

# Quality of life of caregivers of autistic children in Saudi Arabia: Cross-sectional study

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### ABSTRACT

**الأهداف:** قياس تأثير رعاية طفل مصاب بالتوحد على جودة حياة مقدم الرعاية.

**المنهجية:** أجريت دراسة مسحية خلال الفترة من مايو إلى يوليو 2019م في مستشفى جامعة الملك عبد العزيز، جدة، المملكة العربية السعودية. شارك فيها 812 فرداً نصفهم كان من مقدمي الرعاية للأطفال المصابين بالتوحد، والنصف الآخر كانوا مقدمي رعاية لأطفال غير مصابين بالتوحد. جمعت البيانات من خلال استبيان نُشر عبر الإنترنت في جميع مناطق المملكة العربية السعودية الثلاثة عشر.

**النتائج:** أظهر مقدمو الرعاية للأطفال المصابين بالتوحد درجات منخفضة في بعض مجالات جودة الحياة عند مقارنتها بجودة حياة مقدمي الرعاية للأطفال غير المصابين بالتوحد في جميع الجوانب باستثناء جانب واحد  $p < 0.05$ . تم أخذ عوامل إضافية في الاعتبار بعد العثور على علاقة كبيرة بين هذه العوامل وجودة الحياة؛ بما في ذلك العمر وعلاقة مقدمي الرعاية بالأطفال ومحافظاتهم والخدمات الطبية المقدمة لهم.

**الخلاصة:** وجدت هذه الدراسة علاقة عكسية كبيرة بين تقديم الرعاية لطفل مصاب بالتوحد وبين جودة حياة الفرد.

**Objectives:** To assess the impact on quality of life (QOL) caused by caring for children with autism spectrum disorder (ASD) and examine the impact according to provincial residence.

**Methods:** This was an observational, cross-sectional study conducted from May to July 2019 at King Abdulaziz University Hospital in Jeddah. Eight hundred and twelve participants were included and divided equally into caregivers of children with and without ASDs. Data were collected through an online questionnaire distributed via autism associations and parental support groups across all 13 Saudi Arabian provinces.

**Results:** Caregivers of children with ASDs showed lower scores in most quality-of-life domains

compared with those of caregivers of children without ASDs ( $p < 0.05$ , except for one domain). The impacts of additional factors were considered, including the caregivers' age, the relation of the caregiver to the child, the specific province of residence, and the provision of medical services.

**Conclusion:** A significant negative correlation was found between caregiving for children with ASDs and quality-of-life scores.

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Autism spectrum disorder (ASD) is a term that covers a range of neurobehavioral conditions characterized by impairments in social behavior, communication, and language, and is generally coupled with a constrained range of interests involving a focus on specific activities unique to the individual which are often performed repeatedly.<sup>1</sup> The ASDs are usually diagnosed at an early stage in the life of an individual (generally in the first three years) and tend to continue through adolescence and adulthood. According to the World Health Organization, approximately one in

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every 160 children have a symptom that can be placed on the ASD spectrum. Globally, the prevalence of ASDs is increasing.<sup>1</sup>

While there are currently no specific cures for ASDs, there are treatments that improve the quality of life (QOL) of individuals with ASDs which depend on the provision of a certain level of care commencing with early interventions, followed by ongoing monitoring of development by caregivers.<sup>1</sup> A caregiver is usually defined as a family member or any assigned person who takes responsibility for looking after the dependent person, such as a child or a sickly, older, or a disabled person.<sup>2</sup> Caregivers of children with ASDs cover various aspects of care, including physical, psychological, and social support to a degree that may exceed what would normally be provided by parents of children without ASDs. Indeed, caring for a child with ASD can be highly demanding. The increased workload required by caregivers to cover the needs of the child in connection with inadequate access, relevant services, and support could contribute to decreased QOL of caregivers. In light of these factors, empowering caregivers is an essential component of care interventions for ASD management.<sup>1</sup>

The burden of caring for a child with an ASD has been identified in several international studies.<sup>3,4</sup> A study carried out in the United States in 2018 found that mothers of children with autism experienced acute and varied challenges when participating in leisure and recreational activities.<sup>3</sup> They described these challenges as involving insufficient time for themselves, increased effort needed to pay constant attention to their children, and obstacles related to finding an appropriate helper. In the Arab states of the Arabian Gulf, there are insufficient provisions regarding this aspect of child healthcare. Nevertheless, a study published in Qatar in 2012 assessed the QOL of caregivers of children with autism and concluded that there is significant evidence regarding the considerable impact on the QOL of caregivers of children with ASDs and provided various recommendations for policy makers and healthcare institutions, such as focused and increased support for children with ASDs and their caregivers.<sup>4</sup>

