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Effect of autism on parental quality of life in Arar city, Saudi Arabia

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Abstract:

BACKGROUND: The quality of life (QOL) of the families of children with autism is lower than that of families of normal children or children with other disabilities. The study's aim was to describe the severity of effect on the domains of the QOL of caregivers of autistic children and to identify the characteristics of caregivers and children associated with impaired QOL.

MATERIALS AND METHODS: This cross-sectional study included 84 parents of autistic children attending developmental abnormalities clinic in Arar city during January 1 to March 31, 2019. Parents of autistic children were interviewed using an Arabic version of the short-form 36 to assess their QOL. A mean score of <50 was considered to indicate poor QOL. Collected data were analyzed using the Statistical Package for the Social Sciences (SPSS, version 20.0). A Chi-square test was used for comparison between categorical variables.

RESULTS: Of 84 caregivers, 63.1% had impaired QOL. The main domains affected were energy/fatigue and role limitations resulting from emotional problems. Female gender, unemployment, and low income of caregivers were significant factors associated with poor QOL. Autistic children of the first birth order and with long duration of the disease were more likely to be associated with poor parental QOL. Gender, income, occupation, and duration of illness were associated with poor quality of life, but this was not statistically significant.

CONCLUSION: Slightly less than two-thirds of the caregivers had impaired QOL. Caregivers of autistic children need social and emotional support to help them to cope with this disability.

Keywords:

Autism, caregivers, quality of life, Saudi Arabia, short-form 36

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Introduction

“Autism spectrum disorder (ASD) is a subgroup of pervasive developmental disorders, that manifests in many characteristics; deficiency in reciprocal social interactions and communication, restrictive, repetitive and unusual behaviors, and interests.”^[1,2] There is no known cure for ASD, but early intervention and behavioral therapy are associated with a better outcome.^[3]

In the United States, according to the Centers for Disease Control, the prevalence

of ASD increased from 1 in 80 (1.25%) in (2011–2013) to 1 in 45 (2.24%) in 2014, owing to more awareness and research of the disorder.^[4]

In the Gulf countries, a systematic review of the epidemiology of autism revealed a prevalence ranging from 1.4 to 29/10,000 persons.^[5] In a study in Taif, Saudi Arabia, the estimated prevalence of autism in primary school children aged 7–12 years was 0.035%.^[6] A review of the available literature has revealed no recent prevalence statistics for children with autism/ASD in Saudi Arabia.^[7] The Saudi Ministry of Health has indicated that one in every 160 children has an ASD.^[8]

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With such a high prevalence rate of ASD, questions are being raised about its causes and its impact on the quality of life (QOL), not only of the sufferers but also of their family caregivers.^[9]

The Saudi health authority provides services for the care of autistic children and supports their families. The Saudi Governmental funding supports private institutions to care for ASD children, albeit the services provided are inadequate. Students with disabilities receive special education.^[5,10] However, parents of children with ASD in Saudi Arabia face multiple challenges because of the conservative nature of the culture as well as the amount of training time needed (more than 30 h almost every week).^[11]

The symptoms of ASD are persistent and typically appear during the first 3 years of life. Manifestations range from mild-to-severe.^[12] Although there are health-care centers specializing in the treatment of ASD, the majority of the care is provided at home by family members, which present these families with numerous challenges.^[13] The families inevitably have a lot of difficulties raising ASD children. The result of the course is stress on family life and daily routine.^[14] Parents of children with ASD reported more stress than parents of children diagnosed with other disabilities^[15] and children who are developing normally.^[16-18]

The challenges that affect parent's psychological well-being include financial constraints, lack of social support, deficiencies of health services, and labeling with autism.^[11,19] Caring for a child with ASD is associated with increased financial burden owing to the number of visits made to the health-care office, prescribed treatment, special education, and coordinated family services.^[20] This also affects parents' employment decisions; giving up a job, not taking a job, or changing employment to accommodate their child's needs.^[21] To the best of our knowledge, very few studies have described the QOL of the parents of autistic children in Arab countries, and few studies have been conducted in Saudi Arabia to describe the level of QOL of parents of children with ASD.^[11,22,23] The dearth of research on ASD has resulted in significant difficulties in the evaluation and improvement of the services provided to individuals with autism.^[10] The aim of this study was to evaluate the effect of ASD on the QOL of the parents of those children in Arar city.

