



## Original Research Article

## Factors affecting quality of life among parents having a child with autism spectrum disorder in Jeddah, 2019 (cross-sectional study)

Abeer Ahmad Subke<sup>1,\*</sup>, Adeel Ahmed Khan<sup>1</sup>, Safinaz Abdullah Alharthi<sup>2</sup>

<sup>1</sup>Saudi Board Program of Preventive Medicine, Makkah, Saudi Arabia

<sup>2</sup>Saudi National Center for Developmental and Behavioral Disorders, East Jeddah Hospital, Jeddah, Saudi Arabia



## ARTICLE INFO

## Article history:

Received 15-05-2020

Accepted 23-05-2020

Available online 05-08-2020

## Keywords:

Autism spectrum disorder

Quality of life

Parents

Physical health

Psychological

Social relationships

Environment

Jeddah

## ABSTRACT

**Background:** Nurturing a child with Autism Spectrum Disorder (ASD) can cause major distress. As a result, these parents tend to experience a poor quality of life (QoL) compared to those raising typically developing (TD) children.

**Objectives:** To evaluate the factors which affect the QoL of parents raising children clinically-diagnosed with ASD in Jeddah, and to provide knowledge for the establishment of comprehensive policies and projects that can improve their mental well-being.

**Materials and Methods:** A cross-sectional study design was utilized to assess 200 parents of children clinically-diagnosed with ASD at least 3 months prior to the research. A self-administered WHOQOL-BREF questionnaire was employed to assess the QoL of participants through four domains, namely physical health, psychological well-being, social relationships, and environment.

**Results:** Most of the participants were female (58.5%), married (87.0%), and employed (56.5%). Majority completed high school (68.5%), lived in the city (95.5%) and rented their homes (88.5%). Quality of life was significantly affected by gender, employment, social status, and educational attainment of participants. Parents with higher educational attainment and employment and social status exhibited better. Furthermore, female parents experienced lower QoL and more depressive symptoms than males.

**Conclusion:** Gender, educational attainment, and both employment and social status significantly affected the QoL of parents raising children diagnosed with ASD. Furthermore, improving the physical health, psychological, social relationships, and environment of these parents would give them a better QoL and health satisfaction.

© 2020 Published by Innovative Publication. This is an open access article under the CC BY-NC license (<https://creativecommons.org/licenses/by-nc/4.0/>)

### 1. Introduction

Neurodevelopmental disorders usually occur during the early years of children's development. One of the most prevalent types, as stated in the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5) classification system, is the Autism Spectrum Disorder (ASD). This disorder is frequently seen among children of ages three and below.<sup>1</sup>

Although the severity of ASD varies from child-to-child, its clinical manifestations are identical and include personal, social, academic, emotional, and occupational impairment.

\* Corresponding author.

E-mail address: [abeer\\_subki@hotmail.com](mailto:abeer_subki@hotmail.com) (A. A. Subke).

In addition to this, a decline in both verbal and non-verbal communication skills and restrictions in hobbies and behaviors can be perceived.<sup>2,3</sup> Children diagnosed with ASD also typically experience hyperactivity and impulsivity. However, more extreme problems associated with ASD may arise when these children are not given the attention that they need. Self-injury, aggression, and irritability are a few of these problems.<sup>4</sup>

It is said that parental stress and psychological well-being have been consistently predicted by the gravity of the child's behavior. A study done in Greece showed that parental stress significantly worsened in response to the temperament and severity of the symptoms of children with ASD. Furthermore, additional parental pressure has resulted

in the decline of the quality of life (QoL) of participating parents.<sup>5</sup> Similar studies exhibit such connection between a child's behavior and parents' QoL.

According to Schalock et al.,<sup>6</sup> QoL is a multifaceted idea that considers both health and non-health-related disciplines. Some of these common vital domains include common vital aspects, namely, personal growth, interpersonal relationships, social involvement, rights, and overall well-being.<sup>6</sup>

Parenting a child diagnosed with ASD is both demanding and exhausting among many parents. Compared to the parental distress reported by parents of children diagnosed with Down Syndrome, the parental burden of parents nurturing children with ASD was usually reported to be much higher.<sup>7,8</sup> The anxiety felt by parents raising typically developing (TD) children, on the other hand, was lower than those with Down Syndrome and ASD.<sup>9,10</sup>

Many studies have associated the distress faced by parents nurturing a child with ASD with several factors such as its symptoms and severity, the coping strategies utilized by the parents, and other external factors such as educational attainment and social support.<sup>11–15</sup>

It has been reported that both language and cognitive impairment have caused much distress for many parents. The verbal incapability of a child affects the perspective and, consequently, the coping strategies of parents.<sup>12,14,15</sup> In addition to this, the cognitive inconsistency of a child increases the frustration felt by the parents because it would be challenging for the former to improve his or her areas of strength and weaknesses.<sup>12</sup> Moreover, studies have shown that increased behavioral issues, as well as limited social care, have much affected the psychological well-being of parents of children diagnosed with ASD. Nevertheless, this outcome is typically more serious among mothers.<sup>11,13</sup>

The measurement of QoL has, in fact, proven to be a useful and significant mediator to establish effective programs parallel to the struggles experienced by parents raising children diagnosed with ASD. For instance, a study in the United Kingdom showed the need for behavioral and supportive interventions to result in a gradual decline in the frustration felt by parents of children diagnosed with ASD.<sup>16</sup> This finding was also supported by Herring et al., who mentioned the need to address the emotional and behavioral problems of children diagnosed with ASD to improve the QoL of their parents.<sup>17</sup>

## 2. Aim and Objectives

To evaluate and to identify the factors which may influence the QoL of parents raising children diagnosed with ASD in Jeddah.

