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# Psycho-social consequences associated with COVID-19 in people with ASD and their families: A literature review

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## Abstract

**Background:** COVID-19 has become a global pandemic and has inevitably affected the whole world. This effect is greater on people with ASD (ASD) and their families. Depression, attempts to cope with change, and having difficulty interacting with others are some of the challenges people with ASD often face. The aim of this study was to review the psycho-social consequences of COVID-19 in people with ASD and their families.

**Methods:** This study is a Literature Review. Extensive electronic search results for the keywords ASD, COVID-19, Coronavirus, psychological, psychosocial, and consequence in Google Scholar, PubMed, Scopus, ProQuest, Science Direct, SID and Magiran in 2020, eventually provided a total of 130 articles. After reviewing the titles of the articles, we excluded 85 articles as they were duplicated and/or irrelevant. Finally, based on the inclusion and exclusion criteria, 17 articles remained.

**Results:** In general, the change in routine and uncertainty caused by COVID-19 have caused distress for people with ASD and will worsen their symptoms and mental health. Excessive stress worsens the mental health of caregivers, and as this burden increases, they report higher rates of social harm, depression, and anxiety that affect their daily functioning.

**Conclusion:** The COVID-19 epidemic affects all strata of society. People with ASD are particularly vulnerable to the psychosocial effects of this epidemic. COVID-19 increases anxiety, distress, depression, financial problems, loss of a job, and even marital conflict. Access to necessary services and transmission problems are also the result of rapid social and environmental changes.

Keywords: Autism Spectrum Disorder, COVID-19, Coronavirus, Psychological, Psychosocial, Consequence

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### Introduction

Autism Spectrum Disorder (ASD) is one of the most common pervasive developmental disorders, which is considered as the most complex, and at the same time, the

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unknown childhood disorder (1-4). It is a multifactorial neurodevelopmental disorder characterized by certain social communication features such as restricted and re-

# *↑What is "already known" in this topic:*

The COVID-19 pandemic has caused significant stress and anxiety for many people all around the world. This situation can create many psychosocial challenges, especially for people with special needs such as ASD and their families. Few studies have already addressed these challenges. However, the psychosocial consequences of COVID-19 for these individuals have not been accurately identified and collected.

 $\rightarrow$ *What this article adds:* 

In this review article, psychosocial consequences for people with ASD and their families were identified and collected. Both individuals and their families appear to suffer from depression, stress, anxiety, PTSD, loss, worry, mood swings, behavioral changes, and financial problems as a result of rapid social and environmental changes, disruption of daily activities, and reduced access to services.

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petitive patterns in *interests*, behaviors, and activities (5), stereotypes and the use of perceptual and expressive languages (6). The reported preval ence of ASD is still rising in recent years, affecting almost 1 in every 54 children in the United States (7). The approximate prevalence of autism in Iran is equal to 0.1% (10 per 10,000) (8). Parenting an ASD child can be stressful (9). In fact, caring for a child with ASD is associated with more parental stress than any other disability (10).

Coronavirus disease 2019 (COVID-19) is an infectious disease caused by coronavirus. Most people infected with COVID-19 develop mild to moderate respiratory problems. The virus mainly spread through saliva droplets or nasal discharge when an infected person sneezes or coughs (11, 12). COVID-19 is the most crucial issue we face now, and it has had a significant impact on our lifestyle (13). However, children generally suffer from a milder form of the illness (14). The COVID-19 pandemic has touched all parts of society. People with mental disabilities are particularly vulnerable to the physical, psychological, and social effects of this pandemic (15). COVID-19 can also affect ASD patients; the impact of this pandemic on this group will be more significant than ordinary people (16, 17). Children and adolescents with ASD are more susceptible to the disturbing effects of the COVID-19 pandemic and quarantine on their mental health (18). Many governments have now taken more restrictive measures to prevent the spread of the disease. One of these measures is staying at home for parents and children. In this situation, caring for little children with ASD can be upsetting for families and caregivers (19). The coronavirus pandemic is changing the function of society. Environmental changes, disruption of daily activities, and lower access to services and social networks will profoundly affect ASD patients and their families, and sometimes it will devastate them (20). These children usually receive therapeutic interventions a few hours a week at home, hospitals, or private institutions with special therapists. But at present, children with ASD should not be engaged in interventions to maintain their health, prevent more parental stress and aggravation of children's behavioral problems (19). Depression, trying to cope with change, and having difficulty interacting with others are some of the challenges ASD patients deal with most of the time. However, amidst a pandemic, these challenges are exacerbated (21). COVID-19 increases anxiety and distress in ASD patients. Adaptation to increased health recommendations and observance, social isolation, and social distance has changed the usual lifestyle of people with ASD and upset them (22). Overall, 20% of ASD patients are diagnosed with anxiety, and 11% suffer from depressive disorders (23). The further distress caused by the coronavirus pandemic means that ASD patients with a cognitive disturbance may experience worsening their mental health. Even those ASD patients, who did not have mental health problems, were at higher risk for developing them, especially anxiety (24) and depression (25). Also, uncertainty about COVID-19 and the constant flow of new information can affect ASD patients and increase their anxiety and distress (23). The coronavirus, combined

