

# EMOTIONAL STATES AND QUALITY OF LIFE AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD) DURING COVID-19 IN MALAYSIA

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## Abstract

The global pandemic in Malaysia in 2020 has had a worldwide impact and affected the entire world's population. Caring for special needs, children became more difficult than usual during this period. Caring for children with Autism Spectrum Disorder (ASD) particularly could severely influence the parents' emotional well-being and quality of life. This study aimed to identify the emotional states and quality of life among parents of children with ASD during the COVID-19 pandemic. The study obtained quantitative data from the (n = 100) parents of children with ASD from different states in Malaysia using an online survey. The data collected from this study included; demographic characteristics of the parents and children, the Depression Anxiety Stress Scales (DASS-21), and also the World Health Organization Quality of Life Assessment-Bref: WHOQOL-BREF (Malay version). The results found significant differences between demographic characteristics, emotional status, and QoL among parents with autistic children during the COVID-19 pandemic in Malaysia. A statistically significant association existed between the parents' depression symptoms and their mental health status ( $p = 0.03^*$ ). There is also a correlation between the emotional states with the quality of life among the parents of children with ASD, but most of the domains were very weak correlations. Overall, the study found that the COVID-19 pandemic had slightly impacted the emotional states and quality of life among parents in Malaysia.

**Keywords:** Quality of Life, COVID-19 Pandemic, Emotional State, Parents with ASD

## Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder characterized by deficits in social communication and interaction skills, repetitive behavior, interests, and activities in early childhood (1-2). Based on the observation that the United States of America had done, an increasing prevalence of children with ASD at the age of 8 between the years 200 and 2014 from 6.7 to 6.8 in 1000 children (3). As for the prevalence, children with ASD in the Asia Pacific region were only limited to China and Japan, with an estimated 11.6 in 10,000 children. The data for the prevalence of ASD in Asia was unknown as the data availability was limited, and the sample size was too

small (4, 5). This disorder has been increasing dramatically around the world. According to the Ministry of Health, over the past 10 years the number of ASD cases has increased dramatically. According to the ministry's report in 2021, a total of 589 children under the age of 18 faced ASD disorders and this number jumped by 500 percent from 99 cases in 2009 (6).

According to Abdul Rashid (6), there were approximately almost 12,800 cases of ASD in Malaysia, and it was the fastest-growing disorder among children rather than other developmental disorders. The real causes or risk factors for this condition may still be unknown, but in

general, the sign and symptoms of ASD may be present at the age of 2 to 3 years old, mostly it is higher in males than females. According to Bartley (7), this developmental disorder has been found in all ethnic groups, racial, socioeconomic continuum, and others. Caring for children with developmental disabilities was a challenging journey for the parents or caregivers compared to the parents with typical children. This is a lifelong journey that parents of children with disabilities must go through. For example, parents may be exhausted as they must verbally and physically assist the children in taking care of or performing daily living activities such as bathing, toileting, etc. Special needs children have high health maintenance, and the parents require additional financial, emotional, social, and physical resources in order to cope with their situation. Various problems also may occur when individuals have children with ASD, including school challenges, challenges in handling the children's unwanted behavior, the burden of taking care and giving supervision for the children all the time, emotionally unstable, and others. These things might affect their emotions and quality of life (QoL) (8). Quality of life is an individual perception of their life concerning their goals, expectations, and concerns. It may affect the individuals' psychological state, personal beliefs, physical health, and social relationship (9-10). The global outbreak, Coronavirus disease 2019 (COVID-19) pandemic was an unexpected situation that occurred, and it affected the emotional states and QoL of all populations of the world. According to Özdin & Bayrak (11) stated that this pandemic may lead to disturbance, especially in emotional states such as anxiety, depression, stress, and also mental issues among the population. These situations may really affect the disabled community, especially the parents with disabled children, due to the impact of school closures, income loss, limited availability of services, and others. It also changes the family life pattern, causes a lack of social contact and outdoor activities, causes sleep disturbance, and impacts the individual's physical and mental health. Emotional states and the QoL of the caregivers or parents of the autistic children will be affected as they had to experience more burden during the pandemic rather than other people. This is because children or adults with ASD are uncomfortable with the changes in daily life routine or sudden unexpected changes. Their mood may change and sometimes lead to unwanted behavior to occur (12). Therefore, this study aimed to assess the emotional states and the QoL of the parents of children with ASD during COVID-19 in Malaysia.

## **Materials and Methods**

### **Study design**

This research is quantitative, and the study design was cross-sectional. Therefore, it was low-cost, time-saving, relatively quick, and easy to do, and the data was very useful. It also can be conducted at a single point in time, deals with the situation existing at a given time in a group or population, and the data were collected to help answer the questionnaire. As for this study, the cross-sectional

study helps to identify the emotional states and quality of life among the parents of children with ASD during COVID-19 in Malaysia. The sampling method used for the participants' selection was non-probability sampling which is convenience sampling.

### **Identifying the research question**

Three research questions guided this study as follows:

- i. What are the emotional states and quality of life (QoL) of parents of children with ASD during COVID-19?
- ii. What is the association between demographic characteristics with emotional states and quality of life (QoL) among parents of children with ASD during COVID-19?
- iii. Do emotional states linearly correlate with the quality of life (QoL) among parents of children with ASD during COVID-19?

### **Significant of the study**

This study is relevant as preliminary studies have been conducted regarding identifying the quality of life among parents of children with ASD during the COVID-19 pandemic. Most of the studies were conducted to identify the relationship or the association between the quality of life and other components. Perhaps, this study will provide an answer to help parents identify their emotional state and quality of life during an outbreak. In turn, this will increase parents' awareness of mental health problems and also seek help from a doctor or specialist if needed. Therefore, this study would like to identify the differences between which domains in quality of life would have an impact on parents during this pandemic. Furthermore, the study also wants to identify any differences between the score in quality of life and emotional state measurements with the demographic characteristics among the parents with children ASD during the pandemic.

