult to relate to others, understand others, or even tolerate the presence of others. In mothers, dependency of their children on them for care posed some anxiety, as they worried about how their children will be able to cope when they are no longer alive or able to look after them.

The open-ended questions of the study revealed similar difficulties mothers face in dealing with their children with ASD, which are pervasive problem behaviours such as self-stimulatory behaviours, stereotyped movements, self-injurious behaviour, hyperactivity, aggressiveness and poor acceptance of autistic behaviours by society and, other relatives in family. Mothers also expressed deep concern about the dependency of their children on them for care.

Koydemir and Tosun [27] attempted to investigate the impact of having an autistic child on the lives of Turkish mothers. It was found that most of the mothers of children with autism lack accurate information regarding the disability. Although there were some attempts by the mothers to get more information such as consulting school teachers and counsellors or using self-help resources, mothers indicated that they did not see themselves as fully informed about the situation. This study found that one of the consequences of having an autistic child was postponing or finishing career.

Mothers in other cultures also reported that having a disabled child prevented them to seek employment [28]. In the qualitative part of the present study same results are obtained where 6 out of 10 mothers of children with ASD reported that they have either left their jobs or they took up part-time jobs [28].

Stigma is one of the most difficult aspects of public encounters experienced by parents of children with a disability. Parents of children with autism often experience stereotyping and negative public reactions [29]. In the current study, also the mothers of children with ASD reported negative reactions from other people and exclusion from social functions.

Gona and others [30] studied challenges and coping strategies of parents of children with autism on the Kenyan coast. In their study, most parents and the professionals from rural and urban settings interviewed reported nonacceptance of the child with autism by peers, family members, relatives, and the wider community. Lack of acceptance was expressed in the form of social exclusion of the child. The need for constant monitoring of the child with autism has negative economic impact on the parents which was also reported by the mothers.

Most parents, especially mothers, have a strong commitment toward their children, spouse, and other family members. Mothers of children with autism reported more stress and fewer competencies in parenting than mothers of children without disabilities [31]. The present study showed that the characteristics of children with ASD, such as hyperactivity, self-injurious behaviours, stereotyped movements, make it difficult for mothers to deal with their children.

In the present study, it was found that depression and anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disability. The factors that lead to high depression and anxiety in mothers of children with ASD were behavioural issues in children like hyperactivity, aggressiveness, self-injurious behaviour and stereotyped movements. They also have difficulties in their day to day life such as managing household chores plus looking after the child, financial problems and restricted social life.

## CONCLUSION

The current study aimed at comparing the level of depression and anxiety in mothers of children with autism spectrum disorder and intellectual disabilities and to find out which group is at increased risk of suffering from anxiety and depression. The findings indicate that depression and anxiety is higher in mothers of children with autism spectrum disorder as compared to mothers of children with intellectual disability. The results obtained are in line with hypotheses and past research.

