



CODEN [USA]: IAJPBB

ISSN : 2349-7750

**INDO AMERICAN JOURNAL OF  
PHARMACEUTICAL SCIENCES**

SJIF Impact Factor: 7.187

Available online at: <http://www.iajps.com>

Research Article

**ASSESSMENT OF QUALITY OF LIFE AMONG CAREGIVERS  
OF AUTISTIC CHILDREN ATTENDING AUTISTIC CENTERS  
IN JEDDAH, 2020.****Mazin Almoanna<sup>1</sup>, Soliman Alakel<sup>1</sup>, Ismail Khan<sup>1</sup>, Moayad Filimban<sup>1</sup>, and  
Academic Supervisor:****Dr. Wedad Bardisi<sup>2</sup>**<sup>1</sup>Family Medicine Resident at Joint Program of Family Medicine- Jeddah.<sup>2</sup>Family Medicine Consultant and Trainer at Joint Program of Family Medicine-Jeddah.**Article Received:** April 2022**Accepted:** April 2022**Published:** April 2022**Abstract:**

*Aim: To assess the quality of life and identify other factors affecting the quality of life among caregivers of autistic children attending Autistic centers in Jeddah, 2020.*

*Method: The study was an analytic cross-sectional among the caregivers of autistic children. The questionnaire used in the study is The World Health Organization Quality of Life Assessment-Bref.*

*Result: Out of 85 caregivers, 37 (43.5%) were male, 48 (56.5%) were female, 37 (43.5%) were from age groups 26-40 and 41-60 equally. Almost two-thirds of the cases had moderate autism (degree 2), 48 (56.5%) rated their quality of life (Neither poor nor good). The mean score of the four domains were 8.8± 4.8 for physical health, 16.5± 4.5 for psychological, 8.1± 3.1 for social relationships, and 21 ± 4.7 for environment. Females, group age 26-40, married, those with higher education level, non-Saudi, and non-employee had a significant higher score in all the domains.*

*Conclusion: The current study results are consistent with other studies from different countries and cultures that reported that taking care of an autistic child had considerably negative impacts on the caregiver's QOL, where caregivers of children with ASD have poorer QOL due to the physical, social, emotional, and financial burdens in providing good care to a child with a disability.*

*Key words: Quality of Life, Caregivers Of Autistic Children, Autistic Centers, Jeddah*

**Corresponding author:****Mazin Almoanna,**

Family Medicine Resident at Joint Program of Family Medicine- Jeddah.

QR code



Please cite this article in press Mazin Almoanna et al, Assessment Of Quality Of Life Among Caregivers Of Autistic Children Attending Autistic Centers In Jeddah, 2020rs., Indo Am. J. P. Sci, 2022; 09(04)

## 1. INTRODUCTION:

Autism spectrum disorder (ASD) is "a neurodevelopmental disorder marked by impairment of social interaction and communication and restricted and repeated behavioural patterns, interests, or activities".(1) ASD is diagnosed by the 5th Edition of the Diagnostic Statistical Manual (DSM V) criteria, which consolidate the four previously separate categories of autism "Autistic disorder, Asperger syndrome, Childhood disintegrative disorder, and Pervasive developmental disorder-not otherwise specified (PDD-NOS)" into one umbrella diagnosis of "autism spectrum disorder".(2) It is estimated that worldwide, in 160 children has an ASD. The prevalence of ASD appears to be growing globally, which can be explained in many ways, including increased understanding, the extension of diagnostic criteria, better diagnostic tools, and improved reporting.(3) The primary caregiver of an autistic child, especially mothers, faces a social and financial burden that makes them more likely to experience stress, anxiety, and depression during their lifetime, which will have a great influence on their quality of life (QoL).(4)

World Health Organization (WHO) defines QoL as an individual's perception of their position in life in the context of the culture and value systems in which they live and concerning their goals, expectations, standards, and concerns". It is a broad-ranging concept affected complexity by the person's physical health, personal beliefs, psychological state, social relationships, and their relationship to notable characteristics of their environment".(5) Detecting the factors that can affect the caregivers either positively or negatively may help during the management of autistic children because any disruption in parents' health may harm the whole family. The age of the child affects parents' QoL. Studies showed that older autistic children affect QoL negatively for the caregiver more than younger children.(6-8) Socioeconomic status also has an impact on QoL for the caregiver. The study was shown that families with high socioeconomic status have better QoL and less stress(Dardas & Ahmad, 2014b; Hatton & Emerson, 2009; Parish, Seltzer, Greenberg, & Floyd, 2004). The number of family members is considered as a predictor for low QoL and stressor and its effect

on the physical health of the caregiver. (7,8)

