



## Article

# Mothering a Child with Autism Spectrum Disorder during the COVID-19 Outbreak

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**Abstract:** (1) Background: The lockdown that was forced by the Jordanian government as part of the attempt to contain the COVID-19 outbreak included extreme measures such as home confinement and the shutting down of schools' special education centers. This study explores the experiences of mothers of children with autism spectrum disorder (ASD) during this significant life disturbance. (2) Methods: Eleven mothers of children with ASD took part in semi-structured telephone interviews, which were transcribed verbatim and underwent thematic analysis. (3) Results: The analysis was conducted in an iterative consensus-building process to identify mothers' experiences, concerns, challenges, coping strategies, and perceived needs during the lockdown. The main themes that emerged from the analysis were maternal stress, maternal fears, and maternal hopes. Our findings indicate that the COVID-19 outbreak greatly affected the family lives of the mothers interviewed, which required them to optimize their coping strategies and resilience. (4) Conclusions: The mothers faced significant difficulties during the pandemic and there is an urgent need to support them on multiple levels. Additionally, our findings reveal the need for more research that takes Jordan's cultural context into account when determining how best to support children with ASD and their parents.



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## 1. Introduction

ASD is characterized by difficulties with social communication and social interaction, and restricted interests and repetitive and restricted behaviors (American Psychiatric Association 2013). ASDs are neurodevelopmental disorders with heterogeneous symptoms that exert overlapping effects on children and their families (Hyassat et al. 2023). As outlined in the existing literature, parents of children with ASD face constant sequences of challenges and stresses, which have been amplified in the time of COVID-19 (Colizzi et al. 2020; Al-Zyoud and Hyassat 2023). Indeed, the last year (2021) has given rise to a fast-growing body of research on children with ASD during the COVID-19 pandemic from all over the world, most of which concentrates on parents' coping strategies and the methods that they utilize to respond effectively to the needs of their children (Samadi et al. 2020; Stankovic et al. 2022; Tokatly Latzer et al. 2021). This body of research reveals that the pressures of lockdown have placed extreme stress on mothers of children with ASD.

As with their peers around the world, children with ASD in Jordan, as well as their families, have been affected by the social distancing, quarantine, and school closures occasioned by the pandemic (McDevitt 2021; Samadi et al. 2020; Tokatly Latzer et al. 2021). Education for children with ASD in Jordan usually takes place in public or private special education centers for children with ASD, which were closed due to COVID-19 as part of the country's lockdown measures during 2020–2021. It must be noted that the general

Jordanian statistics report, which was issued in 2016 after the country's general census, does not provide an accurate number of children with ASD in Jordan. This can likely be attributed to the absence of a clear definition of ASD, methodological issues, and cultural norms that drive parents to hide or deny their children's disability due to the fear of stigma (Hyassat 2013; Hyassat 2016).

Currently, the available research clearly indicates that parents of children with ASD, especially infants with ASD, are likely to experience a high degree of stress (Hayes and Watson 2013; Miranda et al. 2019). This degree of stress is common even in situations where children's behaviors and ASD symptoms are already the primary stressors for parents (Ingersoll and Hambrick 2011); in the time of COVID-19, the amount and impact of stressors for parents have significantly increased (Stankovic et al. 2022; Tokatly Latzer et al. 2021). While the literature does indicate that children with ASD have faced more difficulties due to the pandemic (Colizzi et al. 2020), it mainly focuses on how parents of children with ASD are responding to the changes in their children's daily routines due to lockdown, with little written about the stress that parents of autistic children are experiencing and the coping strategies they use (Esentürk 2021; Narzisi 2020).

The literature shows the importance of examining the experiences of parents of children with ASD, particularly in the Jordanian context, where very little scholarship has been conducted. Studies suggest that parents of children with ASD experience high levels of anxiety and depression (Cohrs and Leslie 2017; Lai et al. 2015), and experience high levels of stress (Estes et al. 2013). While support systems for parents of children with ASD are distinctly limited in Jordan and other developing countries, there is no evidence that the experiences of Jordanian mothers of children with ASD during the pandemic have been studied. This study aims to bridge that gap and to encourage the establishment of adequate support services for mothers of children with ASD in Jordan by answering the following questions:

1. What stresses did mothers of children with ASD in Jordan encounter with regard to parenting their children during the COVID-19 outbreak?
2. What were the fears of mothers of children with ASD in Jordan during the COVID-19 outbreak?
3. What were the hopes of mothers of children with ASD in Jordan, particularly concerning their children, during the COVID-19 outbreak?

## 2. Materials and Methods

This study focused on mothers of children with ASD rather than other family members due to the cultural norms of family structure in Jordan, where mothers hold primary responsibility for childcare and child-rearing (Al-Zyoud and Hyassat 2023). A descriptive qualitative methodology was utilized to examine the experiences of being a mother of a child with ASD in Jordan during the COVID-19 outbreak. Employing this methodology assisted the researchers in reinforcing their understanding of these experiences by providing a deeper look into participants' perspectives and daily lives (Creswell and Creswell 2017; Liamputtong 2009).

### 2.1. Participants

The researchers utilized snowballing and criterion sampling to select participants for this study (Creswell and Creswell 2017). These methods were employed for two reasons: Firstly, they could function within the cultural perspectives that often lead Jordanian parents to hide their children's autism due to a fear of social stigma, which can ultimately reduce social cohesion (Thompson 2020). Secondly, lockdown measures made it difficult to access demographic information on parents and children.

