

Impact of the COVID-19 Pandemic on Children with ASD and Their Families: An Online Survey in China

This article was published in the following Dove Press journal:
Psychology Research and Behavior Management

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Background: The COVID-19 pandemic and lockdown will have short-term and long-term psychosocial and mental health implications for children. Children with autism may have some specific needs for support because of their difficulties in social communication, stereotyped behavior patterns, and other specificities brought about by autism.

Purpose: The purpose of this study was to investigate the impact of the COVID-19 pandemic on ASD children and their families.

Patients and Methods: A total of 406 parents of ASD children completed an online survey investigating basic information; sleep, outdoor activities, and rehabilitation training; ASD children's frequency of abnormal behaviors; and stress and emotional status of parents.

Results: 50.3% of the parents thought their children had sleep problems, and 47.3% of the parents thought their children's outdoor activity time was reduced. About 40% of parents think that their children have improved cognitive ability, language expression, and understanding. 36.2% of the families reported that their children's emotional and social performance became worse. 60.8% of parents reported that their children's training intensity decreased. The most common abnormal behaviors observed in children with ASD were being easily distracted, losing temper, and crying. 81.3% of parents did not have anxiety, but 98% of parents reported that family training was under pressure.

Conclusion: The main impact of the COVID-19 pandemic on children with ASD is that they do not have access to professional rehabilitation training. These families need more medical support, especially in family training, to help parents improve the social and emotional control skills of ASD children.

Keywords: COVID-19, ASD, child, behavior, rehabilitation training, China

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects 2–7% of children worldwide.¹ ASD is characterized by social communication deficits; social interaction deficits; and limited repetitive patterns of behavior, activities, and interests. It is often associated with mental and behavioral problems such as intellectual impairment, attention and motor coordination difficulties, disruptive behavior, and sleep problems.²

The coronavirus disease (COVID-19) broke out at the end of 2019. On January 30, 2020, the World Health Organization announced that the COVID-19 pandemic constituted a public health emergency of international concern.³ China's central and local governments have taken strict measures to control the pandemic,

including extending the Spring Festival holiday, closing entertainment venues, canceling large gatherings, and encouraging citizens to reduce social activities. This pandemic has led to changes in public psychology. Some studies have reported high levels of psychological stress, anxiety, and depression among the population during the pandemic, indicating the aggravation of psychological problems among the public.⁴⁻⁶

Children's mental and behavioral health is vulnerable to risks from the external environment, and COVID-19, as a global event, will affect their development.⁷ Children may have less physical activity, irregular sleep rhythms, and longer exposure to smartphone screens, leading to physical problems.⁸ Prolonged duration; fear of infection; depression; boredom; lack of information; lack of face-to-face contact with classmates, friends, and teachers; lack of personal space at home; and financial loss to the family may have greater psychological problems and lasting effects on the child.⁹ In addition, children who are isolated are more likely to develop acute stress disorder, adjustment disorders, and to feel sad. Thirty percent of children who were quarantined met the clinical criteria for post-traumatic stress disorder.¹⁰

The consequences of a pandemic may impact every child, but children with neurodevelopmental disorders, including ASD, are at the highest risk. Children with disabilities are more likely to be abused, and this risk increases during the pandemic.^{11,12} Children with ASD lose more opportunities to exercise social skills because of the limitations of social distancing. It is difficult for children with ASD to adapt to a changing environment. It has been found that children with ASD become fidgety and may show behavioral problems and an increase in self-mutilation when existing settings are rearranged or changed.¹³ Furthermore, the suspension of speech therapy courses and social skills groups for children with ASD may lead to missed opportunities for basic skills development.¹⁴

Once the physical and mental conditions of children with ASD are known, we can provide targeted help and interventions. The purpose of this study was twofold. The main purpose was to investigate the effects of COVID-19 on daily activities (sleep, outdoor activities), psychological behavior, and rehabilitation training of children with ASD. Another was to obtain the stress and emotional status of parents of children with ASD during the COVID-19 pandemic.

