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Impact of Autism on Parents/Caregivers Quality of Life in Tabuk

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ABSTRACT

Objectives: *To investigate the impact of Autism spectrum disorders (ASD) on the quality of life (QOL) of parents of the affected child and identify predictors of deteriorating QOL.* ***Subjects and methods:*** *A cross-sectional study was carried out at the Autistic Center, Ministry of Health, Tabuk city included a sample of parents or caregivers of autistic children (aged ≤ 14 years) throughout the study period (August-November, 2019). A self-administered questionnaire was used consisted of socio-demographic variables of the parent/caregiver, autistic child`s data and the different items of the WHOQOL-BREF questionnaire.* ***Results:*** *The study included 100 parents/caregivers. The age of more than half of them (54%) ranged between 31 and 40 years. More than half (58%) were females. The second level of autism was observed among 47% of the affected children while levels one and three were observed among 40% and 13% of them, respectively. Concerning the different domains of QOL, 11%, 21%, 8% and 15% of the parents/caregivers had poor physical, psychological, social and environmental domains of QOL. Overall, 7% of parents/caregivers had poor QOL. Parents/caregivers aged between 31-40 years, unmarried, low income, whose autistic children aged 3 years, had duration of the disease of 3 years were more likely to have poor overall QOL compared to their counterparts.* ***Conclusion:*** *Overall quality of life of parents/caregivers of autistic children in Tabuk was good. The most affected domains were the psychological and environmental domains. The majority of them have self-perceived their quality of life as neutral and were satisfied with their general health.*

Keywords: Autism, Children, Quality of life, Parents, Caregivers, General health

INTRODUCTION

Autism or autism spectrum disorders (ASD) is a neurodevelopmental disorder that affects an individual`s ability to communicate, socially interact with others, and respond to certain stimuli in their surroundings. It is usually diagnosed by the age of 3 years and is more prevalent in boys than girls [1]. ASD is characterized by delayed language development, repetitive and stereotyped patterns of behavior, imagination, and hindered social interaction [2].

Newschaffer, et al., published a model that categorized potential risk factors for ASD into 4 main categories 1) Genetic predisposition of the mother, 2) Environmental factors affecting the mother, 3) Genetic predisposition of the child, and 4) Environmental factors affecting the child [3]. Early diagnosis and subsequent intervention for ASD are mandatory, as many researchers have shown the potential of greater benefit with the early intervention [4-6].

In Saudi Arabia, consanguinity and multiparity are common exposures that are identified as risk factors for neurodevelopmental disorders, including ASD [7]. Alnemary, et al., reported that on average, Saudi children began ASD services by 3.3 years. Most parents utilized non-medical treatments followed by biomedical treatments and cultural and religious treatment for the disorder [8]. The prevalence of ASD in KSA was one/167 with no available data regarding the confirmed cases [9,10], as many children with ASD had not been identified yet [8].

Parents of Autistic children are suffering from stress and had challenging problems than those of normally developed children and, they mostly had higher levels of anxiety [11,12] and depression [12,13]. ASD children demand more time, effort and patience from parents [14]. This often leads to depression, psychological distress, anxiety, and other psychological or physical health problems among parents [15-17].

The aim of the study was to explore the impact of ASD on the quality of life (QOL) of parents of the affected child and identify predictors of deteriorating QOL.

METHODOLOGY

A cross-sectional design was used. The study was conducted at the Autistic Center, Ministry of Health, Tabuk city. Parents or caregivers of autistic children who visited the Autistic center throughout the study period (August-November, 2019) constituted the target population for the study. Parents/caregivers were asked to complete the study questionnaire on a single occasion. The self-administered questionnaire consisted of socio-demographic variables of the parent/caregiver (age, gender, current marital status, number of children, relationship with the autistic child, other children with the disorder, occupation, family income, and the highest qualification), autistic child`s data (age, gender, duration of the disease and its severity level). The different items of the WHOQOL-BREF questionnaire to assess the parents/caregiver`s quality of life [18-23]. Statistical Package for Social Sciences (SPSS) software version 25.0 was utilized for computerized data entry and analysis. Descriptive statistics (number, percentage for categorical variables and mean, standard deviation and range for continuous variables) and analytic statistics using Chi-Square tests (χ^2) (Pearson`s and for trend) to test for the association and/or the difference between two categorical variables were applied and p-value equal or less than 0.05 was considered statistically significant.

