

Mental Health of Jordanian Parents of Children with Autism Spectrum Disorder during COVID-19: A qualitative study

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ABSTRACT:

The COVID-19 pandemic has had significant psychological effects on parents, especially parents of children with autism spectrum disorders. This qualitative study explores the mental health of Jordanian parents of children with autism spectrum disorder during COVID-19. Through phone interviews with nine such parents, this study found that the pandemic was a great source of stress and anxiety for parents of autistic children in Jordan, which was worsened by a lack of formal support for them and their children. This study also found that parents relied on their religious beliefs, shared childcare responsibilities, and engaged in social and family activities to mitigate the psychological toll of raising children during the COVID-19 pandemic.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects children between the ages of 0-8 years and is mainly characterized by communication and social difficulties and the presence of restrictive and repetitive behaviors (American Psychiatric Association, 2013). According to the American Centres for Disease Control and Prevention (CDC), the prevalence of ASD among children in the United States is 1 in 59 (Baio et al., 2018), with about one-third of those children having an intellectual disability (CDC, 2012). In Jordan, the prevalence of such disabilities is 13% (Thompson, 2018); although there is no confirmed estimate of the proportion of children with ASD in Jordan, Masri et al. (2011) found that 5.2% of a sample of 229 disabled Jordanian children had ASD.

Literature indicates that children with ASD experience varied levels of mental health or psychiatric conditions, including anxiety (Lai et al., 2019), depression (Hudson et al., 2019), and lifetime mood disorders (Polanczyk et al., 2015; Steel et al., 2014). These difficulties make the situations worse by changes in routine – such as having to wear a mask to comply with COVID-19 safety measures, which autistic children may have difficulty understanding (Sivaraman et al., 2020) – and can manifest as aggression, bad temper, and refusal to participate in everyday activities (Bellomo et al., 2020; Duan et al., 2020). Such reactions are also detrimental to the psychological well-being of parents: an effect that has been particularly visible during the pandemic. Recent worldwide research indicates that parents of children with ASD already suffer from high levels of stress and that these stress levels have increased during the COVID-19 pandemic due to their children's changing needs and routines (Alhuzimi, 2021; Althiabi, 2021). Social distancing policies have led to the abrupt closure of special education centers and reduced communication with specialists, leading to increased responsibilities, exhaustion, loneliness, and stress for parents (Lim et al., 2020). Additionally, in the absence of specific protocols for dealing with these issues, parents are also struggling with the inability to explain the pandemic to their autistic children, the inability to make their children feel safer, and lack of social and professional support in teaching their children social distancing rules, which further increases their stress and anxiety (Alhuzimi, 2021).

A new study carried out in Spain revealed that parents of autistic children have experienced higher levels of psychological distress, obsessive-compulsive tendencies, in-

terpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism during the pandemic (Lugo-Marín et al., 2021). Moreover, it appears that parents who suffer from high levels of fear, depression, and anxiety have less support from their social networks, less physical exercise, poor diets (Wang et al., 2021), and sleep problems (Mutluer et al., 2020). In another study, parents indicated that these detrimental effects result from having their autistic children at home more often, which led to disruptions in their children's routines (White et al., 2021), and the adoption of ineffective coping strategies (Wang et al., 2021). Although some parents did develop strategies for responding to their autistic children's changing needs during the pandemic (Mumbardó-Adam et al., 2021), others reported that their children refused to wear masks and had difficulty understanding and following social distancing rules (Mutluer et al., 2020). Still, others had to spend extra time with their autistic children to teach them to use distance learning and faced difficulties with spending time outside, which led to poor emotional management, social isolation, and boredom (Amorim et al., 2020).

Parents of children with ASD reported that they received support from various sources to aid them in coping with these disruptions and difficulties, which contributed to reducing stress and fatigue and enhanced their emotional well-being. Alhuzimi (2021) found that in one Arabic country, relatives were the main resource of support for parents of autistic children. In another study, parents indicated that they looked for assistance from their social networks, teachers, doctors, and psychologists (Althiabi, 2021). Other parents indicated that they received support firstly from family, turning to parents' support groups only as a last resort (Manning et al., 2021).

METHODOLOGY

The researchers employed a qualitative methodology to carry out the current study. To reach potential participants, they drew on their wide breadth of experience in the special education field and their social networks. Via telephone conversations, they contacted parents, explained the aims of the study, and responded to parents' inquiries. After two weeks of this communication process with parents, a total of nine parents agreed to participate in this study; their details can be found in table 1. Both researchers were involved in creating a protocol for interviews, which includes consent forms and ethical consideration forms.

