

Quality of Life of Mothers Having Children with Autism Spectrum Disorder

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Abstract

Background: mothering children with autism spectrum disorder (ASD) is widely identified to be associated with life-long stressors and challenges that negatively impact the Quality of Life (QOL) of parents. The study **aimed** to assess the quality of life of mothers having children with autism spectrum disorder. **Settings:** The study was conducted in the Outpatient Psychiatric and Neurological Clinics of both the Main University Hospital and Smouha Specialized University Hospital in Alexandria. **Subjects:** A convenient sample of 100 mothers who have children with ASD comprised the study subjects. **Tools:** Two tools were used to collect the necessary data; namely, Characteristics of Mothers and their Children with ASD Structured Interview Schedule and Pediatric Quality of Life Inventory™: Family Impact Module. **Results:** the overall parent functioning was low among 46% of mothers and moderate among 52% of them. Moreover, the overall family functioning was low among 64% of mothers. Generally, the overall QOL was low among 54% of mothers whereas 46% had a moderate level. **Conclusion:** It can be concluded that mothers of children with ASD are at high risk for impaired QOL across multiple domains of their lives. Accordingly, the overall QOL was low among more than half of mothers with the remaining showing moderate levels. **Recommendations:** A coordinated effort between governmental and non-governmental organizations is essential for providing support for families having ASD children. This collaboration should prioritize providing financial assistance and social support services, particularly for low-income and underserved communities.

Keywords: Autism Spectrum Disorder, Children, Mothers, Quality of Life.

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Introduction

Autism Spectrum Disorder (ASD) is considered "a neurodevelopmental disability that causes significant social communication deficits alongside restricted and repetitive patterns of behavior, interests, or activities". These core features lead to disruptions in daily life functioning (American Psychiatric Association, 2022). According to the World Health Organization (WHO, 2023), the prevalence of ASD is estimated to be 1 in 100 children globally. Whereas, about 1 in 36 children have been identified as ASD in the United States (Maenner et al., 2023). In

Egypt, it has been reported that 89 of 10,000 children had ASD (World Population Review, 2022).

Researchers have not yet identified a single trigger that causes ASD. However, it has been proposed to be a combination of genetic factors and environmental insults (Ali et al., 2019). Some genetic mutations seem to be inherited while others occur spontaneously (Rylaarsdam & Guemez-Gamboa, 2019). Regarding environmental factor, advanced parental age, mothers' exposure to chemicals and drugs during pregnancy, fetal hypoxia and

precipitating causes of ASD (Bölte et al., 2019).

Two domains are identified by the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5) to diagnose ASD. The first domain pertains to social communication and interaction deficits. This is evidenced by significant difficulties with nonverbal communication, and mutual social and emotional engagement. Whereas, the second domain encompasses behaviors characterized by limited flexibility and a tendency towards repetitive actions. This includes a strong focus on specific, uncommon interests and an insistence on following established routines (Hyman et al, 2020).

Raising children with ASD is inevitably associated with significant challenges among mothers that can negatively impact their well-being and Quality of Life (QOL). Quality of life is "a multifaceted concept encompassing an individual's subjective evaluation of their life in the context of their cultural background, value systems with relation to their goals, standards and concerns" (WHO, 2024). In such a context, the QOL of mothers having ASD children is disrupted due to the tremendous challenges they face. These challenges include difficulties in communication with their children, managing behavioral problems such as aggression and self-harm as well as financial strains and limitations imposed on social and leisure activities (Hsiao, 2018).

Pediatric nurses play a crucial role in providing care for children with ASD besides supporting their families, specifically mothers (Kassim & Mohamed, 2019). They are responsible for empowering mothers by acting upon their concerns regarding children's developmental limitations and behavioral problems in addition to directing them to specialists who are proficient in dealing with ASD (Neyoshi, 2018; Corsano et al., 2019). Moreover, they have to guide families toward safety precautions while dealing with their children (Wium &, Jongh,2018; Tola et al,

2021).). In this respect, pediatric nurses can help those mothers increase their awareness regarding such disability and provide them with sufficient resources to enhance their QOL.

