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The Serbian experience of challenges of parenting children with autism spectrum disorders during the COVID-19 pandemic and the state of emergency with lockdown

At the end of 2019, numerous reports of coronavirus infection cases around the world began to emerge. The disease is characterized by several different symptoms. COVID-19 began to spread rapidly in all regions of the world [1]. On January 30th, 2020, the World Health Organization declared a COVID-19 pandemic. Consequently, many countries introduced various restrictive measures to prevent the rapid spread of the disease (free movement restriction, work from home, and home schooling), with recommendations for behavioral changes (social distancing, frequent and thorough hand washing, and avoiding personal contact) [2]. These restrictive measures, in addition to the disease itself, have in their own way evoked different reactions of people. Movement restriction, social contacts restrictions, with constant fear of infecting oneself and loved ones, uncertainty about the duration of the pandemic, and finally concerns about the financial aspect of this situation, have a significant impact on mental health [3].

In Serbia, which is a middle-income country, there are a few different services for individuals with ASD and their families [4]. They are often faced with difficulties, such as poverty, inadequate training and programs, stigma, and various forms of neglect [5]. Globally, these factors lead to stress and significant dissatisfaction with the support provided by the community health and educational services in many parts of the world [6–10].

At the beginning of the pandemic, a state of lockdown initially lasted 9 h per day and increased to 12 h per day.

Major changes in daily organization, almost complete absence of therapists, and unusual schooling conditions have been expected to trigger a change in the behavior of individuals diagnosed with ASD. Also, it is expected that those individuals' caregivers experience higher levels of stress, lack of overall support [11], and concerns about autism symptoms worsening [12–14].

The aim of this study is to provide a comprehensive exploration of challenges experienced by parents of children with autism spectrum disorder (ASD) in Serbia during the beginning of COVID-19 pandemic and the lockdown.

Subjects and methods

The survey

Participants completed a modified Caregiver Needs Survey, primarily developed by Amy Daniels and the National Coordinators of the Southeast European Autism Network (SEAN), as part of the Global Autism Public Health Initiative for Autism Speaks (AS). Modifications resulted from the emerging pandemic situation and the introduction of the state of emergency. The first version of the questionnaire was translated from English into Serbian in 2016, independently by the two researchers, and the translations were compared and combined [15]. After this phase, the back translation was performed by a third party, with the result comparable to the original. The modification was done in the same way. The final form questionnaire contained 50 questions in the Serbian language, designed to be completed within 15-20 min online (link: https://docs. google.com/forms/d/e/1FAIpQLSfI-ws_zjOF62gnvxO2_ u2GMboJffwfOwpjwU5KIVND8Yt8g/viewform?usp=sf_



link). Participants gave consent before completing the questionnaire. The survey was intended for parents or primary caregivers of children with a diagnosis of ASD. The study began 6 days after the onset of the state of emergency in Serbia and lasted during the next 18 days.

Procedure

The study began by uploading the electronic version of the survey to participants' emails and social networks. The email also 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.

Participants

A total of 85 parents and caregivers of 85 children and adolescents with ASD completed the questionnaire: 74% mothers, 22% fathers, and 4% other relatives and foster parents. The mean age of children was 9.2 years (SD 4.5; min. 2; max. 24). Diagnosis of intellectual disability and ASD had 47.7% of children and adolescents. Four parents took care of individuals over 18 years old. 52.5% of parents had completed primary and secondary school, while 47.5% of parents had higher education.

Statistical analysis

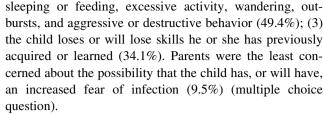
Statistical analysis was performed using the SPSS 17.0 program (SPSS Inc., Chicago, IL, USA). The research results are presented in tabular and graphic form. Descriptive data are presented through frequencies, percentages, means, and standard deviations.

Ethics

The study procedures were carried out in accordance with the Declaration of Helsinki, and were approved by the Ethical Committee of the Institute of Mental Health, University of Belgrade. All participants were informed about the study and all provided informed consent via an online system.

Results

The top three parental concerns related to the pandemic and the state of emergency were noted: (1) the child has or will have worsening symptoms of ASD due to changes in daily routines (the closure of schools and kindergartens, the continuous presence of information related to the pandemic, etc.), 54.1%; (2) the child has, or will have an exacerbation of behavior problems, such as a problem with



Prior to the onset of the pandemic and state of emergency, only 8% of individuals with ASD were not included in any standard or non-standard treatment. Most of them were involved in working with a special educator, (60%), 52% with a speech therapist, 50.7% visited a child psychiatrist regularly, and 38.7% worked with music therapists. After the onset of the pandemic and the state of emergency, most of the participants (81.2%) responded that their child did not have any form of standard developmental non-pharmacological treatments. 9.4% of children had pharmacotherapy and 3.5% had speech therapy.