Materials and Methods

This study comprised parents of 84 autistic children attending developmental abnormalities clinic at Maternal and Children's Hospital (MCH) in Arar city, Saudi Arabia. This hospital, affiliated to the ministry of

health, is the main service provider for children with intellectual disabilities. It provides medical, speech therapy, and behavioral intervention for autistic children. The study was conducted from January 1, 2019, to March 31, 2019. Parents of any child diagnosed with ASD <1 year or with comorbidity, the presence of other siblings with disabilities, and those with chronic diseases were excluded from the study, as these conditions had a high impact on the QOL. Based on *a priori* power analysis, using effect size 0.3,^[24] alpha error 0.05, power 0.8, and two-tailed *P*.^[25] G power indicated that a sample of 90 parents of autistic children was necessary.

Six non-Saudi parents were excluded from the analysis leaving 84 parents. The parents of children diagnosed with ASD were interviewed using a structured two-part questionnaire. The first part had questions on the sociodemographic characteristics of caregiver (e.g., age, sex, and marital status) and questions on child's characteristics (e.g., child gender, age, birth order, and severity of disease). In the second part were questions on QOL for which the Arabic version of short-form-36, a valid reliable tool was used. It had eight domains on general health, physical functioning, physical role limitation, role limitation resulting from emotional issues, energy/fatigue, bodily pain, emotional well-being, and social function.^[26,27] Participants were asked to respond to questions according to how they had felt in the previous 4 weeks. The items used Likert-type scales, some with 5 or 6 points, and others with 2 or 3 points. Specific questions covered each domain. The score for each question was recorded from 0 to 100, with 0 as the worst score.^[28] A mean score of QOL <50 for each domain was considered as poor.

The collected data were coded and analyzed using the Statistical Package for the Social Sciences (SPSS, version 20, IBM Corporation, Armonk, New York, USA). Qualitative data were expressed as number and percentage, whereas quantitative data were presented as the mean and standard error. Chi-square was employed in a comparison between categorical variables. Logistic regression analysis was used to assess the association between caregiver and child characteristics and QOL. $P \leq 0.05$ was considered as statistically significant. Ethical approval was obtained from the Institutional Review Board and the Ethical Research Committee of Northern Borders General Health Affairs. Written informed consent was taken from all participants. Approval was also obtained from the hospital administration of Northern Borders' general health affairs. Before the start of the interview, participants were assured that collected data would be treated with the greatest degree of confidentiality and would be used for research purposes only.

Results

Figure 1 is a pie chart of the proportion of parents of autistic children with impaired QOL. Of the studied parents, 63.1% had impaired QOL.

Table 1 shows the relation between the QOL of caregivers of autistic children and their sociodemographic characteristics. If the caregiver was a mother (odds ratio [OR] =3.7; confidence interval [CI]: 1.19–11.6; $P = 0.01$), unemployed (OR = 2.8; CI: 1.08–7.3; $P = 0.03$)

