



Identifying the Problems Experienced by Parents of Children with Special Needs during the COVID-19 Pandemic

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Abstract

This study aims to determine the problems experienced by parents of children with special needs during the COVID-19 pandemic. The phenomenological patterns technique, which is a qualitative research method, was used in the study. Ten parents with children with special needs who were affected by different types of disabilities were included in the study. The data in the research were collected using interview forms consisting of open-ended questions and a semi-structured interview technique. After the data obtained from the interviews were decoded, they were analyzed with the descriptive analysis technique. At the end of the study, the findings of the problems experienced by parents of children with special needs during the epidemic, the problems they experienced with their children, and the problems and expectations related to the education of their children were discussed in detail within the framework of the literature.

Keywords: COVID-19 Pandemic, individuals with special needs, parents.

It can be argued that the entire world was caught unprepared for the pandemic that started in Wuhan, China on 31 December 2019, spread rapidly as a result of human mobility (Sari & Nayir, 2020), and not enough experience had been accumulated (WHO, 2020). For this reason, the COVID-19 pandemic has become a global health problem, a major crisis, and has spread throughout the world. This highly contagious pandemic that causes disease and deaths in humans (Aslan, 2020), also causes an increase in living costs as well as a global health crisis (Ham, 2020). Due to the COVID-19 pandemic, states have started to implement quarantine practices because the increasing number of cases and mortality rates worldwide have required states to take appropriate measures (Wang, Cheng, Yue & McAleer, 2020). This crisis caused by the COVID-19 pandemic has deeply affected humanity in every field; economic, psychological, social and education (Can, 2020; Zhao, 2020).

One of the measures taken due to the COVID-19 pandemic was the closure of schools. Schools in 188 countries around the world have been closed (UNESCO, 2020; Gupta & Goplani, 2020). In other words, it has affected approximately 92% of the student population worldwide (UNESCO, 2020). The schools that were closed caused children to be deprived of their most natural right, which is education. Therefore, states have switched to distance education to ensure

the continuity of learning while taking measures for human health. Children have continued their online classes at home (Telli-Yamamoto & Altun, 2020). While the quality of distance education is questioned by families in general, the families of children with special needs may experience various other problems.

Under normal circumstances, the lives of families of children with special needs are even more difficult than families of children with normal development. That is because the participation of the child with special needs in the family can negatively affect family functions and psychology (Damiani, 1999; Ohaeri, 2003). When the family learns that the child is an individual with special needs, it develops various reactions. The most well-known model that explains these reactions is the staging model. The staging model is based on clinical judgment and categorically examines the temporal and mental development that parents undergo to return to their psychological state before the stress emerges (Ardic, 2010). The stages families go through according to the staging model are shock, rejection, depression, complex emotions, guilt, anger, negotiation, acceptance, and adjustment.

The fact that the child has special needs causes parents to reconsider their expectations from life. Furthermore, problems such as taking care of the child with special needs, deterioration of daily home routines, deterioration of roles among family members, financial problems, a decrease in household income, etc. can be observed (Ohaeri, 2003). Depending on the child's disability, additional needs such as special physical arrangements and special equipment at home bring extra financial burdens to the family (Turnbull & Turnbull, 1995). Furthermore, it can also cause the spouses to divorce (Damiani, 1999).

The factors, such as observing behavioral problems in children in the home environment (Allen, Ciambone & Welch, 2000), the need of the child with special needs for lifelong care, treatment problems (Sari & Altıparmak, 2008), decreased social support, decreased family satisfaction, emotional problems, or not being able to go to the cinema or park (Trute & Hiebert Murphy, 2002) are among the leading issues that put parents or family members into stress and depression (Ohaeri, 2003). Studies conducted in connection with all these problems indicate that problems such as anxiety, emotional distress, low self-esteem, stress and additional health problems are more severe in the parents of children with a disability than in parents with normal children (Hastings & Brown, 2002). Additionally, according to research, it is observed that life satisfaction levels (Can, 2015; Cho & Kahng, 2015), marital adjustment levels (Ince & Tüfekci, 2015; Gau, Chou, Chiang, Lee, Wong, Chou & Wu, 2012) and parental self-efficacy perceptions of parents with children with special needs are low (Altındag Kumas & Sumer, 2019; Ben-Naim, Gill, Laslo-Roth & Einav, 2019). Finally, it is observed that family resilience levels are low especially among mothers (Altındag Kumas & Sumer, 2019).