During the pandemic, 23.4% of children were enrolled in a regular pre-school and 31.2% in a regular school (inclusion program). Over 36% of parents reported that their children had a special classroom for children with autism or for children with disabilities. From the onset of the pandemic and the state of emergency until the completion of the questionnaire, 84.4% of children did not receive any home assistance or additional education relevant to their child's needs. In 15.3% of cases, teachers were sending weekly plans for learning, or children were treated by a special educator and music therapist.

As a response to the question: "Whom are you currently seeking information from on how to treat your child during a pandemic and the state of emergency?", 43.5% of caregivers responded that they were seeking help online, 22.4% from school staff, 20% from healthcare professionals, 10.6% from a child psychiatrist, 5.9% from a general practitioner or pediatrician, and only 2.4% from a pediatrician at the Development Counselling Centre. 18.8% chose the answer "other", giving comments that "they did not address anyone" or "seeking information from other caregivers and friends", and some of them commented: "because we don't expect help," "already have enough experience," or already have had help from other parents of children with autism.

A feeling of helplessness during the pandemic and the state of emergency was noted by 61.2% of participants (fully agree: 50.6% and mostly agree: 10.6%), while only 15.3% of them expressed complete disagreement. Feeling discriminated against due to the fact of having a child with ASD during the pandemic and the state of emergency was noted by 27.1% of caregivers, while 54.1% of them denied having such experiences.

The research showed that 87% of parents expressed the need for additional education for the child at home during



the pandemic and the state of emergency (77.9% of them completely agree and 9.1% strongly agree). Only 2.3% of caregivers said that they did not need such assistance. A similar situation can be observed when it comes to any additional assistance at home (63.3% of them completely agree, 11.7% strongly agree, 14.3% were indecisive, 6.5% strongly disagree, and 3.9% completely disagree). Overall satisfaction with the support parents received during the pandemic and the state of emergency was low. Most parents (58.4%) were completely dissatisfied with the support.

Only 10.6% of those who had contact with services during the pandemic and the state of emergency were very satisfied, 35.3% indecisive, and 17.6% completely dissatisfied. More than 35% stated that they had no contact and no one worked with their child from any service.

On the other hand, 74.1% of parents stated that it was important for them to have contact with different services. About 5% of parents thought that it was not very important and about 5% stated that it did not matter to them at all, and 16.5% were indecisive. During the pandemic and the state of emergency, 37.5% of parents were in constant contact with the teaching staff, 36.3% with other parents who have children with ASD, 12.5% were using Internet counselling, 11.3% had constant contact with child psychiatrist, and 10% with a pediatrician (multiple choice question).

As the main challenges related to the child's behavior during a pandemic and emergency, parents indicated: repetitive behavior/limited interests/insisting on the same things (50.6%), problems with food choice and feeding (37.6%), problematic behavior (e.g., self-harm, aggressive behavior, and anger attacks) (35.3%), sleep problems (30.6%) problems in communication with the child (29.4%), and social interactions (31.8%). The least challenging were health problems (additional physical illnesses or psychiatric conditions) (14.1%), mastering skills important for daily life (getting used to the toilet, feeding) (15.3%), and child safety concerns (17.6%) (multiple choice question).

Challenges that parents face in receiving the support for their child are referred to: providing adequate social assistance/child support (50.6%), lack of school education (48.2%), inability to provide respite for parents (42.4%), providing protective masks and gloves (38.8%), and protection of fundamental human rights (35.3%) (multiple choice question).

Discussion

Our sample consisted of 74% mothers, 22% fathers, and 4% of other relatives and foster parents. Although available data from relevant literature indicate that mothers more frequently care for the child's health and needs [15–17],

the number of fathers in our study is not negligible, if we consider that mothers are more typically stay-at-home parents in Serbia. This may be due to the more frequent presence of fathers during quarantine, which was registered in one of the comments, with the additional satisfaction of mothers and children. It was assessed as a positive side-effect of the situation. Some parents seem to have experienced the new conditions as a "positive effect" of the pandemic: spending more time at home with children and bringing family members closer [18].

Our results show that the greatest concern of caregivers was the worsening of autism symptoms, due to the routines change and, the worsening of behavioral problems, as well as concerns that the child would lose skills he or she had previously acquired. This is aligned with the similar studies [19, 20] which suggests that autism caregivers' concerns are universal. The biggest challenges for caregivers were worsening of repetitive and problematic behaviors (e.g., self-harm, aggressive behavior, and anger outbursts), problems in communication with the child, and social interactions, as noted in other countries earlier [12]. They also detected the worsening of behavioral problems, increased stereotypes, and aggression. Mutluer et al. [12] highlighted problems with feeding and sleeping too, which we also detected; namely, 30.6% of our respondents answered that one of the top three challenges is a problem with sleep, while 37.6% of them said that this includes problems with eating. This is in line with another study conducted during the pandemic, where a significant disruption of sleep patterns was also found [21].