## 3. Materials and Methods

### 3.1. Study design

This research was an analytical cross-sectional study conducted at the Saudi National Center for Developmental and Behavioral Disorders at East Jeddah Hospital (EJH).

### 3.2. Sampling

The study group consisted of 200 parents of children aged 2 to 14 and clinically diagnosed with ASD at least 3 months before the start of this study. Meanwhile, parents who were diagnosed with any psychiatric illness and those of children with ASD who have siblings diagnosed with ASD or other persistent medical diseases were excluded from the study group.

### 3.3. Instrument

This research utilized a self-administered validated Arabic version of the WHO Quality of Life - BREF (WHOQOL-BREF) questionnaire that assessed the QoL of parents through four areas, namely their physical health, psychological well-being, social relationships, and environment. These self-administered questionnaires were given to the participants on their scheduled appointment days.

### 3.4. Ethics

This study was approved by the Saudi Board of Preventive Medicine Research Committee and the Ethical Committee of the Research and Studies Administration at the General Directorate for Health Affairs in Jeddah prior to data collection. Informed consent forms were obtained from all participants. All data were entered and analyzed anonymously and secured only for the purpose of the study.

### 3.5. Statistical analysis

This research was evaluated using the SPSS version 23. Categorical and nominal variables were presented through frequencies and percentages. Meanwhile, continuous data was analyzed using independent t-test and One-way ANOVA upon the assumption of a normally distributed data. After the ANOVA was performed, a Least Significant Difference (LSD) post hoc test was conducted. Contrarily, Welch's t-test for two group means, as well as Games Howell for multiple groups, were applied as a substitute for the LSD post hoc test. Furthermore, a Pearson's correlation coefficient and a General Linear Regression Model (GLRM) were applied to identify significant predictors using a Main Effect model with a p-value less than 0.05 as a base to renounce the null hypothesis.

## 4. Results

### 4.1. Characteristics of the study population

The study population consisted of 200 parents raising children diagnosed with ASD. The participants aged between 23 and 45, with an average age of 34.46. More than one-half of the parents were females (58.5%) compared to males (41.5%). Majority completed high school (68.5%), whereas only 19.5% completed elementary education, 8.0% postgraduate, and 4.0% primary education. A great majority were married (87.0%), while 11% were divorced and 1.5% widowed. Most of the participants resided in the city (95.5%) and rented their homes (88.5%). More than one-half of the participants were employed (56.5%) (Table 1).

### 4.2. Factors associated with the four domains of quality of life of parents

An array of preliminary investigations was conducted to identify links between demographic parameters (age, gender, education, house, and employment) and the four domains. No significant relationship was determined among the age of the parent for all domains, specifically physical health ( $r = 0.078$ ,  $p = 0.277$ ,  $N = 195$ ), psychological ( $r = 0.052$ ,  $p = 0.474$ ,  $N = 195$ ), social relationships ( $r = -0.021$ ,  $p = 0.738$ ,  $N = 195$ ), and environment ( $r = 0.024$ ,  $p = 0.738$ ,  $N = 195$ ). Hence, the age of the parents does not affect their QoL.

Table 2 shows a significant difference between males ( $44.25 \pm 20.0$ ) and females ( $35.08 \pm 20.1$ ) in terms of social relationships ( $p = 0.002$ ). Male parents had a significantly higher social relationship score indicating that they had better social relationships than the females. A significant difference was also found between parents who owned ( $52.78 \pm 18.2$ ) and rented their house ( $44.05 \pm 12.8$ ) in terms of the psychological domain ( $p = 0.035$ ). Parents who owned their house had significantly higher psychological scores which suggests that they were more psychologically competent than those who rented their homes. Significant differences were also found between employed and unemployed parents in three domains, namely physical health ( $p = 0.002$ ), psychological ( $p = 0.008$ ), and social relationship ( $p < 0.001$ ). Employed parents had higher scores compared to unemployed parents in terms of their physical health ( $52.71 \pm 16.0$ ;  $46.24 \pm 12.8$ ), psychological ( $47.29 \pm 14.2$ ;  $42.09 \pm 12.8$ ), and social relationships ( $43.36 \pm 20.5$ ;  $33.03 \pm 19.2$ ), which suggests that they had better QoL compared to unemployed parents. Lastly, a significant difference was found between the educational status of parents in all the four areas, namely physical health ( $p < 0.001$ ), psychological ( $p < 0.001$ ), social relationship ( $p = 0.014$ ), and environment ( $p = 0.006$ ).

