A Qualitative Study on the Impact of Covid-19 on Individuals with Autism Spectrum Disorder, Families’ Coping Strategies and Beliefs about Online Education

Birgül KOÇAK OKSEV a*, Sedat YAZICI b, Mahir UĞURLU c, Tülay KAYA d, Ayşenur NAZİK FAYIZ e, Pınar ÇELEBİ DEMİRARSLAN f

a*Assoc. Prof. Dr., Bartın University (http://orcid.org/0000-0003-6783-2843) *boglack@gmail.com
b Prof. Dr., Bartın University (http://orcid.org/0000-0002-7939-0722)
c Res. Asst., Bartın University (http://orcid.org/0000-0003-4005-4882)
d Assoc. Prof. Dr., İstanbul University (http://orcid.org/0000-0002-1152-2811)
e Lecturer, Bartın University (http://orcid.org/0000-0002-8330-6071)
f Lecturer, Bartın University (http://orcid.org/0000-0002-0233-291X)

ABSTRACT

For a more in-depth understanding, we have conducted a qualitative study to understand the extent of the impact of the early stage of the pandemic on children with ASD. The findings in this study were obtained from two groups of participants. The first one included 92 parents or caregivers of children with ASD from six cities in Turkey. The participants in this group reported 159 negative behavior changes in 28 different behavior types. We also selected 32 parents, some of them from the first group, to investigate their coping strategies, use of online education, and expectations from institutions and organizations. Whereas most families report increased anxiety and stress, aggressive, obsessive and repetitive behavior, violence towards self and others, a significant number of families declared improvement in speech, social communication, academic skills, and eye contact. The participants also stated that online special education is dysfunctional and inefficient for some groups, depending on age and the severity of ASD.

Keywords: Pandemic, autism spectrum disorder, special education, online education.

Covid-19’un Otizm Spektrum Bozukluğu Olan Bireylere Etkisi, Ailelerin Başa Çıkma Stratejileri ile Çevrimiçi Eğitime İlişkin İnançları Üzerine Nitel Bir Araştırma

Öz

Bu çalışmada, pandeminin ilk döneminde OSB’li bireyler üzerindeki etkisini derinlemesine anlamak üzere bir inceleme gerçekleştirilmiştir. Çalışmadaki bulgular iki grup katılmıcının elde edilmiştir. İlk, Türkiye’deki altı ilden OSB’li çocukların anan- baba veya bakıcılarından oluşan 92 katılmıcının içerisinde bulunan 28 farklı davranış türüne 159 olumsuz davranış değişikliği göstermektedir. Bazıları ilk gruptan olmak üzere, ikinci grupta yer alan 32 veliye daha derinlemesine görüşme sorularıyla bu süreçteki baş etme stratejileri, çevrimiçi eğitim kullananlar, kurum ve kuruluşlardan beklenmeleri incelemiştir. Bu çalışmadan, her iki gruptan da olup bakan, stres, saldırganlık, takıntı ve tekrarlayıcı davranışlar ile kendine ve başkalarına zarar veren davranışların olumuzda gelişme göstermeklilerini bildirmiştir. Önemli sayıda katılmıcının konuşması, sosyal iletişim, akademik beceri ve göz temasında olumu yönde gelişme olduğunu beyan etmiştir. Katılmıcılar ayrıca çocukların çevrimiçi eğitim aspectinin yaş ve etkinliklerine etkileşine bağlı olarak bazı gruplarda işlevsiz ve verimsiz olduğunu belirtmiştir.

Anahtar kelimeler: Salgın, otizm spektrum bozukluğu, özel eğitim, çevrimiçi eğitim.

To cite this article in APA Style:
Koçak Oksev, B., Yazıcı, S., Uğurlu, M., Kaya, T., Nazik Fayız, A., & Çelebi Demirarslan, P. (2022). A qualitative study on the impact of Covid-19 on individuals with autism spectrum disorder, families’ coping strategies and beliefs about online education. Bartın University Journal of Faculty of Education, 11(1), 1-16. https://doi.org/10.1016/buefad.1062733

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1 | Introduction

The Covid-19 pandemic has affected every aspect of human life. Although numerous studies have been conducted to determine the effects of this period, more studies are needed to understand its short-term and long-term results. This effect has been even more widespread and profound in education. More importantly, because of the closure of schools and other education venues at all levels, the restriction of access to health and support services at home and out of the house, rehabilitation centers, and institutions related to special education, this process has resulted in more severe consequences for individuals with special needs. Research shows that children with autism spectrum disorder (ASD) and their families were more negatively affected than others (Alexander et al., 2020; Alyoubi & Ebtisam 2020; Factor et al., 2016; Courtenay & Perera, 2020; Rose et al., 2020; Van Steensel & Heeman, 2017). Students with ASD and their families in less well-off groups in terms of socio-economic opportunities have deeply felt this period (McCallion, 2020; Pelton et al., 2020; Pikulski et al., 2020).

Studies based on clinical findings and family observations show that children with ASD have experienced more intense behavioral problems, anxiety, eating and sleep problems, regressions in speech, and their gained skills, increase in stereotypes, aggressive behavior (Colizzi et al., 2020; Huang et al., 2021; Morris et al., 2021). However, there is also mixed evidence about the impact of Covid-19 on children with ASD. Some studies reported a negative and positive effect of the pandemic period (Lugo-Marín et al., 2021).

