

# The Effects of the COVID-19 Pandemic on Individuals with ASD and Their Families in Qatar

Journal:	Autism
Manuscript ID	AUT-22-0702
Manuscript Type:	Original Article
Keywords:	COVID-19, Social restrictions, Stress, Family functioning and support, Autism Spectrum Disorder
Abstract:	The unprecedented impact of the coronavirus pandemic (COVID-19) has had profound implications for the ASD community, including disrupting daily life, increasing stress and emotional dysregulation in autistic children, and worsening individual and family well-being. This study used quantitative and qualitative survey data from parents in Qatar (n=271), to understand the impact of the COVID-19 pandemic on autistic children and their families in Qatar. Parents expressed significant distress and disturbance in their daily lives, including profound disruptions to their children's access to treatment, education and activities. Most parents reported deteriorations in their children's sleep, behavioral regulation, and acquired skills across multiple domains. Parents also reported decreased access to family and social support networks, as well as decreased quality of clinical and community supports. Parental stress was significantly associated with child developmental regression. The greater impact of the pandemic on the children with ASD and their families emphasizes the need for accessible and affordable health, education, and family services to manage their special needs.

SCHOLARONE\*\*
Manuscripts

#### **Abstract**

The unprecedented impact of the coronavirus pandemic (COVID-19) has had profound implications for the ASD community, including disrupting daily life, increasing stress and emotional dysregulation in autistic children, and worsening individual and family well-being. This study used quantitative and qualitative survey data from parents in Qatar (n=271), to understand the impact of the COVID-19 pandemic on autistic children and their families in Qatar. Parents expressed significant distress and disturbance in their daily lives, including profound disruptions to their children's access to treatment, education and activities. Most parents reported deteriorations in their children's sleep, behavioral regulation, and acquired skills across multiple domains. Parents also reported decreased access to family and social support networks, as well as decreased quality of clinical and community supports. Parental stress was significantly associated with child developmental regression. The greater impact of the pandemic on the children with ASD and their families emphasizes the need for accessible and affordable health, education, and family services to manage their special needs.

Keywords: COVID-19, Social restrictions, ASD, Stress, Support

#### **Abstract**

1 2 3

The unprecedented impact of the coronavirus pandemic (COVID-19) has had profound implications for the ASD community, including disrupting daily life, increasing stress and emotional dysregulation in autistic children, and worsening individual and family well-being. This study used quantitative and qualitative survey data from parents in Qatar (n=271), to understand the impact of the COVID-19 pandemic on autistic children and their families in Qatar. Parents expressed significant distress and disturbance in their daily lives, including profound disruptions to their children's access to treatment, education and activities. Most parents reported deteriorations in their children's sleep, behavioral regulation, and acquired skills across multiple domains. Parents also reported decreased access to family and social support networks, as well as decreased quality of clinical and community supports. Parental stress was significantly associated with child developmental regression. The greater impact of the pandemic on the children with ASD and their families emphasizes the need for accessible and affordable health, education, and family services to manage their special needs.

Keywords: COVID-19, Social restrictions, ASD, Stress, Support

#### Lay Summary

This study administered surveys to 271 parents of children with ASD living in Qatar to understand the effects of the COVID-19 pandemic on their lives. Parents reported that they had less access to high-quality services and education for their children, and that their children's sleep, behavior, and learned skills had gotten worse. Parents whose children had lost skills were the most stressed.

# The Effects of the COVID-19 Pandemic on Individuals with ASD and Their Families in Qatar

There is no doubt that the COVID-19 pandemic, which has rapidly swept through the world, has affected nearly all aspects of life; including the health and safety of all people, especially individuals affected by acute and chronic illnesses. Individuals with neurodevelopmental disorders such as Autism Spectrum Disorder (ASD)¹ are no less immune to the direct and indirect impacts of this pandemic. In fact, early data suggests that people with developmental disabilities may be even more susceptible to adverse health outcomes and death from COVID-19 (Sabatello, Landes, & McDonald, 2020; Turk, Landes, Formica, & Goss, 2020). Measures taken by most countries to control and limit the spread of COVID-19 include the closure of schools and centers providing treatment, rehabilitation, educational and training services. Nonetheless, efforts are being made by most service providers in finding alternative ways to compensate, even partially, for these restrictions in order to alleviate the great burden on families of individuals with ASD. While the measures taken by countries to control and limit the spread of COVID-19 are myriad in number, the can be addressed in the following categories: impact on 1) the provision of health care services, including diagnostic, treatment, and rehabilitation services; 2) educational services; 3) individuals with ASD and their families; 4) medical and intervention service providers; and 5) ASD research.

ASD is characterized by pervasive impairments in social reciprocity, communication, stereotyped behaviors and restricted interests (APA, 2013). Diagnosis of ASD requires a multidisciplinary assessment by healthcare service providers. Before the COVID-19 pandemic, centers and clinics around the world, including in Qatar, usually had a long waiting list for

<sup>&</sup>lt;sup>1</sup> The authors recognize the ongoing and complex conversation around the use of person-first (individual with ASD) versus identity-first (autistic individuals) language. Given that the ASD community in Qatar tends to use person-first language, this manuscript uses primarily person-first language but also employs identity-first language at times.

assessment (Wiggins, Baio, & Rice, 2006). With the rise of this pandemic, many of these services were interrupted for varying periods of time, forcing families to postpone diagnostic evaluations, in turn negatively affecting the outcome of any intervention for the child, as earlier diagnosis is strongly associated with positive lifelong outcomes for individuals with ASD (Stahmer et al., 2005; Boyd et al., 2010; Strain et al., 2011; Warren et al. 2011; Elder et al., 2017). Early intervention (implemented before the age of four) is associated with gains in cognition, language, adaptive behavior, social behavior, and overall quality of life for both the child and the family (Zwaigenbaum et al., 2015; Dawson et al., 2010; Vivanti & Dissanayake, 2016; Remington et al., 2007).