Only a small number of studies have been carried out in Saudi Arabia that have drawn attention to the QOL of caregivers of children with ASDs. Caregivers are generally considered in the context of disabilities, and there have been no studies carried out in Saudi Arabia that specifically focus on caregivers of children with ASDs. One study conducted in 2012 evaluated the QOL of families with children with various disabilities and found that caregivers of children with ASDs had

the lowest QOL scores compared with caregivers of children with other disabilities.<sup>5</sup> Another study based in Riyadh in 2016, assessed QOL among parents of children with and without ASDs and found statistically significant differences between the groups in terms of QOL levels and their respective domains.<sup>6</sup> This cross-sectional study assessed the impact on QOL caused by caring for children with ASDs and examined the impact according to provincial residence.

**Methods.** This was an observational, cross-sectional study conducted from May to July 2019 at King Abdulaziz University Hospital in Jeddah. This study was carried out according to the principles of Helsinki Declaration.

Data were collected using an online questionnaire using Google Forms and distributed to all 13 regions of Saudi Arabia: Riyadh, Makkah, Madinah, Eastern, Asir, Baha, Northern Border, Al Jouf, Qassim, Hail, Jazan, Najran, and Tabuk. We reached caregivers by utilizing autism associations and parental support groups using social media platforms, and incorporated a data collector in each region.

We included a total of 1340 randomly collected responses. We only included caregivers of children aged 2-18 years. Caregivers with any deaths or divorces within the family 2 months prior to study commencement were excluded. After applying these criteria, the maximum remaining number of participants that could be divided into 2 equal groups was 812; therefore, we randomly assigned 406 caregivers of children with and without ASDs to each group.

Data were collected using an online questionnaire, derived from the Arabic version of the RAND SF-36, a validated 36-item instrument called the Short Form Survey developed by the RAND Corporation, California, USA. It contains several QOL domains (for example, physical, emotional, social, general health). Demographics and other variables, such as the number of children with ASDs and the relation of the caregiver to the child with an ASD were included. The questionnaire was distributed to all 13 provinces in Saudi Arabia. Completion of the questionnaire was considered consent to participate.

**Statistical analysis.** Data were analyzed using the Statistical Package for the Social Sciences (2021) (version 21.0, SPSS Inc., Chicago, USA), with frequencies and percentages for categorical variables and means and standard deviations for continuous variables. The student's independent t-test was used to compare the results of the continuous variables, the chi-squared test was used for the categorical variables, and one-way

analysis of variance was used to compare results with >2 sets of means. We considered a *p*-value of <0.05 as statistically significant.

**Results.** This study analyzed the QOL of caregivers of children with and without ASDs in Saudi Arabia. A total of 812 participants consented to participate: 71.3% were women and 28.7% were men. Most of the caregivers of children with ASDs (56.7% were mothers; 21.7% were fathers and a small percentage 16.8% were siblings). The majority 61.2% of caregivers of children with ASDs had a bachelor's degree, while caregivers with PhD constituted the lowest proportion 1.7%. Indeed, most caregivers involved were parents, constituting 78.4% of the total cohort, while 2% were special-education teachers or specialists. Overall, 78.8% of caregivers had only one child diagnosed on the ASD spectrum, whereas 21% had 2 or more children with ASDs. Other demographic details are shown in Table 1.

The results showed significant differences in all domains when comparing the QOL of caregivers of children with and without ASDs except for the domain of health change. Caregivers of children with ASDs tended to have lower scores across most domains, as shown in Table 2. Furthermore, other variables affected the QOL of caregivers of children with ASDs. Age was statistically significant in most domains (except for energy/fatigue and emotional well-being; Table 3). Participants aged >50 years scored the lowest in physical functioning, role limitations due to emotional problems, social functioning, pain, and general health, whereas participants aged 41-50 years had the lowest scores in the health change domain.

The relation of the caregivers to the children with ASDs and QOL appeared to be significantly negatively associated in several domains. The data showed a significant relationship in most areas except in the health change domain, as shown in Table 3. Overall, parents of children with ASDs had the lowest scores in physical functioning, with mothers scoring the weakest: role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, and pain. Notably, the participating fathers of children with ASDs had the lowest scores for general health, whereas brothers reported the lowest scores for emotional well-being and social functioning. The data also showed that the residential provinces of caregivers were associated with QOL, with significant *p*-values in all domains except energy/fatigue. The variation in scores between provinces is presented in Table 4.