RESULTS

Tables 1 and 2 shows the demographic characteristics of Autistic parents/caregivers and Autistic children. Table 3 summarizes the scores of the WHOQOL-BREF items. The highest scores were reported regarding safety (3.85 ± 0.76), social support (3.78 ± 0.77) and physical environment (3.78 ± 0.88) whereas the lowest scores was observed regarding physical pain (2.75 ± 1.02) and dependence medication (2.56 ± 1.11). Self-perceived QOL as shown in Figure 1, 40% of participants perceived their QOL as good, whereas 7 perceived it as poor/very poor. 58% of participants were satisfied/very satisfied with their general health whereas 4% were dissatisfied/very dissatisfied with it. Regarding the Physical domain, 11% of participants had poor physical QOL. Table 4 shows the factors associated with the physical domain of QOL among parents/caregivers of autistic children. Regarding the Psychological domain, 21% of participants had poor psychological QOL. Table 5 shows the factors associated with the psychological domain of QOL among parents/caregivers of autistic children. Regarding the Social domain, only 8% of participants had poor social QOL. Table 6 shows the factors associated with the Social domain of QOL among parents/caregivers of autistic children. Table 7 shows the factors associated with the environmental domain of QOL among parents/caregivers of autistic children. Finally, the overall QOL, 7% of parents had poor overall QOL (Figure 2). Table 8 shows Parents/caregivers aged between 31-40 years, unmarried, low income, whose autistic children aged 3 years, had duration of the disease of 3 years were more likely to have poor overall QOL compared to their counterparts.

Table 1 Demographic characteristic of the Autistic parents/caregivers

Variables	Frequency	Percentage (%)
Age (years)		
20-30	26	26%
31-40	54	54%
>40	20	20%
Gender		
Male	42	42%
Female	58	58%
Current Marital Status		
Married	77	77%
unmarried	23	23%
Number of children		
1	76	76%
2	16	16%
>2	8	8%
Employment Status		

Working	53	53%
Not working	47	47%
Income (SR/month)		
≤ 5000	48	48%
5001-10000	25	25%
10001-15000	11	11%
>15000	16	16%
Highest Qualification		
Illiterate	15	15%
Primary school	29	29%
Intermediate school	9	9%
Secondary school	22	22%
University/above	25	25%
Relation to the Autistic Child		
Mother	55	55%
Father	40	40%
Others	5	5.0%

Table 2 Demographic characteristics of the Autistic children

Variables	**Frequency**	**Percentage (%)**
Age (years)		
1	55	55%
2	24	24%
3	21	21%
Duration of the Disease (years)		
1	76	76%
2	12	12%
3	12	12%
Gender		
Male	58	58%
Female	42	42%

Table 3 Scores of WHOQOL-BREF items among parents of Autistic patients, Tabuk

WHOQOL-BREF	**Direction**	**Mean ± SD of Raw**
Items/Domains	of Scaling	Item Score
Q1 self-perceived QOL	Positive	3.66 ± 0.92
Q2 Satisfaction with general health	Positive	3.69 ± 0.83
Domain 1: Physical Health		
Q3 Physical pain	Negative	2.75 ± 1.02
Q4 Dependence medication	Negative	2.56 ± 1.11
Q10 Energy	Positive	3.35 ± 1.03
Q15 Mobility	Positive	3.50 ± 0.98
Q16 Sleep and rest	Positive	3.32 ± 0.91
Q17 Activities of daily living	Positive	3.45 ± 0.95
Q18 Working capacity	Positive	3.34 ± 0.92
Domain 2: Psychological Health		
Q5 Life enjoyment	Positive	3.44 ± 0.98
Q6 Meaningfulness of life	Positive	3.62 ± 1.02
Q7 Concentration	Positive	3.58 ± 0.97
Q11 Body appearance	Positive	3.51 ± 0.92
Q19 Self-esteem	Positive	3.42 ± 0.86
Q26 Negative feelings	Negative	3.74 ± 1.01

Domain 3: Social Relationships		
Q20 Personal relationship	Positive	3.66 ± 0.93
Q21 Sexual activity	Positive	3.70 ± 0.76
Q22 Social support	Positive	3.78 ± 0.77
Domain 4: Environment		
Q8 Safety	Positive	3.85 ± 0.76
Q9 Physical environment	Positive	3.78 ± 0.88
Q12 Financial resources	Positive	3.67 ± 0.89
Q13 Daily information	Positive	3.64 ± 0.85
Q14 Leisure	Positive	3.74 ± 0.86
Q23 Home environment	Positive	3.73 ± 0.86
Q24 Access to health care	Positive	3.62 ± 0.89
Q25 Transport	Positive	3.34 ± 0.83

Table 4 Factors associated with physical domain of quality of life among parents/caregivers of autistic children