The two criteria for participants were that they needed to have a child officially diagnosed with ASD enrolled in special education centers and needed to be willing to be interviewed by phone. All participants voluntarily agreed to take part in the study. The researchers were fully aware of the disadvantages and limitations of this approach's

ability to meet the criteria of random sampling and representability, and therefore aimed to provide a better understanding of mothering a child with ASD during the pandemic in the Jordanian context specifically rather than providing generalization, representativeness, and external validity.

Since all the researchers in this study work in the field of special education in Jordan and teach field training courses at their respective universities, their professional networks include many special education centers and parents of children with ASD. The recruiting of the sample commenced in Salt City with an acquaintance of the first author—a mother of a child with ASD who had previously sought his help to assess her child’s functioning—which led to the referral of two other potential participants. The second researcher played the same role in Zarqa City, while the third recruited participants in Amman.

At the end of the recruiting process, 11 mothers of children with ASD agreed to take part in this study. The mothers were requested to sign a consent form that they had received and returned it over the WhatsApp platform. Participants lived in three large cities in Jordan: Amman, Zarqa, and Salt. Their ages ranged from 24 to 39 and their children’s ages ranged from 7 to 15. The relevant characteristics of all participants are shown in Table 1 as provided by the participants.

**Table 1.** Characteristics of participants as determined by themselves.

No.	Age	Education	City	Ethnicity	Employing/Private/ Public Sector	Socio-Economic Status	Child Age and Gender	Number of Siblings
P1	36	High School	Salt	Arab	Fulltime/Public	Middle	12-Male	5
P2	39	High School	Salt	Arab	Fulltime/Public	High	9-Male	4
P3	24	University	Amman	Arab	Fulltime/Private	Middle	6-Female	0
P4	28	University	Amman	Arab	No	Middle	7-Male	1
P5	31	University	Salt	Arab	No	Middle	14-Male	2
P6	28	University	Amman	Arab	Fulltime/Private	Middle	8-Male	2
P7	30	University	Zarqa	Arab	No	Middle	11-Female	3
P8	34	High School	Zarqa	Arab	Fulltime/Public	Middle	10-Female	3
P9	27	University	Amman	Arab	Fulltime/Private	Middle	7-Male	4
P10	26	University	Amman	Arab	No	Middle	6-Male	2
P11	26	University	Zarqa	Arab	Fulltime/Private	Middle	7-Female	1

The ethical approval for conducting this research was obtained. This was achieved by emailing the Research Ethics Committee (REC) at Al-Balqa Applied University. The REC checked the application and ensured that the research ethic requirements were met. A written consent form was prepared to reserve the rights of potential participants and was sent to all potential participants prior to conducting the study. The form explained the purpose of the study and reassured potential participants that they would remain anonymous, that their identities and those of their children would not be revealed, and that the data collected would be kept confidential, used for research purposes only, would be recorded and analysed, and would be destroyed once the study had concluded. It also guaranteed participants the right to withdraw from the study at any time without consequences and to be interviewed at a time of their choosing.

After obtaining the ethical approval, the primary researcher started contacting the participants in order to explain the study’s aims and procedures in detail, and to answer any questions they might have in this respect. The number of participants was decided by data saturation, which was reached when no new data were provided by participants, no new themes or sub-themes emerged from the analysis process, and at least six participants were interviewed (Guest et al. 2006).

## 2.2. Instrumentation

Semi-structured interviews with open-ended questions were used to examine mothers’ experiences, knowledge, attitudes, and feelings about parenting a child with ASD during

the pandemic (Fraenkel et al. 2012; Lodico et al. 2010). In order to ensure that all research questions were covered, the researchers developed an interview guide based on the key questions that the study sought to answer. The guide contained the name of the interviewee, the date of the interview, and the start and end time for each interview. The researchers then prepared a list of sub-questions to cover each research question, with the first researcher preparing a list of sub-questions regarding the first research question, the second researcher doing the same for the second research question, and the third researcher doing the same for the third research question, culminating in a total of 16 sub-questions. The reviewed literature and discussion with professionals in the field helped in developing the interview questions. Eventually, the researchers met to organize these sub-questions, which fell into several domains, namely: background, difficulties faced by mothers in caring for their children with ASD during the COVID-19 outbreak, fears of mothers of children with ASD regarding their children during the COVID-19 outbreak, hopes of mothers of children with ASD during the COVID-19 outbreak, and general follow-up questions.

The sub-questions were also reviewed by experts in the fields of special education and qualitative research—two professors, five associate professors, and three assistant professors—to ensure their validity and clarity. Reviewers were asked to review the correlations between each sub-question, the domain each one fell into, and the research question they sought to address; the clarity of content and wording; the grouping of questions; the relevance of the data provided; and the number of questions. The reviewers were provided with a guide to validation containing two parts, with the first covering the reviewers' identification data, and the second part containing validation scales for the domains of the sub-questions. Reviewers were asked to evaluate these domains on the following scale: not appropriate, fairly inadequate, adequate, and very adequate. After the review process, some questions were modified, but no further questions were added. After preparing the final draft, the interview guide was piloted on two potential participants by the first and third authors.

