

Depression, Anxiety and Stress among Mothers of Autism Spectrum Disorder Children

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ABSTRACT

Background: Mothers of children with autism experience more stress, anxiety, depression and other psychiatric problems than those of children with other disabilities. Also, they have an increased rate of antidepressant and psychoactive medications use than the fathers of children with autism.

Objectives: To estimate the prevalence and determinants of psychological problems among mothers of children with Autism and to explore the impact of those psychological problems on their life.

Subjects and Methods: A retrospective cohort study was carried out at one hundred mothers of children diagnosed with Autism were identified as cases. Age matched control of equal size of mothers who had healthy children has been selected for comparison. The Arabic version of Depression, Anxiety and Stress scale (DASS- 42) was utilized for data collection.

Results: There was no statistically significant difference between cases and controls regarding marital status, educational level, occupation, and number of siblings. Depression was reported among 80% of cases, compared to 68% of control group. The difference between cases and controls was statistically significant, $p=0.010$. Anxiety was reported among 84% of cases, compared to 77% of control group. The difference between cases and controls was

statistically significant, $p=0.037$. Stress was reported among 72% of cases, compared to 54% of control group. The difference between cases and controls was statistically significant, $p=0.014$.

Conclusion: Psychological disorders are very common among mothers of children diagnosed with autism compared to general population. Psychological care and social support are highly recommended for those mothers.

Keywords: Autism, Depression, Anxiety, Stress, KSA.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a range of neurodevelopmental disorders in which a child interacts and communicates inadequately, and his behavior becomes restricted and repetitive. It is usually diagnosed during the early childhood most commonly during the first 2 or 3 years of child's life.^{1,2}

The disease is characterized by inadequate processing of information in the brain due to nerve cells malfunction. However, the exact pathophysiology of the disease is still not well understood.³

According to the World Health Organization (WHO), 1 out of every 160 children has autism. In Saudi Arabia, it is estimated that out of each 10,000 children, 18 are diagnosed with autism considering that there may be many other cases that are undiagnosed.^{4,5}

The severity of ASD differs significantly among diagnosed cases. Some patients can live independently while others need life-long support due to the severe disabilities. It has been proven that psychosocial interventions including behavior modification and training programs for parents of children with ASD can have beneficial effect on communication skills and behavior of ASD children. This will definitely improve the quality of life of children with ASD as well as their parents.³

Several studies conducted in Europe, America and Arab/Islamic populations revealed that parents of children with ASD suffer from psychological disorders including stress, anxiety, and depression more than parents of normally developing children. This is because raising an autistic child usually imposes a significant

burden on parents and caregivers. There are several potential causes for the negative effect of ASD on parents' psychological health. However, social criticism due to autism-related behavior stays the main cause.

This effect of autism on the psychological health of parents depends mainly on the severity and frequency of nuclear characteristics of the disease including mental retardation and Behavioral problems such as self-injury or aggressiveness.⁶⁻⁹

A study conducted by Pozo P, et al (2014) revealed that behavioral problems have negative effects on family adaptation including quality of life and psychological well-being) due to the sense of coherence (SOC). These effects were significantly correlated to severity of the disease.¹⁰ Another study conducted in 2015 revealed that mothers of ASD children have more stress rates and have an increased rate of antidepressant and psychoactive medications use than the fathers of ASD children.¹¹ This study was conducted to explore the effect of having children with ASD on the psychological health of their mothers through estimating the prevalence and determinants of depression, anxiety and stress among mothers as well as exploring the impact of those psychological problems on their life.

MATERIALS AND METHODS

Subjects

This retrospective cohort study was conducted in Maternity and pediatrics hospital in Khamis Mushait city (Saudi Arabia). There were two groups of participants; 100 mothers of at least one child with autism (cases) and 100 age –matched mothers with normally developing children (controls). All included mothers were intellectually able to adequately complete the questionnaire. Mothers in each group were asked to fill a different anonymous questionnaire about their psychological health in addition to some general information. The study was conducted during the period from 1435 to 1436 H. All eligible mothers of autistic children (cases) attending maternity and pediatrics hospital in Khamis Mushait city throughout the study duration were asked to take

participate until the required sample size was reached while controls were selected through systematic random sampling from mothers of non-autistic children attending into 4 different primary health care centers to the well-baby until the required sample size was reached. Institutional review board approval was obtained before conducting any study-related procedures.