Caregivers of autistic children seem like a vulnerable group to have a low quality of life, negatively affecting both caregivers and the whole family. Up to the team's knowledge, there is limited research on the quality of life among caregivers of autistic children in Saudi Arabia. The team failed to lay a hand on such a topic. This study aimed to assess the quality of life and identify other factors affecting the quality of life among caregivers of autistic children attending Autistic centres in Jeddah, 2020.

## 2. METHODOLOGY:

The study was an analytic cross-sectional among all the 85 caregivers of autistic children attending the two autism centres belonging to the Ministry of Education in Jeddah.

A self-administered questionnaire was distributed to caregivers of autistic children in the autism centres. The questionnaire used in the study is The World Health Organization Quality of Life Assessment-Bref WHOQOL-BREF Arabic Version. The WHOQOL- BREF has been developed by the WHOQOL group to produce a brief form QoL assessment that looks at domain-level profiles, using information from the WHOQOL-100. It's based on a four-domain structure. Every domain covers many aspects of an individual's life. The WHOQOL- BREF contains a complete of twenty-six items. The range of scores in every item is between one and five, with higher scores denoting higher QoL levels. A valid

### Data Collection technique

The investigators visited the selected autism centres in Jeddah after getting official permission to conduct the study. They explained the aim of the study to the autism centre head. Then, the questionnaire was distributed to caregivers of autistic children after explaining the study purpose and how to fill the questionnaire. Participants who agreed to participate in the study were offered a detailed description of the study purpose, procedures, benefits, risks, duration, confidentiality, and participants' rights.

Dependent Variables: Quality of life.

Independent Variables: (age, gender, nationality, job title, level of education, marital

status number of autistic children).

#### Data entry and statistical analysis:

Data were collected, reviewed, coded, and entered into the personal computer using (SPSS) Statistical Program for Social Sciences version 24.

All ethical approvals were obtained (the Research and Ethical Committee Joint Program of Family Medicine in Jeddah, the directors of autism centres in Jeddah). Also, written consent was obtained from each participant. All

collected data is kept confidential and used for research purposes. The research was self-funded.

#### RESULT:

Out of 85 caregivers, 37 (43.5%) were male, 48 (56.5%) were female, 37 (43.5%) were from age groups 26-40 and 41-60 equally. Less than half of 38 (44.7%) had a university degree. Most of the caregivers, 73 (85.9%), were married, 64 (75.3%) were Saudi, 48 (56.5%) were non-employee. Almost two-thirds of the cases had moderate autism (degree 2). (**Table 1**)

**Table (1) Demographic data:**

variable	N	%
<b>Gender</b>		
Female	48	56.5
Male	37	43.5
<b>Age</b>		
18-25	5	5.9
26-40	37	43.5
41-60	37	43.5
Less than 18	6	7.1
<b>Marital status</b>		
Single	6	7.1
Married	73	85.9
Divorced	6	7.1
<b>Education</b>		
Elementary	6	7.1
High school	36	42.4
University	38	44.7
Diploma	5	5.9
<b>Nationality</b>		
Saudi	64	75.3
Non-Saudi	21	24.7
<b>Occupation</b>		
Not employee	48	56.5
Employee	37	43.5
<b>Autism degree</b>		
Mild (level 1)	23	27.1
Sever (level 3)	10	11.8
Moderate (level 2)	52	61.2

Data presented as numbers and %

The results revealed that more than half of the caregivers, 48 (56.5%), rated their quality of life (Neither poor nor good), and 31 (36.7%) were satisfied with their health. (**Table 2**)

**Table (2) WHOQOL-BREF-(questions one and two)**

variable		N	%	Mean	SD	Rang (min-max)
How would you rate your quality of life?	Very poor	5	5.9	<b>2.8</b>	<b>0.8</b>	<b>(1-4)</b>
	Poor	21	24.7			
	Neither poor nor good	48	56.5			
	Good	11	12.9			
How satisfied are you with your health?	Very dissatisfied	11	12.9	<b>2.9</b>	<b>1.1</b>	<b>(1-5)</b>
	Dissatisfied	21	24.7			
	Neither satisfied nor dissatisfied	22	25.9			
	Satisfied	26	30.6			
	Very satisfied	5	5.9			

Data presented as number and % also as mean and SD.