Table 3 summarizes the results of the Post-hoc comparisons test for education. For physical health, psychological, and social relationship domains, the mean

score of postgraduate parents was significantly different from primary and elementary (I-J = 17.469,  $p = 0.007$ ; I-J = 17.880,  $p < 0.001$ ; I-J = 17.100,  $p = 0.004$ , respectively) and high school graduate parents (I-J = 19.047,  $p = 0.003$ ; I-J = 16.596,  $p < 0.001$ ; I-J = 13.736,  $p = 0.011$ , respectively). However, there was no significant difference between primary and elementary with that of high school graduate parents (I-J = 1.578,  $p = 0.734$ ; I-J = -1.285,  $p = 0.561$ ; I-J = -3.364,  $p = 0.325$ , respectively). These results suggest that a parent with a higher educational status had significantly better physical health, psychological, and social relationships. However, it should be noted that only postgraduate parents were observed to have a significant effect.

Lastly, for the environment, the mean score of post graduate parents was significantly different from primary and elementary (I-J = 12.864,  $p = 0.002$ ) and high school graduates (I-J = 7.565,  $p = 0.048$ ). Furthermore, there was a significant difference between primary and elementary with that of high school graduate parents (I-J = -5.300,  $p = 0.030$ ). Hence, postgraduate parents had significantly higher environmental scores than parents who graduated from high school. Moreover, high school graduate parents had higher environmental scores than primary and elementary school graduates. These results suggest that a parent with a higher educational status had a better environment.

Meanwhile, Table 4 summarizes the association between the QoL and the health satisfaction of the parent, and the corresponding domains. A strong positive relationship was determined for psychological and both QoL ( $r = 0.421$ ,  $p < 0.001$ ,  $N = 200$ ) and health satisfaction ( $r = 0.405$ ,  $p < 0.001$ ,  $N = 200$ ). Moreover, a moderate positive relationship was found for physical health and both QoL ( $r = 0.363$ ,  $p < 0.001$ ,  $N = 200$ ) and health satisfaction ( $r = 0.324$ ,  $p < 0.001$ ,  $N = 200$ ). These results suggest that higher psychological and physical health scores correlated to higher QoL and health satisfaction scores. Hence, parents with better psychological and physical health scores presented with an enhanced QoL and health satisfaction.

On the other hand, a weak positive relationship was found for the environment and both QoL ( $r = 0.291$ ,  $p < 0.001$ ,  $N = 200$ ) and health satisfaction ( $r = 0.259$ ,  $p < 0.001$ ,  $N = 200$ ). Lastly, a weak positive relationship was found for social relationships and QoL ( $r = 0.240$ ,  $p = 0.001$ ,  $N = 200$ ), while a negligible relationship was found for health satisfaction ( $r = 0.158$ ,  $p = 0.026$ ,  $N = 200$ ). These results suggest that higher environmental scores significantly correlated with higher QoL and health satisfaction scores, although there is a weak relationship.

Moreover, higher social relationship scores were related with higher QoL scores only, although there was a weak relationship. It should also be noted that there was no significant correlation between social relationship and health satisfaction. Nevertheless, all the results suggest that

**Table 1:** Characteristics of the participants of the study (n=200).

Demographics	N	Max	Min	Mean	SD
Age	195	23	45	34.46	4.7
Family members	39	2	10	3.51	1.7
		Frequency		%	
Total		200		100.0	
Gender	Male	83		41.5	
	Female	117		58.5	
Education	Primary	8		4.0	
	Elementary	39		19.5	
	High School	137		68.5	
Social Status	Postgraduate	16		8.0	
	Single	1		.5	
	Married	174		87.0	
Residence	Widow	3		1.5	
	Divorced	22		11.0	
House	Rural	9		4.5	
	Urban	191		95.5	
Employment	Owned	23		11.5	
	Rent	177		88.5	
	Yes	112		56.6	
	No	86		43.4	
	Missing	2			

**Table 2:** Independent t-test, Welch's t-test, and One-Way ANOVA test between gender, education, housing, and employment of the parents and the corresponding domains (physical health, psychological, social relationships, and environment).

