

## To assess autism spectrum disorder parental quality of life during covid 19 in Taif, KSA

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### ABSTRACT

**Background:** Considering the fact that family members necessarily spend more time together during the pandemic, this study aims to assess autism spectrum disorder parental quality of life during covid 19. **Method:** Descriptive community base study was conducted at the city of Al-Taif using semi-structured questionnaire during Feb. 2022. A total of 76 parents living in Al-Taif participated in the study. **Results:** The study found that the most frequent effect of the emerging corona virus (Covid 19) on isolating the lives of children with autism was to some extent, the percentage 31, and the most frequent effect of the emerging corona virus (Covid 19) on health condition of children with autism was disagree, the percentage 32.8, the most frequency. **Conclusion:** The Corona epidemic has compounded the suffering of children with special needs, as the quarantine period and restrictions on their ability to go to school and move have been incomprehensible to them, and it has been difficult for them to comprehend the risks, and their health has deteriorated as a result of their failure to attend treatment and follow-up sessions in the Autism House and clinics for months. Children in this category are unable to articulate how they feel about the ongoing trends of people wearing masks and social isolation, which has been imposed in varied degrees for weeks, months, or even a short amount of time.

**Keywords:** Autism Spectrum Disorder, Parent, Quality of Life and Coved 19

### 1. INTRODUCTION

The global prevalence of autism in the population is around 1 percent (Lai et al., 2019). With the COVID-19 pandemic, the new panorama that we are facing makes it difficult for many people to grasp and assimilate all that is going on. This challenge can become severe in people with autism, both in children and in adults around 10% of autistic individuals have co-occurring physical conditions (Rydzewska et al., 2019). In people with autism, an elevated incidence of different chronic disorders and medical problems has been observed (Neumeyer et al., 2019; Alqoer et al., 2021) and atypical immune reactions are also seen (Meltzer et al., 2017). The susceptibility to COVID-19 can be increased by all these factors It indicates that there are signs of anxiety, depression, and posttraumatic stress disorder when witnessing a pandemic

(Jalloh et al., 2018). Since autistic individuals are overwhelmingly likely to suffer mental illness (Cvejic et al., 2018) and nine times more likely to die by suicide than the general population (Hirvikoski et al., 2016). The mental health consequences of COVID-19 may be devastating (den Houting, 2020).

A systematic analysis of the epidemiology of autism in the Gulf countries showed a prevalence ranging from 1.4 to 29/10,000 people. The approximate prevalence of autism in primary school children aged 7-12 years was 0.035 percent in a study in Taif, Saudi Arabia. No new prevalence figures for children with autism/ASD in Saudi Arabia have been revealed in a study of the available literature (Gosadi, 2019). The Ministry of Health of Saudi Arabia has confirmed that one in every 160 children has ASD (Gosadi, 2019).

The Saudi health authority provides and assists its families with resources for the treatment of autistic children. Saudi government funds private institutions to care for ASD children, although the services given are insufficient. Special education is offered to students with disabilities (Salhia et al., 2014). However, because of the conservative nature of the community and the amount of training time needed (more than 30 hours almost every week), parents of children with ASD in Saudi Arabia face several challenges (Sulaimani & Gut, 2019). Very few studies have described the QOL of parents of autistic children in Arab countries to the best of our knowledge, and few studies have been carried out in Saudi Arabia to describe the QOL level of parents of children with ASD (Alshaigi et al., 2020).

## 2. RESEARCH DESIGN AND METHODS

### Study design

The study analyzed cross-sectional parental-reported data and was used to examine the Parental Quality of life (QoL) in Autism Spectrum disorder (ASD) during COVID-19.

### Setting

The study was conducted at the city of Al-Taif using semi-structured online questionnaire during Feb. 2022.

### Study population

Criterion sampling was used to determine the possible participants of the study. The criteria in the study was determined for the parents who have a child diagnosed with ASD according to DSM-5 criteria, providing accepting to participate in the study voluntarily.

### Sample size

A total of 76 parents living in Al-Taif participated in the study in line with the criteria.

### Sampling procedure

The aim and participation process of the study was explained to the parents on the phone by the primary researchers. Then, the parents fills consent forms via email and it was planned when to make phone calls with each parent.

