

Living with autism: Quality of life assessment for young adults with autism in Saudi Arabia



Aljoud Sulaiman Algazlan ^{1,*}, Tarfa Rashed Alsharidi ¹, Banan Sameer Alqady ¹, Maha Fahad Alghamdi ¹, Mayasem Isa Alhazmi ¹, Nada Ismail Babelli ¹, Laila Y. Alayadhi ²

¹College of Medicine, King Saud University, Riyadh, Saudi Arabia

²Department of Physiology, King Saud University, Riyadh, Saudi Arabia

ARTICLE INFO

Article history:

Received 11 October 2023

Received in revised form

10 February 2024

Accepted 25 February 2024

Keywords:

Autism

Quality of life

WHOQOL-BREF questionnaire

Delayed diagnosis

Early intervention

ABSTRACT

Quality of life (QoL) impacts the future health outcomes of people with Autism Spectrum Disorders (ASD). Past research, although limited, has shown that people with ASD often experience a lower quality of life. Yet, there's not much research focusing on the quality of life of young adults with autism, especially in Saudi Arabia, where it appears no studies have assessed the QoL of adults with autism. This study aims to evaluate and compare the quality of life between young adults with ASD and those without (a control group) in Saudi Arabia to pinpoint areas that could be improved. The study included 439 participants, with 107 being adults with autism and 332 without (a 1:3 ratio). An Arabic translation of the World Health Organization (WHO) QoL short version (WHOQOL-BREF) was used for assessment. The average age of participants with ASD was 24.82 years, with the average age for diagnosis and starting treatment being around 7.4 and 8.28 years, respectively. Those with ASD reported a significantly lower quality of life (1.68) in all areas compared to the control group (3.96), especially in social relationships (average score=27.01). A negative correlation was found between the age at diagnosis and at starting treatment with overall QoL, suggesting that a delay in diagnosis is associated with a lower quality of life. The study reveals that adults with ASD in Saudi Arabia have a lower QoL in all areas compared to the general population, indicating that early diagnosis and intervention could improve their quality of life. These results emphasize the need for policy changes to better support individuals with ASD in improving their quality of life.

© 2024 The Authors. Published by IASE. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

1. Introduction

Autism spectrum disorder is a neurodevelopmental disorder that affects language communication and social behavior. It is characterized by repetitive activities and stereotypes, which can hinder their ability to adapt to daily activities (APA, 2017; 2018; Murphy et al., 2016). The global prevalence of autism is reported to be 1 in 100 individuals, according to the World Health Organization (WHO, 2019). In Saudi Arabia, the estimated prevalence is higher at around 2.51-2.81% (AlBatti et al., 2022; Sabbagh et al., 2021). WHO defines quality of life (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 in relation to their goals, expectations, standards, and concerns." The World Health Organization categorizes the quality of life into four domains: Physical, psychological, social, and environmental (Whoqol Group, 1998). Recent studies on adults with autism spectrum disorder have aimed to assess their QoL. However, there is a lack of available data regarding the quality of life for individuals living with autism in the Middle East.

Numerous systematic reviews and recent studies have investigated the quality of life among adults with autism spectrum disorder in developed countries. These studies report that individuals with autism tend to have significantly lower QoL levels compared to the general population (Ayres et al., 2018; Biggs and Carter, 2016; Dijkhuis et al., 2017; Knüppel et al., 2018; Lin, 2014; Mason et al., 2018; Vincent et al., 2020). On the contrary, there are a few exceptions, such as some studies reporting a

* Corresponding Author.

Email Address: aljoudAlgazlan@gmail.com (A. S. Algazlan)

<https://doi.org/10.21833/ijaas.2024.03.011>

Corresponding author's ORCID profile:

<https://orcid.org/0000-0001-5648-8832>

2313-626X/© 2024 The Authors. Published by IASE.

This is an open access article under the CC BY-NC-ND license

(<http://creativecommons.org/licenses/by-nc-nd/4.0/>)

relatively good QoL among individuals with ASD (Hong et al., 2016; Moss et al., 2017). Upon further examination, variations were identified across the four domains of quality of life, with the social relationship domain consistently being reported as having the lowest QoL (Lin, 2014).