### **Scope of the study**

The main focus of this study was the emotional states and the quality of life among parents with ASD. This study was to determine the emotional states and QoL of parents of children with ASD during COVID-19, to determine the significant difference between the variables, and also to determine the relationship between the emotional states and the QoL among parents of children with ASD during COVID-19.

### **Definition of terms**

#### **Autism Spectrum Disorder (ASD)**

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder of early childhood characterized by repetitive, unwanted behavior and problems in social communication and interaction skills (2). The problem in social and communication skills includes; poor eye contact, lack of facial expression, poor attention span, and body gestures

at the early age of 3 years. It was a multifactorial disorder, which could result from the genetic and non-genetic risk factor and their interaction. Although the exact causes were unknown, genetic studies have identified that it may cause interruptions in the central nervous system in utero through childhood. Next, other studies also mentioned that ASD could be a result of disturbances in normal brain developmental growth at an early age. These disturbances may result from gene defects that control the development of the brain and regulate how brain cells communicate with each other. The incidence of autism is 1 in 68 children. The ratio of female to male cases was 1:4, and it affects more males than females, and other researchers have mentioned that the possibility of specific protection for females having effects against ASD might exist (13).

### **Occupational therapy roles in ASD**

Occupational therapy (OT) is defined as a healthcare provider focusing more on the client's independence in all aspects of daily living. There are several components that OT needs to consider in order to get more information and details about the client, including; person, occupational needs, and environment. In general, OT will use certain or selected assessments to identify the client's problem, and then, from the client's problem, OT will plan and implement the intervention. The assessment and intervention will be reviewed to evaluate the progress toward the target outcome. The use of the model, the frame of references, and the approaches were very important to make sure OT delivers evidence-based practices and services to the client (14). Occupational therapists use holistic approaches in order to identify more details, including; the physical, cognitive, sensory, social, emotional, behavioral, and developmental abilities and needs of children with ASD. For instance, most ASD children have sensory processing problems, and occupational therapy will evaluate this problem by using standardized measures to assess the sensory problem, which is the Short Sensory Profile (SSP). In order to improve sensory-motor skills for children, the occupational therapists will decide what approach will be used to plan the intervention and provide the intervention for processing problems such as Sensory integration therapy (SIT) (15).

### **Emotional states**

Emotions were defined as the states that occur by stimuli for an action, behavior responses, and communications such as gestures, words, facial expressions, and others. The emotional state was one of the person's feelings that his or her project depended on their opinion for certain situations. Some parts of the brain provide a foundation understanding for basic emotions, such as the anterior cingulate cortex and orbitofrontal. The function of the emotions itself works to obtain or avoid the punishers and rewards, respectively. Emotions will rise when individuals have effective experiences such as happiness, pleasure, and pain. It also stimulates behavior and cognition and triggers various internal and external adjustments (16). Emotion is

very subjective, it cannot be measured with any tools, but it may express in many ways, including feeling, a sense of purpose, social expression, and bodily arousal. Emotion can be positively or negatively affected by an individual, but positive emotion may be utilized in coping and social functions (17).

### **Quality of life (QoL)**

According to the World Health Organization Quality of Life (WHOQOL) Group 1998 (18), quality of life (QOL) was defined as the individual perceptions regarding their position of life in the context of the environment, culture, value, and spirituality in relation to their standard and concern. Quality of life may also reflect the appreciation of the individual's feelings and satisfaction or their life (19). Many studies define QOL in different concepts, such as the individual's goals or objective of living, a person's well-being, or experience in life. These may occur due to the many researchers contributing to the development, translation, or validation of the assessment measuring quality of life (20).

### **Coronavirus disease 2019 (COVID-19)**

Coronavirus disease 2019 (COVID-19) is a disease that is caused by the virus named SARS-CoV-2. In December 2019, the new virus was detected in Wuhan, China, and the symptoms of coronavirus SARS-CoV-19 included; fever of more than 37-degree Celsius, dry cough, shortness of breath, and in some cases may, loss of taste and smell, headache, fatigue, sore throat, muscle pain, diarrhea, and others. This epidemic was evolving very fast and became a pandemic within two months (21). This has had very serious global impacts and health-treat on a respiratory virus since the influenza pandemic in 1918 (22). The COVID-19 cases in Malaysia were increasing day by day; as of 5 April 2020, the cases were 3,662 and 61 deaths. The government takes action to prevent the cases from rising, for instance, continuing screening and testing, isolating the affected patient, and quarantining the individual with close contact (23). On 16 March 2020, the Malaysian Prime Minister announced the Movement Control Order (MCO), and the first MCO was started on 18 April 2020 (24). All the universities, schools, religious places, and other sectors were closed, and the hospital also limited and rescheduled the appointment of outpatients in order to break the chain of COVID-19. These pandemics have some impact on the economy, health status, quality of life, and others.

### **Sample size calculation**

The population selected in this study was children that have been diagnosed with Autism Spectrum Disorder (ASD) in Malaysia. The target population in this study is parents of children with ASD. According to the Centre for Disease Control (CDC) in the United States, the incidence of autism is 1 in 68 children. The number of children with ASD in Malaysia born every year is expected to be 9,000. By using the Krejcie and Morgan sample size calculation, the sample size is 368. The sample size estimation for this

study uses the Krejcie and Morgan sample size calculation (25). The calculation is as follows:

*Formula for determining sample size*

$$s = \frac{X^2 NP(1 - P) + d^2(N - 1) + X^2 P(1 - P)}{d^2}$$

*s* = required sample size.

$X^2$  = the table value of chi-square for 1 degree of freedom at the desired confidence level (3.841).

