

The moderating effect of financial stress and autism severity on development of depression among parents and caregivers of Autistic children in Taif, Saudi Arabia

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ABSTRACT

Background: Autistic spectrum disorder (ASD) is a common problem in the Kingdom of Saudi Arabia. However, little research explored the extent of anxiety and depressive disorders in parents of children with ASD. **Method:** Descriptive questionnaire-based cross-sectional survey of a sample of parents of children with ASD who attended Prince Mohammed Bin Salman Autistic Centre, Ministry of defense, Taif city. **Results:** The study included ($n = 50$) parents. The prevalence of mild depression was 30%, whereas the prevalence of moderately severe depression was 68%. Increased ASD severity level was associated with a significant impact on the PHQ-9 total score (level II was 1.293 times level I to have an increased PHQ-9 score, and level III was 1.530 times level I to have an increased PHQ-9 score). Economic status did not significantly alter depressive symptoms. **Discussion and Conclusion:** ASD diagnosis in Saudi children is associated with high parental depressive prevalence. However, this result could be bidirectional. Stigma, future-related worry, and stress could mediate parental depressive symptoms. Our findings in Saudi parents of children with ASD corroborate the established association between parental depressive symptoms and ASD severity. Our results corroborated previous findings that neither parental gender nor child gender exert any substantial effect on predictability of depressive symptoms among parents of children with ASD. Comprehensive therapeutic packages for children with ASD should include treatment of emotional problems arising out of carer burden among their parents. Screening for parental emotional problems should be routine in autism treatment facilities.

Keywords: Autism, emotional problems, parental depression, PHQ-9, Saudi Arabia

Introduction

Autism or autism spectrum disorder (ASD) is a neuro-developmental disorder that affects an individual's ability to communicate, socially interact with others, as well as respond to certain stimuli in their surroundings.

The most recent prevalence estimate of ASD in the Kingdom of Saudi Arabia was one/167,^[1] close to the international prevalence

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of the disorder. The majority of children with ASD in the KSA receive ASD treatment services in private schools, at the expense of their families.^[2]

Parents of children with Autism were shown to be more likely to suffer from stress than those of normally developed children.^[3] Studies among parents of children with ASD reported had higher levels of anxiety and depression.^[4,5] Many pathways were proposed to influence the link between parental depression and offspring ASD symptoms. children with ASD are quite demanding on parental time, effort and patience.^[6] Moreover, stigmatization, family conflicts, financial pressures, marital disharmony, and challenging behaviour also put a substantial strain on parents' mental health.^[7,8]

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The current study aims to estimate the prevalence of depressive symptoms among parents of children with ASD in Taif, Saudi Arabia. We also want to evaluate the role of financial pressure and severity of ASD symptoms in the development of such depressive symptoms.

Methodology

Study design

This study was a cross-sectional questionnaire-based descriptive study. The study included a convenient sample of parents of children with ASD who attended Prince Mohammed Bin Salman Autistic Centre, Ministry of defence, Taif city.

A standard questionnaire included the PHQ-9 questionnaire in addition to various socio-demographic factors. The following points were considered when designing the questionnaire:

1. Age and sex of the affected child and age and sex of the surveyed parent.
2. Employment status and income of the participating parent.
3. The duration of ASD diagnosis, the level of ASD diagnosis, and if there were other affected children under the care of the parent.

Setting

The study included a convenient sample of parents of children with ASD who attended Prince Mohammed Bin Salman Autistic Centre, Ministry of defence, Taif city. We obtained approval from the Ethics and Research Committee in AlHada Military Hospital prior to commencement of recruitment of parents into the study. Ethical approval was granted on 15/04/2019 from Research and Ethics Committee in AlHada Armed Forces Hospital, Taif City, Saudi Arabia.

Data analysis

Data was analysed using the R-Statistical Software version 3.4.1. Categorical data (such as educational level, sex of parent, and income category) were summarised using frequencies and displayed using tables and bar-graphs. Numerical continuous data, such as the PHQ-9 score, were summarized using means and standard deviations and displayed using box-and-whiskers plots. The adjusted effect of categorical variables on the outcome variable (PHQ-9 score) was determined using multiple Poisson generalized linear regression modelling. The level of significance was set at $P \leq 0.05$.

