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Experiences of Parenting Child with ASD during COVID-19 Pandemic: A Cross-Sectional Study

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ABSTRACT

Introduction: Autism spectrum disorder (ASD) is a disorder with a set of behavioural expressions. The family life is struggling for having child with ASD. Parenting of autistic child has negative parenting consequences comprising elevated parents-stress and reduced their efficiency as compared to parents of normally developing children. Our aim of this study is to study the experiences of parenting child with ASD during the situation of COVID-19. *Method:* This cross-sectional descriptive survey was conducted during the COVID-19 pandemic between June and September 2020 on the families of autistic children. The Autism Family Experience Questionnaire (AFEQ) was adopted from the reference. It was translated from English to Arabic version by the researchers included

at the study. Then, the linguistic validation was carried on ten volunteers for investigating the equivalence of concepts inside the questionnaire. *Results:* A total of 65 families who participated in the survey; the number of families of autistic male kids in the study was (46) (70.8%). In contrast, the number of families of autistic female kids who participated in the survey was (19) (29.2%). The analysis demonstrated that the weighted averages from all four-themes of the AFEQ lies within the high levels at the likert-scale, which indicated *never*. It means the negative outcomes resulted from the most chosen statements of AFEQ items that is might be reflecting the worsened situations during the pandemic of COVID-19. *Conclusion:* Children with ASD are undoubtedly more vulnerable from the social distancing period because of the pandemic.

Keyword: autism, family, parents, COVID-19, psychosocial

1. INTRODUCTION

Autism spectrum disorder (ASD) is deeply not clear disorder with a set of behavioural expressions that reflect on the social communication and limit the ability of an individual to be emerged into the society (Lai et al., 2014). It starts in the early childhood and might persists until the adulthood with variable patterns that categorized from mild to severe (Bal et al., 2019). Additionally, it can be categorized as verbal or non-verbal ASD with social communication disabilities (Lai et al., 2014).

Recent reports showing that prevalence of ASD are increasing worldwide, it is calculated that one in every 160 offspring has ASD globally (Elsabbagh et al., 2012), with predominance in male subjects (Tillmann et al., 2018).

The family life is struggling for having child with ASD because their behavioural challenges that interferes with their educational and other environmental needs (Greenberg et al., 2006). Reciprocally, parenting of autistic child has negative family outcomes including elevated parents-stress and reduced their efficiency as compared to parents of normally developing children (Bonis, 2016; Karst & Van Hecke, 2012).

A novel coronavirus, designated as COVID-19, emerged in China at the end of 2019. COVID-19 belongs to a large class of viruses called the β-coronavirus family (Y. Liu et al., 2020). As of September 5, 2020, at least 26,468,031 cases had been confirmed globally and 319,141 in Saudi Arabia alone, with 871,166 and 4,015 deaths, respectively (Organization, 2020). COVID-19 is a significant risk to global public health as it has a high rate of infectivity and transmissibility compared to severe acute respiratory syndrome and Middle East respiratory syndrome coronaviruses (Y. Liu et al., 2020).

Also, the ASD has routinely manner in their life that is not easily disturbed (Narzisi et al., 2013). Any alteration from the social distancing might add stressful load for both ASD and their parents (Drogomyretska et al., 2020). Sudden arise in social-communication disaster due to COVID -19 pandemic has phycological impact on normal persons (Brooks et al., 2020; Dalton et al., 2020; Wilder-Smith & Freedman, 2020). That may affect the ASD children with their families even worse.

Therefore, our aim was to study the experiences of parenting child with ASD during the situation of COVID-19, was that affecting their children social-behavioural-developmental progress especially with closing of schools. Also, we were sought if they found appropriate advice from the professionals, was it reflecting on the peaceful of their family life during the pandemic.

2. METHODS

This cross-sectional descriptive survey was conducted during the COVID-19 pandemic between June and September 2020 on the families of autistic children. Written & Oral informed consent was obtained from all individual participants included in the study.