Variables	**Physical domain of QOL**			**p-value**
	Poor (N=11)	**Moderate (N=45)**	**Relatively high (N=44)**	
	N (%)	**N (%)**	**N (%)**	
Age (years)				
20-30 (n=26)	2 (7.7%)	9 (34.6%)	15 (57.7%)	0.041*
31-40 (n=54)	5 (9.3%)	25 (46.3%)	24 (44.4%)	
>40 (n=20)	4 (20.0%)	11 (55.0%)	5 (25.0%)	
Gender				
Male (n=42)	6 (14.3%)	21 (50.0%)	15 (35.7%)	0.326**
Female (n=58)	5 (8.6%)	24 (41.4%)	29 (50.0%)	
Current Marital Status				
Married (n=77)	8 (10.4%)	31 (40.3%)	38 (49.4%)	0.138**
Unmarried (n=23)	3 (13.0%)	14 (60.9%)	6 (26.1%)	
Number of Children				
1 (n=76)	6 (7.8%)	55 (46.1%)	35 (46.1%)	0.021*
2 (n=16)	2 (12.5%)	6 (37.5%)	8 (50.0%)	
>2 (n=8)	3 (37.5%)	4 (50.0%)	1 (12.5%)	
Employment Status				
Working (n=53)	5 (9.4%)	30 (56.6%)	18 (34.0%)	0.045**
Not working (n=47)	6 (12.8%)	15 (31.9%)	26 (55.3%)	
Income (SR/month)				
≤ 5000 (n=48)	8 (16.7%)	27 (57.2%)	13 (27.1%)	0.004*
5001-10000 (n=25)	1 (4.0%)	11 (44.0%)	13 (52.0%)	
10001-15000 (n=11)	1 (9.0%)	5 (45.5%)	5 (45.5%)	
>15000 (n=16)	1 (6.3%)	2 (12.5%)	13 (81.2%)	
Highest Qualification				

Illiterate (n=15)	1 (6.7%)	6 (40.0%)	8 (53.3%)	0.444*
Primary school (n=29)	5 (17.2%)	9 (31.0%)	15 (51.8%)	
Intermediate school (n=9)	3 (33.3%)	5 (55.6%)	1 (11.1%)	
Secondary school (n=22)	2 (9.1%)	14 (63.6%)	6 (27.3%)	
University/above (n=25)	0 (0.0%)	11 (44.0%)	14 (56.0%)	
Relation to the Autistic Child				
Mother (n=55)				0.157*
Father (n=40)	6 (10.9%)	19 (34.5%)	30 (54.5%)	
Others (n=5)	4 (10.0%)	23 (57.5%)	13 (32.5%)	
	1 (20.0%)	3 (60.0%)	1 (20.0%)	
Age of the Autistic Child (years)				
1 (n=55)	4 (7.3%)	24 (43.6%)	27 (49.1%)	0.153*
2 (n=24)	3 (12.5%)	13 (54.2%)	8 (33.3%)	
3 (n=21)	4 (19.0%)	8 (38.1%)	9 (42.9%)	
Duration of the Disease (years)				
1 (n=76)	7 (9.2%)	36 (47.4%)	33 (43.4%)	0.346*
2 (n=12)	1 (8.3%)	5 (41.7%)	6 (50.0%)	
3 (n=12)	3 (25.0%)	4 (33.3%)	5 (41.7%)	
Gender of the Autistic Child				
Male (n=58)	4 (6.9%)	26 (44.8%)	28 (48.3%)	0.261*
Female (n=42)	7 (16.7%)	19 (45.2%)	16 (38.1%)	
Having Autistic Siblings				
Yes (n=15)	3 (20.0%)	5 (33.3%)	7 (46.7%)	0.394**
No (n=85)	8 (9.4%)	40 (47.1%)	37 (43.5%)	
Level of Autism				
First (n=40)	4 (10.0%)	18 (45.0%)	18 (45.0%)	0.328*
Second (n=47)	4 (8.5%)	21 (44.7%)	22 (46.8%)	
Third (n=13)	3 (23.1%)	6 (46.1%)	4 (30.8%)	
*Chi-square for trend; **Pearson`s chi-square				

Table 5 Factors associated with psychological domain of quality of life among parents/caregivers of autistic children

Variables	**Psychological domain of QOL**			**p-value**
	Poor (N=21)	**Moderate N=30**	**Relatively high (N=49)**	
	N (%)	**N (%)**	**N (%)**	
Age (years)				
20-30 (n=26)	4 (15.4%)	5 (19.2%)	17 (65.4%)	0.138*
31-40 (n=54)	12 (22.2%)	17 (31.5%)	25 (46.3%)	
>40 (n=20)	5 (25.0%)	8 (40.0%)	7 (35.0%)	
Gender				
Male (n=42)	6 (14.3%)	13 (31.0%)	23 (54.8%)	0.356**
Female (n=58)	15 (25.9%)	17 (29.3%)	26 (44.8%)	
Current Marital Status				
Married (n=77)	10 (13.0%)	22 (28.6%)	45 (58.4%)	<0.001**
Unmarried (n=23)	11 (47.8%)	8 (34.8%)	4 (17.4%)	
Number of Children				

