Autism Spectrum Disorder Behavioral Implications of the Covid-19 Process, and Individuals’ Awareness and Reactions to Pandemic Conditions based on California, USA

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ABSTRACT

Vulnerable populations, such as patients with mental illnesses, are known to be overly influenced during disasters and pandemics. However, little is known about how people with autism spectrum disorder (ASD), one of the most common neurodevelopmental conditions in the world with a prevalence of 1%, are affected by health-related disasters, particularly the current Covid-19 pandemic. We investigated how individuals with ASD responded to Covid-19 in terms of comprehension and adherence to implemented measures; changes in their behavioral problems; and how the anxiety levels of their caregivers relate to these behavioral changes. Our sample consisted of 50 individuals with ASD (30 male and 20 female; ages ranged from 3 to 14). The majority of our participants had trouble grasping what Covid-19 is and the measurements it necessitates. They also encountered difficulties in implementing pandemic-related social distance and hygiene regulations. During this time, the majority of students stopped receiving special education. In terms of increased stereotypes, aggression, hypersensitivity, behavioral problems, and sleep and appetite changes, we observed a Covid-19-related clinical presentation that resembled PTSD in individuals with ASD. Aberrant Behavior Checklist (ABC) subscales differed significantly before and after the pandemic conditions. There were differences among the caregivers’ anxiety levels between the current behavioral problem levels to the behavioral problem levels prior to the pandemic. The difference in ABC total score, and specifically the lethargy/social withdrawal subscale score, predicted the anxiety score of the parents. Our findings suggest that the Covid-19 period poses unique challenges for people with ASD and their caregivers, emphasizing the importance of targeted, distance special education interventions and other support services for this population.

Key words:
Autism Spectrum, Disorder Behavior, Covid-19, Awareness, Pandemic Conditions, California

4/23/2021

Source of Support: None, No Conflict of Interest: Declared

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**INTRODUCTION**

Individuals with severe and chronic mental illnesses are disproportionately affected by disasters and plagues such as Covid-19 (Druss, 2020). However, there appears to be little evidence on how people with Autism Spectrum Disorder (ASD), one of the most common neurodevelopmental conditions in the world, react to disaster situations. With the numerous disasters around the world, such as terrorist attacks, tsunamis, hurricanes, bombings, and earthquakes, a lack of focus on the psychological implications for children with ASD became apparent (Edmonds, 2017). However, aside from one study that found individuals with ASD to have decreased adaptive behaviors after being exposed to an earthquake, and another that found disaster awareness training to increase disaster preparedness in children with ASD, there is no data on how people with ASD react to disasters in general (Indriasari and Widyarani, 2018). Furthermore, aside from previous disasters, there is no information on how people with ASD are affected by pandemics. The effects of the global lifestyle changes caused by the Covid-19 pandemic on the autism population, in particular, are unknown. Given their complex profiles of social interaction problems, restricted activities, and having special education as the only validated intervention, individuals with ASD are likely to encounter difficulties beyond those faced by the general public, as well as other psychological, physiological, and social ramifications for this population, which is the subject of the current investigation.

Pandemics are similar to other disasters in their unpredictability, fatalities, and long-term effects; however, they differ from disasters in that they prevent victims from converging and gathering, necessitating the opposite reactions of separation, isolation, and quarantine, which end up interfering with family norms and rituals that generally protect family functioning during crises. Such rituals are especially important in the ASD population, where repetitive behaviors and interests are a defining feature of the condition and affected individuals follow strict daily rituals. Pandemics of infectious diseases, in addition to their health and fatality consequences, are known to cause widespread anxiety and psychological problems (Liu *et al.*, 2020).

The risk factors associated with Covid-19 Zhang’s hypotheses for children with ADHD appear to be applicable to individuals with ASD as well, particularly the loss of daily routine, inability to access and receive care from primary care settings, and increased parental worry, all of which exacerbating children’s psychological well-being and increasing their behavioral problems (Zhang *et al.*, 2020). ASD is characterized by difficulties in social communication as well as limited and repetitive areas of interest that begin in childhood and typically last a lifetime. According to the most recent incidence rate, it affects one out of every 54 people (Baio *et al.*, 2018). The majority of patients have comorbid intellectual disability as well as other psychiatric conditions such as ADHD, anxiety disorders, disruptive/impulse-control/conduct disorders, depressive disorders, and obsessive-compulsive disorder (Lai and Baron-Cohen, 2015). According to developmental pediatrician Sharon Smile, children with ASD are “vulnerable to the effects of prolonged isolation and quarantine and may have trouble adapting to this new type, particularly as inflexibility and emphasis on sameness are hallmark characteristics of this disorder.” She stresses the need for easily enforced programs that meet the needs of children with ASD (Smile, 2020). One such program was described in Italy, where researchers developed a protocol based on observations and discussions with parents after parents of children with ASD reported that their children were no longer satisfied with their usual reinforcers, were becoming increasingly uncooperative, and displayed high levels of stereotypy and problem behavior.
There is little known about the effects of Covid-19-related changes in living conditions on people with ASD. Our clinical observations and feedback from patients and caregivers indicate the presence of specific adversities experienced by this population during the pandemic. These adversities can be divided into four categories. To begin, people with ASD appear to have a different understanding and knowledge of Covid-19 than their peers. This can be explained by differences in abstract thinking, because comprehending the non-visible and non-concrete concept of Covid-19, as well as its potential health threats, including death, and related reasoning, all require abstract thinking (Minshew et al., 2002).