### Study period

Over the period between Jan. 30 and Feb. 28. 2022

### Study variables

Personal information form: demographic information about parents (Age, Gender, income level, educational Background) and their children (Gender, Age, Diagnosis).

A semi-structured questionnaire forms at the Arabic version of the short form 36 to assess their QoL It has 8 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 part; participants were asked to respond to questions according to how they had felt during the whole period of the Covid-19 pandemic.

### Data collection technique and tools

Data was collected by semi-structured online questionnaire.

**Data analysis and processing**

The collected data were coded and analyzed using the Statistical Package for the Social Science (SPSS, IBM, Corporation Armonk, New York, USA). Qualitative data were expressed as numbers and percentage whereas quantities data were presented as the mean and standard error. Data were compared by use of Chi-square test.

**Pre-test**

The tools were being tested and modified accordingly.

**Data presentations**

Data was represented in the form of simple frequency, tools, graphs, statistical significance.

**Ethical consideration**

The study had obtained the ethical clearance from ethical committee at Al-Taif University No (HAO-02-T-105) before data collection. No potential identifiers such as name, email or phone no. asked from the participants and the consent was asked at the beginning of the questionnaire.

Message for explaining the major aim of the research was written at the beginning of the survey in order to give the participants clarifications about the research. By agreeing to answer the survey, that has considered as approval of the participants to involving in the study. Additionally, all of the collected data were kept with the researchers in order to protect persons’ confidentiality who involved in this study.

**3. RESULTS**

The study shows that the most frequency of age group distributed among study sampling parents of autism children between 31-40 and 40 and more, the percentage 44.8, the most frequency of relationship distributed among study sampling parents of autism children was the parents, the percentage 82.8, the most frequency of educational qualification distributed among study sampling parents of autism children was the collectors, the percentage 55.2, and the most frequency of presence of job distributed among study sampling parents of autism children don’t have job, the percentage 51.7 (table 1). The study shows that the most frequency of symptoms severity distributed among study sampling parents of autism children was moderate, the percentage 50 (table 2). The study shows that the most frequency of presence of chronic disease distributed among study sampling parents of autism children don’t have chronic disease, the percentage 89.7 (table 3).

**Table 1** The distribution of demographic data for parents who have children with autism during the Covid epidemic (n=100)

Age	Frequency	Percent
20-30	6	10.3
31-40	26	44.8
40 and more	26	44.8
Relationship		
Parents	48	82.8
Grandparents	2	3.4
Brother or sister	8	13.8
Educational qualification		
Uneducated	5	8.6
Diploma	18	31.0
Collectors	32	55.2
Postgraduate	3	5.2
Presence of job		
Yes	28	48.3
No	30	51.7
Total	58	100.0

**Table 2** Symptoms severity among study sampling parents of autism children (n=100)

Symptoms severity	Frequency	Percent
Mild	24	41.4
Moderate	29	50.0
Severe	5	8.6
Total	58	100.0

**Table 3** Presence of chronic disease among study sampling parents of autism children (n=100)

Presence of chronic disease	Frequency	Percent
Yes	6	10.3
No	52	89.7
Total	58	100.0

The table 4 shows that the most frequency of effect of the emerging corona virus (Covid 19) on making the lives of children with autism more isolated distributed among study sampling parents of autism children was to a certain extent, the percentage 31, the most frequency of effect of the emerging corona virus (Covid 19) on health condition of children with autism distributed among study sampling parents of autism children was disagree, the percentage 32.8, the most frequency effect distribution of emerging coronavirus (Covid 19) pandemic on aggressive of children with autism was disagree and the percentage 32.8, and the most frequency effect distribution of emerging coronavirus (Covid 19) pandemic on learning of children with autism was strongly agree and the percentage 44.8.