Most studies on individuals with ASD and their families during the pandemic were conducted via online data collection with short question-answers. For a more in-depth understanding, we have conducted a qualitative study with these questions: To what extent children with ASD were affected by this process? How did their families cope with the difficulties they have experienced? To what extent were they able to perform online education activities? To what extent have the socio-economic factors of families been effective in coping with this process? What are their expectations from institutions and organizations?

Context of the Study

This study was carried out after the first restriction of the Covid-19 period beginning March 16, 2020, in Turkey. The epidemic made it necessary to take measures that have affected entire social life globally. Soon after the first Covid-19 instance in Turkey, public and private schools were closed on March 16, 2020, and a week later, it continued with online education for students in formal education at all levels. All restaurants, cafes, gyms, shopping centers, parks, and gardens were closed, sports games postponed, curfews imposed on individuals over the age of 65 as of March 21, 2020, and under the age of 20 as of April 4, 2020. On April 11, an extended curfew was imposed in 31 provinces, which make up 79.88% of the total population.

These limitations have deprived individuals with ASD of outdoors, sports, and physical activities and limited their social communication opportunities, which are very important for their physical and mental health. Having been affected by this situation, families' complaints about coping with this process have come to the fore in public. The Ministry of Interior issued a circular on April 9, 2020, according to which individuals with ASD, Down Syndrome, severe mental retardation under the age of 20 could go out, walk-in parks and gardens, and travel by car within the borders of the same province, accompanied by their parents or caregivers. As the number of cases decreased, some restrictions gradually stretched from May 4, 2020.

There are no extensive autism statistics in Turkey. According to the Parliamentary Commission Report (2020), of the total 82 million population, there are approximately 1.5 million individuals with ASD, and the population affected by autism, including families, is about 4.5 million. In Turkey, children in need of special education, including autism, can receive instruction in separate special education schools, individual special education classes, or inclusive classes with other students. In addition, all special education students can attend special education and rehabilitation centers for three hours a week, paid for by the government. The monitoring, control, and supervision of the education processes of these institutions, most of which are operated by the private sector, are carried out by the Ministry of National Education.

During the first period of the pandemic, The Turkish Ministry of National Education has launched some training programs via public TV, supported materials such as booklets, and developed a mobile application called “Özelim Eğitimdeyim (I am Special and in Education.” However, researchers have argued that these programs
were suitable for children with average development. They are ineffective for children with disability, and the families lack sufficient knowledge and skills to adopt for their children (Akbulut et al., 2020; Salman, 2020).

2 | METHOD

PARTICIPANTS

The findings in this study were obtained from two groups of participants. The first one included 92 parents or caregivers of children with ASD from six cities in Turkey. This group was asked to reply to one major open-ended and two or three follow-up questions regarding the impact of the Covid-19 on their children. The average age of individuals with ASD evaluated in this group is 9.4, the youngest is 1.5, and the oldest is 39 years old. Of these, 80 are men, and 12 are women. We also aimed at investigating parents’ coping strategies and their expectations from the state or non-governmental organizations. To do this, we selected 32 participants for the second group, some of them from the first group, and 30 were mothers of the individual with ADS. The other two are the father and the uncle. Of the evaluated individuals with ASD, 24 were male, and eight were female. Besides demographic information questions, a semi-structured interview form comprising open-ended questions was used.

DATA COLLECTION

The research team obtained the data through face-to-face interviews and with the help of interviewers with a master's degree in two distant cities. Interviews were held in the parent waiting room during the children's education period. The answers were noted or audio recorded subject to their permission. The data were collected between 8 and 30 July 2020.

Purposive sampling with a maximum variation sampling method was used in the study. In purposive sampling, individuals and groups are selected among those who can respond most appropriately to the researcher's goals, depending on a particular criterion or feature. Maximum variation strategy for purposeful sampling aims at capturing and describing the central themes or principal outcomes that cut across a great deal of participant variation (Patton, 1990). In this context, the sample varies in terms of the city distribution, provincial and metropolitan, the ages of individuals with ASD, the severity of individuals with ASD (mild, medium, and severe), the participants’ education levels, and household income.

DATA ANALYSIS

After transcribing the qualitative data obtained through audio recordings, all answers were read carefully by three research team members, and codes were independently chosen from the transcriptions. Later, the team completed the key themes and codes through discussions and a thorough evaluation process. In line with the themes and codes obtained, the frequency of the most common situations was determined, and the statements that typically reflected them were included in the study. Content analysis and descriptive-interpretative analysis were used in the analysis of the data.

RESEARCH QUESTIONS

The question posed to the first group of participants includes two general objectives: Understanding how the pandemic period has affected children with ASD and determining which behaviors of children with autism were most affected by this period. To this end, the participants were asked:

How did the pandemic period affect your child?

Have you observed any positive or negative changes in your child's behavior?

The 32 participants in the second group were asked questions about benefiting from online education, limiting activities, coping strategies of families, their emotional states, and expectations.

In this context, the following basic questions were asked:

What kind of problems have you experienced regarding your child's education during the pandemic period?