The Autism Family Experience Questionnaire (AFEQ) was adopted from the reference (Leadbitter et al., 2018). It was translated from English to Arabic version by the researchers included at the study. Then, the linguistic validation was carried on ten volunteers for investigating the equivalence of concepts inside the questionnaire. The questionnaire was transformed into the electronic form and distributed to family of autism either through their hospital visits at neuropsychiatry clinics or the administration of special needs school. The electronic form was subdivided into two sections. The first section was explaining the study for taking the permission and gathering the demographic data such as age, sex, etc. The second section was including 48 items of the AFEQ which were organised into four comprehensive themes: 1- experience of being parent, 2-family life, 3-child development and 4-child symptoms. The worded statements of AFEQ was scored on sequence-scale included always, often, sometimes, and never (Leadbitter et al., 2018).

Statistical Analysis

To analyse the survey data, we used the Statistical Package for the Social Sciences (SPSS). First the data were examined to create a description of the sample demographics. The data for all the questions and statements are also summarized by descriptive analyses

to provide users with frequencies of each variable. The 5-likert scale was applied for measuring of frequency (always, often, sometimes, rarely and never), which was breakdown into the following interval levels; High level: (2.40-4), Moderate level: (1.60-2.39), and Low level: (0-1.59).

For studying the role of professionals during the pandemic into family life of autistic children through providing the right help for them, we specified one question which is "My child is getting the right help" and correlated to the statements associated with family life, using the Pearson coefficient.

3. RESULTS

Study Participants

A total of 65 families who participated in the survey; the number of families of autistic male kids in the study was (46) (70.8%). In contrast, the number of families of autistic female kids who participated in the survey was (19) (29.2%). Table 1 shows the distribution of the study sample according to the variables of child gender and age, also parents working status and educational levels.

Table 1: Characteristics of the participants

Variables	Frequency	Percent
Gender		
Male	46	70.8
Female	19	29.2
Age (years)		
(3-5)	24	36.9
(6-12)	37	56.9
(13-18)	4	6.2
Does father work		
Yes	46	70.8
No	17	26.2
Does mother work		
Yes	11	16.9
No	52	80
Father's education level		
Primary	7	10.8
Intermediate	1	1.5
Secondary	17	26.2
Bachelor's	37	56.9
Postgraduate	3	4.6
Mother's education level		
Primary	4	6.2
Intermediate	2	3.1
Secondary	20	30.8
Bachelor's	36	55.4
Postgraduate	3	4.6

Descriptive Analysis of AFEQ 4-Themes

Experience of Being a Parent of a Child with Autism

Table (2) shows descriptive statistics for the current theme, from which we found that the most chosen statement among respondents was "I have realistic milestones for my child's development" (N=7, mean= 3.0923, std. deviation= 1.22121). The next most chosen statement was "I feel I'm getting it wrong" (N=6, mean= 3.0308, std. deviation= 0.95147).

Table 2: Descriptive statistics for Experience of Being a Parent of a Child with Autism

No	Items	Always %	Often %	Sometimes %	Rarely %	Never %	Mean	St. Deviation
1	I lack confidence in knowing how to help my child	16.9	26.2	38.5	13.8	4.6	2.6308	1.06901
2	I feel listened to by professionals	24.6	40	24.6	7.7	3.1	2.2462	1.01598
3	Working with therapists or professionals helps me feel confident	35.4	38.5	18.5	6.2	1.5	2	0.96825
4	I am confident that I understand my child's level of development	23.1	27.7	38.5	10.8	0	2.3692	0.96127
5	I feel I know how to help my child progress	15.4	29.2	29.2	16.9	9.2	2.7538	1.18626
6	I feel I am getting it wrong	6.2	13.8	61.5	7.7	10.8	3.0308	0.95147
7	I have realistic milestones for my child's development	10.8	20	35.4	16.9	16.9	3.0923	1.22121
8	I doubt my ability to help my child's development	7.7	29.2	46.2	12.3	4.6	2.7692	0.93155
9	I feel frustrated at not knowing how to help my child	18.5	23.1	47.7	6.2	4.6	2.5538	1.01598
1	I have coping mechanisms to help my child	6.2	35.4	38.5	15.4	4.6	2.7692	0.94818
11	Professionals do not understand my family's needs	12.3	16.9	43.1	13.8	13.8	3	1.1726
12	It is a continual battle to get the right help for my child	41.5	30.8	21.5	1.5	4.6	1.9692	1.06021
13	My child is getting the right help	16.9	26.2	40	9.2	7.7	2.6462	1.11005
	Average						2.60236	1.047078

The next most chosen statement was "It's a continual battle to get the right help for my child (N=12, mean= 1.9692, std. deviation= 1.06021. The least most chosen statement was "Working with therapists or professionals helps me feel confident" (N=3, mean= 2, std. deviation= 0.96825).