Table 3. **Participants' details**

Name	Parent's gender	Employed	Child's gender	Child's age
A	Male	Yes	Male	11
B	Female	Yes	Male	10
C	Male	Yes	Male	9
D	Female	No	Male	9
E	Female	Yes	Female	7
F	Female	Yes	Male	9
G	Female	Yes	Male	9
H	Female	Yes	Female	8
I	Male	Yes	Male	10

Researchers were fully aware that mental health issues are a sensitive topic in Jordan and that participants might experience confusion when talking about these with strangers. All participants consented to interviews being conducted via telephone and recorded. Copies of consent and ethics forms were emailed to all participants, completed, and returned. The analysis process employed thematic analysis, as set out by Braun and Clarke (2006), which yielded three main themes.

FINDINGS

The iterative process of analysis yielded three main themes, namely stress and anxiety, poor support, and coping methods.

Stress and anxiety

Participants reported that their stress levels had increased during the quarantine and that they generally did not feel that increased stress until more recently. As one participant put it:

"I found myself suddenly under stress and pressure that I was not aware of. At first, I was like everyone else in the country: happy to have a break and to stay at home before I realized I was mistaken".

However, another participant stated that they felt higher levels of stress from the start of the pandemic:

"What a pain! Yes, when corona started... I mean we stayed locked at home; I felt stressed and could not breathe, literally. That stress was really painful and did not know what to do. I felt sorry for myself and my son"

They also agreed that the stress and pressure they felt had come to dominate their lives, which affected even their non-disabled children and thus led them to feel even more stressed. In another participant's words:

"My little daughter (A) always asks me why I care about her brother more than her. I used to shout at her and deny that, but I have to admit that I was wrong and I should not have shouted at her".

Further, participants reported that this stress had affected their overall well-being and led them to recognize that their lives had undergone significant changes:

"For us, it was like a total disaster and I can tell you that our life has changed forever. We cannot deny that we suffered with our disabled son, especially when we discovered his disability, but in this time of coronavirus we do not feel happy or comfortable anymore"

Participants also indicated that the stress they felt from the pandemic was constant; in one participant's words: "yes, I am stressed all the time. It looks like endless pain". Another participant stated that their stress affected all major aspects of their life: "I can tell you that my life was destroyed. Yes, I am unemployed, and I feel for employed mothers – I mean, how they can manage to deal with all of this. I realize that my son is disabled but that was too much for me. It destroyed everything for me, especially my life". As a participant noted, one such aspect was spousal relationships: "I really feel sorry for my husband. I do not think that he deserved the way that I was acting and talking to him. I was nervous, rude, and unfair with him".

In addition to ongoing, comprehensive stress, participants experienced constant anxiety. To quote one participant: *"Oh, yes. We were anxious all the time and what next. In fact, my husband and I were under constant stress and anxiety"*. When asked to elaborate, they answered instantly: *"I was overthinking about the future of my son. I also found difficulties in concentrating, change in appetite, and always felt irritable"*. Another participant indicated that he suffered from some physical symptoms of anxiety:

"I was very worried and always felt not only tired but exhausted. In fact, I became sweaty and my breath was heavy, and my left leg used to shake, and one of my sons told me that I bite my lip, which I did not notice before".

Participants explained that their anxiety and stress resulted at least partly from not knowing how to respond to their autistic children during the pandemic: *"I did not know what to do to persuade him to wear his mask, and that made me mad"*. One participant reported feeling guilty due to their perceived inability to help their autistic son: *"I felt that I could not do anything to help him. Am I a bad mother? I do not know"*. Another participant indicated that their stress became more serious of having a minimally verbal autistic child in the family:

"Wow, what to tell you? I cannot deny that my child is 'silent' and this – to be honest with you – bothers me to death and makes me angry with myself. During the pandemic outbreak, I did my best to communicate with my child but he did not respond at all and kept staring at the ceiling... Can you see why I am angry and devastated?"

One of our participants indicated that having an only child increased tension in the home: *"As I said before, I just have one child, and being alone during the curfew was something crazy for me. I could not control myself dealing with him and I just wished I had some siblings for him"*. Participants' inability to explain imposed restrictions to their autistic children was another source of stress: *"You know, we stayed home when the 'corona story' started, and that put more pressure on us, as I could not have explained to him why we could not go out. I felt helpless"*.

