

THE CHALLENGES OF CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS COMORBIDITY DURING THE COVID-19 PANDEMIC IN SERBIA

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received: 13.1.2022;

revised: 4.4.2022;

accepted: 28.4.2022

SUMMARY

Background: Children with Autism Spectrum Disorders (ASD) experience significantly higher prevalence of other mental disorders, which amplifies their need for overall support. The outbreak of novel coronavirus (COVID-19) resulted in restrictions and limited access to different services with great challenge for families and children with ASD.

Subjects and methods: We used an electronic SurveyMonkey questionnaire to examine the experiences of 114 caregivers of children with ASD. We compared: (a) level of support by the child's school, changes in child behavior, and priority needs for families of ASD and ASD with comorbidities (ASD+) children, during pandemic, and (b) developmental history and diagnosis for ASD and ASD+ children before the pandemic.

Results: Our research shows significant behavioral difficulties in the population with ASD and ASD+ that arose in the field of altered living conditions and overall functioning during the COVID-19 pandemic. Statistically significant results comparing ASD to ASD+ children we found in area of getting additional help and support before the outbreak of the pandemic (47.1% vs 16.0%, $p=0.002$), as well as in worsening of sleep problems, statistically significant more common in children with ASD+ (ASD+ 47.7% vs. ASD 25.7%, $p=0.046$).

Conclusions: Our findings can contribute to the faster development and implementation of protocols for dealing with situations such as pandemics, related to the vulnerable population of children with ASD and their caregivers.

Key words: autism spectrum disorders – comorbidity - COVID-19 pandemic – facilitators - barriers

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INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social communication deficits, restricted interests, repetitive behaviors, and with an estimated global prevalence of 1% (APA 2013). It is a complex condition that significantly affects everyday life as well as the quality of life of the patient himself and that of his/her caregiver. Symptomatology that is often a presentation of comorbid state is very often misunderstood in everyday clinical practice as part of ASD clinical presentation. Individuals with ASD commonly experience significantly higher prevalence of other mental disorders compared to typically developed individuals (Romero et al. 2016). These comorbidities often exacerbate their need for overall support. It is generally considered that persons with comorbidity will have more severe impairments as a result of having more than one disorder (De Filippis 2018). It is estimated that nearly 70% of people diagnosed with ASD have at least one comorbid psychiatric disorder, and approximately 40% of them may have two or more

comorbid psychiatric disorders (Hossain et al. 2020). Common comorbidities in individuals with ASD are Attention Deficit Hyperactivity Disorder (ADHD), mood alterations, sleeping and eating problems, mental retardation, behavioral problems, anxiety disorders, etc. (Lai et al. 2019). ASD continues to remain underdiagnosed in many countries (Elsabbagh et al. 2012). Serbia still does not have a national register of people with ASD. Using the so called "protective diagnosis" is common, avoiding the real, lifetime diagnosis of ASD. Moreover, "gold standard" diagnostic assessment instruments, are rarely used, resulting in an inaccurate estimate of people diagnosed with ASD, which also includes the comorbid conditions (Lakic 2012, Stupar et al. 2015). The lack of exact diagnostic assessment hinders proper treatment, support, and total functioning improvement (Nik Adib et al. 2019). High functioning cases of ASD are often missed and they have been assessed as "normal development" for a long period of time (Elsabbagh et al. 2012). Therefore, it is logical to presume that individuals diagnosed with ASD are those with more severe and less functional forms of the

disorder. It can also be expected that their caregivers could have a higher level of stress and experience lack of social support (Elder et al. 2017).

The outbreak of the novel coronavirus (COVID-19) has resulted in drastic change of usual life style (Pfefferbaum & North 2020). The disease itself is characterized by a large spectrum of symptoms, high virulence and still an insufficiently predictable course (Chopra et al. 2021). The COVID-19 pandemic has resulted in many restrictions and limitations into everyday life, restrictions designed to protect the general population and prevent occurrence of the disease (Yuki et al. 2020). Pandemics are not unheard of in human history, however there is still little experience in managing the pandemics' effects on mental health and wellbeing (Guner 2020). COVID-19 restrictions and limited access to different services have already been a great challenge for families with children and adults diagnosed with ASD.