What problems did the restriction of social life and the closure of physical activity areas cause?
What did you do to cope with the problems you have experienced in this process?

What did you do about your child's education at home?

Did you receive support from teachers, professionals, organizations, or institutions during the process?

Were you aware of online activities with family participation? Did you use any of them?

How did you feel during this process? Can you describe your feelings?

In extraordinary times, such as the pandemic, what can be done to educate children with ASD? What are your expectations from government or non-governmental organizations for that?

RESEARCH ETHICS

The approval of the Bartın University Social and Behavioral Sciences Ethics Committee was obtained for ethical compliance with the research procedures. Verbal and written consent of the participants involved in the study regarding the evaluation of their children was obtained before the interviews.

3 | FINDINGS

FINDINGS ON THE BEHAVIORS OF CHILDREN WITH ASD

Findings obtained from qualitative questions were classified according to pre-specified codes. Although a few participants (N=8) reported that the pandemic did not affect their children, the vast majority (N=68) stated that their children were negatively affected. Another noteworthy finding from the qualitative data was the significant number of participants who reported positive effects of the pandemic on the development of their children. Table 1 includes positive and negative behavior changes reported by at least two or more participants.

| Negatively affected | Frequency | Negatively affected | Frequency |
|---------------------|-----------|---------------------|-----------|
| Generally negative  | 31        | Fear and anxiety    | 3         |
| Being bored and stressed | 17 | Forgetfulness/ forgetting what is learned | 3 |
| Being ratty, aggressive, angry | 14 | Regression in speech | 3 |
| Increase in obsessive and repetitive (stereotypical) behaviors | 10 | Increased shouting | 3 |
| Loss of friends and school community | 9 | Running away | 2 |
| Violence (towards objects, self, and others) | 8 | Weight gain | 2 |
| Stubbornness | 6 | Empty stare | 2 |
| Increased TV and tablet viewing | 5 | Impatience | 2 |
| Reduced social communication | 5 | Lethargy | 2 |
| Increased crying | 5 | Being insistent | 2 |
| Increased tantrums | 4 | Increased echolalia | 2 |
| Sadness, unhappiness | 4 | Fear of crowds | 2 |
| Disrupted eating pattern | 3 | Fear of the virus | 2 |
| Disrupted sleep pattern | 3 |  |  |

| Positively affected | Frequency | Positively affected | Frequency |
|---------------------|-----------|---------------------|-----------|
| Generally positive  | 33        | Improved academic skills | 4         |
| Improved speech     | 11        | Increased eye contact | 3         |
| Improved social communication | 10 | Improved eating pattern | 2 |
| Calming down, reduced anger | 7 | Improvement in toilet training | 2 |
| Improved receptive language | 4 | Improved imitation skills | 2 |

While the total number of negative behavior changes was 159, that of positive behaviors was 80. The negative effects mentioned only once were decreased eye contact, increased self-contracting, timidity, stopping to play with
toys, and decreased interest in books. The positive behavior changes reported only once included pointing at what they wanted and an improved sleep pattern.

The following section includes negative and positive effects related to the key themes. Even when the participants mentioned one key theme or code in the quotes, these statements were given no interpretation.

Disruption in routines, stress, and anger

According to the participants, the most common negative effect of the pandemic was on children's emotional behaviors. Aggression, irritability, increased anger, boredom, stress, stubbornness, and unhappiness were the most frequently reported emotional effects:

“*My child became more stressful, aggressive. He started spending more time on the phone. Echolalia increased. He does not listen to anyone other than his mother. He slept very late at night. He got up late in the mornings, his routine changed. His stress made me more stressed, too. I kept worrying whether he would improve or regress.*” (P. 8)

“The behaviors that were eliminated earlier with the help of training came back. He gained 3 kilograms as he could not exercise. His tantrums increased. His sleep pattern became disturbed. He now sleeps only 3-4 hours at night and 1-2 hours daily. His obsessions have increased. Even though the house is ours and his mother is an educator, we have been experiencing these problems.” (P. 10)

“My daughter was attending the special education class of a kindergarten. We were benefiting from this. Her obsessions were gone. She was gaining skills she could not gain beforehand, but as the pandemic entered our lives, her obsessions reappeared, though not excessively. For example, before special education, my daughter used to "masturbate" (childhood masturbation), which was completely overcome. Unfortunately, it has now reappeared, though not excessively.” (P. 11)

“He became more aggressive, angry. These went away when special education started again.” (P. 23)

“His anger increased. Previously, going to the park helped calm him down. In these three months, there was much tension at home. He became aggressive.” (P. 3)

“As he’s always home, his stress level and anger increased.” (P. 36)

“His obsessions increased. He spun around himself and to spin objects. He started daydreaming more after he quit training.” (P. 9)

“My daughter was previously hurting herself. School had helped with this. But when they closed the school, my daughter got much worse. She hit her head a lot more.” (P. 18)

Linguistic and cognitive regression

In contrast to several families who stated that the close attention of family members had a positive effect on their children's language development, some others reported a clear decline in it:

“My child stopped speaking during this period. [Before the pandemic], she said many words, counted, and sang songs to herself even though she did not speak to others. There has been little change in our daily lives other than this. As we live in a village, we did not break from our immediate environment. We continued our usual activities with her aunt, cousins, and the neighborhood children she saw every day, anyway. The pandemic was a happy time, so I could not understand why she stopped talking. When education started again, her words came back.” (P. 81)