Firstly, people with ASD may be unable to understand, follow, and benefit from basic preventive methods designed for the general population, which may be inapplicable or difficult for this group. We observed specific challenges with social distancing and tolerating long periods of home-isolation. This is supported by a recent article written by an ASD researcher who emphasizes the importance of support for individuals with ASD to cope with the anxiety of Covid-19 while highlighting the absence of both social and professional support due to social distancing measures, as well as the potential mental health consequences of reduced access to their already limited support networks (Houting, 2020). Second, people with ASD have strict daily routines, and the isolation process can disrupt those routines by changing them, such as going to school or special education at a specific time. Third, individuals with ASD can expect their symptoms and behavioral disturbances to worsen as intensive behavioral and educational interventions that are effective in creating positive change in these domains are interrupted (National Autism Center National Standards Project, 2015). This adversity is expected to grow in significance as the pandemic is expected to last for some time. Interruptions in behavioral and educational interventions may exacerbate ASD symptoms and behavioral problems in people with ASD. Finally, caregivers of ASD children report significantly higher levels of stress and anxiety than caregivers of typically developing children. Social support has been shown to be a stress-reducing factor in parents of children with ASD, with support from friends emerging as the most important factor, and support from significant others and family emerging as less potent protectors (Drogomyretska et al., 2020). This social support from friends, which is so important for stress reduction in caregivers of children with ASD, is likely to become less available during the Covid-19 social isolation measures. Furthermore, parents of autistic children had a higher cortisol response to psychosocial stress than parents of typically developing children, indicating an increased physiological reactivity to acute psychosocial stress (Pattini et al., 2019). As a result, the stress and anxiety levels of parents, as well as the difficulties experienced by children, including but not limited to behavioral problems, may exacerbate each other over the course of the pandemic.

Some Covid-19-related situations, on the other hand, may be easier for some children with ASD and their families to deal with. Individuals with ASD have a higher adherence to rules and routines, as well as aversion to socialization and physical contact, which may make it easier to follow mandated hygiene measures such as frequent hand washing or avoiding physical contact with people or surfaces. The risk of sensory overload may be reduced because the children will be out of the house less frequently as a result of the home confinement measures. Asbury et al. discovered in a recent qualitative study of children with special needs, the majority of whom have ASD, and their parents that a small proportion of participants reported some positive effects of the quarantine, such as not experiencing the challenges of daily routines (Asbury et al., 2020). However, these ASD-related strengths for dealing with Covid-19 measures are likely to be limited and will not compensate for the resulting challenges.
We conducted one of the earliest studies, especially amongst high school students, to the best of our knowledge about the effects of Covid-19-related life changes on individuals with ASD, based on our observations through surveys of our volunteer autistic family groups, as well as previous reports and findings. Our three hypotheses were: 1) individuals with ASD would have a poor understanding of Covid-19 and related measures; 2) During the pandemic, their ASD symptoms, behavioral problems, sensory sensitivity, and sleep habits may have worsened. 3) Their caregivers’ anxiety levels would have increased during the pandemic.

**METHODS**

**Participants**

Our sample included 50 people with ASD from the Pacific Autism Center for Education (Santa Clara, CA) and Academy of Music and Arts for Special Education (Cupertino, CA) with 30 (60%) being male and 20 (40%) being female. The inclusion criterion was that the child had been diagnosed with ASD using DSM-5 criteria by a child psychiatrist with more than 10 years of experience in ASD. These patients are followed up on every two months in the child psychiatry outpatient unit and have up-to-date medical records of their evaluations. A severe neurological disease or a complex genetic syndrome was an exclusion criterion.