Aim of the study

The present study aimed to assess the QOL of mothers having children with ASD.

Research question

What is the quality of life of mothers having children with ASD?

Materials and Methods

Study design:

A descriptive research design was used to accomplish this study.

Settings:

This study was conducted in the Psychiatric and Neurological Outpatient Clinics (PNOCs) of the Main University Hospital (MUH) and Smouha Specialized University Hospital for Children (SSUH) in Alexandria. Both settings serve Alexandria and the surrounding governorates. The PNOC of the MUH provides many services as performing intelligence tests and conducting communication skills development programs for children with communication disabilities. For the PNOC of SSUH, it provides many services including follow-up services for children with disabilities such as delayed milestones, Attention Deficit Hyperactive Disorders, and ASD.

Subjects

Epi info program V 10.0 was used to estimate the sample size using the following parameters: expected frequency of errors 50%, margin of error 5%, and Confidence Coefficient 95%. Minimum sample size was 97. So, a convenient sample of 100 mothers having children with any level of ASD and free from other chronic illnesses comprised the study subjects. Children's ages ranged from 3 to 6 years.

Tools

Two tools were used for data collection.

Tool I: Characteristics of Mothers and their Children with ASD Structured

Interview Schedule. It included two parts. Part 1 comprised socio-demographic characteristics and medical data of mothers such as age, educational level, occupation, and presence of chronic health problems. Part 2 involved characteristics and medical data of children such as age, sex, and birth order in addition to the level of ASD and onset of diagnosis.

Tool II: Pediatric Quality of Life Inventory™: Family Impact Module (PedsQL™ 2.0) which was developed by Varni et al. (2004). It contains eight subscales with 36 items. Six of these subscales focus on parent functioning, while the remaining two subscales target family functioning. Each item was rated on a five-point Likert scale ranging from "never a problem (0)" to "almost always a problem (4)". The total score ranged from 0 To 144 the total percent score of mothers' QOL levels was classified as follows: Low QOL (0- less than 50%), Moderate QOL (50%- less than 75%), and High QOL (75% - 100%)

Method

- Approval from the Research Ethics Committee of the Faculty of Nursing, Alexandria University was obtained. Permission was obtained from the previously mentioned settings to conduct the study after clarifying its aim.
- Tools were tested for their content validity by five Pediatric Nursing experts, and it was 95% for Tool I and 94% for Tool II. The reliability of tool II was ascertained by measuring its internal consistency and it demonstrated high reliability where Cronbach's alpha Coefficient ($r = 0.881$)
- The pilot study was carried out on 10 mothers to test the feasibility of tools. No modifications were made. Those mothers were excluded from the study subjects.
- Every mother was interviewed individually, and the interview session lasted for approximately 15-20 minutes. The data were collected for 7 months starting from the beginning of July 2021 to January 2022.

Ethical Considerations

Written informed consent was obtained from mothers after explaining the aim of the study. Their voluntary participation and the right to withdraw from the study at any time were emphasized. Confidentiality of data was ascertained, also the privacy and anonymity of mothers were maintained.

Statistical analysis

Data were fed to the computer and analyzed using IBM SPSS software package version 20.0. (Armonk, NY: IBM Corp). Kolmogorov-Smirnov test was used to verify the normality of data distribution. Qualitative data were described using numbers and percentages. Quantitative data were described using mean and standard deviation. Student t-test was used for normally distributed quantitative variables, to compare between two categories. The F-test (ANOVA) was used for normally distributed quantitative variables, to compare between more than two categories. The significance of the obtained results was judged at the 5% level.

