

# Depression and anxiety among parents and caregivers of autistic spectral disorder children

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## ABSTRACT

**الأهداف:** تقييم ظهور القلق والاكتئاب عند مجموعة من الوالدين أو من يقدمون الرعاية للأطفال المصابين باضطراب التوحد الطيفي بالمقارنة مع مجموعة أخرى من الوالدين والعوامل المؤثرة.

**الطريقة:** أجريت دراسة استرجاعية خلال الفترة من يوليو حتى ديسمبر 2011م هذه على آباء لطفل واحد على الأقل مصاب باضطراب التوحد الطيفي وتم تسميتهم (مجموعة الحالة) عن طريق الجمعية السعودية الخيرية لعائلات الأطفال المصابين بالتوحد في الرياض، وعبادة التوحد في عيادة الأطفال الخارجية في مستشفى الملك فهد للحرس الوطني، مدينة الملك عبدالعزيز الطبية، الرياض. ومجموعة أخرى من الآباء أو من يقدمون الرعاية للأطفال طبيعيين تم تسميتهم (مجموعة الشاهد) عن طريق عيادات الأطفال الأصحاء في مدينة الملك عبدالعزيز الطبية، الرياض. وقد أجري استبيان يحتوي على أسئلة متعلقة بالبيانات الديموغرافية للمشاركين إضافة إلى النسخة العربية لمقياس المستشفى للقلق والاكتئاب.

**النتائج:** اشتملت الدراسة على 100 أب وأم أو من يقدمون الرعاية، منهم 50 من مجموعة الحالة، و50 من مجموعة الشاهد. أكثر من 50% من مجموعة المراقبة كانوا في الفئة العمرية بين 26-30 عاماً (56%)، وبينهما 42% من الحالات كانوا في الفئة العمرية بين 31-35 عاماً. وقد تم تشخيصهم بالتوحد منذ 3 أعوام في ثلث الحالات. كان هنالك مشاكل نفسية لدى 22% من مجموعة الحالة و2% من مجموعة الشاهد لدى الآباء والأمهات وكان الاختلاف مهم بشكل إحصائي ( $p=0.002$ ). وبالمثل متوسط قياس القلق أعلى بنسبة كبيرة عند مجموعة الحالة بالمقارنة مع مجموعة الشاهد  $p<0.001$ .

**خاتمة:** أظهرت الدراسة بأن التوحد مرتبط بالتوتر لدى الآباء ومن يقدمون الرعاية للأطفال المصابين. يسهم الطلب من العاجزين في زيادة حدة الاكتئاب لدى الوالدين ومن يقدمون الرعاية للأطفال والتي تؤثر سلباً على أسلوب حياة الأسرة.

**Objectives:** To evaluate the presence of depression and anxiety in parents/caregivers of autistic spectral disorder (ASD) children, and to identify associated factors.

**Methods:** In this retrospective cohort study carried out between July and December 2011, parents/caregivers of at least one child diagnosed with an ASD (cases group), were recruited through the Saudi Charitable Society of Autism Families and the Autism Clinic in the Pediatric out-patient clinic in King Fahad National Guard Hospital, King Abdulaziz Medical City (KAMC), Riyadh, Kingdom of Saudi Arabia. The parents/caregivers of a normally developed child (control group) were recruited from the Well Child Clinic at King Abdulaziz Medical City, Riyadh. We used a self-reported questionnaire containing questions on demographic data, as well as the Arabic version of the hospital anxiety and depression scale.

**Results:** The study included 100 parents/caregivers, 50 cases and 50 controls. More than 50% of the control group was in the age group 26-30 years (56%), while 42% of cases were in the age group 31-35 years. Time lapsed since autism diagnosis was over 3 years in one-third of cases. Twenty-two percent of cases, and only 2% of control parents/caregivers had a history of psychiatric problems ( $p=0.002$ ). Both the mean depression score, and the mean anxiety score was significantly higher among cases when compared with controls,  $p<0.001$ .

**Conclusion:** Autism is associated with burden and stress for parents/caregivers of the affected child. The demands placed by the disability contribute to a higher overall incidence of depression and anxiety among parents/caregivers.