## REFERENCES

1. Beckman PJ. Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *Am J Mental Retard* 1991;95:585-95.
2. Pisula E, Porębowicz-Dörsmann A. Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. *PloS One* 2017;12(10):e0186536.
3. De Sousa A. Mothers of children with developmental disabilities: An analysis of psychopathology. *Journal of Pakistan Psychiatric Society* 2010;7(2):84-90.
4. Ingersoll B, Hambrick DZ. The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Res Autism Spectrum Disord* 2011;5(1):337-44.
5. Murphy NA, Christian B, Caplin DA, Young PC. The health of caregivers for children with disabilities: caregiver perspectives. *Child Care Health Dev* 2007;33(2):180-7.
6. Olsson MB, Hwang CP. Depression in mothers and fathers of children with intellectual disability. *J Intellect Disabil Res* 2001;45(6):535-43.
7. Al Towairqi W, Alosaimi W, Al Zaidi S, Helmy FF, Al Sherif E. Depression among mothers of autistic spectral disorder children. *Int J Contempr Pediatr* 2015;2(2):119-26.
8. Kiani F, Khodabaksh MR, Khastwo HH. A comparison study about association of stress and depression in children's mothers with and without autism spectrum disorders (ASD). *Int J Pediatrics* 2015;2(3):31-7.
9. Dumas JE, Wolf LC, Fisman SN, Culligan A. Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality: A Special Education Journal* 1991;2(2):97-110.
10. Fairthorne J, de Klerk N, Leonard H. Health of mothers of children with intellectual disability or autism spectrum disorder: a review of the literature. *Med Res Arch* 2015;11(3).
11. Dunn ME, Burbine T, Bowers CA, Tantleff-Dunn S. Moderators of stress in parents of children with autism. *Comm Ment Health J* 2001;37(1):39-52.
12. Estes A, Munson J, Dawson G, Koehler E, Zhou XH, Abbott R. Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism* 2009;13(4):375-87.
13. Gong Y, Du Y, Li H, Zhang X, An Y, Wu BL. Parenting stress and affective symptoms in parents of autistic children. *Science China Life Sciences* 2015;58(10):1036-43.
14. McCabe H. The importance of parent- to- parent support among families of children with autism in the People's Republic of China. *Int J Disabil Dev Educn* 2008;55(4):303-14.
15. Merhaj V, Kika M, Simaku A. Symptoms of stress, depression and anxiety between parents of autistic children and parents of typically developing children. *Academic Journal of Interdisciplinary Studies* 2013;2(2):345-9.
16. McCabe H. Parent advocacy in the face of adversity: Autism and families in the People's Republic of China. *Focus on Autism and Other Developmental Disabilities* 2007;22(1):39-50.
17. Benson PR. Network characteristics, perceived social support, and psychological adjustment in mothers of children with autism spectrum disorder. *J Autism Dev Disord* 2012;42(12):2597-610.
18. Gallagher S, Phillips AC, Oliver C, Carroll D. Predictors of psychological morbidity in parents of children with intellectual disabilities. *J Pediatr Psychol* 2008;33(10):1129-36.
19. Martin C, Nisa M. Meeting the needs of children and families in chronic illness and disease. A greater role for the GP?. *Austr Fam Physician* 1996;25(8):1273-5.
20. Mitchell DB, Hauser-Cram P. The well-being of mothers of adolescents with developmental disabilities in relation to medical care utilization and satisfaction with health care. *Res Dev Disabil* 2008;29(2):97-112.
21. Barlow JH, Cullen- Powell LA, Cheshire A. Psychological well- being among mothers of children with cerebral palsy. *Early Child Dev Care* 2006;176(3-4):421-8.
22. Beck AT, Steer RA, Carbin MG. Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clin Psychol Rev* 1988;8(1):77-100.
23. Knight RG, Waal- Manning HJ, Spears GF. Some norms and reliability data for the State- Trait Anxiety Inventory and the Zung Self- Rating Depression scale. *Br J Clin Psychol* 1983;22(4):245-9.
24. Sharpley CF, Bitsika V, Efremidis B. Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *J Intellect Dev Disabil* 1997;22(1):19-28.

25. DePape AM, Lindsay S. Parents' experiences of caring for a child with autism spectrum disorder. *Qual Health Res* 2015;25(4):569-83.
26. Ludlow A, Skelly C, Rohleder P. Challenges faced by parents of children diagnosed with autism spectrum disorder. *J Health Psychol* 2012;17(5):702-11.
27. Koydemir S, Tosun Ü. Impact of autistic children on the lives of mothers. *Procedia-Social and Behavioral Sciences* 2009;1(1):2534-40.
28. Kerr SM, McIntosh JB. Coping when a child has a disability: exploring the impact of parent- to- parent support. *Child Care Health Dev* 2000;26(4):309-22.
29. Norlin D, Broberg M. Parents of children with and without intellectual disability: couple relationship and individual well- being. *J Intellect Disabil Res* 2013;57(6):552-66.
30. Gona JK, Mung'ala- Odera V, Newton CR, Hartley S. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience ?. *Child care Health Dev* 2011;37(2):175-83.
31. Fisman S, Wolf L, Ellison D, Freeman T. A longitudinal study of siblings of children with chronic disabilities. *Can J Psychiatry* 2000;45(4):369-75.

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