

## Health of Mothers of Children with Autism Spectrum Disorders and Intellectual Disability

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**Objective:** To evaluate the physical health, mental health, and quality of life (QOL) of mothers with Autism Spectrum Disorders (ASD) and Intellectual Disability (ID) children compared to mothers of typically developed controls (TD).

**Design:** A Cross-Sectional Study.

**Setting:** Psychiatric Hospital, Ministry of Health, Kingdom of Bahrain.

**Method:** Mothers' personal characteristics, general health, QOL and functioning were documented through direct interviews. The participants included 90 mothers, 30 in each group.

**Result:** Mothers of ASD children reported more psychological and environmental problems and received more help from family compared to mothers of ID and TD children. All groups obtained a similar score on the QOL total score and physical health score.

**Conclusion:** Mothers of ASD and ID children scored lower than those of TD children on general functioning and global assessment of function (GAF) measurement.

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Mother's mental and physical health, along with QOL is extensively studied; however, not in the Arabic culture regarding ASD and ID. ASD is a neuro-developmental disorder characterized by impairment in verbal and non-verbal communication, socialization, repetitive movements and restricted activities, while ID is a term used for individuals with an intelligent quotient (IQ) of less than 70 and limitation in adaptive skills that manifest before 18 years<sup>1</sup>. In a large population-based study, Kim et al showed that ASD is associated with ID in one-third of the sample<sup>2</sup>.

Mothers of ASD children appear to have poorer physical and mental health compared to mothers of TD children and those with other developmental disabilities<sup>3,4</sup>. Similarly, mothers of ASD and ID children are reported to have reduced QOL<sup>5</sup>.

Studies found poor physical health and lower QOL in mothers of children with ID or ASD<sup>6-8</sup>. Furthermore, mothers of ID children had the highest rate of psychiatric disorders compared to mothers of children without ID or ASD<sup>5</sup>. Therefore, these mothers appear to face more challenges in their ability to raise their children from both financial and healthcare perspectives, not to mention the challenges of stigma<sup>9</sup>.

The health of parents of ASD and ID children and their QOL were investigated in several countries in the Eastern Mediterranean region, including Bahrain. These reports revealed lower QOL and coping abilities in parents of ASD and ID children compared to parents of TD children<sup>10,11</sup>. Similar reports from the Arabian Gulf countries and Pakistan found that anxiety, stress, and depression are more common among mothers of children with ASD and ID compared to control groups<sup>12-14</sup>.

However, the above-mentioned studies suffered from multiple methodological problems, such as inappropriate control and different age groups. However, we investigated the QOL, general functioning and health of mothers of children with ASD and ID using multiple research.

The aim of the study is to evaluate physical health, mental health, and the QOL of the mothers of ASD and ID children compared to mothers of typically developed controls (TD).

### METHOD

Ninety mothers of children aged  $\leq 7$  years were recruited in three groups from the Bahrain Association of Intellectual

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Disability and Autism registry. The first and second were the study groups and the third group was the control. The first group consisted of mothers of children with ASD only (without ID). The second group consisted of mothers of children with an age and a sex-matched child with ID only (without any other medical/psychiatric comorbidity). The third group consisted of mothers of children matched for age group and sex (TD). Mothers of the control group were recruited from social contacts of mothers in groups one and two, to reduce social inequality.

All cases in the ASD and ID groups were diagnosed according to DSM-IV-TR, Criteria. Diagnosis of autism is made using the diagnostic specifics of Childhood Autism Rating Scale (CARS), Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT), the Autism Diagnostic Observation Schedule (ADOS) if applicable and Wechsler Intelligence Scales for Children (WISC). Diagnostic specifics for cases with ID include Wechsler Intelligence Scales for Children (WISC) and Adaptive Behaviour Scale (ABS). There was no exclusion criteria. Cases were recruited as a convenience sample. None of the mothers refused to participate.

Mothers were interviewed face-to-face by a trained research assistant, using a data collection form especially prepared for the study. The sociodemographic information focused on the presence of physical and mental difficulties, legal and mental problems and extra help necessary for the mother to care for the children. Additionally, the mothers were asked to complete two other forms: the General Health Questionnaire comprising 28 items and the WHOQOL-BREF, both of which are self-administered, taking 15–20 minutes to complete. At the end of the interview, the two authors independently completed the GAF for each case. Social class was constructed following modified Hollingshead and Redlich, where class 1 is high and 5 is the lowest<sup>15</sup>.