Additionally, participants indicated that the changes in their children's routines caused by pandemic safety measures negatively affected their children's behaviors, which created more stress all around. As one participant noted: *"We were not ready for this. Suddenly, we found ourselves in a situation where we did not know what to do. I think changing her routine was the biggest*

difficulty we faced". When asked for more clarification, she replied:

"Our daughter used to do things routinely and in a certain way. She suddenly found that she could not do that and this reflected on me. I suffered with her as her behavior changed and I simply could not cope. She started shouting and I shouted back. This was insane".

Moreover, parents indicated that their stress and anxiety also stemmed from a lack of information about COVID-19 and the possibility of their autistic children being affected: *"We just did not have adequate information about the coronavirus and thought for a while that (H) might be affected. I cannot deny that I was feeling horrified and anxious to death that I might lose him"*.

The switch to distance learning from in-person learning proved to be yet another source of stress for participants, who reported that they now had to spend more time than usual with their autistic children to teach them and guide their education. This was especially difficult given that all participants pointed out that they had no experience in educating their autistic children. In one participant's words: *"I do not know how to teach her using e-learning. I just do not know and that drove me crazy"*. Several participants indicated that not knowing how to assist their children with e-learning made them feel guilty and powerless: *"I did not know what to do and how to teach him and that upset me to death. I felt helpless"*. Another participant complained that she was unable to find enough time for her autistic son in this regard: *"How can I do all of that? I have housework, I have my job and its requirements, and I just do not have extra time to give him. I felt sorry for him and for myself"*.

Finally, participants indicated that the boredom they felt as they were forced to spend more time with their autistic children at home was also a source of stress: *"I used to talk to my friends and watch TV but now: no, I have to spend my time with (H) and to reduce many of my activities"*. In some cases, participants even had difficulty sleeping due to their children's poor sleeping patterns: *"(S) has various nightly fluctuations in sleep and that affected me negatively. I just cannot sleep and leave her awake alone. I just cannot"*. One participant indicated that responding to the sleeping problems of their child led to both boredom and disturbed sleep:

"I had to regulate my sleep according to his sleep fluctuations, and this affected me negatively. Many nights I had nothing to do except waiting for him to fall asleep and this

did not occur regularly. I did not really find much to do, especially since I am not a fan of using social media and the internet. Actually, I did not find much to do, and this made me very bored and at times frustrated”.

Poor support

Participants pointed out that they were negatively affected by a lack of adequate support during the pandemic, whether from their immediate social circles, from the local and national government, or healthcare professionals. For instance, one participant stated that she could not have direct contact with her friend due to the curfew imposed in Jordan:

“I was very worried about her, and I used to talk to my friend when I was stressed, but this time we could not meet as the curfew was imposed, and we just talked on the phone and chatted, and that was not enough. She used to be the rock I relied on in difficult times”.

The absence of clear information on the coronavirus also increased participants’ stress and anxiety: *“I did not know what to do. I was terrified that my son was going to get corona and die. You know, in that period, things were not clear and everyone was scared”.* Another participant expressed similar sentiments: *“I felt very anxious and I was nervous and did not know what to do. I used to repress my feelings”.* When the participant was asked why she was anxious and nervous, she replied: *“Because I was worried about him because of corona, and no one was there to explain to me the possibility of my son contracting corona, given that he has ASD, and how to protect him from the virus”.*

Participants complained that their only recourse for dealing with the impact of the pandemic on their children was emergency health services personnel, who were often unqualified to answer their questions: *“They simply did not know. We took him to the hospital at midnight because he had a high temperature, and honestly, it was like I was talking to myself”.* They also indicated that doctors and nurses seemed uninformed about ASD and dealt with their autistic children as though they were typically developed children: *“They simply drove me crazy. I was talking to the doctor in the emergency room, and he did not seem to bother at all when I told him that my child was autistic”.* Moreover, participants who would ideally have turned to special education or psychological support for help with their autistic children’s behavioral difficulties had to visit emergency health services instead, where they did not find the expected assistance:

“I told you that he had a bad temper and some other problems, and I did know not what to do. For a minute I thought he might be sick and eventually, we took him to the nearest hospital. What to say! No one helped, and instead of talking to us, we were laughed at because they did not take us seriously, and they thought that they were dealing with more important things than an angry child”.