with its high rates of infection and mortality, has created global psychosocial effects. The widespread fear of COVID-19, the so-called corona phobia, has led to many psychiatric manifestations in various social groups (26). It is necessary to conduct a study to determine and collect the various psychosocial consequences of COVID-19 for people with ASD due to the high prevalence and many problems compared to other people in the community and even people with other disabilities. These consequences need to be investigated in order to help improve the psychosocial condition of these people by eliminating the unfavorable psychological and social conditions that have doubly affected the lives of these people and their families. This research provided evidence for policymakers, NGO planners, individuals with ASD and their families, as well as psychological and counseling service providers to develop evidence-based protocols and interventions for this group to improve their mental health and social status in the situation of COVID-19 epidemic and even after the end of this condition.

This study aimed to review the psychological and social consequences of COVID-19 on ASD patients and their families.

# Methods

We used a Literature review through various national and international electronic databases to identify studies that report "the psycho-social consequences associated with COVID-19 in people with ASDs".

*Keywords:* Autism Spectrum Disorder, covid-19, coronavirus, psychological, psychosocial, consequence

#### Search strategy

We selected the relevant articles with an extensive electronic search of keywords of Autism Spectrum Disorder, COVID-19, coronavirus, psychological, psychosocial, and consequence (in the title and abstract) in international databases such as Google Scholar, PubMed, Scopus, ProQuest, Science Direct, and national databases, including SID and Magiran in 2020, given the novelty of the corona issue. I used my university subscription (the University of Social Welfare and Rehabilitation Sciences) to access the Science Direct database.

Unfortunately, no Persian study was found in the national databases. In the first stage of the search, 130 articles were found. After reviewing the titles of the articles, we excluded 85 articles as they were duplicated and or irrelevant. Finally, by examining the articles' abstracts and considering the inclusion and exclusion criteria, 17 studies out of the remaining 45 articles were included in the study (Fig. 1). Papers were evaluated using a data extraction form, including objectives, type of study, target group, sample size, and results (Table 1).

#### Search strategy syntax

The search strategy syntax for this article, for example, in the main database that was PubMed, is as follows:

(((((Autism Spectrum Disorder [Title/Abstract]) AND (COVID-19[Title/Abstract])) OR (corona virus [Title/Abstract])) AND (psychological [Title/Abstract])) OR

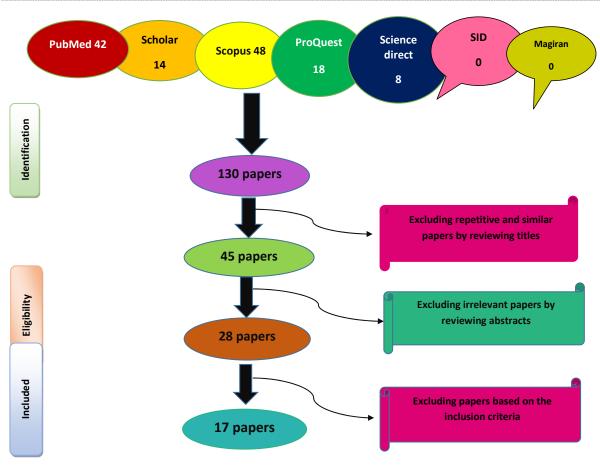


Fig. 1. The flowchart of the article search process

(psychosocial [Title/Abstract])) AND (consequence [Title/Abstract])

#### **Data collection**

Selected articles were entered into EndNote software. After removing the duplicate titles, the remaining articles, their abstracts as well as the full text of the article were independently reviewed by two authors. Another author reviewed the results, and all the results were reviewed by all three authors. The process used to identify related articles is shown in Figure 1. The flowchart of the article search process.

## Inclusion and exclusion criteria

Inclusion criteria: In this article, inclusion criteria were as follows: 1) published articles, 2) articles with full text, 3) articles published in English and Persian, and 4) only articles related to the psycho-social consequences associated with COVID-19 in people with ASDs and their parents.

Exclusion criteria were as follows: This study excluded papers that did not meet the following criteria: 1) Items that do not comply with the inclusion criteria and 2) letters to editors.

#### **Quality assessment**

A quality assessment checklist was used. It was done by

2 researchers from the authors. They reviewed each article and reported independently, and if they approved both articles, we would accept the content. But if any of them rejected the material, the third person reviewed it again.