Variables	Total	0-100				
		Physical health	Psychological	Social relationships	Environment	
Gender	Male	83	51.67 ± 15.6	47.06 ± 13.8	44.25 ± 20.0	45.98 ± 15.4
	Female	117	48.44 ± 14.5	43.63 ± 13.7	35.08 ± 20.1	42.89 ± 14.1
	p-value		0.133	0.083	0.002 <sup>a</sup>	0.143
Education (recoded)	Primary and Elementary	47	49.47 ± 11.7	42.74 ± 10.7	35.21 ± 20.5	39.51 ± 12.8
	High School	137	47.89 ± 14.3	44.03 ± 13.5	38.58 ± 19.7	44.81 ± 14.7
	Post graduate	16	66.94 ± 19.0	60.63 ± 15.4	52.31 ± 23.5	52.38 ± 16.1
	p-value		<0.001 <sup>c</sup>	<0.001 <sup>c</sup>	0.014 <sup>c</sup>	0.006 <sup>c</sup>
House	Owned	23	56.35 ± 20.4	52.78 ± 18.2	44.61 ± 23.6	49.61 ± 17.7
	Rent	177	48.93 ± 14.0	44.05 ± 12.8	38.14 ± 20.0	43.46 ± 14.2
	p-value		0.104	0.035 <sup>b</sup>	0.155	0.059
Employment	Yes	112	52.71 ± 16.0	47.29 ± 14.2	43.46 ± 20.5	46.04 ± 15.0
	No	86	46.24 ± 12.8	42.09 ± 12.8	33.03 ± 19.2	42.41 ± 13.5
	p-value		0.002 <sup>b</sup>	0.008 <sup>a</sup>	<0.001 <sup>a</sup>	0.080

<sup>a</sup>-significant using Independent t-test @<0.05 level.

<sup>b</sup>-significant using Welch's t-test @<0.05 level.

<sup>c</sup>-significant using One-Way ANOVA test @<0.05 level.

the QoL and health satisfaction scores of parents raising children diagnosed with ASD correlated with the four domain scores.

#### 4.3. Effect of the four domains

A General Linear Regression Model (GLRM) was calculated to predict physical health based on education, employment, QoL, and health satisfaction of parents (Table 5). The parent's predicted physical health score

was 3.881 points higher for employed parents compared to unemployed parents (Odds ratio: 3.881, 95% CI: 0.17 to 7.746). A poor QoL decreased physical health by 14.106 points (Odds ratio: -14.109, 95% CI: -26.518 to -1.699). Lastly, physical health scores were 21.764 (Odds ratio: -21.764, 95% CI: -34.439 to -9.089), 20.570 (Odds ratio: -20.570, 95% CI: -33.263 to -7.877), 18.155 (Odds ratio: -18.155, 95% CI: -33.330 to -2.980), and 14.368 (Odds ratio: -14.368, 95% CI: -26.650 to -2.087) points

**Table 3:** Multiple Comparisons Post-hoc test between primary and elementary, high school, and postgraduate parents among the four domains (physical health, psychological, social relationships, and environment) using the Games-Howell and LSD tests.

Dependent Variable	I	J	Mean Difference (I-J)	95% Confidence Interval		p-value
				Lower Bound	Upper Bound	
Physical health 0-100 (Games-Howell)	Primary and Elementary	High School	1.578	-3.43	6.58	0.734
		Post graduate	-17.469*	-30.28	-4.66	0.007
	High School	Primary and Elementary	-1.578	-6.58	3.43	0.734
		Post graduate	-19.047*	-31.61	-6.48	0.003
	Post graduate	Primary and Elementary	17.469*	4.66	30.28	0.007
Psychological 0-100 (LSD)		High School	19.047*	6.48	31.61	0.003
	Primary and Elementary	High School	-1.285	-5.64	3.07	0.561
		Post graduate	-17.880*	-25.33	-10.43	<0.001
	High School	Primary and Elementary	1.285	-3.07	5.64	0.561
		Post graduate	-16.596*	-23.40	-9.79	<0.001
Social relationships 0-100 (LSD)	Post graduate	Primary and Elementary	17.880*	10.43	25.33	<0.001
		High School	16.596*	9.79	23.40	<0.001
	Primary and Elementary	High School	-3.364	-10.09	3.36	0.325
		Post graduate	-17.100*	-28.61	-5.58	0.004
	High School	Primary and Elementary	3.364	-3.36	10.09	0.325
Environment 0-100 (LSD)		Post graduate	-13.736*	-24.25	-3.23	0.011
	Post graduate	Primary and Elementary	17.100*	5.58	28.61	0.004
		High School	13.736*	3.23	24.25	0.011
	Primary and Elementary	High School	-5.300*	-10.09	-0.51	0.030
		Post graduate	-12.864*	-21.07	-4.66	0.002
Environment 0-100 (LSD)	High School	Primary and Elementary	5.300*	.51	10.09	0.030
		Post graduate	-7.565*	-15.06	-0.07	0.048
	Post graduate	Primary and Elementary	12.864*	4.66	21.07	0.002
		High School	7.565*	.07	15.06	0.048

\*The mean difference is significant at the 0.05 level.

**Table 4:** Pearson Correlation of quality of life and health satisfaction of parents among the four domains (physical health, psychological, social relationships, and environment) .

Correlations		How would you rate your quality of life?	How satisfied are you with your health?
Physical health 0-100	r	0.363**	0.324**
	p-value	<0.001	<0.001
	N	200	200
Psychological 0-100	r	0.421**	0.405**
	p-value	<0.001	<0.001
	N	200	200
Social relationships 0-100	r	0.240**	0.158*
	p-value	0.001	0.026
	N	200	200
Environment 0-100	r	0.291**	0.259**
	p-value	<0.001	<0.001
	N	200	200

\*Correlation is significant at the 0.05 level (2-tailed).