The three researchers are Jordanian men who work as associate professors of special education at two public universities in Jordan. They have worked with parents of children with disabilities, both in the past as teachers of special education and at the present time as they teach field training courses. In addition, they often work as consultants for parents of children with ASD on a regular basis. These pre-existing professional relationships with some of the participants did not interfere with the creation and interpretation of the interview questions, and indeed were instrumental in recruiting participants under lockdown conditions. All interviews were carried out via phone in Arabic during the lockdown; each interview was recorded and lasted between 26 and 45 min, depending on the mothers' characteristics. For example, mothers with greater education and knowledge tended to talk more than others. All interviews were transcribed in Arabic and all relevant parts were translated into English by the first researcher, reviewed by the second researcher, and then analyzed in English.

### 2.3. Data Analysis

The data were analyzed using systematic thematic analysis based on the work of Braun and Clarke (2006, 2021), with analysis commencing after the first interview was completed. Thematic analysis was considered the most suitable method for analyzing these types of data due to its flexibility. The analysis process began after the first interview, which was transcribed and read by all researchers. Firstly, all researchers familiarized themselves with the data by reading all the transcripts and taking notes on the data contained therein. Next, the researchers began to generate an initial code based on the goals and questions of the research in order to organize the raw data in a meaningful and systematic way. All relevant parts of the text were coded and open coding was used. Since the purpose of this step was to answer the research questions, this analysis was more of a theoretical thematic analysis than an inductive analysis. The researchers then arrived at search themes by grouping the code into broader topics that addressed aspects of the research questions. Following

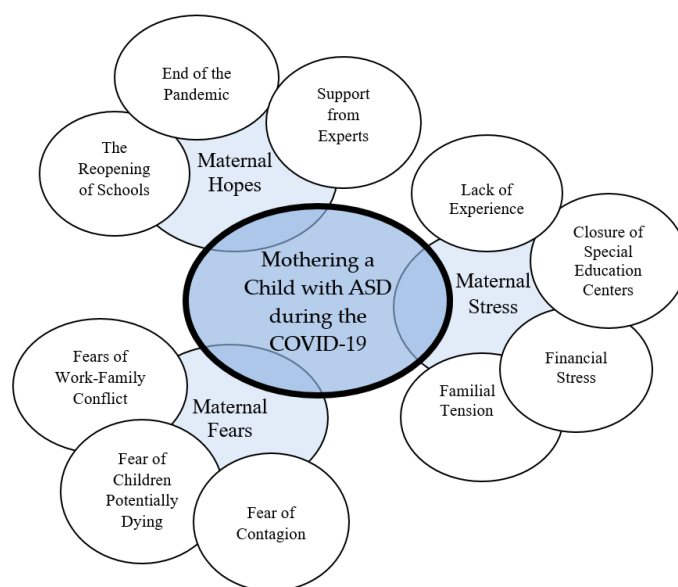
this, the initial themes from the previous step were reviewed to ensure that they were coherent, and supported by data. Finally, the researchers defined the themes by examining the nature of each theme and how they related to each other, and then wrote down the results obtained from the analysis. It would be useful to mention that the analysis process was iterative; themes were developed based on what participants frequently stated, and we tried to uncover patterns that would address our research questions (Braun and Clarke 2021).

#### 2.4. Credibility

We used the member checking technique as described by Bryman (2012) to maintain the trustworthiness of the current study. Five interviewees received full transcripts of their interviews via email, along with a request for feedback on their accounts. These participants indicated that they were happy with the transcripts and did not offer any changes. The process undertaken by the researchers in developing the interview guide could ultimately contribute to the validity of the research. Furthermore, intercoder reliability was ensured by involving the three authors independently and reaching a final consensus between them (Creswell and Creswell 2017).

### 3. Results

Three main themes emerged from the analysis process: maternal stress, maternal fears, and maternal hopes. Within the theme of maternal stress, four sub-themes were determined: lack of experience, the closure of special education centers, financial stress, and familial tension. Under the theme maternal fears, there were four sub-themes: fear of contagion, fear of their children potentially dying, fears regarding relationships with their husband and other family members, and fears of work–family conflict. In the theme of maternal hopes, three sub-themes were identified: support from experts, the end of the pandemic, and schools reopening. Figure 1 highlights the major themes and related sub-themes that capture the experiences of mothers of children with ASD during the COVID-19.



**Figure 1.** Major themes and related sub-themes.

#### 3.1. Maternal Stress

##### 3.1.1. Lack of Experience

The mothers interviewed reported that they were stressed, anxious, and distressed, partly due to their lack of experience with the situations created by the pandemic. One mother, who was 24 years old (P3), linked this lack of experience to her and her husband's relative youth:

*"I have never been in this situation before. . . I mean I know I have a child with disability but I did not know what to do. . . I was really anxious and I am still young. I mean we (my husband and I) are still young to have this responsibility".*

However, age did not seem to be a factor for other participants, as with another mother (P2), who was 39 years old and had five children:

*"I have never been in this kind of situation. To be honest, just when I gave birth to (H), when corona started, I felt it was okay and I did not have enough information—just some information from my colleagues at work that drove me crazy".*

Likewise, a 34-year-old participant (P8) stated that she had been suffering from constant stress despite trusting and following the government's advice regarding COVID-19:

*"Yes—as I said, I followed all instructions issued by the government, but I have to admit that I was extremely worried because I have never been in a situation like this before and was not sure I was doing the right thing".*

As shown by the above extracts, mothers of children with ASD in Jordan experienced stress due to not knowing how to respond effectively to the new climate fostered by COVID-19. Employment status, similar to age, did not seem to affect the amount of stress; mothers who were unemployed seemed to have similar stress as mothers who were employed and could connect with colleagues. Stress appeared to be a defining factor of mothers' experiences during the outbreak, which somewhat ironically was itself rooted in their inexperience with the circumstances brought on by the pandemic.