Results

The study took place between January 2018 and December 2019 in a randomly selected public schools in Taif, Saudi Arabia. The total number of subjects approached to participate in the study was ($n = 50$) parents of children with ASD. All agreed to take part in the study (response rate = 100%). For a detailed account of demographic results see Table 1.

Most parents ($n = 28, 56\%$) were in the 41-50 years, age category, followed by ($n = 18, 36\%$) who were within the 31-40 years of age.

Majority of parents ($n = 30, 60\%$) were males and ($n = 20, 40\%$) were females.

There were only ($n = 9, 18\%$) of the parents who were divorced, with the rest ($n = 41, 82\%$) were in a married relationship. The majority ($n = 42, 84\%$) were employed, whereas ($n = 8, 16\%$) were unemployed. The most frequent income category was ($n = 16, 32\%$) between 10001 and 15000 SAR, followed by ($n = 13, 26\%$) between 15001 and 20000 SAR. Most participants were secondary school educated ($n = 28, 56\%$), followed by ($n = 17, 34\%$) who were university educated, and ($n = 4, 8\%$) who were holders of postgraduate degrees.

Table 1: Baseline demographics of the study participants

Factor	Count (n)/mean	Percentage/SD
Sex		
Males	30	60%
Females	20	40%
Age		
20-30	2	4%
31-40	18	36%
41-50	28	56%
51-60	2	4%
Marital Status		
Married	41	82%
Separated	9	18%
Education		
Primary	1	2%
Secondary	28	56%
University	17	34%
Higher education	4	8%
Employment		
Employed	42	84%
Unemployed	8	16%
Income		
Below 5K	9	18%
5K-10K	13	26%
10K-15K	16	32%
15K-20K	11	22%
Over 20K	1	2%
Relation child		
Father	28	56%
Mother	22	44%
Other ASD Child		
Yes	4	8%
No	46	92%
Child Sex		
Male		
Female		
Number of kids	mean=4.18	SD=1.69
Child age	mean=5.52 years	SD=1.13
ASD duration	mean=2.74	SD=0.75
ASD level		
I	20	40%
II	27	54%
III	3	6%

There were ($n = 28, 56\%$) fathers among the surveyed and ($n = 22, 44\%$) mothers.

In terms of the surveyed children, there were ($n = 20, 40\%$) girls and ($n = 30, 60\%$) boys.

Only ($n = 4, 8\%$) reported having another sibling with ASD, whereas the rest ($n = 46, 92\%$) reported no other family history of ASD.

The majority had level-II ASD ($n = 27, 54\%$), followed by level-I ASD ($n = 20, 40\%$), with only ($n = 3, 6\%$) had the most severe level-III ASD.

To explore the effect of background factors (namely; parents' age, parents' sex, parents' marital status, number of siblings, parents' employment, parents' income level, parents education and relation to the child) on the total PHQ score we modelled the data using multiple linear Poisson regression.

The mean PHQ total score was 10.7 (SD = 2.93). The prevalence of mild depression was ($n = 15, 30\%$, 95% CI: 17.3% to 42.7%), whereas the prevalence of moderately severe depression was ($n = 34, 68\%$, 95% CI: 55.1% to 80.9%). See Figure 1.

Only ASD level was associated with a significant impact on the PHQ-9 total score (level II was 1.293 times level I to have an increased PHQ-9 score, $P = 0.008669$). and level III was 1.530 times level I to have an increased PHQ-9 score, $P = 0.016179$). See Table 2 and Figure 2.

The rest of the factors did not significantly affect the PHQ-9 score. See Figures 3 and 4 for visualization of the estimates of all relevant factors on PHQ-9 scores.