The COVID-19 pandemic has exacerbated health inequalities and increased mental health problems at a worldwide scale. Many studies have been published recently that report increased mental health challenges imposed by COVID-19 (Vavidal et al., 2021; Wadoo et al., 2020; Rajkumar, 2020), including specifically among children with ASD (Kalvin et al., 2021). There has also been a "silver lining" of increased access to telehealth services, which long-term may address underlying disparities in healthcare systems through disseminations of more sustainable and equitable practices for delivering efficient mental health care services (Moreno et al., 2020). An online survey of ASD professionals in English highlighted a number of vulnerability factors of individuals with ASD in coping with the COVID-19 pandemic, including challenges related to core ASD characteristics, neuropsychological traits, executive functioning difficulties, and comorbid mental health problems are all vulnerability factors reported by professionals (Bellomo et al., 2020). Results of initial research have indeed shown a significant negative impact of the COVID-19 pandemic on individuals with neurodevelopmental disorders such as ASD (Dekker et al, 2022; Mutluer, Doenyas, & Aslan, 2020; Suzuki & Hiratani, 2021). Individuals with ASD are

particularly vulnerable to the disruptions caused by the COVID-19 pandemic. Lockdowns seeking to stem the spread of the pandemic led to closures of critical support institutions, such as schools, diagnostic and treatment clinics and agencies, and outpatient mental and medical healthcare, as well as support groups and organizations. Online learning, used widely to maintain access to education, has been an insufficient replacement for many autistic individuals, due to their need for specialized direct instruction and hands-on learning. One study examining telehealth adaptation of cognitive-behavioural therapy (CBT) for anxiety in children with ASD found challenges related to distractibility and reduced control of the environment, as well as decreased reciprocity and engagement in sessions (Kalvin et al., 2021). Attempts to provide online educational instruction for autistic students have also substantially increased demands on both educators and families to support students' learning (Hurwitz et al., 2021), often leaving families with little more than recommendations for how to provide instruction themselves (Autism Speaks, 2020). In addition to educational challenges, autistic individuals and their families are also impacted by reduced access to vocational training and supports, home-based intervention, and access to invaluable outlets for leisure (Baweja et al., 2022). Indeed, reduced independence and disruptions to routines were reported by most families of autistic children (Baweja et al., 2022).

Yet the impacts of the pandemic may not be universally negative. One recent study on the psychological impact of the pandemic on autistic individuals showed reduced psychopathology and stress and improved feeding on both caregiver-report and self-report, despite decreases in social interaction and face-to-face relationships, with particular benefits for young adults, perhaps due to reduced stressors related to these external relationships and demands (Lugo-Marin et al, 2021). In contrast, caregivers reported increased levels of stress and anxiety for themselves. The contrast between the experiences of autistic individuals and those of their caregivers in this study

may be at least partially attributable to the already high stress levels for family members of individuals with ASD prior to the pandemic (DesChamps et al., 2020; Kheir et al., 2012; Smith et al., 2010). A study based in Saudi Arabia found that parents of children with ASD reported significantly increased stress and anxiety related to caring for their children with ASD during the COVID-19 pandemic (Althiabi, 2021). Parents of younger children, and mothers in particular, reported the highest levels of anxiety, and parental anxiety and mental health together predicted perceived mental health needs. Parents of autistic children may be particularly vulnerable to the effects of the COVID-19 pandemic and associated lockdowns, to their pre-existing high stress levels which make the added stresses faced by all parents (e.g., unemployment, working from home, caring for typically developing children engaging in online learning, reduced access to social supports) even more impactful.

The objective of the present study is to evaluate the effect of measures taken to control COVID-19 pandemic on the daily functioning and well-being of individuals with ASD and their families in Qatar, a country which has made critical gains in recent decades in expanding access to ASD diagnosis and treatment. Specifically, this study investigates parent-reported impacts of COVID-19 mitigation measures (i.e., lockdowns restricting access to services and requiring families to remain at home) on the daily functioning of autistic children, access to services, and parent psychological well-being. We hypothesized that parental stress would be significantly associated with parent employment status, access to in-home therapy, access to specialized intervention, presence of hired help in the home (e.g., housekeeper, nanny, etc.), and regression in child skills. Of note, hired help in the home is relatively common in Qatar and these untrained individuals often provide substantial support to families in caring for autistic children in the home. Thus, this variable was important to include in this specific cultural context.

#### Method

#### **Study Design**

To examine and evaluate the effect of measures taken to control COVID-19 pandemic on individuals with ASD and their families, a mixed-method approach, collecting quantitative and qualitative survey data from parents of autistic children in Qatar was used. To collect the data, we created a questionnaire to be completed through Google Forms. The survey took place between September and December of 2020. The Participants gave their informed consent via the online platform or by email. This study was approved by [Anonymized for Review] Institutional Review Board (IRB) research ethics committee. All procedures performed were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

#### **Participants**

A convenience sample of 271 parents who self-identified as having at least one child aged between 3 and 18 years with a formal ASD diagnosis was used. All families resided in the State of Qatar during the COVID-19 pandemic. Participants were recruited via online advertisement through various social media channels, organizations (e.g., Qatar Autism Society) and via existing databases of individuals with ASD that have previously given their consent to be contacted for ASD-related research. We contacted parents of children with the diagnosis of ASD by telephone or by e-mail (online form). Those with more than one child with ASD were asked to focus on just one child (of their own choosing) in their responses.