\*\*Correlation is significant at the 0.01 level (2-tailed).

**Table 5:** General Linear Regression Model of physical health based on education, employment, quality of life (very poor, poor, neither poor nor good, good, and very good), and health satisfaction (very dissatisfied, dissatisfied, neither dissatisfied nor satisfied, satisfied, and very satisfied) of parents raising children with ASD.

<b>Dependent Variable: Physical health 0-100</b>				
<b>Parameter</b>	<b>B</b>	<b>95% C.I.</b>		<b>p-value</b>
		<b>Lower Bound</b>	<b>Upper Bound</b>	
Intercept	81.818	69.545	94.091	<0.001
Education(Primary and Elementary)	-5.140	-14.153	3.873	0.262
Education(High School)	-7.402	-15.789	.985	0.083
Education(Post graduate)	0 <sup>a</sup>			
Employment(Yes)	3.881	.017	7.746	0.049
Employment(No)	0 <sup>a</sup>			
How would you rate your quality of life?(Very poor)	-12.102	-25.654	1.450	0.080
How would you rate your quality of life?(Poor)	-14.109	-26.518	-1.699	0.026
How would you rate your quality of life?(Neither poor nor good)	-8.478	-20.599	3.642	0.169
How would you rate your quality of life?(Good)	-5.207	-17.184	6.770	0.392
How would you rate your quality of life?(Very good)	0 <sup>a</sup>			
How satisfied are you with your health?(Very dissatisfied)	-18.155	-33.330	-2.980	0.019
How satisfied are you with your health?(Dissatisfied)	-21.764	-34.439	-9.089	0.001
How satisfied are you with your health?(Neither satisfied nor dissatisfied)	-20.570	-33.263	-7.877	0.002
How satisfied are you with your health?(Satisfied)	-14.368	-26.650	-2.087	0.022
How satisfied are you with your health?(Very satisfied)	0 <sup>a</sup>			

<sup>a</sup>This parameter is set to zero because it is redundant.

lower for dissatisfied, neither satisfied nor dissatisfied, very dissatisfied, and satisfied parents respectively in terms of their health. These results suggest that better physical health was observed for parents who were employed. Moreover, having a poor and dissatisfied judgment on their QoL and health resulted in lower physical health scores.

The psychological score was 3.175 points higher for parents who owned their house compared to those who rented (Odds ratio: 3.175, 95% CI: -2.588 to 8.938). Moreover, employed parents had 1.883 more points than unemployed parents (Odds ratio: 1.883, 95% CI: -1.623 to 5.389). A very poor and poor QoL decreased psychological scores by 14.756 (Odds ratio: -14.756, 95% CI: -26.953 to -2.559) and 13.581 (Odds ratio: -13.581, 95% CI: -24.773 to -2.389) points respectively. Lastly, very dissatisfied and dissatisfied health satisfaction scores reduced psychological scores by 15.157 (-15.157, 95% CI: -29.180 to -1.135) and 13.206 (Odds ratio: -13.206, 95% CI: -24.827 to -1.586) points, respectively (Table 6). These results suggest that parents who were employed and owned their house were psychologically better compared to unemployed and renting

parents. Moreover, having a very poor and poor QoL, as well as a very dissatisfied and dissatisfied health satisfaction resulted in lower psychological scores.

A good, neither poor nor good, poor, and very poor QoL reduced social relationship scores by 20.632 (Odds ratio: -20.632, 95% CI: -38.370 to -2.894), 25.701 (Odds ratio: -25.701, 95% CI: -43.700 to -7.703), 27.072 (Odds ratio: -27.072, 95% CI: -45.439 to -8.705), and 27.951 (Odds ratio: -27.951, 95% CI: -48.059 to -7.843) points respectively. Moreover, a dissatisfied, satisfied, and neither dissatisfied nor satisfied health satisfaction reduced social relationship scores by 24.230 (Odds ratio: -24.230, 95% CI: -42.963 to -5.497), 23.299 (Odds ratio: -23.299, 95% CI: -41.474 to -5.123), and 19.263 (Odds ratio: -19.263, 95% CI: -37.999 to -0.528) points, respectively (Table 7). These results suggest that a better social relationship was predicted in parents with an improved QoL and health satisfaction.

A very poor, poor, and neither poor nor good QoL reduced environmental score by 19.285 (Odds ratio: -19.285, 95% CI: -33.540 to -5.030), 15.054 (Odds ratio: -15.054, 95% CI: -28.081 to -2.027), and 14.182 (Odds ratio:

**Table 6:** General Linear Regression Model of psychological scores based on education, housing, employment, quality of life (very poor, poor, neither poor nor good, good, and very good), and health satisfaction (very dissatisfied, dissatisfied, neither dissatisfied nor satisfied, satisfied, and very satisfied) of parents raising children with ASD.