Data Collected

The self-reported questionnaire filled by mothers of healthy children (controls) was consisted of 46 questions. Four questions collected general information about mother's marital status, educational level, occupation and number of children. The remaining 42 questions were the Arabic version of Depression Anxiety and Stress Scale (DASS-42). A 4-point liker scale was included for each question.

While the questionnaire filled by mothers of children with autism (cases) was consisted of 58 questions. Six questions collected general information about mother's marital status, educational level, occupation and number of children, number of children in the family, number of children with autism and current age of the child with autism. Ten questions collected data about handling the child with autism and the direct effect of having an autistic child on mother's life. The remaining 42 questions were the Arabic version of Depression Anxiety and Stress Scale (DASS-42). A 4-point likert scale was included for each question.

Based on collected data, rate and severity of depression, anxiety and stress were assessed and compared between the 2 groups.

Statistical Analysis

Data were statistically described in terms of frequencies (number of cases) and percentages for categorical variables. Comparison of categorical data between subgroups was carried-out using Chi-square (X²) test. Spearman's correlation was used to investigate the relationship between 2 scoring systems. P values less than 0.05 were considered statistically significant. All statistical calculations were done using computer program IBM SPSS (Statistical Package for the Social Science; IBM Corp, Armonk, NY, USA) release 21 for Microsoft Windows.

Table 1: (DASS score interpretation was done according to the following table).^{21,22}

Meaning	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely severe	28+	20+	34+

RESULTS

Participants' Characteristics in the 2 Groups

There was no difference between the cases and controls regarding marital status (p=1.00). Out of 100 cases, 98% were married and 2% were divorced. The same percentages were exactly reported among the control group. (Table 2)

The same was revealed for educational status as no significant difference was found between the cases and controls (p=0.993). Out of 100 cases, 40% were university graduates, 22% received secondary education, 20% received primary education, 13% received moderate education, 3% were illiterate while 2% made postgraduate studies. And out of 100 controls, 40% were university graduates, 24 % received secondary education, 19%

received primary education, 11% received moderate education, 3% were illiterate and 3% made postgraduate studies. (Table 3)

There was no difference between the cases and controls regarding occupation (p=1.00). Out of 100 cases, 71% were housewives and 29% were employed. The same percentages were exactly reported among the control group. (Table 4)

No significant difference was found between the cases and controls regarding the number of siblings (p=0.630). Out of 100 cases, 49% have 1-3 children, 42% have 3-6 children and 9% have more than 6 children. Out of 100 controls, 43% have 1-3 children, 45% have 3-6 children and 12% have more than 6 children. (Table 5)

Table 2: Marital status of cases and controls

			Groups		Total
			Control	Cases	
Marital status	Married	Count	98	98	196
		% within groups	98.0%	98.0%	98.0%
	Divorced	Count	2	2	4
		% within groups	2.0%	2.0%	2.0%
Total		Count	100	100	200
		% within groups	100.0%	100.0%	100.0%

Chi-Square Test revealed p=1.000

Table 3: Educational level among cases and controls

			Groups		Total
			Control	Cases	
Educational level	Illiterate	Count	3	3	6
		% within groups	3.0%	3.0%	3.0%
	Primary	Count	19	20	39
		% within groups	19.0%	20.0%	19.5%
	Moderate	Count	11	13	24
		% within groups	11.0%	13.0%	12.0%
	Secondary	Count	24	22	46
		% within groups	24.0%	22.0%	23.0%
	University	Count	40	40	80
		% within groups	40.0%	40.0%	40.0%
	Post graduate	Count	3	2	5
		% within groups	3.0%	2.0%	2.5%
Total		Count	100	100	200
		% within groups	100.0%	100.0%	100.0%

Chi-Square Test revealed p=0.993

Table 4: Occupation among cases and controls

			Groups		Total
			Control	Cases	
Mother's occupation	Housewife	Count	71	71	142
		% within groups	71.0%	71.0%	71.0%
	Employer	Count	29	29	58
		% within groups	29.0%	29.0%	29.0%
Total		Count	100	100	200
		% within groups	100.0%	100.0%	100.0%

Chi-Square Test revealed p=1.000

Table 5: Number of siblings of cases and controls

			Groups		Total
			Control	Cases	
Number of siblings	1-3	Count	49	43	92
		% within groups	49.0%	43.0%	46.0%
	3-6	Count	42	45	87
		% within groups	42.0%	45.0%	43.5%
	>6	Count	9	12	21
		% within groups	9.0%	12.0%	10.5%
Total		Count	100	100	200
		% within groups	100.0%	100.0%	100.0%