Community Involvement Statement: N/A

#### Instrument and procedure

Google Forms was used to create an online parent survey to be shared through the dissemination of a hyperlink. All participants provided electronic informed consent that contained information about the purpose of the study, procedures, benefits of participating, voluntary participation, and contact information of the researchers. Since no questionnaire existed for evaluating the target concept, the researchers in this study created one. All the survey questions were developed based on the available literature in the subject matter e.g. The Autism Parenting Stress Index (APSI) and the World Health Organization's Quality of Life Questionnaire with Parents of Children with Autistic Disorder (Silva & Schalock, 2012; WHO, 2004). The preliminary version of the questionnaire was revised in an iterative process by three of the authors (FA, SA, and IG). All the researchers involved in data collection are Arabs fluent in both English and Arabic who have extensive experience in ASD research within the Arab community. At times, this was disclosed to participants to increase trust and improve participants' openness in responding to questions. The questionnaire was pilot tested first on a sample of three parents of autistic children to assess the study's measures for reliability, and to establish validity before embarking on the full study. Parents were asked to evaluate appropriateness of response options, time taken to complete it, and clarity of the questions in terms of language, wording, and meaning. Necessary corrections were considered and made by authors as appropriate. All measures and informed consent were then translated from English to Arabic by bilingual researchers in this study to enable families to complete forms in their preferred language [N=58 (21.4%) English, N=213 (78.6%) Arabic]. The final version of the questionnaire was comprised of 36 multiple-choice and open-ended questions about sociodemographic information, the impact of the pandemic on autistic children's daily life, access to information and services/support during the pandemic period, parents' pandemic

experience and primary challenges, and parents' overall health status and stress levels. The survey took approximately 10- 15 minutes to fill out. The survey pertained to the COVID-19 pandemic, and more specifically, the period of confinement and physical distancing in 2020.

#### Data analysis

The final raw data were downloaded from Google Forms into a Microsoft Excel file for analysis using SPSS software (Version 26.0). For the quantitative data, descriptive statistics were used to characterize the sample and examine survey responses. Then, chi square tests were used to investigate the association between parents' stress levels and employment status, access to in-home therapy, access to any sort of specialized intervention, presence of hired help in the home (e.g., housekeeper, nanny, etc.), and regression in child skills. In order to identify the challenges that parents with autistic children face during the pandemic, the qualitative data collected by written responses through semi-structured forms was analyzed using thematic content analysis technique by identifying themes and subthemes and associating them with examples (Roberts et al., 2019). Three authors (FA, SA, and IG) independently evaluated responses and placed them into categories (e.g., social isolation, mental and psychological problems, financial issues, access to regular support, service interruption, etc.). In the rare instances of discrepant category attribution, the authors reached consensus through discussion.

#### Results

#### Sociodemographic information

Parents provided basic sociodemographic information about themselves and their autistic child, including parent gender, nationality, and work status, as well as child age, gender, and diagnoses, along with the number of children at home and membership in ASD advocacy/family support networks. The majority of the participants were female (mothers; 66.4%), and non-Qatari (59.4%).

Almost all fathers (90.4%) were employed, while most mothers (53.9 %) were unemployed. The majority of parents do not work from home (64.9 %) and are members of ASD advocacy and family support networks (67.2%). An average of four children lived at the home, including autistic children. The vast majority of autistic children were male (79.0 %; n=214) with most (62.7%) falling between the ages of 9 and 13. Approximately one-third (31.0%) of the children had co-occurring conditions such as ADHD or epilepsy (see Table 1 for more details).

Survey Responses: Quantitative Analyses of Survey Results

#### Impact of COVID-19 on Children with ASD and Their Families

Parent survey responses indicated that the COVID-19 pandemic has had a significant on children with ASD in Qatar. As seen in Table 2, the majority of parents reported that their children's sleeping schedules had been disrupted or changed since the start of home quarantine (69.4%). Most reported that their children displayed new problem behaviors (52.8 %), such as hyperactivity, tantrums, self-injurious behavior, new stereotyped behaviors, and/or disrupted sleep. Most parents also endorsed a noticeable regression in their children's previously gained skills (54.2%), such as difficulty following instructions, reduced self-help skills, worsening social skills, increased attention issues, and/or reductions in communication and academic skills. Furthermore, most parents (64.6%) attributed specific problems/issues to the challenges of being home all day (e.g., boredom, aggression, mood/irritability issues, etc.). However, the vast majority of parents (73.1%) indicated that their children were still participating in physical activities, either inside or outside the home. The COVID-19 pandemic was also found to have a significant impact on the daily lives of families in this study. The vast majority of parents (97.0%) reported that COVID-19 caused significant changes in their daily routine, reduced social contact (96.7%), and increased their stress levels (58.7%).