<b>Dependent Variable: Psychological 0-100</b>				
<b>Parameter</b>	<b>B</b>	<b>95% C.I.</b>		<b>p-value</b>
		<b>Lower Bound</b>	<b>Upper Bound</b>	
Intercept	67.087	55.575	78.599	<0.001
Education(Primary and Elementary)	-7.949	-16.266	.367	0.061
Education(High School)	-6.973	-14.697	.751	0.077
Education(Post graduate)	0 <sup>a</sup>			
House(Owned)	3.175	-2.588	8.938	0.278
House(Rent)	0 <sup>a</sup>			
Employment(Yes)	1.883	-1.623	5.389	0.291
Employment(No)	0 <sup>a</sup>			
How would you rate your quality of life?(Very poor)	-14.756	-26.953	-2.559	0.018
How would you rate your quality of life?(Poor)	-13.581	-24.773	-2.389	0.018
How would you rate your quality of life?(Neither poor nor good)	-9.472	-20.415	1.471	0.089
How would you rate your quality of life?(Good)	-2.681	-13.494	8.133	0.625
How would you rate your quality of life?(Very good)	0 <sup>a</sup>			
How satisfied are you with your health?(Very dissatisfied)	-15.157	-29.180	-1.135	0.034
How satisfied are you with your health?(Dissatisfied)	-13.206	-24.827	-1.586	0.026
How satisfied are you with your health?(Neither satisfied nor dissatisfied)	-4.995	-16.709	6.718	0.401
How satisfied are you with your health?(Satisfied)	-4.084	-15.484	7.315	0.481
How satisfied are you with your health?(Very satisfied)	0 <sup>a</sup>			

<sup>a</sup>-This parameter is set to zero because it is redundant.

-14.182, 95% CI: -26.866 to -1.498) points respectively. Moreover, a very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, and satisfied health satisfaction scores reduced environmental scores by 22.165 (Odds ratio: -22.165, 95% CI: -38.167 to -6.162), 19.990 (Odds ratio: -19.990, 95% CI: -33.342 to -6.638), 17.093 (Odds ratio: -17.093, 95% CI: -30.477 to -3.708), and 15.548 (Odds ratio: -15.548, 95% CI: -28.444 to -2.652) points, respectively (Table 8). These results suggest that a better environment was predicted in parents with an enhanced QoL and health satisfaction.

## 5. Discussion

One of the most frequent neurodevelopmental diseases affecting children of ages three and below is ASD.<sup>1</sup> Previous studies have shown that symptoms associated with this disease significantly influence the QoL of parents raising an ASD child.

### 5.1. Demographic variables

Among the significant demographic variables, the current study presented that male parents raising children diagnosed with ASD had better social relationships than females. This is in line with the studies in which mothers exhibited more depressive symptoms and had lower QoL the more time spent with their children compared to the fathers in the sampling group.<sup>18,19</sup> Hence, since mothers are typically displayed as the caregivers of the household, their QoL is often more affected negatively. The lower social relationship scores were due to mothers having less time for leisure activities in their personal relationships since they would often attend to the demands of their children.

The current study revealed that parents who owned their house were psychologically more competent than those who rented their homes. This is in line with the study in which parents who lived in free and safe living spaces had better QoL.<sup>1</sup> The lower psychological score was due to parents

**Table 7:** General Linear Regression Model of social relationships based on gender, education, employment, quality of life (very poor, poor, neither poor nor good, good, and very good), and health satisfaction (very dissatisfied, dissatisfied, neither dissatisfied nor satisfied, satisfied, and very satisfied) of parents raising children with ASD.

<b>Dependent Variable: Social relationships 0-100</b>					
<b>Parameter</b>	<b>B</b>	<b>95% C.I.</b>		<b>p-value</b>	
		<b>Lower Bound</b>	<b>Upper Bound</b>		
Intercept	77.414	59.344	95.484	<0.001	
Gender(Male)	5.700	-1.141	12.541	0.102	
Gender(Female)	0 <sup>a</sup>				
Education(Primary and Elementary)	-0.001	-13.284	13.281	1.000	
Education(High School)	2.350	-10.015	14.715	0.708	
Education(Post graduate)	0 <sup>a</sup>				
Employment(Yes)	5.258	-1.842	12.358	0.146	
Employment(No)	0 <sup>a</sup>				
How would you rate your quality of life?(Very poor)	-27.951	-48.059	-7.843	0.007	
How would you rate your quality of life?(Poor)	-27.072	-45.439	-8.705	0.004	
How would you rate your quality of life?(Neither poor nor good)	-25.701	-43.700	-7.703	0.005	
How would you rate your quality of life?(Good)	-20.632	-38.370	-2.894	0.023	
How would you rate your quality of life?(Very good)	0 <sup>a</sup>				
How satisfied are you with your health?(Very dissatisfied)	-18.883	-41.250	3.483	0.097	
How satisfied are you with your health?(Dissatisfied)	-24.230	-42.963	-5.497	0.012	
How satisfied are you with your health?(Neither satisfied nor dissatisfied)	-19.263	-37.999	-0.528	0.044	
How satisfied are you with your health?(Satisfied)	-23.299	-41.474	-5.123	0.012	
How satisfied are you with your health?(Very satisfied)	0 <sup>a</sup>				

<sup>a</sup>-This parameter is set to zero because it is redundant.

having a difficult time concentrating since they would need to attend to their monthly rent dues, adding to the distress caused by the symptoms of their child's ASD.