Healthcare providers have often overlooked the needs of young adults with autism in the medical literature. Young adults with ASD, especially those who are non-verbal and cognitively challenged, may face additional marginalization. Despite requiring specialized support and services for their specific medical, psychiatric, and social needs, they have been consistently underserved (Asi, 2016; Iannuzzi et al., 2015). Moreover, third-world countries are still struggling to provide these services to them (Taha and Hussein, 2014). The limited research conducted has led to significant challenges in assessing and enhancing the available services (Iannuzzi et al., 2015; Sulaimani and Gut, 2019). To address the needs of individuals with ASD in Saudi Arabia, the government provides funding to private institutions. However, there is a need for improvement as the current services provided are insufficient (Salhia et al., 2014; Zeina et al., 2014).

While there has been significant research on ASD in children, the same cannot be said for adults with ASD. The quantity and quality of research on this population lag behind. There is a growing focus on investigating the importance of QoL in adults with ASD, but further investigations are still needed (Whoqol Group, 1998). The majority of the studies conducted on QoL in individuals with ASD are small and are not representative. Therefore, larger samples are needed for more accurate assessments of the QoL in this population (Ayres et al., 2018). Furthermore, there has been limited local and regional research on the quality of life of adults with ASD in Saudi Arabia. Additionally, individuals with ASD encounter challenges in their daily lives that are greater compared to the general population (Iannuzzi et al., 2015). In order to enhance the quality of life for individuals with autism, it is important to recognize and address those challenges. This can aid in determining suitable goals for interventions and improving services provided to them. Based on the aforementioned research, this study aims to measure and evaluate the WHOQOL in adults with ASD in comparison to the control group in Saudi Arabia. The study also hypothesizes that individuals with ASD in Saudi Arabia have a quality of life that is at least 12.37% lower than those without the disorder (Dijkhuis et al., 2017).

2. Methods

2.1. Study design and sampling

This was a questionnaire-based case-control study conducted at King Saud University Medical City, Riyadh, Saudi Arabia. The study duration was from June 2021 to December 2021. Using a QoL standard deviation of 11.6 for the study group and 6

for the control group (Atherton et al., 2022), with a power of 90%, and at a 95% confidence interval, the study required 180 participants (90 per group). Anticipating a non-response rate of 20%, the sample size was increased to a target size of 216 individuals.

A convenience sampling technique was applied. The study group was sampled by distributing an online survey through the contact database at King Saud University's Autism Research and Treatment Center (ARTC). The survey was filled out using a self-reporting strategy if feasible for the participant. Alternatively, participants were advised to use a proxy-reporting strategy by the parent, guardian, or caregiver. For the control group, a voluntary response sampling strategy was applied through the online social media application WhatsApp. WhatsApp is the most used social media application among the Saudi population, with a prevalence of 91.5%, as reported (AlMuammar et al., 2021).

2.2. Inclusion criteria

In the study, Saudi individuals aged 18 years and older who were diagnosed with ASD were included in the study group. For the control group, Saudi individuals aged 18 years and older who were not diagnosed with ASD or any other neurodevelopmental disorder were included in the study.

2.3. Exclusion criteria

Individuals who were not Saudi, younger than 18 years of age, or not diagnosed with ASD or other neurodevelopmental disorders were excluded from the study group. Similarly, for the control group, non-Saudi individuals, those younger than 18 years, and those diagnosed with ASD or other neurodevelopmental disorders were also excluded.

2.4. Questionnaire

The questionnaire consisted of two parts; the first part explored the demographic data. The second part contained the WHOQOL-BREF questionnaire to measure the quality of life. The demographics were concerned with the independent variables. These include the age of the participants, age at ASD medical diagnosis, and age at ASD medical intervention, which have been shown to affect the trajectory of the QoL (Atherton et al., 2022). The WHOQOL-BREF assessment tool was developed and validated by WHO. With high validity and reliability indices (Cronbach's alpha ≥ 0.7), a translated Arabic version was permitted, used, and obtained from The WHOQOL Group (Ohaeri and Awadalla, 2009). The questionnaire consists of 26 items. Two items assess the overall perception of QoL (Q1) and overall perception of health (Q2). The remaining items are arranged to cover four domains: physical (including pain and energy), psychological (including positive and negative feelings and self-esteem), social

(including personal relationships and friendships), and environmental (including financial resources and home environment). Items were scored on a five-point scale to determine a raw item score. Raw domain scores were transformed to a 0-100 scale and scaled in a positive direction, where higher scores indicate higher QoL (Ohaeri and Awadalla, 2009).

