

Quality of Life among the Parents of Saudi Arabian children with Autistic Spectrum Disorder, Riyadh, KSA

A Alhazmi ¹, A Alduraibi ¹, M Alhemaïd ², A Albreakan ³, R Alshaqha ⁴

(1) Behavioral and Developmental Department, Pediatric Hospital, King Saud Medical city, Riyadh, KSA.

(2) Pediatric Hospital, King Saud Medical City, Riyadh, KSA.

(3) Pediatric Hospital, Imam Abdulrahman Alfaisal Hospital, Riyadh, KSA.

(4) Medical Intern, Almarefaa University, Riyadh, KSA.

Corresponding author:

Ayman Alhazmi MD

Developmental and Behavioural Paediatric Consultant

Head of Developmental Pediatric Department

King Saud Medical City, Saudi Arabia

Children Hospital

Tel: 0114356666 Ext:145

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Abstract

Objective: To assess the factors influencing the quality-of-life differences between families caring for a child with Autistic Spectrum disorder diagnosis.

Methods: Cross-sectional study of either parent of ASD child aged 1 to 14 years following up at the OPD setting in Riyadh, KSA from June 2019 through to the end of January 2020 at the Division of Developmental Pediatrics at King Saud medical city in Riyadh, Saudi Arabia via a structured questionnaire, (The World Health Organization Quality of Life Assessment-BREF

(WHOQOL-BREF). Inclusion criteria: Parent of child with ASD who has been diagnosed by a developmental pediatrician at least 6 months prior to the commencement of this study, parent of child with ASD who receives follow-up treatment at the King Saud medical city children's Hospital. Parent should be the primary caregiver of the child with ASD. (For the purposes of this study, "primary caregiver" is defined as the individual in the family whose main responsibility is to provide care to the ASD child). Parent who has no history of previous psychological, psychiatric disorder or physical disability. Parents who have been residing in Saudi Arabia for at least 6 months prior to the commencement of this study. Parent who has offered informed consent. Exclusion criteria: parent of any

child who has dysmorphic features or a diagnosed genetic syndrome, parent of child with ASD who has sibling diagnosed with ASD, or parents of child with ASD who has sibling diagnosed with other chronic medical illness.

Results: Marital status, housing settings, total household income, current employment, being part of support groups and associated illness in the ASD child significantly impacted at least one domain of WHOQOL-BREF.

Conclusion: Modifiable factors that have the ability to elevate the quality of life for parents of ASD children are marital status, housing settings, total household income, current employment, being part of support groups and overall care of ASD children.

Key words: ASD, Quality of Life, Autism Spectrum disorder, WHOQOL-BREF

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder affecting children with various degrees in relation to their communication, social interaction, and milestones acquisition (1) and poses social and economic challenges on families caring for their beloved offspring afflicted by ASD across diverse cultures in the world (2).

WHO defines health as an equilibrium of physical, mental, and social well-being and not merely the absence of diseases or burdens (3). Many factors play a role in the development of the overall wellbeing of families, such as coping mechanisms, the family support system and acceptance by society and is largely affected by cultural contexts (4).

Research on the effects of parenting an ASD child is needed (5). Over recent years there has been an increasing body of research in evaluating the quality of life (QOL) through WHO questionnaires (6) in hope of creating the most supportive environments for ASD children.

Reports from developed and developing countries alike show Japan, and Italy, South Africa, and India (7,8,9,10) have illustrated a reduced QOL in families caring for an ASD child. Regionally too, reports from Oman, Qatar, and Saudi Arabia (11,12,13) have shown similar findings.

This study sets out to explore, evaluate and compare the QOL among parents of children with ASD in Riyadh, Saudi Arabia, and explores correlations between QOL and diverse socio-demographic differences of parents and ASD children and provides insights and suggestions for further studies.