Regarding the physical health domain, the mean score was  $8.8 \pm 4.8$ , indicating a poor level of feeling of good physical health, where all the items had a mean score of less than 3. (**Table 3**)

**Table (3) WHOQOL-BREF (Physical health domain)**

variable		N	%	Mean	SD	Rang (min-max)
3 (F1.4) To what extent do you feel that physical pain prevents you from doing what you need to do?	Not at all	6	7.1	<b>2.9</b>	<b>1.1</b>	<b>(1-5)</b>
	A little	27	31.8			
	A moderate amount	16	18.8			
	Very much	31	36.5			
	An extreme amount	5	5.9			
4(F11.3) How much do you need any medical treatment to function in your daily life?	Not at all	6	7.1	<b>2.8</b>	<b>0.9</b>	<b>(1-5)</b>
	A little	12	14.1			
	A moderate amount	32	37.6			
	Very much	30	35.3			
	An extreme amount	5	5.9			
10 (F2.1) Do you have enough energy for everyday life?	Not at all	6	7.1	<b>2.6</b>	<b>0.8</b>	<b>(1-4)</b>
	A little	31	36.5			
	Moderately	38	44.7			
	Mostly	10	11.8			
15 (F9.1) How well are you able to get around?	Poor	10	11.8	<b>2.2</b>	<b>0.6</b>	<b>(1-3)</b>
	Neither poor nor good	48	56.5			
	Good	27	31.8			
16 (F3.3) How satisfied are you with your sleep?	Very dissatisfied	16	18.8	<b>2.4</b>	<b>1.0</b>	<b>(1-4)</b>
	Dissatisfied	36	42.4			
	Neither satisfied nor dissatisfied	16	18.8			
	Satisfied	17	20.0			
17 (F10.3) How satisfied are you with your ability to perform your	Very dissatisfied	11	12.9	<b>2.7</b>	<b>1.0</b>	<b>(1-4)</b>
	Dissatisfied	27	31.8			

daily living activities?	Neither satisfied nor dissatisfied	20	23.5			
	Satisfied	27	31.8			
18(F12.4) How satisfied are you with your work capacity?	Very dissatisfied	11	12.9	<b>2.6</b>	<b>1.0</b>	<b>(1-4)</b>
	Dissatisfied	32	37.6			
	Neither satisfied nor dissatisfied	20	23.5			
	Satisfied	22	25.9			
<b>Total domain one score</b>				<b>8.8</b>	<b>4.8</b>	<b>(10-29)</b>

Data presented as number and % also as mean and SD.

Regarding the Psychological domain, the mean score was  $16.5 \pm 4.5$ , indicating a moderate level of feeling good Psychologically, where the items mean score was divided equally to 3 items less than three and the other three items were more than 3. (Table 4)

**Table (4) WHOQOL-BREF (Psychological domain)**

variable		N	%	Mean	SD	Rang (min-max)
5(F4.1) How much do you enjoy life?	Not at all	11	12.9	<b>2.3</b>	<b>0.8</b>	<b>(1-4)</b>
	A little	48	56.5			
	A moderate amount	16	18.8			
	Very much	10	11.8			
6(F24.2) To what extent do you feel your life to be meaningful?	Not at all	6	7.1	<b>2.6</b>	<b>0.9</b>	<b>(1-4)</b>
	A little	41	48.2			
	A moderate amount	23	27.1			
	Very much	15	17.6			
7(F5.3) How well are you able to concentrate?	Not at all	12	14.1	<b>2.5</b>	<b>0.9</b>	<b>(1-4)</b>
	A little	26	30.6			
	A moderate amount	36	42.4			
	Very much	11	12.9			
11 (F7.1) Are you able to accept your bodily appearance?	Not at all	6	7.1	<b>3.1</b>	<b>1.1</b>	<b>(1-5)</b>
	A little	12	14.1			
	Moderately	47	55.3			
	Mostly	5	5.9			
	Completely	15	17.6			
19 (F6.3) How satisfied are you with yourself?	Very dissatisfied	17	20.0	<b>3.1</b>	<b>1.2</b>	<b>(1-5)</b>
	Dissatisfied	5	5.9			
	Neither satisfied nor dissatisfied	22	25.9			
	Satisfied	36	42.4			
	Very satisfied	5	5.9			
26 (F8.1) How often do you have negative feelings such as blue mood, despair, anxiety, depression?	Seldom	15	17.6	<b>3.4</b>	<b>0.9</b>	<b>(1-5)</b>
	Quite often	33	38.8			
	Very often	26	30.6			
	Always	11	12.9			
<b>Total domain score</b>				<b>16.9</b>	<b>4.5</b>	<b>(9-27)</b>

Data presented as number and % also as mean and SD.