#### Data extraction

The authors reviewed the final articles line-by-line and extracted key points of the articles. Parallel independent assessments were conducted to minimize the risk of errors. The extracted data were entered in an electronic data extraction form on Excel.

# Results

From the remaining articles, 17 articles based on the inclusion and exclusion criteria had the necessary conditions to enter the study. The specifications of these studies can be seen in Table 1. Characteristic of the studies included in the Literature review. The most important features of the articles are the following: The geographical location of the studies was scattered in different countries. The findings of this study show that many psychosocial challenges have arisen for people with ASD during the outbreak of coronavirus. Some of these challenges include depression, stress, anxiety, behavioral changes as a result of rapid social and environmental changes, disruption of daily activities and reduced access to services.

# Psychosocial consequences of COVID-19 in people with ASD

Authors	Country	Title	Objectives	Type of study	Target group and sample size	Study results
Nisticò V, et al. (27)	Italy	The psychological impact of COVID-19 among a sample of Italian individ- uals with High Function- ing ASD	Assessing the prevalence of stress, anxiety, depression, and symptoms of post-traumatic stress disorder (PTSD) among a sample of 45 adults with a high-functioning ASD during the first two months of the COVID- 19 pandemic in Italy and according to a sample of 45 healthy controls.	A cross- sectional study using an online survey	Adults with ASD, 45 person with high- functioning ASD under the age of 18 and 45 healthy controls	Patients with high-functioning ASD suffer more from depression, anxiety, stress, and symptoms related to PTSD than the healthy group during the first two months of the COVID-19 pandemic.
Rodríguez C, et al. (28)	Cuba	Psychological impact on children with ASD during COVID-19 confinement	To describe the psychological disturbances of ASD children during confinement by COVID-19 and to stimulate the family to self-manage psychological resources to control misbehaviors	A review study	Providing a characterization of the manifestations in chil- dren with this disorder from detention by COVID-19 and providing psychological resources and general guidelines to parents for immediate attention to the alterations presented by these children to better cope with the period of confine- ment.	In crises like this pandemic, there are changes in ASD children's mental health. Aggression, sleep disorders, irritability, screaming, and the occurrence of stereotyped behaviors are the most common changes. The Quarantine can be very challenging for autistic children who react inappropriately to their daily changes.
Asbury K, et al. (29)	England	How is COVID-19 Af- fecting the Mental Health of Children with Special Educational Needs and Disabilities and Their Families?	Investigating the effect of coronavirus out- break on the mental health of children with various disorders and special educational needs, and their families	A qualitative study	Participants were 241 parents or guardians of school-age children with various disor- ders and special educational needs in the UK, of whom 197 were autistic children.	Many families reported that COVID-19 affected their mental health, often leading to increased fear and anxiety. A few families also reported increased anxi- ety, low mood, and stress. The data suggest that parents experienced more stress and anxiety than children. But the frequency of fear was similar among parents and children
Bent S, et al. (30)	China	The Experience of Par- ents of Children with ASD Spectrum Disorder Dur- ing the COVID-19 Pan- demic: A Qualitative Analysis	To identify some general challenges and highlight strategies that families are currently using to address the unique experiences of supporting a child with ASD amidst a worldwide pandemic	A qualitative study, including semi-structured telephone inter- views with parents	Fifteen parents of children and adolescents in a non- governmental school for children with level two and three of ASD (11 to 21 years old)	Parents discussed their experiences with social skills, e-learning, transfer, the structure, difficulty, and stress associated with COVID- 19, and the positive changes during the COVID-19 pandemic.
Colizzi M, et al. (31)	Italy	Psychosocial and Behav- ioral Impact of COVID- 19 in ASD: An Online Parent Survey	Evaluation of the effect of COVID-19 pan- demic on ASD patients and determining whether pre-pandemic social, demographic, or clinical characteristics predict adverse outcomes	A cross- sectional, de- scriptive, quali- tative study, an online parent survey	Data from 527 participants, including parents and guardi- ans of people with ASD, were available in the survey.	The majority of the parents of ASD patients found the period of change and emergency restrictions as challenging. They need more commitment than ever. Many parents reported problems managing their children's daily activities, especially regarding lei- sure and structured activities. Behavioral problems worsened in more than a third of the ASD patients.