Chi square tests were then used to assess the relationship between parental stress levels and key variables of interest, including: parent employment status, access to in-home therapy, access to any sort of specialized intervention, presence of hired help in the home (e.g., housekeeper, nanny, etc.), and regression in child skills. Findings indicated that from the predicted variables (Table 3), parent stress was significantly associated only with a regression in the child's previously gained skills, such that child skill regression was associated with increased parental stress [ $X^2$  (4, N=271) = 12.580, p=.014), such that child regression increased the likelihood of high parental stress thirteen-fold (Likelihood Ratio=13.127).

#### Impact of COVID-19 on Accessing and Receiving Services/Support

As shown in Table 4, the majority of parents in this study stated that they had difficulty receiving support from extended families/friends/community during the pandemic (57.6%), that they could not access usual supports due to COVID-19 (63.1%), that they were only partially or not at all supported by their families and community (55%), and that they did not have access to any online ASD support (e.g. family support groups, therapeutic support) (63.5%). Most also reported that their autistic children were not participating in online learning (58.7 %) and did not receive any intervention sessions from a qualified specialist during the home quarantine period (76.0%).

#### Qualitative Analyses: The Main Challenges Families Face During the Pandemic

Parents' opinions regarding the main challenges they face during the pandemic were analyzed with thematic content analysis (Table 5). The main challenges that parents face during the pandemic are grouped under Social isolation, Mental health/psychological problems, Access to regular support, Service Interruption, Financial and job challenges, Increase in child's negative behaviors and skill regression, Outdoor activities, and Learning/Education challenges. The highest frequency is in the Mental health/Psychological problems, Increase in child's negative behaviors and skills regression categories, Social isolation, and Lack of outdoor activities. The lowest frequency is in

the Financial and job challenges category. The sub-categories with the highest frequency are Regression in gained skills (f=56), Fear from getting the virus (f=30), lack of outdoor activities (f=20), and Restricted all social outing and interaction (f=20).

#### Discussion

This study used parent report surveys to gain insight into the impacts of the COVID-19 pandemic on the lives of children with ASD and their families in the state of Qatar. As expected, parents reported high levels of distress and disruption to their daily lives, as has been widely reported throughout the world. The majority of parents reported that their children's access to activities, education, and treatment was either substantially reduced or non-existent. Parents also reported reduced access to family and social support networks during this critical time of increased stress and strain. Interestingly, parental stress was not significantly associated with support factors, such as access to treatment and social supports, nor was it associated with parental employment status. This is in direct contrast to prior studies of families caring for children with ASD, which routinely find a significant association between familial stress and access to support services (N. Kheir et al., 2012; Pilapil, Coletti, Rabey, & DeLaet, 2017). It is possible that families were under so much stress and strain during this intense period of lockdown that even access to support provided minimal relief.

The data also indicate that families had minimal access to supports and that available supports were routinely of lower quality than those provided prior to the COVID-19 pandemic; thus, the lack of association indicates that the services provided were insufficient to impact family stress levels. Parental stress was significantly associated with child developmental regression, indicating that children whose support needs increased even more during this time due to skill loss

likely increased parental stress. Furthermore, the majority of parents indicated that their children's sleeping habits had been interrupted or changed since the start of home quarantine, that their children had showed negative behaviors and that there had been a clear regression in the children's previously acquired abilities. Beyond the quantitative data collected in this study, the qualitative data analysis provides valuable additional insights into the unique experience of parenting a child with ASD during the COVID-19 pandemic. While many of the experiences endorsed by parents in quantitative data were likely shared by parents of neurotypical children (e.g., reduced access to activities, financial and employment stress, lack of connection to support networks), the qualitative data reveal stressors and experiences unique to parents of children with ASD. Throughout the major themes that emerged, two major underlying threads were clear that connected the stress expressed in each of the themes and subthemes.

Firstly, parents emphasized that they had already been under enormous stress with insufficient support to care for their child prior to the start of the COVID-19 pandemic and subsequent lockdowns. Parents indicated that services for ASD were already scarce and that there was little societal understanding and support for the challenges that they and their children faced prior to the pandemic. Parents in this study shared feeling "forgotten" by society, stating that because their needs were already overlooked and their children ignored prior to the COVID-19 pandemic, it felt clear to them that the unique impact of the pandemic on their children and families was not recognized or considered by society at large. Thus, while they reported concerns that are similar to those echoed by parents of neurotypical children, these concerns emerged in the context of pre-existing distress and unmet support needs. The lockdown was often framed in their comments as a new layer of stress that felt "impossible" to handle on top of their pre-existing experiences.

Secondly, parents highlighted the ways in which their child's symptoms of ASD compounded the stressors of the COVID-19 pandemic lockdown experienced by all families. Although all families experienced stressful disruptions to their daily routines, parents in this study noted that their children relied intensively on predictable routines prior to the pandemic, even more so than their peers, with even small changes having the potential to be highly disruptive. The catastrophic changes wrought by the COVID-19 pandemic were thus felt even more intensely by these families. Similarly, families around the world were negatively impacted by the lack of opportunities for social interaction for their children. The lack of social interaction was particularly worrisome to families in this study, as difficulties with social communication and engagement skills are a core feature of ASD which are targeted directly in treatment and education for these children. Families expressed their worries that the social isolation of the pandemic would lead to further delays in their children and/or loss of skills. Concerns about regression, which occurs much more commonly in children with ASD than in neurotypical children, also emerged across themes. Parents highlighted that not only was their child failing to learn and gain new skills during this time, but that there was a very real risk that their child might lose previously gained skills (and in some cases had already). In addition to developmental regression and skill loss, parents also shared that their children experienced exacerbations in pre-existing negative behaviors or developed new negative behaviors, as a unique expression of the impact of the lockdowns on autistic children. Finally, their children's underlying difficulties with learning and social attention made attempts at online education and intervention, when available, extremely difficult or even impossible to access. Since these learners require different types of instruction, they were often left with recommendations for instruction to be practiced by the families, rather than direct instruction. The online learning format substantially increased demands on both educators and families to support

students' learning around the world (Hurwitz, Garman-McClain, & Carlock, 2021), with minimal time and resources to adapt special education curriculums to online learning with the unique needs of autistic students in mind.