Material and Methods

This study was conducted from the first of June 2019 through to the end of January 2020 at the Division of Developmental Pediatrics at King Saud medical city in Riyadh, Saudi Arabia via a structured questionnaire, (The World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF) (14) Arabic language version (Appendix 1) which contains 26 items of measurement of QOL. This instrument includes four domain scores (physical, psychological, social, and environmental health) and two separate items regarding an individual's overall perception of their QOL and health. Scores range from 1 to 5, with higher scores denoting higher QOL. The World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF) interpretation was conducted according to the manual protocol. (Appendix 2).

Parents characteristics were collected; (gender, age, marital status, education level, current employment, total household income, housing settings, the total number of children, and affiliation to family support groups). Children's characteristics were also collected: (gender, age, age at diagnosis, gestational age, schooling, and receiving specialized care programs in terms of speech therapy, occupational therapy or behavioral therapy, level of global developmental delay and associated disorders).

Inclusion criteria:

- Parent of child with ASD who has been diagnosed by a developmental pediatrician at least 6 months prior to the commencement of this study.
- Parent of child with ASD who receives follow-up treatment at the King Saud medical city children's Hospital.
- Parent of child with ASD who is between the age of 1 years and 14 years.
- Parents should be the primary caregiver of the child with ASD. (For the purposes of this study, "primary caregiver" is defined as the individual in the family whose main responsibility it is to provide care to the ASD child.)
- Parents who have no history of previous psychological, psychiatric disorder or physical disability.
- Parents who have been residing in Saudi Arabia for at least 6 months prior to the commencement of this study.
- Parent who has offered informed consent.

Exclusion criteria:

- Parents of any child who has dysmorphic features or a diagnosed genetic syndrome.
- Parent of child with ASD who has sibling diagnosed with ASD,
- Parent of child with ASD who has sibling diagnosed with other chronic medical illness.

Analysis was carried out using SPSS 25.0 (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.). The variables under study were categorical and presented as percentages. One-way ANOVA for correlations and eta squared for the level of association.

Results

54 children with ASD met the inclusion criteria and were enrolled in the study (n. 54), 75.9% were males (Table 1).

Table 1

Gender of the ASD Child		Number (54)	Percentage %
Female		13	24.1%
Male		41	75.9%
Age at Diagnosis		Minimum	Maximum
Mean (years)		1	8
		3.54 ± 1.6	
Current age of ASD child		Minimum	Maximum
Mean		4	14
		7.76 ± 2.5	
Gestational age		Number (54)	Percentage %
Preterm		4	7.4%
Term		50	92.6%
ASD child attend school		Number (54)	Percentage %
No		12	22.2%
Yes		42	77.8%
Type of school		Number (54)	Percentage %
ASD center		17	31.5%
General education		12	22.2%
Intellectual disability school		10	18.5%
Merged		2	3.7%

Table 1 (continued)

Type of specialized care		Number	Percentage %
		(54)	
	Speech Therapy	14	25.93%
	Speech Therapy & Occupational Therapy	22	40.74%
	None	18	33.33%
Medications			
		Number	Percentage %
		(54)	
	Atomoxetine	1	1.9%
	Risperidone	8	14.8%
	Methylphenidate	8	14.8%
	None	37	68.5%
Child speaks more than 10 words			
		Number	Percentage %
		(54)	
	No	32	59.3%
	Yes	22	40.7%
Global Developmental delay			
		Number	Percentage %
		(54)	
	GDD Mild	23	42.6%
	Moderate	22	40.7%
	Severe	9	16.7%
Associated disorders			
		Number	Percentage %
		(54)	
	ADHD	40	74.1%
	ADHD, Aggression, Destructive	1	1.9%
	Defiant	1	1.9%
	N/A	10	18.5%
	Self-harm	2	3.7%



One of the primary caregivers of our study population were included in the study; 51% of were fathers, and 49% were mothers. They were further sub-grouped into age intervals of 10 years (20 – 30 years, more than 30 - 40 years, more than 40 - 50 years, more than 50 years of age) (Table 2).

