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Impact of COVID-19 Pandemic-Associated Social Changes on Boys with Moderate to Severe Autism

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Abstract

Objectives The COVID-19 pandemic and the resulting social changes have made unprecedented changes in our lifetime with unknown repercussions on children with autism spectrum disorders. We sought to assess the effect of the COVID-19 pandemic and resulting social changes on boys with autism spectrum disorder.

Methods We conducted a survey using the *CRISIS-AFAR* questionnaire of caregivers of a population of boys ($n=40$) with moderate to severe autism spectrum disorder for changes in environment and behavior before and after the pandemic.

Results We found several interesting findings, including an increase in self-injurious behaviors after the start of the pandemic, but not in the level of hyperactivity, anxiety, or aggressive behavior, or amount and frequency of stereotypies/repetitive behaviors in the children before and after the start of the pandemic. There was an increased difficulty in adjusting to new daily routines after the pandemic, as well as increased difficulty falling asleep.

Conclusions The study showed that a majority of boys with moderate/severe autism in our study were negatively affected by the pandemic across several domains. Additionally, this study highlights the need for educational and mental health resources to be prepared for similar events in the future.

Keywords Autism · Autism spectrum disorder · Coronavirus · SARS-CoV-2 · COVID-19 pandemic

The COVID-19 pandemic caused by SARS-CoV-2 has resulted in several impactful societal changes, including children having to stay home from schools as institutions around the country were closed following the start of the pandemic. Likewise, temporary stay-at-home orders and subsequently other infection prevention measures have impacted everyday behavior and routines. Since the beginning of the pandemic, there has been an awareness that such measures may have a significant impact on the well-being of vulnerable individuals, such as those with disabilities and mental health problems (Brooks et al., 2020; Druss, 2020). Indeed, the psychological impact of the pandemic and the associated societal changes have already been well documented around the world (Luo et al., 2020).

Autism spectrum disorder (ASD) is a common neurodevelopmental condition characterized by challenges in social communication and rigid and/or repetitive patterns of behavior. The clinical features vary significantly between individuals and over time in a given individual (American Psychiatric Association, 2013). It is commonly associated with other physical and mental health conditions including anxiety disorders, ADHD, sleep disorders, and depression (Lai et al., 2019). Given the clinical features of autism, it has been hypothesized that individuals with autism and their families would have increased challenges coping with the broad societal changes associated with the pandemic since its beginning (Ameis et al., 2020).

Pandemics are different from other societal events in that they lead to increased social isolation and interfere with family and educational routines. This is particularly relevant to the ASD population, where repetitive behaviors and interests are a defining feature of the condition and affected individuals adhere to rigid daily rituals. Staying at home, and in most cases not attending school, may create a uniquely stressful situation for children with ASD and their families. On the other hand, these measures may reduce stress on children

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with autism as the nature and frequency of social interactions change. It is important to investigate how the pandemic has affected the psychologic health of these children and be ready to address similar situations should they arise again in the future.

An online survey in Northern Italy of parents and guardians of children with ASD demonstrated that 93.9% of families had increased difficulty in managing daily activities. Children had more intense and more frequent behavioral problems in 35.5% and 41.5% of cases respectively, and a history of prior behavioral problems predicted worsening behavior during the pandemic (Colizzi et al., 2020). A questionnaire study conducted in Portugal showed changes in behavior in children with autism and increased anxiety in autistic children and their families compared to a control group. Within the ASD group, children that maintained their prior routines had lower levels of anxiety than those that did not maintain routines (Amorim et al., 2020). A study in Michigan measuring levels of stress and access to supportive resources showed high increases in levels of stress in caregivers of younger children and in older individuals with ASD (Manning et al., 2020). Similar survey studies in the UK, Turkey, and Saudi Arabia also demonstrated measurable increases in anxiety, low mood, loss, and fear in individuals with autism and their families (Alhuzimi, 2021; Asbury et al., 2020; Mutluer et al., 2020). Interestingly, the UK study identified a minority of individuals for whom physical distancing, social isolation, and school closure led to an increase in positive emotions and decreased stress (Asbury et al., 2020).

California is a region with high impact from the pandemic in terms of disease cases and the social measures and restrictions undertaken to reduce viral spread. School closures, the associated interruption of therapies and services, and the resulting disruption of routines and schedules for children with autism and their families may have a significant but unmeasured impact on the behavioral health of these children. Furthermore, the maintenance of therapies and educational services, even in modified form, may help mitigate this impact. To investigate further, a survey was conducted of parents and caregivers of boys with ASD regarding the impact of the pandemic and the associated social changes on the lives of their child with ASD.