Chi-Square Test revealed p=0.630

Table 6: Depression among cases and controls

			Groups		Total
			Control	Cases	
Depression	Normal	Count	32	20	52
		% within groups	32.0%	20.0%	26.0%
	Mild	Count	13	8	21
		% within groups	13.0%	8.0%	10.5%
	Moderate	Count	16	10	26
		% within groups	16.0%	10.0%	13.0%
	Severe	Count	14	13	27
		% within groups	14.0%	13.0%	13.5%
	Very severe	Count	25	49	74
		% within groups	25.0%	49.0%	37.0%
Total		Count	100	100	200
		% within groups	100.0%	100.0%	100.0%

Chi-Square Test revealed p=0.010

Table 7: Anxiety among cases and controls

Anxiety	Normal	Count	Groups		Total
			Control	Cases	
		Count	23	16	39
		% within groups	23.0%	16.0%	19.5%
	Mild	Count	9	4	13
		% within groups	9.0%	4.0%	6.5%
	Moderate	Count	14	8	22
		% within groups	14.0%	8.0%	11.0%
	Severe	Count	12	8	20
		% within groups	12.0%	8.0%	10.0%
	Very severe	Count	42	64	106
		% within groups	42.0%	64.0%	53.0%
Total		Count	100	100	100
		% within groups	100.0%	100.0%	100.0%

Chi-Square Test revealed p=0.037

Table 8: Stress among cases and controls

Stress	Normal	Count	Groups		Total
			Control	Cases	
		Count	46	28	74
		% within groups	46.0%	28.0%	37.0%
	Mild	Count	10	5	15
		% within groups	10.0%	5.0%	7.5%
	Moderate	Count	14	14	28
		% within groups	14.0%	14.0%	14.0%
	Severe	Count	11	19	30
		% within groups	11.0%	19.0%	15.0%
	Very severe	Count	19	34	53
		% within groups	19.0%	34.0%	26.5%
Total		Count	100	100	100
		% within groups	100.0%	100.0%	100.0%