Concerning the provided medical services, caregivers of children with and without ASDs were prompted

**Table 1 -** Demographics of the caregivers in this study.

Demographics	Participants (n)	
	Caregiver of child with ASD	Caregiver of child without ASD
<i>Gender</i>		
Male	140	93
Female	266	313
<i>Age</i>		
<20	23	21
20-30	84	128
31-40	177	118
41-50	85	110
>50	37	29
<i>Academic level</i>		
Primary school	15	10
Middle school	35	16
High school	95	71
Bachelors	221	276
Masters	30	29
PhD	10	4
<i>Nationality</i>		
Saudi Arabian	377	397
Non-Saudi Arabian	29	9
<i>Province</i>		
Riyadh	45	32
Makkah	65	49
Madinah AlMonawarah	11	3
Al-Qassim	24	34
Eastern province	42	50
Aseer	6	11
Tabouk	43	37
Hail	46	51
Northern borders	6	8
Jazan	12	14
Najran	46	28
Al-Bahaa	30	81
Al-Jouf	30	8
<i>Relation to child with ASD</i>		
Mother	230	
Father	88	
Sister	34	
Brother	34	
Other relatives	12	
Special education teacher/ Specialist	8	
<i>Number of ASD children</i>		
1	320	
2	60	
3	12	
More than 3	14	

ASD: autism spectrum disorder

**Table 2 -** Domains of quality of life and caregiving status.

Domains	Caregiver of child with ASD	Caregiver of child without ASD	P-value
	Mean±SD		
Physical functioning	77.9±24.9	82.0±21.9	0.012
Role limitations due to physical health	62.1±39.2	71.5±36.6	0.000
Role limitations due to emotional problems	56.9±43.7	64.6±42.1	0.011
Energy/ fatigue	48.4±18.8	52.3±18.4	0.003
Emotional well-Being	55.8±18.7	58.6±17.6	0.025
Social functioning	62.4±25.5	72.2±21.2	0.000
General health	55.9±13.7	61.8±12.9	0.000
Health change	60.1±22.5	61.3±24.7	0.418

**Table 3 -** P-values of caregiver quality of life, age, and relation to child with ASD.

Domains	QOL and age	QOL and relation to the ASD child
Physical function	0.000	0.006
Role limitations due to physical Health	0.003	0.001
Role limitations due to emotional problem	0.002	0.010
Energy/fatigue	0.158	0.000
Emotional well-being	0.937	0.014
Social functioning	0.027	0.014
Pain	0.000	0.004
General health	0.000	0.019
Health change	0.001	0.202

Values are presented as p-value. ASD - autism spectrum disorder, QOL - quality of life

for their opinions on institutional provisions. Among caregivers of children with ASDs 36.2% believed that relevant medical services required improvement, whereas 44.1% of caregivers of children without ASDs described them as “good” (Figure 1). Feedback from non-ASD caregivers was also significantly associated with the residential province. Regarding the findings of both groups in Najran, many responses (46.7%) described medical services as “excellent.” In contrast, 66.7% of participants in Aseer were “highly unsatisfied” with the provision of medical services and 80% of caregivers in Jazan reported that medical services “required improvement.” Interestingly, caregivers that reported “poor” and “totally unsatisfying” regarding service options scored lowest for QOL in all domains, as shown in Table 5.

**Discussion.** This study assessed the QOL of caregivers of children with and without ASDs across

Saudi Arabia. The data showed that most caregivers were women, possibly owing to the cultural context, as it is traditional for women to be the primary caregivers of children.

The key finding was a significant relationship between caregiving for children with ASDs and individual QOL scores. This conflicts with the findings of a similar study conducted in Qatar by Kheir et al,<sup>4</sup> who found no statistically significant difference between caregiving for children with ASDs and QOL domains, except for the general health domain. The reason for this might be that there is a much smaller population in Qatar, which may make it easier for support systems to provide the basic needs for children with ASD and their caregivers, possibly enhancing QOL. This is suggested by various findings in previous research where a significant connection has been found between population size and healthcare service utilization.<sup>7</sup>

According to the findings of the present study, several variables affect the QOL of caregivers of children with ASDs. For example, there is a noticeable decline in the QOL scores of older caregivers, perhaps because this group has a higher probability of comorbid health disorders.<sup>8</sup> However, this finding is inconsistent across all QOL domains. In the health change domain, the most affected age group was people aged 41-50 years, conceivably due to chronic diseases that may emerge at this age (such as hypertension, hypercholesterolemia, and osteoporosis) as mentioned in several previous studies.<sup>9-12</sup> However, unexpectedly, our findings showed that age did not strongly affect the energy/fatigue and emotional well-being domains.