### 3.1.2. Closure of Special Education Centers

Another source of stress for mothers of autistic children in Jordan was the closure of special education centers, which meant their children were at home when they would normally have been in school. The mothers interviewed were not adequately prepared to have their autistic children at home all day, which led them to feel stressed. All mothers interviewed indicated that although they expected schools to close, they did not know how to respond to the reality of this closure, as stated by participant (P6):

*"Yes, I know that everyone in Jordan was talking about curfew and closing all schools but I was not ready to have (M) at home. I just was not ready. Actually, nobody was. Not his father, not me, not his siblings. We just were not ready".*

(P6) appeared not to know how to cope with having her child at home rather than in education: *"we simply did not know what to do with him"*. Some mothers viewed having their autistic children at home as a new burden they needed to carry, as revealed by participant (P9):

*"I thought it was just easy to have him at home, and of course safer, but I then said to myself: oh my God, who would look after him if I was at work or I have to go out?"*

Additionally, having to care for a child with ASD at home during what would otherwise have been school hours prevented mothers from taking part in social activities that would have allowed them to connect with others. One participant (P5), who was not employed, stated that she hoped she would not have to take constant care of her child:

*"I know that is vicious but I was really confused and did not what to do. After a week, I realized that I had to look after him 24/7 and I really did not enjoy my life. I did not even have the chance to phone my mother and friends as I used to".*

### 3.1.3. Financial Stress

Participants reported that financial issues were another key stressor for them during the pandemic. Some participants were upset over having to pay tuition for their children's special education when classes only took place online due to lockdown, and complained that the online teaching their children received was not adequate. As participant (P4) stated:



*"I paid for my son to receive proper service. I want his teacher to teach him face-to-face, not online. Distance teaching is just a joke. I paid all fees and my child deserves proper teaching. Otherwise, we should have a refund, though."*

She also alluded to the difficulties she faced in paying her child's school fees: "You know how difficult it is to save this amount of money in the country and how difficult it is to pay all the fees for these centers. You certainly know from your experience that these fees are high".

These financial difficulties were compounded by constant pressure from special education centers to pay their fees in full, as in the case of participant (P10):

*"Miss X, the head teacher of the center, keeps calling and texting me asking us to pay the rest of the fees. I mean, why we would have to pay the rest? My child is at home for ages now and the teacher just gives him less than half an hour a day and I highly doubt that he understands or responds to her".*

She also stated that these financial issues were a strain on her marriage: "My husband stays at home all the time and we fight all the time since he was sacked. I do not think that we can cope".

In fact, several mothers, such as participant (P11), also indicated that their husbands had lost their jobs as a result of the pandemic, which increased their financial stress:

*"You know, the whole country just stopped working and we found ourselves with no sufficient support. My husband used to work as a self-employed carpenter and suddenly found himself with nothing. No work, no money. All people who owed him some money did not pay him anything".*

The financial difficulties that mothers of children with ASD faced were part of a larger-scale stress cycle where many families found themselves short of money during the pandemic. For the mothers interviewed in this study, this left them unable to meet the needs of all their children, which in turn caused them to feel inadequate. As one participant (P5) stated: "suddenly we found ourselves short of money and I could not buy him some stuff I used to do". She also expressed guilt over her inability to provide for her child: "It is not enough that I brought him to life as a child with disability; now I cannot buy him what he wants".

#### 3.1.4. Familial Tension

Another source of stress for mothers was familial conflict between their neurotypical children and their children with ASD, and between themselves and their partners. Participants reported that they had to mediate more conflicts than usual between their children with disabilities and their typically developing children. For instance, participant (P1) indicated that she spent a great amount of her time trying to stop her neurotypical children from hurting their sibling:

*"I do not know what their problem with him is. I mean every single time I leave them alone, they start fighting with him. I am really fed up with this situation. Several times I lose my nerve and start beating them and I do not think that this is fair for them".*

When asked, she elaborated on being "fed up" by saying: "What about me too? I am a human being too and I need some break from this". Many participants reported being in similar situations to R's, finding themselves engaging in arguments with their typically developing children, who complained that their ASD siblings were a burden on them. Participant (P2), for example, stated that her typically developing children did not comply with her request to look after their sibling with a disability:

*"When I asked them to look after him, they did at first while I was doing the domestic work, but then they suddenly started to complain about it and this drove me crazy. I have to look after six children, a husband, and a house and they do not help me".*

In addition, another participant (P7) reported that her typically developing children started to lash out when she asked them to help her with domestic chores: "They just do not

*want to help; one of them shouted at me when I asked her to wash some dishes as I had to look after [my autistic child]”.*

These stressors were frequently exacerbated by tension between participants and their partners, who in some cases seemed to resent the time and effort that participants spent on caring for their children with ASD (P5):

*“My husband was very angry when I did not give him attention. I really do not have an extra hand. I mean, how can I give him attention when I have to cook, tidy up, and look after the whole family? We just fight and argue all the time”.*

Another participant (P9) reported that she could not stand the pressure exerted by her husband as well as by the responsibility of mothering a child with ASD during the pandemic, and almost had a nervous breakdown:

*“I do not know if that because I am still young and (R) is my first child but I spent most of this outbreak fighting with F [her husband]. For a minute, I thought I was going to have a nervous breakdown—just one problem after another. I could not stand what happened. Staying with F in one place for a long time is such a bad idea”.*