Table 2

Parents' Characteristics			
Gender of the parent			
		Number (54)	Percentage %
	Father	28	51.90%
	Mother	26	48.10%
Age			
	In years	Number (54)	Percentage %
	20-30	4	7.41%
	31-40	24	44.44%
	41-50	19	35.19%
	>50	7	12.96%
Marital Status			
	Status	Number (54)	Percentage %
	Divorced	4	7.40%
	Married	48	88.90%
	Separated	2	3.70%
Currently Employed			
	No	Number (54)	Percentage %
	Yes	16	29.60%
		38	70.40%
Income			
	Total income	Number (54)	Percentage %
	equal or < 5k	8	14.81%
	>5k - <10k	20	37.04%
	10k - < 15k	18	33.33%
	equal or > 15k	8	14.81%
Housing			
	Type of housing	Number (54)	Percentage %
	Family house	9	16.70%
	Apartment	16	29.60%
	Floor	11	20.40%
	Villa	18	33.30%

Table 2 (continued)

Level of Parents' Education		
	Number (54)	Percentage %
primary school	4	7.40%
secondary school	4	7.40%
high school	16	29.60%
university	30	55.60%

Part of Family support group		
	Number (54)	Percentage %
No	29	53.70%
Yes	25	46.30%

Number of Siblings		
Total children	Number (54)	Percentage %
1	11	20.37%
2	12	22.22%
3	7	12.96%
4	6	11.11%
5	8	14.81%
more than 5	10	18.52%

The World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF) estimates the mean of four different domains: physical, psychological, emotional, social, and environmental aspects as well as the mean of the total domains (Table 3). The scoring of each domain takes from 4 to 20 before converting the score on a 100-scale based on WHO manual. A higher number closer to 100 would signify a positive report, while a score closer to 0 would signify a negative report. There is no cut-point to signify a good score.

Table 3

Scores of WHOQOL-BREF in our studied population

	Mean	Std. Deviation
Physical	50.7	±11.6
Psychological	61.7	±13.7
Social Relationships	74.2	±25.1
Environment	72.5	±18.3
Total Score	259.2	±55.3

Table 4

WHOQOL-BREF in relation to Marital Status

	P-value
Physical	0.381
Psychological	0.735
Social Relationships	0.011
Environment	0.014
Total Score	0.028

Table 5

WHOQOL-BREF in relation to Housing settings

	P-value
Physical	0.024
Psychological	0.041
Social Relationships	0.659
Environment	0.016
Total Score	0.033

Table 6

WHOQOL-BREF in relation to total household Income

	P-value
Physical	0.501
Psychological	0.616
Social Relationships	0.000
Environment	0.164
Total Score	0.021

Table 7

QOL domain in relation to current Employment

	P-value
Physical	0.208
Psychological	0.673
Social Relationships	0.406
Environment	0.037
Total Score	0.134

Table 8

WHOQOL-BREF in relation to Part of Support Groups

	P-value
Physical	0.444
Psychological	0.156
Social Relationships	0.02
Environment	0.195
Total Score	0.065

Table 9

WHOQOL-BREF in relation to other associated illnesses

	P-value
Physical	0.526
Psychological	0.412
Social Relationships	0.114
Environment	0.037
Total Score	0.038

No statistical significance was observed in terms of quality of life and other studied elements in terms of parental age, gender, level of education, number of total siblings, level of global developmental delay or gestational age of ASD children, school attendance of ASD child, nor ability of ASD child to speak 10 words (Table 10).