Results

Table (1) illustrates the socio-demographic characteristics and medical data of mothers. More than half of mothers were in the age group from 30 to less than 40 years (59%). Nearly one-third of mothers (29%) finished secondary education whereas 22% were illiterate. The majority of mothers (81%) were housewives and 88% had one or two children. The income of 63.0% of families was insufficient for living. Regarding medical data, 23% of mothers had chronic health problems as 47.8% of them had diabetes mellitus.

Table (2) portrays the characteristics and medical data of children with ASD. The age of 51% of children ranged from 5 to 6 years. The majority of children (87%) were males and 65% were first-born. The majority of children (81%) had been diagnosed with ASD at the age of 3 to 4 years. Less than half of children (47.0%) had a mild level of ASD

and 19.0% had a severe level. Nearly one-third of mothers (31%) were not committed regularly to their children's follow-up.

The percentage distribution of mothers' quality of life levels is illustrated in **Table (3)**. Concerning parents' functioning, 74% and 68% of mothers had **low** QOL related to worry and communication respectively. Moreover, 53%, 48% and 44% had **low** QOL in emotional, social and physical functioning respectively. However, 51% had **high** cognitive functioning. Regarding family functioning, 69% of mothers had **low** QOL in daily activities. In family relationships, 47% of mothers had **moderate** QOL and 39% had a **low** level. Overall parent functioning was **low** among 46% of mothers and **moderate** among 52% of them. Moreover, the overall family functioning was **low** among 64% of mothers.

Figure (1) illustrates mothers' overall quality of life levels. Overall QOL was **low** among 54% of mothers. Nevertheless, 46% of mothers had a **moderate** level.

The relationship between mothers' quality of life and their characteristics is presented in **Table (4)**. The QOL was lower among older mothers aged 40 years or more (53.14 ± 17.36) compared to younger ones with no statistically significant difference. Illiterate mothers demonstrated the lowest level of QOL (55.41 ± 16.83) compared to other educational levels and the difference was highly significant ($P=0.001$). Also, mothers who had four children obtained the lowest QOL (46.08 ± 9.39) compared to other mothers and the statistical difference was highly significant ($P=0.001$). Regarding family income, mothers who reported having insufficient income obtained lower QOL (63.65 ± 19.11) compared to those with sufficient income and the difference was statistically significant ($P=0.004$).

Table (V) presents the relationship between mothers' quality of life and their children's characteristics. Mothers of older children in the age group from 6 to 7 years encountered the lowest QOL (62.65 ± 20.07)

compared to other ones having younger age groups. Mothers of female children also had lower QOL (64.92 ± 16.12) compared to mothers of male children (68.32 ± 19.78). Mothers whose third-born child was diagnosed with ASD experienced lower QOL (55.09 ± 17.65) compared to those having children with other birth orders and the difference was statistically significant ($P=0.001$). Regarding the severity level of ASD, mothers of children with severe ASD had the most disrupted QOL (49.11 ± 16.87) with a highly statistically significant difference ($P=0.001$). Predictably, mothers who were committed to regular follow-up of their children's condition had high QOL (71.14 ± 19.52) compared to those who were not with a statistically significant difference ($P=0.011$).

Discussion

Parenting comes with normal distinct stress, which emanates explicitly from a range of responsibilities (Crnic & Ross, 2017). However, parents have to redefine their journey of parenthood when their children are diagnosed with ASD. As a primary care provider, mothers spend extraordinary physical and emotional efforts to support their children's needs which results in a grave impact on their QOL (Koçak et al., 2023). In this regard, the result of the current study highlighted that nearly half of mothers had **low** QOL (Figure 1). This finding may be attributed to the chronicity of ASD and associated stressors that serve as a source of chronic psycho-social and physical pressure which in turn affect mothers' well-being and QOL. This aligns with the findings of Musetti et al. (2021), whose research indicated that parents of children with ASD experience a greater risk of diminished QOL compared to parents of typically developing children.