#### *Table 1.* Characteristic of the studies included in the Literature review

Table 1. Ctd

Authors	Country	Title	Objectives	Type of study	Target group and sample size	Study results
Lee V, Et al (32)	Canada	Impact of COVID-19 on the Mental Health and Wellbe- ing of Caregivers and Families of Autistic people A Rapid Synthesis Review	Identifying and eliminating knowledge gaps and providing evidence for the family's desires, abilities, and perceptions of their current experiences with COVID- 19. Providing a summary of evidence relat- ed to the mental health needs of caregiv- ers and families of children and adolescents with ASD disorder in a short search period and a description of how these needs relate to family mental health and caregiver and resilience	A Review study. Three types of search strategies were used in this study	Twenty-two articles were included in this review.	Eleven articles published in research journals showed increasing social disorders such as Job loss, increased marital conflicts, and finan- cial instability. Some reports showed increased behavioral challenges that lead to difficulty in parent- child interactions and tension in family rela- tionships. Some studies showed that parents experienced increased anxiety and stress and needed more support. One in three empirical studies discussed the psychological distress, health challenges, and mental health in caregivers and families during the COVID-19 pandemic.
Charles E, et al. (33)	America(USA)	COVID-19 and Adults With Intellectual Disability, ASD, Epilepsy, or Brain Injuries: Findings From an Online Survey	Investigating the impact of the corona- virus pandemic in adults with a wide range of disabilities such as ASD	An online survey. The survey was available online from April 17, 2020, to May 1, 2020	A total of 2469 adults afflicted with disabilities	About 93% of respondents reported observing the pandemic's recommendations, and 7% reported disregarding them. Respondents who felt anxious or depressed over COVID-19 were asked about their access to emotional and support services. About 80% reported having access to these services, and 20% reported inaccessibility to them. Around 72% of respondents received direct health care and services, and 76% continued to provide these services during the pandemic. But only 50% could keep a safe distance from each other.
Cassidy SA, et al. (17)	Multi national (Canada, UK, USA)	An expert discussion on ASD in the COVID-19 Pandemic	This roundtable, therefore, aims to bring together autistic adults, their families, practitioners, and academics across the fields of disability rights, public health, medicine, psychology, and mental health across different countries and contexts	Commentary	8 Participants	Provide some issues that need to be addressed during this epidemic, especially for adults with ASD. Things that can be done during this period, suggestions as well as opportunities that this pandemic has created for people.

# Psychosocial consequences of COVID-19 in people with ASD

Authors	Country	Title	Objectives	Type of study	Target group and sample size	Study results
Narzisi A. (19)	Italy	Handle the ASD spectrum condition during Corona- virus (COVID-19) Stay at Home period: Ten tips for help- ing parents and caregivers of young children	The main aim of this editorial is to give some advice, summarized in 10 tips, to help families to handle children with ASD during this period.	editorial	Italian colleagues	COVID-19 is questioning the routine of our young children with ASD, and they are called to respect rules and habits that are not always understandable for them (i.e., disin- fect your hands, do not touch your eyes or nose, and cover your mouth. They are also not able to see people they would like to meet and must stay at home). These changed routines could cause pro- found suffering for them. For this reason, we all (parents, therapists, and researchers) must be united and quickly establish new and functional rou- tines to allow our young children to be safe and peaceful. As ASD experts we have to find different ways to get close to our pa- tients and their families.
Ersoy K, et al. (34)	Turkey	The Comparison of Im- pact of Health Anxiety on Dispositional Hope and Psychological Well-Being of Mothers Who Have Children Diagnosed with ASD and Mother Who Have Normal Chil- dren, in COVID-19 Pan- demic	It aimed to compare the effect of health anxiety on the dispositional hope and the psychological wellbeing levels between mothers with autistic children and mothers with normal children in the COVID- 19 pandemic	An empirical article – Quantitative	Participants of the research constitute a total of 126 mothers (60 mothers with autistic children and 66 mothers with normal children) living in İstanbul	Results of the study revealed that the impact of health anxiety on the psychological well- being levels among mothers with autistic children are more substantial than it was among mothers with normal children. It was found that mothers with autistic children, compared to mothers with typical children tended to have a higher level of health anxiety about chronic diseases and were inclined to have a lower level of dispositional hope and psychological wellbeing.
Degli Espinosa F, et al. (35)	Italy	A Model of Support for Families of Children With ASD Living in the COVID-19 Lock- down: Lessons From Italy	Include some parents' comments at the end to share the parent perspective in real-time as this pandemic unfolds across the world	Commentary – ABA Parent protocol	Parents of children with ASD	Parental report of challenging behavior; of their ability to maintain the agreed structure; direct measurements of children's adher- ence to parental instructions; direct meas- urements of challenging behavior during the coaching session; and parents' procedural fidelity