1 (n=76)	15 (19.7%)	24 (31.6%)	37 (48.7%)	0.753*
2 (n=16)	4 (25.0%)	4 (25.0%)	8 (50.0%)	
>2 (n=8)	2 (25.0%)	2 (25.0%)	4 (50.0%)	
Employment Status				
Working (n=53)	11 (20.8%)	17 (32.1%)	25 (47.2%)	0.886**
Not working (n=47)	10 (21.3%)	13 (27.7%)	24 (51.1%)	
Income (SR/month)				
≤ 5000 (n=48)	14 (29.2%)	12 (25.0%)	22 (45.8%)	0.152*
5001-10000 (n=25)	4 (16.0%)	8 (32.0%)	13 (52.0%)	
10001-15000 (n=11)	1 (9.1%)	4 (36.4%)	6 (54.5%)	
>15000 (n=16)	2 (12.5%)	6 (37.5%)	8 (50.0%)	
Highest Qualification				
Illiterate (n=15)	4 (26.7%)	4 (26.7%)	7 (46.6%)	0.168*
Primary school (n=29)	7 (24.1%)	6 (20.7%)	16 (55.2%)	
Intermediate school (n=9)	4 (44.5%)	2 (22.2%)	3 (33.3%)	
Secondary school (n=22)	6 (27.3%)	6 (27.3%)	10 (45.4%)	
University/above (n=25)	0 (0.0%)	12 (48.0%)	13 (52.0%)	
Relation to the Autistic Child				
Mother (n=55)	12 (21.8%)	15 (27.3%)	28 (50.9%)	0.756*
Father (n=40)	7 (17.5%)	14 (35.0%)	19 (47.5%)	
Others (n=5)	2 (40.0%)	1 (20.0%)	2 (40.0%)	
Age of the Autistic Child (years)				
1 (n=55)	7 (12.7%)	16 (29.1%)	32 (58.2%)	0.004
2 (n=24)	5 (20.8%)	9 (37.5%)	10 (41.7%)	
3 (n=21)	9 (42.9%)	5 (23.8%)	7 (33.3%)	
Duration of the Disease (years)				
1 (n=76)	10 (13.2%)	25 (32.9%)	41 (53.9%)	0.001*
2 (n=12)	5 (41.7%)	2 (16.7%)	5 (41.7%)	
3 (n=12)	6 (50.0%)	3 (25.0%)	3 (25.0%)	
Gender of the Autistic Child				
Male (n=58)	11 (19.0%)	17 (29.3%)	30 (51.7%)	0.778*
Female (n=42)	10 (23.8%)	13 (31.0%)	19 (45.2%)	
Having Autistic Siblings				
Yes (n=15)	4 (26.7%)	5 (33.3%)	6 (40.0%)	0.731**
No (n=85)	17 (20.0%)	25 (29.4%)	43 (50.6%)	
Level of Autism				
First (n=40)	5 (12.5%)	10 (25.0%)	25 (62.5%)	0.010*
Second (n=47)	11 (23.4%)	15 (31.9%)	21 (44.7%)	
Third (n=13)	5 (38.5%)	5 (38.5%)	3 (23.1%)	
*Chi-square for trend; **Pearson`s chi-square				

Table 6 Factors associated with social domain of quality of life among parents/caregivers of autistic children

Variables	**Social domain of QOL**			**p-value**
	Poor (N=8)	**Moderate (N=25)**	**Relatively High (N=67)**	
	N (%)	**N (%)**	**N (%)**	
Age (years)				
20-30 (n=26)	2 (7.7%)	4 (15.4%)	20 (76.9%)	0.394*
31-40 (n=54)	4 (7.4%)	15 (27.8%)	35 (64.8%)	
>40 (n=20)	2 (10.0%)	6 (30.0%)	12 (60.0%)	
Gender				

