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Exploring Problems of Moms with Children with Autism Spectrum Disorder during COVID-19

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Abstract

The COVID-19 pandemic, which emerged in 2019, disrupted global education and training activities. During the epidemic, online education has replaced face-to-face education. During the epidemic, the routines of all families and their children have changed. This situation adversely affected the lives of both families with normally developing children and families with children with special needs. Significantly during the pandemic process, the workload of mothers has increased. From this point of view, the research aims to reveal the problems experienced by the mothers of children diagnosed with autism spectrum disorder during the COVID-19 pandemic. For this purpose, the opinions of 20 mothers who had a child diagnosed with autism spectrum disorder and participated in the study voluntarily were taken. The case study design was used as a qualitative research approach. In the study, data were collected by voice recording through semi-structured interviews, one of the qualitative data collection techniques. The obtained data were written down, checked and analyzed through descriptive analysis. According to the study, mothers stated that their children were bored at home and wanted to go out; they encountered behavioral problems and forgot what their children learned at school. They reported that their children spend more time with digital tools such as phones, tablets, and computers. They stated that they could not get feedback from the online courses, the courses were not organized according to individual differences, they had connection problems, and they could not benefit enough due to a lack of resources. All the mothers who participated in the interview emphasized that they wanted the education to be face-to-face.

Keywords: COVID-19, Pandemic, Autism Spectrum Disorder, Special Education

1. Introduction

Due to the (COVID-19) pandemic, countries switched to online education instead of face-to-face activities. In this process, educational institutions in Turkey were suspended on March 16, 2020, and it was decided to continue educational activities through 3 television channels and the Educational Information Network (EBA) within the scope of open and online education practices at primary, secondary and high school levels (MEB, 2020a). Thus,

the continuity of education was tried to be ensured with online education, which we did not have enough control over (Karip, 2020).

Like all students, students with special needs had to continue their online education. However, since moms cannot replace special education teachers in online education and assistive technologies are unavailable, the problem of providing special education assistance to children arises (İnce & Yıkılmış, 2021). This situation negatively affects the development of children with special needs such as Special Learning Disability (SLD), Down Syndrome (DS), and Autism Spectrum Disorder (ASD). It is known that families of children with special needs face more stress than those with normal development, even in regular times (Karabulut, 2021; McConnell & Savage, 2015; McStay vd., 2014; Sönmez et al., 2018). During the COVID-19 period, families with special needs children faced many problems such as high levels of anxiety and worry (Tsibidaki, 2021), behavioral changes (Asbury et al., 2021), lack of professional support (Petretto et al., 2020) during the pandemic and online education process. It appears to be together. In this context, it is essential to determine the difficulties experienced by families with children with special needs.

1.1. The Purpose of the Study

This study aims to determine the problems experienced by the mothers of students with ASD during the pandemic process. When the special education literature is examined, the roles and responsibilities of mothers and the problems experienced by children with special needs in the process of starting primary school (Altın, 2014); loneliness levels of mothers with children with special needs and mothers with children with normal development (Sarihan, 2007); anxiety and depression levels of mothers of children with SLD (Yıldız, 2019); there are studies examining the anxiety levels of mothers (Fiorillo & Gorwood, 2020) caused by uncertainties about when life will return to everyday life during the pandemic process and revealing the problems experienced by mothers. Since there is no study in the literature about online education among mothers with children with ASD, and in the light of research conducted in the field, the research was designed and conducted with mothers, considering that the people who take responsibility for the education of their children in families with special needs children are mostly mothers during the pandemic process.

For this purpose, the following questions have been tried to be answered.

1. What are mothers' problems regarding their children's education during COVID-19?
2. What problems were with online education applied during the COVID-19?
3. What are mothers' views on the adequacy of the contents prepared by the Ministry of National Education during the COVID-19?
4. What are the problems they experience in keeping their children at home during the bans implemented during the COVID-19 process?

The structure of the paper is arranged as follows: Section II presents the details of the Methodology. Section III contains the findings of the study. Finally, section IV will discuss study results within the literature and give recommendations for future research directions.

2. Method

This section contains information about the research design, participants, data collection, and data analysis.

2.1 Study Group

The study group of the research consists of mothers attending A Special Education and Rehabilitation Center with a child diagnosed with ASD. From the sampling methods for the study group, the criterion was selected sampling method. The basic understanding of the criterion sampling method is to study the situations that meet a set of predetermined criteria (Yıldırım & Şimşek, 2018). In this study, being a child with ASD, going to primary school,

and participating in the study voluntarily were determined as criteria. The study was conducted with 20 mothers who met these criteria. The demographic information of the participants is shown in Table 1.