The present findings show that parents of children with ASDs have lower QOL scores in most domains compared with other types of caregivers, as determined in other studies, perhaps because they are the primary caregiver of the child with ASD in most cases. Surprisingly, brothers of children with ASDs scored

**Table 4 -** Quality-of-life domain scores according to province.

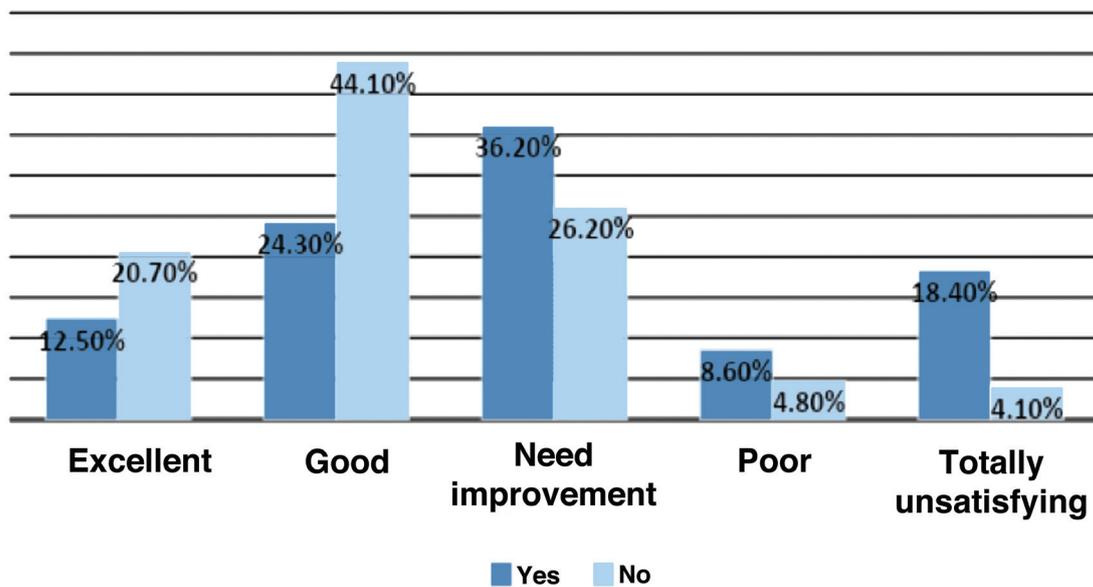
Province	D1	D2	D3	D4	D5	D6	D7	D8	D9
	Mean (SD)								
Riyadh	85.78 ±19.01	66.67 ±41.63	54.07±47.30	48.44 ±20.47	58.13±17.96	66.11±28.53	73.56 ±25.76	56.56 ±12.78)	62.22 ±24.78)
Al-Qassim	81.88 ±18.23	84.38±26.29	69.44 ±40.43	57.50 ±16.62	70.50±14.58	76.56±18.18	81.98 ±19.59	67.29 ±14.52	59.38 ±16.17
Makkah	83.08 ±18.83	60.39 ±41.20	56.41 ±44.85	46.15 ±22.51	56.49±23.38	61.73±29.39	67.04 ±27.49	57.15 ±15.10	56.15 ±26.53
Madinah	81.82 ±18.07	38.64 ±40.87	39.39 ±44.27	44.09 ±20.35	54.18±21.57	69.32 ±27.02	72.27 ±20.96	52.73 ±20.78	54.55 ±29.19
Northern Borders	73.33 ±18.35	54.17 ±45.87	77.78 ±40.37	41.67 ±16.63	48.00 ±16.78	66.67 ±30.28	72.08 ±21.41	46.67 ±14.38	54.17 ±10.21
Tabouk	83.61 ±19.65	80.81 ±29.30	82.95 ±30.31	48.26 ±7.47	51.72 ±7.53	75.29 ±25.22	84.59 ±20.42	54.07 ±8.95	56.40 ±11.04
Al-Jowf	71.83 ±36.07	50.00 ±50.86	53.33 ±50.74	57.17 ±21.99	61.47 ±22.27	62.92 ±23.09	73.17 ±23.05	56.67 ±12.13	71.67 ±22.49
Hael	62.61±33.84	62.50 ±27.26	42.75 ±38.27	43.91 ±13.08	55.57 ±13.04	47.28 ±12.88	55.49 ±18.54	47.50 ±11.91	58.15 ±14.96
Aseer	87.50 ±19.94	62.50 ±41.08	55.56 ±50.19	49.17 ±17.15	49.33 ±23.96	66.67 ±24.58	71.67 ±18.01	60.83 ±18.55	54.17 ±29.23
Jazan	71.67 ±23.58	31.25 ±42.81	47.22 ±43.71	52.50 ±19.83	54.67 ±17.34	56.25 ±21.65	66.46 ±23.54	58.33 ±11.74	62.50 ±25.00
Najran	68.37 ±26.48	55.98 ±37.34	53.62 ±40.66	46.96 ±16.07	53.57 ±14.45	54.62 ±24.35	70.44 ±24.82	55.11 ±14.59	63.59 ±22.18
Al-Baha	81.83 ±19.80	57.50 ±37.23	55.56 ±42.29	52.17 ±21.12	58.13 ±20.39	70.83 ±19.51	71.00 ±23.89	58.33 ±10.03	70.00±24.03
Eastern province	82.02±20.75	61.91±39.52	54.76 ±47.04	45.24 ±21.695	47.52 ±21.02	55.66 ±25.63	68.63 ±24.86	57.38 ±13.08	53.57 ±25.04
P-value	0.000	0.000	0.008	0.060	0.001	0.000	0.000	0.000	0.019