Male (n=42)	3 (7.1%)	12 (28.6%)	27 (64.3%)	0.773**
Female (n=58)	5 (8.6%)	13 (22.4%)	40 (69.0%)	
Current Marital Status				
Married (n=77)	5 (6.5%)	18 (23.4%)	54 (70.1%)	0.408**
Unmarried (n=23)	3 (13.0%)	7 (30.4%)	13 (56.5%)	
Number of Children				
1 (n=76)	6 (7.9%)	20 (26.3%)	50 (65.8%)	0.897*
2 (n=16)	1 (6.3%)	4 (25.0%)	11 (68.8%)	
>2 (n=8)	1 (12.5%)	1 (12.5%)	6 (75.0%)	
Employment Status				
Working (n=53)	2 (3.8%)	19 (35.8%)	32 (60.4%)	0.014**
Not working (n=47)	6 (12.8%)	6 (12.8%)	35 (74.4%)	
Income (SR/month)				
≤ 5000 (n=48)	6 (12.5%)	13 (27.1%)	29 (60.4%)	0.187*
5001-10000 (n=25)	1 (4.0%)	5 (20.0%)	19 (76.0%)	
10001-15000 (n=11)	0 (0.0%)	4 (36.4)	7 (63.6%)	
>15000 (n=16)	1 (6.3%)	3 (18.8)	12 (75.0%)	
Highest Qualification				
Illiterate (n=15)	1 (6.7%)	5 (33.3%)	9 (60.0%)	0.553*
Primary school (n=29)	3 (10.3%)	5 (17.2%)	21 (72.4%)	
Intermediate school (n=9)	2 (22.2%)	3 (33.3%)	4 (44.4%)	
Secondary school (n=22)	0 (0.0%)	7 (31.8%)	15 (68.2%)	
University/above (n=25)	2 (8.0%)	5 (20.0%)	18 (72.0%)	
Relation to the Autistic Child				
Mother (n=55)	4 (7.3%)	11 (20.0%)	40 (72.7%)	0.621*
Father (n=40)	4 (10.0%)	12 (30.0%)	24 (60.0%)	
Others (n=5)	0 (0.0%)	2 (40.0%)	3 (60.0%)	
Age of the Autistic Child (years)				
1 (n=55)	3 (5.5%)	12 (21.8%)	40 (72.7%)	0.334
2 (n=24)	3 (12.5%)	8 (33.3%)	13 (54.2%)	
3 (n=21)	2 (9.5%)	5 (23.8%)	14 (66.7%)	
Duration of the Disease (years)				
1 (n=76)	5 (6.6%)	17 (22.4%)	54 (71.1%)	0.079*
2 (n=12)	1 (8.3%)	3 (25.0%)	8 (66.7%)	
3 (n=12)	2 (16.7%)	5(41.7%)	5 (41.7%)	
Gender of the Autistic Child				
Male (n=58)	3 (5.2%)	16 (27.6%)	39 (67.2%)	0.417*
Female (n=42)	5 (11.9%)	9 (21.4%)	28 (66.7%)	
Having Autistic Siblings				
Yes (n=15)	3 (20.0%)	4 (26.7%)	8 (53.3%)	0.158**
No (n=85)	5 (5.9%)	21 (24.7%)	59 (69.4%)	
Level of Autism				

First (n=40)	1 (2.5%)	10 (25.0%)	29 (72.5%)	0.053*
Second (n=47)	4 (8.5%)	13 (27.7%)	30 (63.8%)	
Third (n=13)	3 (23.1%)	2 (15.4%)	8 (61.5%)	

*Chi-square for trend; **Pearson`s chi-square

Table 7 Factors associated with environmental domain of quality of life among parents/caregivers of autistic children