Regarding the social relationships domain, the mean score was  $8.1 \pm 3.1$ , indicating a poor level of social relationships, where all the items had a mean score of less than 3. (Table 5)

**Table (5) WHOQOL-BREF (Social relationships domain)**

variable		N	%	Mean	SD	Rang (min-max)
20(F13.3) How satisfied are you with your relationships?	Very dissatisfied	17	20.0	<b>2.9</b>	<b>1.3</b>	<b>(1-5)</b>
	Dissatisfied	21	24.7			
	Neither satisfied nor dissatisfied	5	5.9			
	Satisfied	37	43.5			
	Very satisfied	5	5.9			
21(F15.3) How satisfied are you with your sex life?	Very dissatisfied	16	18.8	<b>2.8</b>	<b>1.2</b>	<b>(1-5)</b>
	Dissatisfied	21	24.7			
	Neither satisfied nor dissatisfied	21	24.7			
	Satisfied	22	25.9			
	Very satisfied	5	5.9			
22(F14.4) How satisfied are you with the support you get from your friends?	Very dissatisfied	17	20.0	<b>2.5</b>	<b>1.1</b>	<b>(1-5)</b>
	Dissatisfied	31	36.5			
	Neither satisfied nor dissatisfied	21	24.7			
	Satisfied	11	12.9			
	Very satisfied	5	5.9			
<b>Total domain score</b>				<b>8.1</b>	<b>3.1</b>	<b>(3-15)</b>

Data presented as number and % also as mean and SD

Regarding the environment domain, the mean score was  $21 \pm 4.7$ , indicating a moderate level of environment, where most of the items (6) had a mean score of less than three and only two items had a mean score of more than 3. **(Table 6)**

**Table (6) WHOQOL-BREF (Environment domain)**

variable		N	%	Mean	SD	Rang (min-max)
8 (F16.1) How safe do you feel in your daily life?	Not at all	6	7.1	<b>2.8</b>	<b>0.8</b>	<b>(1-4)</b>
	A little	21	24.7			
	A moderate amount	41	48.2			
	Very much	17	20.0			
9 (F22.1) How healthy is your physical environment?	Not at all	6	7.1	<b>2.7</b>	<b>0.8</b>	<b>(1-4)</b>
	A little	28	32.9			
	A moderate amount	41	48.2			
	Very much	10	11.8			
12 (F18.1) Have you enough money to meet your needs?	Not at all	5	5.9	<b>2.4</b>	<b>0.6</b>	<b>(1-3)</b>
	A little	38	44.7			
	Moderately	42	49.4			
13 (F20.1) How available to you is the information you need in your day-to-day life?	A little	17	20.0	<b>2.1</b>	<b>0.8</b>	<b>(1-4)</b>
	Moderately	47	55.3			
	Mostly	16	18.8			
	Completely	5	5.9			
14 (F21.1) To what extent do you	Not at all	22	25.9	<b>2.1</b>	<b>0.8</b>	<b>(1-4)</b>

have the opportunity for leisure activities?	A little	37	43.5			
	Moderately	21	24.7			
	Mostly	5	5.9			
23(F17.3) How satisfied are you with the conditions of your living place?	Very dissatisfied	11	12.9	<b>3.0</b>	<b>1.1</b>	<b>(1-5)</b>
	Dissatisfied	16	18.8			
	Neither satisfied nor dissatisfied	26	30.6			
	Satisfied	27	31.8			
	Very satisfied	5	5.9			
24(F19.3) How satisfied are you with your access to health services?	Very dissatisfied	6	7.1	<b>3.2</b>	<b>1.1</b>	<b>(1-5)</b>
	Dissatisfied	21	24.7			
	Neither satisfied nor dissatisfied	20	23.5			
	Satisfied	27	31.8			
	Very satisfied	11	12.9			
25(F23.3) How satisfied are you with your transport?	Very dissatisfied	6	7.1	<b>2.9</b>	<b>0.9</b>	<b>(1-4)</b>
	Dissatisfied	27	31.8			
	Neither satisfied nor dissatisfied	26	30.6			
	Satisfied	26	30.6			
<b>Total domain score</b>				<b>21.1</b>	<b>4.7</b>	<b>(10-31)</b>

Data presented as number and % also as mean and SD.