The surprising result for us was that the caregivers expressed the least concern about the possibility of infection, especially having in mind that people with autism may have genetic vulnerability to COVID-19 (increased levels of proinflammatory cytokines in individuals with ASD) [22]. Also, it was not a great concern that their children would have trouble learning new skills, such as getting used to frequent hand washing during the pandemic. However, the reason for this result may be the fact that our research was performed at the beginning of the pandemic, when the parents were still unaware of all the aspects of the disease, and most importantly, the resistance to protective measures that individuals with autism might show [23]. Namely, Mutluer et al. [12] showed that among their respondents, most children could not understand what protective measures meant, nor did they agree to them. Also, the problem was understanding and imposing social distancing, as well as recommendations for better hygiene and more frequent hand washing. A special problem highlighted by another study was the habit of wearing masks, with poor cooperation of individuals with ASD, especially due to problems with sensory hypersensitivity [24].



The beginning of the pandemic brought a complete cessation of specialized services and education that these people had around the world, and they were left without personal contact with therapists and teachers. [23]. This leads to potentially significant changes in their behavior, due to a lack of understanding the reasons for interrupting daily routines and usual activities. Even though 90% of parents were in need for additional education for their child in home environments during the pandemic, 84.4% of children have not received any assistance or additional education relevant to their child's needs while being at home. A similar situation can be observed with any additional assistance at home.

Challenges that caregivers face in getting support for their child during the pandemic are related to obtaining adequate social assistance/support for the child, lack of school education, the inability to provide respite for parents, getting protective masks and gloves, and the protection of fundamental rights. These answers were very similar with those in other studies [25, 26], and it is emphasized how much these individuals and their families depended on various forms of support, which became prominent during the COVID-19 pandemic [27]. These data warn that it is necessary to prepare centralized strategies for the continuity of support for people with ASD for all future situations.

The overall satisfaction with the support during the pandemic and the state of emergency is estimated as low among our respondents, with more than half of them being completely dissatisfied with the support. They maintained contact with other parents of children with ASD and have had Internet counselling. A smaller number of them have had contact with a child psychiatrist or a pediatrician, with more than 35% stating they had no contacts at all, and no one was working with their children. Considering the assumption that the most basic factors contributing to parental dissatisfaction are: child's behavioral problems, lack of social support, and lack of adequate health and educational services [28, 29]; the results of the research are not at all surprising.

Among those who have had contact with services during the pandemic and the state of emergency, only 10.6% were very satisfied. 12.5% were seeking out help online, while only 20% did so from health care providers, to obtain information on how to treat a child during a pandemic and the state of emergency. Unsurprisingly, the most expected assistance and advice was from a team of specialists, a child psychiatrist, a pediatrician, or a psychologist. In several studies, we found that child psychiatrists and therapists, due to the inability to see the patients, offered online counseling and instructions, due to their close connection with the families of these individuals [18, 30, 31]. Parents are looking for medical and social informative

support in caring for their child [21], to reduce stress and decrease the level of anxiety [23], associated with their child's ASD diagnosis. Our results are consistent with those from several studies that have addressed the stress and anxiety of parents of children with ASD during the COVID-19 pandemic. [32, 33].

Feeling of helplessness during the pandemic and the state of emergency was experienced by 60% of the caregivers. Approximately one-third of the caregivers reported being frustrated in efforts to obtain services for their child, and have had some feelings of stigma, which may be due to the low public awareness. This is more often than what we expect from parents of children diagnosed with ASD [17, 23]. Additionally, 27.1% of parents felt discriminated against for having a child diagnosed with ASD, compared to more than 50% of them who did not feel that way.

The limitations of the 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 use 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 the generalizability of the findings.

Conclusions

There is no doubt that there is a connection between the pandemic with the police-enforced lockdown and the change of overall functioning of families with children with ASD. The survey revealed a lack of support, feelings of helplessness, various challenges, and needs among parents which, although present before, have become more prominent during the state of emergency. At the beginning of the lockdown, most caregivers of individuals with ASD had to take care of children on their own, suggesting that the government needs better plans and strategies for future similar situations. The results also suggest that better understanding of specific needs of individuals with ASD may help provide precise information regarding areas of functioning that should be targeted with the interventions, and that it should be implemented through the government strategies. New guidelines should be developed, in consultations with mental health professionals.

Additional research, such as a follow-up of this study, as well as longitudinal research is required to further understand the effects of pandemics and the state of emergency for families with ASD diagnosed children. Researchers should address long-term outcomes, to encourage changes in government strategies for future crises relating to



pandemics, which could simultaneously turn into a mental health crisis.

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Declarations

Conflict of interest The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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