Caregiver Perspective on the Impact of COVID-19 on the Psychosocial and Behavioral Health of Children with ASD in the United States: A Questionnaire-Based Survey

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Abstract: Children with Autism Spectrum Disorder (ASD) were particularly vulnerable to disruptions caused by the COVID-19 pandemic. In this study we conducted an anonymous caregiver survey to assess the impact of the COVID-19 pandemic on the psychosocial and behavioral health of children with ASD. Data from 700 responses identified several significant factors predicting greater difficulties for the child including pre-existing behavioral challenges (OR = 5.179; 95% CI: 2.696, 9.951), disrupted sleep (OR = 2.618; 95% CI 1.341, 5.112), and a diagnosis of depression (OR = 3.425; 95% CI: 1.1621, 4.116). Greater difficulties for caregivers in managing their child’s behaviors were associated with sleep disturbances (OR = 1.926; 95% CI: 1.170, 3.170), self-injurious behavior (OR = 3.587; 95% CI: 1.767, 7.281), and managing the child’s school activities (OR = 3.107; 95% CI: 1.732, 5.257) and free time (OR = 3.758; 95% CI: 2.217, 6.369). However, being under the care of a neuropsychiatrist was associated with less difficulty in managing the child’s behaviors (OR = 2.516; 95% CI: −1.046, −5.382). Finally, the presence of comorbidities (OR = 2.599; 95% CI: 1.053, 4.067) and a greater difficulty in managing the child’s school activities (OR = 2.531; 95% CI: 1.655, 3.868) and free time (OR = 1.651; 95% CI: 1.101, 2.478) were associated with an increased likelihood of caregiver desire for their child to return to in-person school in the fall. The COVID-19 pandemic had a wide-ranging impact on the behaviors of children with ASD and challenges for their caregivers.

Keywords: autism spectrum disorder; COVID-19 pandemic; comorbidities; behavior; family supports

1. Introduction

The global coronavirus (COVID-19) pandemic which began in 2020 has disrupted life worldwide, impacting travel, commerce, and the daily activities of millions of individuals. As various countries imposed lockdown restrictions in an attempt to slow the spread of the virus, concerns arose regarding the impact of COVID-19 on at-risk populations [1–6]. Individuals with autism spectrum disorder (ASD) represent a particularly vulnerable population [7]. Imposed isolation carries the risk of disrupting their daily routine, with little access to the various medical and therapeutic interventions and external supports they need to manage and minimize symptoms [8–12]. Many individuals with ASD also have underlying comorbid conditions [13], such as seizures or epilepsy, which can increase the risk of serious complications to COVID-19 [5]. Individuals with comorbid psychiatric conditions, such as obsessive compulsive disorder, depression, and anxiety disorders were particularly impacted by the social distancing and hygiene-related constraints of the pandemic [14]. The enforced isolation not only elicited aberrant ASD behaviors [15], but may have also triggered worsening symptoms in these comorbid conditions, resulting in a decline of overall well-being and mental health [12].

As the pandemic has progressed, the reported impact of COVID-19 on individuals with ASD and their families has been significant [8,16–18]. Specifically, children with ASD have
experienced increased mental health issues [1,12,19], a decline in positive social behaviors and other conduct [19], and an increase in sleep disturbances [20,21]. A number of factors may exacerbate these effects [15,22], including the presence of behavioral issues prior to the pandemic [23] and parental stress levels [24,25]. In fact, the impact of the lockdown on caregivers of children with ASD has been extensive [26–28], with many parents thrust into the role of teacher, therapist and caregiver, all while working from home [29]. Not surprisingly, the more severe symptoms the individual with ASD is reported to have, the greater the level of stress reported by the caregiver [16]. In one study, as many as 75% of parents reported extreme or moderate stress due to disruptions in their child’s services and supports [30]. More specifically, hyperarousal, or feelings of panic when thinking about COVID-19, was particularly prevalent among parents of children with ASD [26]. These studies highlight some of the many struggles that families faced during the lockdown, particularly for those children who lost critical behavioral therapies and mental health supports.

This survey-based study strives to add to the existing literature by offering the perspective of caregivers of children with ASD in the United States (U.S.) during the lockdown caused by the COVID-19 pandemic. The purpose of this study was twofold: to assess the sociodemographic and clinical features of children with ASD that contributed to poorer behavioral outcomes during the COVID-19 pandemic, and to examine how the pandemic and associated restrictions impacted the caregiver’s ability to attend to their children’s needs.

2. Materials and Methods

2.1. Participants

This study was reviewed by the Advarra Institutional Review Board and deemed to be Exempt. A caregiver survey was created online using Alchemer, a survey software company who have extensive experience in developing HIPPA-compliant features such that they meet all mandated guidelines. The study was conducted for 12 weeks between June and August 2020, when the U.S. and other countries around the globe, were on an enforced lockdown to curb the spread of the COVID-19 virus. The survey was anonymous and no protected health information was collected. Caregivers were invited to participate in the study primarily through a number of national and local partnerships, including support groups, list-servs, and clinics serving those with ASD, as well as through multiple social media platforms. Inclusion criteria were as follows: caregiver of a child 2–18 years of age living in the U.S., with a prior diagnosis of ASD from a licensed professional. In a previous questionnaire-based study examining nutrition in children with ASD [31], we found that the primary caregiver completing the questionnaire was not always a parent. This is not surprising since many families rely on extended family members to provide care for their child with ASD [32], and this was especially true during the COVID-19 pandemic [16].