There was a significant association between all demographic data and all four domains, where females, those from group age 26-40, being married, those with higher education level, a non-Saudi, non-employee had higher mean scores in all the domains. On the other hand, the social relationships domain showed no significant association with nationality and occupation. Also, the environment domain showed no significant association with nationality, occupation, and autism degree. (Table 7)

**Table (7) The relation between domains and demographic data:**

Variable	Physical health		Psychological		Social relationships		Environment	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
<b>Gender<sup>s</sup></b>								
Female	20.4792	4.19721	18.1458	4.32208	9.0208	2.67764	22.8333	3.24420
Male	16.5946	4.70496	15.4865	4.38825	7.0000	3.17105	18.9189	5.41797
<b>P value</b>	<b>0.0001**</b>		<b>0.006*</b>		<b>0.002*</b>		<b>0.0001**</b>	
<b>Age<sup>#</sup></b>								
18-25	18.0000	0.00000	15.0000	0.00000	7.0000	0.00000	24.0000	0.00000
26-40	20.3514	5.20265	17.3784	5.17661	8.9730	3.26162	22.8649	4.46071
41-60	18.7568	3.36985	18.1622	2.86273	8.2973	2.41367	20.8108	2.66498
Less than 18	10.0000	0.00000	9.0000	0.00000	3.0000	0.00000	10.0000	0.00000
<b>P value</b>	<b>0.0001**</b>		<b>0.0001**</b>		<b>0.0001**</b>		<b>0.0001**</b>	
<b>Marital status<sup>#</sup></b>								
Single	10.0000	0.00000	9.0000	0.00000	3.0000	0.00000	10.0000	0.00000
Married	19.8219	4.26986	17.5616	4.25893	8.3288	2.82378	22.1370	3.81268
Divorced	15.0000	0.00000	18.0000	0.00000	11.0000	0.00000	20.0000	0.00000
<b>P value</b>	<b>0.0001**</b>		<b>0.0001**</b>		<b>0.0001**</b>		<b>0.0001**</b>	
<b>Education<sup>#</sup></b>								
Elementary	10.0000	0.00000	9.0000	0.00000	3.0000	0.00000	10.0000	0.00000
High school	19.6667	3.58569	18.0000	3.16228	7.6667	1.51186	21.3056	2.65996
University	19.8421	4.89084	17.8158	4.77525	9.8158	3.21193	23.3947	3.86627
Diploma	15.0000	0.00000	13.0000	0.00000	5.0000	0.00000	16.0000	0.00000
<b>P value</b>	<b>0.0001**</b>		<b>0.0001**</b>		<b>0.0001**</b>		<b>0.0001**</b>	



<b>Nationality<sup>§</sup></b>								
Saudi	17.9375	5.16667	15.9375	4.72708	7.8281	3.36912	20.7969	5.26196
Non-Saudi	21.3810	1.88351	20.1905	1.12335	9.0952	1.48003	22.1429	2.22004
<b>P value</b>	<b>0.004*</b>		<b>0.0001**</b>		<b>0.099</b>		<b>0.259</b>	
<b>Occupation<sup>§</sup></b>								
Not employee	19.8542	5.23487	18.0208	4.56858	8.6458	3.23866	21.7083	5.32740
Employee	17.4054	3.82579	15.6486	4.15141	7.4865	2.70413	20.3784	3.72940
<b>P value</b>	<b>0.019*</b>		<b>0.016*</b>		<b>0.83</b>		<b>0.200</b>	
<b>Autism degree<sup>#</sup></b>								
Mild (level 1)	20.1304	5.87216	17.8696	5.98714	9.2609	3.75642	22.6522	4.63787
Sever (level 3)	21.0000	0.00000	20.0000	0.00000	9.0000	0.00000	22.0000	0.00000
Moderate(level 2)	17.7692	4.50975	16.0192	3.89313	7.4808	2.85252	20.2885	5.05009
<b>P value</b>	<b>0.042*</b>		<b>0.020*</b>		<b>0.041*</b>		<b>0.111</b>	