2.5. Ethical consideration

Voluntary response was ensured by providing a written consent form to all participants. The consent form was clear, indicating the purpose of the study and the right of the participants to withdraw at any time without any obligation toward the study team. Participants' anonymity was ensured by assigning each participant a code number for the purpose of analysis only. No incentives or rewards were provided to participants. There was no conflict of interest to be reported.

2.6. Statistical analysis

Data analysis was performed using SPSS version 19 (IBM Inc., Chicago, USA). Descriptive statistics such as frequencies, percentages, means, and standard deviations were employed to summarize the categorical and quantitative variables. For univariate analysis, the Student's t-test was used to compare independent samples and a one-way analysis of variance with a subsequent post-hoc test was applied to compare mean values across categorical variables with two or more categories. The Pearson Correlation test was utilized to examine the relationship between study variables and overall quality of life. Statistical significance and the precision of the results were indicated by a p-value of ≤ 0.05 and 95% confidence intervals.

3. Results

Table 1 lists the distribution of characteristics of the study and control group participants. This study comprised 439 participants, among which 107 had ASD (Study Group), and the remaining 332 participants were non-ASD (Control Group). The mean age of the study group participants was 24.82 years, while the control group participants were slightly younger, with a mean age of 21.2 years. Among the study group participants, the mean age of diagnosis and medical intervention was 7.4 years and 8.28 years, respectively. The gender distribution showed that only 8.4% of the participants from the study group were female, compared with 73.5% of the control group being female. The major proportion of the participants from both the study group (97.2%) and the control group (99.7%) were born in Saudi Arabia, with only (2.8%) of the ASD group and (0.3%) of the control group being born abroad. However, this number drastically changed in the city of residence, where (44.9%) of the study

group reported living abroad, in comparison to only (0.6%) of the control group. The education status assessment showed that a large portion of participants in the study group were uneducated (25.2%), while only 5.1% of the control group were so. Most of the study group participants attended Boarding Centers (43.9%) and Autistic centers with special needs (30.8%), while all of the control group participants attended formal schooling (100%). About 95% in the ASD group and 85% in the control group reported that they were single. Nearly 64% of participants in the study group had a family monthly income of less than 14000 SR, while 35% of participants in the control group had a family monthly income of more than 20000 SR monthly.

The WHOQOL-BREF questionnaire was employed to assess and compare the quality of life among all participants in the study. Responses were recorded on a five-point Likert scale. A notable difference in the overall quality of life, as indicated by the question "Q1 How would you rate your quality of life?" was observed between the two groups. Participants diagnosed with ASD reported a lower quality of life (1.68), whereas the control group indicated a higher quality of life (3.96). Despite this, participants from both the study and control groups reported satisfactory health, with scores around 4. Quality of life scores were adjusted to a 0-100 scale for all domains before comparing between groups. Statistically significant differences were found in all four domains, with the study group scoring lower than the control group across all comparisons, as detailed in Table 2. The parametric Pearson correlation test revealed a statistically significant association of overall quality of life with the age when they were diagnosed and the age when they received medical intervention ($p=0.001$). Both the variables showed a negative correlation (-0.4 and above) with the overall quality of life. This reflects that as the age of diagnosis and age of medical intervention increased, the overall quality of life decreased, as shown in Table 3.

4. Discussion

This study provides the first examination of the quality of life of adults with ASD in Saudi Arabia. Our results show that the average age of ASD diagnosis is 7.4 years, which is higher than the global mean age of diagnosis of 60.48 months (van't Hof et al., 2021). Receiving an early diagnosis before four years of age was significantly associated with higher quality of life (Knopf, 2016). The diagnosis of ASD can be made before the age of two years (Gabbay-Dizdar et al., 2022). Research suggests that the severity of ASD symptoms and traits may represent a barrier to early diagnosis; those with more subtle symptoms (e.g., language deficits, impaired social relatedness, and gaze aversion) are often diagnosed later (Li et al., 2018). ASD presentation may not necessarily be the case. Other factors that can limit access to early diagnosis and interventions include socioeconomic status, gender, and culture (Hong et al., 2016).