Looking at all these problems, it is seen how difficult the lives of parents with children with special needs are. Especially during the COVID-19 pandemic, the closure of schools and the distancing of children from education can negatively affect their development. Furthermore, parents can stay at home with children all day long. This situation may increase the stress of the child with special needs and their parents and cause them to experience various problems. Therefore, this study aimed to determine the problems experienced by parents of children with special needs during this period when schools had interrupted education and parents stayed at home with their children due to the COVID-19 pandemic; and to elucidate their expectations for these problems.

1. Purpose and scope of the research

The purpose of this research is to determine the problems experienced by parents of children with special needs during the COVID-19 pandemic. For this purpose, the following questions were sought to be answered:

1. What are the problems that parents with special needs children experienced during the pandemic?
2. What are the problems they are facing with their child?
3. What are the problems they had regarding their child's education?

What are the expectations of parents of children with special needs during the pandemic period?

2. Method

2.1 Research model

In this study, the phenomenological design, a qualitative research method, was used to determine the problems experienced by parents of children with special needs during the COVID-19 pandemic period. A phenomenological study is a strong qualitative research pattern that examines social phenomena in depth by focusing on the experiences of individuals and is frequently used across disciplines (Cresswell, 2018; Capar, 2020).

2.2 Participants

This section includes demographic information about the participants. The sample of the study consists of 10 parents of children with special needs. The two-stage sampling model was used in the study. In the first stage, the criteria sampling method was used. The criteria determined for selecting the participants were that (a) the parent must have a child with special needs, (b) the child with special needs must be enrolled in a school, (c) the child with special needs must attend school except for the pandemic period (must have attended school for at least 6 months) and must not be homeschooled. Of the parents who meet these criteria, 10 parents residing in Sakarya and Antalya provinces, who were selected with the convenience sampling method, constitute the study sample. Demographic information of the participants is given in Table 1.

Table 1. Demographic data of parents

Code Name	Age	Educational Status	Parent's Gender	Employment Status	Child's Age	Child's Gender	Child's Type of Disability
P1	55	High School	M	Retired Civil Servant	19	F	MI
P2	35	High School	F	Medical Secretary	14	F	MI
P3	47	Primary School	F	Not Working	15	F	MI
P4	43	None	F	Not Working	15	F	MI/PI
P5	37	Primary School	F	Not Working	15	M	MI

P6	30	High School	F	Not Working	7	F	DI
P7	52	University	F	Not Working	7	M	ASD
P8	38	University	F	Teaching	10	M	ASD
P9	41	Primary School	F	Not Working	11	M	ASD
P10	39	Primary School	F	Not Working	15	M	MI

MI: Mental Incompetency,
 ASD: Autism Spectrum Disorder,
 PI: Physical Incompetency
 DI: Developmental Incompetency.

Examining Table 1 it is seen that the ages of the parents participating in the study vary between 30 and 55. One of the parents is male and the other nine participants are female, one is illiterate, four are primary school graduates, three are high school graduates, two are university graduates, two parents are employed, and the others are unemployed. The ages of the children with special needs vary between 7 and 19, five are males and five are females. Looking at the types of disabilities of the children with special needs, it is seen that five children have an intellectual disability, three have autism spectrum disorder, one has developmental incompetency and one has multiple types of disabilities.

2.3 Collection of data

The data in the study were collected using the semi-structured interview technique. The interview form, prepared by the researchers by scanning the literature to collect the research data, was finalized by taking the opinions of field experts working in the field of special education.

The interview questions prepared following the semi-structured interview technique were asked to the parents online by conducting audio and video interviews, and their opinions were recorded by asking questions one-to-one. The interviews lasted between 6 and 23 minutes.

Before starting the interview, the researcher introduced himself/herself explained the purpose of the interview, declared that he/she would have audio and video recordings during the interview, and that participants' names would not be mentioned in the research. After the consent of the parents who participated in the study were obtained, the audio video-recording was started and the data were collected.

2.4 Validity and reliability

Validity and reliability studies of the research were conducted. The questions asked to parents within the scope of the research on internal validity, the data obtained and the comments on the data were presented for an expert opinion. Moreover, the findings and comments obtained in the research were shown to 25% of the parents participating in the research, and participant approval was obtained. Regarding the external validity of the research, direct quotations are given in quotation marks by presenting examples of the sentences that the participants expressed their opinions with.

To ensure internal reliability in the research, the field expert was asked to examine the consistency between the data and the results of the research. As a result of the consistency analysis made by the field expert, it was determined through analysis that there is consistency between the research data and the research results. To ensure external reliability, approval of a field expert was obtained for the raw data of the research, the results regarding the data, and the comments made on these data.