Data presented as mean and SD

§ Comparison was made using an independent t-test

# Comparison was made using one way ANOVA

\*P-value 0.05 considered significant

\*\* P-value 0.0001 considered extremely significant

There was a significant association between the "How would you rate your quality of life?" question and age, marital status, occupation, and education, where those from the group age 26-40, being married, those with higher education level, and the non-employee had higher mean score. Also, there was a significant association between the "How satisfied are you with your health?" question and age, gender, occupation, education, and autism degree, where females, those from group age 26-40, those with higher education level, and the non-employee had higher mean score. **(Table 8)**

**Table (8) The relation between questions one and two and demographic data:**

<b>Variable</b>	<b>1(G1) How would you rate your quality of life?</b>		<b>2 (G4) How satisfied are you with your health?</b>	
<b>Gender<sup>§</sup></b>				
Female	2.88	.570	3.38	1.104
Male	2.62	.924	2.32	.915
<b>P value</b>	<b>0.123</b>		<b>0.0001**</b>	
<b>Age<sup>#</sup></b>				
18-25	2.00	0.000	2.00	0.000
26-40	2.86	.822	2.81	1.371
41-60	2.57	.502	2.70	.878
Less than 18	4.00	0.000	2.00	0.000
<b>P value</b>	<b>0.0001**</b>		<b>0.008*</b>	
<b>Marital status<sup>#</sup></b>				
Single	4.00	0.000	4.00	0.000
Married	2.73	.692	2.82	1.194
Divorced	2.00	0.000	3.00	0.000
<b>P value</b>	<b>0.0001**</b>		<b>0.061</b>	
<b>Education<sup>#</sup></b>				
Elementary	2.00	0.000	2.00	0.000
High school	2.58	.732	3.14	1.125
University	2.84	.638	2.66	1.169
Diploma	2.00	0.000	2.00	0.000
<b>P value</b>	<b>0.0001**</b>		<b>0.006*</b>	
<b>Nationality<sup>§</sup></b>				



Saudi	2.69	.852	2.91	1.191
Non Saudi	3.00	0.000	2.95	1.024
<b>P value</b>	<b>0.098</b>		<b>0.874</b>	
<b>Occupation<sup>\$</sup></b>				
Not employee	3.00	.684	3.75	.636
Employee	2.46	.730	1.84	.646
<b>P value</b>	<b>0.001*</b>		<b>0.0001**</b>	
<b>Autism degree<sup>#</sup></b>				
Mild (level 1)	2.96	.706	2.91	1.411
Sever (level 3)	3.00	0.000	4.00	0.000
Moderate (level 2)	2.63	.817	2.71	1.016
<b>P value</b>	<b>0.132</b>		<b>0.004*</b>	

Data presented as mean and SD

\$ Comparison was don using independent t test

# Comparison was done using one way ANOVA

\*P value 0.05 considered significant

\*\* P value 0.0001 considered extremely significant

### DISCUSSION:

Autism Spectrum Disorder is a complex, lifelong and heterogeneous neurodevelopmental disorder described by stereotyped and repetitive behaviours and disrupted social and communication skills. (9,10)

The current study aimed to assess the quality of life among caregivers of Children with Autistic Spectrum Disorders (ASD) and explore the relationship between socio-demographic variables and QOL using the WHOQOL-BREF tool.

Usually, child-care-related stress is present when the family has a child with special needs and cause less time for parents to take care of their own needs. Parents of children with autism have reported more serious troubles and are vulnerable to developing physical or psychological problems. The key predictors of mental health for the parents of children with autism were; financial issues, physical health, and low stress. Where further studies on the potential stress of these parents are required. Also, there is a need for services targeting the parents' mental health and the treatments for the child's problems. (11,12) Inconsistent, the current study revealed that the score of physical and physiological domains was poor.