Methods

Participants

Due to the pandemic, the Chinese government advised the public to reduce face-to-face social activities. Therefore, we chose to conduct an electronic network investigation for this study. We designed a cross-sectional study using anonymous online questionnaires to investigate the status of children with ASD and their families during the COVID-19 pandemic. Before the survey, experts were organized to demonstrate and modify the scientific nature, rationality, and applicability of the survey plan. The quality of the questionnaire was controlled by setting the core question as a required answer, logical jump and restriction, and filling in the scope. The questionnaire was sent to the respondents through the online survey platform WJX.CN (<https://www.wjx.cn/app/survey.aspx>), and a questionnaire link through social media (WeChat, Tencent, Shenzhen, China). The survey was conducted from May 12 to May 31, 2020. The announcement of the questionnaire was sent to parents of children with ASD by six hospitals in south, east, central, and western China.

Questionnaire Content

The questionnaire included four parts: basic information; ASD children's daily sleep and outdoor activities, and rehabilitation training; ASD children's frequency of abnormal behaviors; and stress and emotional status of parents.

The first part was collected from information about the children with ASD, their parents, and families. It included children's age and gender, grade, place of residence, province, number of children in the family, rank in the children, parents' education, monthly per capita household income, and changes in per capita monthly income of families after the pandemic.

In part two, the daily sleep and outdoor activities and their time per day, sleep problems, and changes in recent sleep and activities time as compared to usual for children with ASD was collected. Changes in psychological behavior, the current status of rehabilitation, online consultation were also collected.

The third part was concerned with ASD children's frequency of abnormal behaviors, including frequencies of listlessness, gnawing at nails, feeling depressed, easy to lose temper, easy to cry, easy to be distracted, excessively worried, and often complaining of discomfort.

The last part was the parents' emotions and stress. The Self-Rating Anxiety Scale (SAS) was used to assess

parents' anxiety. The SAS was compiled by Zung in 1971.¹⁵ It contains 20 items and is scored 1–4 according to symptom frequency. The standard score was obtained by multiplying the rough score by 1.25. According to the norm of the Chinese version of SAS, less than 50 points are defined as normal, 50–59 points as mild anxiety, 60–69 points as severe anxiety, and >70 points as severe anxiety.

Statistical Analysis

The final original data were downloaded from WJX.CN to a Microsoft Excel file. SAS 9.4 was used for data analysis. An analysis of descriptive statistics was conducted to illustrate the basic information, sleep, outdoor activities, psychological behavior, rehabilitation status of children with ASD, and stress and emotional status of parents.

Results

A total of 421 parents participated in the survey, while 15 parents did not complete all the questions. Eventually, 406 parents participated in the study.

Basic Information of Children with ASD

Table 1 shows the basic information of children with ASD. The mean age of the children was 4.6 years (SD=2.3). Of the 406 children, 331 were boys and 75 were girls. Approximately two-thirds (66.5%) of the children did not attend school, and a third (33.5%) attended kindergarten or a general school for mainstream education. These children with ASD came from five provinces in China, mainly Guangdong (33.0%), Shaanxi (24.1%), and Fujian (23.4%) provinces.

The investigation revealed that the income of most families declined, and 38.8% of them indicated a significant decrease after the pandemic.

Daily Activities, Psychological Behavior and Rehabilitation Training During the Outbreak

As shown in Table 2, the average sleep time of all children with ASD was 9.6 hours per day (SD=1.3). Of the parents, 18.5% reported that their children's sleep time was higher than usual, and 11.8% of parents thought their children's sleep quality was better. Half of the parents (49.7%) thought their children did not have sleep problems, while the remaining half (50.3%) reported one or more sleep problems. As shown in [Supplementary Table S1](#), the

Table 1 Basic Information of the ASD Children (n=406)