Chi-Square Test revealed p=0.014

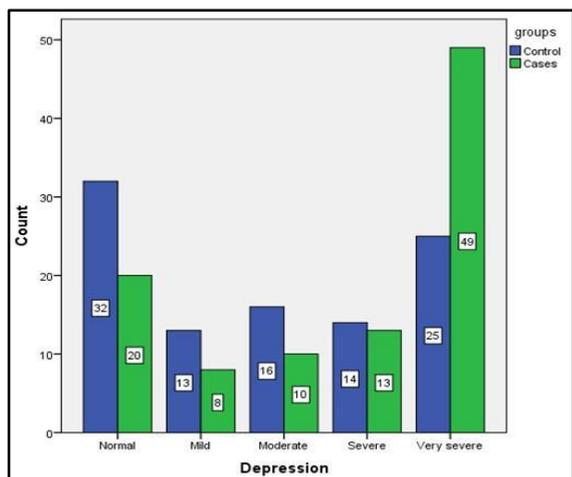


Figure 1: Depression among cases and controls

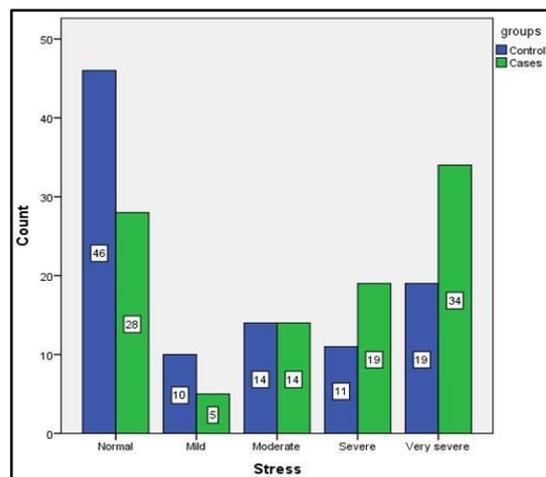


Figure 3: Stress among cases and controls

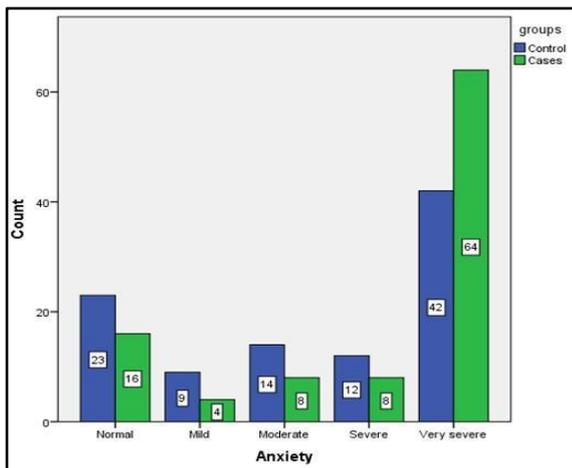


Figure 2: Anxiety among cases and controls

Depression, Anxiety and Stress Rates in the 2 Groups

Depression was reported among 80% of cases; being severe and very severe among 13% and 49% of them, respectively compared to 68% of control group; being severe and very severe among 14% and 25% of them, respectively. The difference between cases and controls was statistically significant, p=0.010. (Table 6 and figure 1)

Anxiety was reported among 84% of cases; being severe and very severe among 8% and 64% of them, respectively compared to 77% of control group; being severe and very severe among 12% and 42% of them, respectively. The difference between cases and controls was statistically significant, p=0.037. (Table 7 & figure 2)

Stress was reported among 72% of cases; being severe and very severe among 19% and 34% of them, respectively compared to

54% of control group; being severe and very severe among 11% and 19% of them, respectively. The difference between cases and controls was statistically significant, $p=0.014$. (Table 8 & figure 3)

Characteristics of Mothers with Autistic Child

Among mothers of autistic children, DAS score didn't differ significantly between married cases and divorced cases ($p=0.074$). The same was revealed between groups of different educational levels ($p=0.614$), between housewives and employed mothers ($p=0.933$) and between mothers with different number of

siblings ($p=0.521$). Moreover, the score didn't differ significantly between mothers with 1 autistic child and those with 2 autistic children ($p=0.376$). And the same was reported for the current age of the autistic child that was found to have no significant effect on DAS score ($p=0.454$).

On the other hand, there was a nearly moderate uphill (positive) relationship between DAS score and mothers' suffering score among studied mothers having autistic child (Spearman's correlation coefficient is 0.446, $p<0.001$). (figure 4)

