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AVAILABILITY OF SPECIAL TREATMENTS AND SERVICES FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS DURING COVID-19 STATE OF EMERGENCY AND LOCKDOWN IN SERBIA

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Restrictive measures and major lifestyle changes were brought for entire population during the beginning of the COVID-19 pandemic, and for individuals with Autism Spectrum Disorder (ASD) and their caregivers as well. Specialized treatments, organized education, and other services intended for the ASD population ceased, which affected overall functioning of this population and their caregivers. ASD itself significantly affects lives of individuals with this disorder and their families, and these individuals are particularly sensitive to changes in routines and daily functioning. The aim of this study was to explore changes in different treatments and services availability for individuals with ASD in Serbia at the beginning of the pandemic and during the state of emergency, and its impact on their caregivers. Participants completed the "Autism and COVID-19" survey, which was designed for primary caregivers of individuals with ASD. A sample of 89 participants completed the survey. They were recruited from patient databases, the parents' association (NGOs), and the specialized schools. The study was conducted during the state of emergency in the country, from April 13 to 25, 2020. The survey revealed a complete absence of specialized treatments, lack of support, feelings of helplessness of the caregivers, which have become more prominent during emergency state. The pandemic reveals underdeveloped strategies to maintain support for this population, and the need for better predictions in the future to protect this vulnerable population and their caregivers.

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Introduction

At the end of 2019, there was a rapid spread of new corona virus infection, and the disease caused by it was called COVID-19. The disease was characterized by symptoms of various organic systems, and high contagiousness followed by very rapid spread of the disease. On January 30, 2020, the World Health Organization declared the pandemic (1). In many countries, various restrictive measures were introduced in an attempt to prevent the spread of the disease, with demands to change people's behavior. Namely, in many countries, restrictions of movement, work from home, schooling from home came into force, which led to a significant change in previous life habits. (2). These restrictive measures, as well as COVID-19 disease itself, influenced significantly the psychological functioning of people, people's mental health, and previously existing mental illnesses (3).

Autism spectrum disorder (ASD) is a neurodevelopmental disorder recognized in early childhood, and it extends throughout the life of the individual, with the incidence higher than 1/100 (4). Main characteristics of ASD are difficulties in social communication and interaction, and the existence of restricted, repetitive behaviors, interests and specific response to sensory input (5). This is a population of people with special needs (6), and their caregivers constantly face challenges. One of the main characteristics of ASD is extreme resistance to any form of change. People with ASD usually have a strict daily routine; they are involved in working with specialized therapists, in specialized institutions. The beginning of the pandemic brought great changes in the lives of individuals, including people with ASD (especially during the state of emergency), had a huge impact on families with ASD members, and multiplied the challenges they face every day anyway.

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However, at the beginning of the pandemic, and especially during the state of emergency, children with ASD usually stayed home with their family members, without contact with their therapists (7). Restrictive measures themselves could lead to an exacerbation of behavioral problems of people with ASD (8). In Serbia, there are several different services for individuals with ASD (9); however, they often face difficulties, such as the unavailability of specialized programs in all parts of the country (10). A state of emergency with a police lockdown was declared in Serbia on March 15, 2020 and imposed movement restrictions, shortening working hours of various institutions, schooling from home and the cessation of many services that had existed until then. Complete absence of work with therapists and previous daily routines could cause various changes in behavior and reactions of people with ASD. In addition, it could be expected for caregivers to experience lack of overall support and higher level of stress (11), and concerns about worsening of symptoms (12). In addition to the characteristics of the disorder itself, the main problems of individuals with ASD and their family members are stigmatization, lack of general public awareness and knowledge (13), lack of society acceptance, and low level of social support (14).

The aim of the study was to explore availability of treatments, service and overall support for families of individuals with ASD in Serbia during the COVID-19 pandemic beginning and the police lockdown.

Subjects and methods

Participants completed a modified Caregiver Needs Survey, earlier developed by Amy Daniels and the National Coordinators of the Southeast European Autism Network (SEAN), which is a part of the Global Autism Public Health Initiative for Autism Speaks (AS). Modifications consisted of changes that issues were directly linked to the pandemic situation and the state of emergency. The final questionnaire contained 50 questions in Serbian language, which could be filled online in 15-20 minutes (link: https://docs.google.com/forms/d/e/1FAIpQLSfI-ws_zjOF62gnvxO2_u2GMboJffwfOwpjwU5KlVND8Yt8g/viewform?usp=sf_link). Before completing the questionnaire, participants gave consent. The survey was intended for caregivers of individuals with a diagnosis of ASD. The study was conducted from April 13 to 25, 2020, during the state of emergency in the country. A total of 89 caregivers completed the questionnaire; 80.9% mothers, 16.9% fathers and 2.2% other relatives and foster parents. The average age of ASD individuals at the time of survey competition was 8.9 years (SD 4.5; min 2; max 22).