“His speech is disturbed. He used to utter good sentences before, but now his speaking has become disjointed. As he is describing a toy that he has at home, he suddenly switches to talking about a bird in the park.” (P. 54)

REGRESSION IN SOCIAL BEHAVIORS

An unfavorable outcome of staying at home has been disturbance by crowded and noisy environments and avoiding others:
“B. normally did not avoid sitting next to people in the park. When he went out for the first time after four months, he didn’t want to go to the crowded parts of the park. When we forced him, he shouted at us, grabbed our hands, and led us out of the park.” (P. 18)

“There have been negative changes. He used to be a very calm child; he did not use to cry. Now he cries when he wants something. He doesn’t like crowds and goes to sit in other rooms. Previously, even when I didn’t hold his hand outside, he wouldn’t run from me. He started doing so after the pandemic.” (P. 67)

“As he stayed away from other children, he experienced communication problems. He stopped playing games. He stopped playing with his toys. He became shy around strangers.” (P. 30)

“During the pandemic, his sensitivity to sounds increased. He never used to cover his ears. During the pandemic, hearing another child cry made him start crying too. Sometimes he even covered his ears upon hearing birdsong. Such behaviors decreased as he resumed education and became familiar with crowded environments again.” (P. 92)

**REASONS FOR POSITIVE DEVELOPMENTS**

Some participants claimed that parents being able to spend more time at home, playing more games with their children, spending quality time with them, and especially the increase in the time spent with the father due to restrictions led to positive developments in their children:

“There was a negative change during the first month because he wanted to go out as we normally used to do all the time. When he couldn’t, he became angry and aggressive. After a month, he got used to staying at home. He calmed down. His eye contact improved as I had more opportunities to give him individual attention. His perceptions became more acute. He started to spend better time with his relatives and loved ones. He became a more normal kid. He was more unresponsive before the pandemic.” (P. 60)

“He spent more time with his father as they were both at home, so my son was pleased…. During our family time at home, he communicated better with us, his imitation skills improved.” (P. 7)

“His older sister was also at home; they drew together. We didn’t waste our time. He read books with his father. We did everything together. Daily chores, making beds. We folded laundry together. We tried to include him in everything. His perception became better. His writing became faster, his reading and comprehension improved. It was good for him to spend more time at home.” (P. 84)

“He started saying single-syllable words. As he spent more time with his older brothers, he learned to play games. He liked eating more. His eye contact increased. He responded more to his name.” (P. 22)

Problems related to the restriction of outdoor activities

Most participants stated that restriction of outdoor activities caused a very challenging situation and increased the existing behavioral problems of their children:

“He was more into digital because he could never go out. His screen time increased. Tablet and computer time increased a lot, so when we took it away, he became more aggressive…we couldn’t go too far, we released him.” (P. 4)

“Right now, the minute I take him outside, he goes crazy, the sound of cars, at the smallest sound. He goes crazy in crowded places or when he sees people.” (P. 27)

“Since the house was a bit crowded during the curfew, the child could sometimes derail when he was very calm. It was especially negatively impacted by the crowd.” (P. 21)

It seems that socioeconomic conditions and place of residence played a determinant role in the level of influence by the restrictions. Those who own a house with a garden, live in the complex or rural village are less affected by the restriction of outdoor activities: “We were not affected, because we live in a house with a garden. This is how we live, even normal time. We don’t go to other places. There is a pool, swing, etc. in the house.” (P. 15)
"He played with animals in the village, visited the vineyard or garden, it was good for M. He’d probably go completely crazy if we stayed at home." (P. 26)

Coping strategies and parents’ educational support for their children

The most obvious consequence of the pandemic was that parents had to assume the role of education. They tried to apply what they learned from their children's educators or various sources in their ways:

"I supplied home education. Education continued in the same way. I found intelligence-enhancing games. I learned figures from special education teachers. We carried out a behavior study in front of the mirror to keep him from forgetting behaviors. I involved him with beading, bead removing, collecting, woodworking... as directed by his teachers." (P. 2)

Most participants stated that the basic strategies during the pandemic were to keep their children busy with something, not leave them alone, and expose them to a constant stimulus. Household chores such as doing activities together at home, going to the kitchen and cooking, vacuuming the house together, hanging laundry were considered opportunities. Some parents stated that spending time together at home and involving the child in daily chores at home reduced behavioral problems:

"I have involved her in everything. For example, if I was vacuuming the house, he got dust." (P. 3), "We laid the laundry together and loaded the machine together. We bought brain teasers. She likes to paint on pencil and paper. We played them," (P. 10), "I did many activities. He likes to play with water very much. Here I filled the basins with water; I built a ship... His father was always interested and played. We concentrated very much on the things he likes." (P. 5), "I tried different things. I turned on music; we changed venues. We changed channels. Water painting, salt work, hand printing, playing with the soil, carrying water in buckets, trying to distract him." (P. 12)

Given the findings obtained in this study, variables such as the child's age and the level of being affected by autism, the mother's emotional state, education level, and domestic workload played an essential role in this process. Some mothers stated they could not cope with the problems, remained unresolved, and could not receive any support. For example, a mother who stated that she was “not conscious” said that she could not help her child: "I usually tried to silence him because he cried a lot." (P. 6) Regarding her 16-year-old child, whom she described as severely autistic, a mother said: "There is no solution. He was shouting. There was a sedative I was giving it, and I was taking him for a walk. I couldn't do anything else. When I couldn't find a cure, sometimes I used to give medicine and put him to sleep." (P. 18) said.