Method

Participants

Participants were enrolled from the *Cannabidiol for the Treatment of Problem Behaviors in Autism* study. All participants who consented to the study were asked to

complete the survey regarding the time period before starting any trial intervention.

Procedures

Surveys were collected online. Caregivers of participants who consented to the study were asked to complete a baseline survey online regarding the participants' health and psychosocial functioning. The survey questionnaire features questions regarding behavior in the 3 months before the coronavirus crisis, and in the 8 weeks prior to survey participation. The survey was conducted prior to any study intervention. A total of 40 surveys were obtained from caregivers of study participants. Participants were boys aged 7 to 14 years with moderate to severe autism and very frequent to daily behavioral problems such as stereotyped behaviors, aggression, self-injurious behaviors, or extreme hyperactivity that interfered with daily activities. All participants had a diagnosis of autism spectrum disorder based on previously obtained ADOS-2 scores and/or diagnostic expertise of a qualified expert. Prior to the pandemic, 31 participants were enrolled in an elementary school, 7 were in middle or high school, and 2 were homeschooled. Among those students not homeschooled, 23 were in a special education classroom within a public-school district, 7 were in a special education classroom in a non-public school, and 8 were in a general ed program with support services (e.g., aide). Participants resided in or around San Diego County, with the majority (68%) residing in a suburban environment. Most participants had some language ability, with 10 able to have some conversation, 12 able to communicate with short phrases or sentences, 9 able to use single words meaningfully, and 9 who were non-verbal or did not speak meaningfully.

Measures

We used the *Coronavirus Health Impact Survey (CRISIS)—Adapted for Autism and Related Neurodevelopmental Conditions* – version 0.4, modified by us to reflect the length of the outbreak in California (see www.crisissurvey.org/crisis-afar/, Nikolaidis et al., 2021).

Data Analyses

The survey data was pooled by question/category and responses regarding the time period before and after the pandemic were compared using ratios/percentages calculated from the rate of each possible response to each survey question.

Results

In the 8 weeks prior to survey participation, only five children were known to have been exposed to someone likely to have COVID-19 and one child was suspected of having the infection. In that time period, caregivers reported 33% of children had “some” or “a few” positive changes in the child’s life related to the crisis. Conversely, 38% responded that the restrictions on leaving home have been “very” or “extremely” stressful for their child and 33% responded that the cancellation of important life events and gatherings has been “very” or “extremely” difficult for their child. The cancellation of such events was at least somewhat difficult for 78% of children.

Notably, there was no indication of change in adjusting to changes in routine, level of hyperactivity, anxiety, or aggressive behavior, or amount and frequency of stereotypies/repetitive behaviors in the children before and after the start of the pandemic. The only exception was in the frequency of children with self-injurious behaviors, which were reported in about 52% of the children after the pandemic compared to about 43% prior to the pandemic. There was no effect of baseline language ability or IQ on any of the variables examined. There were, however, differences seen across several domains—namely with access to school and services/therapies, daily routines, and sleep patterns.

School and Services

Following the start of the pandemic, 95% of children who were enrolled in in-person schooling prior to the pandemic moved to at-home schooling. Among those, 63% received their schoolwork using telehealth (Zoom, skype, phone conversations), 17% through emails and materials sent to their home, 14% received educational services through in-person appointments outside of the home, and 6% received services by a teacher, behaviorist, or therapist going to their home. Four families (10%) said education and services had not been impacted due to COVID-19. Regarding other interventions and services outside school, 63% of participants lost access to at least some additional educational/support services, with 38% losing speech therapy, 54% losing occupational therapy, and 17% losing ABA/behavioral therapy. When services were not lost, they were often modified to online interventions.

Daily Routines and Behavior

A small number of children (10%) had more difficulty adjusting to changes in daily routines during the pandemic than before. Repetitive motor mannerisms became more frequent

in over 20% of children, with a smaller percentage experiencing improvement in some of these behaviors. Roughly equal numbers (about 20%) of children experienced either improvement or, conversely, increase in sensory-seeking behavior and restricted interests. About one-third of children spent more time watching TV/digital media (e.g., YouTube) during the pandemic. Only 3 families reported less media time during the pandemic. Almost none of the children spent time on social media before the pandemic, and this did not change. Half of the children played video games prior to the pandemic. During the pandemic, 2 children began playing video games and 4 others increased their time spent on those games.