**Table 4** The distribution of effect of emerging coronavirus (Covid 19) pandemic on lives of children with autism

more isolated	Frequency	Percent
Strongly agree	16	27.6
Agree	10	17.2
To a certain extent	18	31.0
Disagree	13	22.4
Strongly disagree	1	1.7
health condition		
Strongly agree	15	25.9
Agree	7	12.1
To a certain extent	13	22.4
Disagree	19	32.8
Strongly disagree	4	6.9
Aggressive behavior		
Strongly agree	12	20.7
Agree	9	15.5
To a certain extent	14	24.1
Disagree	19	32.8
Strongly disagree	4	6.9
Effect on learning		
Strongly agree	26	44.8
Agree	10	17.2
To a certain extent	11	19.0
Disagree	8	13.8
Strongly disagree	3	5.2
Total	58	100.0

**Table 5** The distribution of quality of life of parents who have autistic children during the Corona pandemic (n=100)

Enjoying life	Frequency	Percent
Strongly agree	7	12.1
Agree	14	24.1
To a certain extent	23	39.7
Disagree	5	8.6
Strongly disagree	9	15.5
Meaningful life		
Strongly agree	14	24.1
Agree	24	41.4
To a certain extent	12	20.7
Disagree	3	5.2
Strongly disagree	5	8.6
Medical treatment need		
Strongly agree	5	8.6
Agree	9	15.5
To a certain extent	11	19.0
Disagree	29	50.0
Strongly disagree	4	6.9
Get support		
Strongly agree	6	10.3
Agree	10	17.2
To a certain extent	26	44.8
Disagree	12	20.7
Strongly disagree	4	6.9
Perform the duty		
Strongly agree	12	20.7
Agree	16	27.6
To a certain extent	21	36.2
Disagree	4	6.9
Strongly disagree	5	8.6
Access to health services		
Strongly agree	2	3.4
Agree	15	25.9
To a certain extent	19	32.8
Disagree	18	31.0
Strongly disagree	4	6.9
physical pain		
Strongly agree	9	15.5
Agree	7	12.1
To a certain extent	27	46.6
Disagree	12	20.7
Strongly disagree	3	5.2
Effect on concentration		
Strongly agree	7	12.1
Agree	12	20.7
To a certain extent	22	37.9
Disagree	15	25.9
Strongly disagree	2	3.4

Enough energy		
Strongly agree	9	15.5
Agree	19	32.8
To a certain extent	26	44.8
Disagree	1	1.7
Strongly disagree	3	5.2
Enough money		
Strongly agree	7	12.1
Agree	19	32.8
To a certain extent	25	43.1
Disagree	4	6.9
Strongly disagree	3	5.2
Information availability		
Strongly agree	11	19.0
Agree	23	39.7
To a certain extent	21	36.2
Disagree	1	1.7
Strongly disagree	2	3.4
Quarantine effect on quality of life		
Strongly agree	4	6.9
Agree	17	29.3
To a certain extent	25	43.1
Disagree	9	15.5
Strongly disagree	3	5.2
negative emotion		
Strongly agree	8	13.8
Agree	6	10.3
To a certain extent	24	41.4
Disagree	12	20.7
Strongly disagree	8	13.8
Effect of presence autistic child		
Strongly agree	15	25.9
Agree	9	15.5
To a certain extent	19	32.8
Disagree	10	17.2
Strongly disagree	5	8.6
Effect of existence of pandemic		
Strongly agree	15	25.9
Agree	19	32.8
To a certain extent	15	25.9
Disagree	3	5.2
Strongly disagree	6	10.3
Total	58	100.0

The study (table 5 and 6) shows that the most frequency of the distribution of enjoyable lives for parents with autistic children was to a certain extent, percentage of 39.7, the most frequency of the distribution of meaning lives for parents with autistic children was agree, percentage of 41.4, the most frequency of the distribution of medical treatment needed for parents with autistic children was disagree, percentage of 50, the most frequency of the distribution of get supported for parents with autistic children was to a certain extent, percentage of 44.8, the most frequency of the distribution of perform duty without need help for parents with autistic