For some families, the process was quite challenging: “Believe me, I tried so hard to get away from the phone, I brought my nephews home... Even though we tried to lock the door to block car sounds or something, it didn't work because he was most reactive to the road and cars. After that, we tried to paint, although we were not very good at it because he was always biting and eating the paint tips.” (P. 17)

Research shows that restrictions increased the responsibilities of families in the home education process and caused them to need professional support (Hyseni Duraku & Nagavci, 2020). During the pandemic, one of the most important issues forcing families is that education is on families’ shelters (in most cases, mothers). Some participants could keep the child busy at home, develop a hobby, and gain educational attainment.

"We tried to work according to the curriculum. We painted as they [teachers] said, we played with play dough. We played with his toys, jumped together, played on the table, that things.” (P. 4)

“She didn't like to read books. I mean, he didn't like to listen when I read a book. I cared for her a lot. She hated to sing out loud. We are over it. She's trying to accompany me….B. We had a teacher, I contacted him. I asked what I should do. He said that I wouldn't get bored too much... We cooked together... We spread the laundry together while laying the laundry... So both she and I tried to relax a little somewhere.” (P. 5)

The following statements of the mother of 24-year-old D. reveal the importance of being an educated parent of a child with ASD in homeschooling:
I made a checklist for D showing the points he is weak at. I wrote what I did on certain days on that checklist. I knew that D was weak in painting, math and rhythm, and articulation problems. I worked in these areas every day. Again, we learned to crawl in this process. This is important. Our children are already in a panic. He developed in rhythm. When playing badminton, for example, the racket could not be synchronized. We have turned our hall into an area to play badminton. Each week we focused on an English song from youtube. Now he can recite it. In painting, perspective works. So we improved our weaknesses a lot.” (P. 31)

Some participants pointed to the importance of parent involvement in their children’s education process. The mother of a 34-year-old individual thinks that no child can learn to read, write, do the math, or anything in special education rehabilitation centers and that parental education is more critical: “Children with autism have a quality memory. You have to process it. You have to do everything together, repeating together, playing together. These things happen with parents rather than an outside educator. This doesn't happen in special education centers, so you can’t make any progress by doing something for one hour and two hours a week.” (P. 32)

**ONLINE FAMILY EDUCATION ACTIVITIES AND SUPPORT FROM OTHER ORGANIZATIONS**

During the pandemic, live broadcasts were made through social media channels such as YouTube and Instagram for families with special needs who stayed at home and were deprived of professional support. In these live broadcasts, academics, psychologists, special education teachers shared much information to families on how to cope with their children’s problem behaviors to create new routines and activities that can be done. Parents also tried to develop a “solidarity network” by sharing their daily life and straightforward activity tools that can be done at home for their children through other social media channels such as Facebook and WhatsApp.

When asked, “Did you follow educational activities made by various institutions and individuals for families through online broadcasting (channels such as Instagram, YouTube) during the epidemic period?” Few participants gave a positive answer.

“Yes, we followed it intensely. Online programs were very busy. One was ending, the other was beginning. We had an intense process during these three months.” (P. 32)

Another mother, who answered positively, stated that she took part in the broadcasts of “academic mothers” who broadcast live on social media and shared videos, rather than experts in the field:

“I think it’s [useful]. For example, I was doing the activities that academic mothers did at home, with what I saw from them. They guided us during this time.” (P. 5)

All of the families interviewed in one of the major cities stated that they were “informed”, but only some of them followed:

“I was aware of the online educations. But I didn’t follow because they were on Instagram. I already know what they’re talking about. Nothing was new to me. Moreover, our child no longer needs basic education because of his age. We need more doctors and psychiatrists.” (P. 29)

“I was informed, but I did not follow. I was so integrated into my normal routine that there was no time left to watch other people’s live broadcasts and listen to do this or that etc. Because I was already very busy.” (P. 31)

Some parents said they had not heard of these activities for families and had no knowledge of the subject. Very few knowledgeable ones declared that they regularly follow a comprehensive training program. Table 2 includes frequencies about parents’ use of online education and support from other organizations.

| Themes                                    | Sub-code                  | Frequency |
|-------------------------------------------|---------------------------|-----------|
| Professional support                      | Received from teachers    | 23        |
|                                           | Not received any support  | 9         |
| Online family education activities        | Not participated          | 27        |
| (on Youtube, Instagram, etc.)             | Participated              | 3         |
|                                           | Know but not participated | 2         |
Apart from limited support of the school teacher or the teacher in the rehabilitation center over the phone or online talk, most parents interviewed stated that they did not receive institutional or organizational support during the pandemic, although they needed it:

“A WhatsApp group was created, material sets were thrown over that group, the reading sets, audio stories, museum trips, etc... were supported. They said that we were here if there were anything we could do. That was the only support we got.” (P. 2)