Children with ASD experience a complex range of difficulties that put mothers at risk of experiencing a devastating state of worry and social withdrawal (Bramhe, 2019). Likewise, the current study findings revealed that impaired mothers' QOL was reflected

mostly in feelings of worry and disrupted communication. As, nearly three-quarters of mothers had low QOL related to worries and communication (Table 3). Mothers' worries may be related to the ambiguity of such disability prognosis that may affect their children in the future besides being overwhelmed by the education process as they have concerns regarding the non-admission of their children in mainstream schools. In this regard, Herrema et al. (2017) reported that parents of ASD children often have worries and fears due to the impact of such disability on their children in the future.

Regarding debilitated mothers' communication, the reaction of others toward disabled children may explain the present findings where some people can be dismissive and judgmental about children with ASD. As well, the complexity of health professionals' language and failure to include parents' voices in their children's plan of care may impose further communication obstacles. The current study finding is congruent with Smith-Young et al. (2020) who cited that parents of children with ASD often have communication obstacles.

Mothers of children with ASD commonly experience higher levels of anxiety, stress, and depression (Li et al., 2022). Similarly, the present study findings displayed that more than half of mothers of children with ASD demonstrated low emotional functioning (Table III). This finding could be attributed to the stress and frustration experienced by mothers due to their children's maladaptive behavior. Additionally, mothers may have guilt feeling and anger resulting from the rejection of their children concurrent with the stigmatization of such disorder. All these factors can threaten the emotional health of the whole family, particularly mothers. Accordingly, Al-Tourah et al. (2020) who reported that emotional problems such as anxiety, anger and depression were highly prevalent among mothers of children with ASD which affect their well-being.

The present study findings also illustrated that nearly half of mothers had low QOL related to physical and social functioning (Table 3). Low physical functioning may be due to the extra physical activities these mothers have to do because of the continuous care required by their children with ASD. Also, follow-up appointments and constant monitoring of their children's condition can be overwhelming for most mothers. Because of this physical malfunctioning, mothers may complain of not having enough energy or time for social activities which impacts their social life. Simultaneously, social withdrawal may be displayed by mothers as a maladaptive coping strategy that serves to alleviate their anxiety and embarrassment. Similar findings were reported by Whittaker and Gallagher (2019) who found that caregivers of children with ASD often experience poorer physical health compared to their counterparts. Also, Shattnawi et al. (2020) reported that social functioning was jeopardized among mothers of children with ASD.

Interestingly, the present study finding revealed that half of the mothers had “**high**” QOL related to the cognitive domain (Table III). These findings may be justified by the acceptance and patience demonstrated by some mothers during critical situations that are linked with devotion to God and being a step to heaven in the Islamic culture. Some mothers also tend to think and take positive actions regarding their children's disability rather than just getting anxious or depressed. The current study result is not consistent with the findings of Lovell and Wetherell (2024) who stated that Caregivers of children on the autism spectrum reported more prospective memory failures.

Regarding family functioning, the current study showed that two-thirds of mothers of children with ASD demonstrated low QOL (Figure 2). This finding may be justified by impaired family daily activities and relationships as demonstrated by Table III. Hence, family members are drastically

forced to alter their everyday routines to accommodate with the new reality of having a disabled child suffering from ASD. Furthermore, having a child with such a disorder puts added strain on the marriage and partnership. simultaneously, Godfrey et al. (2023) reported that having a child with ASD drives the family to less family cohesion and poor overall family functioning.

Several factors affect the QOL of mothers who have children with ASD, such as maternal age and educational level (kasem, 2024). Concerning maternal age, the results of the present study showed that QOL was low among older mothers compared to younger ones (Table 4). This finding may be attributed to the lack of physical energy required to deal with the demands of those children. Moreover, younger mothers can use social media and connect with different social groups concerned with caregiving of children with ASD which helps them adapt positively. Conversely, Yorke et al (2018) stated that increased maternal age was associated with lower stress and boosted well-being among mothers of children with ASD.