Table 1: Information related to Participants of Research

No	Participant Code	Age	Education Level	Family Type	Number of Child in the Family	Average Monthly Income	Job
1	A1	35	Basic Literacy	Nuclear Family	3	2.324 TL	Housewife
2	A2	44	Elementary School	Nuclear Family	2	2.324 TL	Employee
3	A3	27	Secondary School	Nuclear Family	3	2.324 TL	Housewife
4	A4	57	Elementary School	Nuclear Family	5	2.000 TL	Housewife
5	A5	42	High School	Nuclear Family	1	2.324 TL	Housewife
6	A6	30	High School	Nuclear Family	2	4.000 TL	Sales Assistant
7	A7	38	Elementary School	Nuclear Family	2	2.324 TL	Housewife
8	A8	38	Elementary School	Nuclear Family	2	2.324 TL	Housewife
9	A9	41	Elementary School	Nuclear Family	2	2.324 TL	Housewife
10	A10	42	Secondary School	Nuclear Family	1	2.324 TL	Housewife
11	A11	42	High School	Nuclear Family	1	2.324 TL	Housewife
12	A12	40	Elementary School	Nuclear Family	2	2.324 TL	Housewife
13	A13	42	Secondary School	Nuclear Family	4	1.850 TL	Housewife
14	A14	41	Elementary School	Nuclear Family	2	2.400 TL	Housewife
15	A15	67	Basic Literacy	Nuclear Family	3	2.324 TL	Housewife
16	A16	31	Ortaokul	Nuclear Family	2	3.000 TL	Housewife
17	A17	30	Elementary School	Nuclear Family	2	2.324 TL	Housewife
18	A18	51	Elementary School	Nuclear Family	1	2.324 TL	Housewife
19	A19	37	Elementary	Nuclear Family	3	5.000 TL	Housewife
20	A20	-	Basic Literacy	Nuclear Family	2	2.324 TL	Housewife

As seen in Table 1, all the families participating in the study were nuclear. The age range of the participants ranged from 67 to 27 years. Most of the mothers participating in the study are housewives. In addition, the average income of the families participating in the study is the minimum wage. Considering the educational status of the mothers, it is seen that most of them are elementary school graduates. Finally, the number of children that mothers have varies between 1 and 5.

2.2 Data Collection Tools

At the end of the literature review, interview questions were determined, and the researchers created an interview form consisting of seven questions. The prepared interview form was presented to the opinion of two experts with a doctorate in special education and who are experienced in qualitative research. The interview form was given its final form with five questions, which two of the experts whose opinions were asked stated that they were suitable for the research. However, since the interviewed experts stated that two questions were not ideal for the study, they were excluded from the interview form. The questions asked to the mothers in the interviews are given below, respectively:

1. What problems did you experience with your child's education during the COVID-19?
2. What problems did you experience with online education during COVID-19?
3. What are your thoughts on the content prepared by the Ministry of National Education for your child's online education during COVID-19?
4. What problems did you experience keeping your child at home during the curfews implemented during the COVID-19?
5. Is there anything you would like to add to this interview?

2.3 Research Design

This research, which was conducted to determine the opinions of mothers with children with ASD on the problems they experienced during the COVID-19 pandemic process, was conducted as a case study, one of the qualitative research designs (Bogdan & Biklen, 2007; Yıldırım & Şimşek, 2018). Case studies are classified differently according to their characteristics (Yin, 2003). However, this study was designed according to the holistic single case study design, as it aimed to examine the problems related to the difficulties experienced by mothers with children with ASD during the pandemic period in a multidimensional and in-depth manner (Yin, 2003).

2.4. Data Collection Process

Semi-structured interviews, one of the qualitative data collection methods, were conducted to collect the data. The mothers who had a child diagnosed with an autism spectrum disorder in the institution where the research was conducted were informed about the study, the names of the mothers who wanted to participate in the study voluntarily were determined, and it was decided to conduct the interviews on the appropriate day and time. The research data were collected between 16.09.2020 and 21.09.2020 in the proper periods of the participants. All of the interviews were conducted face to face by the first researcher. Before each interview, the researcher explained the purpose of the research and how the interview would be conducted to the mother. Then, 5 semi-structured interview questions were directed to the participants in the order. During the interviews, a demographic information form, voluntary participation form, documents with interview questions and a voice recorder were used for each mother. The interviews took place between 12 and 18 minutes. Instead of mothers' names, codes such as A1, A2,...A20 were given.