Table 10

WHOQOL-BREF in relation to age

	P value
Physical	0.371
Psychological	0.644
Social Relationships	0.488
Environment	0.208
Total Score	0.354

Table 10 (continued)

WHOQOL-BREF in relation to Level of Parents' Education

	P-value
Physical	0.471
Social Relationships	0.194
Environment	0.343
Total Score	0.211

WHOQOL-BREF in relation to Number of Siblings

	P-value
Physical	0.086
Psychological	0.142
Social Relationships	0.124
Environment	0.171
Total Score	0.085

WHOQOL-BREF in relation to Type of support school

	P-value
Physical	0.91
Psychological	0.305
Social Relationships	0.323
Environment	0.246
Total Score	0.26

WHOQOL-BREF in relation to level of Global Developmental Delay (Mild, moderate, severe)

	P-value
Physical	0.952
Psychological	0.515
Social Relationships	0.732
Environment	0.904
Total Score	0.912

Discussion

An increasing body of research has adopted the questionnaire of World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF) and established lower QOL scores in parents caring for ASD child when compared to families of healthy, or children with chronic illnesses like Cerebral Palsy (8, 9), while others have reported no statistical differences between quality of life (12). Fewer studies have focused on assessing the particular differences among families caring for Autistic children.

A study conducted in Arar (13), in Saudi Arabia with similar cultural, and regional populations has demonstrated a poor quality of life in 63% of families of ASD children. The authors found significantly poorer reports in relation to employment status ($p=0.03$), gender of the parent ($p=0.001$) for mothers, and total household income ($p=0.01$). Although the researchers (11) have identified a cut-off point in WHOQOL-BREF to be below 50 as a score that would indicate a poor QOL, their report might underestimate the status quo of this population as no consensus in the scientific community has yet been reached (Appendix 2).

Silva, et al created the first statistical cut-off point for WHOQOL-BREF as a measure of quality of life in 2010 (15). The authors established a statistical cut-point at 60 or below in elderly population and advised need for further studies of validity and reliability to identify different cut-off points for various age groups.

The World Health Organization Quality of Life Assessment-BREF (WHOQOL-BREF) estimates the mean of four different domains: physical, psychological, social, and environmental aspects as well as the mean of the total domains (Appendix 2).

The Physical domain explores the activities of daily living, dependence on medicinal or medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work capacity. We found this domain to be positively affected in relation to the housing settings of our population ($p=0.024$). This might be explained by the cultural context; in Saudi Arabia, families live in the same household of the extended family or close by. This would create added responsibilities explaining the physical domain, and with recent decades of growth in Saudi Arabia, autonomy has become a major value. This might explain higher scores in other domains, psychological domain

($P=0.041$), environmental domain ($P=0.016$) and overall quality of life scores ($P=0.033$) in families caring for ASD child living alone in Villas, or apartments, whereas lower scores of QOL in families living in the same household with their extended family.

Environmental domain explores the financial resources, freedom, and physical safety and security, health and social care quality and accessibility, along with home environment, participation in recreational activities, and

gaining new skills and information. This domain was impacted positively ($p=0.014$) in contrast to similar studies, (9,10, 13) in relation to marital status; married parents have better quality of life also in Social Relationships domain ($P=0.011$), and total score of WHOQOL-BREF ($p=0.028$). This finding might be explained by the cultural context of Saudi Arabia around the importance of family cohesiveness.

Understanding cultural differences can help in creating tools and programs to support these families. Understanding the cultural context of different families can play a major role in improving the quality of life. This has been observed in a study conducted by Fong VC et al (16) studying the differences between immigrants and locals in Canada. Family bond and social acceptance were the key factors in immigrants' well-being whereas it was emotional support for locals.

Similar findings have demonstrated the impact of total household income on QOL (9, 13, 17). This might be explained by the need for quality tools and resources to educate, support and care for an ASD child, although, a study by Bassema et al showed no impact as governmental subsidies were allocated to support ASD children's schooling and resources (11). Similar governmental aid in Saudi Arabia has not changed the need for better total household income (18).

Our study is consistent with studies (13,17, 19) in light of current employment status effects on the quality of life. We observed a positive impact on the environmental domain ($p=0.037$). This finding was not in line with a study conducted in South Africa (9); cultural context might play a role in explaining the disparity in home environments, participation in recreational activities and financial resources. The environmental aspect was also impacted by the presence of associated illness in the ASD child (ADHD, Aggression, Destructive, Defiant, Self-Harm) ($p=0.037$). This might be explained by the environmental measure of physical safety and security of the families (Appendix 2).