**Procedure**

In our research group, we had several members associated with ASD patients volunteering. So we invited them to participate. We sent families an online survey link containing the written informed consent, socio-demographic form, and the following questions and questionnaires after they verbally consented to participate in the study. Individuals with ASD were asked about their understanding of Covid-19, communication methods, and reactions to pandemic measures. Whether tics, stereotypical behaviors, or appetite were affected was one of the questions. Before and during the Covid-19 measurements, the sensory hypo/hypersensitivity level, Aberrant Behavior Checklist (ABC), and sleep parameters were all questioned. The Beck Anxiety Inventory (BAI) was used to assess the anxiety level of the primary caregivers only in the present. Aside from the parent-reported surveys, relevant data from medical records were gathered.

**Measures**

*Socio-demographic classification*

A socio-demographic form was used to collect information such as the participant’s age, gender, educational level, special education status, and the number of siblings.

*Clinical registration data*

In order to determine our sample characteristics, we collected ASD-related clinical information online. We graded autism severity using the DSM-5’s definition of the appropriate level of help; language level as the three categorizations of “absence of language,” “speech via words only,” “speech via sentences”; and IQ as indicated through “no intellectual disability (ID) or borderline IQ,” “mild ID,” and “moderate or severe ID.” We recorded other psychiatric comorbidities and assessed their severity according to the Clinical Global Impression scale with ratings ranging between 1 (Normal, not at all ill) and 7 (among the most extremely ill patients).
Pandemic-related questions

These questions tested our participants’ knowledge and comprehension of Covid-19, adaptation to Covid-19-related measures, special education situation. And parents addressed questions such as how much their autistic child understands the pandemic, the child’s level of understanding of the explanations made when he/she wants to go out, reactions to the use of masks, gloves, disinfectants, if they are continuing their education, and if they are using conference or other communication applications.

Aberrant Behavior Checklist (ABC)

A parent-reported aberrant behavior checklist (ABC) for their child for the present and before the pandemic measures began was used to assess changes in ASD-related symptoms and behavioral problems after one and a half months of Covid-19-related measures. This data was cross-referenced and supplemented by the cross-referenced additional questions on the questionnaire.

ABC is a four-point Likert type scale, which was developed to evaluate the behavioral problems observed in individuals with ASD and intellectual disabilities (Aman et al., 1985). It has been used to measure the effects of pharmacological, behavioral, and other treatments on these behaviors (Aman et al., 2004). It has 58 objects that are broken down into five subscales. The subscales and the numbers of items are as follows: (a) irritability (15 items), (b) lethargy/social withdrawal (16 items), (c) stereotypic behavior (7 items), (d) hyperactivity/noncompliance (16 items), and (e) inappropriate speech (4 items). Three items from the irritability factor can be used to calculate a score for the self-injury factor. A total combined score of 3 or higher indicates severe self-injury (Brinkley et al., 2007).

Beck Anxiety Inventory (BAI)

We used BAI to assess the level of anxiety among primary caregivers during the pandemic. The BAI is a four-point Likert scale questionnaire that assesses the severity of self-reported anxiety. It consists of 21 items with scores ranging from 0 (not at all) to 3 (severely). Anxiety levels are classified as minimal (0–7 points), mild (8–15 points), moderate (16–25 points), and severe (26–63 points) based on the total BAI score.

Analysis

Statistical analyses were performed using the Python version 3.8. Depending on the nature of the data, descriptive data were reported as numbers and percentages. The paired samples t-test and multivariate repeated measures ANOVA tests were used to compare continuous variables before and during the pandemic. To determine the relationship between continuous variables, Spearman correlation analyses were performed. To find child-related predictors of parent anxiety, we used a linear regression analysis.

RESULTS

Our participants were aged between 3-14 years. They included 20 girls (40%) and 30 boys (60 %). The socio-demographic information about the participants is depicted in Table 1. Comorbidity was common in a clinical ASD sample, all of the participants having at least one psychiatric comorbid condition. 34% of those in this sample had ADHD, 30% had mood disorders, 16% had tic disorders, and 20% had anxiety disorders.
Table 1: Socio-demographic information.