2.5 Data analysis

The answers given to questions in determining the problems experienced by parents of children with special needs in the COVID-19 period were transcribed verbatim. The reliability study of the decoding process was performed for 30% of the documents and was calculated as 100%. The descriptive analysis (thematic analysis) method was used in the analysis of the data, and the following steps were followed in the analysis process:

1. The interviews made by the researchers were deciphered.
2. A document with a total of 48 pages were obtained from the audio recordings of the interviews.
3. Codes such as P1, P2, etc. were used to code the parents.
4. The answers of the parents for the same question were grouped.
5. The answers to each question were read several times.
6. The questions were accepted as themes, and codes were created within the framework of these themes.
7. The frequency of the codes expressed by parents was calculated and reported as a frequency.
8. Quotations were made with the parents' own expressions.

In studies where the descriptive analysis technique is used, direct quotations are frequently used to reveal the opinions of the participants (Yildirim & Simsek, 2008). In this research, the words of the parents were included in quotation marks without being changed.

The data transferred to the computer environment were analyzed with the descriptive analysis method, taking into account the frequency and by accepting the research questions as themes. In the research, the statements of the interviewees were stated in quotation marks exactly as they were stated and with participant codes such as P1 and P2.

3. Results

In this section, findings obtained from the interviews to determine the problems experienced by parents of children with special needs during the COVID-19 pandemic are included.

1. Findings regarding the problems experienced by parents of children with special needs during the pandemic period

The findings regarding the individual problems experienced by parents, the difficulties they experienced regarding other members of the family, economic and health-related difficulties they experienced, and the solidarity of family members with each other during the COVID-19 pandemic are given below.

1.a. Findings regarding the individual problems experienced by parents during the COVID-19 pandemic

The parents stated that during the COVID-19 pandemic, they were locked up inside the house because they could not go out (f=7), their responsibilities towards their children increased (f=7), they were inactive because they stayed at home all the time (f=3), they could not find a job during this period (f=2), they had difficulties because they did not meet the demands and needs of their children (f=2), they lived separately from their children (f=1), they contracted

COVID-19 (f=1) and they were anxious about contracting COVID 19. The statements of the parents are given below.

P1. Well... I mean, economically, we don't have problems, but we were locked up inside the house, eating, drinking and resting. We did nothing else like doing sports, that's the way it is, sometimes we go out and take walks.

P6. So, we got over this disease in the end...We were in separate rooms during COVID-19. Then the process was a bit difficult after I was infected with it. The fact that she got over the disease lightly and I got over it heavily affected me a little badly. I had a pretty bad cough.

P2. Well, I worked in the hospital for about two months during the pandemic period because I couldn't find a job. As a janitor, I was separated from the children for two months to avoid COVID infection. Well, I had this difficulty.

P4. Of course, we have a lot of difficulties, they are not like other normal children. We are going through a very difficult period. They cannot go out and come out easily. Normally, I would take her to the shopping centers with her father to clear her head. There is always trouble at home. Well, because there is no school.

1.b. Findings regarding the difficulties experienced by parents towards other family members

Parents stated that the responsibilities of the other members of the family for the child with special needs increased (f=3), siblings remained separated (f=1), and the needs of elderly and dependent family elders increased (f=1). They also added that family members spent time together (f=3) and had the opportunity to get to know their child better (f=1), therefore they did not experience any difficulties regarding the other members of the family during the COVID-19 pandemic. The statements of the parents are given below.

P5. Well, my husband goes to work on weekdays, you know, he stays at home at the weekend, only. My daughter works like that too, she goes to a rehabilitation center in a private school, so she can't help me, either. In terms of Emre, just the two of us stay at home, I'm just struggling with Emre at home.

P2. I did not have any health problems, but you may know that I broke up with my husband, so I am separated from my other children, now we live with Esma.

P3. I go to the market on certain days of the week, and I am in the village on certain days. I'm looking after my dad. I stay in the village for a week, then go to the market, those are my difficulties.

1.c. Findings regarding the economic difficulties experienced by the parents

While some parents in this process stated that they experienced difficulties such as being dismissed (f=4), not being able to find a job (f=2), their workplaces being closed (f = 2), not being able to pay the rent (f=1), and the bills (f=1), some others stated that they did not experience any problems (f=4). The statements of the parents are given below.

P3. I am two months behind in rent, I could not pay it. I cannot work. They were going to give me a job, but they still haven't. Well, the rent was already being paid by my father. My father is also in bad health, his blood pressure is falling and rising. The Social Welfare Center was giving me my supplies, so they paid 250 Turkish Liras every two months, they gave me a card, I can go shopping with it, and nothing else.