The weighted average of this section was (2.602362) with a std. deviation of (1.0470). Using the 5-likert scale, this indicates that the trend of this section is *never*, since the weighted average lies in the interval (2.40-4).

Family Life

Table (3) shows descriptive statistics for family life, from which we find that the most selected statement was "My child has fussy eating that makes it difficult to go away for a break" (N=22, mean= 3.2615, std. deviation= 1.29031), followed by "I feel confident to go out to family events with my child (N=19, mean= 3.0769, std. deviation= 1.32650).

Table 3: Descriptive Statistics for Family Life

No	Items	Always	Often	Sometimes	Rarely	Never	mean	St. Deviation
14	Family life is a battle	26.2	20.0	33.8	15.4	4.6	2.5231	1.17404
15	I feel guilty about not giving other members of the family enough attention	13.8	26.2	26.2	10.8	23.1	3.0308	1.36896
16	My child is flexible in adapting to the demands of family life	9.2	21.5	40.0	20.0	9.2	2.9846	1.08242
17	Family life is calm	15.4	38.5	21.5	10.8	13.8	2.6923	1.26149

18	I know how to cope with my child when going on an outing in a public place e.g. café or restaurant	20.0	24.6	27.7	6.2	21.5	2.8462	1.40569
19	I feel confident to go out to family events with my child	10.8	30.8	18.5	20.0	20.0	3.0769	1.32650
20	I feel confident in making routines at home more manageable for my child	13.8	32.3	29.2	12.3	12.3	2.7692	1.20894
21	I feel comfortable about having visitors to our home	18.5	33.8	21.5	13.8	12.3	2.6769	1.27607
22	My child has fussy eating that makes it difficult to go away for a break	13.8	9.2	35.4	20.0	21.5	3.2615	1.29031
	Average						2.873	1.266

The next most chosen statement was "Family life is a battle" (N= 14, mean= 2.5231, std. deviation= 1.17404), followed by "I feel comfortable about having visitors to our home (N=21, mean= 2.6769, std. deviation= 1.27607).

The weighted average of this section was (2.873504) with a std. deviation (1.266046717). According to the likert scale, this indicates a trend of *never*. The weighted average (2.873504) lies in the interval of (2.40-4), a high level.

Child Development, Understanding, and Social Relationships

Table (4) shows descriptive statistics for child development, understanding and social relationships, from which we find that the most selected statement was "My child gets invited to birthday parties" (N=34, mean= 3.8462, std. deviation= 1.31376), followed by the statement "My child is aware of other people's needs" (N=33, mean= 3.6308, std. deviation= 1.25710).

The next most chosen statement was 'I know when my child feels poorly" with (N=29, mean= 1.9538, std. deviation= 1.08153). The least most chosen statement was "My child gets frustrated at not being understood" (N=27, mean= 2.1231, std. deviation= 1.26871).

The weighted average of this section was (2.94725) with a std. deviation of (1.2483). This indicates that the trend of this section is *never* under the likert scale. Since the weighted average (2.94725) lies in the interval of (2.40-4), this is considered a high level.

Table 4: Descriptive Statistics for Child Development, Understanding and Social Relationships