Table 1: Distribution of characteristics of ASD and non-ASD group participants

		ASD group (N=107)		Non-ASD group (N=332)	
		Mean (years)	SD	Mean (years)	SD
	Age	24.82	5.35	21.2	4.4
	Age of ASD diagnosis	7.40	2.4	NA	NA
	Age of medical intervention	8.28	2.36	NA	NA
		N	%	N	%
Gender	Female	9	8.4	244	73.5
	Male	98	91.6	88	26.5
Speak status	Verbal	88	82.24		
	Non-verbal	19	17.76		
Needed assistance to fill the form	Yes	97	90.7	45	13.6
	No	10	9.3	287	86.4
City of birth	Local (Inside of Saudi Arabia)	104	97.2	331	99.7
	Abroad (Outside of Saudi Arabia)	3	2.8	1	0.3
Birth complications	No Birth complications	92	86.0%	278	83.7%
	Dystocia	11	10.2%	25	7.5%
	Others *	5	4.7%	34	10.3%
Current city of residence	Local (Inside of Saudi Arabia)	59	55.2	330	99.4
	Abroad (Outside of Saudi Arabia)	48	44.9	2	0.6
	None	27	25.2	17	5.1
Current level of education	Basic education*	71	66.3	63	19
	Post-secondary**	9	8.4	252	75.9
Type of school	Formal school***	27	25.3	332	100
	Informal national school****	33	30.8	NA	NA
	Informal international school (Boarding Autism centers)	47	43.9	NA	NA
Participants marital status	Ever been married	6	5.6	50	15
	Single	101	94.4	282	84.9
Parents blood relation	Relatives	19	17.8%	149	44.9%
	Not related	88	82.2%	183	55.1%
Age of (mother)	Less than 30	0	0%	11	3.3%
	30-50	49	45.8%	236	71.1%
	More than 50	58	54.2%	85	25.6%
Age of (Father)	Less than 30	0	0%	7	2.1%
	30-50	31	28.9%	167	50.3%
	More than 50	76	71%	158	47.6%
Mothers medical status	Psychological illness	1	0.9	5	1.5
	Autoimmune disease	13	12.2	14	4.2
	Type one diabetes mellitus	1	0.9	15	4.5
	Type two diabetes mellitus	25	23.4	20	6
	Having 2 diseases or more	8	7.4	24	7.2
	None	59	55.2	254	76.5
	Psychological illness	3	2.7	2	0.6
	Autoimmune disease	2	1.8	10	3
Fathers medical status	Type one diabetes mellitus	1	0.9	29	8.7
	Type two diabetes mellitus	36	33.6	39	11.7
	Having 2 diseases or more	9	8.1	13	3.9
	None	56	52.3	239	71.7
	None	0	0	21	6.3
Mothers education level	Basic education**	21	19.6	130	39.1
	Diploma	27	25.2	16	4.8
	Post-secondary***	59	55.2	165	49.8
	None	0	0	13	3.9
Fathers education level	Basic education**	27	25.3	94	28.4
	Diploma	38	35.5	37	11.1
	Post-secondary***	42	39.2	188	56.6
Family's monthly income	14000 and less monthly	68	63.5	148	4.6
	Between 14000-20000 SR monthly	22	20.6	69	20.8
	More than 20000 SR monthly	17	15.9	115	34.6

NA: Not applicable; *: Forceps or vacuum delivery, labor induction medications, nuchal cord, preterm labor; **: Primary school, middle school, secondary school; ***: Universities, colleges, vocational schools; ****: Public school, private school

Table 2: Comparison of the WHO-BREF quality of life mean scores between ASD and non-ASD groups

	ASD group			Non-ASD group			t Value	p-value
	Mean	SD	95% CI for the mean	Mean	SD	95% CI for the mean		
How would you rate your quality of life?	1.64	0.82	1.45, 1.8	3.96	1.09	3.84, 4.07	-23.347	.001*
How satisfied are you with your health?	3.96	1.09	1.63, 1.92	3.80	1.16	3.68, 3.93	-16.908	.001*
Physical health	32.2	10.9	30.19, 34.37	57.0	13.8	55.59, 58.58	-19.086	.001*
Psychological	31.5	9.07	29.76, 33.24	53.9	14.8	52.37, 55.57	-18.782	.001*
Social relationship	27.01	11.2	24.87, 29.16	54.3	17.6	52.42, 56.24	-18.778	.001*
Environment	31.5	10.9	29.45, 33.65	64.2	18.1	62.25, 66.16	-22.472	.001*