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Autism is defined as a disorder of neural development characterized by impairment of social interaction and communication, and by restricted and repetitive behavior. These signs all begin in children before the age of 3 years.<sup>1</sup> It affects information processing in the brain by altering how nerve cells and their synapses connect and organize; however, how this occurs is not well understood.<sup>2</sup> It is one of 3 recognized disorders in the autism spectrum (ASDs), the other 2 being Asperger syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).<sup>3</sup> The prevalence of autism is approximately 1-2 per 1,000 people worldwide; however, the Centers for Disease Control and Prevention (CDC) reports that approximately 9 per 1,000 children in the United States are diagnosed with ASD.<sup>4,5</sup> The prevalence of autism has increased dramatically since the 1980s, partly due to advances in diagnostic practice; the question of whether actual prevalence has increased is unresolved.<sup>6</sup> Studies of autism frequency have been particularly rare in the Middle East. Estimates for ASD prevalence in Saudi Arabia are not available in the literature.<sup>7</sup>

Autism is associated with burden and stress for parents.<sup>8</sup> Compared with parents of children with other intellectual, developmental, or physical disabilities, the demands placed on parents caring for a child with autism associate with a higher overall incidence of parental stress, depression, and anxiety, which adversely affects family functioning and marital relationships.<sup>9,10</sup> It has been reported that parents of children with an ASD experience greater levels of stress, anxiety, and depression than parents of children without this particular developmental disorder.<sup>11-14</sup> Mothers of children with autism are more liable to suffer from depression than those of children with intellectual disability (ID) without autism, and mothers with typically developing children.<sup>15-17</sup>

While there are multiple possible underlying causes for this prominent level of distress, the major factors appear to be associated with unlikely remission of the autism-based behaviors that cause social criticism,<sup>18</sup> the lack of wider understanding among the public about the nature of ASD,<sup>12</sup> the negative effects on the marital relationship,<sup>19</sup> and the reduced care that can be provided to the siblings of the child with ASD.<sup>20</sup> Some other factors that have been demonstrated as linked with parental stress include the age of the child with

ASD (parents of older children show higher levels of stress than parents of younger children),<sup>21</sup> and the age of diagnosis (later diagnosis is associated with higher depression levels).<sup>18</sup>

Although in our Saudi community, the awareness of autism has increased lately, we were unable to find research carried out in Saudi Arabia regarding anxiety and depression among parents/caregivers of children with ASD. Therefore, the primary objective of this study was to evaluate of the presence of depression and anxiety in a group of parents of ASD children in comparison with a group of parents of normally developing children. The other objectives of this study were to determine the factors associated with depression and anxiety among parents of autistic children (parental factors, child factors, and medical factors), to estimate the impact of the child's autism on the parents' quality of life, and to increase awareness among the population as well as the medical team of the psychosocial impact of autism on parents of autistic children.

**Methods.** We carried out a retrospective cohort study comparing 2 groups. Parents/caregivers of at least one child diagnosed with an ASD were enrolled in the group called "cases". The ASD was diagnosed by specialists using the Diagnostic and Statistical manual of Mental Disorders (DSM-IV) criteria.<sup>22</sup> Parents/caregivers of a normally developed child were enrolled in the group called "controls". All parents/caregivers had to have the intellectual ability to complete the questionnaire in order to be included in the study. The study was conducted from July to December, 2011. All cases attending study centers throughout the period of the study were included until we reached the required sample size. Controls were selected through a systematic random sampling technique (every fifth parent/caregiver visiting the study centers until we reached the required sample size). The sample size was calculated based on a previous study.<sup>23</sup> One hundred participants (50 participants for each of the "cases" and "control" group) were sufficient to fulfill the aim of the current study.

A self-reported questionnaire was utilized containing 14 questions regarding demographic data, psychiatric history of parents, and the Arabic version of the hospital anxiety and depression (HAD) scale.<sup>24</sup> The scale consists of 14, 4-point items ranged from 0 (not present) to 3 (considerable), with 7 assessing largely the anhedonic rather than somatic aspects of depression, and 7 assessing anxiety. The HADS has good concurrent validity,<sup>25,26</sup> and performs well as a tool for psychiatric screening.<sup>26</sup> The cutoff point of the score was 8 out of

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21 for both anxiety and depression. A mean score of  $\geq 8$  for the 7-item depression questions indicates clinically suspected depression, and  $\geq 8$  for the 7-item anxiety questions indicates clinically suspected anxiety. The Arabic version was validated and retested by el-Rufaie and Absood.<sup>27</sup> The overall Cronbach alpha measures of internal consistency were 0.7836 for anxiety, and 0.8760 for depression. Nurses and clerks distributed the questionnaires to the participants, explained any difficult questions, answered any queries, and collected the questionnaires making sure that all questions had been answered properly.