| Characteristics                  | Categories          | Participants |     |
|----------------------------------|---------------------|--------------|-----|
|                                  |                     | Number       | Percentage |
| Child’s age                      | 3-5                 | 10           | 20%          |
|                                  | 6-10                | 21           | 42%          |
|                                  | 11-14               | 19           | 38%          |
| Child’s gender                   | Male                | 30           | 60%          |
|                                  | Female              | 20           | 40%          |
| Educational status               | Kindergarten        | 21           | 42%          |
|                                  | Elementary school   | 15           | 30%          |
|                                  | Middle school       | 4            | 8%           |
|                                  | No school           | 10           | 20%          |
| Receiving special education      | Yes                 | 38           | 76%          |
|                                  | No                  | 12           | 24%          |
| Severity of autism (DSM-5 based) | Severe              | 14           | 28%          |
|                                  | Moderate            | 25           | 50%          |
|                                  | Mild                | 11           | 22%          |
| Verbal ability                   | Can speak with sentences | 17     | 34%          |
|                                  | Can speak with words | 20       | 40%          |
|                                  | Cannot speak at all | 13           | 26%          |
| Intellectual disability          | None or borderline  | 9            | 18%          |
|                                  | Mild                | 21           | 42%          |
|                                  | Moderate or Severe  | 20           | 40%          |
| Psychiatric comorbidities        | ADHD                | 17           | 34%          |
|                                  | Mood disorders      | 15           | 30%          |
|                                  | Anxiety disorders   | 10           | 20%          |
|                                  | Tic disorders       | 8            | 16%          |
| Medical comorbidities            | All medical comorbidities | 36     | 72%          |
|                                  | Epilepsy comorbidity | 14         | 28%          |

Figure 2 contains parent-reported data on their child’s comprehension of Covid-19-related requirements, adaptation to Covid-19-related requirements, special education condition, and access to online services. Table 3 shows parent reactions to behavioral, appetite, sleep, and other problems their children had during the pandemic. When asked about changes their child during the pandemic, 42% of parents said their child became more aggressive, 34% said their child’s tics increased or new tics appeared, 30% said their child’s communication skills deteriorated, and 52% of parents reported as appetite increased and 62% parents said sleep decreased, respectively.

Our findings show that ASD-related behaviors, sleep quality, and hypersensitivity all changed significantly between before and during the pandemic. It compares the total and sub scores of the Aberrant Behavior Checklist (ABC) before and after the Covid-19 measures using a paired-samples t-test. According to our findings, participants’ ASD-related behaviors increased overall, and this increase was seen across all subscales, including irritability, lethargy/social withdrawal, stereotypical behavior, hyperactivity, and inappropriate speech.

Figure 4 shows parents' anxiety levels before and during the Covid-19 period with their children’s behavioral issues as measured by the ABC total score before and during the Covid-19 period.
Figure 2: Individuals with ASD with Covid-19-related understanding and problems, as reported by their parents.

Table 3: Behavioral and other issues reported by parents during the pandemic.

| Question                                                                 | Response                                           | Frequency (%), number (n) |
|-------------------------------------------------------------------------|----------------------------------------------------|---------------------------|
| Problems related to ASD                                                 | Communication skills deteriorated                   | 30% (15)                  |
|                                                                          | Stereotypies increased                             | 58% (29)                  |
|                                                                          | Hypersensitivity increased                         | 12% (6)                   |
| Behavioral problems other than ASD                                      | Aggression                                         | 42% (21)                  |
|                                                                          | Hyperactivity                                      | 24% (12)                  |
|                                                                          | Tics (increased or new tics emerged)               | 34% (17)                  |
| Appetite                                                                | Increased                                          | 52% (26)                  |
|                                                                          | Decreased                                          | 48% (24)                  |
| Sleep                                                                    | Increased                                          | 38% (19)                  |
|                                                                          | Decreased                                          | 62% (31)                  |

Parental anxiety had changes with the child’s total ABC score prior to the pandemic. Parent anxiety significant difference with the child’s total ABC score during the pandemic, and with the irritability, hyperactivity, and inappropriate speech subscales. All of the significant associations are positive, implying that a rise in child behavior in the associated domain or subscale leads to a rise in parent anxiety.
Choi et al.: Autism Spectrum Disorder Behavioral Implications of the Covid-19 Process, and Individuals’ Awareness and Reactions to Pandemic... (29-40)

By subtracting the previous (pre-pandemic) from the current (during pandemic) scores of the ABC total scale and ABC subscales, we provided new variables of difference scores. Then, to look at the predictors of current parent anxiety, we ran two separate linear regression analyses, one with the ABC total difference score and the other with the ABC subscale difference score as predictors. We found that the difference in ABC’s total score and ABC’s lethargy/social withdrawal subscale score predicted the total score of the parents’ anxiety. The anxiety of parents was not significantly predicted by differences in other ABC subscales.