*: Statistical significance at p ≤ 0.05

Table 3: Correlation of study variables with overall quality of life in the ASD group

Overall quality of life	r value**	P value
Age	0.214	0.027*
Age of ASD diagnosis	-0.439	0.001*
Age of medical intervention	-0.483	0.001*

** : Pearson Correlation test; *: Statistical significance at p ≤ 0.05; r = correlation coefficient

The pattern of gender prevalence in this study showed that 91.6% of the participants from the study group were male. This finding aligns with a

previous study which showed that ASD is significantly more common in males than in females (Brugha et al., 2016). This could be related to the

lower likelihood of developing autism in females as well as the underdiagnosis of ASD in females (Hull et al., 2020). The results of the educational status assessment confirm a previous study that found adults with ASD to have lower levels of education compared to controls (Taylor and DaWalt, 2017). 25.2% of participants in the study group were uneducated, and only 8.4% had post-secondary education. 60% of the participants in the study group live in autism boarding school/sheltered housing. This high percentage could be due to a lack of services and insufficient information about them in Saudi Arabia (Alnemary et al., 2017).

Unlike other studies (Andersen et al., 2023; Charlton et al., 2023), it is important to note that approximately half of the participants with ASD in our study were living abroad. This significant proportion of participants residing outside Saudi Arabia may be a critical factor to consider. Additionally, our findings reveal a notably higher number of single individuals in the control group. This observation, along with the significant number of participants living abroad, may significantly impact QoL. Being single and separated from family can lead to loneliness, which may adversely affect mental health (Schiltz et al., 2021) and subsequently lead to poorer QoL.

In accordance with the literature, this research established that participants with ASD reported lower QoL in all domains compared to the control group (Lin and Huang, 2019; Mason et al., 2018). However, some studies reported higher results when asked to rate their QoL (Hong et al., 2016; Moss et al., 2017). The discrepancies could stem from variations in methodology, as noted by Moss et al. (2017). This discrepancy indicates that quality of life can be improved through certain factors, such as the presence of a caring environment and support (Hong et al., 2016).

In contrast to a finding by Knüppel et al. (2018), where the emotional domain was the lowest, this study found that the social relationships domain was the lowest domain in the ASD group, as found by Lin (2014). This result is expected, considering that autism typically causes major difficulties in communication and social behavior (APA, 2017).

Consistent with a previous study (Atherton et al., 2022), our results show a negative correlation between both "age at diagnosis" and "age at medical intervention" with the overall quality of life. The older they are at diagnosis, the worse their quality of life. The importance of early diagnosis of ASD and access to medical interventions and formal support systems is well established by previous studies. These studies reported a significant association with long-term improvement in social and adaptive behavior, mental health, and cognitive and language improvements (Atherton et al., 2022; Huang et al., 2020; Vivanti et al., 2016). Lack of self-understanding, misdiagnosis, and subsequently delayed access to medical interventions lead to mental health issues such as depression and anxiety,

all of which can negatively impact the overall QoL (Zener, 2019).

This research has several limitations. The study was conducted during the COVID-19 pandemic, which resulted in difficulty in reaching the participants. An online questionnaire and convenience sampling methods were then used. Additionally, a multicenter study with a larger and matched sample could provide a better representation of the population. In addition, due to the lack of an Arabic QoL tool used for individuals with ASD and their language difficulties, proxy reporting measures were partially used. All of this could introduce bias and compromise the accuracy of the assessment (Bertelli et al., 2019).

5. Conclusion and recommendations

In summary, individuals with ASD generally have a significantly lower quality of life across various areas compared to those without ASD. Additionally, diagnosing autism early and starting medical treatment during childhood are associated with a better quality of life in adulthood. This study highlights the importance of increasing investment in the recruitment and training of personnel to ensure that individuals with ASD receive timely and effective support. Future research should assess the quality of educational and vocational training programs to enhance the services provided to those with ASD, thereby improving their quality of life. It is also important to consider how factors like cultural context and healthcare accessibility impact the quality of life in adults with ASD. Moreover, developing a comprehensive and translated tool to measure the quality of life for individuals with ASD, which considers their specific characteristics and language challenges, is essential for an accurate assessment.