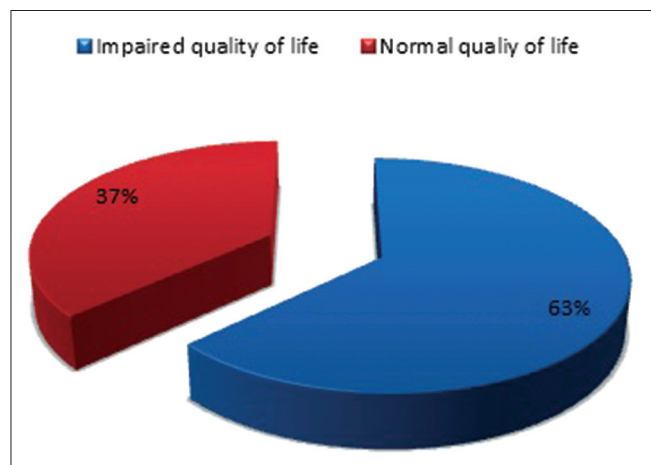


Figure 1: Distribution of parents of autistic children by quality of life

and on low income (OR = 4.8; CI: 1.2–17.9; $P = 0.01$), they were more likely to suffer from poor QOL.

Table 2 shows that parents of female autistic children were two to three times more likely to complain of poor QOL than those whose autistic children were male, but this difference did not reach the statistical level of significance ($P = 0.1$). The first birth order and long duration of the disease (≥ 5 years) were associated with poor parental QOL (OR = 5.04; CI: 1.3–19.4; $P = 0.012$ and OR = 4.2; CI: 1.2–14.4; $P = 0.01$, respectively).

Table 3 shows the correlation among domains of QOL. Emotional well-being had significant strong positive correlation with both energy/fatigue ($r = 0.75$) and social functioning domains ($r = 0.61$).

Table 4 demonstrates that the main domains affected were role limitation as a result of emotional problems (mean score = 31.3 ± 4.7) and energy/fatigue domain (mean score = 40.8 ± 2.05), as they had a mean score below 50. The mean score of the social function domain was borderline (50.4 ± 2.5).

Table 5 logistic regression analysis of the factors associated with impaired paternal QOL showed the significant factors by univariate analysis as not statistically significant.

Table 1: Relationship between sociodemographic characteristics and quality of life of caregivers of autistic children attending MCH at Arar city, Saudi Arabia

Caregiver's characteristics	Total (n=84) N (%)	Poor QOL (n=53) N (%)	P-Value	OR	95% CI OR
Age (years)					
<40	46 (54.8)	29 (63.0)	0.9	0.9	0.4-2.42
40+	38 (45.2)	24 (63.2)		Ref	
Sex					
Male	16 (19.1)	6 (37.5)		Ref	
Female	68 (80.9)	47 (69.1)	0.018	3.7	1.19-11.6
Marital status					
Married and living together	61 (72.6)	36 (59.0)	0.2	Ref	
Separated, widow, and divorced	23 (27.4)	17 (73.9)		1.9	0.68-5.6
Education					
< Secondary	24 (28.6)	18 (75.0)	0.15	2.1	0.74-6.16
Secondary +	60 (71.4)	35 (58.3)		Ref	
Occupation					
Not employed	58 (69.1)	41 (70.7)	0.03	2.8	1.08-7.3
Employed	26 (30.9)	12 (46.2)		Ref	
Income in relation to expenditure					
Not enough	21 (25.0)	18 (85.7)	0.013	4.8	1.28-17.9
Enough	63 (75.0)	35 (55.6)		Ref	
Housing					
Owned	62 (73.8)	39 (62.9)	0.9	0.9	0.35-2.6
Rented	22 (26.2)	14 (63.6)		Ref	
Number of family members					
<7	51 (60.7)	33 (64.7)	0.7	1.19	0.48-2.9
7+	33 (39.3)	20 (60.6)		Ref	

Ref=Reference category, QOL=Quality of life, CI=Confidence interval, OR=Odds ratio, MCH=Maternal and Children's Hospital

Table 2: Relationship between child's characteristics and quality of life of caregivers of autistic children attending MCH at Arar city, Saudi Arabia