Similar findings to our study have highlighted the positive impact of support groups in the social domain ($p=0.02$). This can be explained by the generated sense of empathy, understanding and shared experience (20).

Modifiable factors have the ability to elevate the quality of life. These elements: marital status, housing settings, total household income, employment, and being part of support groups can ultimately provide ASD children the required environment to gain needed social skills, and communication skills. In Saudi Arabia, the housing setting has the most impact on the quality of life in all domains except social relationships. Further research is warranted to describe the differences in the quality of life in families caring for an ASD child.

Ethical statement

Participants were informed about the research aim and their optional, voluntary participation. Institutional Review Board, at King Saud Medical City, Riyadh, KSA. Ref number H1RI-13Nov19-06 was obtained before the subjects' enrollment.

Ethical approval

We obtained consent from the families from enrollment in the study

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Appendix 1

The Arabic version of WHOQOL-Brief

الأسئلة التالية تُستفسر عن مدى تعرضك لأشياء معينة خلال الأسبوعين الماضيين

درجة بالغة	كثير جدا	درجة متوسطة	قليلًا	لا يوجد		
5	4	3	2	1	إلى أي حد تشعر بأن الأحم الجسدي بمنحك من القيام بالأعمال التي تريدها؟	(F1.4)3
5	4	3	2	1	إلى أي مدى أنت بحاجة للعلاج الطبي لتتمكن من القيام بأعمالك اليومية؟	(F11.3)4
5	4	3	2	1	إلى أي مدى تستمتع بالحياة؟	(F4.1)5
5	4	3	2	1	إلى أي مدى تشعر بأن حياتك ذات معنى؟	(F24.2)6
5	4	3	2	1	إلى أي مدى أنت قادر على التركيز؟	(F5.3)7
5	4	3	2	1	إلى أي مدى تشعر بالأمان في حياتك اليومية؟	(F16.1)8
5	4	3	2	1	إلى أي حد تعتبر أن البيئة المحيطة بك صحية؟	(F22.1)9

الأسئلة التالية تُستفسر عن مدى قدرتك على إتمام أمور معينة خلال الأسبوعين الماضيين

درجة بالغة	كثير جدا	درجة متوسطة	قليلًا	لا يوجد		
5	4	3	2	1	هل لديك طاقة كافية لمزاولة الحياة اليومية؟	(F2.1)10
5	4	3	2	1	هل أنت قادر على قبول مطهرتك الخارجي؟	(F7.1)11
5	4	3	2	1	هل لديك من المال ما يكفي لتلبية احتياجاتك؟	(F18.1)12
5	4	3	2	1	ما مدى توفر المعلومات التي تحتاجها في حياتك اليومية؟	(F20.1)13
5	4	3	2	1	إلى أي مدى لديك الفرصة لممارسة الأنشطة الترفيهية؟	(F21.1)14

جدة جدا	جدة	لا بأس	سيئة	سيئة للغاية		
5	4	3	2	1	إلى أي مدى أنت قادر على التنقل بسهولة؟	(F9.1)15

يرجى قراءة كل سؤال وتقييم ما تشعر به ووضع دائرة حول الرقم الذي يعطي أفضل إجابة بالنسبة لك

جيدة جدا	جيدة	لا بأس	سيئة	سيئة للغاية	
5	4	3	2	1	كيف تقبل نوعية حياتك (G1)1

راضٍ تماما	راضٍ	لا راضٍ ولا غير راضٍ	غير راضٍ	غير راضٍ على الإطلاق	
5	4	3	2	1	ما مدى رضاك عن صحتك (G4)2

الأسئلة التالية تطلب منك أن تعبر عن مدى رضاك نحو جوانب مختلفة من حياتك خلال الأسبوعين الماضيين