Even when participants were able to see specialists, this did not necessarily provide the support they needed in caring for their children. Several participants indicated that they did receive some assistance from their children’s special education teachers: *“I contacted his teacher and I asked her some questions about how to deal with his behavior”.* However, other participants stated that their children’s teachers fell short of their expectations: *“I expected the teacher to interact with me more and show more interest, but unfortunately she did not”.* In some cases, participants did receive support from specialists but considered themselves unqualified to apply the procedures they used at home: *“My daughter used to receive regular training from an occupational therapist when she was in the center. He gave me some instructions to implement these exercises, but unfortunately, it was difficult for me to do so”.*

Visiting specialists was not always an option for participants; as one mother noted, her family tried unsuccessfully to work with her autistic son on their own: *“He had huge difficulties and bad behaviors, and we tried to work with him, but we failed as we do not have any experience”.* When asked to elaborate on her actions, she replied: *“What can we do? Actually, we did nothing, as we do not have enough money to take him to a private doctor or a psychologist”.* Other participants chose not to take their autistic children to a psychologist for cultural rather than financial reasons: *“Hmm, yes, we thought about it, but at the end of the day, you live in Jordan where everyone watches you, and I cannot deny that the reputation of our family might be damaged”.*

Financial difficulties affecting their abilities to provide care for their autistic children were a common thread among participants; for instance, one participant said of their daughter: *“We were thinking of having a private teacher for her at home, but we did not have enough money”.* Not receiving financial support from the Jordanian government worsened these difficulties: *“We expected some money from the Ministry of Social Development, but we received nothing, unfortunately”.* Several female participants indicated that they had to quit their jobs to care for their autistic children, which placed more pressure on them financially and generally: *“I did not have the choice*

as I have no one to look after him. Yes, we were short of money but had no choice. What can I do?"

Coping methods

Participants employed various methods to cope with the struggles that they faced during the pandemic. One such method was reliance on religion, as outlined in the words of one participant:

"It was a very difficult time for me and my family, especially my husband. We think that we endured that period because of God who knows us and knows everything about us. I am a believer, and with the help of God we were able to pass through this difficult and bad time".

Another coping method mentioned by several participants was support from family members, both within and outside the home. Several participants reported that they took turns with their spouses in caring for their autistic children, which gave them time to rest and tend to other domestic duties: *"My wife and I used to look after (A) alternately, and this gave us the required time to look after the rest of our children and, honestly, gave us the time to look after ourselves"*. Another participant pointed out that alternating childcare duties with her husband gave her the time to practice her hobbies:

"I like cooking, but as I was looking after my child and have my online job, I could not cook and that upset me.

Since my husband started looking after him, I have found the time to cook my favorite meals, and that has helped me to relax".

Family support from non-spouses helped to ease the stress of strained spousal relationships. As a participant said, speaking about her autistic daughter:

"I was nervous and had no clue how to deal with her and her problems. That led me to have constant fights with my husband, and he accused me, saying that I am responsible for all this mess. If I was not a believer in fate and the support I received from my mother, I would be divorced by now".

Such support often came through remote conversations; participants reported that talking to friends and close relatives via phone and online platforms was a key source of emotional and psychological support. As one participant said: *"Yes, I speak to my sister in Khobar (Saudi Arabia) on WhatsApp, and I complain to her and tell her ev-*

everything". Another participant stated that they used Facebook to maintain contact with their friends: *"You know, we get news from Facebook, and I spend my time browsing and have a look on my friends' profiles and write down some comments"*. Notably, male participants seemed to prefer talking to their friends rather than to family members: *"I normally have a chat on phone or WhatsApp with one or two of my friends, and we talk frankly (laugh); we complain to each other"*. This support continued after Jordan lifted its curfew, with participants eager to meet friends in person. One participant described meeting with her friend thus: *"All cafes and restaurants were closed, and we had to meet up in Amman, and we just walked in Rainbow Street. We talked and I felt that I was freed as I have not been out for a while"*. When asked about the kind of support this provided, she replied: *"Mainly psychological support. I just wanted someone to listen to me, and I wanted to feel that I was free again"*.

Finally, participants indicated that they used daily activities to lessen their stress and anxiety, such as taking walks with or without their autistic children: *"If you remember, curfew used to be lifted in the morning until 6 p.m. and I used to take (Kh) and just walk"*. Other participants relied on grocery shopping – *"I occasionally take my children and walk to the grocery and buy some stuff"* – or exercising at home: *"Fortunately I have a walking machine and used it a lot. It helped me to keep fit and relaxed"*.