Research on COVID-19 can inform the rapidly evolving knowledge base and identify strategies for developing resources to help families affected by ASD in the context of the COVID-19 pandemic (Victor & Ahmed 2019, Colizzi et al. 2020). To this end, a primary step is to understand the needs of individuals affected by ASD as well as the needs of their caregivers.

The aim of this study was to compare: a) level of support by the child's school, changes in child behavior, and priority needs for families of children with ASD and ASD with comorbidities (ASD+) during pandemic, and b) developmental history and diagnosis for ASD and ASD+ children before the pandemic.

We want to engage knowledge in supporting diverse individuals and communities affected by neurodevelopmental disorders.

SUBJECTS AND METHODS

The Survey

Participants completed an electronic SurveyMonkey questionnaire developed by the Research Team from McGill University, Montreal, Canada. The survey was developed and pilot-tested with parents of children with neurodevelopmental conditions and was specifically designed to document the experiences of caregivers and/or parents of children (of all ages) with a neurodevelopmental condition before and during the pandemic. Survey questions were based on COVID-19 policy guidance recommendations for persons with disabilities and included topics such as response to the pandemic, access to care, and barriers and facilitators to keeping safe.

The questionnaire was translated from English to Serbian, independently by two researchers. The translations were then compared and combined. After this phase, back translation was performed by an independent consultant from the McGill University Research Team. The final Serbian questionnaire contained 149 of questions in 15 of sections and was designed to be completed in 20-30 minutes

(link:<https://docs.google.com/forms/d/1Za1DmF18g7MGrU2NtPfw4VYcVAwq38G57r4aZ-ykNc/edit#responses>).

Procedure

Caregivers of children with ASD were invited to participate in this study. The databases used to recruit participants belong to the child psychiatrist on the team as well as the parent association (NGOs) and specialized schools with whom we partnered. An email with the link to the survey was sent to parents and caregivers in the databases. The email included a brief explanation of the survey and its purpose. Participants were asked to forward the survey link to other caregivers of children diagnosed with ASD. Clicking the link automatically opened the survey. Data were collected from September to November 2020.

Participants

The survey was completed by 114 participants (parents and caregivers), 70 of which have children with an ASD only diagnosis, and 44 have children with ASD with some comorbid condition, disorder or disease (ASD+).

Statistical analysis

The data are presented in the form of arithmetic mean and standard deviation, i.e. in the form of absolute and relative numbers. The comparison of continuous values was performed by the t-test, and the comparison of categorical variables by the Chi-square test. We used a significance threshold of $p < 0.05$. Statistical data processing was done in the software package R.

Ethics

The study procedures were carried out in accordance with the Declaration of Helsinki and approvals of the Ethical Committee of the Clinical Center of Nis, Serbia and McGill University, Montreal, Canada. All participants were informed about the study and all provided informed consent via an online system.

RESULTS

The survey was completed by 114 participants. They were caregivers of 70 individuals with ASD diagnosis (ASD), and 44 with ASD and comorbidities (ASD+). Most participants were women (80.0% in the group with ASD and 84.1% in the group with ASD+), average age 42.80 ± 7.05 years, biological parents (100.0% of ASD individuals 95.4% of ASD+). Over half indicated having completed higher education (69.0% ASD and 52.3% ASD+). Majority of the participants had full or part time work (72.8% with individuals with ASD and 65.9% ASD+). All examined characteristics were uniform between the groups. Demographic characteristics of the caregivers and children by diagnosis (ASD vs. ASD+) are presented in Table 1.