Funding

This project was funded by the National Plan for Science Technology and Innovation (MAARIFAH), King Abdulaziz City for Science and Technology, Kingdom of Saudi Arabia (award number 08-MED 510-02).

Acknowledgment

The authors thank the WHO for providing the WHO QOL-BREF and manual in support of this study. The authors are very grateful to families of adults with ASD for their participation in the study.

Compliance with ethical standards

Ethical consideration

Ethical approval was obtained from the International Review Board at the College of

Medicine, King Saud University (Ref No.: 21/0628/IRB - CMED-305/F3 [2021-2022]).

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

References

- AlBatti TH, Alsaghan LB, Alsharif MF, Alharbi JS, BinOmair AI, Alghurair HA, Aleissa GA, and Bashiri FA (2022). Prevalence of autism spectrum disorder among Saudi children between 2 and 4 years old in Riyadh. *Asian Journal of Psychiatry*, 71: 103054. <https://doi.org/10.1016/j.ajp.2022.103054> **PMid:35248844**
- AlMuammar SA, Noorsaeed AS, Alafif RA, Kamal YF, Daghistani GM, Almuammar S, and Alafif Sr R (2021). The use of Internet and social media for health information and its consequences among the population in Saudi Arabia. *Cureus*, 13(9): e18338. <https://doi.org/10.7759/cureus.18338> **PMid:34722089 PMCid:PMC8551798**
- Alnemary FM, Aldhalaan HM, Simon-Cerejido G, and Alnemary FM (2017). Services for children with autism in the Kingdom of Saudi Arabia. *Autism*, 21(5): 592-602. <https://doi.org/10.1177/1362361316664868> **PMid:28610540**
- Andersen PN, Orm S, Fossum IN, Øie MG, and Skogli EW (2023). Adolescence internalizing problems as a mediator between autism diagnosis in childhood and quality of life in emerging adults with and without autism: A 10-year longitudinal study. *BMC Psychiatry*, 23: 149. <https://doi.org/10.1186/s12888-023-04635-w> **PMid:36894901 PMCid:PMC9996871**
- APA (2017). DSM-5 update, supplement to diagnostic and statistical manual of mental disorders. 5th Edition, American Psychiatric Association, Arlington, USA.
- APA (2018). What is autism spectrum disorder? American Psychiatric Association, Arlington, USA.
- Asi KY (2016). Quality of life among parents of children with autism spectrum disorder in Riyadh. *International Research in Education*, 4(2): 76-93. <https://doi.org/10.5296/ire.v4i2.9958>
- Atherton G, Edisbury E, Piovesan A, and Cross L (2022). Autism through the ages: A mixed methods approach to understanding how age and age of diagnosis affect quality of life. *Journal of Autism and Developmental Disorders*, 52(8): 3639-3654. <https://doi.org/10.1007/s10803-021-05235-x> **PMid:34482523 PMCid:PMC9296439**
- Ayres M, Parr JR, Rodgers J, Mason D, Avery L, and Flynn D (2018). A systematic review of quality of life of adults on the autism spectrum. *Autism*, 22(7): 774-783. <https://doi.org/10.1177/1362361317714988> **PMid:28805071**
- Bertelli MO, Bianco A, Rossi A, Mancini M, La Malfa G, and Brown I (2019). Impact of severe intellectual disability on proxy instrumental assessment of quality of life. *Journal of Intellectual and Developmental Disability*, 44(3): 272-281. <https://doi.org/10.3109/13668250.2017.1350835>
- Biggs EE and Carter EW (2016). Quality of life for transition-age youth with autism or intellectual disability. *Journal of Autism and Developmental Disorders*, 46: 190-204. <https://doi.org/10.1007/s10803-015-2563-x> **PMid:26340956**