Discussion

The results of our current survey confirm that ASD diagnosis in a child is associated with high prevalence of the severe form of depression among parents in Taif. Two-thirds of the participating parents showed symptoms of moderately severe depression. The remaining third were categorized into the mild depressive form. This result is overly concerning. Our findings show high level of emotional suffering among Saudi parents of children with ASD. We demonstrate that heightened levels of distress are associated with parenting a child with ASD. This is consistent

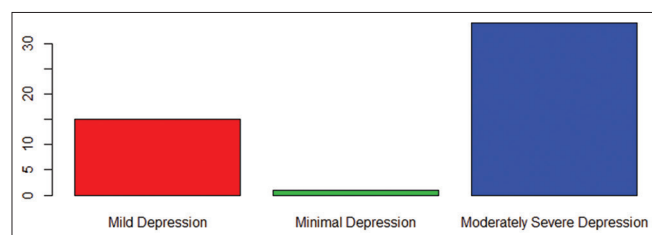


Figure 1: Prevalence of mild depression was ($n = 15, 20\%$), whereas the prevalence of moderately severe depression was ($n = 34, 68\%$)

with findings from longitudinal autism-related research. Past Saudi-based surveys confirmed increased rates of depressive and anxiety symptoms among parents caring for children with ASD.^[9] Many studies confirmed increased rates of parental depression in children with ASD, particularly a positive correlation exists between child behavioural challenges and parental depressive scores.^[10] Conversely, depressive psychopathology in parents is likely to be associated with emotional problems in their offspring^[11] particularly issues related to hyperactivity and inattention.^[12] However, a recurring theme in ASD children parental research is the shared-method bias as parents remain the source of information about both parent and child emotional problems.^[13] Hence, emotionally disturbed parents overreport their children's ASD severity.^[14]

Many theories exist to explain emergence of depressive symptoms among parents of children with ASD. One recent study confirmed a role for stigma felt by parents in fuelling depression. Stigma is largely caused by defective social interaction in autistic children and further worsened by repetitive behaviours in severe forms of ASD.^[15] Among Arabic-speaking communities, stigma was one of the most prominent theme for parents in dealing with ASD children.^[16]

One further proposed mechanism for how parenting children with ASD lead to depressive symptoms, is the so-called 'family process model'.^[17] A range of factors exert a positive association with parental affective symptoms. Future-related worry focuses on how the ASD child would cope in the future given their maladaptive characteristics. Parenting stress would arise when ASD child demands exceed parental capabilities.^[18] ASD in the child could cause marital disharmony and conflicts.^[19] Notably, prenatal stress and marital conflicts are inter-related and bidirectional in terms of causation.^[20] Finally, family economic pressures are likely to arise secondary to specific needs that are to be met for the ASD child.

Another important association we uncovered in the current survey is the increase in depressive symptoms with the severity of ASD. Our findings in Saudi parents of children with ASD

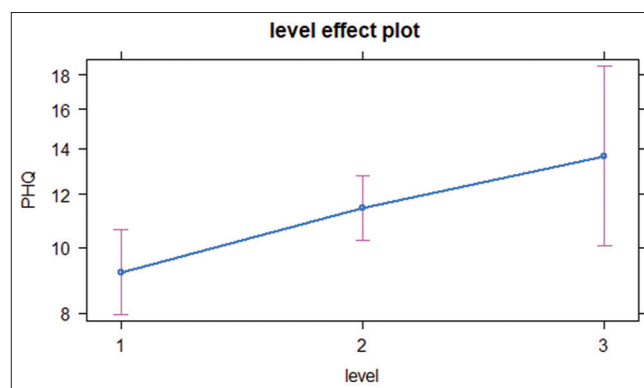


Figure 2: Level II ASD was 1.293 times level I more likely to have an increased PHQ-9 score, ($P = 0.008669$), and level III was 1.530 times level I more likely to have an increased PHQ-9 score, ($P = 0.016179$)