Table 1. Basic demographic characteristics of survey participants

Characteristics	ASD		ASD+		p ¹
	n	%	n	%	
Age*	42.69±6.58		42.98±7.82		0.831 ²
Gender					0.764
Male	14	20.0	7	15.9	
Female	56	80.0	37	84.1	
Relationship with the patient					0.255
Biological parent	70	100.0	42	95.4	
Other	0	0.0	2	4.6	
Educational level					0.121
High school	22	31.4	21	47.7	
High education	48	69.0	23	52.3	
Work engagement					0.187
Full-time job	43	61.4	28	63.6	
Part-time job	8	11.4	1	2.3	
Does not work	19	27.2	15	34.1	
Child's gender					0.241
Male	65	92.9	37	84.1	
Female	5	7.1	7	15.9	
Child's age					0.366
<7	13	18.6	6	13.6	
7-14	40	57.1	22	50.0	
>14	17	24.3	16	36.4	

* Mean ± Standard deviation; ¹ Chi-square test; ² t-test

Table 2. Data on early development and diagnosis

Question	Answer	Total		ASD		ASD+		p
		n	%	n	%	n	%	
What was the age of your child when he/she was diagnosed with ASD?	One year or less	2	1.8	0	0.0	2	4.5	0.263
	1-3 years	50	43.9	31	44.3	19	43.2	
	4-8 years	55	48.2	35	50.0	20	45.5	
	9-12 years	7	6.1	4	5.7	3	6.8	
What was the main reason for seeking help because of your child's symptoms?	Availability of previously unavailable medical services (eg opening of hospitals near the living place, transport to health centers, cheaper health services)	1	0.9	0	0.0	1	2.3	0.365
	Other	29	25.4	16	22.9	23	29.5	
	Suggestion from friends and family members	11	9.6	6	8.6	5	11.4	
	The symptoms worsened	73	64.0	48	68.6	25	56.8	
How much time has passed from the moment you sought help to the diagnosis?	1-3 months	23	20.2	14	20.0	9	20.5	0.467
	4-6 months	13	11.4	6	8.6	7	15.9	
	7-11 months	8	7.0	7	10.0	1	2.3	
	Two years or more	29	25.4	16	22.9	13	29.5	
	One year	29	25.4	19	27.1	10	22.7	
	Less than a month	11	9.6	7	10.0	4	9.1	
	My child has not been diagnosed yet	1	0.9	1	1.4	0	0.0	

The following disorders were present in the group with ASD+: 21 children had intellectual developmental disorders (47.7%), 6 had anxiety disorders (13.6%), 15 epilepsy (34%), 6 allergies (13.6%), 3 vision/hearing problems (6.8%), 3 had problems with mobility (6.8%), 1 had chronic breathing problems (2.3%), 7 gastrointestinal disorders (15.9%), 9 sleep disorders (20.5%), 6 feeding and eating disorders (13.6%) (Figure 1).

The diagnosis of ASD was made between 1-3 years of age in 43.9% of children, between 4-8 years of age in 48.2% and between 9-12 years of age 6.1%. Two children (1.8%) with ASD + were diagnosed before the age of one. There was no significance between ASD and ASD + groups. The main reasons for caregivers to seek help of professionals was worsening of their child's symptoms, in 64.0% (68.6% in those with ASD, and in

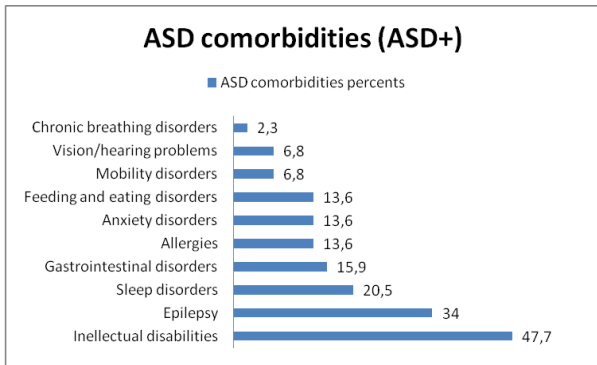


Figure 1. ASD comorbidities (ASD+)