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Authors	Country	Title	Objectives	Type of study	Target group and sample size	Study results
Stankovic M et al. (36)	Serbia	The serbian experience of challenges of parenting children with asds during the COVID-19 pandemic and the state of emergency with police lockdown	This study aims to provide a comprehensive exploration of challenges experienced by parents of autistic children spectrum disorder (ASD) in Serbia during the COVID-19 pandemic and police lockdown	An empirical Article – Quantitative	A total of 85 par- ents completed a survey in this study (74% mothers, 22% fathers, 4% other relatives).	The survey revealed a lack of support, feelings of helplessness, various challenges and needs amongst parents, which although were present before, have become more prominent during an emergency state. At the beginning of police lockdown, most parents of the children with ASD handled their children on their own, which suggests that the government needs better plans and strategies for future similar situa- tions.
Szabo TG et al. (37)	USA	From Helpless to Hero: Promoting Values-Based Behavior and Positive Family Inter- action in the Midst of COVID-19	Focused on the ways to promote prosocial conduct at home by pointing out that these actions are reflections of superpow- ers possessed by children	A commentary – Parental guideline	Target group: Par- ents and Sample size: not mentioned.	The current crisis has created an unprecedented demand for parent support. Still, it has also forced us to curtail in-person services and, instead, interact via phone and the Internet media. With simple exercises based on known principles, strategies, and kernels, behavior analysts connecting with parents online may promote positive parenting to the extent that had never happened before. We have focused on the ways to promote prosocial conduct at home by pointing out that these actions are reflec- tions of superpowers possessed by children. But it is equally valid that parents, navigating an unprecedented situation with no lead time, are the unsung heroes of this era.
Brondino N et al. (38)	Italy	Effective Strategies for Managing COVID-19 Emergency Restrictions for Adults with Severe ASD in a Daycare Center in Italy	To evaluate the impact of restrictions on challenging behaviors in a sample of individuals with ASD and cognitive impairment attending a daycare center before complete lockdown	retrospective study	A total of 18 young adults, of which 13 are males that all presented severe ASD	At present, the COCID-19 emergency is still repre- senting a massive psychological overload for all individuals. Addi- tionally, returning to the same level of activity as before the COVID-19 pandemic may not be easy. Our retrospective study did not show a significant change in our individuals' prob- lematic behaviors with ASD after initiation of COVID-19 restrictions. We could cautiously hy- pothesize that the preventive countermeasures we adopted effectively reduced distress in individuals with ASD.

# Psychosocial consequences of COVID-19 in people with ASD

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Authors	Country	Title	Objectives	Type of study	Target group and sample size	Study results
Jeste S et al. (39)	USA	Changes in access to edu- cational and healthcare services for individuals with intel- lectual and developmental disabilities during COVID-19 restrictions	The objectives of this online survey were to understand the changes in ac- cess to services caused by COVID-19 restrictions for individuals with genetic syndromes associated with IDDs and to survey caregivers about helpful resources in both educa- tion and health care	An online survey (with the online question- naire)	A total of 818 respondents (669 within the USA and 149 outside the USA)	COVID-19 restrictions have significantly affected the access to services for individuals with syndromic IDDs. Telehealth may provide opportunities for the delivery of care and education in a sustainable way, not only as restrictions endure but also after being lifted.
Manning J et al. (40)	USA	Perceptions of Families of Individuals with ASD during the COVID-19 Crisis	The primary aim was to explore the extent and causes of stressors experienced by families of individuals; and the sec- ondary purpose was to determine whether there was an association between working status of parent, level of severity of the individual with ASD, and previous levels of support on the current expressed distress due to COVID-19.	an online survey	A total of 471 respondents were included (of families in Michigan)	Our study revealed that during the COVID-19 crisis, individuals with ASD and their families report high levels of stress and disruption to life. The most outstanding areas of stress were around isolation, illness, and finance, and we noted many free-text responses revealing a desire of families to communicate the burden with which they are living. Not surprisingly, the more severe symptoms the individual with ASD is reported to have, the greater the caregiver's reported degree of stress. Additionally, caregivers report a higher degree of stress when the individual with ASD is younger, while they report individuals with ASD who are older are
Tromans S et al. (41)	UK	Priority concerns for peo- ple with intellectual and developmental disa- bilities during the COVID-19 pandemic	To provide systematic and evidence-based information of the priority concerns for people with intellectual disabilities and or ASD regarding the COVID-19 pandem- ic	A cross-sectional study	Thirty-two organizations were contacted, of which 26 (81%) responded.	<ul> <li>experiencing greater stress.</li> <li>The recommendations highlight the expectations of people with intellectual disabilities and or ASD in the current pandemic. It could support policymakers and professionals' delivery and evidence person-centered care. They were asked to report the 5 highest-ranking concerns pertaining to the COVID-19 pandemic in each of the following three domains: <ul> <li>(a) mental health and challenging behavior,</li> <li>(b) physical health and epilepsy, and</li> <li>(c) social circumstances and support.</li> </ul> </li> </ul>