| Variables | Means (SD)/ N (%) |
|--|----------------------|
| Age (years) | 4.6(2.3) |
| Gender | |
| Boy | 331(81.5) |
| Girl | 75(18.5) |
| Grade | |
| Not going to school | 270(66.5) |
| Kindergarten | 122(30.0) |
| Primary school | 12(3.0) |
| Middle school | 2(0.5) |
| Place of residence | |
| Country | 194(47.8) |
| City | 212(52.2) |
| Province | |
| Guangdong | 134(33.0) |
| Fujian | 95(23.4) |
| Hubei | 40(9.9) |
| Shandong | 23(5.7) |
| Shaanxi | 114(28.0) |
| Number of children in the family | |
| 1 | 193(47.5) |
| 2 | 197(48.5) |
| 3 | 14(3.5) |
| >3 | 2(0.5) |
| Rank in the children | |
| First | 271(66.7) |
| Second | 123(30.3) |
| Third | 10(2.5) |
| Other | 2(0.5) |
| Mother's education | |
| Primary school and below | 8(2.0) |
| Junior middle school | 76(18.7) |
| Senior middle school | 90(22.2) |
| Junior college | 94(23.2) |
| Bachelor's degree | 115(28.3) |
| Master's degree or above | 23(5.7) |
| Father's education | |
| Primary school and below | 6(1.5) |
| Junior middle school | 71(17.5) |
| Senior middle school | 89(21.9) |
| Junior college | 110(27.1) |
| Bachelor's degree | 103(25.4) |
| Master's degree or above | 27(6.7) |
| Monthly per capita household income (CNY) | |
| 1000< | 23(5.7) |
| 1000–2999 | 95(23.4) |

(Continued)

Table 1 (Continued).

| Variables | Means (SD)/ N (%) |
|--|----------------------|
| 3000–4999 | 113(27.8) |
| 5000–6999 | 77(19.0) |
| 7000–9999 | 47(11.6) |
| >10,000 | 51(12.6) |
| Changes in per capita monthly income of families after the pandemic | |
| Significantly reduced | 167(38.7) |
| Certainly reduced | 138(34.0) |
| Almost unchanged | 105(25.9) |
| Certainly increased | 3(0.7) |
| Significantly increased | 3(0.7) |

most common sleep problems were difficulty falling asleep (29.3%), waking up at night (14.3%), and difficulty in falling asleep again after waking (16.5%).

The children's average outdoor activity time was 1.9 hours per day (SD=1.3). Of the parents, 47.3% reported a decrease in their children's outdoor activity time, while only 15.3% reported an increase.

Cognitive ability (45.6%), language understanding (40.2%), and language expression (38.7%) were considered by more parents to improve their child's abilities. Regarding worsened abilities, 147 (36.2%) parents reported that their children's social and emotional problems had become more serious.

Of the 406 children with ASD, 54 (13.3%) did not receive any rehabilitation training, 82 (20.2%) received home-based training, and 107 (26.4%) took online training courses at home. During the pandemic, 43.8% of parents reported that they could receive online counseling services for rehabilitation training at any time, while 12.6% reported no online counseling services at all. Of the parents, 60.8% thought that the training intensity of their children during the pandemic was lighter than usual.

Frequency of Abnormal Behaviors

The frequency of abnormal behaviors in children with ASD is shown in Table 3. Being easily distracted was the most unusual behavior observed by parents, with 51% reporting that their children were sometimes easily distracted and 35.2% reporting frequent distraction. Losing tempers and crying were also unusual behaviors that parents observed in their children, with more than 50% of

parents reporting that these two behaviors occurred sometimes or often.

Stress and Emotional Status of Parents

Table 4 shows the stress and emotional states of the parents. Half of the parents (50.7%) reported that they experienced some pressure when training their children, and 36.5% felt great pressure. Forty-three parents did not know how to help their children with rehabilitation training. Most parents (90.0%) thought that the main reason for the pressure was that their children did not cooperate during the training. In terms of emotional stability, 30.3% of parents reported that they were more likely to get angry with their children during the outbreak.

Of the 406 parents, approximately four-fifths (81.3%) had no symptoms of anxiety, while the proportions of parents with mild, moderate, and severe anxiety were 15.0%, 3.0%, and 0.7%, respectively.

Discussion

The COVID-19 pandemic has adversely affected psychiatric research in children and adolescents. Understanding the mental health effects of physical distancing as soon as possible has become a priority research issue.¹⁶ Children with ASD and special needs are affected differently than children without ASD by the COVID-19 pandemic. Our survey shows, of the 406 parents of children with ASD, most reported their children's sleep as usual, and half thought their children had sleep problems. Nearly half of children with ASD spent less time outdoors during the pandemic. Since the outbreak, children with ASD showed improvement in many aspects such as cognition, and language comprehension and expression. However, more than a third of parents reported that their children's social and emotional status had worsened. Many parents observed that their children were easily distracted, angry, and crying. Three-fifths of children with ASD had no access to professional rehabilitation training, and more than half of families had no online counseling. Almost all parents were under pressure to train their children at home, and the main source of stress was that children did not cooperate with parents' training. Most parents of ASD children had no anxiety.