2.2. ASD Caregiver Questionnaire

The ASD Caregiver Questionnaire is an online survey completed by the primary caregiver of a child/children with ASD. The questionnaire examined the medical, behavioral, and educational concerns of children with ASD before COVID-19 (prior to March 2020) and during the lockdown (April to August 2020), as well as the support needs for the families during this time. The survey consisted of ninety-four questions in the following categories: (i) screening questions; (ii) questions about the person completing the questionnaire; (iii) questions about the child and their family; (iv) questions about the child’s diagnosis, comorbidities, and medications use; (v) questions about the child’s health; (vi) questions about the child’s schooling and therapies; (vii) questions about the impact of COVID-19 on the child and their family; and (viii) questions about supports needed. Caregivers were only able to select 1 answer for each multiple-choice question, except for the last question, which was optional, and included a free response. All questions required an answer. Incomplete surveys were excluded. The full questionnaire is provided as Supplementary Table S1.
2.3. Statistical Methods

Surveys were completed by caregivers of children with a prior diagnosis of ASD. Data was captured by and downloaded from Alchemer.com. Descriptive analysis of the data was performed using SPSS (IBM Corp. Released 2020. IBM SPSS Statistics for Windows, Version 27.0. Armonk, NY, USA: IBM Corp). All demographic and clinical variables were summarized using frequencies and percentages for categorical variables. Pearson’s chi-square tests were conducted to examine statistically significant univariate relationships between categorical variables and the binary outcome variables. Logistic regression was conducted to examine associations of demographic and clinical factors associated with whether this period of time has been challenging for children with ASD in terms of the changes and restrictions from the lockdown caused by the COVID-19 pandemic. A second model investigated the associations of ASD individuals’ socio-demographic or clinical characteristics with the parents’ ability to manage their child’s behaviors following the COVID-19 outbreak. Odds ratios for each explanatory variable and the corresponding 95% confidence interval (CI) and \( p \)-value are presented. Finally, a logistic regression was used to investigate factors associated with caregiver desire/plans to have their child return to in-person school in the fall. A \( p \)-value of less than 0.05 was considered significant for all the analyses.

3. Results

Out of 1159 surveys initiated, 226 were excluded from the study based on inclusion criteria and 233 were excluded as they were only partial responses. Data from 700 complete survey responses were included in the analyses. The majority of caregivers completing the survey were married/cohabitating, highly educated, and reported an annual household income above $75,000 (Table 1). Respondents were primarily parents: 98.3% (688/700), with only 1.7% (12/700) being extended family members. Over 75% (534/700) of caregivers had multiple children in the home.

Caregivers reported on 555 (79.2%) male and 138 (19.7%) female children in this study, with a mean ± SEM age of 10 ± 4.68 years. The majority of children (620/700; 88.6%) had a diagnosis of ASD (including Autism and Autistic Disorder), with only 28 (4.0%) and 52 (7.4%) having a diagnosis of PDD-NOS or Asperger’s Syndrome, respectively. ASD comorbid conditions were prevalent (500/700; 71.4%), with anxiety (65%), ADD/ADHD (58.2%), and sensory processing disorder (56.8%) most commonly reported (Table 2). Furthermore, 57.3% of children had two or more comorbidities. Around 15% of children were non-verbal, while 42% had fluent language. Behavior problems were present in 573 (81.9%) children before the outbreak of COVID-19, with 249 (35.6%) receiving ABA therapy, 142 (20.3%) being under the care of a neuropsychiatrist or psychologist, and 215 (30.7%) receiving pharmacological interventions. In addition, caregivers reported that 204 (29.1%) of children engaged in self-injurious behavior (Table 2). There were 98 (14%) parents reporting that they or another family member were concerned for their safety due to their child’s behavior, and 24 (3.4%) children were taken to the Emergency Room due to behavioral concerns. A large percentage of parents reported difficulties in managing their child’s structured online school activities (72.4%) and free time (69.7%) during the lockdown. Parents also reported more difficulties in managing their child’s behaviors (57.6%), therapies (57.6%), and sleep schedule (47.7%), while challenges in managing meals/dietary needs (27%) and medications (8.6%) were less of a concern.

A logistic regression was performed to ascertain the effects of sociodemographic and clinical variables on the likelihood that children had significant difficulties due to changes and restrictions from the COVID-19 pandemic (Table 3). The logistic regression model was statistically significant (\( \chi^2 = 60.798; p < 0.001 \)). Children who had behavioral challenges prior to COVID, who experienced difficulties with falling asleep/night time wakening, or who were diagnosed with depression, were 5.2, 2.6, and 3.4 times more likely to find this period of time more challenging in terms of changes and restrictions due to lockdown from the COVID-19 pandemic, respectively. Having a mother who was working was also
significantly associated with an increased likelihood of the child experiencing behavioral challenges (Table 3).