# Discussion

Despite the novelty of the disease and the lack of published research in this area, experts believe that COVID-19 may worsen the mental status of ASD patients, primarily due to uncertainty about the situation (17). Establishing new routines for ASD patients may create challenging behavior and resistance and increase caregivers' stress, especially if administered suddenly and without warning (23). COVID-19 pandemic affects all parts of society. People with mental disabilities are especially vulnerable to the physical, psychological, and social effects of the pandemic (15). Excessive stress may worsen caregivers' mental health; as this burden increases, higher rates of depression and anxiety are reported by the patients. These conditions affect their daily functioning and prevent them from providing optimal care (42). Therefore, policymakers must recognize this group's complex needs and the psychological damages they encounter. Particular attention should be paid to this group of people, and efforts should be made to minimize and alleviate their discomfort (21). To better deal with this type of psychosocial problem of different groups of society, the government, health care personnel, and other stakeholders should develop proper models of intervention and prevention of psychosocial crises (26). The aim of this study was to investigate the psychological and social consequences of COVID-19 on ASD patients and their families. The evaluation of the published articles showed significant points.

Nisticò et al. (2020) noted that people with a highfunctioning ASD in the first two months of the COVID-19 pandemic suffer more from depression, anxiety, stress, and the symptoms of post-traumatic stress disorder (PTSD) compared to the healthy control group (27). The study results by Rodriguez showed that the mental health of the children with ASD changes in crises such as this pandemic. Violence, sleep disorders, irritability, screaming, and stereotyped behaviors were the most common changes (28). In the Asbury et al. study, many families reported that COVID-19 impacted their mental health and often led to an increase in their fear and anxiety, and a few families reported increased anxiety, low mood, and stress (29). In the Bent study, parents with autistic children expressed their experiences with social skills, e-learning, transfer, structure, difficulty and the stress associated with COVID-19 during the COVID-19 pandemic (30). The Colizzi study also showed that most parents of ASD patients found the period of change, and the restrictions followed the onset of emergencies so challenging that they needed more commitment than before. Behavioral problems worsened in more than one-third of ASD patients (31). Lee et al. (2020) showed an increase in social disorders such as loss of a job, increased marital conflict, and financial instability. These increasing behavioral challenges lead to problems in parent-child interactions and stress in family relationships. Some other papers in this study also indicated that parents have experienced increased anxiety and stress and needed more support (32). Cassidy and Nicolaidis (2020) revealed the points and challenges considered for all people, especially adults with ASD. Some of them included dealing with uncertainty, changing daily routines, amassed social isolation, increased vulnerabilities, more financial and job instability; increased mental health problems, including anxiety, and challenges in managing concurrent physical health issues, increasing need for formal and informal supports and concerns about health care resources (17). Narzisi study showed that COVID-19 disrupted the routines of little children with ASD, and they were asked to respect the rules and customs which were never understandable by them (9). In Stankovich et al. study, parents of autistic children raised their concerns about pandemics and emergencies. The main challenges were related to the child's behavior and the problems that parents encountered in receiving the necessary services and support for these children (36). The results of the Szabo et al. study showed that the current crisis had created an unprecedented demand for parental support (37). Brondino et al. also found that the loss of specific long-term interventions in this group might lead to a loss of skills, decreased positive behaviors, and an increase in incompatible behaviors (38).

The Jeste et al. study results showed that telemedicine and tele-rehabilitation are available during the COVID-19 restriction period. Also, it may provide opportunities for sustainable care and education once these restrictions are waived (39). The results of the Manning et al. study showed that during the COVID-19 crisis, ASD patients and their families report high levels of stress and disturbance in life. Most of the stress areas were related to isolation, illness, and financial problems (40).

The quarantine can be very challenging for people with ASD who react inappropriately to their daily routine changes. This change in the routine can make them suffer. That is why all of us (parents, therapists, and researchers) must be united and quickly develop new and practical routines to provide peace and security for them. Other findings suggest that the COVID-19 pandemic has become an element of fear and anxiety for people. They have higher levels of anxiety in health and chronic diseases and tend to have lower levels of hope, psychological wellbeing, and mental health. The more severe the symptoms reported in a person with ASD, the higher the amount of stress reported by the caregiver, which is also true in non-pandemic periods.

#### Conclusion

The most recurring psychosocial challenges in the reviewed articles are as follows: Anxiety disorders and symptoms, stress about all aspects of their life, PTSD symptoms, depressive disorder, and low level of hope. Also, the most important social consequences of this epidemic include daily management, financial problems, access to necessary services, transfer, loss of a job, increased marital conflict, increased vulnerabilities and even reduction of social skills. Other psychological consequences include sleep disorders, violence, irritability, fear, helplessness and behavioral problems such as incompatible behavior.

In general, the change in routine and also the uncertainty caused by COVID-19 cause distress in ASD patients and will worsen their primary symptoms and mental health. Policymakers should recognize that the needs of ASD patients are different from those of the general population. Policymakers must provide more support to the mental health of ASD patients and their caregivers as the nation emerges out of its current state. In case of further outbreaks or subsequent pandemic peaks, the law should provide additional freedom and support for ASD patients. Policymakers also should protect ASD patients from catching COVID-19 (21).