An additional challenge not captured by the present survey is the delay in diagnosis and identification. In addition to the impact on treatment and educational services, diagnostic assessments have also been affected, causing delays in diagnosis for many individuals. This in turn can have severe negative long-term outcomes due to delays in access to treatments and appropriate interventions. Access to early diagnosis and intervention has been shown to be a strong predictor of long-term outcomes (Fuller & Kaiser, 2020; Turner & Stone, 2007), meaning that children whose diagnosis and access to treatment are delayed during this time are at substantial risk for even more negative long-term outcomes with higher support needs.

#### Limitations

The current study also has some limitations. First, like many online research studies, our sample may reflect some degree of selection bias. In particular, we expect certain underestimations of extreme cases, that is, people that were either minimally or very affected by the pandemic. Second, the results of this study are limited to the immediate experience at the onset of the pandemic and, therefore, to the short-term effects of the pandemic. Future studies also need to consider the long-term effects of the pandemic as it is becoming increasingly clear that this pandemic and future pandemics are likely to have a prolonged course.

#### **Conclusions**

The COVID-19 pandemic and recurrent lockdowns have already had an enormous impact on our world, and their effects will clearly be felt for years to come. As vaccinations continue to become more available and access to services and education steadily increase, we cannot simply

"go back to normal." It will be critical for providers and educators to consider the effects of the ongoing pandemic on children's development, academic progress, and emotional well-being. Moreover, the medical community has an obligation learn from this crisis and to support families with ASD in navigating burdensome times to enable children with ASD to thrive. As evidenced by the high levels of distress described by parents in this study, the development of personalized formulation-based-psycho-social interventions to support and engage individuals with ASD and their caregivers to help cope with the consequences of the pandemic and similar waves in the future is critical (Bellomo et al., 2020). As highlighted in this study, there have been substantial disruptions to the lives and developmental progress of children with ASD. These disruptions will have lasting effects on their skills, including potential skill loss. Adjustments will need to be made to educational and treatment planning that adjust developmental and educational goals to remediate skills and begin helping children to catch up on lost time. The emotional impacts of this time will also need to be considered, including that many children may have had a trauma reaction to the disruptions in their routines and lives. Trauma-informed approaches to both treatment and education are likely to have much more relevance in the field of ASD going forward than they have in the past.

There will be a pressing need for society to not only stop neglecting the needs of autistic children and their families, but to begin actively supporting them in enhanced ways. Local and national governments will need to consider increased supportive initiatives for psychological support, financial support, training workshops, and online sessions for families and providers. This should also include additional supports and incentives for provider and teacher training in ASD. The interruption of service provision whether home-, school-, or center-based, by experienced and highly skilled multi-disciplinary professionals is expected to have a negative effect on these service

providers as they have acquired their skills and continue to enhance them through their daily practices while working with individuals with ASD. This has also limited opportunities for trainees to develop critical skills needed for working in ASD. Reduced training opportunities will in turn mean fewer qualified providers are available, in a system that is already unable to fully meet the needs of autistic children. Increasing access to services through supports to providers will also be critical. Moving forward into the "new normal," governments around the world will need to make significant and lasting investments in training, family support, education, and services for this vulnerable group of children and their families. The greater impact of the pandemic on the children with ASD and their families emphasizes the need for accessible and affordable (continued) health, education, and family services to manage their special and immediate needs.

#### References

- Althiabi, Y. (2021). Attitude, anxiety and perceived mental health care needs among parents of children with Autism Spectrum Disorder (ASD) in Saudi Arabia during COVID-19

  Pandemic. Research in Developmental Disabilities. 111:103873.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596.
- Baweja, R., Brown, S.L., Edwards, E.M. et al. (2022) COVID-19 Pandemic and Impact on Patients with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 52, 473-482. doi <a href="https://doi.org/10.1007/s10803-021-04950-9">https://doi.org/10.1007/s10803-021-04950-9</a>.
- Bellomo, T. R., Prasad, S., Munzer, T., & Laventhal, N. (2020). The impact of the COVID-19 pandemic on children with autism spectrum disorders. *Journal of Pediatric Rehabilitation Medicine*, 13(3), 349-354.

- Boyd, B. Odom, S.L., Humphreys, B.P., & Sam, A.M. (2010). Infants and Toddlers with Autism Spectrum Disorder: Early Identification and Early Intervention. *Journal of Early Intervention*, 32 (2): 75-98.
- Dawson G, Rogers S, Munson J, et al. (2010). Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*, 125(1):e17–e23.
- Dekker L, Hooijman L, Louwerse A, et al. (2022). Impact of the COVID-19 pandemic on children and adolescents with autism spectrum disorder and their families: a mixed-methods study protocol. *BMJ Open 12*: e049336. doi: 10.1136/bmjopen-2021-049336
- DesChamps, T.D., Ibañez, L.V., Edmunds, S.R., Dick, C.C. and Stone, W.L. (2020). Parenting stress in caregivers of young children with ASD concerns prior to a formal diagnosis.