56.8% in ASD+) (list of symptoms and behaviors are shown in table 2). From the moment when the caregivers sought the help of experts, until the diagnosis of ASD or ASD+, 1-3 months have passed for 20.2% children, 4-6 months for 11.4%, and 7-11 months for 7.0%. But, most often the diagnosis is made after one year (in 25.4%), or two or more years (25.4%), after initial contact with mental health professionals. There is no significant difference between the ASD and ASD+ groups.

Caregivers answered questions about the level of support before the pandemic, as well as the impact of the pandemic on the behavior and overall daily functioning of their children which is presented in Table 3.

Table 3. Services before pandemic outbreak and problems with symptoms and behavior of the child during the pandemic

Question	Answer	Total		ASD		ASD+		p ¹
		n	%	n	%	n	%	
Did the school / kindergarten your child attend provide additional help / support services for your child before pandemic outbreak?	yes	40	35.1	33	47.1	7	16.0	0.002
	no	62	54.4	30	42.9	32	72.7	
	don't know	12	10.5	7	10.0	5	11.4	
During a pandemic, did you notice a change in your child's behavioral problems (eg, self-harm, aggression, outbursts of anger)?	improvement	11	9.6	4	5.7	7	15.9	0.170
	no change	54	47.4	36	51.4	18	40.9	
	deterioration	49	43.0	30	42.9	19	43.2	
During the pandemic, did you notice a change in your child's daily life skills (eg, using the toilet, dressing, eating)?	improvement	11	9.6	6	8.6	5	11.4	0.172
	no change	81	71.1	54	77.1	27	61.4	
	deterioration	22	19.3	10	14.3	12	27.3	
During the pandemic, did you notice a change in your child's health problems (epileptic seizures, various illnesses)?	improvement	4	3.5	1	1.4	3	6.8	0.179
	no change	107	93.9	68	97.1	39	88.6	
	deterioration	3	2.6	1	1.4	2	4.5	
During the pandemic, did you notice a change in your child's mental health problems (eg, anxiety)?	improvement	5	4.4	2	2.9	3	6.8	0.355
	no change	73	64.0	48	68.6	25	56.8	
	deterioration	36	31.6	20	28.6	16	36.4	
During a pandemic, did you notice a change in your child regarding sleep problems (e.g., problems with falling asleep or maintaining sleep)?	improvement	2	1.8	1	1.4	1	2.3	0.046
	no change	73	64.0	51	72.9	22	50	
	deterioration	39	34.2	18	25.7	21	47.7	
During the pandemic, did you notice a change in your child regarding feeding problems?	improvement	7	6.1	3	4.3	4	9.1	0.281
	no change	89	78.1	58	82.9	31	70.5	
	deterioration	18	15.8	9	12.9	9	20.5	
During the pandemic, did you notice a change in your child regarding difficulties in social interactions (eg answering a call by name, socializing)?	improvement	5	4.4	2	2.9	3	6.8	0.265
	no change	83	72.8	49	70.0	34	77.3	
	deterioration	26	22.8	19	27.1	7	15.9	
During the pandemic, did you notice a change in your child regarding repetitive behavior / limited interests / insistence on sameness)?	improvement	4	3.5	1	1.4	3	6.8	0.101
	no change	65	57.0	37	52.9	28	63.6	
	deterioration	45	39.5	32	45.7	13	29.5	
During the pandemic, did you notice a change in your child due to communication difficulties (eg delay in language development, inability to express emotions)?	improvement	12	10.5	8	11.4	4	9.1	0.922
	no change	71	62.3	43	61.4	28	63.6	
	deterioration	31	27.2	19	27.1	12	27.3	
During the pandemic, did you notice a change in your child's security issues (eg problems with the police, neighbors, foreigners)?	improvement	5	4.4	1	1.4	4	9.1	0.063
	no change	106	93.0	66	94.3	40	90.9	
	deterioration	3	2.6	3	4.3	0	0.0	
During a pandemic, did you notice a change in your child regarding sensory problems (hypersensitivity to certain sounds or light)?	improvement	1	0.9	0	0.0	1	2.3	0.281
	no change	87	76.3	56	80.0	31	70.5	
	deterioration	26	22.8	14	20.0	12	27.3	
During the pandemic, did you notice a change in your child's education (for example, school achievement)?	improvement	11	9.6	7	10.0	4	9.1	0.899
	no change	67	58.8	42	60.0	25	56.8	
	deterioration	36	31.6	21	30.0	15	34.1	