DISCUSSION

Our findings show that the changes to daily life brought about by COVID-19 have negatively affected the mental health of parents of children with ASD in Jordan. These correspond with previous studies indicating that parents of autistic children have high levels of stress and anxiety (Alhuzimi, 2021; Amorim et al., 2020). In our study, participants described themselves as experiencing permanent anxiety (Lai et al., 2015), and reported that need to deal with their autistic children's requirements and behaviors was a source of anxiety and stress (Hickey et al., 2019). In particular, they agreed that having their autistic children at home caused difficulties that, contrary to the findings of other studies, did not assist them in adapting to life during the pandemic (Narzisi, 2020). Participants' well-being was significantly affected by the dramatic life changes they experienced during the pandemic, which affected the quality of life of their families (Liu et al., 2021; Wang et al., 2021), including their spousal relationships (Meadan et al., 2010) and their typically developed children – all of which increased their anxiety and stress (Hartley et al., 2017).

In a conservative society like Jordan, raising a child with ASD appears to be a complicated and exhausting process due to various overlapping factors that place parents under enormous pressure, psychological stress, and burdens. Participants felt that they were unqualified to take on the challenges of raising their autistic children and that doing so was a burden (Estes et al., 2013). They also felt guilty due to their inability to assist their children, which was heightened by the changes in their children's routines and schedules brought about by COVID-19 safety measures (Althiabi, 2021), the belief that they may have caused their children's autism, and the lack of sufficient information to help their children. This last instance manifested in difficulties in explaining the pandemic to their children, especially when parents felt that they did not have the information they needed (Bent et al., 2020). These factors may have undermined the relationship between parents and children (Wang et al., 2021) and placed additional pressure on parents who already suffer from a great amount of stress, anxiety, and depression.

Our findings indicated that the need to spend extra time caring for and educating their autistic children was another source of stress for participants (Amorim et al., 2020). Parents found themselves feeling bored spending extra time with their children and, in several cases, were unable to balance their own lives with those of their autistic children (Behnia et al., 2017; Rios et al., 2020). Some parents were forced to quit their jobs to care for their children, creating financial difficulties that compounded their existing stress and anxiety: an issue that raises the importance of psychological and financial support for parents during the pandemic (Althiabi, 2021). Adding to this, participants suffered from a lack of support from professional and governmental sources, the latter of which may have been due to the general absence of information about the effect of the pandemic on autistic children (Lima et al., 2020). Parents were also forced to deal with unqualified teachers, doctors, nurses, and emergency health services when trying to seek help for their autistic children. This raises questions about the relationships between parents of autistic children and specialists such as special education teachers and occupational therapists, and to what extent parents can rely on professionals for applicable advice. Additionally, the comprehensive curfew and social distancing policy imposed in Jordan made it more difficult for participants to obtain support from and connect with their social networks (Brookings Doha Center, 2020).

To cope with these many stressors, participants turned to various strategies to help them endure the struggles of life during the pandemic, one of which was relying on religious beliefs (Al-Aoufi et al., 2012; Papadopoulos, 2021). Family members, particularly mothers, and sisters of participants, were another source of support for participants, a finding that reflected the important support roles that female relatives play for parents in developing countries (Papadopoulos, 2021). Participants also alternated childcare responsibilities with their spouses, which provided them with opportunities to rest and re-engage in their routines. In addition, online platforms such as WhatsApp and Facebook, as well as phone conversations, allowed participants to communicate with and receive support from friends and relatives (van Schalkwyk et al., 2017).

CONCLUSION

To the best of our knowledge, this study is the first qualitative study to explore the mental health of parents of children with ASD during the pandemic in Jordan. Our findings show that parents of children with ASD have reported high levels of stress, anxiety, and tension. Due to a lack of support services, parents have used various methods to try to cope with the stress and difficulties they face during the pandemic, which have negatively affected their psychological and mental health. Additionally, in the absence of accurate and adequate information from Jordanian health authorities, parents have been affected by rumors, false beliefs, and misinformation regarding the effect of the pandemic on their disabled children.

The current findings highlight the necessity for policymakers to provide professional support services to parents of children with ASD in Jordan. These services may include reliable, up-to-date information about the influence of coronavirus on their children, online courses and training to help parents adjust to having their children at home, and sending fully vaccinated service providers to the homes of autistic children to offer hands-on support.

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DECLARATION OF INTEREST STATEMENT

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