The study was conducted in 3 areas: (1) Autism Clinic in the Pediatric out-patient clinic of King Fahad National Guard Hospital (KFNGH), King Abdulaziz Medical City (KAMC), Riyadh; (2) The Saudi Charitable Society of Autism Families in Riyadh; and (3) The Well Child Clinic in Kashmalaan Family Medicine Center (HCSC), KAMC, Riyadh, Saudi Arabia.

The data were analyzed using the Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA) software, version 15. Chi-square test, student t-test, and ANOVA tests were utilized to find the association and/or difference between cases and controls as well as the difference in depression and anxiety scores according to studied variables. Independent variables were age of parents/caregivers, gender, education level, number of children and number of ASD child, relation to autistic child, child's age, as well as duration since diagnosis. The dependent variable was the HAD scale results. The significance was determined at a *p*-value of  $<0.05$ .

Ethical considerations including informed consent of parents/caregivers participating in the study were obtained, and approval of the local research and ethics committee at KAMC, Riyadh was obtained. As the study involved human subjects, the principals of the Helsinki Declaration were adopted.

**Results. Socio-demographic characteristics.** The study included 100 parents/caregivers, 50 of them had at least one diagnosed child with ASD, while the other 50 had a normally developed child or children. Table 1 presents their socio-demographic characteristics. More than half of the control group was in the 26-30 years (56%) age group, while 42% of cases were in the 31-35 years age group. More than half of the participants (cases and controls) had at least a university grade of education (66% of cases, 56% of controls) while only 10% of cases, and 12% of controls had an educational level lower than high school. Females represent 68% of cases, and 62% of controls. Similarly, more than half of the participants were mothers of children (66% for

cases and 58% for controls). Slightly less than half of cases (48%) and only 12% of controls had more than 3 children. There was a statistically significant difference between cases and controls regarding age ( $p<0.001$ ), and number of children ( $p<0.001$ ) where the percentage of cases having more than 3 children was 48% in comparison with 12% in controls. There was no statistically significant difference between cases and controls regarding gender ( $p=0.529$ ), relation to the child ( $p=0.695$ ), or educational level ( $p=0.585$ ).

**The ASD history among cases.** Most of the cases (96%) had only one child with ASD, while 2 cases had 3 children with ASD (4%). The age of children with ASD ranged between 2-10 years, with a mean of  $5.24\pm 3.13$  years; 48% of them were aged between 4-7 years. The time lapsed between ASD diagnoses and completing the questionnaire was over 3 years in exactly one-third of cases (in 11 cases out of 33 cases with available data).

**Psychiatric history among participants.** As shown in Table 2, 22% of cases and only 2% of controls had a history of psychiatric problems. This difference was statistically significant ( $p=0.002$ ). Similarly, 16% of cases compared with 4% of controls gave a history of visiting a psychiatrist or psychologist. This difference was statistically significant ( $p=0.046$ ). In addition, 12% of cases compared to 2% of controls gave a history of

**Table 1 -** Comparison between parents/caregivers of autistic spectral disorder children and parents/caregivers of normally developed children regarding their socio-demographic characteristics.

Characteristics	Cases (n=50)	Controls (n=50)	X <sup>2</sup> (P-value)
	n (%)		
<b>Age in years</b>			23.82 (<0.001)
<20	2 (4.0)	2 (4.0)	
20-25	5 (10.0)	11 (22.0)	
26-30	11 (22.0)	28 (56.0)	
31-35	21 (42.0)	8 (16.0)	
>35	11 (22.0)	1 (2.0)	
<b>Gender</b>			0.40 (0.529)
Male	16 (32.0)	19 (38.0)	
Female	34 (68.0)	31 (62.0)	
<b>Relation to the child</b>			0.73 (0.695)
Father	15 (30.0)	19 (38.0)	
Mother	33 (66.0)	29 (58.0)	
Other caregiver	2 (4.0)	2 (4.0)	
<b>Educational level</b>			1.07 (0.585)
<High school	5 (10.0)	6 (12.0)	
High school	12 (24.0)	16 (32.0)	
$\geq$ University	33 (66.0)	28 (56.0)	
<b>Number of children</b>			19.01 (<0.001)
One	5 (10.0)	17 (34.0)	
2	11 (22.0)	18 (36.0)	
3	10 (20.0)	9 (18.0)	
>3	24 (48.0)	6 (12.0)	

**Table 2** - Comparison between parents/caregivers of autistic spectral disorder children and parents/caregivers of normally developed children regarding their psychiatric history.