The current study findings revealed that mothers who finished either university or secondary education encountered high QOL compared to other educational levels with highly statistically significant difference (Table 4). This finding could be attributed to the higher level of education that could function as a protective factor in understanding the child's internal world and accepting such a diagnosis. Furthermore, mothers who had university or secondary education may have a higher awareness of the nature of ASD, recent management strategies and prognosis which positively impact their well-being. The current study result is consistent with the findings of Ahmed et al. (2023) who stated that parents with high educational levels have improved QOL.

Characteristics of children with ASD such as gender and severity level of the disease may have an impact on the QOL of parents (Ooi et al., 2016). Concerning the

gender and birth order of children with ASD, the present study findings revealed that mothers of female and third-born children had lower QOL compared to other mothers (Table 5). These findings might be justified by mothers' anxiety regarding the inability of their female children to protect themselves against physical or psychological threats they may experience later in life. In such context, the findings of Alenazi et.al (2020) illustrated that parents of female children with ASD were five times more likely to have poor QOL compared to other mothers.

Regarding the severity of ASD, the current study findings portrayed that mother of children with a severe level of ASD had significant impairment in their QOL compared to mothers of children with other levels (Table 5). These challenges may stem from the increased care and attention needed for children with severe ASD which contribute to higher levels of anxiety and stress among mothers, ultimately impacting their overall well-being. Also, children with severe ASD suffer from much deviation in their behavior and communication skills which adversely results in lower self-efficacy and QOL among those mothers. Likewise, Patel et al. (2022) concluded that mothers of ASD children with severe behavioral impairment had lower QOL.

The findings of this study underscore the urgent need to address the significant challenges faced by mothers raising children with ASD. These challenges can have a debilitating impact on the mothers' QOL, by affecting their psychological, physical, and social functioning, and ultimately impacting the entire family.

Conclusion

Depending on the findings of the current study, it can be concluded that mothers of children with ASD are at high risk for impaired QOL across multiple domains of their lives. Accordingly, the overall QOL was low among more than half of mothers with the remaining showing moderate levels. It is noteworthy that nearly half of the mothers

reported low QOL in overall parent functioning, and a significantly higher proportion, approximately two-thirds, experienced low QOL in the overall family functioning.

Recommendations

Based on the findings of the current study; the following recommendations can be suggested:

- Simple illustrated booklets and posters including guidelines for mothers about the care of their children with ASD should be available in each setting providing care for those children
- Support groups of parents who share similar experiences should be created to strengthen their coping mechanisms and enhance the self-sufficiency of families raising children with ASD.
- Governmental and non-governmental organizations' efforts should be integrated to provide support for families of children with ASD. This collaboration should include financial assistance and social support for low-resource and underserved communities.

Table (1): Socio-demographic Characteristics and Medical Data of Mothers

Socio-demographic characteristics of mothers		No (n=100)	%
Age /year	▪ 20-	34	34
	▪ 30-	59	59
	▪ 40 and more	7	7
Min-max 22.0 – 42.0 Mean ± SD 32.06 ± 5.44			
Educational level	▪ Illiterate	22	22
	▪ Read and write.	13	13
	▪ Finished primary education	4	4
	▪ Finished preparatory education	10	10
	▪ Finished Secondary education	29	29
	▪ Finished university education	17	17
	▪ Enrolled or completed post-graduate studies	5	5
Number of children	▪ 1-	88	88
	▪ 3- 5	12	12
Occupation	▪ Housewives	81	81
	▪ Employed	19	19
Type of family	▪ Extended	44	44
	▪ Nuclear	56	56
Residence	▪ Rural	12	12
	▪ Urban	88	88
Family Income	▪ Sufficient	37	37
	▪ Insufficient	63	63
Having chronic health problems	▪ Yes	23	23
	▪ No	77	77
Type of health problems * (n= 23)	▪ Hypertension	7	30.4
	▪ Diabetes mellitus	11	47.8
	▪ Arthritis	4	17.4
	▪ Asthma	1	4.35
	▪ Thyroid gland	3	13.0
	▪ Irritable bowel syndrome	2	8.69

* Multiple responses were given

Table (2): Characteristics and Medical Data of Children with Autism Spectrum Disorder.