¹ Chi-square test

Table 4. Caregiver's priorities for families whose child is affected by some developmental disorder in Serbia

	Total		ASD		ASD+		p ¹
	n	%	n	%	n	%	
Better protection of the human rights of persons with special needs	70	61.4	37	52.9	33	75.0	0.030
Specialized services improvement	50	43.9	28	40.0	22	50.0	0.393
Educational system improvement	68	59.6	42	60.0	26	59.1	1.000
Improving community awareness	42	36.8	21	30.0	21	47.7	0.087
Mental health protection services improvement	75	65.8	46	65.7	29	65.9	1.000
Somatic health services improvement	31	27.2	19	27.1	12	27.3	1.000
More information relevant to my child's condition	41	36.0	25	35.7	16	36.4	1.000
Finances	64	56.1	38	54.3	26	59.1	0.757

¹ Chi-square test

We obtained data regarding services before pandemic outbreak and problems during the pandemic. To the question if the school / kindergarten that the child attended provided additional help/support services before pandemic, we obtained statistically significant results, comparing patients who have only ASD to ones with ASD+ children. Namely, school/ kindergarten that the child attended provided more often additional help and support services to children diagnosed with ASD, before the outbreak of the pandemic compared to respondents with ASD+ (47.1% vs 16.0%, $p=0.002$) (Table 3).

During the pandemic, worsening of sleep problems was registered in 34.2% of the total sample, statistically significant more common in children with ASD+ (ASD+ 47.7% vs. ASD 25.7%, $p=0.046$) (Table 3). When it comes to changes in behavior and everyday life skills, as well as general functioning, there was no statistically significant difference between these two groups. However, we obtained clinically significant data that during the pandemic, there was worsening of problematic behavior present in 43.0% of the total population and uniformly between groups (42.9% and 43.2%, $p=0.170$). Everyday life skills deteriorated during the pandemic in 19.3% of the total sample and were equalized between groups (14.3% and 27.3%, respectively, $p=0.172$). Mental health deteriorated in 31.6% of the total sample and was uniform between groups (68.6% and 56.8%, respectively, $p=0.355$). The other important area of overall functioning is worsening of repetitive behavior, and it was observed in 39.5% of the total sample, i.e. in 45.7% of ASD and 29.5% of ASD+ during pandemic ($p=0.101$). Also, we observed worsening of social interaction in 22.8% of the total population which was equalized between groups (27.1% and 15.9%, respectively, $p=0.265$). Deterioration in communication was observed in 27.2% of the total sample, i.e. 27.1% ASD and 27.3% ASD+ ($p=0.922$). Sensory problems worsened in 22.8% of the total population, respectively 20.0% ASD and 27.3% ASD+ ($p=0.281$). Worsening of education problems was observed in 31.6% of the total population, i.e. 30% of ASD and 34.1% of ASD ($p=0.899$). During the pandemic, health

problems remained unchanged in 93.9% of the total sample, i.e. in 97.1% of ASD and 88.6% of ASD+ ($p=0.179$). There were no significant changes in feeding problems and issue of insecurity during the pandemic compared to the previous period.