The WHOQOL-BREF tool has 26 items and four broad domains: physical health, psychological health, social relationships and the environment<sup>15</sup>. It has sound psychometrics with an internal consistency—measured using Cronbach alpha as 0.89, ranging from 0.74 to 0.77 for individual domains. All internal consistency estimates were above 0.70, demonstrating adequate internal consistency<sup>16</sup>. Inter-rater reliability measurements were within the acceptable ranges of -1.00 to 1.00 for most items<sup>17</sup>.

The GHQ-28 is an assessment tool intended to measure the risk of psychiatric illnesses. Several studies have investigated the reliability and validity of the GHQ-28 in various clinical populations and showed that the tool is psychometrically sound<sup>18</sup>.

The GAF is considered as axis III in the DSM-IV scale used by psychiatrists and professionals working in psychiatry to subjectively appraise an individual's social, job-related, and emotional functioning. Scores in the GAF range from 0 to 100. Zero is interpreted as unable to assess, 1–10 stand for severely impaired general level of functioning, and 90–100 is interpreted as extremely high level of general functioning<sup>19</sup>.

Informed written consent for participation in the study was signed by the mothers and the researcher.

Data were entered into SPSS version 25. The mean and Standard Deviation (SD) were reported for continuous variables; count and percentage were reported for categorical variables. Pearson Chi or Fisher's Exact test and One-way ANOVA were used to investigate the differences between groups<sup>2</sup>.

**RESULT**

Personal characteristics of the mothers and children from the three groups are shown in table 1.

**Table 1: Mother's Personal and Social Characteristics**

Item	Group						P Value
	< 7 Years ASD		< 7 Years ID		< 7 Years Control		
	N	%	N	%	N	%	
<b>Mother's Age*</b>	33.6±6.5		33.3±6.5		32.4±4.4		0.78
<b>Child's Age*</b>	4.9±1.0		4.5±1.5		3.7±1.0		0.001
<b>Marital Status</b>							
Married	29	96.7	28	93.3	29	96.7	0.73
Divorce	1	3.3	2	6.6	1	3.3	
<b>Mother's Education</b>							
University and Above	18	60	11	37	17	56.7	0.4
<b>Mother's Employment</b>							
Housewife	18	60	16	53.3	9	30	0.10
Employed	10	33.3	13	43.3	21	70	
<b>Socio-Economic Class</b>							
Classes 4 and 5 (Low)	20	66.7	24	80	19	63.4	0.002
<b>Chronic Illness</b>							
Present	9	30	4	13.3	3	10.7	0.10
<b>Psychiatric Illness</b>							
Present	3	10	0	0.0	0	0.0	0.04
<b>Family Problems</b>							
Present	7	23	1	3.3	2	6.7	0.08
<b>Legal Problems</b>							
Present	3	10	1	3.3	1	3.3	0.23
<b>Consanguinity</b>							
1st Degree	7	23.3	6	21.4	3	10	
2nd Degree	2	6.7	0	0.0	1	3.3	0.43
<b>Child Care</b>							
Family Member	23	76.7	8	26.7	11	36.7	0.002

\* Mean± Standard Deviation

The results of the GHQ28, WHOQOL BREF and GAF for the participants are presented in Table 2. Based on the GHQ-28, it was apparent that mothers of children with ASD or ID scored higher than mothers of healthy controls with a mean score of 7.5, 6.8 and 4.8, respectively. In particular, the prevalence of anxiety/insomnia is more pronounced among mothers of children with ASD and ID compared to mothers of TD children.

The overall QOL profile was similar for the three groups with a mean score of approximately 67%, using the WHOQOL-BREF. Subscale analyses revealed that mothers of ASD children scored lower than the other two groups. Mothers of

healthy children demonstrated a greater impact on the social relationship domain. Finally, mothers of ASD and ID children showed a greater impact on the environmental domain when compared to mothers with a healthy child.

**Table 2: Mother's Scores of GHQ-28, WHOQOL, and GAF**

Instrument	Group			Significance P Value
	< 7 Years ASD	< 7 Years ID	Controls	
GHQ-28 Total – Mean	7.5±1.1	6.8±1.1	4.6±0.90	0.149
Somatic Symptom – Mean	1.76±0.39	1.13±0.3	1.46±0.39	0.501
Anxiety/Insomnia – Mean	2.73±0.44	2.43±0.4	1.03±0.27	0.008
Social Dysfunction – Mean	1.60±0.28	1.46±0.2	1.06±0.28	0.392
Severe Depression – Mean	1.40±0.3	1.46±0.3	0.86±0.19	0.270
WHO QOL (Total)	67.5±3.3	67.7±2.6	68.1±1.5	0.987
Physical Health – Mean	69.5±2.8	73.1±2.4	74.9±2.4	0.32
Psychological Health – Mean	62.9±2.9	70.3±2.6	72.9±2.2	0.024
Social Relationships – Mean	69.4±2.8	60.4±4.0	51.3±1.8	0.001
Environment – Mean	61.8±2.8	66.8±3.0	73.1±2.2	0.017
GAF Mean Score	71.27±1.8	72.61±2.9	88.73±0.60	0.001