Sleep and Outdoor Activities

Studies have reported changes in sleep time and quality in children and adolescents during this pandemic.^{17,18}

Table 2 Daily Activities, Psychological Behavior and Rehabilitation Training of Children with ASD During the Outbreak (n=406)

| Variables | Means (SD)/ N (%) |
|---|-------------------|
| Sleep time per day (hours) | 9.6(1.3) |
| Recent sleep time compared to usual | |
| Increase | 75(18.5) |
| No change | 287(70.7) |
| Decrease | 44(10.8) |
| Changes in sleep quality compared to usual | |
| Better | 48(11.8) |
| Same | 319(78.6) |
| Worse | 39(9.6) |
| Sleep problems^a | |
| None | 202(49.7) |
| 1 | 114(28.1) |
| 2 | 53(13.0) |
| 3 | 31(7.6) |
| >3 | 6(1.6) |
| Daily outdoor activity time (hours) | 1.9(1.3) |
| Outdoor activity time compared to usual | |
| Increase | 62(15.3) |
| No change | 152(37.4) |
| Decrease | 192(47.3) |
| Improvement in ability and behavior (multiple choices) | |
| None | 66(16.3) |
| Gross-motor | 114(28.1) |
| Fine-motor | 96(23.7) |
| Cognitive ability | 185(45.6) |
| Language comprehension | 163(40.2) |
| Language expression | 157(38.7) |
| Social and emotional | 102(25.1) |
| Aggressive behavior | 6(1.5) |
| Self-stimulating behavior | 16(4.0) |
| Eating problems (picky, eating too much or too little) | 51(12.6) |
| Worsened ability (multiple choices) | |
| None | 154(37.9) |
| Gross-motor | 25(6.2) |
| Fine-motor | 25(6.2) |
| Cognitive ability | 41(10.1) |
| Language comprehension | 61(15.0) |
| Language expression | 78(19.2) |
| Social and emotional | 147(36.2) |
| Aggressive behavior | 24(5.9) |
| Self-stimulating behavior | 70(17.2) |
| Eating problems (picky, eating too much or too little) | 52(12.8) |

(Continued)

Table 2 (Continued).

| Variables | Means (SD)/ N (%) |
|--|-------------------|
| Current status of rehabilitation training | |
| No rehabilitation training | 54(13.3) |
| Self-training at home | 82(20.2) |
| Learning rehabilitation course online | 107(26.4) |
| Part-time at hospital or institution | 41(10.1) |
| Go to the hospital or institution as usual | 122(30.0) |
| Online consultation in the training process | |
| At any time | 178(43.8) |
| Sometime | 177(43.6) |
| Never | 51(12.6) |
| Training intensity during the pandemic | |
| Lighter than usual | 247(60.8) |
| The same as usual | 123(30.3) |
| Heavier than usual | 36(8.9) |

Notes: ^aThis question includes the following nine options: none, difficulty falling asleep, difficulty waking up, waking at night, nightmares, night terrors, sleepwalking, sleep rhythm disturbance, grinding teeth in sleep, and difficulty falling asleep again after waking. Choose one and get one point. A higher score indicates a higher number of sleep problems that the child has.

Table 3 Frequency of Abnormal Behaviors in Children with ASD (n=406)

| Variables Questions and Options | N (%) | | |
|---------------------------------|-----------|-----------|-----------|
| | Never | Sometimes | Often |
| Listlessness | 281(69.2) | 119(29.3) | 6(1.5) |
| Gnawing at nails | 294(72.4) | 86(21.2) | 26(6.4) |
| Feeling depressed | 264(65.0) | 133(32.8) | 9(2.2) |
| Easy to lose temper | 118(29.1) | 230(56.7) | 58(14.3) |
| Easy to cry | 150(37.0) | 205(50.5) | 51(12.5) |
| Easy to be distracted | 56(13.8) | 207(51.0) | 143(35.2) |
| Excessively worried | 312(76.9) | 81(20.0) | 13(3.2) |
| Often complaining of discomfort | 352(86.7) | 46(11.3) | 8(2.0) |