  \*Autism Research. 13: 82-92.
- Elder, J.H. (2016). Assisting parents in adapting and making decisions regarding the most efficacious treatment options. In: Giarelli E, Fisher KM, editors. *Integrated Health Care for People with Autism Spectrum Disorders: Interdisciplinary Planning and Delivery of Care*. Springfield, IL: Charles C. Thomas, Publishers Ltd; pp. 173–192.
- Fuller, E. A., & Kaiser, A. P. (2020). The effects of early intervention on social communication outcomes for children with autism spectrum disorder: A meta-analysis. *Journal of Autism and Developmental Disorders*, 50(5), 1683-1700.
- Hurwitz, S., Garman-McClaine, B., & Carlock, K. (2021). Special education for students with autism during the COVID-19 pandemic: "Each day brings new challenges." *Autism*, 13623613211035935.

- Kalvin, C.B., Jordan, R.P., Rowley, S.N. et al. (2021). Conducting CBT for Anxiety in Children with Autism Spectrum Disorder During COVID-19 Pandemic. *Journal of Autism and Developmental Disorders*, 51, 4239-4247.
- Kheir, N., Ghoneim, O., Sandridge, A. L., Al-Ismail, M., Hayder, S., & Al-Rawi, F. (2012).

  Quality of life of caregivers of children with autism in Qatar. *Autism*, 16(3), 293–298.

  https://doi.org/10.1177/1362361311433648
- Lugo-Marin, J, Ramos-Quiroga, J. (2021). COVID-19 Pandemic Effects in People with Autism Spectrum Disorder and their Caregivers: Evaluation of Social Distancing and Lockdown Impact on Mental Health and General Status. *Research in Autism Spectrum Disorder*. 83:101757.
- Moreno, C., Wykes, T., Galderisi, S., et al. (2020). How Mental Health Care Should Change as a Consequence of the COVID-19 Pandemic. *The Lancet Psychiatry*. 7(9): 813-824.
- Mutluer, T., Doenyas, C., and Aslan, Genc H. (2020). Behavioral Implications of the Covid-19

  Process for Autism Spectrum Disorder, and Individuals' Comprehension of and Reactions to the Pandemic Conditions, *Frontiers in Psychiatry*, 11:561882. doi:

  10.3389/fpsyt.2020.561882
- Newlove-Delgado, T., McManus, S., Sadler, K., Thandi, S., Vizard, T., Cartwright, C., & Ford, T. (2021). Child mental health in England before and during the COVID-19 lockdown.

  The Lancet Psychiatry, 8(5), 353-354.
- Pilapil, M., Coletti, D. J., Rabey, C., & DeLaet, D. (2017). Caring for the Caregiver: Supporting Families of Youth with Special Health Care Needs. *Current Problems in Pediatric and Adolescent Health Care*, 47(8), 190–199. https://doi.org/10.1016/j.cppeds.2017.07.003

Rajkumar R. P. (2020). COVID-19 and mental health: A review of the existing literature. *Asian journal of psychiatry*, 52, 102066. https://doi.org/10.1016/j.ajp.2020.102066

- Remington B, Hastings RP, Kovshoff H, et al. (2007). Early intensive behavioral intervention: outcomes for children with autism and their parents after two years. *American Journal on Mental Retardation*,112(6):418–438.
- Roberts, K., Dowell, A., & Nie, J.-B. (2019). Attempting rigour and replicability in thematic analysis of qualitative research data; A case study of codebook development. *BMC Medical Research Methodology*, 19(1), 1–8. https://doi.org/10.1186/s12874-019-0707-y
- Silva, L. M. T., & Schalock, M. (2012). Autism parenting stress index: Initial psychometric evidence. *Journal of Autism and Developmental Disorders*, 42, 566-574.
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010).

  Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders2*, 40(2), 167–178.

  https://doi.org/10.1007/s10803-009-0844-y
- Stahmer, A., Collings, N.M., & Palinkas, L.A. (2005). Early Intervention Practices for Children with Autism: Descriptions from Community Providers. *Focus on Autism and Other Disabilities*, 20 (2): 66-79.
- Strain, S. P., Schwartz, S.I., & Barton, E.E. (2011). Providing Early Interventions for Young Children with Autism Spectrum Disorders: What We Still Need to Accomplish. *Journal of Early Intervention*, 33 (4): 321-332.

- Suzuki, K., & Hiratani, M. (2021). Impact of the COVID-19 Pandemic on Children with Neurodevelopmental Disorders When School Closures Were Lifted. *Frontiers in* 
  - Pediatrics, 9, 789045. https://doi.org/10.3389/fped.2021.789045

- Turner, L. M., & Stone, W. L. (2007). Variability in outcome for children with an ASD diagnosis at age 2. *Journal of Child Psychology and Psychiatry*, 48(8), 793-802.
- Vadivel, R., Shoib, S., El Halabi, S., et al. (2021). Mental health in the post-COVID-19 era: challenges and the way forward. *General Psychiatry 2021;34*:e100424. doi: 10.1136/gpsych-2020-100424
- Vivanti, G. & Dissanayake, C. (2016). Victorian ASELCC Team Outcome for children receiving the Early Start Denver Model before and after 48 months. *Journal of Autism and Developmental Disorders*, 46(7):2441–2449.
- Wadoo O, Latoo J, Reagu SM, et al. (2020). Mental health during COVID-19 in Qatar. *General Psychiatry*, 33:e100313. doi: 10.1136/gpsych-2020-100313
- Warren, Z., McPheeters, M., Sathe, N., Foss-Feig, J., Glasser, A., & Veenstra-VanderWeele, J. (2011). A Systematic Review of Early Intensive Intervention for Autism Spectrum Disorders. Official Journal of the American Journal of Pediatrics, 127(5):E1303-E1311.
- Wiggins, L.D., Baio, J., & Rice, C. (2006). Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Developmental and Behavioral Pediatrics*, 27(2), S79-S87.
- World Bank. (2022). Global Economic Prospects, January 2022. Washington, DC: World Bank. doi: 10.1596/978-1-4648-1758-8. License: Creative Commons Attribution CC BY 3.0 IGO.