GAF scores revealed that mothers of a child with ASD or ID scored within the category 71–80 mean (71), which is defined as “symptoms are present, transient and expectable reactions to psychosocial stressors; no more than slight impairment in social, occupational, or school functioning”. Mothers of healthy children scored significantly higher on the GAF with a mean of 88.8, which reflects the category 81–90 and is defined as “absent or minimal symptoms (mild anxiety before an exam), good functioning in all areas, interested and involved in a wide range of activities, socially effective, generally satisfied with life, no more than everyday problems or concerns.”

## DISCUSSION

Two groups (ASD, ID) shared with the control group the mean maternal age, number of siblings, marital status, education level and the absence of legal issues related to their children. However, the ASD and ID groups differed in their social class representation (low classes 4 and 5), the presence of psychiatric disorders, family problems related to child-rearing practices and availability of familial help. More mothers from the ID group came from the lower social class. More mothers of ASD children had psychiatric disorders and family problems related to child rearing and receiving help from other family members compared to the ID and control group.

The rates of consanguinity among ASD and ID mothers (24% and 21%, respectively) were greater than mothers of TD children (13%). The rate of consanguinity among control group was similar to the general population<sup>20</sup>. This might emphasize the genetic role in the causation of ASD and ID<sup>21</sup>.

Physical and mental health were assessed using GHQ-28, completed by mothers, and GAF scored by two team members who agreed on the final score for each mother in each group. Both mothers of ASD children and ID children reported poor physical and mental health than mothers with healthy children.

The total score of GHQ-28 was 7.5, 6.8 and 4.6 among ASD, ID, and the control group, respectively. The GAF mean scores for the three groups were significantly different: 71.27, 72.61 and 88.73 for ASD, ID and the control group, respectively. Similar findings were reported by other studies<sup>22</sup>.

Tosko et al found no differences between the mothers' physical health, regardless of ASD or ID children compared to mothers of healthy controls<sup>22</sup>. Looking at the results from the physical health domain of WHOQOL, we found no significant differences between the three groups. These results suggest that the impact on mothers' physical health is not as strong as the effect on other aspects of QOL. The fact that mothers were not subjected to physical examination and medical files were not reviewed for the presence of physical illness might interfere with the accuracy of assessing the impact of having a developmentally delayed child on parental physical health.

The mothers of children with ASD and ID had poorer mental health than mothers of children without these disorders. This was clear from both the GAF and QOL psychological scores and the GHQ section on anxiety/insomnia. This is similar to other studies<sup>8</sup>.

Several studies confirmed the great impact of rearing a child with ASD on mother's mental health compared to mothers of TD children<sup>23,24</sup>. Fairthorne et al reported that mental health of the mothers of children with ID might be less adversely affected than that of the mothers of children with ASD, which is similar to our study<sup>8</sup>. However, the QOL total scores of the 3 groups remained similar, which could be the result of variation in the scores of subscales.

All previous studies found lower levels of well-being perception amongst mothers of children with ASD or ID. However, some studies reported more impairment among mothers of children with ASD, while others claimed poor QOL among mothers of children with ID<sup>25,26</sup>. The psychological and environment mean scores were significantly worse among mothers of children with ASD compared to mothers of children with ID or normally developed children.

The impact of raising a child with ASD was greater on maternal mental health and QOL than ID and control group.

Neither mothers nor children were the subjects of physical examinations. Data regarding children's cognitive function were not obtained either at initial diagnosis or at the time of the study. Another limitation is that we did not quantify the magnitude of disability among children with ASD or ID and its impact on mothers.

Further limitations include small sample size, selection bias and generalizability and that the study results were obtained from one cross section.

## CONCLUSION

**Mothers of children with ASD were identified as having more impaired mental health and psychological and environment section of QOL instruments compared to**

**mothers of children with ID and normally developed children. There was no significant difference between ASD, ID, control group in physical health, as well as a total score of QOL.**

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**Competing Interest:** None.

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**Ethical Approval:** Approved by the Secondary Healthcare Research Ethics Committee, Ministry of Health, Kingdom of Bahrain.

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