Table 1. Sociodemographic characteristics of caregivers and their families (n = 700).

| Characteristics                      | n (%)                        |
|--------------------------------------|------------------------------|
| Caregiver Age                        |                              |
| <20                                  | 2 (0.3%)                     |
| 21–30                                | 42 (6%)                      |
| 31–40                                | 231 (33%)                    |
| 41–50                                | 289 (41.3%)                  |
| 51–60                                | 121 (17.3%)                  |
| 61–70                                | 11 (1.6%)                    |
| >70                                  | 4 (0.6%)                     |
| Marital Status                       |                              |
| Married/cohabitating                 | 557 (79.6%)                  |
| Separated                            | 37 (5.3%)                    |
| Single parent                        | 106 (15.1%)                  |
| Household Income                     |                              |
| Less than 25,000                     | 73 (10.4%)                   |
| 25,000–49,999                        | 113 (16.1%)                  |
| 50,000–74,999                        | 105 (15%)                    |
| 75,000–99,999                        | 99 (14.1%)                   |
| 100,000–124,999                      | 96 (13.7%)                   |
| >125,000                             | 125 (17.9%)                  |
| Prefer not to answer                 | 89 (12.7%)                   |
| Education Level                      |                              |
| Some high school/no diploma          | 6 (0.9%)                     |
| High school or GED                   | 46 (6.6%)                    |
| Trade/Technical/Vocational Training  | 34 (4.9%)                    |
| Some college/no diploma              | 94 (13.4%)                   |
| Associate/Bachelor’s Degree          | 312 (44.6%)                  |
| Master’s/Doctorate/Professional Degree| (28.4%)                    |
| Prefer not to answer                 | 9 (1.3%)                     |
| Location of Residence                |                              |
| Rural                                | 107 (15.3%)                  |
| Suburban                             | 422 (60.3%)                  |
| Urban                                | 171 (24.4%)                  |
| Multiple siblings on the home        |                              |
| Yes                                  | 534 (76.3%)                  |
| No                                   | 166 (23.7%)                  |
| Multiple siblings diagnosed with ASD |                              |
| Yes                                  | 96 (17.9%)                   |
| No                                   | 438 (82.1%)                  |

* Expressed as a percentage of those children with siblings (n = 534).
Table 2. Clinical characteristics of children with ASD (n = 700).

| Characteristics                        | n (%)          |
|----------------------------------------|----------------|
| Mean age ± SEM                         | 10.56 ± 4.68   |
| **Gender of Child**                    |                |
| Female                                 | 138 (19.7%)    |
| Male                                   | 555 (79.2%)    |
| Non-Binary                             | 3 (0.4%)       |
| Prefer not to answer                   | 4 (0.6%)       |
| **Diagnosis of Child**                 |                |
| Autism Spectrum Disorder               | 609 (87.0%)    |
| Autistic Disorder                      | 11 (1.6%)      |
| PDD-NOS                                | 28 (4.0%)      |
| Asperger’s Syndrome                    | 52 (7.4%)      |
| **Child’s language level**             |                |
| Fluent Speech                          | 295 (42.1%)    |
| Phrase Speech                          | 201 (28.7%)    |
| Few words                              | 89 (12.7%)     |
| Non-verbal                             | 115 (16.4%)    |
| **Presence of ASD comorbidities**      |                |
| Yes                                    | 500 (71.4%)    |
| No                                     | 200 (28.6%)    |
| **ASD comorbidities reported**         |                |
| Anxiety                                | 327 (46.7%)    |
| ADD/ADHD                               | 291 (41.6%)    |
| Sensory Processing Disorder            | 284 (40.6%)    |
| Gastrointestinal disorder              | 168 (24.0%)    |
| Sleep disorder                         | 151 (21.6%)    |
| Intellectual disability                | 125 (17.9%)    |
| Seizures                               | 37 (5.3%)      |
| Epilepsy                               | 21 (3.0%)      |
| Learning disorder                      | 18 (2.6%)      |
| Obsessive Compulsive Disorder (OCD)    | 15 (2.1%)      |
| Other                                  | 23 (3.2%)      |
| **Number of comorbidities reported per child** |        |
| One comorbidity                        | 98 (14.0%)     |
| Two comorbidities                      | 113 (16.1%)    |
| Three comorbidities                    | 127 (18.1%)    |
| Four or more comorbidities             | 162 (23.1%)    |
| **Child has behavioral problems**      |                |
| Yes                                    | 573 (81.9%)    |
| No                                     | 127 (18.1%)    |
Table 2. Cont.

| Characteristics                                      | n (%)   |
|------------------------------------------------------|---------|
| **Child receiving ABA therapy**                      |         |
| Yes                                                  | 249 (35.6%) |
| No                                                   | 451 (64.4%) |
| **Child receiving pharmacological intervention**      |         |
| Yes                                                  | 215 (30.7%) |
| No                                                   | 485 (69.3%) |
| **Child engages in self-injurious behavior**         |         |
| Yes                                                  | 204 (29.1%) |
| No                                                   | 496 (70.9%) |
| **Child has difficulty falling asleep**               |         |
| Yes                                                  | 442 (63.1%) |
| No                                                   | 258 (36.9%) |
| **Child takes medication to help them fall asleep**  |         |
| Yes                                                  | 270 (61.1%) |
| No                                                   | 172 (38.9%) |

* Expressed as a percentage of those children having difficulty falling asleep (n = 442).