- World Health Organization. (2004). The World Health Organization quality of life (WHOQOL) BREF, 2012 revision. World Health Organization. *Pediatrics*, 136:S60-S81.
- YoungMinds. (2020). Coronavirus: Impact on young people with mental health needs; survey 2: summer 2020. London: *YoungMinds*.
- Zwaigenbaum, Kasari, et al. (2015). Early Intervention for Children with Autism Spectrum

  Disorder Under 3 Years of Age: Recommendations for Practice and Research.

EFFECTS OF COVID-19 ON AUTISM SPECTRUM DISORDER IN QATAR

Table 1: Sociodemographic Information of Children with ASD and Their Parents

	n with ASD and Their	Parents
Variable	N (Total N=271)	%
Parent gender		
Female	187	69.0 %
Parent nationality (Qatari v. Non-Qatari)		
Qatari	110	40.6 %
Parental employment status		
Employed fathers	245	90.4 %
Employed mothers	125	46.1 %
Employed parent currently working from home	95	35.1%
Member of ASD advocacy/support group	182	67.2%
Child gender		
Male	214	79.0 %
Child age range		77.0 70
3 to 8	81	29.9 %
9 to 13	170	62.7 %
14 to 18	12	4.4 %
above 18	8	3.0 %
Child ASD diagnosis		J.0 70
ASD	260	05.004
ASD: High Functioning	4	95.9%
ASD and Down syndrome		1.5 %
ASD: Nonverbal	4	1.5 %
	3	1.1 %
hild co-occurring conditions present	84	31.0 %

Table 2: Impact of COVID-19 Children with ASD and Their Families

Survey Question	Yes (N)	% Yes
Is your child practicing any physical activity inside the home or outdoors?	198	73.1 %
Did your child's sleeping schedule change since the start of the home quarantine?	188	69.4 %
Did your child exhibit any negative behaviors since the start of the home quarantine?	143	52.8 %
Did you face any problems/issues with your child being at home all day?	175	64.6 %
Since the start of the home quarantine, did you notice any regression in your child's		
previously gained skills?	147	54.2 %
Has your family been reducing social contact as a result of COVID19?	262	96.7 %
Has COVID-19 led to significant changes in your family's daily routine?	263	97.0 %
Survey Question	N	%
On a scale of 1-5, how would you rate your stress level during this time:		
Not stressed at all	16	5.9 %
Normal level of stress	50	18.5 %
Neutral	46	17.0 %
Stressed	85	31.4 %
Very stressed	74	27.3 %
4 × × × × × × × × × × × × × × × × × × ×		1.

Table 3: Summary Results of Chi Square Tests of Predictors with Parent Stress Level

Pearson's X <sup>2</sup>	Likelihood Ratio
1.441 (4, N=271; p=.837)	1.501
4.050 (4.37.2	
4.838 (4, N=271; p=.302)	4.903
11.0-6	
11.972 (4, N=271; p=.152)	14.446
7.905 (4, N=271; p=.443)	7.720
11.522 (4, N=271; p=.485)	11.236
10.500 //	
12.580 (4, N=271; p=.014)	13.127
	Pearson's X <sup>2</sup> 1.441 (4, N=271; p=.837)  4.858 (4, N=271; p=.302)  11.972 (4, N=271; p=.152)  7.905 (4, N=271; p=.443)  11.522 (4, N=271; p=.485)  12.580 (4, N=271; p=.014)

#### Table 4: The Impact of COVID-19 on Accessing and receiving services/support

Survey Question	Yes (N)	% Yes
Did you find difficulty receiving support from your extended		
family/friends/community during this time?	156	57.6 %
Is your child with ASD presently participating in online learning?	112	41.3 %
Is your child receiving any intervention sessions from a qualified specialist during		
the period of the home quarantine?	65	24.0 %
Does your family presently have access to any online ASD support (e.g., family		
support groups, therapeutic support, etc.)?	99	36.5 %
Is there any type of support that your family usually receives but cannot access in		
the meantime because of COVID-19?	171	63.1 %
Survey Question	N	0/0
On a scale of 1-4, how supported do you feel, whether from other family		
members, the community, etc.		
Not supported at all	65	24.0 %
Slightly supported	84	31.0 %
Supported	76	28.0 %
Very supported	46	17.0 %