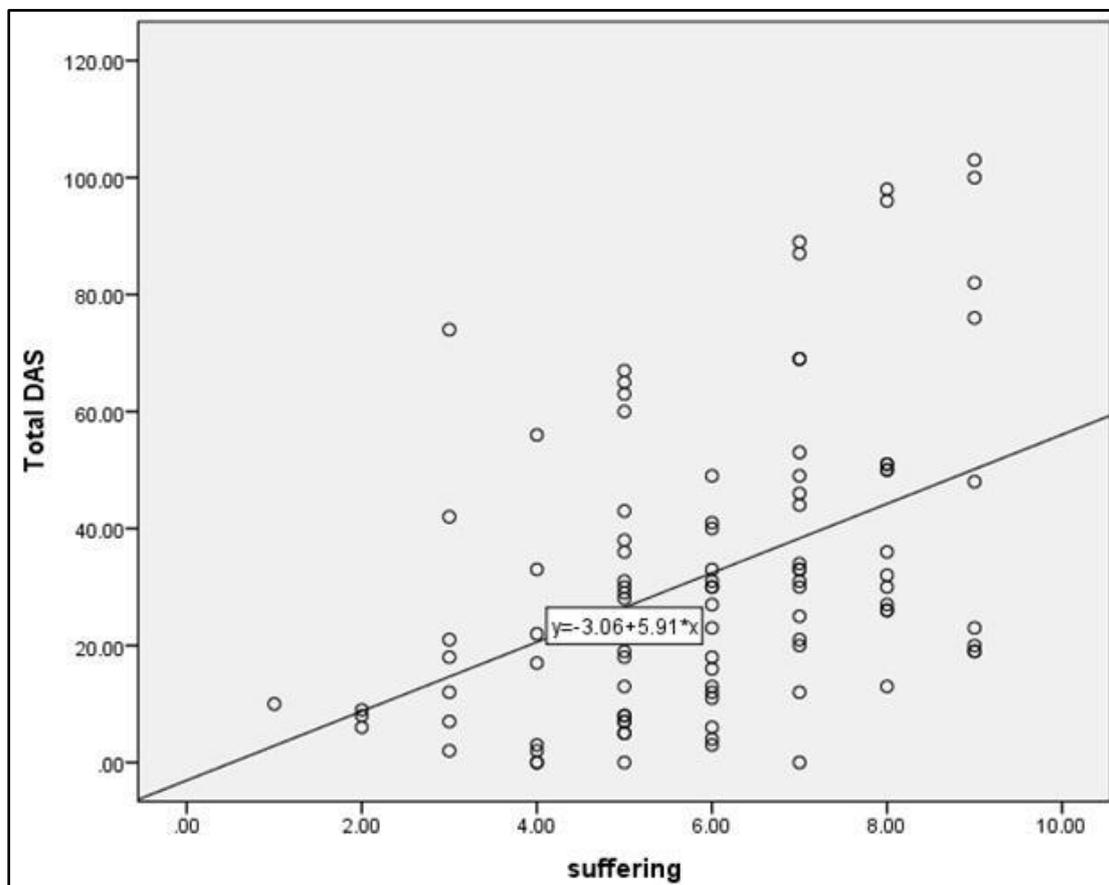


Figure 4: Scatter plot chart for the correlation between DAS score and mothers' suffering score

DISCUSSION

According to WHO factsheet 2017 entitled "Autism spectrum disorders", the disease imposes significant economic and emotional burdens not only on the patients but also on their families and caregivers.⁵

Previous studies conducted in several countries worldwide revealed high rates of stress, anxiety, and depression among parents with autistic children. This psychological burden may be due to having to look after a child with special needs.¹²⁻¹⁶

This retrospective cohort study was conducted in Saudi Arabia to estimate the prevalence and determinants of depression, anxiety and stress among mothers of children with autism as well as to explore the impact of those psychological problems on their life.

A total of 100 mothers of autistic children (cases) and 100 age-matched mothers of normally developing children (controls) took part in this study. Two anonymous questionnaires were filled by participating mothers (one for the cases and the other for the controls). Both questionnaires included the Arabic version of the 42-item depression Anxiety Stress Scale (DASS-42) to measure the emotional state of participating mothers in each group.¹⁷

There was no significant differences between characteristics of cases and controls in terms of marital status ($p=1.00$), educational level ($p=0.993$), occupation ($p=1.00$), and number of siblings ($p=0.631$).

While for presence and severity of depression, the difference between cases and controls was statistically significant ($p=0.010$). Depression was reported among 80% of cases; being severe and very severe among 13% and 49% of them respectively compared to 68% of control group; being severe and very severe among 14% and 25% of them respectively. This is consistent with the findings of the study conducted by Cohrs and Leslie (2017) where depression was more prevalent among parents of autistic children compared to those with non-autistic children with higher odds among Mothers (OR 2.95, 95% CI 2.81–3.09) compared to fathers (OR 2.41, 95% CI 2.25–2.58). The same as depression, anxiety rate among cases was 84%; being severe and very severe among 8% and 64% of them respectively while among controls, the rate was 77%; being severe and very severe among 12% and 42% respectively. The difference between cases and controls was statistically significant, $p=0.037$. A study conducted to examine the

association between parental anxiety, autistic Child Behavior and Parenting Self-Efficacy suggested that there is a bidirectional relationship between autistic child behavior and parenting self-efficacy. This relationship is mediated through parent's anxiety.

And the same was found for stress that was reported among 72% of cases; being severe and very severe among 19% and 34% respectively compared to 54% of controls; being severe and very severe among 11% and 19% respectively with a statistically significant difference between the 2 groups ($p=0.014$). This consistent with the results of a case-control study conducted by Duarte et al (2005) to examine the determinants of stress in mothers with autistic children. The study revealed several factors to be associated with mothers' stress however; having an autistic child was the primary factor responsible for developing stress.²⁰

CONCLUSION

The current study findings support the evidence that mothers of children with ASD are more prone to develop depression, anxiety and stress compared to mothers with non-autistic children. They are a vulnerable group having special emotional needs that should be taken into consideration while planning the care interventions for children with ASD.

Providing adequate support to caregivers of ASD children will minimize the potential risks of developing psychological disorders and improve their wellbeing and self-efficacy which is a critical component to enhance the care provided to ASD children and to ensure a better quality of life.

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