Table 3. Regression analysis of clinical characteristics of children with ASD associated with whether this period of time has been challenging for children with ASD (n = 700). $\chi^2 = 60.798$ ($p < 0.001$).

| Characteristics                                      | $\beta$  | S.E.  | Wald  | $p$-Value | Odds Ratio | 95% CI    |
|------------------------------------------------------|----------|-------|-------|-----------|------------|-----------|
| Behavioral challenges existing pre-COVID             | 1.645    | 0.333 | 24.370| 0.001 *   | 5.179      | 2.696, 9.951|
| **Level of language a**:                              |          |       |       |           |            |           |
| Few Words                                            | -0.202   | 0.829 | 0.060 | 0.807     | 0.817      | 0.161, 4.144|
| Phrased                                              | 0.572    | 0.588 | 0.945 | 0.331     | 1.771      | 0.559, 5.609|
| Fluent                                               | 0.561    | 0.583 | 0.927 | 0.336     | 1.753      | 0.559, 5.491|
| **Level of cognitive impairment b**:                 |          |       |       |           |            |           |
| Mild to Moderate                                     | -0.688   | 0.709 | 0.941 | 0.332     | 0.502      | 0.125, 2.018|
| Normal                                               | -1.246   | 0.734 | 2.878 | 0.090     | 0.288      | 0.068, 2.018|
| Sleep disturbances                                   | 0.962    | 0.341 | 7.945 | 0.003 *   | 2.618      | 1.341, 5.112|
| Diagnosed with depression                            | 0.856    | 0.493 | 3.016 | 0.042 *   | 3.425      | 1.162, 4.116|
| ASD comorbidities                                    | 0.598    | 0.364 | 2.703 | 0.100     | 1.818      | 0.891, 3.708|
| Receiving ABA therapy                                | -0.005   | 0.493 | 0.100 | 0.336     | 0.425      | 0.162, 1.116|
| Receiving care from a neuropsychiatrist/psychologist | -0.101   | 0.424 | 0.336 | 0.082     | 0.904      | 0.394, 2.075|
| Sibling diagnosed with ASD                           | -0.195   | 0.251 | 0.605 | 0.437     | 0.882      | 0.503, 1.346|
| Family member hospitalized with COVID                | -0.415   | 0.708 | 0.343 | 0.588     | 0.661      | 0.165, 2.647|
| Mother working                                       | 0.840    | 0.364 | 2.703 | 0.009 *   | 2.317      | 1.238, 4.337|

* Reference category is non-verbal; b Reference category is severe; * $p$-value < 0.05 is significant.

A logistic regression was performed to ascertain the effects of sociodemographic and clinical variables on the caregiver’s ability to manage their child’s behaviors during this time (Table 4). The logistic regression model was statistically significant, ($\chi^2 = 126.94$;
p < 0.001). Caregivers who reported that their child experienced greater difficulty in falling asleep/night time waking or exhibited self-injurious behavior were 1.9 and 3.6 times more likely to experience difficulty in managing child’s behavior, respectively. Caregivers who reported greater difficulty in managing their child’s structured school activities and their free time were 3.1 and 3.8 times more likely to experience difficulty in managing their child’s overall behaviors, respectively. However, caregivers of children who were receiving care from a neuropsychiatrist/psychologist prior to the lockdown were 2.5 times less likely to face difficulties in managing their child’s behaviors (Table 4).

Table 4. Regression analysis of clinical characteristics of children with ASD associated with caregiver responses on whether they had difficulties in managing their child’s behaviors since COVID-19 on (n = 700). \( \chi^2 = 88.755 \) (p < 0.001).

| Characteristics                              | \( \beta \) | S.E. | Wald \( \chi^2 \) | p-Value | Odds Ratio | 95% CI    |
|----------------------------------------------|-------------|------|-------------------|---------|------------|-----------|
| Level of language a:                         |             |      |                   |         |            |           |
| Few Words                                    | -0.445      | 0.703| 0.400             | 0.527   | 0.641      | 0.162, 2.543 |
| Phrased                                      | 0.104       | 0.478| 0.048             | 0.827   | 1.110      | 0.435, 2.832 |
| Fluent                                       | -0.341      | 0.494| 0.475             | 0.491   | 0.711      | 0.270, 1.874 |
| Level of cognitive impairment b:             |             |      |                   |         |            |           |
| Mild to Moderate                              | 0.789       | 0.498| 2.516             | 0.113   | 2.202      | 0.830, 5.841 |
| Normal                                       | 0.695       | 0.523| 1.764             | 0.184   | 2.004      | 0.718, 5.590 |
| Sleep disturbances                           | 0.655       | 0.254| 6.638             | 0.010*  | 1.926      | 1.170, 3.170 |
| Diagnosed with depression                    | -0.713      | 0.392| 3.311             | 0.069   | 0.490      | 0.228, 1.056 |
| ASD comorbidities                            | 0.422       | 0.292| 2.096             | 0.148   | 1.525      | 0.861, 2.701 |
| Self-injurious behavior                     | 1.277       | 0.361| 12.506            | 0.002*  | 3.587      | 1.767, 7.281 |
| Complex medical condition                    | 0.298       | 0.402| 0.549             | 0.459   | 1.347      | 0.613, 2.960 |
| Receiving care from a neuropsychiatrist/psychologist | -0.851      | 0.434| 4.179             | 0.040*  | 2.516      | -1.046, -5.382 |
| Receiving ABA therapy in Spring 2020         | 0.290       | 0.279| 1.079             | 0.299   | 1.336      | 0.773, 2.309 |
| Difficulty managing child’s school activities| 1.104       | 0.283| 15.206            | 0.001*  | 3.107      | 1.732, 5.257 |
| Difficulty managing child’s free time        | 1.324       | 0.269| 24.1933           | 0.001*  | 3.758      | 2.217, 6.369 |
| Additional sibling in the house              | 0.149       | 0.281| 0.280             | 0.597   | 1.160      | 0.669, 2.013 |
| Mother working                               | -0.200      | 0.239| 0.702             | 0.402   | 0.819      | 0.513, 1.308 |

\( * \) Reference category is non-verbal; \( b \) Reference category is severe; \( p \)-value < 0.05 is significant.