Variables	**Environmental domain of QOL**			**p-value**
	Poor (N=15)	**Moderate(N=33)**	**Relatively High (N=52)**	
	N (%)	**N (%)**	**N (%)**	
Age (years)				
20-30 (n=26)	4 (15.4%)	5 (19.2%)	17 (65.4%)	0.275*
31-40 (n=54)	8 (14.8%)	17 (31.5%)	29 (53.7%)	
>40 (n=20)	3 (15.0%)	11 (55.0%)	6 (30.0%)	
Gender				
Male (n=42)	5 (11.9%)	16 (38.1%)	21 (50.0%)	0.580**
Female (n=58)	10 (17.2%)	17 (29.3%)	31 (53.4%)	
Current Marital Status				
Married (n=77)	9 (11.7%)	23 (29.9%)	45 (58.4%)	0.047**
Unmarried (n=23)	6 (26.1%)	10 (43.5%)	7 (30.4%)	
Number of Children				
1 (n=76)	10 (13.2%)	26 (34.2%)	40 (52.6%)	0.271*
2 (n=16)	3 (18.8%)	3 (18.8%)	10 (62.5%)	
>2 (n=8)	2 (25.0%)	4 (50.0%)	2 (25.0%)	
Employment Status				
Working (n=53)	6 (11.3%)	23 (43.4%)	24 (45.3%)	0.058**
Not working (n=47)	9 (19.1%)	10 (21.3%)	28 (59.6%)	
Income (SR/month)				
≤ 5000 (n=48)	11 (22.9%)	16 (33.3%)	21 (43.8%)	0.019*
5001-10000 (n=25)	3 (12.0%)	7 (28.0%)	15 (60.0%)	
10001-15000 (n=11)	1 (9.0%)	5 (45.5%)	5 (45.5%)	
>15000 (n=16)	0 (0.0%)	5 (31.3%)	11 (68.8%)	
Highest Qualification				
Illiterate (n=15)	3 (20.0%)	6 (40.0%)	6 (40.0%)	0.098*
Primary school (n=29)	2 (6.9%)	8 (27.6%)	19 (65.5%)	
Intermediate school (n=9)	4 (44.4%)	2 (22.2%)	3 (33.3%)	
Secondary school (n=22)	5 (22.7%)	8 (36.4%)	9 (40.9%)	
University/above (n=25)	1 (4.0%)	9 (36.0%)	15 (60.0%)	
Relation to the Autistic Child				
Mother (n=55)	9 (16.4%)	13 (23.6%)	33 (60.0%)	0.276**
Father (n=40)	5 (12.5%)	18 (45.0%)	178 (42.5%)	
Others (n=5)	1 (20.0%)	2 (40.0%)	2 (40.0%)	
Age of the Autistic Child (years)				
1 (n=55)	6 (10.9%)	17 (30.9%)	32 (58.2%)	0.063*
2 (n=24)	3 (12.5%)	10 (41.7%)	11 (45.8%)	
3 (n=21)	6 (28.6%)	6 (28.6%)	9 (42.8%)	
Duration of the Disease (years)				
1 (n=76)	8 (10.5%)	25 (32.9%)	43 (56.6%)	0.005*
2 (n=12)	2 (16.7%)	4 (33.3%)	6 (50.0%)	
3 (n=12)	5 (41.7%)	4 (33.3%)	3 (25.0%)	
Gender of the Autistic Child				

Male (n=58)	9 (15.5%)	21 (36.2%)	28 (48.3%)	0.663*
Female (n=42)	6 (14.3%)	12 (28.6%)	24 (57.1%)	
Having Autistic Siblings				
Yes (n=15)	3 (20.0%)	6 (40.0%)	6 (40.0%)	0.593**
No (n=85)	12 (14.1%)	27 (31.8%)	46 (54.1%)	
Level of Autism				
First (n=40)	4 (10.0%)	16 (40.0%)	20 (50.0%)	0.316*
Second (n=47)	8 (17.0%)	12 (25.5%)	27 (57.4%)	
Third (n=13)	3 (23.0%)	5 (38.5%)	5 (38.5%)	
*Chi-square for trend; **Pearson`s chi-square				

Table 8 Factors associated with overall quality of life among parents/caregivers of autistic children

Variables	**Overall QOL**			**p-value**
	Poor (N=7)	**Moderate (N=51)**	**Relatively High (N=42)**	
	N (%)	**N (%)**	**N (%)**	
Age (years)				
20-30 (n=26)	1 (3.8%)	10 (38.5%)	15 (57.7%)	0.036*
31-40 (n=54)	5 (9.3%)	25 (46.3%)	24 (44.4%)	
>40 (n=20)	1 (5.0%)	16 (80.0%)	3 (15.0%)	
Gender				
Male (n=42)	3 (7.1%)	24 (57.1%)	15 (35.7%)	0.544**
Female (n=58)	4 (6.8%)	27 (46.6%)	27 (46.6%)	
Current Marital Status				
Married (n=77)	3 (3.9%)	37 (48.1%)	37 (48.1%)	0.017**
Unmarried (n=23)	4 (17.4%)	14 (60.9%)	5 (21.7%)	
Number of Children				
1 (n=76)	6 (7.9%)	37 (48.7%)	33 (43.4%)	0.543*
2 (n=16)	0 (0.0%)	8 (50.0%)	8 (50.0%)	
>2 (n=8)	1 (12.5%)	6 (75.0%)	1 (12.5%)	
Employment Status				
Working (n=53)	4 (7.5%)	31 (58.5%)	18 (34.0%)	0.221**
Not working (n=47)	3 (6.4%)	20 (42.6%)	24 (51.1%)	
Income (SR/Month)				
≤ 5000 (n=48)	6 (12.5%)	26 (54.2%)	16 (33.3%)	0.047*
5001-10000 (n=25)	1 (4.0%)	10 (40.0%)	14 (56.0%)	
10001-15000 (n=11)	0 (0.0%)	7 (63.6%)	4 (36.4%)	
>15000 (n=16)	0 (0.0%)	8 (50.0%)	8 (50.0%)	
Highest Qualification				
Illiterate (n=15)	1 (6.6%)	7 (46.7%)	7 (46.7%)	0.054*
Primary school (n=29)	1 (3.4%)	16 (55.2%)	12 (41.4%)	
Intermediate school (n=9)	3 (33.3%)	5 (55.6%)	1 (11.1%)	
Secondary school (n=22)	2 (9.1%)	12 (54.5%)	8 (36.4%)	
University/above (n=25)	0 (0.0%)	11 (44.0%)	14 (56.0%)	
Relation to the Autistic Child				
Mother (n=55)	3 (5.5%)	24 (43.6%)	28 (50.9%)	0.269**
Father (n=40)	3 (7.5%)	24 (60.0%)	13 (32.5%)	
Others (n=5)	1 (20.0%)	3 (60.0%)	1 (20.0%)	
Age of the Autistic Child (years)				
1 (n=55)	2 (3.6%)	23 (41.8%)	30 (54.5%)	0.006*
2 (n=24)	2 (8.3%)	15 (62.5%)	7 (29.2%)	
3 (n=21)	3 (14.3%)	13 (61.9%)	5 (23.8%)	
Duration of the Disease (years)				