D1 - physical function, D2 - role limitations due to physical health, D3 - role limitations due to emotional problems, D4 - energy/fatigue, D5 - emotional well-being, D6 - social function, D7 - pain, D8 - general health, D9 - health change

**Table 5 -** Quality-of-life domain scores and caregiver feedback on medical services.

Feedback on medical services	D1	D2	D3	D4	D5	D6	D7	D8	D9
Excellent	81.05	64.74	56.14	53.42	62.31	63.16	74.21	59.47	55.26
Good	84.46	72.97	77.48	55.13	61.62	72.63	79.12	63.65	65.54
Needs Improvement	80.27	54.54	52.73	45.82	55.34	61.14	63.41	56.82	56.82
Poor	77.69	44.23	25.64	34.61	44.92	46.15	56.35	50.00	53.85
Totally Unsatisfying	82.32	42.86	29.76	45.18	53.14	48.21	64.73	53.21	44.64
P value	0.804	0.027	0.000	0.013	0.065	0.001	0.005	0.011	0.014

values are presented as mean



**Figure 1 -** Caregiver's feedback on the provided medical services. Yes - caregiver of child with ASD, No - caregiver of child without ASD

the lowest in the emotional well-being and social functioning domains, possibly because of the strong family bond inherent in Saudi Arabian culture where siblings are expected to be actively involved in the care of their siblings, which puts significant pressure on sibling caregivers.

These results show that the province of residence also affected the QOL domains, except for the energy/fatigue domain. One possible explanation for this might be the differential provision of medical services across provinces. Indeed, Ministry of Health statistics indicate a significant differential distribution of healthcare services by geographical area.<sup>4</sup> This may also explain the diversity in evaluations of medical services attested by caregivers.

While this study was carefully organized and carried out, it was difficult to mitigate certain limiting contingencies. Primarily, it was difficult to find approved background statistics regarding the general and particular prevalence of ASDs in Saudi Arabia. Furthermore, differences in the academic levels of participants may have affected the caregivers' ability to utilize the Internet or read, comprehend, and complete the questionnaire appropriately, which may have affected the variation in caregivers' responses. A further limitation is that it is possible that some individuals who submitted questionnaires may not have been the child's main caregiver but a secondary caregiver who helps the main caregiver, which could have affected the findings. In addition, according to the perspectives of some respondents, misinterpretations of some questions could have affected the responses, and thus some results may have been mildly affected.

This study found a significant negative correlation between caregivers of children with ASDs and QOL. Significant differences were found in the QOL domains of caregivers of children with ASDs compared with those of children without ASDs, except for the health change domain. In general, caregivers of children with ASDs tend to have lower overall QOL scores in most domains, suggesting an increased burden of caring for children with ASDs.

In conclusion, the Saudi Arabian government is undertaking large-scale programs to improve the QOL of individuals with various health conditions and their careers in Saudi Arabia, our findings reveal the importance of considering the QOL of children with ASDs and their caregivers to provide relevant medical, psychological, and financial support services. A possible solution to avoid unfavorable variation of services across provinces is to establish unified national centers with qualified employees, enabling advanced healthcare

services with affordable teaching and training sessions for caregivers. To address the insufficient research carried out in this area, research facilities may promote attention to individuals with ASD and their caregivers through funding initiatives.

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