Child's characteristic	Total (n=84) N (%)	Poor QOL (n=53) N (%)	P-Value	OR	95% CI OR
Child's age (years)					
<7	27 (32.1)	17 (62.9)		Ref	
7-10	36 (42.9)	22 (61.1)	0.8	0.9	0.6-1.4
>10	21 (25.0)	14 (66.7)	0.7	1.1	0.35-3.8
Child's gender					
Male	70 (83.3)	42 (60.0)		Ref	
Female	14 (16.7)	11 (78.6)	0.1	2.4	0.62-9.5
Birth order					
1 st	21 (25.0)	18 (85.7)	0.012	5.04	1.3-19.4
2 nd	17 (20.2)	10 (58.8)	0.7	1.2	0.38-3.7
3 rd +	46 (54.8)	25 (54.3)		Ref	
Disease duration (years)					
1-2	22 (26.2)	10 (45.5)		Ref	
3-4	35 (41.7)	22 (62.9)	0.1	2.03	0.6-6.0
5+	27 (32.1)	21 (77.8)	0.01	4.2	1.2-14.4
Disease severity					
Mild	22 (26.2)	10 (45.5)		Ref	
Moderate	44 (52.4)	31 (70.5)	0.048	2.8	0.9-8.2
Severe	18 (21.4)	12 (66.7)	0.17	2.4	0.6-8.7
Age at intervention (years)					
<3	21 (25.0)	14 (66.6)		Ref	
3-5	36 (42.9)	18 (50.0)	0.2	0.5	0.1-1.5
>5	27 (32.1)	22 (81.4)	0.2	2.2	0.5-8.3

Ref=Reference category, QOL=Quality of life, CI=Confidence interval, OR=Odds ratio, MCH=Maternal and Children's Hospital

Table 3: Correlation between various domains of quality of life among caregivers of autistic children (n=84)

Domains	Physical functioning	Role limitations due to physical health	Role limitations due to emotional problems	Energy/fatigue	Emotional well-being	Social functioning	Pain	General health
Physical functioning								
Role limitations due to physical health	0.446							
Role limitations due to emotional problems	0.152	0.427						
Energy/fatigue	0.176	0.416	0.562					
Emotional well-being	0.125	0.271	0.541	0.758**				
Social functioning	0.287**	0.429**	0.563**	0.689**	0.613**			
Pain	0.301**	0.310**	0.159	0.180	0.006	0.458**		
General health	0.287	0.448	0.402**	0.531**	0.449**	0.612**	0.554**	

Figures presented in the table are values of Pearson's correlation coefficient. **Significant at $P \leq 0.01$

Table 4: The mean score for quality of life domains among caregivers of autistic children (n=84)

Domains	Mean±SEM	Minimum	Maximum
Physical functioning	67.3±2.7	5.00	100.00
Role limitations due to physical health	47.02±4.8	0.00	100.00
Role limitations due to emotional problems	31.3±4.7	0.00	100.00
Energy/fatigue	40.8±2.05	0.00	75.00
Emotional well-being	53.4±2.1	16.00	100.00
Social functioning	50.4±2.5	0.00	100.00
Pain	73.15±2.5	12.50	100.00
General health	59.2±1.8	10	90

SEM=Standard error of mean

Table 6 revealed that 72.6% of the studied group reported less accomplishment in the past 4 weeks than they would like because of emotional problems. In the subscale of the social domain, 57.1% of parents reported moderate to extreme interference with their normal social activities because of their children's problems.

Discussion

Autism is a leading cause of childhood disability. Families of autistic children have many challenges in the rearing of their children. Of the studied parents, 63% had impaired QOL, which is consistent with previous

Table 5: Logistic regression analysis: Factors associated with impaired quality of life of caregivers of autistic children (n=84)