P5. It's going well economically. My husband is already retired, thank God, we do not have a problem, we are trying to manage.

P2. Just as you said, I am experiencing economic difficulties. My family is supporting me, and I had a lot of problems with unemployment. I'm trying to survive with the support of my family.

P9. When you become a tradesman, expenses continue all the time, and income decreases. Therefore, we don't hire staff anymore. So that we can manage it ourselves. There has always been trouble. We are a family that always lives on a small income. I mean, we still have problems.

1.d. Findings regarding the health difficulties experienced by parents

Parents stated that they experienced some health difficulties during the pandemic process. They stated that they contracted asthmatic bronchitis (f=1), underwent heart surgery (f=1), and caught COVID-19 (f=1) and they had difficulties in this period, while some parents participating in the study stated that they did not experience any health problems (f=7). The statements of the parents are given below.

P2. No, we didn't have any problems with health.

P3. Well...related to health... I also have asthma and bronchitis. Dust is not good for me. When I get dust, it makes me sneeze and I have allergies. The doctor said you have allergies, you can't stay in the dust.

P1. My children, my nuclear family, my son, my married son, my daughter Seray, my husband, or I did not have any health problems.

1.e. Findings regarding the solidarity of family members with each other

Parents stated regarding the solidarity of family members with each other during the COVID-19 pandemic that the family members supported each other morally (f=9), shared the responsibilities and needs regarding the child with special needs (f=6), supported each other financially (f=3), and their shared dreams for the future increased (f=1). The statements of the parents are given below.

P6. Of course, he (her husband) made Miray do physical exercises like Pilates; he did this kind of thing with her. I also helped with other activities such as motor development activities. I made her do exercises. It was good in that respect, we also had good days.

P4. Well, it's not so frequent but, for example, when I am not at home, it is the nature of a house, you know there are things to do and needs at home, we have our own problems, when I am out, he had to take care of them. I mean it doesn't happen as long as I'm home. He just deals with his own stuff, because he is a boy, it would be different if he were a girl. He doesn't do that much because he is a boy. He doesn't get it, we tell him, he doesn't get it.

P5. So, what can I say regarding solidarity? So, to be frank, we're trying to act shoulder to shoulder. I can say that, what else can I say? To be honest, the burden is on me a little, I bat around, I do everything. Since my husband is outside, he cannot do much with the child's lessons. Usually, the child and I are together and it is mostly on me, frankly.

2. Findings regarding the problems that parents of children with special needs experienced during the pandemic period

The findings regarding the problems experienced by parents of children with special needs related to their children's problematic behaviors, health, eating habits, and communication parent-child communication, sibling relationships, and realization of self-care skills are given below.

2.a. Findings regarding the problems experienced by parents with children with special needs regarding their problematic behaviors

Regarding the problematic behaviors of their children with special needs, parents stated that they exhibit aggressive behaviors (f=6), and that there is an increase in behaviors such as not doing what they are told (f=4), stubbornness (f=3), biting nails (f=1), eating scabs (f=1), tearing apart assigned activities and homework (f=1), hair pulling (f=1), hand biting (f=1), wanting to do activities continuously (f=1), constantly putting toys in their mouths (f=1), being over-emotional (f=1), and repetitive behavior (f=1). The statements of the parents are given below.

P3. Although I tell her otherwise, she bites her nails, she eats her scabs, I still could not make her give it up.

P5. He got very aggressive and angry, he wants to do what he wants, you know, he doesn't want to study much, we forced him to study. He even doesn't want to go to special education, he goes by force. I'm not going, I don't want to study, we try to tell him, if you do it like this or it happens like that and so on. We tell him: if you manage to read you will have a job, but I don't think he understands us right now at all.

P1. Well, at home, due to her being twenty years old, sometimes, of course, she has things related to puberty, let's say. She has special requests at home. So, she can give us some trouble.

2.b. Findings regarding the problems that parents experienced regarding the health of their child with special needs

Some parents stated that during the COVID-19 pandemic their children with special needs experienced allergies (f=1), gallstones (f=1), and heart-related health problems (f=1). While some parents who participated in the study stated that their children did not experience any health problems during this period (f=8). The statements of the parents are given below.

P1. Of course, sometimes she acted aggressively against her mother. She does what her mother doesn't like and doesn't do what she likes, so of course, we had some aggression at this point.

P4. She had stones in her gall bladder, she was uncomfortable. We did not know about it. How many times have we taken her to the hospital and brought her back for so many years? The doctors sent us back saying she had no problems, I told the last doctor we went to that I wanted an ultrasound scan, and as a result, we learned that she had many stones in her gall bladder. It was because of this that she couldn't eat anymore. She was always in pain, she was holding her stomach, she was sick. The doctor said surgery straight away, after corona.