Results

The study included 89 participants, caregivers of individuals with ASD who were involved in different types of specialized treatments before the beginning of the pandemic. The majority of the participants were mothers (80.9%), with 16.9% of fathers and another 2.2% of other caregivers. Most of the guardians had secondary school and a university degree, while a smaller part of them completed only primary school, or had unfinished university education, and more than a university degree. The individuals with ASD were mostly males (79.8% vs. 20.2%): 24.7% of them were nonverbal, 14.6% used only one word, 29.2% used sentences of 2-3 words, while a smaller percentage used simple and complex sentences (Table 1).

Table 1. Demographic characteristics of the study participants

Caregiver's education level	No	%
1. Elementary school	2	2.2
2. High school	39	43.8
3. Unfinished university Education	8	9.0
4. University education	39	43.8
5. More than university Degree	1	1.1
Caregiver		
Mother	72	80.9
Father	15	16.9
Other	2	2.2
Gender of individual with ASD		
Male	71	79.8
Female	18	20.2
Language development level		
Language not developed	22	24.7
Uses only single words	13	14.6
Uses 2-3 words sentences	26	29.2
Uses 4+ words sentences	10	11.2
Uses complex sentences	18	20.2

Prior to the pandemic, individuals with ASD were involved in the different types of treatment and support; most of them in two or more types of support (Table 2).

At the onset of the pandemic and emergency state, most of the participants (77.5%) responded that their child was not receiving any form of standard developmental non-pharmacological treatments any longer; 22.4% of the surveyed population remained in some form of contact with single information source and services; some percentage of guardians who had contact with a service reported contact with a child psychiatrist, general practitioner, child teacher, while some of them sought help from the Internet. Most guardians turned to other parents of children with autism for help (39.3%) (Table 3).

However, 75.3% of the responders felt that it was important to have contact with the services that worked with their child during the pandemic and the state of emergency in the country (61.8% thought that it was very important, while 13.5% thought that it was "most important").

Most respondents agreed that during the pandemic and the state of emergency they felt helpless because they had a child with autism (completely agreed 42.7%; mostly agreed 13.5%) (Table 4).

During the pandemic and the state of emergency in the country, 25.9% of the surveyed population felt discriminated because they had a child with autism, 11.2% were neutral, while 63% of them did not have this experience.

When it comes to satisfaction with the overall support received by the families of children with ASD during the beginning of the pandemic and the state of emergency, the majority stated that they were unsatisfied (Table 5).

Table 2. Specialized treatments and services used by individuals with ASD before the beginning of the pandemic

Service	Number	%
Personal assistant	24	29.2
Behavioral therapist	13	14.6
Developmental Pediatrician	8	9.0
Pedagogue	7	7.9
Nutritionist	3	3.4
Psychiatrist	44	49.4
Psychologist	42	47.2
Defectologist	54	60.7
Speech therapist	45	50.6
Music therapy	22	24.7

Table 3. Contacts with services after beginning the pandemic and introducing the lockdown

Service	No	%
Internet counseling	2	11.1
General practitioner	3	16.7
Child’s teacher	6	33.3
Parents of individuals with ASD	6	39.3
Child psychiatrist	3	16.7

Table 4. Feeling helplessness because of having child with ASD during the pandemic

Statement	No	%
Completely agree	38	42.7
Mostly agree	12	13.5
Neither agree nor disagree	19	21.3
Mostly don’t agree	9	10.1
Completely disagree	11	12.4

Table 5. Overall satisfaction with support after the beginning of the pandemic and introducing lockdown

Statement	Number	%
Completely satisfied	15	16.9
Mostly satisfied	3	3.4
Not satisfied nor Dissatisfied	24	27
Mostly dissatisfied	6	6.7
Completely dissatisfied	41	46.1

Discussion

Our sample consisted of 80.9% of mothers, 16.9% of fathers and 2.2% of other relatives and foster parents. This sample is in accordance with data from the relevant literature, which indicates that mothers more frequently take care of children's needs (15-17). However, the number of fathers participating in our study as the main caregivers is not small. The reason for this can be the state of quarantine and lockdown, which brought many families together, and put the fathers in the position of the main caregiver (18).