Characteristics of children		No (n=100)	%
Age /years	▪ 3-	11	11
	▪ 4-	38	38
	▪ 5- 6	51	51
Min-max 3 - 6 Mean±SD 3.81±1.43			
Gender	▪ Male	87	87
	▪ Female	13	13
Birth order	▪ First	65	65
	▪ Second	24	24
	▪ Third	11	11
Onset of ASD (years)	▪ 2	19	19
	▪ 3-4	81	81
Level of ASD	▪ Mild	47	47
	▪ Moderate	34	34
	▪ Severe	19	19
Commitment to regular follow-up	▪ Yes	69	69
	▪ No	31	31
Reasons of non-commitment * (n=31)	▪ Financial constraints	22	70.9
	▪ Distance obstacles	5	16.1
	▪ Lack of time	12	38.7
	▪ Physical exhaustion	18	58.1

* Multiple responses were given

Table (3): Percentage Distribution of Mothers' Quality of Life Levels.

Mothers' QOL	Levels of QOL (n=100)			
	Low	Moderate	High	Mean percentage score
	%	%	%	
Parents' functioning	46.0	52.0	2.0	49.50 ± 15.67
▪ Physical functioning	44.0	42.0	14.0	53.87 ± 18.62
▪ Emotional functioning	53.0	38.0	9.0	43.30 ± 20.69
▪ Social functioning	48.0	30.0	22.0	46.13 ± 25.53
▪ Cognitive functioning	24.0	25.0	51.0	64.75 ± 28.14
▪ Communication	68.0	28.0	4.0	37.00 ± 18.74
▪ Worries	74.0	25.0	1.0	37.90 ± 14.74
Family functioning	64.0	30.0	6.0	43.56 ± 18.01
▪ Daily activities	69.0	21.0	10.0	36.25 ± 21.85
▪ Family relationships	39.0	47.0	14.0	47.95 ± 21.99

Figures (1): Mothers' Overall Quality Of Life Levels.

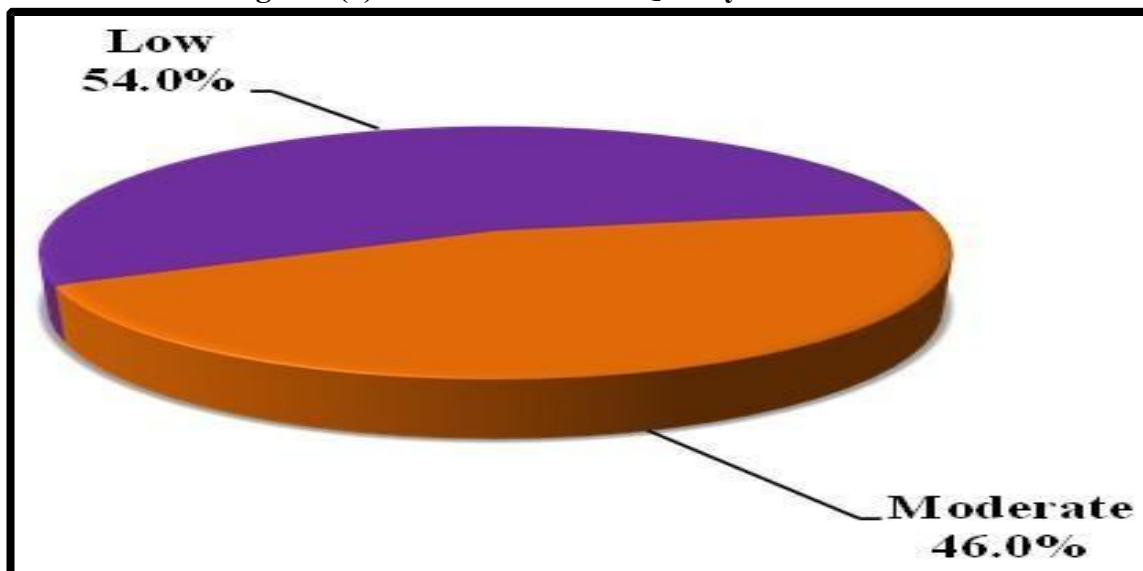


Table (4): Relationship between Mothers' Quality of Life and their Characteristics