### Limitations

One of the limitations of this study is that other language articles are not reviewed due to the lack of proficiency in other languages.

# **Conflict of Interests**

The authors declare that they have no competing interests.

#### References

- Lazar M, Miles LM, Babb JS, Donaldson JB. Axonal deficits in young adults with High Functioning Autism and their impact on processing speed. Neuroimage Clin. 2014;4:417-25.
- Sarabi JM, Hasanadadi A, Mashhadi A, Asgharinekah M. The effects of parent education and skill training program on stress of mothers of children with autism. J Fam Res. 2012;8(31):261-272.
- 3. Volkmar FR, Lord C, Bailey A, Schultz RT, Klin A. Autism and pervasive developmental disorders. J Child Psychol Psychiatry. 2004;45(1):135-70.
- Aarabi MA, Abdi K, Khanjani MS. Using of Rehabilitation Services, The Main Concern of Autism Spectrum Disorder: What Can Be Done? Autism. 2020;19(7):824-31.
- 5. Association AP. Diagnostic and statistical manual of mental disorders (DSM-5®): American Psychiatric Pub; 2013.
- Pennington ML, Cullinan D, Southern LB. Defining autism: variability in state education agency definitions of and evaluations for autism spectrum disorders. Autism Res Treat. 2014;2014.
- Maenner MJ, Shaw KA, Baio J. Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2016. MMWR Surveill Summ. 2020 Mar 27; 69(4):1–12.
- Mohammadi MR, Ahmadi N, Khaleghi A, Zarafshan H, Mostafavi SA, Kamali K, et al. Prevalence of Autism and its Comorbidities and the Relationship with Maternal Psychopathology: A National Population-Based Study. Arch Iran Med. 2019;22(10):546-53.
- 9. Bonis S. Stress and Parents of Children with Autism: A Review of Literature, Issues Ment Health Nurs. 2016;37(3):153-63.
- Hayes SA, Watson SL. The impact of parenting stress: a metaanalysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. J Autism Dev Disord. 2013;43(3):629-42.
- 11. WHO. Coronavirus overview 2020 [Available from: https://www.who.int/health-topics/coronavirus#tab=tab\_1.
- 12. Aarabi MA, Abdi K, Khanjani MS. Letter to Editor: COVID-19 and Mental Health of People with Autism Spectrum Disorder and Their Families; What Can Be Done? Middle East J Rehabil Health Stud. 2021;8(2):e112188.
- 13. Rose J, Willner P, Cooper V, Langdon PE, Murphy GH, Stenfert Kroese B. The effect on and experience of families with a member who has Intellectual and Developmental Disabilities of the COVID-19 pandemic in the UK: developing an investigation. Int J Dev Disabil. 2020:1-3.
- Lim T, Tan MY, Aishworiya R, Kang YQ. Autism Spectrum Disorder and COVID-19: Helping Caregivers Navigate the Pandemic. Ann Acad Med Singap. 2020;49(6):384-6.
- Courtenay K, Perera B. COVID-19 and people with intellectual disability: impacts of a pandemic. Ir J Psychol Med. 2020;37(3):231-6.
- Nollace L, Cravero C, Abbou A, Mazda-Walter B, Bleibtreu A, Pereirra N, et al. Autism and COVID-19: A Case Series in a Neurodevelopmental Unit. J Clin Med. 2020;9(9).
- 17. Cassidy SA, Nicolaidis C, Davies B, Rosa SDR, Eisenman D,

Med J Islam Repub Iran. 2021 (7 Oct); 35:131.

Onaiwu MG, et al. An expert discussion on autism in the COVID-19 pandemic. Autism Adulthood. 2020.