**DISCUSSION**

Individuals with ASD were found to be influenced by the current Covid-19 pandemic with a significant worsening of their behavior problems, which significantly predicted the anxiety of their caregivers in this study. Findings from typically developing samples show that depression and anxiety symptoms were higher in elementary school children during the current Covid-19 pandemic than before the pandemic (Xie et al., 2020). The Covid-19 lockdown was reported to have a significant negative impact on typically developing children’s psychological, social, and physical well-being, while some children experienced mixed emotions because they felt happy and relaxed spending time with their families during the lockdown (Idoiaga et al., 2020). These findings suggest that pandemic preparedness measures may be stressful and traumatizing for all children and their parents (Sprang and Silman, 2013). There were no publications at the time of this study that looked into the reactions of people with ASD to a pandemic or other health-related disaster. The only relevant finding was that individuals with ASD experienced declines in adaptive functioning, primarily in the socialization domain, 6 months and 1 year after the traumatic event (Valenti et al., 2012). A few studies on this topic were published after we collected our results and submitted our manuscript.
Figure 4. Parents’ anxiety levels before and during the Covid-19 period with their children’s behavioral issues

In one study, during the Covid-19 period, parents reported increased anxiety and fear in ASD families, as well as increased distress, stress, and low mood (Asbury et al., 2020).
Another parent-reported survey found increased difficulties in managing daily activities such as free time and structured activities, and less than half of parents reported more intense and frequent behavior problems in their children during the pandemic (Colizzi et al., 2020). Our study is the first to report by high school students on the specific responses of individuals with ASD to the Covid-19-related behavioral measures, as well as the resulting changes in three major domains: Understanding and reactions to Covid-19, behavioral changes during the pandemic, and how they relate to parental anxiety levels.

For starters, most individuals with ASD were unable to comprehend what Covid-19 is, adapt to its measures of social distancing and staying at home, and perform the necessary hygiene requirements. Specific ASD challenges, such as hypersensitivity, may have an impact on mask wearing status, preventing them from taking precautions. These findings are consistent with parent reports from around the world on how their children with ASD are coping with and reacting to Covid-19 measures. Our findings not only corroborate reported experiences from around the world, but they also take them beyond personal accounts and into the realm of scientific measurement. ASD behavioral challenges such as hyperactivity and fidgetiness may also result in a reduced adaptation to suggested hygiene procedures due to a desire to complete or perform them. These issues not only have an impact on autistic people’s infection prevention, but they may also contribute to an increase in the spread of infection and disease in their family and community. Second, we investigated the behavioral difficulties encountered by people with ASD during the pandemic, focusing on the main problematic areas of core ASD symptoms, aberrant behaviors, sleep schedules, and associated problems such as aggression, hypersensitivity, tics, appetite, and self-injury.

In line with our findings, a recent Italian study investigating the impact of Covid-19 found that parents reported more severe and more frequent behavior problems in their children with ASD compared to before (Colizzi et al., 2020). Given that pandemic life changes may be classified as a trauma-like condition, our reported clinical presentation of Covid-19 reactions in ASD individuals is likely to share characteristics with PTSD. This idea is supported by a recent review, which found that behavioral profiles in individuals with ASD after trauma are similar to our findings. After investigating specific trauma symptomatology in ASD, they concluded that PTSD symptoms such as aggressive behavior, self-injury, concentration problems, and sleep problems are common in ASD after trauma (Peterson et al., 2019). These similarities suggest that Covid-19 may cause a clinical presentation similar to PTSD in people with ASD. This is an important consideration because depression and PTSD in people with ASD are linked to an increased risk of suicidal thoughts and behaviors (Storch et al., 2013). In general, caregivers of ASD patients have been found to have higher rates of anxiety and depression. Our research shows how the Covid-19 process affected people with ASD shortly after the pandemic. This understanding is critical in developing psychiatric, psychosocial, and educational interventions for them. Given that individuals with ASD face similar challenges in the face of this pandemic around the world, research into ASD populations through clinical and academic expertise emerges as a top priority during these trying times.

**AUTHOR CONTRIBUTIONS**

MC were responsible for study design and contributed to data interpretation and article writing. KL, IC, EB, KK and JK performed data collection. MC, JK, and KK performed statistical analyses. MC was responsible for data visualization using Power bi. KL was responsible for data collection from AMAZE. All authors personally revised and approved the final version of the manuscript.
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How to Cite:

Choi, M. S., Chon, I., Lee, K., Kang, K., Kim, J., & Bae, E. (2021). Autism Spectrum Disorder Behavioral Implications of the Covid-19 Process, and Individuals’ Awareness and Reactions to Pandemic Conditions based on California, USA. *Engineering International, 9*(1), 29-40. [https://doi.org/10.18034/ei.v9i1.527](https://doi.org/10.18034/ei.v9i1.527)