2.5. Data Analysis

Research data were analyzed with the descriptive analysis technique. According to Yıldırım & Şimşek (2018), the data obtained in the descriptive analysis are summarized and interpreted according to the previously determined themes. After the research questions were prepared, the main themes and codes were created. In addition, according to the answers received after the interviews, the coding key was given its final shape by adding new codes and removing some codes. After the interviews were completed, the audio recordings were transcribed. In the transcription of the recordings, all the interviews were transcribed as they were heard without any corrections. To check the accuracy of the data obtained, the records were listened to once again, the transcribed data were read simultaneously, and it was seen that the data were transferred correctly. Later, the researchers divided the data into themes and prepared the interviews for coding. As a result of the interview transcripts, new codes were added to the predetermined codes, and some codes were removed. The data obtained by calculating the frequencies of the codes were digitized. In creating the coding key, the researchers carried out their studies independently. The codes

with consensus on the results were determined, and the level of reliability for the codes created for each main theme was determined. In the calculation using the [Reliability = Consensus/Agreement + Disagreement] formula developed by Miles & Huberman (1994), the reliability level between encoders was determined to be 100%. In the interpretation of the findings, direct quotations were included to reflect the views of the interviewee in a striking way (Yıldırım & Şimşek, 2018).

3. Results

In this section, to reveal the views of mothers who have a child diagnosed with ASD and who are educated in a Special Education Center regarding the problems they experience regarding their children's education during the COVID-19 pandemic process; the findings obtained as a result of the descriptive analysis of the data collected through semi-structured interview questions are included. The conclusions were arranged according to the order in which the questions in the interview form were asked and were given based on this order. The excerpts from the data breakdown were written as an example at the end of the findings by providing a code number to the interview transcripts of each mother interviewed.

3.1. Findings Related to problems experienced by mom's child's education during the COVID-19

To the mothers of children diagnosed with ASD, "What kind of problems did you experience regarding your child's education during the COVID-19?" question was posed. The answers received from the interviewed mothers and their frequency distributions are shown in Table 2.

Table 2: The Problems Mothers Experience with Their Children's Education During the COVID-19 Pandemic Process

Codes of Problems	f
My child is bored at home	6
We had problems giving directions	5
We had problems with internet connection	4
My child forgot what she learned	2
We couldn't adapt to online education	1
We had difficulty following the lessons	1

Regarding the education of their children during the pandemic process, mothers of children diagnosed with ASD stated that their children were bored at home, had difficulties in giving instructions to their children, had problems with an Internet connection, and forgot the information their children learned at school. In addition, mothers stated that their children could not adapt to online education and had difficulty following the lessons. Some of the mothers' views on these findings are as follows; A7 "After the closure of the special education school where the schools normally went, the pandemic period entered. The child started to get bored at home, so he was bored. So he stayed away from education. Moms love it, okay, but if something happens to a child given by a teacher, there is no discipline in the moms. He is afraid, but the teacher disciplines the child." A1 "He didn't listen to us, so be it homework or something, force it." A5 "My Child forgot what he knew. Since this Covid-19 came out, what he lost, he forgot what he knew. Online education has never been good for us. There are disconnections on the Internet, and we do not understand what the teacher is saying. They are trying to write, the children cannot keep up." expressed their opinions.

3.2. Findings Related to problems experienced by mom's child's online education during the COVID-19

To the mothers of children diagnosed with ASD, "What kind of problems did you experience with online education applied during the COVID-19 pandemic process?" question was posed. The answers received from the interviewed mothers and their frequency distributions are shown in Table 3.

Table 3: Views of Mothers on Online Education during the COVID-19 Pandemic Process

Codes of Problems	f
My child couldn't pay attention to the lessons	5
We had a resource and support problem	5
Our workload at home has increased	4
We experienced internet connection problems	4
Individual differences are not considered in EBA courses	2
Broadcast hours of live lessons are early	1
We experienced a tablet/computer shortage	1