The present study also showed that employed parents had better physical health, psychological well-being, and social relationships compared to unemployed parents. This is in line with the studies in which employed parents exhibited higher QoL than those who did not.<sup>1,20</sup> The lower physical health scores among unemployed parents may be due to having less family income. The lower the income of a household, the fewer the opportunities for social support, education, and other basic services they would have.

In connection with educational status, the current findings showed that a parent with a higher educational status had significantly better physical health, psychological well-being, social relationships, and environment. This is in contrast with the study that showed no significant relationship between the educational attainment of parents and their QoL.<sup>21</sup> This discrepancy may be correlated with

the finding in the present study that only postgraduate parents were observed to have a significant effect with regards to physical health, psychological well-being, and social relationships. Nonetheless, this result supports the logical reasoning in which higher levels of educational background would prompt for better employment choices and a stronger social support system.

The current study also showed that the age of the parent does not significantly affect their QoL. This is in contrast with the findings that revealed older parents tend to experience better QoL because they can adapt better over time.<sup>22</sup> This discrepancy may be due to having an insignificant age gap difference among the participants.

The present study also revealed that the QoL and health satisfaction scores of parents raising children with ASD positively associated with all the four domain scores. Hence, parents with better physical health, psychological well-being, social relationships, and environment presented with a better QoL and health satisfaction. This is in agreement



**Table 8:** General Linear Regression Model of environment based on education, quality of life (very poor, poor, neither poor nor good, good, and very good), and health satisfaction (very dissatisfied, dissatisfied, neither dissatisfied nor satisfied, satisfied, and very satisfied) of parents raising children with ASD.

Parameter	B	95% C.I.		p-value
		Lower Bound	Upper Bound	
Intercept	73.300	60.802	85.798	<0.001
Education(Primary and Elementary)	-2.691	-11.559	6.177	0.550
Education(High School)	2.785	-5.596	11.166	0.513
Education(Post graduate)	0 <sup>a</sup>			
How would you rate your quality of life?(Very poor)	-19.285	-33.540	-5.030	0.008
How would you rate your quality of life?(Poor)	-15.054	-28.081	-2.027	0.024
How would you rate your quality of life?(Neither poor nor good)	-14.182	-26.866	-1.498	0.029
How would you rate your quality of life?(Good)	-9.355	-21.955	3.245	0.145
How would you rate your quality of life?(Very good)	0 <sup>a</sup>			
How satisfied are you with your health?(Very dissatisfied)	-22.165	-38.167	-6.162	0.007
How satisfied are you with your health?(Dissatisfied)	-19.990	-33.342	-6.638	0.004
How satisfied are you with your health?(Neither satisfied nor dissatisfied)	-17.093	-30.477	-3.708	0.013
How satisfied are you with your health?(Satisfied)	-15.548	-28.444	-2.652	0.018
How satisfied are you with your health?(Very satisfied)	0 <sup>a</sup>			

<sup>a</sup>-This parameter is set to zero because it is redundant.

with the earlier findings.<sup>1,18,20,21</sup> An improved QoL is due to better opportunities and broadened knowledge. Moreover, greater health satisfaction is due to fewer causes of stress. Hence, improving all these domains would lead to an improved QoL.

Effect of the demographic characteristics, quality of life, and health satisfaction of parents on the four domains.

This study also showed that physical health worsened the most for unemployed parents and parents who have a poor and dissatisfied judgment on their QoL and health. Psychological well-being worsened the most for unemployed, renting parents who have a very poor and poor QoL, as well as a very dissatisfied and dissatisfied health satisfaction. Social relationships worsened the most for parents with a poorer and less satisfactory QoL and health satisfaction, while demographic variables had no significant effect. Lastly, the environment worsened the most for parents with a poorer and less satisfactory QoL and health satisfaction, while demographic variables had no significant effect.

Overall, the findings suggest that employed parents who owned their houses had the best physical health and psychological well-being. Conversely, unemployed and

renting parents were the most affected in terms of their physical health and psychological well-being. This is in line with the previous results. Hence, financial income and social status significantly impact the QoL of parents raising an ASD child.

## 6. Conclusion

The findings of the present study revealed that gender, educational attainment, and both employment and social status significantly affected the QoL of parents raising children diagnosed with ASD. It showed that female parents are more prone to be experiencing a lower QoL than male parents. Furthermore, higher educational attainment and employment status are associated with having better QoL due to the increased social opportunities and services presented to them. The findings also suggest that the QoL and health satisfaction of parents raising children with ASD positively correlated with the four areas being studied, particularly their physical health, psychological well-being, social relationships, and environment. Hence, improving these four domains for parents would result in better QoL and health satisfaction. These findings can serve as basis in establishing clear and comprehensive policies and programs

that prioritize the mental health for these parents.