A large number of parents (480; 68.5%) indicated that during the lockdown they needed behavioral support for their child, whether center-based (16.4%), home-based (38.4%), or web-based (13.7%). In preparation for the start of the new school year, 371 (53%) parents were planning to send their child to school for in-person learning, 96 (13.7%) would opt for remote learning, while 125 (17.9%) would opt for a combination of in-person/remote learning (Table S2). A logistic regression was performed to ascertain the effects of sociodemographic and clinical variables on the caregiver’s desire to have their child return to ‘in person’ school in the fall (Table 5). The logistic regression model was statistically significant (\( \chi^2 = 50.376; p < 0.001 \)). Caregivers who had a child with ASD comorbidities, or who had greater difficulty in managing their child’s structured school activities and their free time were 2.6, 2.5 and 1.7 times more likely to seek to have their child return to in person school in the fall, respectively.
4. Discussion

Children with ASD and their families represent a vulnerable population at risk for complications during disruptive periods like the COVID-19 pandemic. The objective of this paper was to assess the psychosocial and behavioral challenges associated with the COVID-19 pandemic in children with ASD and their families. Specifically, we examined the effects of clinical characteristics of children with ASD on (i) the child’s behavior during the lockdown; (ii) the caregiver’s difficulties in managing their child’s behaviors during this time; and (iii) the caregivers desire to have their child to return to ‘in-person’ school in the fall. Survey responses were collected from June to August 2020, with caregivers reporting on the period of time from early March (prior to the lockdown) until the end of the school year in May.

A number of sociodemographic and clinical characteristics of children with ASD were significantly associated with increased behavioral challenges for the child during this period of time. Behavioral concerns existing pre-COVID, sleep disturbances, depression, and the mother working from home were all significant predictors of increased behavioral challenges for the child. A large number of children had behavioral concerns prior to the pandemic, although only 35% were receiving ABA therapy and 30% were receiving pharmacological interventions. The presence of behavioral concerns prior to the pandemic was the primary predictor for greater behavioral problems during the lockdown. This finding was also reported in an Italian, survey-based study [23]; however, it should be noted that Italy suffered some of the most extreme restrictions during the lockdown and experienced very high infection fatality rate [33], taking a great toll on families [34]. In a similar survey-based study conducted in China, a number of parents reported that their child’s cognitive and language skills improved during the pandemic [35]. The authors concluded that the long-term lockdown restrictions meant that parents had more time for family activities. A similar finding was also reported in a small South African study, where increased interactions and emotional attachment with siblings had a positive effect on children with ASD [36].

Self-injurious behaviors were reported in almost 30% of children, and 3% of children were taken to the Emergency Room due to the severity of their behaviors. Interestingly, in one study, a clinical presentation that resembled PTSD was reported in individuals with ASD, characterized by increased stereotypies, aggression, hypersensitivity, behavioral problems, and sleep disruptions [14]. In our study, disturbed sleep, whether difficulty in falling asleep or night time wakening, was a significant challenge for children. Furthermore, while 25% of children were reported to have a sleep disorder as a comorbid condition,
63% of children had disturbed sleep. Of these, approximately 60% of children took at least one sleep aid such as melatonin. There are a number of factors that may have influenced sleep patterns during the lockdown, including spending more time indoors, lack of social interactions, increased use of technology due to remote learning, and more flexibility in sleep and awake times [37]. Children with ASD that were also diagnosed with depression may also be particularly vulnerable to disturbed sleep [37].

This study also identified a number of significant predictors associated with increased difficulties the caregivers had managing their child’s behaviors. These included sleep disturbances in the child, self-injurious behavior, and difficulties in managing the child’s structured school activities and free time. As reported above, disrupted sleep among children with ASD has negative consequences for the caregivers [38,39], especially when they are also working [29]. Caregiver burden and parental stress not only impacts caregivers but can also have a negative impact on the parent-child relationship, subsequently impeding child development [40]. Self-injurious behaviors were reported in almost 30% of children. A surprisingly large number of parents (98/700; 14%) reported that they or another family member were concerned for their safety at home due to their child’s behavior during the lockdown, and 3% of children were taken to the Emergency Room due to the severity of their behaviors. ASD comorbidities, particularly those associated with sleep disturbances and child behavioral problems, have been shown to negatively impact the well-being of the caregiver [41]. In our study, managing their child’s structured school activities and free-time was also a significant challenge for the caregivers due to their child’s behaviors. The unexpected transition to distance/remote learning for a child’s education was abrupt [42]. While many parents had to assume the role of teacher during the lockdown [29], parents of children with special needs were also tasked with supporting their child’s special education services [14,30], often with little support.

Even while living through the pandemic, over 50% of caregivers indicated that ‘in-person’ learning would be preferred for their child in the new school year, while only 13.7% would opt for remote learning. Caregivers also indicated that financial support for private school/therapies, as well as respite care/parent support were their most pressing needs, further highlighting the burden caregivers faced during the lockdown. Managing their child’s free time was also challenging for the caregiver, due to their child’s behaviors. With the loss of social interactions at school, children with ASD frequently relied more heavily on solitary screen time, which is known to worsen ASD core symptoms [43].