children was to a certain extent, percentage of 36.2, the most frequency of the inability to access health services cause in reduced quality of life for parents with autistic children was to a certain extent, percentage of 32.8, the most frequency of the distribution of feeling physical pain for parents with autistic children was to a certain extent, percentage of 46.6, the most frequency of the concentration affected for parents with autistic children was to a certain extent, percentage of 37.9, the most frequency of the distribution of having enough energy for parents with autistic children was to a certain extent, percentage of 44.8, most frequency of the distribution of presence of enough money for daily life for parents with autistic children was to a certain extent, percentage of 43.1, the most frequency of the distribution of information availability for parents with autistic children was agree, percentage of 39.7, the most frequency of the distribution of effect of quarantine on the quality of life for parents with autistic children was to a certain extent, percentage of 43.1, most frequency of the distribution of feeling of negative emotion for parents with autistic children was to a certain extent, percentage of 41.4, the most frequency of the presence of autistic child affect the quality of life for parents with autistic children was to a certain extent, percentage of 32.8, and the most frequency of the effect of pandemic existence quality of life for parents with autistic children was agree, percentage of 32.8.

**Table 6** Distribution of reasons that affected on quality of life during the Corona pandemic among study sampling parents of autism children (n=100)

Reasons	Frequency	Percent
Close educational centers and external flights	2	3.4
Self-reliance, strength, confronting the pandemic and ability to save money	1	1.7
Fear of disease, anxiety from gatherings with relatives and loneliness, which led to isolation	14	24.1
The presence of the family and the closeness of each other	1	1.7
The reason for the emergence of child's behaviors and autism in significant and caring for him all the time	2	3.4
The inability to go to work because it's self employment and lack of income	2	3.4
The strict laws, lifestyle change and lack of entertainment	8	13.8
Stress, stopping energy and positive feelings	2	3.4
Difficult access to medical help	1	1.7
Lack of communication skills, failure to develop dialogue and difficult learn sufficient skills academically, professionally and gain experience	4	6.9
Lack of exercise, training and difficulty adapting to quarantine	10	17.2
Distance education and relapse of autistic children	2	3.4
No causes	9	15.5
Total	58	100.0

The table 7 and 8 shows that the more frequency of distribution of reason that affected on quality of life during the Corona pandemic among study sampling parents of autism children was Fear of disease, anxiety from gatherings with relatives and loneliness, which led to isolation and the percentage 24.1. We can see from the graph 1 that older parents feel that pandemic has an affect on their quality of life. The graph 2 shows that despite the education of parents, the presence of the epidemic while caring for an autistic child affected their quality of life.

**Table 7** Quantitative research for analyzing the relationship between age and how having an autistic child affect the quality of life. N=100

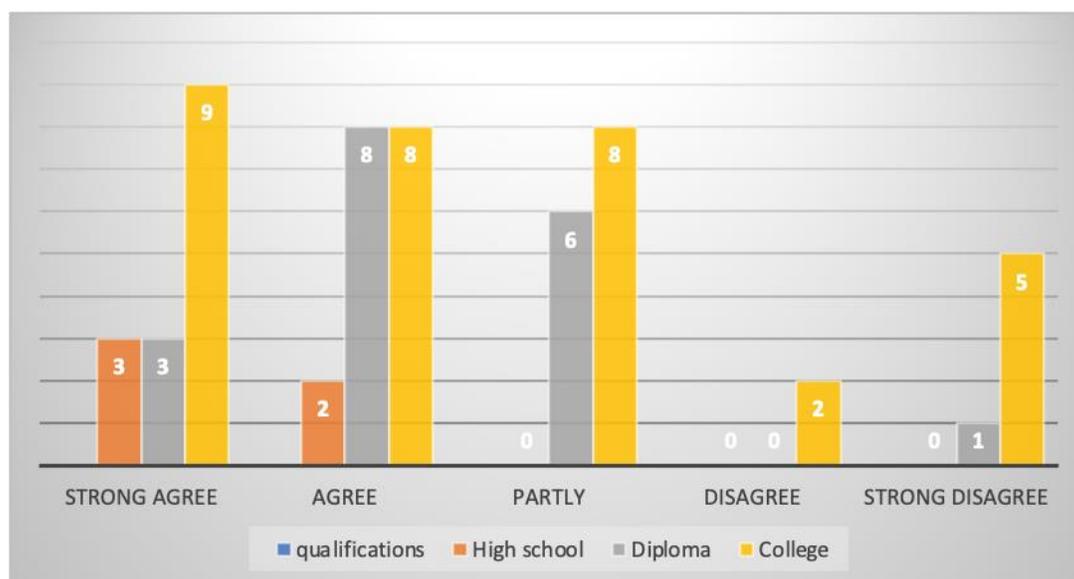
Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	17.497 <sup>a</sup>	8	.025
Likelihood Ratio	13.921	8	.084
Linear-by-Linear Association	5.841	1	.016
N of Valid Cases	58		