History	Cases (n=50)	Controls (n=50)	Total (n=100)	X <sup>2</sup> (P-value)
	n (%)			
<i>Psychiatric problems</i>				9.47 (0.002)
Yes	11 (22.0)	1 (2.0)	12 (12.0)	
No	39 (78.0)	49 (98.0)	88 (88.8)	
<i>Visiting psychiatrist or psychologist</i>				4.00 (0.046)
Yes	8 (16.0)	2 (4.0)	10 (10.0)	
No	42 (84.0)	48 (96.0)	90 (90.0)	
<i>Using anti-depressants</i>				3.84 (0.056)
Yes	6 (12.0)	1 (2.0)	7 (7.0)	
No	44 (88.0)	49 (98.0)	93 (93.0)	

antidepressant intake. However, this difference was not statistically significant ( $p=0.056$ ).

**Depression and anxiety among cases versus controls.**

The mean depression score was significantly higher among cases as compared with controls ( $9.52 \pm 3.24$  versus  $4.98 \pm 2.99$ ,  $p < 0.001$ .) Similarly, the mean anxiety score was also significantly higher among cases as compared with controls ( $10.54 \pm 3.93$  versus  $5.58 \pm 3.76$ ,  $p < 0.001$ ).

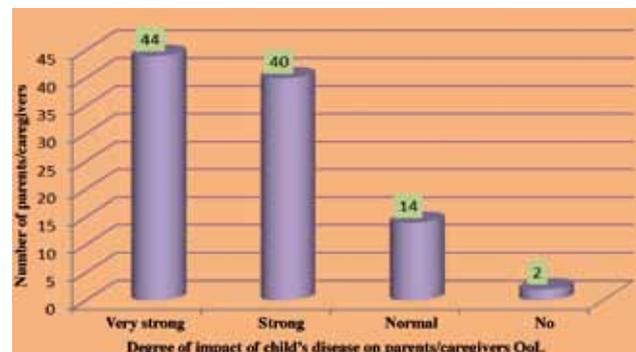
**Factors associated with depression and anxiety among cases.**

As clear from Table 3, among cases, between male and female, there was no statistically significant difference regarding depression ( $p=0.877$ ), and anxiety scores ( $p=0.741$ ). Similarly, there was no statistically significant impact of the participants' relation to ASD children on both the depression ( $p=0.999$ ) and anxiety ( $p=0.862$ ) scores (namely, no difference between mothers, fathers, and other caregivers). The parent/caregiver's age was not significantly associated with depression ( $p=0.527$ ), and anxiety ( $p=0.251$ ). The cases' educational level was not significantly associated with depression score ( $p=0.073$ ), although it was higher among more educated cases. However, it was significantly associated with anxiety score as it was higher among more educated cases ( $p=0.042$ ). There was no statistically significant impact of the number of children of the participants on both the depression ( $p=0.490$ ), and anxiety scores ( $p=0.775$ ). Contrary to that, the number of autistic children was significantly associated with depression and anxiety scores, as cases with 3 autistic children showed significantly higher depression ( $p=0.003$ ) and anxiety ( $p=0.005$ ) scores compared with those with only one autistic child. The

**Table 3** - Factors associated with depression and anxiety among parents/caregivers of autistic children.

Characteristics	Depression score (n=16) mean (SD)	Anxiety score (n=34) mean (SD)	(P1-value)	(P2-value)
<i>Gender</i>			0.877	0.741
Male (n=16)	9.63 (2.50)	10.81 (3.71)		
Female (n=34)	9.47 (3.57)	10.41 (4.08)		
<i>Relation to autistic child</i>			0.999	0.862
Father	9.53 (2.56)	11.00 (3.76)		
Mother	9.52 (3.62)	10.36 (4.14)		
Others	9.50 (2.12)	10.00 (2.83)		
<i>Parent/caregiver age</i>			0.527	0.251
≤25	9.43 (2.76)	8.71 (3.20)		
26-30	9.27 (3.72)	11.18 (4.54)		
31-35	10.24 (3.21)	11.48 (3.66)		
>35	8.45 (3.17)	9.27 (4.00)		
<i>Educational level</i>			0.073	0.042
<High school	7.20 (4.60)	6.40 (3.29)		
High school	11.00 (3.81)	11.17 (4.41)		
University or above	9.33 (2.59)	10.94 (3.56)		
<i>Number of children</i>			0.490	0.775
One	10.20 (4.60)	11.2 (4.32)		
2	8.64 (2.20)	9.45 (3.27)		
3	10.70 (3.43)	10.60 (4.65)		
>3	9.29 (3.29)	10.88 (3.98)		
<i>Number of autistic children</i>			0.003	0.005
One	9.25 (2.95)	10.23 (3.65)		
3	16.00 (4.24)	18.00 (4.24)		
<i>Child's age</i>			0.544	0.608
≤3 years	8.82 (3.41)	9.82 (3.81)		
4-7 years	9.79 (3.22)	11.08 (3.81)		
>7 years	10.11 (3.10)	10.44 (4.69)		
<i>Time since autism diagnosis</i>			0.199	0.414
One year	7.70 (3.02)	8.80 (3.68)		
2-3 years	9.75 (2.34)	10.67 (2.77)		
>3 years	9.82 (3.52)	10.73 (4.56)		