Conversely, being under the care of a neuropsychiatrist or psychologist prior to the lockdown was a predictor of decreased difficulties for caregivers in managing their child’s behaviors. Out of the 142 children under the care of a neuropsychiatrist/psychologist prior to the lockdown, 97 (68%) were also taking psychotropic medications, such as anti-anxiety medications, anti-depressive medications, and/or stimulants. These may have helped combat or slow the decline in mental health status that has been reported in youth with ASD and other developmental disabilities during the lockdown [44,45].

Of note was the high incidence (>70%) of comorbidities reported in children with ASD, suggesting that many caregivers in this study had to manage multiple and/or complex diagnoses and medications for their child during the lockdown. ASD comorbidities, particularly those associated with child behavioral problems and sleep disturbances, negatively impact the well-being of the caregiver [41]. Therefore, it was not surprising that the presence of ASD comorbidities was positively associated with the caregiver’s desire for their child to return to school in the fall. Caregiver difficulties in managing their child’s structured school activities and free time were also both positively associated with the desire to have their child return to in-person school in the fall.

There are several limitations to this study in terms of the survey methodology and the composition of the sample. We primarily reached caregivers through social media platforms, which restricted access to the study to those without access to a computer, and the questionnaire was only available in English. All responses were caregiver-reported and the questionnaire used was not a validated measure, although many of the questions were
based on a previously published, questionnaire-based study for caregivers of children with ASD [31]. In a small number of cases (8/700; 1.1%), the questionnaire was not completed by the primary caregiver. However, the respondent still identified themselves as a caregiver for the child. While the majority of caregivers were parents, a small percentage (12/700; 1.7%) were other relatives, such as an aunt or grandparent. How they perceived the child’s behaviors and/or challenges may have been different from a parent [32]. Despite our efforts to enroll a diversity of families, the education level of the caregiver and their household income were both higher than in the general population, which would likely impact the services and supports a family has access to. Even with these limitations, a robust number of caregivers participated in the study, allowing us to capture quantitative data for analyses during the lockdown period.

In summary, this paper adds to the existing literature on the impact of COVID-19 on children with ASD and their families. Our results suggest that the lockdown caused by the COVID-19 pandemic exacerbated behaviors in children with ASD, highlighting the need for targeted, remote special education interventions and other support services for this vulnerable population. Access to emergency neuropsychiatric care and/or mental health support may be specifically beneficial, particularly when a child does not already have an established relationship with a neuropsychiatrist/psychologist. Finally, caregivers of children with ASD, particularly working mothers, have been disproportionately affected by the pandemic, and it is imperative that they receive adequate supports and services to have a positive impact on their families and children with ASD.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/covid2070072/s1, Table S1: Online COVID-19 questionnaire administered between June and August 2020; Table S2: The most helpful health, behavioral, and educational supports requested by caregivers for the new school year for children with ASD.

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References
1. Courtenay, K.; Perera, B. COVID-19 and people with intellectual disability: Impacts of a pandemic. *Ir. J. Psychol. Med.* 2020, 37, 231–236. [CrossRef] [PubMed]
2. Amerio, A.; Aguglia, A.; Odone, A.; Gianfredi, V.; Serafini, G.; Signorelli, C.; Amore, M. COVID-19 pandemic impact on mental health of vulnerable populations. *Acta Biomed.* 2020, 91, 95–96. [CrossRef] [PubMed]
3. Gordon, J.; Evans, J.D. Aging, mental illness and COVID-19: Focusing research on vulnerable populations. *Aging Brain* 2021, 1, 100007. [CrossRef] [PubMed]
4. Lee, Y.J. The Impact of the COVID-19 Pandemic on Vulnerable Older Adults in the United States. *J. Gerontol. Soc. Work* 2020, 63, 559–564. [CrossRef]
5. Wood, C. COVID-19: Protecting the medically vulnerable. *Br. J. Nurs.* 2020, 29, 660. [CrossRef]
6. Siegler, E.L. Challenges and Responsibilities in Caring for the Most Vulnerable During the COVID-19 Pandemic. *J. Am. Geriatr. Soc.* 2020, 68, 1172–1173. [CrossRef]
7. Bellomo, T.R.; Prasad, S.; Munzer, T.; Laventhal, N. The impact of the COVID-19 pandemic on children with autism spectrum disorders. *J. Pediatr. Relatbl. Med.* 2020, 13, 349–354. [CrossRef]
8. Asbury, K.; Fox, L.; Deniz, E.; Code, A.; Toseeb, U. How is COVID-19 Affecting the Mental Health of Children with Special Educational Needs and Disabilities and Their Families? *J. Autism Dev. Disord.* 2021, 51, 1772–1780. [CrossRef]

9. Bawoje, R.; Brown, S.L.; Edwards, E.M.; Murray, M.J. COVID-19 Pandemic and Impact on Patients with Autism Spectrum Disorder. *J. Autism Dev. Disord.* 2022, 52, 473–482. [CrossRef]

10. Bitan, D.T.; Krieger, I.; Weinstein, O. Challenges of the COVID-19 Pandemic among Individuals with Autism Spectrum Disorder. *JAMA Psychiatry* 2022, 79, 389–390. [CrossRef]