Additionally, extra stress is placed upon single mothers raising children with ASD by Jordan’s conservative society. One participant (P3), who was divorced, reported that she felt high levels of pressure despite having just one child and not having to care for a husband:

*“You know, I live with my parents after I got divorced. I have to look after my child alone. I sometimes receive some help from my sisters but that is not adequate. When I asked my sister to look after him, as I had to sleep after a horrible night, she simply refused and I have been left alone. And that is just horrible; I wish I was not divorced”.*

### 3.2. Maternal Fears

In the second theme, our participants reported experiencing fears relating to children with disabilities, their family members, and themselves. Participants were quite direct in reporting these, revealing that they had reached their limits of tolerance. From this main theme, four sub-themes emerged as follows: fear of contagion, fear of children potentially dying, fears regarding their relationships with their husbands and other family members, and fears regarding work–family conflict.

#### 3.2.1. Fear of Contagion

Our participants reported that, in light of a relative absence of information about the pandemic, they feared that their children with ASD might be more prone to developing the disease than their nondisabled children (P6): *“I was really terrified that (O) would develop the corona. You know, at first, we did not know much about it”.*

One of our participants (P5) described her early experiences of general lockdown as being filled with fear and anxiety:

*“I was watching the television all the time trying to hear something about this disease. I could not hide it, but I was really scared to death that my daughter would have it because of her disability. I had very bad days thinking about this matter”.*

Some mothers blamed their fears on outside parties spreading rumors about the pandemic and its effects on people with disabilities versus typically developing people (P2):

*“You know people in Jordan; as the disease started in the country they started to say wrong things about it. I mean, they just tell stories and what they think is facts, while it is all fake. They just do not know. If you do not know, why do you say such things?”*

When the mother (P1) who provided the above quote was asked who she blames for spreading these rumors, she replied: *“I do not know whom to blame exactly. But I have to admit that the government has to do something with those people. You do not know the horror and panic we have been through”.*



Several mothers were also afraid that their children with ASD might pass on the virus to other members of the family (P10): *“My husband and I were very worried that (W) could pass the virus to us if he was infected with it or to my old father-in-law who lives with us or even to his younger siblings”*. However, these fears appeared to stem from a larger fear of their children with ASD dying due to the pandemic.

### 3.2.2. Fear of Children Potentially Dying

Although a large proportion of mothers in this study expressed fears regarding contagion, these tied into fears that their children could die from COVID-19, which emerged when they were asked about the future of their children:

*“At first, I was very worried about my son, and to be honest I could not sleep at all. I was reading and searching about this disease. Then I thought I might lose him and that was the scariest thing that ever came into my mind”*. (P7)

*“To be honest with you, when I gave birth to him and knew that my child was not normal, I cried and moaned for months and months but he becomes now as part of my life and I cannot imagine my life without him. . . I do not want to lose him”*. (P11)

Some mothers complained that the lack of information and “rumors” exacerbated these fears (P5): *“People kept saying false things about coronavirus and I was really worried that I was going to lose her. I have been told several times that children with ASD are more likely than other children to die from the coronavirus”*.

Additionally, participants worried about how the potential deaths of their children with ASD might affect other family members, especially their typically developing children (P2):

*“If I lost him—God forbid—what would I tell his brothers and sisters? Every single time I think about it, I panic. I really feel sorry for them. I am afraid that I am going to have a nervous breakdown”*.

When this mother was asked to elaborate on the projected reaction of her other children, she replied (P2):

*“Mmm, I spent so much time trying to explain to them why (A) is like this, if you see what I mean. How can I re-explain to them what is going on? I am sure they would be shocked and devastated”*.

Some mothers worried that such an eventuality would cause them to be negatively perceived by society, and expected that the stigma of having children with ASD would continue if those children died (P4): *“We suffered a lot with those who do not want to understand the situation of our child. Do you expect them to understand now? No way”*. They reported that this stigma came from neighbors, relatives, and work colleagues; this last category, according to several mothers, also related to anxiety about how having their children with ASD at home would affect their jobs.

### 3.2.3. Fears of Work–Family Conflict

Participants reported that one of their sources of stress was the conflict between their work and their family duties caused by having their children with ASD at home during the pandemic. One participant (P11) described her experience of having her daughter at home as follows:

*“You know, at the beginning of the pandemic, I had to work from home and that was just painful. I had to look after her and to answer all phone calls when I ought to be fully concentrating. My boss kept asking me what was going on and I just did not know what to say. I mean, I have never told him that I have a child with disability”*.

It appears that part of the difficulty for this participant stemmed from the fact that she had never divulged her child’s autism and did not feel comfortable doing so in her current work environment. Likewise, another participant (P6) raised similar points when mentioning that one of her clients shouted at her on the phone: *“He just shouted at me*

*because of the noise in the background. I could not say that was just because of him but rather my other children*". This again highlights the issue of feeling the need to hide autism in Jordanian society.