There was a significant relationship between autism severity and the physiological domain in the current study. Several studies reported similar results, where parents' emotional problems and parental stress had a considerable positive association with the severity of a child's behavioural problem as well as the poor ability to perform communication tasks. (13) In two different studies, the authors stated that with the availability of bigger externalizing problems in the

children, the parents showed poorer QoL. (14,15) Also, another study reported that the mothers suffered from mental health problems with the children with lower scores on prosocial behaviours and higher scores on hyperactivity and problems behaviours. (16,17)

Regarding the QOL of caregivers based on age, the psychological domain showed the highest value, which indicated that the majority of the caregivers who were between 26-40 years had significantly better psychological QOL compared to other age groups. While, in the India study, a significantly better psychological QOL was reported among caregivers between 25-35 years. (18) This reveals the need for more commitment to investing in providing more assistance and interference to meet the caregivers' needs. Another study reported that with the ageing of the caregivers, the QOL scores became worse, which could be explained by the fact the level of frustration became higher due to the increase in the responsibilities (quantitative and qualitative). (19)

Considering the QOL of caregivers based on gender, females had a better QOL regarding the four domains compared to males. A similar result was reported in the India study (18). In contrast, the females had indicated poor mental health compared to males in the Qatar study. (20) The diversity in the result of the studies could be due to several factors; socioeconomic variables, diversity in culture, and the level of social and psychological support that female caregivers receive from their friends and family. Also, the higher female rate compared to the males in the present study.

The social, personal, and financial responsibilities the autistic children's families experience lead to a more difficult, challenging, fatiguing, and sometimes painful life. Which makes the family more exposed to stress and family dysfunction. (21-24) So, it wasn't strange or uncommon to see ASD caregivers quit their jobs to take care of their children. (25,26) 56.5% of participants were unemployed in the current study, confirming this tendency. In the Brazil study, the authors reported that 40% of the parents were non-employee. (21)

The findings of the study highlighted the huge influence of chronic diseases on the families & caregivers of autistic children. Where the result demonstrated the considerable physical, emotional and social loads on them, which mean that it is important to focus on helping them and solving their physical and psychological problems so they can focus more on their sick children and help them cope with their illness.

#### **Limitations of the study**

Time constraints, the researcher finished the data collection within one month only, and this study was conducted at only two autism centres in Jeddah.

#### **CONCLUSION:**

Clarifying the quality-of-life concept among caregivers, social support, and socio-demographic variables is essential in revealing factors affecting QOL for caregivers of children with ASD and for managing future treatment development efforts. The current study results are consistent with other studies from different countries and cultures that reported that taking care of an autistic child had considerably negative impacts on the caregiver's QOL, where caregivers of children with ASD have poorer QOL due to the physical, social, emotional, and financial burdens in providing good care to a child with a disability.

#### **Recommendation**

The administrators in MOH should organize and conduct health education programs about autism and the burden on families in familiar and straightforward language among the community through mass media to increase public awareness and knowledge regarding autism. Encourage the caregivers to talk about their problems and seek help and support, where health care providers have two prominent roles in helping better manage child health and maintaining parents' wellness. There is a need for more nationwide studies on assessing autistic children caregivers' QOL in larger sample sizes and cities other than Jeddah.

#### **REFERENCES:**

1. Kroncke AP, Willard M, Huckabee H. Assessment of Autism Spectrum Disorder. 2016; Glendale, USA: Springer International Publishing, 345–373.
2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
3. World Health Organization " Autism Spectrum Disorders Epidemiology" April 2018, <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>.
4. R Khanna, SS Madhavan, MJ Smith, JH Patrick, C Tworek, B Becker-Cottrill. Assessment of Health-Related Quality of Life Among Primary Caregivers of Children with Autism Spectrum Disorders 2011.
5. World Health Organization. (1996). Quality of life(WHOQOL)-Brief questionnaire, field trial version. Geneva: WHO.
6. Dardas LA, Ahmad MM. Predictors of quality of life for fathers and mothers of children with autistic disorder. *Res Dev Disabil*. 2014 Jun;35(6):1326-33. doi: 10.1016/j.ridd.2014.03.009. Epub 2014 Apr 2. PMID: 24704547.
7. Hatton, C., & Emerson, E. Does socioeconomic position moderate the impact of child behavior problems on maternal health in South Asian families with a child with intellectual disabilities. *Journal of Intellectual and Developmental Disability*.2009; 34(1): 10–16.
8. Parish, S., Seltzer, M., Greenberg, J., & Floyd, F. Economic implications of caregiving at midlife: Comparing parents with and without children who have developmental disabilities. *Mental Retardation*.2004; 42(6): 413–426.
9. Alharbi A. Knowledge and Attitude of Families and Health Care Providers towards Autism. *Open Access Journal of Public Health*. 2018;2(2):14.
10. Altay MA. Family Physicians' Awareness of Autism Spectrum Disorder: Results from a Survey Study. *Journal of Medical Sciences*. 2019 Mar 30; 7(6):967-972.
11. Predescu, E., & Şipoş, R. (2017). Family Quality of Life in Autism Spectrum Disorders (ASD). In M. Fitzgerald, & J. Yip (Eds.), *Autism - Paradigms, Recent Research, and Clinical Applications*. IntechOpen. <https://doi.org/10.5772/66201>
12. Lee GK, Lopata C, Volker MA, Thomeer ML, Nida RE, Toomey JA, et al. Health-related quality of life of parents of children with high