Our survey shows that during the pandemic, sleep time and sleep quality of most children with ASD did not change much compared to their usual patterns. The constant sleep patterns of children with ASD may be due to their stubborn behavior patterns. However, consistent with sleep patterns, there were also sleep problems in children with ASD reported, which mainly include bedtime resistance and night waking. People with ASD often have sleep problems or disorders, and the most common sleep problem is the inability to get to

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Table 4 Stress and Emotional Status of Parents (n=406)

| Variables | N (%) |
|---|-----------|
| Stress during the process of assisting children in rehabilitation training | |
| No pressure at all | 8(2.0) |
| Some pressure | 206(50.7) |
| Much pressure | 149(36.7) |
| Do not know how to help children | 43(10.6) |
| Main sources of stress (multiple choices) | |
| Difficulties in using the online learning platform | 78(19.2) |
| Do not understand the online course | 81(20.0) |
| Children do not cooperate with parents' training | 365(90.0) |
| Family members do not support/understand | 46(11.3) |
| Emotional stability during the outbreak | |
| Did not get angry | 67(16.5) |
| Occasionally get angry | 26(6.4) |
| The same frequency of outbursts as usual | 190(46.8) |
| Easier to get angry than usual | 123(30.3) |
| Anxiety level | |
| Normal | 330(81.3) |
| Mild anxiety | 61(15.0) |
| Moderate anxiety | 12(3.0) |
| Severe anxiety | 3(0.7) |

sleep or stay asleep.¹⁹ Our results are consistent with previous research results.

The outbreak of COVID-19 has led to the implementation of physical distancing policies in many countries, which have significantly affected how children spend their time outside their home. Studies from Canada reported a decrease in children's outdoor time, which is consistent with our observations.^{20,21} Children with ASD have a variety of motor impairments,^{22,23} and the reduction of outdoor exercise time may further aggravate cognitive-motor deficits. In addition, the reduction of outdoor activities also reduce the opportunities for children with ASD to exercise social skills.

Changes in Ability and Behavior

Quite a number of parents reported that children with ASD have improved their cognitive and language skills during the pandemic. With long-term restrictions at home, parents have had more time to accompany their children, thus carrying out more family activities. The results of the British Millennium Cohort study found that in the early development of children, a series of activities with parents and children, including reading with children, in addition to usual routines and practices, have a significant effect on

children's cognitive development.²⁴ Long-term home life also increases the chance of home language input. Home language input is positively correlated with children's cognitive ability and vocabulary diversity.²⁵ This has a positive effect on the development of children with ASD's language abilities.

Many parents reported that their children's social problems had become more serious. This may be caused by the social distancing and difficulty to socialize during the COVID-19 pandemic and may be related to parents' behavior. Individuals with ASD may have a wide range of autism phenotypes in their families. Parents of children diagnosed with ASD often exhibit social tendencies similar to ASD, such as extensive communication difficulties and poor social skills.²⁶ During long periods of isolation at home, deficiencies in parents' social skills can be amplified and affect children. In addition, parents observed that children were easily distracted and prone to temper tantrums, and some parents reported that their children's emotional problems were more serious. Therefore, in future medical services, more methods need to be provided to help children with ASD control emotions, as well as parents and their children improve social skills.

Rehabilitation Training

Due to the closure of hospitals and institutional rehabilitation departments, children with ASD were unable to receive on-site professional training and guidance. Children with ASD could only receive rehabilitation training at home. Most parents reported that the training intensity was lighter than usual. At present, many hospitals have launched network counseling services for special needs children. However, according to our data, one-third of parents did not receive timely and useful rehabilitation guidance information. A recent survey from the United States also showed that only 56% of families with children with intellectual and developmental disabilities had received continued services through tele-education during the pandemic.²⁷

In a recent survey on the prevalence of ASD in children in China, 43.3% of the children with ASD were diagnosed for the first time, and an increasing number of children with mild to moderate ASD were diagnosed.²⁸ Rehabilitation of these children requires more medical resources. With the prevalence of COVID-19, many medical services for children with ASD have been transferred to online services. Online services should ensure that more

families with children with ASD are covered and that more professional and comprehensive services can be provided to help parents train their children from cognitive, social and emotional aspects.