When asked about caregiver's top three priorities for families whose child is affected by some developmental disorder in Serbia, they most often stressed the need to improve mental health services (65.8%), relatively evenly among ASD and ASD+ groups (Table 4). Second in line is better protection of human rights of persons with special needs, 61.4% (ASD 52.9%, ASD+ 75.0%). In third place is the improvement of the education system (59.6%), without significant differences by groups. Other needs highlighted by parents as very important for people with ASD in Serbia are: service development (43.9%), finance (56.1%), greater community awareness (36.8%), and more information relevant to the child's condition (36.0%) and improvement of health services in the field of physical health (27.2%).

DISCUSSION

When it comes to comorbidities, our results differ from the data available in literature where ADHD presents the most common comorbidity of ASD. Our results show the absence of ADHD as a comorbidity, which can be interpreted as a cultural influence on the diagnosis of ADHD (Taylor & Timimi 2004, Mazzone & Vitiello 2016). In Serbia, diagnosis of both disorders also is not based on "gold standards". The results show that ASD is diagnosed after the age of four in more than 52% of cases. The explanation can be found in the fact that ASD in clinical practice is replaced with the diagnosis "Disharmonic development" (Xaviera et al. 2015), most often in order to prevent stigmatization (Pejovic-Milovancevic et al. 2018). Among pediatricians, general psychiatrists and psychologist the prevailing tendency is to wait until the child is 36 months old. Underdiagnosing of ASD is also present in developed countries (Lai et al. 2019, Elsabbagh et al. 2012). On the other hand, ADHD is often recognized as a "normal development," and within ASD, ADHD

appears to be difficult to recognize as a comorbid diagnosis. It can also be seen that the wait for an ASD diagnosis is also long (in 48.8% of cases it lasted longer than a year).

The presumption of our study was that altered living conditions and daily functioning during the COVID-19 pandemic could have a particular impact on the ASD and ASD+ populations. Pandemic conditions certainly disrupt daily routines, and an important part of the clinical presentation of ASD is hypersensitivity and poor response to change (Umucu & Lee 2020).

The results of our study show that in both groups, ASD and ASD+, there was a worsening of both autism symptoms and general behavioral problems. This result is consistent with the findings of other researchers who have dealt with behavioral changes in children with ASD during altered pandemic conditions, even with very similar results (Patel et al. 2020).

Our results also reveal that in both groups there was deterioration in repetitive behavior patterns (as much as 39.5%), acquired skills of daily self-care, social interaction and sensory problems, with additional difficulties in education. A natural course of social communication problems and sensory problems in people with ASD, has either improvement, or the condition has remained unchanged over the years (Hasen et al. 2014, Mazurek et al. 2012). Our findings of deterioration could represent a significant change and confirms the potential negative impact of the emerging pandemic conditions on this population. Also, our findings are consistent with a similar study, during the COVID-19 pandemic, where it was found that in their examined population of parents of children with ASD there was a worsening of problematic behavior patterns, problems with aggression, self-harm and sensory problems (Mutluer et al. 2020). In addition, participating caregivers report deterioration in social communication, increased stereotypes, sensory hypersensitivity and aggression during the COVID-19 pandemic (Mutluer et al. 2020). Research on this topic by other authors also reveals much more intense (in 35.5% of respondents) and much more frequent (in 41.5% of respondents) behavioral problems in the population with ASD whose parents participated in this study, compared to the period before the pandemic (Colizzi et al. 2020). Lifestyle changes during a pandemic can also be classified as a potentially traumatic experience, especially given that individual reactions of people with ASD to altered pandemic conditions are similar to symptoms of posttraumatic stress disorder (PTSD) (Peterson et al. 2019). This view is based on the study of specific symptoms of PTSD in people with ASD (aggressive behavior, self-harm, sleep and concentration problems, common in people with ASD after trauma) (Storch et al. 2013). It can be observed that the main finding of PTSD symptoms in children with ASD, namely,

increased behavioral problems, aggressive behavior, irritability, increased stereotypes, worsening of social communication, as well as problems with feeding and sleeping, are all symptoms that overlap with obtained in behavioral changes in children with ASD during the COVID-19 pandemic, as supported by the findings of our research. Therefore, it is important to keep in mind that the current, prolonged pandemic situation can cause such symptoms, and professionals who deal with the mental health of this population should notice the appearance of these symptoms on time, or their worsening, for a prompt therapeutic response (Narzisi 2020).