Participants who worked for the private sector seemed to experience more stress in this regard than those who worked in public sector jobs. As one mother (P4) working in the private sector noted: *"My boss asked me to contact some clients around 10 a.m. and that was not perfect for a working mother"*. She also stated that her boss refused her request to pass the task on to another colleague: *"I texted him and asked him gently to ask my colleague Rima to contact our clients, but he simply refused and simply did not want to listen"*. Another participant (P3) who also held a private sector job revealed that she was afraid of being fired: *"I have no choice but work very hard and I had to ask my sister to come over to help me out. Obviously, I did not want to be sacked"*. By contrast, mothers in the public sector appeared to have more time to care for their children; as one mother (P1) stated: *"To be honest with you, having him at home during this pandemic was not a nice experience but thank God I was off from work"*. When asked if she had been granted continuous time off, she replied: *"No, I did not, but you know, we work for the government and we can skip many duties; I do not work for a private company"*.

Furthermore, mothers reported that their husbands and typically developing children were having difficulty coping with the amount of time they had to devote to work and their children with ASD. One mother (P2) described her husband's actions as follows: *"I am not sure if he [her husband] was jealous [laughing] but it appeared to me that he was upset, as I spent most of the time looking after (T) and on the phone and my PC working"*. Similarly, another mother (P7) felt that she was neglecting her typically developing children due to the time she spent working from home and caring for their sibling with ASD:

*"I do not think this is fair for them. I mean I work from home and most of my time spent on (H)—having to look after and helping him learn online. No, that was not fair for my children"*.

### 3.3. Maternal Hopes during the COVID-19 Outbreak

During these interviews, mothers discussed their hopes for the near future (or rather, the near future in relation to when the interviews were carried out), which fell into three sub-themes as follows: support from experts, the end of the pandemic, and schools reopening.

#### 3.3.1. Support from Experts

Mothers of children with ASD clearly stated that they were in urgent need of constant professional support. One of our participants (P11) justified her need for such support thusly:

*"I am a working lady and I do not really know what to do with him. I mean, I used to send him to a special education center and they used to do everything but now, no, I have to do these things which I am not familiar with"*.

Other participants specifically wanted assistance from educational professionals, and felt that they were under great pressure as a result of not receiving said assistance (P5): *"His teacher did not tell me what to do with him—I mean how to teach him—I was so frustrated. . . How come I am his mother and do not know how to teach him?"* They also worried that their children's intellectual advancement would regress without this assistance (P8): *"We do not know how long he is going to stay at home and I am really terrified he is going to lose everything he was taught"*. Along similar lines, they worried that their children's behaviors would become worse without support from teachers and other professionals (P3): *"You know, he spent three years now in the center and many of his behaviours have modified, but now it appears to me he is back to his routine"*. Thus, mothers in this study were desperate to learn some behavior modification techniques for their autistic children, but they reported that teachers were not always ready to share these techniques with them. As one mother (P6) stated: *"I asked her several questions and she simply did not give me clear answers"*. Another (P11) said that trying to ask a teacher for help with her child was confusing: *"She was speaking a different language; how can I understand the phrase 'positive practice'?"*

Outside of their children's education, participants asked for professional assistance with techniques for responding to the consequences of the pandemic (P7):

*"Honestly, no one has the required knowledge to answer me. I was terrified of what would I do if (M) had the disease. I just want someone with the knowledge to help me out if he—God forbid—had Corona".*

### 3.3.2. End of the Pandemic

Another hope that participants expressed was for the pandemic, and the pressure associated with it, to end (P9): *"I just want this nightmare to finish. I cannot tolerate anymore. I mean look around you and you will see everyone is mad because of the curfew"*. Much of their hopes in this regard primarily related to their children with disabilities (P2): *"I am really looking for that day when everything of this disease is gone and we are just back to our normal life. I just want him to be like other children and I want my life back if you see what I mean"*.

More specifically, they revealed a desire to be able to respond effectively to their children's needs once the pandemic ends (P5): *"I want to help him, but I do not know how. I mean, Corona does not give us the time to think properly"*. They also noted that the pandemic had shown them the limitations of their knowledge of autism (P10):

*"I want to be honest with you; I discovered that I do not how to deal with him at all. I think some of my children might know more about him than I do since I spent most of my time working. I really need to know him better and I am just waiting for the end of Corona"*.

Furthermore, participants indicated that the end of the pandemic would provide them with opportunities to better know their children with disabilities, learn some teaching and behavior modification techniques, and work on their relationships with teachers and other professionals (P4): *"I really want to know more about her and her school—I mean her center—and her classes and how to deal with her weird behaviors"*.

### 3.3.3. The Reopening of Schools

Finally, mothers stated that they were looking forward to the reopening of schools and special education centers and re-enrolling their children in these institutions. As touched upon earlier, they indicated that there was an urgent need to reopen these centers, since they felt that alternative methods of teaching were not sufficient (P1):

*"Yes, of course, I want him to go back to his school. Actually, he must go back to his school, as I do not think that he benefits from distance learning at all, and I am really mad because of this"*.

In addition, mothers in this study believed that teachers were more capable of dealing with their children with ASD than they were, and that this also justified a call for reopening schools and special education centers (P7):

- *"I do not think closing the special education is going to resolve the problem. . ."*
- *Which problem, ma'am?*
- *"I mean reducing cases of Corona"*.
- *All right.*

*"So, I think these centers should be open all the time as they are unlike schools where overcrowding is apparent and special education teachers can teach those children better than us"*.

Another participant (P6) expressed similar views regarding her child with ASD: *"His teacher changed several of his inappropriate behaviours and, as you know, we cannot bring her home, so it is better for her to have him at the center and deal with these behaviors"*.