Variables	β	SE	Wald	P-Value	Exp β (OR)	95% CI for Exp β (OR)	
						Lower	Upper
Sex	-0.616	0.747	0.680	0.410	0.540	0.125	2.334
Occupation	0.485	0.656	0.546	0.460	1.624	0.449	5.877
Income	1.044	0.736	2.011	0.156	2.840	0.671	12.020
Birth order	0.037	0.223	0.028	0.867	1.038	0.671	1.607
Disease duration	-0.658	0.336	3.837	0.050	0.518	0.268	1.000
Constant	-0.740	2.414	0.094	0.759	0.477		

SE=Standard error, CI=Confidence interval

Table 6: Percentage distribution of item responses on short-form 36 for subscales of most affected domains (n=84)

Item	Response options					
	Yes %			No %		
Role limitations due to emotional problems						
Q17-cut down the amount of time you spent on work or other activities	65.5			34.5		
Q18-accomplished less than you would like?	72.6			27.4		
Q19-did not do work or other activities as carefully as usual	64.3			35.7		
Role limitation due to physical problems						
Q13-cut down the amount of time you spent on work or other activities	53.3			46.7		
Q14-accomplished less than you would like	56.7			43.3		
Q15-were limited in the kind of work or other activities	50.0			50.0		
Q16-had difficulty performing the work or other activities	53.3			46.7		
Energy/fatigue	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
	%	%	%	%	%	%
Q23-feel full of pep?	0	8.4	9.5	44	33.3	4.8
Q27-have a lot of energy?	0	15.5	20.2	27.4	29.8	7.1
Q29-feel worn out?	7.2	34.5	23.8	19	15.5	0
Q31-feel tired?	17.9	16.7	13.1	28.6	21.4	2.3
Social functioning	Not at all	Slightly	Moderately	Quite a bit	Extremely	
	%	%	%	%	%	
Q20-your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups	13.1	29.8	34.5	16.6	6.0	
Q32-how much of the time has your physical health or emotional problems interfered with your social activities (such as visiting with friends, and relatives)?	15.5	27.4	28.5	22.6	6.0	

studies that reported compromised QOL of the families of autistic children.^[24,29,30]

Autism negatively affects the QOL of parents and poses a significant challenge for them, because they have to deal with abnormal behaviors of their children and other people's judgmental attitude toward them. Besides, the child's disability prevents the parents from engaging in social events to avoid being embarrassed.^[31]

Regarding caregivers' characteristics, the current study found that caregiver mothers had more impaired QOL than fathers who were caregivers. This finding was also reported in a study in Riyadh.^[22] A similar result was obtained by Vasilopoulou and Nisbet who reported poorer mental health, more bodily pain, more fatigue, and tiredness in mothers than fathers.^[29] Mothers reduced QOL can be explained by the fact that mothers are the

main caregivers for their children. The present study found that the unemployed and carers whose incomes were low significantly suffered from impaired QOL since the employment of parents has its rewards because of the social support it provides, and the possible improvement of the chances of obtaining skilled childcare. Work can alleviate home stress while caring for the child can hinder career development.

The previous finding was also reported by Torres, who stated that parents' employment, high income, and parents living together were associated with higher QOL scores.^[32] Furthermore, Özgür *et al.* reported that mothers on low income and the unemployed had significantly low QOL scores.^[33] The financial resources required for a disabled child far exceed what is required for a healthy child.^[22] On the other hand, a study in Oman revealed no correlation between parents' income and education with their QOL, as the authors reported that services provided for autistic children are provided by the government.^[34]

In Saudi Arabia, though governmental services are provided for autistic children, there are disparities in service utilization.^[35] Moreover, parents of autistic children may still have financial issues.

The current results revealed that family characteristics (number of family members and housing) were not significantly associated with impaired QOL although the family circumstances constitute the social environment that helps developing a child ability to cope with this disability.