No	Items	Always	Often	Sometimes	Rarely	Never	mean	St. Deviation
23	My child can concentrate on an activity for a short time	12.3	13.8	40.0	18.5	15.4	3.1077	1.20056
24	My child can spontaneously begin communication with me	21.5	26.2	33.8	13.8	4.6	2.5385	1.11911
25	My child spontaneously begins communication with other members of the family	20.0	23.1	33.8	10.8	12.3	2.7231	1.25633
26	My child can request his/ her needs appropriately	13.8	12.3	26.2	30.8	16.9	3.2462	1.27513
27	My child gets frustrated at not being understood	44.6	20.0	21.5	6.2	7.7	2.1231	1.26871
28	My child can let me know when he/ she is hurt	23.1	13.8	18.5	13.8	30.8	3.1538	1.56356
29	I know when my child feels poorly	46.2	24.6	18.5	9.2	1.5	1.9538	1.08153
30	My child has repetitive behaviour and sensory interests that make it difficult to go on an outing	20.0	20.0	21.5	15.4	23.1	3.0154	1.45229
31	My child is good at sharing with others	1.5	26.2	29.2	29.2	13.8	3.2769	1.05338
32	My child must have his/ her own way	7.7	32.3	32.3	15.4	12.3	2.9231	1.13616

33	My child is aware of other people's needs	4.6	16.9	24.6	18.5	35.4	3.6308	1.25710
34	My child gets invited to birthday parties	9.2	7.7	15.4	24.6	43.1	3.8462	1.31376
35	My child plays with other children (bro & sis)	4.6	20.0	36.9	10.8	27.7	3.3692	1.21924
36	I must go with my child to supervise play with other children (bro & sis)	35.4	23.1	16.9	20.0	4.6	2.3538	1.28002
	Average						2.9472	1.248341

Child Symptoms (Feelings and Behaviour)

Table (5) and figure 1 show descriptive statistics for feelings and behaviour, from which we find that the most chosen statement was "My child is embarrassing when going out" (N=47, mean= 3.6000, std. deviation= 1.37840), followed "My child understands appropriate behaviour in familiar social situations" (N=44, mean= 3.4154, std. deviation= 1.19755).