- functioning autism spectrum disorders. Focus on Autism and Other Developmental Disabilities. 2009;24:227–239.
13. Khanna R, Madhavan SS, Smith JM, Patrick HJ, Tworek C, Becker-Cottrill B. Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2011;41:1214–1227.
  14. McStay R, Trembath D, Dissanayake C. Stress and family quality of life in parents of children with autism spectrum disorder: Parent gender and the double ABCX model. *Journal of Autism and Developmental Disorders*. 2014;44:3101–3118.
  15. Tung LC, Huang CY, Tseng MH, Yen HC, Tsai YP, Lin YC, et al. Correlates of health-related quality of life and the perception of its importance in caregivers of children with autism. *Research in Autism Spectrum Disorders*. 2014;8:1235–1242..
  16. Hsiao YJ. Pathways to mental health-related quality of life for parents of children with autism spectrum disorder: roles of parental stress, children's performance, medical support, and neighbor support. *Research in Autism Spectrum Disorders*. 2016;23:122–130.
  17. Totsika V, Hastings RP, Emerson E, Berridge DM, Lancaster GA. Behavior problems at 5 years of age and maternal mental health in autism and intellectual disability. *Journal of Abnormal Child Psychology*. 2011;39(8):1137–1147.
  18. Renford NG Robert, Arulappan J, Thomas KD Edward, Karuppiah KM, Chinnathambi K Thangaswamy GC. Quality of Life of Caregivers of Children with Autism Spectrum Disorder in Tamil Nadu, South India. *Int J Nutr Pharmacol Neurol Dis* 2020;10:57-64 .
  19. Dardas LA, Ahmad MM. Quality of life among parents of children with autistic disorder: A sample from the Arab world. *Research in Developmental Disabilities* 2014;35:278-87.
  20. Kheir N, Ghoneim O, Sandridge AL, Al-Ismael M, Hayder S, Al-Rawi F. Quality of life of caregivers of children with autism in Qatar. *Autism* 2012;16:293-8.
  21. Pratesi, C.B.; Garcia, A.B.; Pratesi, R.; Gandolfi, L.; Hecht, M.; Nakano, E.Y.; Zandonadi, R.P. Quality of Life in Caregivers of Children and Adolescents with Autistic Spectrum Disorder: Development and Validation of the Questionnaire. *Brain Sci*. 2021, 11, 924. <https://doi.org/10.3390/brainsci11070924>
  22. McKechnie, A.G.; Moffat, V.J.; Johnstone, E.C.; Fletcher-Watson, S. Links between autism spectrum disorder diagnostic status and family quality of life. *Children* 2017, 4, 23.
  23. Marchese, A.; Klersy, C.; Biagi, F.; Balduzzi, D.; Bianchi, P.I.; Trotta, L.; Vattiato, C.; Zilli, A.; Rademacher, J.; Andrealli, A.; et al. Quality of Life in Coeliac Patients: Italian Validation of a Coeliac Questionnaire. *Eur. J. Intern. Med*. 2013, 24, 87–91.
  24. Thullen, M.; Bonsall, A. Co-Parenting Quality, Parenting Stress, and Feeding Challenges in Families with a Child Diagnosed with Autism Spectrum Disorder. *J. Autism Dev. Disord*. 2017, 47, 878–886 .
  25. Cidav, Z.; Marcus, S.C.; Mandell, D.S. Implications of Childhood Autism for Parental Employment and Earnings. *Pediatrics* 2012, 129, 617–623.
  26. McCabe, H. Employment Experiences, Perspectives, and Wishes of Mothers of Children with Autism in the People's Republic of China. *J. App. Res. Intellect. Disabil*. 2010, 23.