Some mothers believed that reopening schools would reduce tension in the household by giving all of their children a place to go during the day (P1): *"I have to admit that I wish that schools and centers will open so I can send my kids away because they fight all the time. I am worried about (T) as he cannot defend himself"*. Another participant (P11) indicated that

schools reopening would ease conflict between herself and her husband, who had been fired from his job and had to look after their child with ASD during the day: *"We agreed he would look after him while I am at work, but that obviously did not work, and we fight all the time. I wish schools were open"*.

Furthermore, most mothers believed that schools and special education centers reopening would lessen their responsibilities towards their children with ASD and other family members (P6): *"I am just fed up and I feel everything is going wrong. I am full of responsibilities and do not [know] anymore"*. This sentiment was especially visible among mothers who felt that they were incapable of responding effectively to their children's needs (P2): *"Yes, I failed. I admit that although I do not work, I did not know how to deal with her and when and where. My husband and I just wish she were at school"*.

#### 4. Discussion

To the best of our knowledge, this paper is the first to examine the perspectives of mothers of children with ASD during the COVID-19 outbreak in Jordan, and one of the first to examine the perspectives of mothers of children with ASD in any national or cultural context. As new mutated strains and waves of COVID-19 emerge, and the Jordanian government imposes new closures while continuing to close most schools and special education centers, it is hoped that this article will deepen understanding of the process of mothering a child with ASD during the COVID-19 outbreak—particularly given the relative absence of existing research related to the subject of this paper.

Although it has frequently been stated that mothers of children with ASD faced similar obstacles even before the pandemic (Cohrs and Leslie 2017; Gobrial and Shoeib 2023), the authors made multiple efforts to distinguish between the stresses, fears, and hopes these mothers had before and during the pandemic. Firstly, the mothers were directly probed during the interviews about the fears and hopes they specifically experienced during the pandemic. Secondly, during the analysis, the authors used data that related to the stresses and hopes during the crisis rather than any kind of data that related to any situation that existed before the pandemic. Finally, in some cases, the authors stressed during the interviews about asking the participants about their new experience and comparing it to their traditional experience with professionals and the types of support they received during their journey to raise their child with ASD.

##### 4.1. Theme 1: Maternal Stress during the COVID-19 Outbreak

In this study, mothers of children with ASD in Jordan stated that they faced constant pressure and disruptions to their lives during the COVID-19 outbreak. It is not surprising that they felt such pressure (Miranda et al. 2019) since the literature indicates that parents of children with ASD, especially mothers, experience a great amount of it even in normal, pre-pandemic circumstances (Hyassat 2013; Gomes et al. 2015; Lee et al. 2009; Mori et al. 2009). These pressures have increased in the pandemic; as the literature indicates, parents of children with ASD have suffered from great anxiety, a loss of confidence, feelings of worthlessness, and depression during COVID-19 (Althiabi 2021).

The mothers interviewed in this study reported that they had no experience that could have prepared them to effectively deal with or respond to the needs of their children during the pandemic. This reflects previous research findings that parents often bear great burdens and responsibilities in finding the appropriate interventions for their children with disabilities (Gentles et al. 2019), and that mothers of children with ASD appeared to have a poor connection with health professionals, which increased their stress (Reddy et al. 2019). Additionally, research shows that parents of children with ASD, such as the mothers in the current study, tend to lack adequate knowledge of autism (Fox et al. 2017). These factors led mothers in the present study to suffer from constant stress for which they were not prepared, and which may have been exacerbated by the confusion they faced when trying to access services for their children, similar to minority communities in Western countries (Hussein et al. 2019). Furthermore, in line with previous research, mothers of children of

ASD seemed to conceal their children's condition due to the fear of incurring social stigma (Cohen and Miguel 2018; Lovelace et al. 2018).

In addition, these mothers had to provide full care for their children during the outbreak, which negatively affected their social activities and daily routine (Jiu and Rungreangkulkij 2019). As with the subjects of previous research, the mothers in this study experienced financial stress, which is typically caused by low income and a lack of financial support (Hyassat 2013; Sharpe and Baker 2007), and which strains marital relationships between mothers and fathers of children with ASD (Landon et al. 2018; Papp and Hartley 2019). In this study, mothers reported experiencing all of these stresses and relational tensions as a result of having their autistic children at home throughout the day.

#### 4.2. Theme 2: Maternal Fears during the COVID-19 Outbreak

The mothers interviewed in this study expressed a range of fears, among which was a fear that their children would contract or pass on COVID-19. Participants in the current study were afraid of conditions that their children might develop, which was made worse by a lack of information about the pandemic; all participants reported that they did not receive sufficient information from a formal and trustworthy source about the pandemic and its risk for their children. These fears reflect existing research findings that children with ASD are at high risk for developing certain health conditions and chronic diseases (Cashin et al. 2016; Da Silva et al. 2016), and that the mortality risk among those with ASD is nearly twice that of the typically developing population (Hirvikoski et al. 2016). Additionally, the literature shows that fears of social stigma and feelings of guilt associated with having a child with ASD are common (Kinnear et al. 2016), with many parents believing that they are responsible for having a child with disability, which reduces their sense of parental competence (Dunn et al. 2001).

Mothers in this study also felt torn between meeting their families' needs and fulfilling their work requirements; this conflict is considered one of the costs of parenting (Fletcher et al. 2012). Echoing the findings of previous research, the mothers in the current study found themselves needing to make several adaptations and adjustments in their life to accommodate their children with ASD (Dieleman et al. 2018). Furthermore, the mothers who work for the public sector experienced less stress than those who work for the private sector, where there appeared to be less leeway for their roles as working mothers and, thus, greater levels of stress (Hill et al. 2015).