Regarding the impact of gender of autistic child on QOL, parents with female autistic children were nearly two to three times more likely to suffer from impaired QOL than those with male autistic children, but this difference was not statically significant (OR = 2.4; 95% CI: 0.62–9.5; $P = 0.1$). This finding is contrary to that of a study conducted in Riyadh, Saudi Arabia, which reported significantly lower QOL in participants with female autistic children and explained this by the fact that social stigma against a female autistic child was more severe.^[22]

A long duration of ASD was significantly associated with impaired parental QOL. In Turkey, a similar finding was observed by Özgür *et al.* 2018, who reported a significant worsening of QOL scores with longer than 5 years duration after the diagnosis of autism.^[33]

This study showed that parents of children with severe ASD were nearly three times more likely to suffer from poor QOL than those of children with mild ASD, but the difference did not reach the level of statistical

significance. A study conducted in Riyadh Asi, 2016 found a significant decrease in family QOL when there was increased severity of ASD.^[22] Other studies conducted in the UK, Turkey, and Iran demonstrated that QOL of families of children with ASD was significantly associated with the severity of the child's disorder.^[17,33,36,37]

Regarding the impact of birth order of autistic child on parental QOL, the current study found that parents whose autistic child was the first in birth order were five times more likely to have poor QOL than those whose children were third or more in birth order (OR = 5.04; 95% CI: 1.3–19.4; $P = 0.01$).

Of the domains of QOL affected by having an autistic child, we found that role limitation as a result of emotional problems and energy/fatigue domains were mainly associated with lower mean QOL scores (31.3 and 40.8, respectively). However, social functioning and emotional well-being domains were associated with borderline mean scores of QOL slightly above 50 (50.4 and 53.4). Other QOL domains were less affected. Similar studies support our present results. Perumal *et al.* reported that parents of children with ASD showed significantly lower QOL compared with parents of normal children and parents of children with physical disabilities in all the four domains (physical health, psychological health, social relationship, and environment).^[38] In a Qatar study, the general health domain was the only one affected. It showed that caregivers of an autistic child had a significantly lower mean score on general health than those with a nonautistic child.^[39] An Egyptian study reported that caregivers of autistic children had significantly lower QOL in the domains of physical function and energy/fatigue compared with the control group.^[24] In a study done in Abha, Saudi Arabia, the participants reported a negative impact of their autistic child on the family's social life and parents' relationship.^[23] The current study found that on logistic regression analysis, factors significantly relating to impaired QOL by univariate analysis became nonsignificant. Parents of autistic children suffer regardless of their sociodemographic features or clinical characteristics of the autistic children. According to a study in Riyadh on autistic children in the early intervention phase, 50% of the studied children had weak social interaction, and 39% were hyperactive.^[40] Autistic child abnormal behaviors lead to social criticism and stigma and this results in the social isolation of the parents. The cultural context significantly affects parental expectations and concerns about how to manage the problem.^[11] A qualitative study about the unmet needs of mothers of autistic children in Saudi Arabia stated that mothers might experience periods of depression and self-blame and may even need psychiatric intervention.^[41]

This is in agreement with the current study. The parents feel guilty or that the evil eye or magic might be behind the condition^[42] In addition, helplessness, depression, or tiredness also aggravates the burden of the situation.

In their study, Almana *et al.* stated that 50% of Saudi parents believed that autistic children do not mature without intervention. Intense behavioral intervention and enrolment of autistic children in special learning programs may increase the independence of the child and reduce the burden on his/her parents.^[43] However, early intervention can be delayed because of misdiagnosis, the lack of information, or reliance on informal treatments.^[10]

Conclusion

A high percentage of parents of autistic children had impaired QOL. Parents of autistic children suffer from impaired QOL regardless of their characteristics. The domains of QOL affected were those on role limitations as a result of emotional problems, energy/fatigue, and social functioning. The caregivers of autistic children require medical and social support. They also need social acceptance and a friendly environment that would help them cope with their difficulties. This requires an increase in public awareness of ASD. Services, including counseling of parents, will help them manage their children's behaviors. Additional research could generate accurate prevalence rates and analyze effective interventions.

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Conflicts of interest

There are no conflicts of interest.

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