*N* = the population size.

*P* = the population proportion (assumed to be .50 since this would provide the maximum sample size).

*d* = the degree of accuracy expressed as a proportion (.05).

Source: Krejcie & Morgan, 1970

$$s = \frac{(3.84) (9000) (0.5) (1-0.5) + (0.05)^2 (9000-1) + (3.84)^2 (0.50) (1-0.5)}{(0.05)^2} = 368$$

**Research instruments**

**Demographic characteristic form**

This form consists of demographic details of the participants like age, gender, marital status, number of dependents, household income, ethnicity, working states, working status, educational level, relationship to the children with ASD, mental health status, and person with disabilities (OKU) status. This section also includes information on children with ASD, such as age, gender, and also children’s educational status.

**The Depression Anxiety Stress Scale-21 (Malay version)**

The Depression Anxiety Stress Scales (DASS-21) is designed to measure the magnitude of three negative emotional states: depression, anxiety, and stress. DASS-Depression focuses on reports of low mood, motivation, and self-esteem; DASS-anxiety focuses on physiological arousal, perceived panic, and fear; and DASS-stress on tension and irritability (26). There were 21 questions in this questionnaire; every magnitude of three negative emotional states has seven questions. The DASS may be administered and scored by non-psychologists, but decisions based on particular score profiles should be made only by experienced clinicians who have carried out an appropriate clinical examination. It takes approximately around 5 to 10 minutes (27). The interpretation of this assessment is the higher scores on each subscale indicate increasing severity of depression, anxiety, or stress.

**The World Health Organization Quality of Life Assessment-Bref: WHOQOL-BREF (Malay version)**

The World Health Organization Quality of life Assessment; Brief (WHOQOL-BREF) was an abbreviated version of the WHOQOL-100 quality of life assessment. The original version of WHOQOL was developed by the WHOQOL group in 15 international field centers for the purpose of creating a standardized assessment that is applicable cross-culturally in order to measure the quality of life, and

it has 236 items that are related to the quality of life. The revised version of the assessment (WHOQOL-100) has been developed. It has 100 items encompassing 24 facets and grouped into four categories: physical health, psychological health, social relationships, and environment; however, it seems too long for the users to answer. In 1991, Berwick and partners developed the trial version (WHOQOL-BREF), and the WHOQOL group agreed upon it. For every facet in WHOQOL-100, one item has been included and also includes the two items from the Overall Quality of Life and General Health facet. Therefore the new version of assessment quality of life (WHOQOL-BREF) was the 5-Likert scale, and several facets were incorporated in every domain. It has a total of 2 items and four domains as in Figure 1. The domains were; physical health, social relationship, psychology, and environment (28).

Domain	Facets incorporated within domains
1. Physical health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work Capacity
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory and concentration
3. Social relationships	Personal relationships Social support Sexual activity
4. Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport

Figure 1: shows the four domains in WHOQOL-BREF.

**Data analysis**

The description of the result was according to the research objectives of this study. Simple descriptive statistics such as the percentile values, central tendency (mean, median, mode), and dispersion (standard deviation, variance, range, maximum and minimum) were utilized to identify the demographic characteristics, score from the Depression Anxiety Stress Scale (DASS-21) and the World Health Organization Quality of Life Assessment-Bref: WHOQOL-BREF (Malay version). The demographic characteristics may include parents and also the children’s information; age, gender, marital status, number of dependents, household income, ethnicity, working states, working status, mental health status, person with disabilities (OKU) status., educational level, relationship with the autistic children, number of autistic children in the family, children’s age, children’s gender, and also children’s educational level. Further, various statistical tools like t-test and Pearson’s correlation coefficient, and also inferential statistics such



as One-way ANOVA analysis were utilized in order to identify the significant differences between demographic characteristics with the emotional states and the quality of life (QoL) and also the correlation between the emotional states and the quality of life (QoL) among parents of children with ASD during COVID-19. All the tests were analyzed using IBM's Statistical Package for the Social Sciences (SPSS) software version 26, and the significance was  $p < 0.05$ .

## Results

### Participation in study

Out of the 150 parents of children with Autism Spectrum Disorder (ASD) has been approached, only 73 have completed the online questionnaire given. The average time to complete the survey was approximately 10 to 15 minutes.

### Demographic data

The participants' demographic characteristics are summarized in Table 1. The majority of the participants were female, 52 (71.2%), with an age range between 31

to 40 years old ( $M = 2.14$ ,  $SD = 0.58$ ). Also, the majority of the participants were married, 71 (97.3%). More than half of the participants were Malay 57 (78.1%) in ethnicity, followed by *Bumiputera Sabah/Sarawak* 13 (17.8%) and Chinese, other, and non-citizen1 (1.4%). Due to the no Indian participant, the data has been excluded from the analysis. The vast majority that completed the questionnaires given were mothers of children with ASD 52 (71.2%). Many of the participants have tertiary educational level 58 (79.5%), followed by secondary 12 (16.4%) and 3 (4.1%) primary educational level. Mostly the mean number of dependents in the family was 4.66. The majority of the parents were still working during the COVID-19 pandemic, working states mostly in Kelantan 42 (57.5%) and Labuan 18 (24.7%), mostly the working status was permanent 48 (65.8%), followed by others 14 (19.2%), contract 6 (8.2%) and daily 4 (5.5%). Moreover, their household income was in category B40 39 (53.4%) and M40 34 (46.6%). The participating families' majority had one child with ASD 69 (94.5%), and the majority of the children were aged between  $6.48 \pm 3.00$  years old, male 58 (79.5%) and female 15 (20.5%), and most of them received early childhood special education 40 (54.8%).