1 (n=76)	3 (3.9%)	37 (48.7%)	36 (47.4%)	0.001*
2 (n=12)	0 (0.0%)	8 (66.7%)	4 (33.3%)	
3 (n=12)	4 (33.3%)	6 (50.0%)	2 (16.7%)	
Gender of the Autistic Child				
Male (n=58)	4 (6.9%)	31 (53.4%)	23 (39.7%)	0.841*
Female (n=42)	3 (7.1%)	20 (47.6%)	19 (45.2%)	
Having Autistic Siblings				
Yes (n=15)	2 (13.3%)	9 (60.0%)	4 (26.7%)	0.320**
No (n=85)	5 (5.9%)	42 (49.4%)	38 (44.7%)	
Level of Autism				
First (n=40)	1 (2.5%)	21 (52.5%)	18 (45.0%)	0.115*
Second (n=47)	4 (8.5%)	23 (48.9%)	20 (42.6%)	
Third (n=13)	2 (15.4%)	7 (53.8%)	4 (30.8%)	
*Chi-square for trend; **Pearson`s chi-square				

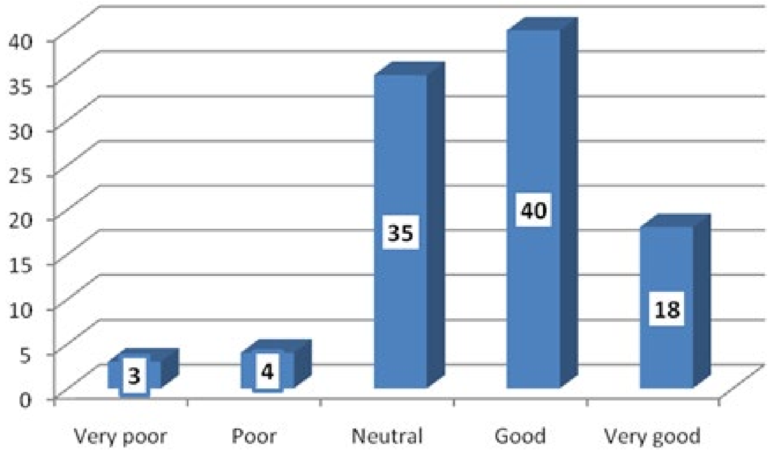

Figure 1 Self-perceived quality of life among parents/caregivers

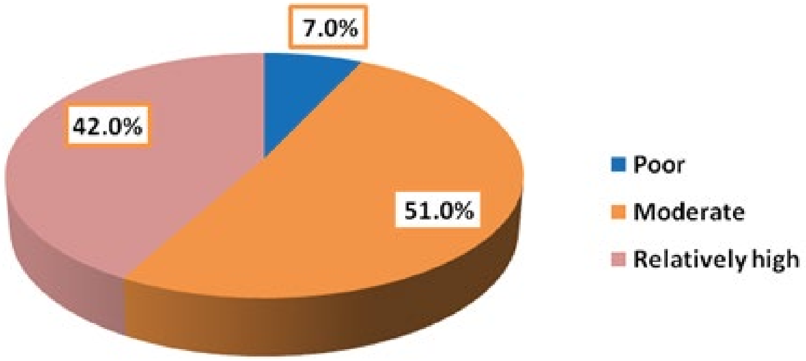

Figure 2 Level of overall WHOQOL-BR score among parents/caregivers of autistic children