Stress and Emotional Status of Parents

ASD children are easily distracted and lose their temper, and do not cooperate with their parents for family training at home, which brings great pressure to their parents. Parents of ASD children need professional family training guidance.

As a result of the COVID-19 outbreak, the economies of many countries will derogate and there will be large global effects, some of which are already visible.²⁹ Along with this economic decline is the decrease in family income. Many studies have reported the loss of personal income and the consequent increase in family life pressure.^{30,31} This pressure will increase parents' anxiety. However, the vast majority of parents in our study had normal levels of anxiety. It may be that the improvement in children's overall behavior alleviates the anxiety of parents. In addition, at the time of our online survey, COVID-19 had entered Phase 2 and the lockdown was significantly reduced in most parts of China, therefore the adverse impact of COVID-19 on families may have been reduced.

The Limitation of This Study

In March, The Lancet wrote that COVID-19 would change the way science is studied.¹⁶ An online survey has proved to be a powerful data collection tool, as it can obtain a large sample size, short response time, timely data processing, and is low cost.³² We obtained sample data over a short period of time from five representative regions of China through multicenter peers to understand the current psychological status and rehabilitation status of children with ASD. However, the results of this study must be viewed from certain limitations. The survey lacks clinical data on children with ASD, such as the severity of the disease and comorbidities. These aspects may limit the comparability of the results to different studies as well as the internal comparison of any subsequent assessments. Due to the nature of the network survey, only the perspective of parents was available to investigate the psychological and behavioral development of children with ASD. Further investigation and detailed assessment of the use of standardized methods are needed.

Conclusion

In summary, this survey shows half of the children with ASD had sleep problems and spent less time outdoors

during the pandemic. Some children with ASD showed improvements in cognitive and language skills, while some showed the aggravation of social and emotional problems. Three-fifths of children with ASD had no access to professional rehabilitation training, and more than half of families had no online counseling. In family training, parents have great pressure because their children do not cooperate with the training. Most parents of ASD children had no anxiety. These families need more medical support, especially in family training, to help parents improve the social and emotional control skills of ASD children.

Ethics Statement

This study was conducted in accordance with the Declaration of Helsinki. The online survey was approved by the medical theory Committee of School of public health, Sun Yat-sen University. All participants provided electronic informed consent that contained information about the purpose of the study, procedures, benefits of participating, voluntary participation.

Acknowledgments

All authors thank the active and enthusiastic collaboration of children and their caregivers in this study. And we also acknowledge all team members, participating hospitals for their support.

Author Contributions

Conceptualization, Jin Jing, Hong Yu, Saijun Huang; Methodology, Jin Jing, Hong Yu, Saijun Huang, Yanna Zhu; Software, Tao Sun; Validation, Tao Sun; Formal analysis, Tao Sun, Yanna Zhu; Investigation, Jie Zhang, Linjuan Huang, Qiang Chen, Guangyang Peng, Dongmei Zhao, Shanshan Song; Resources, Jie Zhang, Linjuan Huang, Qiang Chen, Guangyang Peng, Dongmei Zhao, Shanshan Song; Data curation, Shanshan Song; Writing-original draft preparation, Tao Sun, Saijun Huang; Writing-review and editing, Jin Jing; Visualization, Yanna Zhu; Supervision, Hong Yu; Project administration, Hong Yu; Funding acquisition, Jin Jing, Saijun Huang. All authors contributed to data analysis, drafting or revising the article, have agreed on the journal to which the article will be submitted, given final approval of the version to be published, and agreed to be accountable for all aspects of the work.

Funding

This study was funded by the Foshan Autism Spectrum Disorder Early Rescue Engineering Technology Research

Center (Foshan Science and Technology Bureau, NO.2020001003942); and the project “Relationship between the expression of estrogen receptor β (ER β) in peripheral blood and autism spectrum disorder in children” (Foshan Science and Technology Bureau, NO.1920001000541).

Disclosure

The authors declare that they have no conflicts of interest for this work.

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