$p1$  - depression score,  $p2$  - anxiety score



**Figure 1** - Negative impact of child's disease on parents/caregivers' quality of life (QoL).

autistic children's age was not significantly associated with cases' depression ( $p=0.544$ ) or anxiety scores ( $p=0.608$ ). The time since diagnosis of autism was not significantly associated with cases' depression ( $p=0.199$ ) or anxiety scores ( $p=0.414$ ).

Regarding the impact of the child's autism on the cases' quality of life, as illustrated in **Figure 1**, most participants mentioned that their life was strongly affected by the disease (84%). Only 2% stated that the disease did not affect their life.

**Discussion.** This study shows that parents/caregivers of children with autism were more susceptible to negative psychological outcomes. The mean depression and anxiety scores were significantly higher among cases compared with controls. These results are in accordance with other international research,<sup>2,26</sup> however, there is a lack of available data locally for comparison.

Parents of children with autism often experience an extreme set of difficulties in parenting and otherwise maintaining a normal family life. Consequently, it is to be expected that support from one's spouse, wider family, and community would be a critical coping resource for parents. In the present study, most parents reported that their quality of life was strongly affected by their child's disease. Older children and larger families were not found in this study to be significantly related to higher scores of depression or anxiety. The same has been documented by others.<sup>22</sup> Some of the results of the present study are incongruent with other internationally available studies. For example, no major effect of the children's age or time passed since diagnosis of autism has been found on anxiety or depression of parents/caregivers of autistic children, in the current research. The former finding counters Hastings' report<sup>27</sup> of increased dysphoria in mothers of older autistic children. Regarding the gender effect, unexpectedly, the gender of the parent was not found in this study to be a significant determinant of parental depression or anxiety. It was expected that mothers of children with autism experience more distress than the fathers. The mothers typically assume a disproportionate amount of the often difficult child-care tasks and have the most contact with the child. Due to the demands of parenting, many of these mothers cannot work outside the home, and, consequently, unlike their husbands, have no additional source of self-identity and self-esteem. Further research could gather similar data from a national survey, and any demographic or geographic differences could be defined more clearly.

The unique aspect of the present research was the negative perceptions of parents/caregivers of autistic children. It is important to point out that in addition to reporting stress associated with their child's disability; they reported negative perceptions about their child, and his or her negative impact on their quality of life. Howlin et al<sup>8</sup> found that mothers and fathers of autistic children experienced substantial effects in their daily life from having a handicapped child. Family adaptation to a disabled child is not a single event, but a long life process.<sup>28</sup>

Of greater importance is the issue of developing parental support services. While these already exist in a general and informal manner, there is a need to form and evaluate specific parent support groups. Earlier attempts at this specific form of parent support have been previously reported.<sup>29,30</sup> A significant improvement in parental distress and depression has been reported in these studies.

The results from the present study are limited in their generalizability due to the relatively small study sample. However, the data indicate clearly that having an autistic child results in a negative psychological impact on parents/caregivers. The need for more research on the psychosocial well-being of the parents of children with autism is clear. Given the absence of a cure for autism, the limited range of support services for parents, and the consequent burden of coping with autism experienced by the families, makes the question of what factors assist parents in successfully coping with autism an important one.

To date, the limited amount of research on this issue has identified a few factors consistently associated with parental psychosocial well-being. Previous research using small samples has indicated that the distress levels found among such parents are not a direct effect of their child's degree of impairment. Rather, a variety of personal and social factors serve to mediate the stress of parenting a child with autism. The role of other factors has yet to be completely determined and a greater number of studies using large samples, rigorous research designs, and varied populations will be essential to supply the knowledge that is presently lacking.

In conclusion, autism is associated with burden and stress for parents and caregivers. The demands placed on parents caring for a child with autism contribute to a higher overall incidence of parental depression and anxiety, and adversely affects family quality of life. There is a need for more research on the psychosocial well-being of the parents/caregiver of children with ASD.

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