- Brugha TS, Spiers N, Bankart J, Cooper SA, McManus S, Scott FJ, and Tyrer F (2016). Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*, 209(6): 498-503. <https://doi.org/10.1192/bjp.bp.115.174649> **PMid:27388569**
- Charlton RA, McQuaid GA, and Wallace GL (2023). Social support and links to quality of life among middle-aged and older autistic adults. *Autism*, 27(1): 92-104. <https://doi.org/10.1177/13623613221081917> **PMid:35362329 PMCid:PMC9806477**
- Dijkhuis RR, Ziermans TB, Van Rijn S, Staal WG, and Swaab H (2017). Self-regulation and quality of life in high-functioning young adults with autism. *Autism*, 21(7): 896-906. <https://doi.org/10.1177/1362361316655525> **PMid:27407040 PMCid:PMC5625847**
- Gabbay-Dizdar N, Ilan M, Meiri G, Faroy M, Michaelovski A, Flusser H, Menashe I, Koller J, Zachor DA, and Dinstein I (2022). Early diagnosis of autism in the community is associated with marked improvement in social symptoms within 1–2 years. *Autism*, 26(6): 1353-1363. <https://doi.org/10.1177/13623613211049011> **PMid:34623179 PMCid:PMC9340129**
- Hong J, Bishop-Fitzpatrick L, Smith LE, Greenberg JS, and Mailick MR (2016). Factors associated with subjective quality of life of adults with autism spectrum disorder: Self-report versus maternal reports. *Journal of Autism and Developmental Disorders*, 46: 1368-1378. <https://doi.org/10.1007/s10803-015-2678-0> **PMid:26707626 PMCid:PMC4788526**
- Huang Y, Arnold SR, Foley KR, and Trollor JN (2020). Diagnosis of autism in adulthood: A scoping review. *Autism*, 24(6): 1311-1327. <https://doi.org/10.1177/1362361320903128> **PMid:32106698**
- Hull L, Petrides KV, and Mandy W (2020). The female autism phenotype and camouflaging: A narrative review. *Review Journal of Autism and Developmental Disorders*, 7: 306-317. <https://doi.org/10.1007/s40489-020-00197-9>
- Iannuzzi D, Kopecky K, Broder-Fingert S, and Connors SL (2015). Addressing the needs of individuals with autism: Role of hospital-based social workers in implementation of a patient-centered care plan. *Health and Social Work*, 40(3): 245-248. <https://doi.org/10.1093/hsw/hlv032> **PMid:26285365**
- Knopf A (2016). Timely autism diagnosis-before 4 years of age-improves treatment. *The Brown University Child and Adolescent Behavior Letter*, 32(9): 3-3. <https://doi.org/10.1002/cbl.30151>
- Knüppel A, Telléus GK, Jakobsen H, and Lauritsen MB (2018). Quality of life in adolescents and adults with autism spectrum disorder: Results from a nationwide Danish survey using self-reports and parental proxy-reports. *Research in Developmental Disabilities*, 83: 247-259. <https://doi.org/10.1016/j.ridd.2018.09.004> **PMid:30312897**
- Li C, Zhu G, Feng J, Xu Q, Zhou Z, Zhou B, Hu C, Liu C, Li H, Wang Y, and Yan W (2018). Improving the early screening procedure for autism spectrum disorder in young children: Experience from a community-based model in Shanghai. *Autism Research*, 11(9): 1206-1217. <https://doi.org/10.1002/aur.1984> **PMid:30230702**
- Lin LY (2014). Quality of life of Taiwanese adults with autism spectrum disorder. *PLOS ONE*, 9(10): e109567. <https://doi.org/10.1371/journal.pone.0109567> **PMid:25299379 PMCid:PMC4192352**
- Lin LY and Huang PC (2019). Quality of life and its related factors for adults with autism spectrum disorder. *Disability and Rehabilitation*, 41(8): 896-903. <https://doi.org/10.1080/09638288.2017.1414887> **PMid:29228834**
- Mason D, McConachie H, Garland D, Petrou A, Rodgers J, and Parr JR (2018). Predictors of quality of life for autistic adults. *Autism Research*, 11(8): 1138-1147.