DISCUSSION

In the current study, the majority of parents/caregivers self-perceived their QOL as neutral, good or very good and were satisfied with their general health. Concerning the different domains of QOL, 11%, 21%, 8% and 15% of them had poor physical, psychological, social and environmental domains of QOL. In South Africa, parents of children with ASD had significantly lower mean QOL scores in the four domains of QOL; physical, psychological, social and environmental health compared with parents of the normally developing children [24]. In the Philippines, using the WHOQOL-BREF, the social relationship domain was significantly higher than the physical, psychological, and environmental domains of QOL [25]. In other studies, there was a significant affection of having a child with ASD on the psychological status of parents, particularly stress [26,27].

Overall, 7% of participants in the current study had poor QOL. In a similar study carried out in Riyadh, the level of QOL among parents was medium [28]. In Tunisia, using the Tunisian SF-36 form to evaluate the QOL of parents, impaired QOL was observed among 64% of parents of autistic children [27]. Australia, QOL was found to be poorer in parents with ASD children compared to that with parents of typically developing children or even parents with children having other disabilities [29].

The poor QOL observed among parents in most studies is mostly as a result of emotional, physical, social and financial stresses of caring for a child with ASD. The relatively low rate of poor QOL among parents in the present study compared to others could reflect the religious background of parents/caregivers as they believe that all things from God should be of benefit. Poor QOL was more encountered among parents/caregivers aged between 31 and 40 years. Other studies did not find a relation between QOL and age parental age [26-28]. In the present study, the gender of the parents/caregivers of autistic children had no role in affecting the QOL. Some others [28] reported more deterioration of quality of life among mothers than fathers, because of their caring role of children as well as the difference between genders in coping [30].

In the current study, unmarried parents/caregivers were more likely to have poor overall QOL compared to married ones. The same has been observed in a study conducted in the Philippines [25]. This could be due to an additional psychological and social burden of being divorced or widowed. Parents/caregivers with low income were more likely to have poor QOL. The same has been reported in a study carried out in South Africa [24] in the Philippines [25]. Also, this could be due to additional economic and psychological burden.

Parents/caregivers of autistic children aged 3 years were more likely to have poor QOL compared to those whose children aged one year. Contradicting result has been observed in a study carried out in Tunisia as the older age of the child at the moment of the diagnosis was associated with better parental QOL [28]. In the current study, the parent/caregiver`s QOL was not affected by the gender of the affected child. However, in Riyadh, QOL was significantly affected by the gender of the autistic child [28]. Parents/caregivers whose autistic children had duration of the diseases of 3 years were more likely to have poor overall QOL compared to those whose disease duration was one or two years. This agrees with what has been reported by others [28,29].

Level of the disease affected the psychological domain of QOL of parents/caregivers in the present study. However, it did not affect the overall QOL. In accordance with our findings, in the Philippines, autism severity was not associated with caregivers` QOL [25]. However, in Riyadh, QOL was associated with the severity of the disability [28]. Also, in South Africa [24], the severity level of ASD was associated with parental QOL and in Thailand, a significant negative correlation has been confirmed between the severity of ASD and parental QOL [31]. In Tunisia [27], and Australia [29], QOL score of parents was significantly altered by the severity of autism. The explanation of more affection of QOL by severing forms of the disability is that the presence of this severe form presents a source of pressure for the family and preventing them from practicing their daily life activities of daily life, where their care and requirements are much more [32,33]. Some authors suggested that maladaptive behavior is more important than the severity of ASD in affecting the QOL of parents [34]. Comparison between this study and others is not practical, mainly due to using different instruments in assessing QOL, none of them specific for ASD.

There are some limitations to this study. First, the relatively small sample size is a possible limitation. In addition, the sample was recruited from Autistic center which provides services for children with ASD and their parents, resulting in sampling bias, as the parents of these children are already seeking support and this could explain partially the relatively acceptable level of QOL among them. The design of the study as a cross-sectional is another limitation as it is valuable in demonstrating associations and no unidirectional causative relationships.

CONCLUSION

The overall quality of life of parents/caregivers of autistic children in Tabuk was good with a minority of them had poor quality of life. The most affected domains were the psychological and environmental domains. The majority of them have self-perceived their quality of life as neutral and were satisfied with their general health. Parents/caregivers aged between 31 and 40 years, unmarried, with low income, lower educate autistic, having autistic children aged 3 years and had duration of the diseases of 3 years were more likely to have a poor overall quality of life than others.

DECLARATIONS

Conflicts of Interest

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

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