#### 4.3. Theme 3: Maternal Hopes during the COVID-19 Outbreak

The mothers of children with ASD in this study expressed various hopes for the near future, such as the hope and need for support from experts. Parents of children with ASD normally face unique barriers and challenges (Hartley and Schultz 2015), and responding to the needs of children with ASD can be complicated. Our participants reported that the required support was unavailable or difficult to understand; as the literature shows, the availability of necessary support is a factor in reducing mothers' stress (Hastings et al. 2005). In some cases, it appears that the support mothers needed was for someone to listen to them (White and Hastings 2004), which could help to repair the strain placed upon their marital relationships during this period (Hartley and Schultz 2015).

Mothers in this study were also hoping for an end to the pandemic, with the hope that they could resume their regular activities once restrictions ease (Vaughn et al. 2002). As new strains of COVID-19 develop, the Jordanian government may have to open and close schools and special education centers for safety. Mothers additionally reported that the pandemic ending could enable their children with disabilities to receive necessary services that they felt unqualified to provide. As highlighted in the literature, many of these services can only be delivered by qualified professionals such as speech-language pathologists, physical and occupational therapists, behavioral therapists, and special education teachers (Whitaker 2007).

Another hope mentioned by participants, as touched on above, was the reopening of schools and special education centers. In addition to their hopes regarding the provision of services, they noted that special education teachers were more capable of addressing their children's needs than they were, and that they did not feel prepared for the responsibility of continuously responding to these needs, which included challenging and repetitive behaviours (Polimeni et al. 2005). This also extended to other family members, especially participants' typically developing children, who found it difficult to deal with having an autistic child in the family (Ross and Cuskelly 2006).

Although the positions of Jordanian mothers of children with ASD in the COVID-19 pandemic have many similarities to those reported for mothers worldwide, the experiences of Jordanian mothers specifically were influenced by several factors, including local cultural perspectives. Our participants indicated that Jordan's social norms played an important role in their responses to the pandemic, and that, despite the eventual lifting of the restrictions imposed by the government, they still suffered from high levels of stress, which significantly affected their lives.

It might be worth mentioning that mothers of typically developing children experience difficulties balancing work, child care, and domestic duties during the COVID-19 lockdown. For mothers of children with ASD, they experience greater difficulties. The sudden and unexpected disruption of routines, limited access to support services, and the increased demand for a stable framework posed unique difficulties. These mothers often deal with the additional responsibility of managing their child's specific needs, potentially causing greater strain on their overall well-being compared to mothers of typically developing children.

## 5. Implications

Our findings highlight the urgent need for effective support systems to be put in place for mothers of children with ASD in Jordan, and for policymakers and government officials to consider the needs of mothers and their children with ASD in this time and in similar situations in the future. The findings suggest that teachers of children with ASD can help by increasing mothers' self-confidence, responding efficiently and positively to their children's needs, and supporting them in teaching their children and modifying their behaviors at home.

Children with ASD in Jordan attend public and private special education centers that provide them with basic special education services. Most government-funded centers offer general services rather than specific services and have a long waiting list, whereas private centers provide more specific educational services. Neither public nor private centers offer family support services for the parents or relatives of children with ASD. This has significant implications for policymakers, who have a responsibility to create a strong support system for children and their families by understanding ASD as a social issue rather than an individual mother's or family's dilemma. Furthermore, the results reinforce the need for mothers of children with ASD to share their children's diagnosis with their employers and to join support networks, which can help to alleviate their stress. Furthermore, social media has a significant impact on promoting inclusion in all aspects of society and better support for mothers and their children with ASD, as their well-being influences that of their entire families.

## 6. Limitations

There are some limitations that should be considered when interpreting the findings of this research. Firstly, the sample size was relatively small and only consisted of mothers of children with ASD from three main cities in Jordan; mothers in rural areas and other less urban regions may have different family structures from mothers in large cities, which in turn may affect their experiences in different ways. Secondly, the obtained sample was limited to participants with school-aged children; mothers of children who are too young for school or who have aged out of the school system might have experiences that diverge



from those recounted in this study. Finally, as all participants took part in this research voluntarily, their accounts might not reflect those of mothers of children with ASD who were not willing to share their experiences.

To minimize threats to the validity of this study, the researchers interviewed all available participants, with no potential participants being excluded, which was facilitated via the use of the snowball technique to compile the interview sample. The researchers also ensured that all interviews were recorded and fully transcribed. Additionally, they did not impose any interpretations that differed from those reported by the participants, and were careful not to subject the data to any particular theory.

## 7. Conclusions

The findings of this research show that mothers of children with ASD in Jordan generally felt stressed, anxious, and distressed due to a range of factors. Firstly, all special education centers and schools were shut down, forcing children with ASD to stay home and, in turn, creating an increased burden on mothers to meet their children's needs and deal with financial pressures. Mothers were afraid that their children with ASD would become sick with or die from COVID-19, and were subject to significant stress from family conflicts and work pressures caused by having their children with ASD at home.

This study seeks to build strong connections between mothers of children with ASD and special education centers and schools, which are greatly needed in the current cycle of pandemic lockdowns. This may help mothers to feel supported and increase their sense of control regarding their children. Future research may expand in scope to study other family members such as fathers, siblings, or even extended family who may help mothers to better cope with the stress of the pandemic.

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