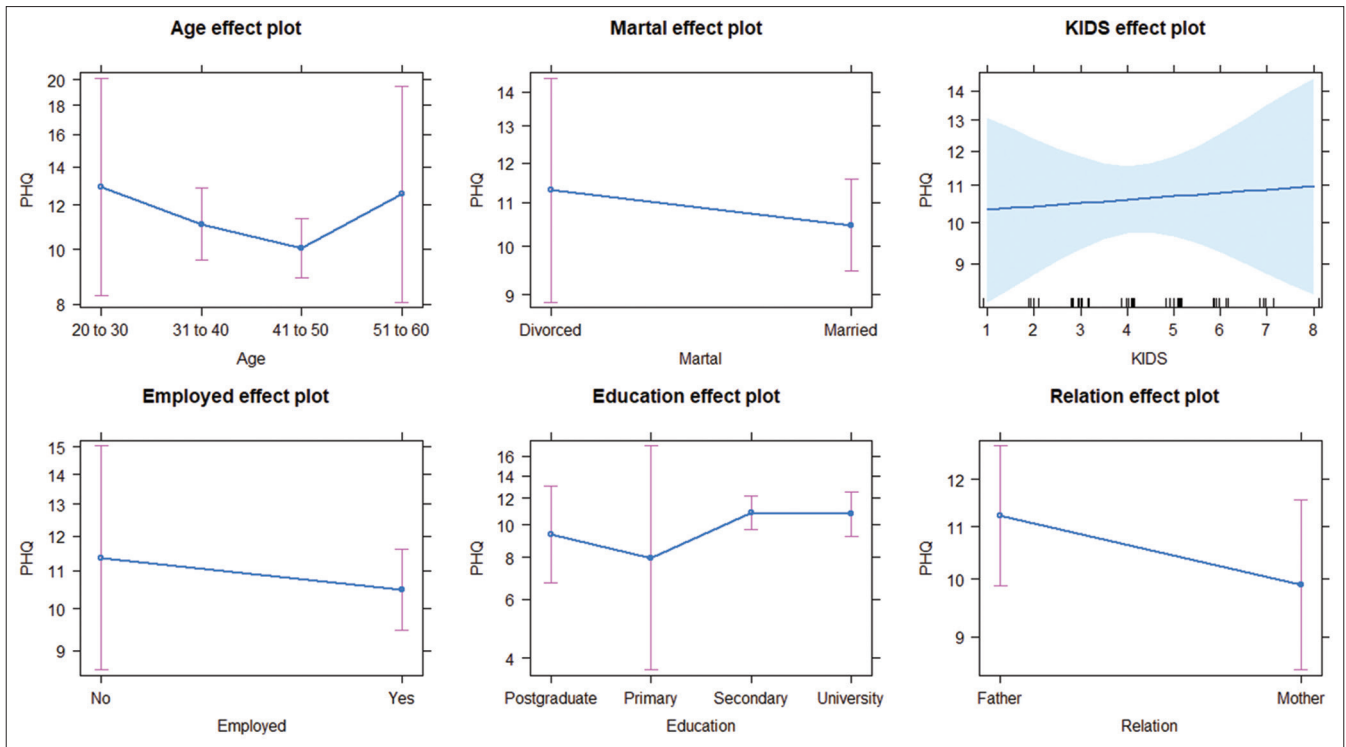


Figure 3: PHQ-9 score was not significantly affected by and of the parent-related background factors