11 cells (73.3%) have expected count less than 5. The minimum expected count is 52.  
 The results indicate a statistically significant relationship (0.02) between age and the extent to which quality of life affects the presence of autistic children .

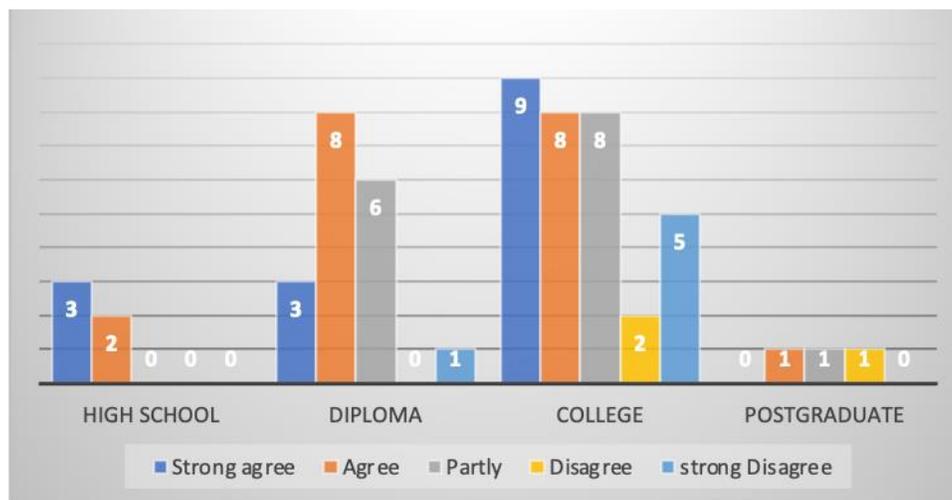
**Table 8** Quantitative research for analyzing the relationship between academic qualifications and how the existence of the pandemic affect on the quality of life. N=100

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	14.805 <sup>a</sup>	12	.252
Likelihood Ratio	15.688	12	.206
Linear-by-Linear Association	3.902	1	.048
N of Valid Cases	58		

16 cells (80.0%) have expected count less than 5. The minimum expected count is 16.  
 The results indicate a statistically significant relationship (0.03) between educational qualifications and assessment the quality of life in the presence of Covid-19 epidemic .



**Graph 1** Is there a relationship between the age of parents of autistic children and their quality of life during Pandemic?



**Graph 2** Relationship between academic qualifications and how the existence of the pandemic affects on the quality of life.

#### 4. DISCUSSION

The study shows that the more frequent the age group distributed among the parents of the study of autistic children between the ages of 31-40 and 40 and over, the more frequent the relationship distributed between the parents of the study sample of children with autism are the parents. The previous studies mentioned parents’ perceptions of family support, the predictability of ASD symptoms, and treatment able to "control" ASD linked to parenting stress. However, the positive coping did not dilute the relationship between these perceptions and parental tension.

Present study showed that The study shows that the most frequency of age group distributed among study sampling parents of autism children between 31-40 and 40 and more (44.8%), the most frequency of relationship distributed among study sampling parents of autism children was the parents. the percentage 82.8, the most frequency of educational qualification distributed among study sampling parents of autism children was the collectors (55.2%) and the most frequency of presence of job distributed among study sampling parents of autism children don’t have job, the percentage 51.7%. Another study by Dalal et al., (2019) is about the effect of autism on parental quality of life in Arar city, Saudi Arabia of 84 caregivers, 63.1% had impaired QOL. The main domains affected were energy/fatigue and role.