**Table 1:** Parents and children demographic characteristics

Variables	Categories	Frequency, n (%)	Mean	SD
Age	21-30	7(9.6%)	2.14	0.58
	31-40	50(68.5%)		
	41-50	15(20.5%)		
	51 and above	1(1.4%)		
Gender	Male	21(28.8%)		
	Female	52(71.2%)		
Marital status	Married	71(97.3%)		
	Other	2(2.7%)		
Ethnicity	Malay	57(78.1%)		
	Chinese	1(1.4%)		
	<i>Bumiputera sabah/sarawak</i>	13(17.8%)		
	Other	1(1.4%)		
	Non-citizen	1(1.4%)		
Number of dependents			4.66	1.44
Household income	B40	39(53.4%)		
	M40	34(46.6%)		
Working states	Kedah	1(1.4%)		
	Kelantan	42(57.5%)		
	Labuan	18(24.7%)		
	Melaka	1(1.4%)		
	Negeri sembilan	1(1.4%)		
	Perak	1(1.4%)		
	Perlis	3(4.1%)		
	Pulau pinang	1(1.4%)		
	Sarawak	1(1.4%)		
	Selangor	1(1.4%)		
	Terengganu	3(4.1%)		

**Table 1:** Parents and children demographic characteristics (continued)

Variables	Categories	Frequency, n (%)	Mean	SD
<b>Working status</b>	Permanent	48(65.8%)		
	Contract	6(8.2%)		
	Daily	4(5.5%)		
	Part-time	1(1.4%)		
	Other	14(19.2%)		
<b>Educational level</b>	Primary	3(4.1%)		
	Secondary	12(16.4%)		
	Tertiary	58(79.5%)		
<b>Relationship with autistic children</b>	Mother	52(71.2%)		
	Father	21(28.8%)		
<b>Number of children with ASD</b>	1	69(94.5%)	1.07	0.30
	2	3(4.1%)		
	3	1(1.4%)		
<b>Age of children with ASD</b>			6.48	3.00
<b>Gender of children with ASD</b>	Male	58(79.5%)		
	Female	15(20.5%)		
<b>Children Education</b>	No education	12(16.4%)		
	Early childhood special education	40(54.8%)		
	Preschool	11(15.1%)		
	Primary	9(12.3%)		
	Secondary	1(1.4%)		

**Depression Anxiety Stress Scale (DASS-21)**

Descriptive statistics analysis was used to analyze the data. Table 2 shows the summary of the parents of children with ASD who have indicated depression, anxiety, and stress as measured by DASS-21, and table 3 shows the association between the emotional states of parents of children with ASD. It showed that 67 (91.8%) of the participating parents had a normal depression score in DASS-21, followed by mild depression 4 (5.5%), and 1 (1.4%) participant had moderate depression. Next, 65 (89.0%) of the participants had normal anxiety scores in DASS-21 followed by 6 (8.2%) moderate and mild 1 (1.4%). As for the stress score in DASS-21, mostly the participants had normal stress 71 (97.3%) and followed by mild stress 2 (2.7%). Due to the no data for moderate and severe stress, it was excluded from the summarized table.

**Association between the demographic characteristic and the parents’ depression symptoms**

The p-value is < 0.05, rejecting the null hypothesis, and the association was significant. It showed that there was a statistically significant association between the parents’ depression symptoms and the mental health status ( $p = 0.03^*$ ), the number of children with ASD in the family ( $p = 0.03^*$ ), and the children’s educational level ( $p = 0.03^*$ ). The p-value is > 0.05, does not reject the null hypothesis, and the association was not significant. There is no statistically significant association between the parents’ depression

**Table 2:** The Depression Anxiety Stress Scale (DASS-21) among parents of children with ASD

Items	Study participants (n = 73) Frequency (%)
Depression score	
• Normal	<b>67(91.8%)</b>
• Mild	<b>4(5.5%)</b>
• Moderate	<b>2(2.7%)</b>
Anxiety score	
• Normal	<b>65(89.0%)</b>
• Mild	<b>1(1.4%)</b>
• Moderate	<b>6(8.2%)</b>
• Severe	<b>1(1.4%)</b>
Stress score	
• Normal	<b>71(97.3%)</b>
• Mild	<b>2(2.7%)</b>

It showed that 67(91.8%) of the participating parents had an average depression score in DASS-21, followed by mild depression 4(5.5%), and 1(1.4%) participants had moderate depression. Next, 65(89.0%) of the participants had normal anxiety scores in DASS-21 followed by 6(8.2%) moderate and mild 1(1.4%). As for the stress score in DASS-21, mostly the participants had normal stress 71(97.3%) and followed by mild stress 2(2.7%). Due to the no data for moderate and severe stress, it was excluded from the summarized table.