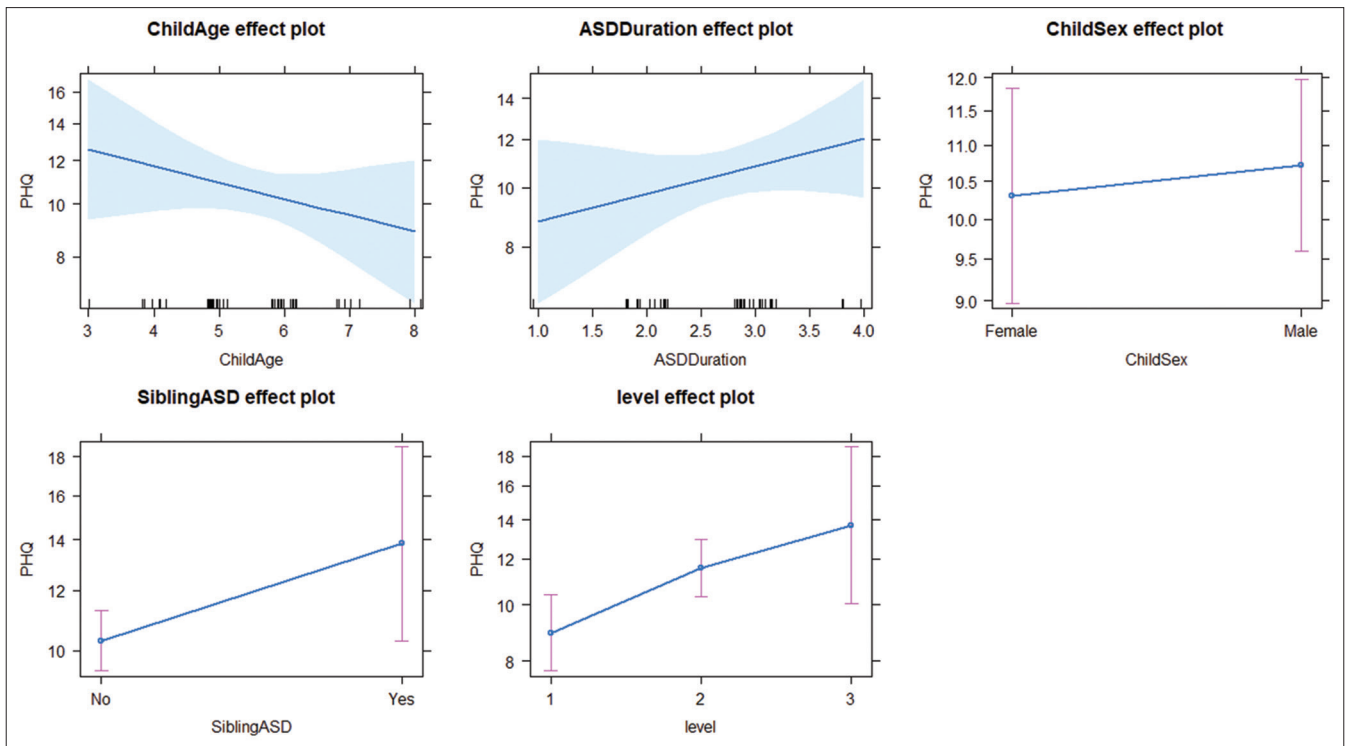


Figure 4: PHQ-9 score was not significantly affected by any of the child-related background factors except ASD severity level

corroborate the established association between parental depressive symptoms and ASD severity.^[21] One substantial facet in research into parenting and ASD is the strain in parent-child relationship caused by impaired social skills in the children with

ASD. Similarly, children with ASD development could be affected negatively by parental stress.^[22] Many recent behavioural parent interventions were effective in tackling ASD-related emotional problems in their children.^[23] Moreover, children with ASD

Table 2: Estimates for the effects of background parent and child factors on the PHQ-9 score

	Estimate	Odds	SE	95% CI odds	P
Age 31-40	-0.138	0.871	0.236	0.558-1.411	0.5582
Age 41-50	-0.277	0.758	0.255	0.466-1.271	0.2775
Age 51-60	-0.222	0.801	0.396	0.370-1.752	0.5756
Sex Male	0.275	1.317	0.254	0.786-2.134	0.2778
Married Status	-0.163	0.849	0.156	0.627-1.157	0.2951
Number of kids	0.038	1.039	0.039	0.961-1.122	0.3331
Employment	-0.570	0.566	0.425	0.231-1.243	0.1801
Income: 10001-15000	0.311	1.364	0.414	0.636-3.282	0.4524
Income: 15001-20000	0.498	1.646	0.454	0.702-4.235	0.2721
Income: 5001-10000	0.498	1.645	0.398	0.796-3.858	0.2104
Income: Over 20001	0.620	1.858	0.615	0.557-6.317	0.3139
Education: Primary	-0.132	0.877	0.486	0.323-2.208	0.7866
Education: Secondary	0.261	1.298	0.268	0.775-2.225	0.3311
Education: University	0.204	1.226	0.244	0.769-2.008	0.4039
Mother	0.070	1.073	0.236	0.661-1.670	0.7656
Child Age	-0.069	0.933	0.058	0.831-1.045	0.2368
ASD Duration	0.103	1.109	0.085	0.939-1.313	0.2267
Child Sex: Male	0.039	1.040	0.092	0.870-1.246	0.6715
Sibling with ASD	0.294	1.342	0.160	0.971-1.817	0.0653
ASD level II	0.257	1.293	0.098	1.069-1.570	0.0087*
ASD level III	0.425	1.530	0.177	1.068-2.141	0.0162*

