



Article 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



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Copyright: © 2022 by the authors. Licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license (https:// creativecommons.org/licenses/by/ 4.0/). 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 chisquare 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 \pm SEM age of 10 \pm 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 on-line 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).

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%)
	EQ ()

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

* Expressed as a percentage of those children with siblings (n = 534).

Characteristics	n (%)		
Mean age \pm 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. Clinical characteristics of children with ASD (n = 700).

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%)

Table 2. Cont.

* 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	β	S.E.	Wald	<i>p</i> -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	3.016	0.082	0.425	0.162, 1.116
Receiving care from a neuropsychiatrist/psychologist	-0.101	0.424	0.057	0.811	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

^a 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 wakening 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	β	S.E.	Wald χ^2	<i>p</i> -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

^a 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.

Characteristics β S.E. Wald χ^2 p-Value **Odds Ratio** 95% CI 2.065 Behavioral challenges existing pre-COVID 0.325 0.226 0.151 1.384 0.889, 2.155 0.198 6.561 0.010 * 2.599 ASD comorbidities 0.508 1.053, 4.067 0.273 1.896 0.169 1.456 Complex medical condition 0.376 0.853, 2.486 Child on psychotropic medication -0.0380.187 0.042 0.837 0.962 0.667,1.388 0.183 0.156 1.075 Self-injurious behavior 0.0720.693 0.751, 1.540 Difficulty managing child's school activities 0.928 0.217 18.387 0.001 * 2.531 1.655, 3.868 0.015 * Difficulty managing child's free time 0.502 0.207 5.873 1.651 1.101, 2.478 0.780 0.078 1.038 Sibling diagnosed with ASD 0.038 0.135 0.797, 1.352 Mother working 0.254 0.163 2.420 0.120 1.289 0.936, 1.776 0.093 0.250 0.710 1.097 0.672, 1.792 Father working 0.138

Table 5. Regression analysis of clinical characteristics of children with ASD associated with caregiver desire/plans to have their child return to in person school in the fall on (n = 700). $\chi^2 = 50.376$ (p < 0.001). * p-value < 0.05 is significant.

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 COVID-19, 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 freetime 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 'inperson' 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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