- <https://doi.org/10.1002/aur.1965>
PMid:29734506 PMCID:PMC6220831
- Moss P, Mandy W, and Howlin P (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders*, 47: 1830-1837.
<https://doi.org/10.1007/s10803-017-3105-5>
PMid:28343343 PMCID:PMC5432629
- Murphy CM, Wilson CE, Robertson DM, Ecker C, Daly EM, Hammond N, Galanopoulos A, Dud I, Murphy DG, and McAlonan GM (2016). Autism spectrum disorder in adults: Diagnosis, management, and health services development. *Neuropsychiatric Disease and Treatment*, 12: 1669-1686.
<https://doi.org/10.2147/NDT.S65455>
PMid:27462160 PMCID:PMC4940003
- Ohaeri JU and Awadalla AW (2009). The reliability and validity of the short version of the WHO quality of life instrument in an Arab general population. *Annals of Saudi Medicine*, 29(2): 98-104.
<https://doi.org/10.4103/0256-4947.51790>
PMid:19318760 PMCID:PMC2813624
- Sabbagh HJ, Al-Jabri BA, Alsulami MA, Hashem LA, Aljubour AA, and Alamoudi RA (2021). Prevalence and characteristics of autistic children attending autism centres in 2 major cities in Saudi Arabia: A cross-sectional study. *Saudi Medical Journal*, 42(4): 419-427.
<https://doi.org/10.15537/smj.2021.42.4.20200630>
PMid:33795498 PMCID:PMC8128630
- Salhia HO, Al-Nasser LA, Taher LS, Al-Khathaami AM, and El-Metwally AA (2014). Systemic review of the epidemiology of autism in Arab Gulf countries. *Neurosciences Journal*, 19(4): 291-296.
- Schiltz HK, McVey AJ, Dolan Wozniak B, Haendel AD, Stanley R, Arias A, Gordon N, and Van Hecke AV (2021). The role of loneliness as a mediator between autism features and mental health among autistic young adults. *Autism*, 25(2): 545-555.
<https://doi.org/10.1177/1362361320967789>
PMid:33126822
- Sulaimani MF and Gut DM (2019). Autism in Saudi Arabia: Present realities and future challenges. *Review of Disability Studies: An International Journal*, 15(2): 1-12.
- Taha GR and Hussein H (2014). Autism spectrum disorders in developing countries: Lessons from the Arab world. In: Patel V, Preedy V, and Martin C (Eds.), *Comprehensive guide to autism*: 2509-2531. Springer, New York, USA.
https://doi.org/10.1007/978-1-4614-4788-7_98
- Taylor JL and DaWalt LS (2017). Brief report: Postsecondary work and educational disruptions for youth on the autism spectrum. *Journal of Autism and Developmental Disorders*, 47(12): 4025-4031.
<https://doi.org/10.1007/s10803-017-3305-z>
PMid:28889215 PMCID:PMC5677531
- van't Hof M, Tisseur C, van Berckeleer-Onnes I, van Nieuwenhuyzen A, Daniels AM, Deen M, Hoek HW, and Ester WA (2021). Age at autism spectrum disorder diagnosis: A systematic review and meta-analysis from 2012 to 2019. *Autism*, 25(4): 862-873.
<https://doi.org/10.1177/1362361320971107>
PMid:33213190
- Vincent A, Da Fonseca D, Baumstarck K, Charvin I, Alcaraz-Mor R, and Lehucher-Michel MP (2020). The quality of life and the future of young adults with Asperger syndrome. *Disability and Rehabilitation*, 42(14): 1987-1994.
<https://doi.org/10.1080/09638288.2018.1544297>
PMid:30669888
- Vivanti G, Dissanayake C, and Victorian ASELCC Team (2016). Outcome for children receiving the early start Denver model before and after 48 months. *Journal of Autism and Developmental Disorders*, 46: 2441-2449.
<https://doi.org/10.1007/s10803-016-2777-6>
PMid:27020055
- WHO (2019). *Autism spectrum disorder*. World Health Organization, Geneva, Switzerland.
- Whoqol Group (1998). Development of the world health organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, 28(3): 551-558.
<https://doi.org/10.1017/S0033291798006667>
PMid:9626712
- Zeina RM, Al-Ayadhi L, and Bashir S (2014). Autism spectrum disorder: Main problem waiting for solution in Kingdom of Saudi Arabia. *International Journal of Medical and Health Sciences*, 8(8): 526-529.
- Zener D (2019). Journey to diagnosis for women with autism. *Advances in Autism*, 5(1): 2-13.
<https://doi.org/10.1108/AIA-10-2018-0041>