Regarding the online education process, mothers stated that their children could not pay attention to the lessons, had problems with resources, increased their workload at home, and had internet connection problems. In addition, they stated that individual differences are not taken into account in the live lessons, the broadcast hours are in the early hours, and they lack materials such as tablets and computers. Regarding these findings, A7 said, "After the special education school where the schools went normally, the pandemic period entered. The child started to get bored at home, so he was bored. So he stayed away from education. Moms love it, okay, but if something happens to a child given by a teacher, there is no discipline in the moms. He is afraid, but the teacher disciplines the child." A1 "He didn't listen to us, so be it homework or something, force it." A4 "An environment that I do not know is a digital environment. We don't know; we're trying to open it but can't. Our resources are limited. It was difficult for the children to write the files one by one, page by page, with the help of our teacher from other friends. It was difficult to write. It was different for the teacher to say and write at school. We had problems for the first month, which happened before we started the live class. Because we were not ready for content, it was difficult for us to log in to EBA, receive files and download them. We had an adaptation problem in the child." expressed their opinions.

3.3. Findings Related to educational content prepared by the Ministry of National Education for Online Education during the COVID-19

To the mothers of children diagnosed with ASD, "What are your thoughts on the content prepared by the Ministry of National Education in your child's online education during the COVID-19 process?" question was posed. The answers received from the interviewed mothers and their frequency distributions are shown in Table 4.

Table 4: Mothers' thoughts on the content prepared by the Ministry of National Education in the COVID-19 process

Codes of Problems	f
Insufficient as there was no feedback	6
Content was sufficient but we couldn't use it	5
Lesson duration was short	4
Course content wasn't sufficient	3
Lessons are not understood because they are online	3

Regarding the content prepared by the Ministry of National Education, the mothers stated that there was a lack of feedback, they could not benefit from the content sufficiently, and the course duration was short. In addition, mothers noted that the content was insufficient and could not be understood because it was online. Regarding these findings, A5 said, "I don't know whether it is heavy on the lessons or not. What will be the process, and how will it go. It is more beneficial if my child goes to school. At least he asks the teacher to show something he does not know, and he has the opportunity to ask the teacher. But what can we ask the teacher on the computer in online education? I throw it there, and the child tries to ask something; one of the children has a dog next to him—the dog barks, drowning the teacher's voice. There is a disconnection on the Internet. EBA is kicking us out. So we don't understand at all." A2 "It is also made from TRT EBA, but the child does not sit and do it. The lessons are enough, but no matter how much I say, he doesn't." A6 "You know, with examples and so on, their time is very short for such children. They give a little time to a subject. Normally, if they did it one-on-one at school, they

would do two or three lessons. They will be places to ask questions that they do not understand. But since this is no such thing, I think it was not very productive." A18 "I think it was not enough. Because we have never taken advantage of it, since he didn't want it, we couldn't use it. I mean, I don't know how something could have been bought, but we couldn't make any use of it. He's never done it himself, either." A11 "No, sir. Face-to-face training would be better because nothing is understood in the internet environment. Then they post something from the group about the life lessons. We are having a connection problem, and we cannot connect. When we contact the class teacher, he says you will fill in the following, but we enter the site. The site is not opening in any way. We are in trouble." expressed his views.

3.4. Findings Related experience of moms keeping child at home during the curfews implemented during the COVID-19?

To the mothers of children diagnosed with ASD, "What kind of problems did you experience keeping your child at home during the curfews applied during the COVID-19 process?" question was posed. The answers received from the interviewed mothers and their frequency distributions are shown in Table 5.

Table 5: Problems Mothers Experience in Curfews During the Covid-19 Pandemic Process

Codes of Problems	f
Played too much with phone/tablet	5
He harmed himself and his environment	5
We had no problems	5
He wanted to go to the park	4
Bored of being alone	2
Gained weight	1

Regarding the problems they experienced during the curfews during the pandemic, the mothers stated that their children play with their phones or tablets too much, harm themselves and their surroundings, gain weight, are bored, and want to go out. On the other hand, five mothers reported that they had no problems. Regarding these findings, A6 said, "We had a lot of difficulties. Even adults had a hard time thinking about our children and their energies. They wanted to go out, and they wanted to play. They wanted to go somewhere and do social activities. Keeping them at home all the time has done quite a bit. We tried to do something ourselves, but the bad part was that they clung to phones and tablets more. Since we live in an apartment, the possibility of friends and the fear of avoiding constant contact is very natural. Having fewer friends than before was very impressive."