- Nonweiler J, Rattray F, Baulcomb J, Happé F, Absoud M. Prevalence and Associated Factors of Emotional and Behavioural Difficulties during COVID-19 Pandemic in Children with Neurodevelopmental Disorders. Children. 2020;7(9):128.
- Narzisi A. Handle the Autism Spectrum Condition During Coronavirus (COVID-19) Stay At Home period: Ten Tips for Helping Parents and Caregivers of Young Children. Department of Child Psychiatry and Psychopharmacology. Brain Sci. 2020;10(4).
- 20. Ameis SH, Lai MC, Mulsant BH, Szatmari P. Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond. Mol Autism 2020;11(1):61.
- Patel J, Badiani A, Nielsen F, Assi S, Unadkat V, Patel B, et al. COVID-19 and autism: Uncertainty, distress and feeling forgotten. Public Health Pract. 2020.
- 22. Fuld S. Autism Spectrum Disorder: The Impact of Stressful and Traumatic Life Events and Implications for Clinical Practice. Clin Soc Work J. 2018;46(3):210-9.
- Bull LE, Oliver C, Woodcock KA. Signalling changes to individuals who show resistance to change can reduce challenging behaviour. J Behav Ther Exp Psychiatry. 2017;54:58-70.
- 24. Gillott A, Standen P. Levels of anxiety and sources of stress in adults with autism. J Intellect Disabil. 2007;11(4):359-70.
- 25. Liu X, Kakade M, Fuller CJ, Fan B, Fang Y, Kong J, et al. Depression after exposure to stressful events: lessons learned from the severe acute respiratory syndrome epidemic. Compr Psychiatry. 2012;53(1):15-23.
- Dubey S, Biswas P, Ghosh R, Chatterjee S, Dubey MJ, Chatterjee S, et al. Psychosocial impact of COVID-19. Diabetes Metab Syndr. 2020;14(5):779-88.
- 27. Nisticò V, Gambini O, Faggioli R, Demartini B. The psychological impact of COVID-19 among a sample of Italian individuals with High Functioning Autism Spectrum Disorder. Available from: https://assets.researchsquare.com/files/rs-47184/v1/9d9fc950-51b7-4e92-be8f-eaacb1c2efb4.pdf?c=1595454469.DOI: https://doi.org/10.21203/rs.3.rs-47184/v1. 2020.
- Carmenate Rodríguez ID, Rodríguez Cordero A. Psychological impact on children with autism spectrum disorder during COVID-19 confinement. Multimed. 2020;24:690-707.
- 29. 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. 2020:1-9.
- 30. Bent S, Hossain B, Chen Y, Widjaja F, Breard M, Hendren R. The Experience of Parents of Children with Autism Spectrum Disorder During the COVID-19 Pandemic: A Qualitative Analysis. Available from: https://assets.researchsquare.com/files/rs-46426/v1/b209bd58-1621-44a1-a5e2-9967d293a50a.pdf?c=1595540041.DOI: https://doi.org/10.21203/rs.3.rs-46426/v1. 2020.
- Colizzi M, Sironi E, Antonini F, Ciceri ML, Bovo C, Zoccante L. Psychosocial and Behavioral Impact of COVID-19 in Autism Spectrum Disorder: An Online Parent Survey. Brain Sci. 2020;10(6).
- 32. Carly Albaum M, Modica PT, Gorter JW, Nazilla Khanlou R, Lee V, Weiss J. Impact of COVID-19 on the Mental Health and Wellbeing of Caregivers and Families of Autistic people. Canad Institutes Health Res. 2020.
- 33. Drum ChEM, Oberg A, Ditsch J, Cooper Jarc K. COVID-19 & adults with intellectual disability, autism, epilepsy, or brain injuries findings from an online survey. Am Assoc Health Disabl. 2020.
- 34. Ersoy K, Altin B, Sarikaya BB, Özkardaş OG. The Comparison of Impact of Health Anxiety on Dispositional Hope and Psychological Well-Being of Mothers Who Have Children Diagnosed with Autism and Mothers Who Have Normal Children, in Covid-19 Pandemic. Odüsobiad. 2020;9(2):117-26.
- 35. Degli Espinosa F, Metko A, Raimondi M, Impenna 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(3):1-9.
- 36. Stankovic M, Jelena S, Stankovic M, Shih A, Stojanovic A, Stankovic S. The Serbian Experience of Challenges of Parenting Children with Autism Spectrum Disorders During the COVID-19 Pandemic and the State of Emergency with the Police Lockdown. Lancet Child Adolesc Health. 2020.

<sup>10 &</sup>lt;u>http://mjiri.iums.ac.ir</u>

- 37. Szabo TG, Richling S, Embry DD, Biglan A, Wilson KG. From Helpless to Hero: Promoting Values-Based Behavior and Positive Family Interaction in the Midst of COVID-19. Behav Anal Pract. 2020;13(3):1-9.
- Brondino N, Damiani S, Politi P. Effective Strategies for Managing COVID-19 Emergency Restrictions for Adults with Severe ASD in a Daycare Center in Italy. Brain Sci. 2020;10(7).
- 39. Jeste S, Hyde C, Distefano C, Halladay A, Ray S, Porath M, et al. Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. J Intellect Disabil Res: JIDR. 2020.
- 40. 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. 2020:1-9.
- 41. Tromans S, Kinney M, Chester V, Alexander R, Roy A, Sander JW, et al. Priority concerns for people with intellectual and developmental disabilities during the COVID-19 pandemic. BJPsych Open. 2020;6(6):e128.
- 42. Souza ALR, Guimarães RA, de Araújo Vilela D, de Assis RM, de Almeida Cavalcante Oliveira LM, Souza MR, et al. Factors associated with the burden of family caregivers of patients with mental disorders: a cross-sectional study. BMC Psychiatry. 2017;17(1):353.