11. Bruni, O.; Melegari, M.G.; Breda, M.; Cedrone, A.; Finotti, E.; Malorgio, E.; Doria, M.; Ferri, R. Impact of COVID-19 lockdown on sleep in children with autism spectrum disorders. *J. Clin. Sleep Med.* 2022, 18, 137–143. [CrossRef]

12. Vasa, R.A.; Singh, V.; Holingue, C.; Kalb, L.G.; Jang, Y.; Keefer, A. Psychiatric problems during the COVID-19 pandemic in children with autism spectrum disorder. *Autism Res.* 2021, 14, 2113–2119. [CrossRef]

13. Neumeyer, A.M.; Anixt, J.; Chan, J.; Perrin, J.M.; Murray, D.; Coury, D.L.; Bennett, A.; Farmer, J.; Parker, R.A. Identifying Associations Among Co-Occurring Medical Conditions in Children With Autism Spectrum Disorders. *Acad. Pediatr.* 2019, 19, 300–306. [CrossRef]

14. Mutluer, T.; Doenyas, C.; Aslan Genc, H. Behavioral Implications of the COVID-19 Process for Autism Spectrum Disorder, and Individuals’ Comprehension of and Reactions to the Pandemic Conditions. *Front. Psychiatry* 2020, 11, 561882. [CrossRef]

15. Siracusano, M.; Segatori, E.; Riccioni, A.; Emberti Gialloreti, L.; Curatolo, P.; Mazzone, L. The Impact of COVID-19 on the Adaptive Functioning, Behavioral Problems, and Repetitive Behaviors of Italian Children with Autism Spectrum Disorder: An Observational Study. *Children* 2021, 8, 96. [CrossRef]

16. Manning, J.; Billian, J.; Matson, J.; Allen, C.; Soares, N. Perceptions of Families of Individuals with Autism Spectrum Disorder during the COVID-19 Crisis. *J. Autism Dev. Disord.* 2021, 51, 2920–2928. [CrossRef]

17. Young, E.; Milligan, K.; Henze, M.; Johnson, S.; Weyman, K. Caregiver burnout, gaps in care, and COVID-19: Effects on families of youth with autism and intellectual disability. *Can. Fam. Physician* 2021, 67, 506–508. [CrossRef]

18. Papanikolaou, K.; Ntre, I.M.; Tagkouli, E.; Tzavara, C.; Pehlivanidis, A.; Kolaitis, G. Parenting Children with Autism Spectrum Disorder during Crises: Differential Responses between the Financial and the COVID-19 Pandemic Crisis. *J. Clin. Med.* 2022, 11, 1264. [CrossRef]

19. Nonweiler, J.; Rattray, F.; Baulcomb, J.; Happe, F.; Absoud, M. Prevalence and Associated Factors of Emotional and Behavioural Difficulties during COVID-19 Pandemic in Children with Neurodevelopmental Disorders. *Children* 2020, 7, 128. [CrossRef]

20. Bruni, O.; Breda, M.; Ferri, R.; Melegari, M.G. Changes in Sleep Patterns and Disorders in Children and Adolescents with Attention Deficit Hyperactivity Disorders and Autism Spectrum Disorders during the COVID-19 Lockdown. *Brain Sci.* 2021, 11, 1139. [CrossRef]

21. Reynaud, E.; Pottelette, J.; Rabot, J.; Rolling, J.; Royant-Parola, S.; Hartley, S.; Coutelle, R.; Schroder, C.M. Differential effects of COVID-related lockdown on sleep-wake rhythms in adults with autism spectrum disorder compared to the general population. *Autism Res.* 2022, 15, 945–956. [CrossRef]

22. Fumagalli, L.; Nicolli, M.; Villa, L.; Riva, V.; Vicovaro, M.; Casartelli, L. The (a)typical prevalence of COVID-19 pandemic scenario in Autism Spectrum Disorder. *Sci. Rep.* 2021, 11, 22655. [CrossRef]

23. Colizzi, M.; Sironi, E.; Antonini, F.; Ciceri, M.L.; Bovo, C.; Zoccolante, L. Psychosocial and Behavioral Impact of COVID-19 in Autism Spectrum Disorder: An Online Parent Survey. *Brain Sci.* 2020, 10, 341. [CrossRef]

24. Levante, A.; Petrocchi, S.; Bianco, F.; Castelli, I.; Colombi, C.; Keller, R.; Narzisi, A.; Masi, G.; Lecciso, F. Psychological Impact of COVID-19 Outbreak on Families of Children with Autism Spectrum Disorder and Typically Developing Peers: An Online Survey. *Brain Sci.* 2021, 11, 808. [CrossRef]

25. Corbett, B.A.; Muscatello, R.A.; Kleemencic, M.E.; Schwartzman, J.M. The impact of COVID-19 on stress, anxiety, and coping in youth with and without autism and their parents. *Autism Res.* 2021, 14, 1496–1511. [CrossRef]

26. Kalb, L.G.; Badillo-Goicoechea, E.; Holingue, C.; Riehm, K.E.; Thrul, J.; Stuart, E.J.; Smail, E.J.; Law, K.; White-Lehman, C.; Fallin, D. Psychological distress among caregivers raising a child with autism spectrum disorder during the COVID-19 pandemic. *Autism Res.* 2022, 14, 2183–2188. [CrossRef]