“His teacher was already meeting once a week as a class, and he was meeting. He was giving a class lesson during the time we were closed. He was doing lessons from Zoom again. Other than that, we did not receive any professional support.” (P. 3)

“We had support from his teacher in the rehabilitation center. He guided behavioral problems. He suggested that I be calmer. He suggested I use the tactic of ignoring.” (P. 9)

“I talked to his teacher in the rehabilitation center once, that's all.” (P. 11)

“We didn’t talk to anyone other than talking to the sports coach on the phone.” (P. 14)

“The teacher here formed a group and threw us activities so that you can do this or that. His school teachers also supported him in the same way. They were interested enough. We always talked. We only got support from here and the public education school.” (P. 26)

**BELIEFS ABOUT THE EFFECTIVENESS OF ONLINE EDUCATION**

Using technology, online education, interactive access, active participation have created various problems for families of individuals with special education (Serafini et al., 2020). As a result, a significant part of individuals who received special education could not benefit from online education or did not get the desired benefit compared to face-to-face education. Some researchers have stated differences in the socio-economic status of families in terms of the use of online education in special education settings (Bozkurt et al., 2020; Cluver et al., 2020; Nicola et al., 2020). Our research findings show that the benefit of online education varies according to the levels of ASD range (mild, moderate, severe), the age of the child, the family’s education, and the income level. In addition, regional differences make the quality of online education relative. The absence of qualified teachers, specialists, and educational institutions in rural provinces exposes families to situations such as "not knowing what to do, not being able to find someone to support.” This situation was observed in families' statements in provinces such as Van, Konya, and Bartın.

The mother of 34-year-old A also stated that online education support was beneficial:

“It wasn’t that he couldn’t get an education, but on the contrary, he was affected by the state of being too much educated... It is a very intense education process. It was almost more and more intense training than at the rehabilitation center. ... I will continue for at least another six months, as long as I can afford it. If I run out after that, I quit. Because it is based on material things... In other words, we have been very positively affected by this process.” (P. 32)

It is striking that older autistic individuals benefited much more from online education.

The mother of 39-year-old E. stated that the pandemic process was very productive:

“We had a great time during the pandemic. He followed the programs offered online with the cooperation of İZEV and Tomurcuk. He admitted no one could go anywhere because he saw his friends in online classes, whom he already knew from the center. I was very pleased with these special programs during this period. These programs filled his life, and he didn't keep it for us to go out.” (P. 30)

Other parents stated that the restriction period did not have any positive or negative effect on their children. A mother:

“The pandemic like everyone else affected us. Nevertheless, not enough to change my child's behavior. We live in a condominium. I took my child out to the park every day. He rode his bicycle. He met his friends by keeping
their social online. My child’s disability rate is 40% anyway. He behaves normally. We were not extremely negatively affected.” (P. 49)

| Table 3: Use and evaluation of online education |
|-------------------------------|-----------------|-------------|
| **Themes**                  | **Sub-code**    | **Frequency** |
| Use of online education     | Used            | 6           |
|                              | Not used        | 26          |
| Evaluation of online education | Not helpful/efficient/suitable | 10 |
|                              | Helpful         | 3           |

On the other hand, opinions were also voiced on the ineffectiveness and limitations of online education:

“I don’t think online education is useful for my child. He is already addicted to the phone. Using it for education as well makes him even more addicted. If there is ever a similar process again, I would like my child to receive one-to-one education at home.” (P. 43)

A mother of a 9-year-old child with severe autism stated that online education did not work at all:

“EBA didn’t work. We couldn’t get an education, it didn’t interest him. We downloaded some things [special education apps] on the phone, but it did nothing. What he received from individual training, what he learned was disappeared. He was learning to hold a pencil, he doesn’t want to hold a pencil right now. A program was sent to us from the school that we can’t it at home. He does everything with his teacher, but not with us.” (P. 14)

We found differences according to some variables in the effect of online education and the benefit of families. A mother replied whether online learning was helpful for her 5-year-old daughter with mild autism:

“So it’s better than nothing, of course… At least it wasn’t empty, it would have been worse if it was empty. Z. shows more signs of autism when we quit education.” (P. 3)

When educational institutions are closed, it is possible to see results such as students losing their interaction with the school. Some families devalued the importance of their children's education from the school. Some parent statements also make the view that education is worthless or dysfunctional. One participant said that since their child has already received education since early years, he was not affected much by not receiving education in this process. Another said, “It does not matter whether he gets an education or not.” (P. 12)

Interestingly, another participant not receiving education and leaving the child whatever he wants is better: “I can’t say it impressed him. We were interested, but not too much. He was relieved. Tablet-TV, cycling in front of the door, gave him much relief.” (P. 20)

The mother of 24-year-old D. considers special education “useless” even though her daughter has been receiving special education since she was three and a half years old:

“She wasn’t affected at all; on the contrary, she had a better time with me. Every day we did activities such as cooking, dancing, studying math, music, and English. Even when we went to the village, we continued our activities. I taught arithmetic with stones one by one. Now she can easily add numbers. In this process, we did not receive online education.” (P. 31)

We observed that most parents consider this situation a part of the disruption of their routine, since they cannot fully measure the effect of not receiving education. The answers to the problems arising from not going out and the lack of socialization environments are mainly similar to the answers about education. We can say that families see "going" to special education as part of the routine that keeps the child and themselves busy.