**Table 3:** The association between the emotional states in parents of children with ASD

Variables		Depression			Anxiety			Stress		
		Yes	No	p	Yes	No	p	Yes	No	p
<b>Age</b>	21-30	2(28.6%)	5(71.4%)	0.23	2(28.6%)	5(71.4%)	0.41	2(28.6%)	5(71.4%)	<0.001*
	31-40	3(6.0%)	47(94.0%)		4(8.0%)	46(92.0%)		0(0.0%)	50(100.0%)	
	41-50	1(6.7%)	14(93.3%)		2(14.3%)	13(86.7%)		0(0.0%)	15(100.0%)	
	51 and above	0(0.0%)	1(100.0%)		0(0.0%)	1(100.0%)		0(0.0%)	1(100.0%)	
<b>Gender</b>	Male	2(9.5%)	19(90.5%)	0.80	2(9.5%)	19(90.5%)	0.80	1(4.8%)	20(95.2%)	0.50
	Female	4(7.7%)	48(92.3%)		6(11.5%)	46(88.5%)		1(1.9%)	51(98.1%)	
<b>Marital status</b>	Married	6(8.5%)	65(91.6%)	0.67	8(11.3%)	63(88.7%)	0.62	2(2.8%)	69(97.2%)	0.81
	Other	0(0.0%)	2(100.0%)		0(0.0%)	2(100.0%)		0(0.0%)	2(100.0%)	
<b>Ethnicity</b>	Malay	4(7.0%)	53(93.0%)	0.87	5(8.8%)	52(91.2%)	0.63	1(1.8%)	56(98.2%)	0.83
	Chinese	0(0.0%)	1(100.0%)		0(0.0%)	1(100.0%)		0(0.0%)	1(100.0%)	
	Bumiputera	2(15.4%)	11(84.6%)		3(23.1%)	10(76.9%)		1(7.7%)	12(92.3%)	
	Sabah/Sarawak									
	Other									
<b>Household income</b>	B40	4(10.3%)	35(89.7%)	0.50	5(12.8%)	34(87.2%)	0.58	2(5.1%)	37(94.9%)	0.18
	M40	2(5.9%)	32(94.1%)		3(8.8%)	31(91.2%)		0(0.0%)	34(100.0%)	
<b>Mental health</b>	Yes	1(50.0%)	1(50.0%)	0.03*	2(100.0%)	0(0.0%)	<0.001*	1(50.0%)	1(50.0%)	<0.001*
	No	5(7.0%)	66(93.0%)		6(8.5%)	65(91.5%)		1(1.4%)	70(98.6%)	
<b>OKU</b>	Yes	0(0.0%)	3(100.0%)	0.60	0(0.0%)	3(100.0%)	0.54	0(0.0%)	3(100.0%)	0.77
	No	6(8.6%)	64(91.4%)		8(11.4%)	62(88.6%)		2(2.9%)	68(97.1%)	
<b>Working status</b>	Permanent	4(8.3%)	44(91.7%)	0.80	5(10.4%)	43(89.6%)	0.57	1(2.1%)	47(97.9%)	0.84
	Contract	0(0.0%)	6(100.0%)		0(0.0%)	6(100.0%)		0(0.0%)	6(100.0%)	
	Daily	0(0.0%)	4(100.0%)		0(0.0%)	4(100.0%)		0(0.0%)	4(100.0%)	
	Part-time	0(0.0%)	1(100.0%)		0(0.0%)	1(100.0%)		0(0.0%)	1(100.0%)	
	Other	2(14.3%)	12(85.7%)		3(21.4%)	11(78.6%)		1(7.1%)	13(92.9%)	
<b>Educational level</b>	Primary	0(0.0%)	3(100.0%)	0.87	0(0.0%)	3(100.0%)	0.77	0(0.0%)	3(100.0%)	0.77
	Secondary	1(8.3%)	11(91.7%)		1(8.3%)	11(91.7%)		0(0.0%)	12(100.0%)	
	Tertiary	5(8.6%)	53(91.4%)		7(12.1%)	51(87.9%)		2(3.4%)	56(96.6%)	
<b>Relationship with autistic children</b>	Mother	4(7.7%)	48(92.3%)	0.80	6(11.5%)	46(88.5%)	0.80	1(1.9%)	51(98.1%)	0.50
	Father	2(9.5%)	19(90.5%)		2(9.5%)	19(90.5%)		1(4.8%)	20(95.2%)	
<b>Number of children with ASD</b>	1	1.33(0.82)	1.04(0.21)	0.03*	1.25(0.71)	1.95(0.21)	0.07	1.00(0.00)	1.07(0.31)	0.75
	2									
	3									
<b>Age of children with ASD</b>		6.50(5.12)	6.48(2.80)	0.99	6.00(4.44)	6.54(2.81)	0.64	2.00(0.00)	6.61(2.94)	0.03*
<b>Gender of children with ASD</b>	Male	5(8.6%)	53(91.4%)	0.81	7(12.1%)	51(87.9%)	0.55	1(1.7%)	57(98.3%)	0.30
	Female	1(6.7%)	14(93.3%)		1(6.7%)	14(93.3%)		1(6.7%)	14(93.3%)	
<b>Children Education</b>	No education	2(16.7%)	10(83.3%)	0.03*	3(25.0%)	9(75.0%)	0.001*	1(8.3%)	11(91.7%)	0.73
	Early childhood special education	1(2.5%)	39(97.5%)		1(2.5%)	39(97.5%)		1(2.5%)	39(97.5%)	
	Preschool	2(18.2%)	9(81.8%)		3(27.3%)	8(72.7%)		0(0.0%)	11(100.0%)	
	Primary	0(0.0%)	9(100.0%)		0(0.0%)	9(100.0%)		0(0.0%)	9(100.0%)	
	Secondary	1(100.0%)	0(0.0%)		1(100.0%)	0(0.0%)		0(0.0%)	1(100.0%)	

Test of significance: Pearson's Chi-Square test

\*Statistically significant ( $p < 0.05$ )

symptoms with age, gender, marital status, ethnicity, household income, personal disabilities status (OKU), working status, educational level, relationship with autistic children, age of the autistic children, children gender and also children’s level of education.

**Association between the demographic characteristic and the parents’ anxiety symptoms**

The p-value is < 0.05, rejecting the null hypothesis, and the association was significant. A significant association between the parents’ anxiety symptoms and the mental health status ( $p < 0.001^*$ ) and the children’s educational level ( $p = 0.001^*$ ). The p-value is > 0.05, does not reject the null hypothesis, and the association was not significant. There is no statistically significant association between the parents’ depression symptoms with age, gender, marital status, ethnicity, household income, personal disabilities status (OKU), working status, educational level, relationship with autistic children, number of children with ASD in the family, age of the autistic children, and children gender.