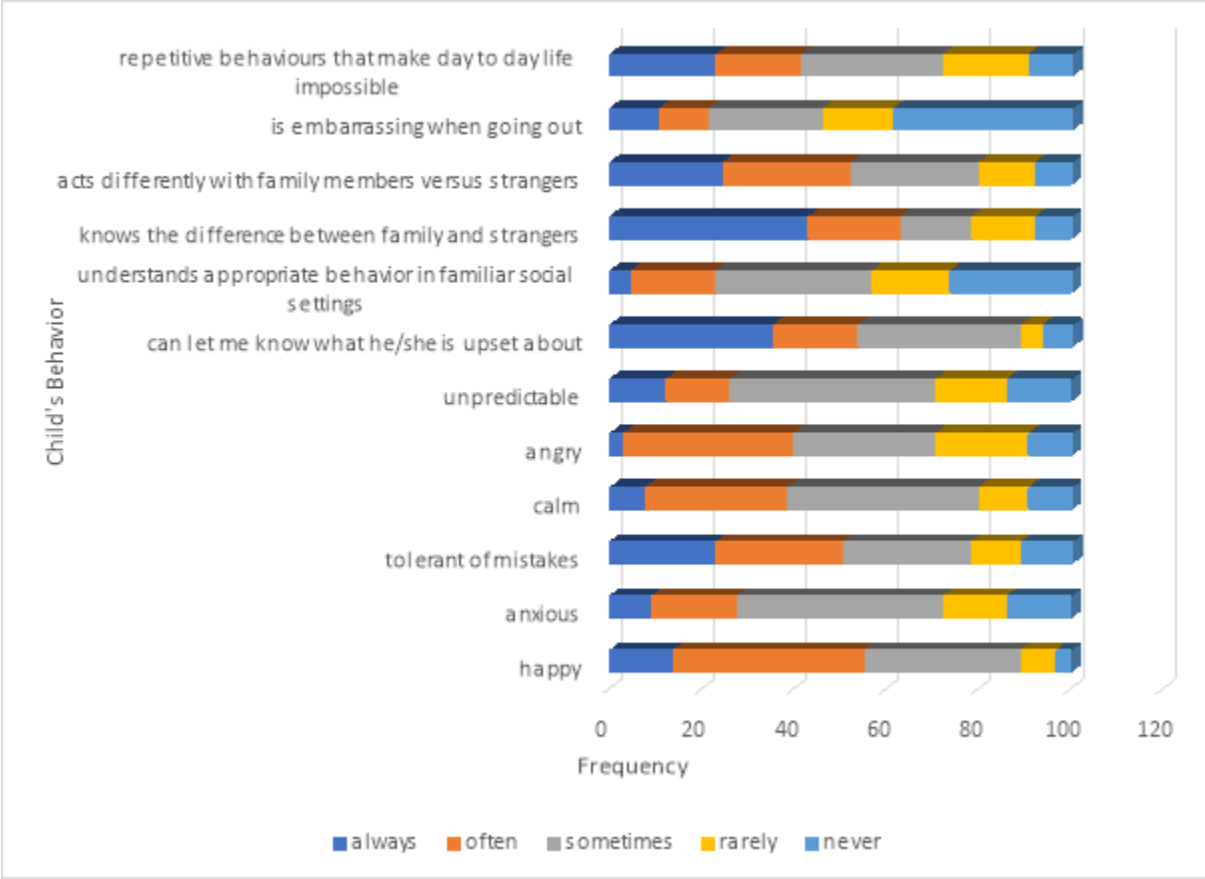

Figure 1: Frequency of various behaviours

Table 5: Descriptive Statistics for Child Symptoms (Feelings and Behaviour)

No	Items	Always	Often	Sometimes	Rarely	Never	mean	St. Deviation
37	My child is happy	13.8	41.5	33.8	7.7	3.1	2.4462	.93593
38	My child is anxious	9.2	18.5	44.6	13.8	13.8	3.0462	1.12404
39	My child is tolerant of mistakes	23.1	27.7	27.7	10.8	10.8	2.5846	1.26110
40	My child is calm	7.7	30.8	41.5	10.8	9.2	2.8308	1.03937
41	My child is angry	3.1	36.9	30.8	20.0	9.2	2.9538	1.03729
42	My child is unpredictable	12.3	13.8	44.6	15.4	13.8	3.0462	1.16499

43	My child can let me know what he/she is upset about	35.4	18.5	35.4	4.6	6.2	2.2769	1.17935
44	My child understands appropriate behaviour in familiar social situations	4.6	18.5	33.8	16.9	26.2	3.4154	1.19755
45	My child knows the difference between family members and strangers	43.1	20.0	15.4	13.8	7.7	2.2308	1.34361
46	My child acts differently with family members compared with strangers	24.6	27.7	27.7	12.3	7.7	2.5077	1.21351
47	My child is embarrassing when going out	10.8	10.8	24.6	15.4	38.5	3.6000	1.37840
48	My child has repetitive behaviours that make day to day life impossible	23.1	18.5	30.8	18.5	9.2	2.7231	1.26871
	Average						2.80513	1.17865

The next most chosen statement was "My child knows the difference between family members and strangers" (N=45, mean= 2.2308, std. deviation= 1.34361), followed by "My child can let me know what he/she is upset about" (N=43, mean= 2.2769, std. deviation= 1.17935).

The weighted average of this section was (2.80513) with a std. deviation of (1.17865), which indicate that the trend of this section is *never*, according to the likert scale. Since the weighted average (2.80513) lies in the interval (2.40-4), this is a high level.

Correlation between Q13 and *Family Life*

Using the Pearson coefficient, Table (6) shows the correlation between Q13 (My child is getting the right help) and the statements associated with *family life*. Results show an insignificant correlation between Q13 and Q (14, 17, 22). On the other hand, there was a positive significant correlation between Q13 and Q (16, 18, 19, 20, 21), and a significant negative correlation between Q13 and Q15.

Table (6): Correlation between Q13 and *Family Life*

No	items	Pearson correlation	sig
14	Family life is a battle	0.012	0.922
15	I feel guilty about not giving other members of the family enough attention	-0.301	0.015*
16	My child is flexible in adapting to the demands of family life	0.412	0.001**
17	Family life is calm	-0.001	0.995
18	I know how to cope with my child when going on an outing in a public place e.g. café or restaurant	0.225	0.072
19	I feel confident to go out to family events with my child	0.38	0.002**
20	I feel confident in making routines at home more manageable for my child	0.497	0
21	I feel comfortable about having visitors to our home	0.315	0.011*
22	My child has fussy eating that makes it difficult to go away for a break	-0.153	0.225

Significance Values: * P ≤ 0.05; ** P ≤ 0.01

4. DISCUSSION

A novel coronavirus, designated as COVID-19, emerged in China at the end of 2019 (Y. Liu et al., 2020). Then after the world is suffering from the pandemic of COVID-19 until today and might progressed up to next two years. The outbreaks erupted the peace of normal life affecting schools, daily activities, economy and most importantly health sectors (Garfin et al., 2020; Mahase, 2020; Wilder-Smith & Freedman, 2020). Such life disturbance will be making the ASD children vulnerable to routine-functioning deficits (Narzisi et al., 2013).