راضٍ تماما	راضٍ	لا راضٍ ولا غير راضٍ	غير راضٍ	غير راضٍ على الإطلاق	
5	4	3	2	1	كم أنت راضٍ عن نومك؟ (F3.3)16
5	4	3	2	1	إلى أي مدى أنت راضٍ عن قدرتك على القيام بنشاطاتك اليومية؟ (F10.3)17
5	4	3	2	1	كم أنت راضٍ عن قدرتك على العمل؟ (F12.4)18
5	4	3	2	1	كم أنت راضٍ عن نفسك؟ (F6.3)19
5	4	3	2	1	كم أنت راضٍ عن علاقاتك الشخصية؟ (F13.3)20
5	4	3	2	1	كم أنت راضٍ عن حياتك الجنسية؟ (F15.3)21
5	4	3	2	1	كم أنت راضٍ عن الدعم أو المساعدة من الأصدقاء؟ (F14.4)22
5	4	3	2	1	كم أنت راضٍ عن الأوضاع في مكان سكنتك؟ (F17.3)23
5	4	3	2	1	كم أنت راضٍ عن الخدمات الصحية المتوفرة لك؟ (F19.3)24
5	4	3	2	1	كم أنت راضٍ عن وسائل المواصلات التي تستخدمها؟ (F23.3)25

يرجى قراءة كل سؤال وتقييم ما تشعر به ووضع دائرة حول الرقم الذي يعطي أفضل إجابة بالنسبة لك

جيدة جدا	جيدة	لا بأس	سيئة	سيئة للغاية		
5	4	3	2	1	كيف تقيم نوعية حياتك	(G1)1

راض تماما	راض	لا راض ولا غير راض	غير راض	غير راض على الإطلاق		
5	4	3	2	1	ما مدى رضاك عن صحتك	(G4)2)2

الأسئلة التالية تطلب منك أن تدبر عن مدى رضاك نحو جوانب مختلفة من حياتك خلال الأسبوعين الماضيين

راض تماما	راض	لا راض ولا غير راض	غير راض	غير راض على الإطلاق		
5	4	3	2	1	كم أنت راض عن نومك؟	(F3.3)16
5	4	3	2	1	إلى أي مدى أنت راض عن قدرتك على القيام بنشاطاتك اليومية؟	(F10.3)17
5	4	3	2	1	كم أنت راض عن قدرتك على العمل؟	(F12.4)18
5	4	3	2	1	كم أنت راض عن نفسك؟	(F6.3)19
5	4	3	2	1	كم أنت راض عن علاقاتك الشخصية؟	(F13.3)20
5	4	3	2	1	كم أنت راض عن حياتك الجنسية؟	(F15.3)21
5	4	3	2	1	كم أنت راض عن الدعم أو المساعدة من الأصدقاء؟	(F14.4)22
5	4	3	2	1	كم أنت راض عن الأوضاع في مكان سكنك؟	(F17.3)23
5	4	3	2	1	كم أنت راض عن الخدمات الصحية المتوفرة لك؟	(F19.3)24
5	4	3	2	1	كم أنت راض عن وسائل المواصلات التي تستخدمها؟	(F23.3)25

الأسئلة التالية تُشير إلى كم من المرات شعرت أو تعرضت فيها لأشياء معينة خلال الأسبوعين الماضيين

دائماً	غالباً جداً	غالباً	نادراً	أبداً		
5	4	3	2	1	كم من المرات كانت لديك مشاعر سلبية مثل المزاج السيء، اليأس، الغضب، الاكتئاب؟	(F8.1)26

لا	نعم	هل قام أحد هم بمساعدتك لتحيته هذه الاستمارة؟ (رجاءاً قم بوضع دائرة: نعم أو لا)
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كم استغرق من الوقت لتحيته هذه الاستمارة؟

شكراً لك

Appendix 2

The reference for interpretations of WHOQOL-Brief

https://github.com/seschneck/arc_scoring_code/raw/main/WHOQOL-BREF/WHOQOL-BREF_Introduction%2C%20Administration%2C%20Scoring.pdf