are likely to have one or more comorbid mental disorder^[24,25] thereby putting further stress on parental wellbeing and family functioning.^[26] On a positive note, many studies found that mothers are mostly resilient, and, by time, develop better coping strategies to effectively mitigate the negative stressful impact of caring for an ASD child.^[27] Furthermore, ASD children fathers reported gradual acceptance of their children disorder and a focus on their integration and independence.^[28] Surely, such high level of resilience should be capitalized on when designing interventions that tackle affective problems in parents of children with ASD.

We found no significant difference between fathers and mothers in terms of depressive symptoms. Most previous research tended to focus on maternal depression. A positive association was established between depressive symptoms among mothers and higher burden of behavioural problems among children with ASD.^[29] One study explored paternal depression in the context of ASD child-related distress and found association with father-child relationship and early childhood behavioural difficulties.^[30] Our results corroborated previous findings that neither parental gender nor child gender exert any substantial effect on predictability of depressive symptoms among parents of children with ASD.^[10]

Although statistically nonsignificant, there was an upward increase in PHQ-9 score for the parents as the duration of ASD increased. This was intuitive, given the research findings that the longer the duration of living with ASD, the higher the rate of depressive and anxiety symptoms among parents.^[31] Local surveys confirmed that longer duration of ASD could directly lead to poorer quality of life among carers.^[32,33] Mothers tend to harbour a wide range of negative thoughts related to death and mortality that help

shape their depressive cognitions.^[34] The constellation of distress, depressive symptoms, and difficulties coping with ASD children needs, substantially negatively impact parents' quality of life.^[35,36] In Saudi Arabian parents of children with ASD, poor quality of life was found more in mothers and in families with poverty and unemployment issues.^[33] Mental health disorders in parents could be helped by addressing the self-perspective taken by parents and by boosting their problem-solving skills.^[37] Indeed, constructive psychoeducational interventions were effective in ameliorating stress-related and depressive symptoms among Saudi mothers of children with ASD.^[38]

The current study has many strengths. We used a validated structured tool, namely the PHQ-9, to identify the extent of depressive symptomatology. The response rate was substantial, as 100% of approached parents agreed to complete the survey. However, several limitations must be acknowledged. The cross-sectional one-off design does not allow for external generalizability of the attained results. Also, shared method bias (Podsakoff *et al.* 2003) could have affected the ASD severity rating by parents, as those with affective symptoms may over-estimate the ASD child-related behavioural disturbance.

Future research should explore the mediators that accentuate parental depression; namely stigma (vicarious stigma, courtesy stigma, public stigma, and self-stigma) and anxiety burden. Also, future research should explore the three-way association between depression in parents, ASD severity, and parental perception of their own parenting. Moreover, longitudinal and qualitative studies would give better estimates and in-depth thematic results that could inform effective clinical practice.

To sum up, increased risk of parental depression is posed by an ASD diagnosis in Saudi children. Depressive symptoms are potentially mediated by ASD severity, stigma, future-related worry, and stress. Screening for parental emotional problems should be routine in autism treatment facilities.

An important message to be highlighted is that holistic therapeutic packages for children with ASD should include treatment of emotional problems arising out of carer burden among their parents. Moreover, primary care physicians should be aware of such mental health issues in parents of children with ASD. Family physicians should be able to screen and treat depressive symptoms effectively in parents as well as children with ASD.

Conclusion and Recommendations

1. Interventions to reduce and eradicate ASD-related stigma could help attenuate stress, depression, and anxiety symptoms among parents
2. Multipronged family-targeting intervention programs should aim at improving family processes and reduce depressive symptoms
3. Comprehensive therapeutic packages for children with ASD should include treatment of emotional problems arising out

of carer burden among their parents

4. Screening for parental emotional problems should be routine in autism treatment facilities
5. Research on parental depression should include path analysis to explore how depressive symptoms develop and ascertain their moderators.

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Conflicts of interest

There are no conflicts of interest.

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