27. Lugo-Marin, J.; Gisbert-Gustemps, L.; Setien-Ramos, I.; Espanol-Martin, G.; Ibanez-Jimenez, P.; Forner-Puntonet, M.; Arteaga-Henriquez, G.; Soriano-Dia, A.; Duque-Yemail, J.D.; Ramos-Quiroga, J.A. 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. *Res. Autism Spectr. Disord.* 2021, 83, 101757. [CrossRef]

28. Tokatly Latzer, I.; Leitner, Y.; Karnieli-Miller, O. Core experiences of parents of children with autism during the COVID-19 pandemic lockdown. *Autism Res.* 2021, 25, 1047–1059. [CrossRef]

29. Mifsud, D. Parents as educators during lockdown: Juggling multiple simultaneous roles to ‘keep atop’ home-schooling amid the COVID-19 pandemic? *J. Educ. Adm. Hist.* 2021. [CrossRef]

30. White, L.C.; Law, J.K.; Daniels, A.M.; Toroney, J.; Vernoia, B.; Xiao, S.; Consortium, S.; Feliciano, P.; Chung, W.K. Brief Report: Impact of COVID-19 on Individuals with ASD and Their Caregivers: A Perspective from the SPARK Cohort. *J. Autism Dev. Disord.* 2021, 51, 3766–3773. [CrossRef]

31. Barnhill, K.M.; Richardson, W.; Rodriguez, L.; Moreno, H.; Devlin, M.; Sachdev, P.K.; Hewitso, L. Caregiver perspective on use of the Specific Carbohydrate Diet In children with Autism Spectrum Disorder. *J. Nutr. Health* 2019, 5, 6.
32. Prendeville, P.; Kinsella, W. The Role of Grandparents in Supporting Families of Children with Autism Spectrum Disorders: A Family Systems Approach. *J. Autism Dev. Disord.* **2019**, *49*, 738–749. [CrossRef]

33. Modi, C.; Bohn, V.; Ferraro, S.; Stein, G.; Seljak, U. Estimating COVID-19 mortality in Italy early in the COVID-19 pandemic. *Nat. Commun.* **2021**, *12*, 2729. [CrossRef]

34. Degli Espinosa, F.; Metko, A.; Raimondi, M.; Impenina, M.; Scognamiglio, E. A Model of Support for Families of Children With Autism Living in the COVID-19 Lockdown: Lessons From Italy. *Behav. Anal. Pract.* **2020**, *13*, 550–558. [CrossRef]

35. Huang, S.; Sun, T.; Zhu, Y.; Song, S.; Zhang, J.; Huang, L.; Chen, Q.; Peng, G.; Zhao, D.; Yu, H.; et al. Impact of the COVID-19 Pandemic on Children with ASD and Their Families: An Online Survey in China. *Psychol. Res. Behav. Manag.* **2021**, *14*, 289–297. [CrossRef]

36. Adams, S.N.; Seedat, J.; Neille, J. Life under lockdown for children with autism spectrum disorder: Insights from families in South Africa. *Children Care Health Dev.* **2022**, 1–9. [CrossRef]

37. Becker, S.P.; Gregory, A.M. Editorial Perspective: Perils and promise for child and adolescent sleep and associated psychopathology during the COVID-19 pandemic. *J. Children Psychol. Psychiatry* **2020**, *61*, 757–759. [CrossRef]

38. Gallagher, S.; Phillips, A.C.; Carroll, D. Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. *J. Pediatr. Psychol.* **2010**, *35*, 728–737. [CrossRef]

39. Abdullah, M.M.; Neville, R.D.; Donnelly, J.H.; Lakes, K.D. Are parental depressive symptoms related to the sleep quality and physical activity of their children with developmental disabilities? *Res. Dev. Disabil.* **2021**, *119*, 104091. [CrossRef]

40. Crowell, J.A.; Keluskar, J.; Gorecki, A. Parenting behavior and the development of children with autism spectrum disorder. *Compr. Psychiatry* **2019**, *90*, 21–29. [CrossRef]

41. Lanyi, J.; Mannion, A.; Chen, J.L.; Leader, G. Relationship between Comorbid Psychopathology in Children and Adolescents with Autism Spectrum Disorder and Parental Well-being. *Dev. Neurorehabilitation* **2022**, *25*, 151–161. [CrossRef] [PubMed]

42. Senn, S.; Wessner, D.R. Maintaining student engagement during an abrupt instructional transition: Lessons learned from covid-19. *J. Microbiol. Biol. Educ.* **2021**, *22*, 22.1.47. [CrossRef] [PubMed]

43. Gwynette, M.F.; Sidhu, S.S.; Ceranoglu, T.A. Electronic Screen Media Use in Youth With Autism Spectrum Disorder. *Child. Adolesc. Psychiatr. Clin. N. Am.* **2018**, *27*, 203–219. [CrossRef]

44. Valicenti-McDermott, M.; Rivelis, E.; Bernstein, C.; Cardin, M.J. Letter to the Editor: The Impact of the COVID-19 Pandemic on the Mental Health of Youth with Developmental Disabilities. *J. Children Adolesc. Psychopharmacol.* **2021**, *31*, 697–698. [CrossRef] [PubMed]

45. Charalampopoulou, M.; Choi, E.J.; Korczak, D.J.; Cost, K.T.; Crosbie, J.; Birken, C.S.; Charach, A.; Monga, S.; Kelley, E.; Nicolson, R.; et al. Mental health profiles of autistic children and youth during the COVID-19 pandemic. *Paediatr. Children Health* **2022**, *27*, S59–S65. [CrossRef] [PubMed]