Characteristics and medical data of Mothers		Mean Percentage Scores of QOL	Significance
Age /year	<ul style="list-style-type: none"> ▪ 20 - ▪ 30 – ▪ 40 and more 	70.26 ± 20.60 68.25 ± 18.27 53.14 ± 17.36	F= 2.374 P=0.098
Educational level	<ul style="list-style-type: none"> ▪ Illiterate ▪ Read and write ▪ Finished primary education ▪ Finished preparatory education ▪ Finished Secondary education ▪ Finished university education ▪ Enrolled/ completed post-graduate studies 	55.41 ± 16.83 59.77 ± 16.31 64.00 ± 9.97 57.10 ± 13.49 73.76 ± 16.21 80.0 ± 18.91 65.60 ± 13.01	F=5.154* P=0.001*
Occupation	<ul style="list-style-type: none"> ▪ Employed ▪ Housewife 	69.26 ± 17.11 67.56 ± 19.87	t=0.345 P=0.731
Having health problems	<ul style="list-style-type: none"> ▪ Yes ▪ No 	66.39 ± 21.52 68.62 ± 18.68	t=0.703 P=0.484
Type of family	<ul style="list-style-type: none"> ▪ Nuclear ▪ Extended 	67.25 ± 18.79 68.68 ± 20.13	t=0.367 P=0.715
Number of children	<ul style="list-style-type: none"> ▪ 1 ▪ 2 ▪ 3 ▪ 4 	87.27 ± 17.24 70.86 ± 15.04 62.90 ± 18.27 46.08 ± 9.39	t=16.353 P=0.001*
Place of residence	<ul style="list-style-type: none"> ▪ Urban ▪ Rural 	68.66 ± 19.25 62.17 ± 19.57	t=1.094 P=0.277
Family Income	<ul style="list-style-type: none"> ▪ Sufficient ▪ Insufficient 	75.08 ± 17.64 63.65 ± 19.11	t=2.969 P=0.004*

Table (5): Relation between Mothers' Quality of Life and their Children's Characteristics

	Characteristics of Children	Mean Percentage Scores of QOL	Test of Significance
Age /years	<ul style="list-style-type: none"> ▪ 3- ▪ 4- ▪ 5- ▪ 6-7 	79.73 ± 21.41 69.67 ± 15.32 68.61 ± 19.02 62.65 ± 20.07	F=2.474 P=0.066
Gender	<ul style="list-style-type: none"> ▪ Male ▪ Female 	68.32 ± 19.78 64.92 ± 16.12	t=0.590 P=0.556
Birth order	<ul style="list-style-type: none"> ▪ First ▪ Second ▪ Third 	72.80 ± 17.89 60.42 ± 19.32 55.09 ± 17.65	F=7.096* P=0.001*
Enrollment in nursery school	<ul style="list-style-type: none"> ▪ Yes ▪ No 	64.56 ± 19.04 76.43 ± 17.55	t=2.860* P=0.005*
Level of ASD	<ul style="list-style-type: none"> ▪ Mild ▪ Moderate ▪ Severe 	72.62 ± 18.14 71.82 ± 15.91 49.11 ± 16.87	F=14.034* P=0.001*
Commitment to regular follow-up	<ul style="list-style-type: none"> ▪ Yes ▪ No 	71.14 ± 19.52 60.61 ± 16.95	t=2.595* P=0.011*

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