**PARENTS’ EMOTIONAL STATES**

In normal times, families of children with special do already face many problems in the education process of their children. Studies show that the unknown and uncertainties experienced in this process increase the anxiety levels of their families (McConnell & Savage, 2015). Many researchers have observed this finding during the pandemic (Asbury et al., 2021; Colizzi et al., 2020; Fiorillo & Gorwood, 2020). Considering the statements of the interviewed mothers, it can be said that they felt inadequate, tired, and exhausted and in this process:
“Well, frankly, I can’t say that I felt excellent as a mother in this situation because my anxiety is getting worse. When we are in the special education center outside, I feel more comfortable because I think he’s learning. We’re more comfortable when he is in education and as a family. Because he’s learning, the learning process continues... In this process, of course, I was a worried mother too...” (P. 3)

We have observed that the mood of the family, especially the mother, has affected the children. “Especially the shouting increased a lot. It was necessary to ignore them, but I couldn’t do much to ignore them. we were in a constant fight. Then he slowly calmed down... When I calmed myself down, he calmed down too because he was very impressed with me.” (P. 24)

In most societies, women are given the role of caring for children, sick and older people, cleaning the house, and cooking. Although women spend long hours on these regular but unpaid jobs, their labor is ignored. Studies show that women's housework load has increased during the pandemic period and that various types of domestic violence became widespread (Başterzi & Yılgör, 2013; Kalaylıoğlu, 2020). Some statements of the participants support this finding:

“I felt tired, exhausted, helpless. We were at a dead-end. quarrel. Quarrels with my wife multiplied. We didn’t know what to do.” (P. 9)

“I had trouble, I fell asleep, I suffer from panic attacks, I take medication. I had a nervous breakdown.” (P. 12)

This burden was even more remarkable for the mother with over one child: “I’m exhausted. The trouble of four children, two of them children with special educated, I’m completely exhausted.” (P. 8) Most mothers see their children’s school hours as a "breathe time" for themselves at the same time. Because during the time of school closure women were in totally locked in the house and could not spare time for themselves given because of their traditional responsibilities such as education and care, this situation adversely has affected their psychological state:

“Of course you are bored, you have to find something for that child all the a time. If our child were normal , she/he would manage himself somehow, but you have to take care of the autistic child.” (P. 23)

“It was bad not being able to go anywhere, staying at home. Normally, I am not a person who goes out much, but I was bringing my children to school, my daughter was going to kindergarten, my son was in the first grade, I was bringing them, I was going to the tying course myself, I could not go out for this, I could not take it at home in any way, for example, this affected me a lot.” (P. 24)

The fear of being infected with the Covid-19 virus has also been one of the most worrying situations in this process. The mothers of children with different disabilities besides autism are more concerned about the risk of infection. “I was terrified that the virus would come because God bless, N. should not get sick. He cannot go to the hospital, he cannot use every drug. I was most afraid for him.” (P. 25) Frequencies about parents’ emotional states during the pandemic are shown in Table 3.

| Table 4. Parents’ positive and negative emotional states during the pandemic |
|---|---|---|
| Themes | Sub-code | Frequency |
| Positive Emotions | Good | 8 |
| | Happy | 2 |
| | Bad | 8 |
| | Fear and Anxiety | 6 |
| | Exhusted | 4 |
| | Stressful irritable | 4 |
| | Sad | 2 |
| | Hopeless | 2 |
| | Insufficient | 1 |

What has mostly affected families psychologically is that the burden of education fell on families, especially mothers, who did not get expected results. This situation caused mothers to feel more inadequate. “Clearly, I felt...” (P. 24)
very inadequate, and when it wasn't the same as before, I felt a lack in myself. No matter how much I did, he never reacted to me.” (P. 27)

Some mothers have stated that being at home together with all family members has made them psychologically good. “His father was also at home... In that way, family ties became stronger, and we spent more time with each other.” (P. 3)

Others, on the contrary, stated that being together has negative effects: “In other words, staying at home with the whole family together causes friction after a while, and everyone became aggressive. Frankly, we're overwhelmed.” (P. 4)

**EXPECTATIONS AND DISAPPOINTMENTS**

Like everyone else, the pandemic caught families with children with special needs unprepared to close home with their children. Our finding is that the younger mothers had difficulties managing the process and did not know. In general, schools providing special education were uninterested in families and children’s education. One participant explained this situation by saying, “Government institutions could have provided guidance. But they didn’t. We were alone.” (P. 11) Another mother similarly expressed her expectation: “I would expect more education and daycare centers. I would like the children to be followed at home.... I would like the government to show more interest.” (P. 14)

Based on the interviews, families have received limited support from the schools, such as the individual efforts of the teachers by making a few phone calls, creating a group on social media, and sharing an event video. Those families who did not know how to overcome the process increased their anxiety levels and fatigue.

The expectations of the families comprise requests such as being called by their schools during weekly class hours, doing one-to-one online interviews with the family and the child, showing the methods they can apply in the lessons to the families with video, the teacher visiting the home and giving education at home, and providing psychological support to the families. In general, the perceived judgment is that online special education for children is dysfunctional and inefficient, and these children cannot learn from the screen. They believe that more family participation education would be better and more effective.