Sleep Patterns

The sleep routines of the children were affected by the pandemic. During the pandemic, 28% of children had more difficulty getting to sleep compared to before the pandemic. Once asleep, children were slightly less likely to awaken during the night (20% less nighttime awakening, 15% more). A small percentage (19%) slept fewer hours during the pandemic than they had before.

Parent comments on the survey included the frequent observation that their child was unable to sit and focus for online classes on a computer. Often, a parent had to sit with the child for constant supervision and individual instruction for them to attend the online classes at all. An increase in anxiety around the pandemic and the disease was also noted by several parents. Further examples of parent comments are listed in Table 1.

Discussion

In the present study, the majority of boys with moderate/severe autism in our study were negatively affected by the pandemic across several domains. There was an inability to attend school with peers and have in-person learning. Similarly, there was a loss of ancillary services and therapies, including interventions such as speech therapy, occupational therapy, and ABA. Most children experienced difficulty due to the cancellation of family events and other social events.

Behavioral problems became more prominent during the pandemic. There was an increase in the frequency of self-injurious behaviors. Some children had difficulty adjusting to changes in routine and some had more repetitive behaviors. There were roughly equal numbers, however, of children who had either an increase or decrease in sensory-seeking behaviors and restricted interests. This roughly equal split may be related to normal fluctuations in the frequency of these behaviors over time, but it may be that certain children were more sensitive to school closure and loss of activities/

Table 1 Parent/caregiver comments in response to: *Please describe anything else that concerns you about the impact of coronavirus/COVID-19 on your child*

No social stability or access to extracurricular activities with peers

[He has a] fear of exploring, unless away from people, if they don't have PPE

He is very dysregulated (like his nervous system is totally out of control) when he is not on his attention medication (i.e., in mornings and evenings). This has been going on for several months and is very difficult as we are not able to re-direct him. He is not able to control himself (e.g., as if he were intoxicated). In addition to having attention difficulties, he also struggles with perseverations (i.e., he is very obsessive, currently into historical timelines, human evolution, and video games), executive functioning (organization, planning, etc.), sensory regulation, social skills (e.g., back and forth conversation, paying attention to social cues)

[There were] various moments where he seemed dysregulated and seeking extraordinary amounts of sensory input

Since the lock-down in March 2020, my son had no speech and OT-therapy outside school through the insurance. We are concerned about because he needs these therapies to improve. He is not able to have sessions online. We would like to change also the ABA therapy but there is no flexibility

He is very much peer-motivated in his academics. This has been a challenge with online learning. He is also supposed to have a 1:1 aide during school which has been very challenging to arrange and maintain

services while others did better with less demands on their time. Indeed, decreases in stress as a result of physical distancing, social isolation, and school closure were noted in a minority of patients in a UK study (Asbury et al., 2020).

The changes in routine led to more time spent on digital media (TV, YouTube, etc.), but little to no time spent in peer social interactions. Likewise, while digital media use increased, social media use did not—almost none of the children used social media before and after. There was a notable increase in difficulty falling asleep, but no increased difficulty staying asleep.

Limitations and Future Research

There are limitations to what we can identify from a questionnaire such as the one used in this study. Some of the questions relied on qualitative rather than quantitative measurement of frequency of certain behaviors and change in behavior. Parental responses may have differed for this reason. The questionnaire was administered during the pandemic and relied on parental memory of the child's behavior in the 3 months before the start of the pandemic. The questions were broad, and addressed several domains in the child's life, and may not have been focused enough to identify specific problems in a certain domain. Parents may also have noticed certain behaviors more if they spent more time with them after the start of the pandemic and school closures.

The study data raise the question of the long-term impact of the pandemic on children with ASD. While the short-term changes in behavior appeared relatively mild based on the questionnaire data, the long-term impact of these changes is more difficult to ascertain. Based on the results of this study, we hypothesize that these changes have an impact on the short-term behavioral health of these children. The loss of school, therapy, and routine

activities might have a longer-term impact on behavior, socialization, and learning. These include changes in interest in school and other activities, participation in social interactions, emergence or worsening of aggressive, self-injurious, and other problematic behaviors. The extent of such an impact is not reflected in the relatively short-term data presented in our study, and is also an area of potential future investigation.

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Author Contribution APH: assisted with the data analysis and wrote the paper.

CK: obtained survey data and collaborated in data analysis and the writing of the study.

DJG: collaborated in the design of the study.

DAT: designed and wrote the study and collaborated in data analysis and editing of the manuscript.

Declarations

Ethics Statement This study was approved by the UC San Diego Institutional Review Board.

Informed Consent Statement Written informed consent was obtained from the parents/guardians of the study participants.

Conflict of Interest The authors declare no competing interests.

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