**Association between the demographic characteristic and the parents’ stress symptoms**

The p-value is < 0.05, rejecting the null hypothesis, and the association was significant. The result identified a significant association between the parents’ stress symptoms and the age of the parents ( $p < 0.001^*$ ), mental health status ( $p < 0.001^*$ ), and the age of the children with ASD ( $p = 0.03^*$ ). The p-value is > 0.05, does not reject the null hypothesis, and the association was not significant. There is no statistically significant association between the parents’ stress symptoms with gender, marital status, ethnicity, household income, personal disabilities status (OKU), working status, educational level, relationship with autistic children, number of children with ASD in the family, children gender and also children’s level of education.

**The World Health Organization Quality of Life Assessment-Bref: WHOQOL-BREF (Malay version).**

Descriptive statistics analysis was used to analyze the data. Table 4 shows the summary of the comparison of quality of life among parents of children with ASD based on four domains as measured by WHOQOL-BREF, and table 5 shows the association between the quality of life in parents of children with ASD with the demographic characteristics.

**Table 4:** The World Health Organization Quality of Life Assessment-Bref: WHOQOL-BREF (Malay version) among parents of children with ASD

Items	Study participants (n = 73)			
	Mean	Standard deviation (SD)	Minimum	Maximum
Domain 1: Physical health	54.51	12.56	19.00	81.00
Domain 2: Psychological	56.62	15.06	19.00	88.0
Domain 3: Social relationships	62.34	23.50	0.00	100
Domain 4: Environment	63.49	17.38	19.00	100.00

It showed the mean (SD) for every domain in the WHOQOL-BREF. For example, the mean and standard deviation for domain physical health were (M = 54.51 SD = 12.56). Next, for the psychological domain were (M = 56.62, SD = 15.06) followed by domain social relationships (M = 62.34, SD = 23.50) and domain environment (M = 63.49, SD = 17.38).

**Table 5:** The association between the quality of life in parents of children with ASD and the demographic characteristics

Variables		Domain WHOQOL-BREF											
		Physical health			Psychological			Social relationships			Environment		
		Mean (SD)	t-statistic (pdf)	p	Mean (SD)	t-statistic (pdf)	p	Mean (SD)	t-statistic (pdf)	p	Mean (SD)	t-statistic (pdf)	p
Age	21-30	57.29(16.76)	1.08(2,69)	0.37	50.00(16.63)	1.30(2,69)	0.28	75.00(31.21)	0.88(2,69)	0.46	59.14(16.17)	1.28 (2,69)	0.29
	31-40	53.12(13.15)			56.24(14.71)			60.50(21.67)			63.14(17.34)		
	41-50	58.53(7.09)			61.80(15.07)			63.40(25.98)			68.40(17.52)		
	51 and above	44.00(0.00)			44.00(0.00)			260.00(0.00)			38.00(0.00)		
Gender	Male	54.86(14.34)	0.02(1,71)	0.88	56.57(17.29)	0.00(1,71)	0.99	59.52(25.63)	0.42(1,71)	0.52	64.10(21.82)	0.04(1,71)	0.85
	Female	54.37(11.92)			56.63(14.24)			63.46(22.75)			63.25(15.48)		
Marital status	Married	54.62(12.55)	0.21(1,71)	0.65	56.62(15.12)	0.00(1,71)	0.99	62.77(23.21)	0.88(1,71)	0.35	63.44(17.55)	0.03(1,71)	0.87
	Other	50.50(17.68)			56.50(17.68)			47.00(39.60)			65.50(13.44)		
Ethnicity	Malay	54.53(12.47)	1.30(1,68)	0.28	56.79(16.16)	0.51(1,68)	0.73	63.82(23.73)	1.61(1,68)	0.18	63.63(18.13)	0.20(1,68)	0.94
	Chinese	44.00(0.00)			44.00(0.00)			50.00(0.00)			50.00(0.00)		
	Bumiputera	54.92(12.41)			56.85(10.08)			57.69(19.99)			64.54(16.07)		
	Sabah/Sarawak												
	Other	38.00(0.00)			44.00(0.00)			19.00(0.00)			56.00(0.00)		
Non-citizen	75.09(0.00)	69.00(0.00)	94.00(0.00)	63.00(0.00)									
Household income	B40	52.85(13.98)	1.47(1,71)	0.23	52.64(14.66)	6.27(1,71)	0.02*	59.33(26.02)	1.38(1,71)	0.24	56.74(16.80)	15.10(1,71)	<0.001*
	M40	56.41(10.60)			61.18(14.39)			65.79(20.06)			71.24(14.77)		



**Table 5:** The association between the quality of life in parents of children with ASD and the demographic characteristics (continued)