A9 "It was forbidden, but we had a lot of difficulties. He was constantly looking at the phone and playing, but after a certain time, he got bored. It was constantly on top of me. He was trying to hit me, biting himself." A2 "Well, we were keeping it hard at home. It didn't stop. After that, she wanted to go to the park all the time, she wanted to go out, and when we didn't take her out, she went crazy at work. We had a lot of problems in this process." A4 "We had problems keeping it at home because my child gained 10 kilograms in this process. She gained weight very fast. I don't know if this brought health problems with it, but our troubles started. We get tired quickly. We went towards asociality for a while."

A3 "We had no problems keeping it at home. My child never wanted to go out, and normally, he doesn't want to go out either. He never came out when he was sick. I forcibly removed it so that it could breathe." A11 "Well, he wasn't a kid who goes out often. He sat with me and played. I cooked, he watched cartoons, and he solved the test. I mean, it didn't get boring like that, I wasn't leaving the house because he had a chronic illness. He was standing next to me." expressed their opinions.

3.5. Findings Related additional experiences and views moms

To the mothers of children diagnosed with ASD, "Finally, is there anything you would like to add to this interview?" question was posed. The answers received from the interviewed mothers and their frequency distributions are shown in Table 6.

Table 6: Suggestions of Mothers for the Education of Their Children in the COVID-19 Pandemic Process

Codes of Problems	f
Let Education Be Face-to-Face	20
Shaping education with different methods	3

All of the mothers of children diagnosed with autism spectrum disorder who participated in the interview stated that they wanted the education to be face-to-face and that the lessons should be designed with different methods if there would be online education. Regarding these findings, A9 "As long as schools open, go to school." A12 "I want him to come to the school where he goes to face-to-face education." A6 "For the education process, I think it would be much more useful if different methods were created that would be more useful. As I mentioned, not every child's perception level is the same. There are children with learning disabilities like my child. But some children understand chickpeas without saying leblebi. Teachers working in the education sector may be moms, and there may be moms who will take extra care. It would be better if a separate system were created especially for children who need special education." expressed their opinions.

4. Discussion & Conclusion

In this study, interviews were conducted to determine the views of mothers with children diagnosed with ASD regarding the problems they experienced during the COVID-19 pandemic process. Considering the findings of the interviews, the mothers' taking on the educational roles of their children in their daily routines, limited Internet, inability to use technological tools, the situation of keeping their children at home, and their children's increasing tablet and phone addictions, etc. These situations increase stress and anxiety levels, so they have anxiety and problems. By examining the literature, we can see an increase in problem behaviors. Mothers' coping strategies are one of the issues discussed in online education, mainly because their routines change and they frequently spend time with online education materials (Alexander et al., 2020; Courtenay & Perera, 2020); Rose et al., 2020). Therefore, the study's finding is in line with the literature.

When another finding was examined, many moms said their children did not want to leave the house for fear of catching COVID-19. According to a study conducted on this subject in the literature, children with ASD who fear catching the Covid-19 virus do not want to leave the house due to these concerns during the epidemic (Hughes & Anderson, 2020). This finding aligns with the literature also.

Considering the research findings, some mothers stated that their children harmed themselves and their environment. When the literature is examined, it has been said that there is an increase in problem behaviors. Mothers' coping strategies are one of the issues discussed in online education, mainly because their routines change, and they must spend time with online education materials (Alexander et al., 2020; Courtenay & Perera, 2020; Rose et al., 2020).

All the families with children with ASD found online education incomplete, and it was seen that they wanted to switch to face-to-face education. In line with these opinions obtained from mothers, it can be stated that face-to-face teaching should be given in addition to online education. Furthermore, Picciani et al. (2020) said in their study that online education did not provide learning results such as face-to-face education in children with ASD. Based on these findings, it can be said that face-to-face education of individuals with special needs should not be interrupted in any way.

According to another study, one of the mothers' most significant problems is the increase in phone and tablet addiction in their children during the epidemic. It has been observed that such problems occur primarily due to the use of these devices in online education and that mothers have to allow their children to use phones and tablets to keep them at home. Furthermore, Toran (2016) stated that the increase in the frequency of use of technological devices in children had caused discussions and problems between families and children.

Based on the findings of this study, in which the views of mothers with children with ASD on the problems experienced during the COVID-19 pandemic process are tried to be determined for future studies; during the COVID-19 epidemic, the opinions of the families of the children from the other disability group who received online education and need special education can be taken. Teachers of children with learning difficulties, who are a part of the online education process, can also receive their opinions on the pandemic process in the future. On the other hand, online family training can be organized for practice. In addition, online training can be differentiated. Face-to-face education can be continued by taking the necessary precautions.

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