“At least they could come and visit. They could call on the phone and give directions about their lessons. The doctors who follow our kid from hospitals could call and tell us what to do, for example, in a tantrum. The Ministry of National Education could send materials that these children would love. We couldn't go and get it because everywhere was closed.” (P. 9)

Interestingly, some interviewees had no expectations from the institutions and were unaware of what could be done. Most parents said they have no plans for what to do in a possible re-closure period in the future.

Besides expectations related to the pandemic period, the participants also expressed other general expectations from schools and education institutions related to special education. The most striking of these is to increase the weekly hours of special education courses paid by the government. Some participants also pointed out the necessity of in-service special education for classroom teachers:

“The classroom teachers in the schools are very uneducated, very incompetent; there are those who say that they have encountered these children for the first time... Attending the seminars should be compulsory... You see all kinds of teacher negativity, but you have to take it from the bottom, making you exhausted. At least during the pandemic, our teacher could show more interest and say, how are you, are you okay, what are you doing, other than just calling once or twice.” (P. 2)

**4 | DISCUSSION & CONCLUSION**

Just like others, the pandemic has let individuals with ASD stay at home and to significant educational losses. Our results show that online education during this period was not helpful. First, online education seems to be dysfunctional because of the very nature of special education. Teaching techniques should be arranged according to one-to-one education. Whereas adult autistic individuals could adapt more quickly to online education and benefit from it, early years children have gained minimal benefit.
A Qualitative Study on the Impact of Covid-19 on Individuals with ASD

The most intense problem experienced by individuals with ASD in this process is behavioral problems that arise due to the change in their usual routine. Whereas positive developments (language skills, toilet training, etc.) were observed in some aspects, behavioral problems that challenged families increased. For some families, the father's being at home and taking care of the child has led to positive developments.

Most families saw education as significantly related to their routine rather than being deprived of education in this period. Their statements about the impact of the pandemic were interwoven and failed to identify the importance of education independently. Few participants evaluated the deprivation of direct education regarding their child's academic success and behavioral development. This perception may be because of common judgment about the ineffectiveness of special education in Turkey. Indeed, some families complained about the ineffectiveness of special education in general and demanded more weekly hours paid by the government during the pandemic.

On the other hand, some families have experienced deep concern about their children, an alarming uncertainty about what to do because they cannot receive qualified and professional support. We found evidence that this concern varies according to the family’s location, the parents' knowledge about autism, their education level, financial conditions, the child's age, and the level affected by autism. Families who could identify their child's needs well managed this process. While highly educated and wealthy mothers living in big cities were aware of it, mothers with low socioeconomic levels in rural provinces said they had never heard of it. It was observed that he was not aware of these activities.

Our findings are consonant with research evidence that access to educational activities for children with ASD and their consistency depends on socio-cultural, economic, and individual factors (Barry et al., 2020; Dawson et al., 2010; Khateeb et al., 2019), and that parental beliefs and attitudes are likely to affect their education. This study also provides evidence of such an effect in extraordinary circumstances, such as a pandemic.

Spending time together with their children at home has also been an opportunity for some families to get to know them. As a mother has said: “During the pandemic period, I observed my child more. I had more time to care. Eye contact increased because I was so interested. I taught him to count to ten when he was interested one-on-one.” (P. 6) Very similar evidence was obtained by Cahapay (2020) on Filipino parents with children with ASD during the pandemic. Given their experience during the pandemic, the participants declared a precise determination and will to take a more active and more extended role in their children's education.

Both in the ordinary course of life and extraordinary conditions, such as a pandemic, the function of special education would remain limited unless it spreads to all areas of the life of the individual with special needs. In Turkey, making education for families an essential part of the special education system and ensuring that families actively participate in the education process of individuals with autism are of strategic importance. Online education during extraordinary conditions is not the only cure, but it can be used actively. Educators and program developers should research reliable and valid online education models for individuals with special needs.

STATEMENTS OF PUBLICATION ETHICS

Ethical permission of the research was approved by Bartin University Social and Human Sciences Ethics Committee.

RESEARCHERS’ CONTRIBUTION RATE

| Authors               | Literature review | Method | Data Collection | Data Analysis | Results | Discussion & Conclusion |
|-----------------------|-------------------|--------|-----------------|---------------|---------|-------------------------|
| Birgül Koçak Oksiev   | ☒                 | ☒      | ☒              | ☒            | ☒       | ☒                      |
| Sedat Yazıcı          | ☒                 | ☒      | ☒              | ☒            | ☒       | ☒                      |
| Mahir Uğurlu          | ☒                 | ☒      | ☒              | ☒            | ☒       | ☒                      |
| Tülay Kaya            | ☒                 | ☒      | ☒              | ☒            | ☒       | ☒                      |
| Ayşenur Nazik Fayız   | ☒                 | ☒      | ☒              | ☒            | ☒       | ☒                      |
| Pınar Çelebi Demirarslan | ☒             | ☒      | ☒              | ☒            | ☒       | ☒                      |

CONFLICT OF INTEREST

We confirm that there are no conflicts of interest associated with this research.
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