#### EFFECTS OF COVID-19 ON AUTISM SPECTRUM DISORDER IN QATAR

Table 5: The main challenges families face during the pandemic

Theme	Subthemes	f	Quotations
1. Social isolation	Abrupt Social Change and social anxiety Restricted all social outing and interaction	20	"The mandatory home quarantine has protected my family; however, it has also caused isolation and social anxiety in my son with ASD."  "Social isolation was difficult for the whole family."  "City closure and quarantine restricted or diminished all social outings and opportunities for children to go out, interact, exert energy."
	Total	(13.5%)	"The social isolation affected us all negatively as a family."
2. Mental health/psychological problems	Anxiety	10	"I became anxious about cleanliness, not seeing our families."  "Fear of regression and integrating back into society and social life after quarantine."
	Depression	5	"Being at home all day with the kids was difficult for me and them."
71	Family Stress	10	"The pandemic has added more stress to an already stressful situation. Autistic children have daily routines when that routine is disrupted it has a mental and physical effect on the families and on the child with ASD We have been lockdown since March no one has bothered to ask the already struggling family's how to cope with the lockdown."
			"The online learning is a struggle, and the interruption of all additional therapies that were supporting my son's progress has caused a real stress and regression on our family and on his skills."
		14	"Interruption of therapy and negative effect on my child, and caused high stress in our home."
	Fear of getting the virus	30	"My wife and I are both frontline healthcare workers, this has made it very difficult physically and psychologically straining and caused anxiety as we were worried that we would bring the virus home or catch the virus and then we would have to be quarantined away from our child. This is especially difficult for expat families who have no one here."
			"Emotional and psychological effects of the quarantine (depression, anxiety, fear for catching the virus), fear that the child with ASD contracts the virus, how he would be able to handle self-quarantine (it would be impossible)."
			"Scared my kid would get the virus, who would take care of him if I had COVID: I am a single Mom and don't have family here."
			"Fear of getting the virus and fear that if mother or father get the virus, who would take care of the child with ASD during the time of quarantine or probable serious health complications."
	Health and psychological impact on children	10	"This epidemic has negative effects on the student's psyche. Children with special needs do not understand quarantine and not go out, do not like to sit at home. The school was an outlet for them."

			"The usual stress out because we can't see family and scared for them."
			"Restricted movement and mental stress."
			"My child and wife went to Egypt before the COVID-19 spread in Qatar, they couldn't return and now he had to be registered in a center in Egypt while they wait for the return, and it is not safe there in terms of prevention measures, and also my son's condition is much worse now because of this big change. This time has been very challenging for us."
	Feeling negative	3	"Job stress, interruption of everything"
	Total	68 (26.3%)	"Paralyzed our life and put us in really threatening issues"
3. Accessing to regular support	Restricted Access to Therapeutic support and	4	"Difficulty accessing Therapeutic support, medical care when we needed, and overall support from friends and community as we had been quarantined."
	medical care		"Doctors' appointments stopped, and we didn't know when they will return."
	Loss of support from the center and family	12	"Loss of support from the center and family".
	Total	16 (6.2%)	
4. Services interruption	Change in family daily routine and activities	12	"The interruption and complete change of our daily activities and routines this period has affected our child's progress very negatively Overall got worse in everything".
	Interruption of intervention services	20	"Everything in the ASD service provision is profit based, everything is expensive, everything is a "show", it is so hard to find quality intervention, the change in the daily routine affected my child greatly"
			"There was a definite negative effect from the stop of intervention"
			"The interruption of all activities and therapies that I was doing for my child to develop her social and communication skills. the interruption of services and social gatherings to me is considered the most negative aspect of COVID-19 time".
	Total	22 (8.5%)	W. T. Lord Lowing this time as this was one of the added
5. Financial and job challenges	Financial strain	5	"My wife lost her job during this time, so this was one of the added stresses for us as a family, the financial strain and fear for job loss for me as well. this was definitely a stressful time for everyone".
	Fear for job loss add stressors	6	"All life and daily routine changes associated with the quarantine and how COVID-19 affected our lives was a challenge and continues to be a challenge. Fear for job loss is also a challenge".
			"Worry about if our son worsens (due to the social isolation) and also the stress due to the financial impact of COVID-19 on all jobs in the

# 

	Total	11 (4.2%)	"All measures taken were in our favor to protect our families and residents in Qatar. The only negative aspects are the financial strains and stress from fear job loss as this has affected the economy".
6. Increase in child's negative behaviors and skills regression	Regression in gained skills	56	"Challenge to convince a child of why they can't go out, left alone a child with communication issues. Intervention stopped and child regressed."
			"Fear of child regressing."
	Behavioral challenges	10	"It was a big struggle for me not being able to deal with my child's behavior and feeling that I can't help continuing the intervention at home."
			"Regression in skills due to stop of intervention, trying to give them useful activities to do, stress, social isolation, lack of leisure activities."
			"Communication and behavioral regression in my child as a result of being home all day and stopping of intervention, social isolation, lack of leisure or extracurricular activities."
	Total	66 (25.5%)	
7. Outdoor activities	Lack of outdoor and leisure activities	20	"Lack of social outings, leisure activities, and social interaction due to the quarantine."  "Closure of everything, no leisure activity, not even beaches or parks, everything was closed, it was hard, and we weren't able to take him out to exert some energy."
	Travelling restriction	7	"Social isolation, not being able to travel"
	Total	27 (10.4%)	
8. Learning/ Education challenges	Lack of trust on online learning	3	"The online learning is not working out for us. It is not enough for our child and this type of learning isn't for all learners".
	School closure&	6	"Regression in education and daily skills"
	regression in education		"Fear of lowering his school level".
	Lack of educational programs for special needs and extracurricular	5	Stopped extracurricular activities, school closures, social isolation, etc**
	Total	14 (5.4%)	