Variables		Domain WHOQOL-BREF											
		Physical health			Psychological			Social relationships			Environment		
		Mean (SD)	t-statistic (pdf)	p	Mean (SD)	t-statistic (pdf)	p	Mean (SD)	t-statistic (pdf)	p	Mean (SD)	t-statistic (pdf)	p
<b>Mental health</b>	Yes	41.00(4.24)	2.42(1,71)	0.12	50.00(8.49)	0.39(1,71)	0.53	43.50(17.68)	1.33(1,71)	0.25	50.00(8.49)	1.24(1,71)	0.27
	No	54.89(12.52)			56.80(15.19)			62.87(23.52)			63.87(17.45)		
<b>OKU</b>	Yes	63.00(0.00)	1.44(1,71)	0.23	69.09(6.00)	2.15(1,71)	0.15	58.33(19.86)	0.09(1,71)	0.77	68.68(12.50)	0.27(1,71)	0.60
	No	54.14(12.71)			56.09(15.12)			62.51(23.75)			63.27(17.59)		
<b>Working status</b>	Permanent	54.13(11.96)	1.05(3,68)	0.39	57.31(15.69)	0.13(3,68)	0.97	60.42(23.17)	1.76(3,68)	0.15	63.69(18.92)	0.51(3,68)	0.73
	Contract	60.50(12.31)			56.17(17.68)			73.00(21.20)			65.67(11.66)		
	Daily	48.74(10.79)			53.25(18.50)			40.75(14.77)			51.75(10.59)		
	Part-time	38.00(0.00)			50.00(0.00)			81.00(0.00)			69.00(0.00)		
	Other	56.07(14.87)			55.86(12.50)			69.21(24.63)			64.86(15.86)		
<b>Educational level</b>	Primary	56.33(18.50)	0.86(2,70)	0.43	58.67(13.95)	4.72(2,70)	0.01*	62.67(38.99)	0.11(2,70)	0.90	64.67(9.61)	3.19(2,70)	0.05
	Secondary	50.17(13.55)			45.00(8.37)			59.42(28.66)			52.25(14.18)		
	Tertiary	55.31(12.13)			58.91(15.26)			62.93(21.99)			65.76(17.54)		
<b>Relationship with autistic children</b>	Mother	54.62(11.96)	0.01(1,71)	0.91	57.12(14.23)	0.20(1,71)	0.66	64.08(22.80)	0.98(1,71)	0.32	63.96(15.43)	0.13(1,71)	0.72
	Father	54.24(14.25)			55.38(17.25)			58.05(25.22)			62.33(21.88)		
<b>Number of children with ASD</b>	1	54.04(12.63)	1.04(1,70)	0.36	56.45(15.09)	0.78(1,70)	0.46	62.42(22.44)	5.00(1,70)	0.01*	63.36(16.63)	4.01(1,70)	0.02*
	2	64.67(9.61)			64.67(1.57)			81.33(16.44)			79.33(18.88)		
	3	56.00(0.00)			44.00(0.00)			0.00(0.00)			25.00(0.00)		
<b>Gender of children with ASD</b>	Male	53.79(12.46)	0.91(1,71)	0.34	54.97(15.51)	3.51(1,71)	0.07	60.59(23.87)	1.59(1,71)	0.21	62.31(17.85)	1.31(1,71)	0.23
	Female	57.27(13.01)			63.00(11.43)			69.13(21.42)			68.07(15.08)		
<b>Children Education</b>	No education	50.58(14.70)	0.44(3,68)	0.78	53.33(15.65)	0.82(3,68)	0.78	54.75(27.23)	2.56(3,68)	0.05	57.92(20.53)	1.80(3,68)	0.14
	Early childhood special education	56.80(11.48)			59.30(15.81)			64.85(22.26)			65.75(16.85)		
	Preschool	55.27(12.39)			52.91(8.99)			61.91(19.09)			64.91(8.55)		
	Primary	52.89(15.93)			55.00(17.04)			68.78(20.73)			63.44(20.10)		
	Secondary	56.09(0.00)			44.00(0.00)			0.00(0.00)			25.00(0.00)		

Test of significance: One-way ANOVA

\*Statistically significant (p < 0.05)

**Association between the demographic characteristic and the physical health**

The p-value is > 0.05, does not reject the null hypothesis, and the association was not significant. There is no statistically significant association between the parents' physical health with age, gender, marital status, ethnicity, household income, mental health status, person disabilities status (OKU), working status, educational level, relationship with autistic children, number of children with ASD in the family, children gender and also children's level of education.

**Association between the demographic characteristic and the psychological**

The p-value is < 0.05, rejecting the null hypothesis, and the association was significant. The result identified a significant association between the parents' psychological and household income (p = 0.02\*) and parents' educational level (p = 0.01\*). The p-value is > 0.05, does not reject the null hypothesis, and the association was not significant. There is no statistically significant association between the parents' physical health with age, gender, marital status, ethnicity, mental health status, personal disabilities status (OKU), working status, educational level, relationship with

autistic children, number of children with ASD in the family, children gender and also children's level of education.

**Association between the demographic characteristic and the social relationships**

The p-value is < 0.05, rejecting the null hypothesis, and the association was significant. The result identified a significant association between the parents' social relationships and the number of children with ASD in the family (p = 0.01\*). The p-value is > 0.05, does not reject the null hypothesis, and the association was not significant. There is no statistically significant association between the parents' social relationships with age, gender, marital status, ethnicity, household income, mental health status, personal disabilities status (OKU), working status, educational level, relationship with autistic children, children gender and also children's level of education.

**Association between the demographic characteristic and the environment**

The p-value is < 0.05, rejecting the null hypothesis, and the association was significant. The result identified a significant association between the environment and household income (p = < 0.001\*) and the number of

children with ASD in the family ( $p = 0.02^*$ ). The p-value is  $> 0.05$ , does not reject the null hypothesis, and the association was insignificant. There is no statistically significant association between the parents' physical health with age, gender, marital status, ethnicity, mental health status, personal disabilities status (OKU), working status, educational level, relationship with autistic children, number of children with ASD in the family, children gender and also children's level of education.