The education of people with autism is organized in different ways in different regions of the world (6). There is a number of different treatments in Serbia, although they are not uniformly organized throughout the country, and there are many areas where very few or none is available (15). In our study, we included only caregivers who stated that they received a certain type of support, and most of them used multiple modalities of support, most often the services of speech therapists, special educators, psychologists (Table 2). However, with the beginning of the pandemic, and especially the introduction of a state of emergency and strict movement restrictions, parents found themselves in a situation where they spent time with children at home, and they were completely isolated from contact with therapists, which significantly disrupted their daily routines. This is common to many countries around the world, that the beginning of the pandemic brought a complete cessation of specialized services and education for individuals with ASD (18). Namely, due to the restrictive measures that were introduced in almost all countries, the education of these individuals had to be stopped, and they were left without personal contact with therapists and teachers (19). Almost 80% of guardians in our research stated that at the beginning of the pandemic and during the state of emergency, they did not have contact with any of the services, and most of them emphasized the importance of such contacts (75%). In our sample, the majority of individuals with ASD has low level of language and speech development, most children are almost unable to express their needs in words, which makes them completely dependent on caregivers help. It also makes their treatments and rehabilitation essential for overall functioning, and their cessation can greatly affect worsening of problematic behaviors and loss of skills acquired so far (20).

Analyzing the results, we noticed that in the group of guardians who had contact with some service (less than 20% of participants), contacts with doctors, teachers and parents of other children, searching for information on the Internet were dominant, while contacts with specialized therapists that were present before the pandemic were completely missing (Table 3). Interrupting the continuity of their training leads to potentially significant changes in their behavior, because they do not understand the reasons for interrupting daily routines and usual activities. Psychosocial interventions in individuals with ASD can improve specific skills such as social communication, joint attention, language, engagement in social group, and this can affect further development and social adaptation (19). 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 completely dissatisfied with the support. They maintained contact with other parents of children with ASD, and they searched for advice online.

In several studies from developed countries, we found that different specialized therapist and child and adolescent psychiatrist offered online counseling, because it was not possible to see their patients (18, 21, 22). Caregivers in these studies were looking for a medical and social support in taking care of ASD individuals (23), and reducing stress and anxiety level (24) in changed conditions of the pandemic.

Feeling of helplessness during the pandemic and the state of emergency was experienced by 56.2% of the caregivers. This is more often than what we expect from parents of children diagnosed with ASD (17). Twenty-five point nine percent of parents felt discriminated for having a child with ASD in challenging conditions of the pandemic. We believe that complete cessation of contact with various services, and the experience of being left to themselves and excluded from regular types of support contribute to the experience of discrimination and helplessness of ASD caregivers. In addition, we believe that it is essential to develop various strategies that would enable the smooth operation of specialized services working with these children for future emergency situations, especially bearing in mind how important for them is the structured environment and continuity of work, and that they are essential for their overall functioning.

Conclusion

This survey was completed by 89 primary caregivers of individuals with ASD during the beginning of the COVID-19 pandemic and police lockdown in Serbia. The survey revealed almost total cessation of specialized treatments, low overall support, feelings of discrimination and helplessness. At the beginning of the pandemic, most caregivers of individuals with ASD were left without any kind of specialized support, and had to take care of the needs of the children on their own at home. We believe that in the future, it is necessary to develop strategies for all types of emergencies in order to protect and give adequate support for individuals with ASD and their families.

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DOSTUPNOST SPECIJALIZOVANIH TRETMANA I USLUGA ZA OSOBE SA POREMEĆAJEM IZ SPEKTRA AUTIZMA TOKOM VANREDNOG STANJA UZROKOVANOG PANDEMIJOM VIRUSA COVID-19 U SRBIJI

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Početak pandemije virusa COVID-19 i restriktivne mere donele su velike promene načina života celokupnog stanovništva, pa i osoba sa poremećajem iz spektra autizma (PSA) i njihovih staratelja. Ukidanje specijalizovanih tretmana, organizovanog obrazovanja i drugih usluga namenjenih populaciji sa PSA, uticalo je na ukupno funkcionisanje ove populacije i njihovih staratelja. Sam PSA značajno utiče na život osoba sa ovim poremećajem i njihove porodice i čini ove osobe posebno osetljivim na promene u rutini i svakodnevnom funkcionisanju. Cilj ovog istraživanja je da ispita promene u dostupnosti različitih tretmana i usluga za osobe sa PSA u Srbiji na početku pandemije virusa COVID-19 i tokom vanrednog stanja, kao i uticaj ovih promena na njihove staratelje. Učesnici su popunili upitnik „Autizam i COVID-19", koji je dizajniran za primarne staratelje osoba sa PSA. Osamdeset devet ispitanika učestvovalo je u ovom istraživanju. Istraživanje je sprovedeno tokom vanrednog stanja u Srbiji. Rezultati su pokazali potpuno odsustvo specijalizovanih tretmana, nedostatak podrške, kao i osećaj bespomoćnosti staratelja. Vanredni uslovi pandemije otkrivaju nedovoljno razvijene strategije za održavanje podrške ovoj populaciji i potrebu za boljim predviđanjima u budućnosti, kako bi se zaštitili ova ranjiva populacija i njihovi staratelji.

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Ključne reči: *poremećaji iz spektra autizma, staratelji, podrška, COVID-19*