Current study Showed that Symptoms severity among study sampling parents of autism children. The study shows that the most frequency of symptoms severity distributed among study sampling parents of autism children was moderate, (50%). A study by Rattaz et al., (2017) is the Quality of Life in Parents of Young Adults with ASD: EpiTED Cohor. 38.1% of parents perceived a high impact of ASD on their QoL, 28.6% a moderate impact and 33.3% no impact. As regards subdomain scores, the daily disturbance QoL was highly impacted in 41.9% of parents, moderately impacted in 31.4% of parents, and not impacted in 26.7% of parents. The study shows that the most frequency of effect of the emerging corona virus (Covid 19) on making the lives of children with autism more isolated distributed among study sampling parents of autism children was to a certain extent, the percentage 31, the most frequency of effect of the emerging corona virus (Covid 19) on health condition of children with autism distributed among study sampling parents of autism children was disagree, the percentage 32.8, the most frequency effect distribution of emerging coronavirus (Covid 19) pandemic on aggressive of children with autism was disagree and the percentage 32.8, and the most frequency effect distribution of emerging coronavirus (Covid 19) pandemic on learning of children with autism was strongly agree and the percentage 44.8.

A study by Alhuzimi (2021) deals with stress and emotional wellbeing of oldsters’ thanks to change in routine for youngsters with Autism Spectrum Disorder (ASD) reception during COVID-19 pandemic in Saudi Arabia. Research in Developmental Disabilities 37 caregivers of the children/adolescent group completed the questionnaire and survey. In the adult group, a complete of 35 ASD adults completed the questionnaire and survey, and 32 informants completed the survey. The mean evaluation window was estimated at 14.07 months (SD = 7.58; 95% CI [11.6, 16.5]) in the children/ adolescent group and 9.41 months (SD = 4.42; 95% CI [7.95, 10.9]) in the adult group. No significant differences were observed. Another study talk about the main areas affected are energy / fatigue and a limited role due to emotional problems. Female sex, unemployment, and low income for caregivers were important factors associated with poor quality of life. Children with autism from first-order birth who had a prolonged period of illness were more likely to be associated with poor parental quality. Sex, income, occupation, and disease duration were associated

with poorer quality of life, but this was not statistically significant. Just under two-thirds of the caregivers had a poor QOL. Caregivers of children with autism need social and emotional support to help them cope with this disability.

## 5. CONCLUSION

The Corona epidemic has doubled the suffering of children with special needs, as the quarantine period and the reduction in the movement to go out to schools and movement have been an incomprehensible thing for them, and it is difficult for them to realize its risks, and the deterioration of their health condition has increased in light of their failure to follow the treatment and follow-up sessions in the Autism House and clinics for months. Children of this category are unable to express what is going on inside them towards the ongoing developments of people wearing masks and social distancing, which has been imposed in varying proportions for weeks and months, even for a short period.

The economic situation of poor families worsened the situation, as many of their heads lost work temporarily or throughout the last period, which made them live under economic and social pressures that accumulated with the epidemic, and this matter reflected, as Noura Auntung Wasito said on the psychological state of children who did not enroll in the studies and treatment sessions and did not mix with their friends for months, and that is why the Foundation Care for Children with Autism and People with Special Needs decided to reopen its doors, realizing that these children are different from other general children who follow study remotely through visual communication applications.

### Limitations

The data presented here consist of a subset of a much larger study, which aims to study the developmental pathway of Autism Spectrum Disorder. It was interesting to have more information on other parental variables that may be related to quality of life such as coping, depression and parental stress, and to include them in the multivariate model. Among the limitations, a small number of participants can be detrimental to generalizability of results. The improvement in this score may not be directly related to the onset of lockdown.

### Acknowledgement

We thank the participants who were all contributed samples to the study.

### Author Contributions

Amal Abdlgadir - Conceived and designed the analysis; Somia Jadalla Ali Frag - Collected the data and Contributed data or analysis tools, Suheir AM Sayed - Performed the analysis and Wrote the paper.

### Ethical approval

The study was approved by the Medical Ethics Committee of Al -Taif University, Ethical approval code : (HAO-02-T-105).

### Funding

This study has not received any external funding.

### Conflicts of interest

The authors declare that there are no conflicts of interests.

### Data and materials availability

All data associated with this study are present in the paper.

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