**Correlation between the WHOQOL-BREF and DASS-21 among the parents of children with ASD**

Table 6 shows the correlation between the WHOQOL-BREF and DASS-21 among the parents of children with ASD. There was a correlation between the average score of the domains in WHOQOL-BREF and the average total score on the DASS-21 ( $p < 0.05$ ). The correlation (Pearson's) between the average score of physical health in WHOQOL with the average score of depression is significantly different from 0 ( $p$ -value = 0.019 5% level of significance). Thus, reject the null hypothesis. There is a statistically significant, negative, and fair correlation between the average score of physical health in WHOQOL with the average score of depression ( $r = 0.27$ ). The correlation (Pearson's) between the average score of psychological health in WHOQOL with the average score of depression ( $p$ -value = 0.001) and anxiety ( $p$ -value = 0.037) is significantly different from 0 ( $p$ -value = 0.019) at a 5% level of significance. Thus, reject the null hypothesis. There is a statistically significant, negative, and fair correlation between the average psychological health score in WHOQOL with the average score of depression ( $r = 0.37$ ) and anxiety ( $r = 0.25$ ). Next, the correlation (Pearson's) between the average score of social relationships in WHOQOL with the average score of depression ( $p < 0.001$ ), anxiety ( $p = 0.003$ ), and stress ( $p = 0.002$ ) is significantly different from 0 at a 5% level of significance. Thus, reject the null hypothesis. There is a statistically significant, negative, and moderate correlation between the average score of social relationships in WHOQOL with the average score of depression ( $r = 0.54$ ) and a negative and fair correlation with anxiety ( $r = 0.25$ ) and stress ( $r = 0.36$ ). The correlation (Pearson's) between the average score of the environment in WHOQOL with the average score of depression ( $p < 0.001$ ), anxiety ( $p = 0.012$ ), and stress ( $p$ -value = 0.048) is significantly different from 0 at a 5% level of significance. Thus, reject the null hypothesis. There is a statistically significant, negative, and fair correlation between the average score of the environment in WHOQOL with the average score of depression ( $r = 0.46$ ), anxiety ( $r = 0.29$ ), and stress ( $r = 0.23$ ).

**Table 6:** Correlation between the WHOQOL-BREF and DASS-21 among the parents of children with ASD ( $n = 73$ )

Variables		WHOQOL-BREF			
		Physical health	Psychological health	Social relationships	Environment
DASS-21	Depression	$r$ -0.27*	-0.37**	-0.54**	-0.46**
		$p$ 0.019	0.001	< 0.001	< 0.001
Anxiety		$r$ -0.11	-0.25*	-0.34**	-0.29*
		$p$ 0.340	0.037	0.003	0.012
Stress		$r$ -0.05	-0.13	-0.36**	-0.23*
		$p$ 0.683	0.281	0.002	0.048

\*Correlation is significant at the 0.01 level (2-tailed)

\*\*Correlation is significant at the 0.05 level (2-tailed)

**Discussion**

To our knowledge, the study regarding the emotional states and the quality of life was limited, or this may be the first study to be conducted among the parents of children with ASD in Malaysia. The objectives of this study were to identify the emotional states and the QOL, the relationships, and also the correlation between the emotional states and quality of life of the parents during the COVID-19 pandemic in Malaysia. The findings will contribute to the evidence that there is a relationship and correlation between the two variables that have been tested in the study. Several factors in the demographic characteristics play an important role in either having negative or positive effects on the emotional states and quality of life during this global outbreak. The prior studies from other countries confirmed the finding that there was higher stress and lower well-being among parent who has children with ASD (29-32).

The finding of this study showed that the number of children with ASD in the family and household income affected the environmental domain in the quality of life among the parents. The environment is essential to the quality of life, by addressing the environmental issues may help to ensure sustainability in the environment (33). The COVID-19 pandemic truly changed the environmental condition and economic activity and affected individual income as the government restricted people's movements to avoid spreading the disease. Some will be affected by this

condition if it continues for a long time, especially parents with autistic children (34).

Besides, age, parents' mental health status, age of the autistic children, and children's education have an impact on the emotional well-being of the parents of autistic children. There was a significant relationship between these variables in this study. The previous studies by Mackintosh et al. (35) and Vohra et al. (36) found a significant impact on parental stress and emotional well-being related to the family ASD status, age, gender, and others. This study mostly has a fair and negative correlation between the domains of quality of life and emotional states such as depression, anxiety, and stress. The prior study also found a positive correlation between the parent's stress and well-being with the gender of children with ASD and also a negatively correlated with the age of the autistic children (37-39).

### **Implications & limitation**

There were several limitations regarding this study; one of the major limitations was using the online platform as the medium for collecting the data. Most of the parents that have been approached to participate in this study did not respond to participate. Next, the study was only conducted within a month. Getting the participant to meet the sample size numbers was very time-consuming. The sample size was too small to represent the overall population. The response rate is only 19.8%, which tends to be lower than the other method of collecting data. According to Leckey and Neill (40), their study also used an online platform to collect the data, and the respondents seemed skeptical and unwilling to participate. Some authors mentioned that there are no other factors related to the lower response rate, and no evidence mentioned that the lower response rate produced bias during the evaluation (41). Besides, the questionnaires for this survey were too long and took time to complete. As for the limitations occurring during the study, it was recommended to change the method of collecting data. Instead of using the questionnaires, DASS-21 and WHOQOL-BREF were used, the QOL-DASS, for further study to measure the overall quality of life and emotional states. Further study may be done to compare the emotional states and quality of life among parents who have children with other developmental disabilities.

### **Conclusion**

Overall, a total of 73 respondents participated in this study. The study demonstrated a significant association between emotional states and quality of life for parents with autistic children's demographic data. No statistically significant association between the parents' physical health with age, gender, marital status, ethnicity, household income, mental health status, personal disabilities status (OKU), working status, educational level, relationship with autistic children, number of children with ASD in the family, children gender and also children's level of education. Next, as for the correlation between the two measurement tools that

were used in this study, the DASS-21 and WHOQOL-BREF, most of the correlation was negative and fairly correlated to emotional states. They were between the average score of physical health, psychological, and environment. The average score for social relationships was negative and had a moderate correlation to the score of emotional states in DASS-21.

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### **Competing interests**

The authors have no conflict of interest to declare.

### **Ethical clearance**

The Universiti Teknologi MARA (UiTM) ethics committee gave its approval to the study titled "Emotional States and Quality of Life Among Parents of Children with Autism Spectrum Disorder (ASD) During COVID-19 in Malaysia," with reference number REC/12/2021(MR/935). During this epidemic, online platforms were chosen to distribute the questionnaire to the parents of children with ASD in all states of Malaysia.

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