The results show that the worsening of ASD symptoms and behavioral problems has occurred during the pandemic, however, the difference between the groups was not significant. This may indicate that the primary disorder (ASD) presents a major risk for symptom exacerbation of this vulnerable group rather than its comorbidities. Namely, prolonged time of confinement in the house and changes in daily routines with insufficient understanding of the resulting changes can affect these deteriorations. However, perhaps the factor that has the greatest impact on such worsening of symptoms and overall functioning is the lack of previous help from experts dealing with this population and changes in the school system (online teaching, termination of schooling and direct participation in previous school routines, which also affects the structure of daily functioning (O'Sullivan et al. 2021). We believe that this factor should be especially considered in relation to planning future support for this population in the changed general conditions of functioning. Namely, the results we obtained show that sufficient education provided by school or another institution had only 9.6% of respondents, which is a significantly smaller number than before the pandemic. As many as 67.5% had no education provided at all, which may be a significant additional factor in the general deterioration of the functioning of this population.

Challenges that parents face in getting support for their child during the pandemic, are related to getting adequate social assistance/support for the child, lack of school education and the protection of fundamental rights. Caregivers of children with ASD+ are significantly more committed to the protection of the human rights of individuals with special needs, compared to those with ASD children only. This is expected, given that the needs of their children are objectively greater. In 65.8% of cases, both groups of caregivers are in favor of improving health services in the field of mental health, in contrast to the needs of improving health services in the field of physical health, for which 27.2% of caregivers are in favor.

The overall satisfaction with the received support during a pandemic is estimated as low. Most basic factors contributing to the parental dissatisfaction are: child's behavioral problems, lack of social support, and lack of adequate health and educational services.

CONCLUSIONS

Our research shows significant behavioral difficulties in the population with ASD and ASD + that arose in the field of altered living conditions and overall functioning during the COVID 19 pandemic. Understanding its impact on this population is crucial for planning psychosocial and therapeutic interventions, as well as those related to the education of these individuals, and educational treatments related to everyday life skills (Peterson et al. 2019).

By identifying all aspects of this problem, we can contribute to the faster development and implementation of protocols for dealing with situations such as pandemics, related to the vulnerable population of children with ASD and their caregivers. Therefore, such research is positioned as a priority in order to see global needs and barriers and develop strategies to address the problems of the ASD population and their caregivers in changed and more complex living conditions.

Limitations of study are that the questionnaire was distributed exclusively through electronic communications and social networks. Therefore, the questionnaires were filled out on a voluntary basis only by those who wanted and who are otherwise users of these networks. It is possible that the findings of this study might be more prominent in the excluded group of families. Also, self-report measures may lead to different response biases or memory recall, which impedes generalization of our findings.

Acknowledgements: None.

Conflict of interest: None to declare.

Contribution of individual authors:

Miodrag Stankovic: conceived of and design the study, acquired, analyzed and interpreted the data, drafted the manuscript, and gave final approval of the version to be published.

Aleksandra Stojanovic: writing the article, analyzed and interpreted the data, drafted the manuscript literature searches and analyses

Aleksandra Ignjatovic: statistic.

Mayada Elsabbagh: leader of Questionnaire developers Research Team and design the study.

Miriam Gonzalez, Afiqah Yusuf, Alaa Ibrahim & Keiko Thomas: Questionnaire developers Research Team

Jelena Stojanov & Matija Stankovic: literature search and analyses.

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