During the pandemic, we aimed to ask the participating parents of child with autism about key outcomes affecting them under four-themes of questions for: themselves, their family, their child development and symptoms (Leadbitter et al., 2018). The analysis demonstrated that the weighted averages from all four-themes of the AFEQ lies within the high levels at the likert-scale, which indicated *never*. Unfortunately, it means the negative outcomes resulted from the most chosen statements of AFEQ items that is might reflecting the worsened situations during the pandemic of COVID-19.

Despite the high educational levels of parents as shown from demographic data, still they struggled in seeking appropriate advice from the professionals with most chosen statements are "I feel I'm getting it wrong", "It's a continual battle to get the right help for my child", "My child has fussy eating that makes it difficult to go away for a break", "Family life is a battle", and "My child is embarrassing when going out". On the other hand, parents recognized what their children needs with most chosen statements are "My child is aware of other people's needs" and 'I know when my child feels poorly".

Additionally, the current study focus on the correlation if the parents follow appropriate advice from the professionals, how they would improve their family life by showing a significant positive outcomes with the following statements "My child is flexible in adapting to the demands of family life", " I know how to cope with my child when going on an outing in a public place e.g. café or restaurant", " I feel confident to go out to family events with my child", " I feel confident in making routines at home more manageable for my child", " I feel comfortable about having visitors to our home". However, it affects other member of families by showing a significant negative outcome with the following statement "I feel guilty about not giving other members of the family enough attention".

Mental health status considered as an essential issue during the social distancing of COVID-19 outbreaks for vulnerable populations including paediatric, adolescence and people suffering mental problems (J. J. Liu et al., 2020; Loades et al., 2020; Narzisi, 2020; Yao et al., 2020; Ye, 2020a). Psycho-behaviours of individuals with ASD has been tested during outbreaks by Italian researcher's survey (Colizzi et al., 2020). They reported that the emergency-quarantine due to COVID-19 increased parents' difficulties in controlling of their children daily-activities specifically the free-time plus structured events. Also, they showed most of ASD individuals presenting with more highly intensive behaviour problems, that was consisting with our data showing the negative outcomes resulted from the most chosen statements at feelings and behaviour domain. In agreement with Marco Colizzi report (Colizzi et al., 2020), the participants of our study showed their demanding of support from the healthcare providers, however, they did not focus in their study how the emergency reflect on family life as we did it.

Currently, the evolving technologies have been playing gradually a key role to solve social disaster from this pandemic (Ye, 2020b). Meanwhile face-to-face healthcare is less accessible, while the remote consultation via tele-health is more feasible (Ye, 2020a).

In Summary, Paediatric patients with autism disorder are more susceptible to anxiety and mental issues as consequences of social distancing during COVID 19. For supporting them and their families, health-care workers need strong evidence-based guidelines including psychosocial-communication support for the families of children with ASD as part of the health responding to disaster of current pandemics or any future similar evolved crisis in the world (Narzisi, 2020; Vivanti et al., 2018).

5. CONCLUSION

Children with ASD are undoubtedly more vulnerable from the social distancing period because of the pandemic. As a result, A health care workers require to have a guideline to have better communication and psychological support for the family of autistic child. This will improve their condition and proper manage their stressful situation.

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Author Contributions

Contribution of Dr. Reem Alyoubi is Data collection and revision of manuscript work & production.
Contribution of Dr. Ebtisam A. Alofi is Manuscript writing and analysis of data

Conflict of Interest (includes financial disclosures)

The other authors have no conflicts of interest to disclose.

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Data and materials availability

All data associated with this study are available upon request to the corresponding author.

Peer-review
External peer-review was done through double-blind method.

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