To improve the findings of this study, further research can be conducted. Considering the characteristics of children, such as their age, the duration of their diagnosis, and the severity of their ASD can be done. Furthermore, considering outside support systems, coping strategies, and the household environment could give the researchers a more transparent and detailed view of the factors affecting the QoL of parents. Other domains of QoL, such as level of independence, family, and spiritual relations, can also be explored. In addition to this, performing the study with more participants from different centers and regions of the Kingdom of Saudi Arabia can be done to get a more generalized view of the barriers affecting the QoL of parents raising children with ASD.

## 7. Source of Funding

None.

## 8. Conflict of Interest

None.

## References

- Kuru N, Piyal B. Perceived social support and quality of life of parents of children with Autism. *Niger J Clin Pract.* 2018;21(9):1182–9.
- Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group. *Psychol Med.* 1998;28(3):551–8.
- Skevington SM, Lotfy M, O'Connell KA. The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A Report from the WHOQOL Group. *Qual Life Res.* 2004;13(2):299–310.
- Aman MG. Management of hyperactivity and other acting-out problems in patients with autism spectrum disorder. *Semin Pediatr Neurol.* 2004;11:225–8.
- Konstantareas MM, Papageorgiou V. Effects of temperament, symptom severity and level of functioning on maternal stress in Greek children and youth with ASD. *Autism.* 2006;10(6):593–607.
- Schalock RL, Bonham GS, Verdugo MA. The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Eval Program Plann.* 2008;31(2):181–90.
- Hastings RP, Kovshoff H, Brown T, Ward NJ, Espinosa FD, Remington B. Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism.* 2005;9(4):377–91.
- Sanders JL, Morgan SB. Family Stress and Adjustment as Perceived by Parents of Children with Autism or Down Syndrome: Implications for Intervention. *Child Fam Behav Ther.* 1997;19(4):15–32.
- Baker-Ericzén MJ, Brookman-Frazee L, Stahmer A. Stress Levels and Adaptability in Parents of Toddlers with and without Autism Spectrum Disorders. *Res Pract Persons Severe Disabl.* 2005;30(4):194–204.
- Ergüner-Tekinalp B, Akkök F. The Effects of a Coping Skills Training Program on the Coping Skills, Hopelessness, and Stress Levels of Mothers of Children with Autism. *Int J Adv Couns.* 2004;26(3):257–69.
- Abbeduto L, Seltzer MM, Shattuck P, Krauss MW, Orsmond G, Murphy MM. Psychological Well-Being and Coping in Mothers of Youths With Autism, Down Syndrome, or Fragile X Syndrome. *Am J Ment Retard.* 2004;109(3):237–54.
- Bebko JM, Konstantareas MM, Springer J. Parent and professional evaluations of family stress associated with characteristics of autism. *J Autism Dev Disord.* 1987;17(4):565–76.
- Bromley J, Hare DJ, Davison K, Emerson E. Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. *Autism.* 2004;8(4):409–23.
- Kasari C, Sigman M. Linking parental perceptions to interactions in young children with autism. *J Autism Dev Disord.* 1997;27(1):39–57.
- Lecavalier L, Leone S, Wiltz J. The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research.* 2006;50(3):172–183. Available from: <https://dx.doi.org/10.1111/j.1365-2788.2005.00732.x>. doi:10.1111/j.1365-2788.2005.00732.x.
- Hastings RP, Johnson E. Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *J Autism Dev Disord.* 2001;31(3):327–36.
- Herring S, Gray K, Taffe J, Tonge B, Sweeney D, Einfeld S. Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *J Intellect Disabil Res.* 2006;50(12):874–82.
- Eapen V, Črnčec R, Walter A, Tay KP. Conceptualisation and Development of a Quality of Life Measure for Parents of Children with Autism Spectrum Disorder. *Autism Res Treat.* 2014;2014. doi:10.1155/2014/160783.
- Ozgur BG, Aksu H, Eser E. Factors affecting quality of life of caregivers of children diagnosed with autism spectrum disorder. *Indian J Psychiatry.* 2018;60(3):278–85.
- Dardas LA, Ahmad MM. Predictors of quality of life for fathers and mothers of children with Autistic Disorder. *Res Dev Disabil.* 2014;35(6):1326–33.
- Alhazmi A, Petersen R, Donald KA. Quality of life among parents of South African children with autism spectrum disorder. *Acta Neuropsychiatr.* 2018;30(4):226–31.
- Dardas LA, Ahmad MM. Psychosocial Correlates of Parenting a Child With Autistic Disorder. *J Nurs Res.* 2014;22(3):183–91. Available from: <https://dx.doi.org/10.1097/jnr.000000000000023>.

## Author biography

**Abeer Ahmad Subke** Senior Resident

**Adeel Ahmed Khan** Senior Registrar

**Safinaz Abdullah Alharthi** Center Director, Consultant Pediatric Neurology

**Cite this article:** Subke AA, Khan AA, Alharthi SA. Factors affecting quality of life among parents having a child with autism spectrum disorder in Jeddah, 2019 (cross-sectional study). *J Prev Med Holistic Health* 2020;6(1):27-36.