2.c. Findings of the problems experienced by parents regarding the nutritional habits of their child with special needs

Regarding the nutritional habits of their children with special needs during the pandemic, parents stated that they experienced problems such as choosy eating (f=3) and consuming more in quantity (f=2). Some parents who participated in the study stated that they did not experience any problems (f=4) and that their children started eating foods that they had not eaten before (f=1). The statements of the parents are given below.

P4. Well, in terms of nutrition, she chooses her food, but not much, and then it's me who feeds her. I serve her food; she eats her own food. I feed her the morning breakfast, you know, I take care of her like a small child.

P5. He's eating well. We do not have any problems. He's eating very well. After the surgery, he got a super appetite. But he does not gain any weight, so his weight is normal. But he's eating very well He eats everything.

P1. No, we have no problems with nutrition. Well, she did not have any problems.

E10. During this period, we started to feed him fruits. We started to give him something to eat. He doesn't eat everything, but he started to eat some things...compulsorily. I said; don't get sick, you have to eat something. We can't go to hospitals. They won't be able to take care of you, we have to be careful. And I make him eat.

2.d. Findings related to the problems experienced by parents regarding communication with their child with special needs

While some parents stated that their children did not communicate with them (f=4) and their children did not do what they were told (f=2) during the COVID-19 pandemic; some parents who participated in the study stated that they did not have any problems with their children (f=3). The statements of the parents are given below.

P1. We do not have any problems, we are doing good on this point, we do not have any problems with communication.

P3. Well, we had some problems actually. When I shout at her, she cries, is offended, goes away, and blushes. You know you can't really say anything to her. When you say something to her, she blushes from her face to her tongue.

P5. How can I say, the thing between us, sometimes he listens to me, sometimes he makes me angry, sometimes he doesn't do what I want. For example, as I said, you know, he does not want to study or have a bath.

2.e. Findings regarding problems experienced by parents of their children with special needs regarding the relationship between siblings

Some parents stated that their children with special needs could not get along with their siblings during the epidemic (f=2), while some parents who participated in the study stated that their children did not have any problems with their siblings (f=4). Some parents also stated that the COVID-19 pandemic increased positive relationships between siblings (f=3). The statements of the parents are given below.

P5. He's on good terms with his sister, so he doesn't have a problem.

P1. There is a problem like this, for example, because her brother is always with her, she grew up with him here, after getting married, of course, her elder brother calls her every day, when he doesn't she reacts "why didn't he call me?". We have this kind of difficulty. I mean, but her brother usually calls her.

P2. We didn't have any problems, but because she missed her brothers so much, we had some problems on this point. Apart from that, she has good communication with her brothers. She loves her brothers very much.

2.f. Findings of the problems experienced by parents with realizing the self-care skills of their children with special needs

Regarding the realization of self-care skills of their children with special needs, some parents stated that they experienced problems such as not being able to do their personal hygiene (f=5) and not being able to go to the toilet (f=3). In contrast, some parents who participated in the study stated that they did not experience any problems (f=3) and that their children made progress during this process (f=2) because they had the opportunity to constantly practice their self-care skills at home. The statements of the parents are given below.

P2. Well, of course, there have been things that she couldn't do until now in this period. Well, now she can do all of them by herself, she can take care of all her self-care, except for nail cutting.

P1. We have problems with only one thing while going to the toilet, but not much else. There is no other problem.

P3. She cannot do her self-cleaning, she cannot do her self-cleaning by himself, to be frank.

3. Findings regarding the problems experienced by parents with the education of children with special needs during the pandemic

The findings regarding the problems that parents experienced with the educational activities of their children with special needs, their teachers, their teachers in special education and rehabilitation center, physiotherapy specialists, and other people involved in their education (school principal, bus driver, etc.) are given below.

3.a. Findings regarding the problems experienced by parents with the educational activities of their child with special needs

Some parents stated regarding the educational activities of their child with special needs experienced reluctance to participate in distance education (f=6), could not do homework by himself/herself (f = 4), could not continue education due to fear of infection (f=3), had a decline in reading and writing skills (f=3), had a regression in performance (f=2) and experienced a decline in sociality due to the pandemic (f=1). Other parents stated that they did not experience any problems regarding the educational activities of the child during this period (f=2). The statements of the parents are given below.

P1. Well, of course, we're having trouble getting out because of today's virus, so we're fearful, so we're driving our own car when we go out, but sometimes when we're not in our car. I mean, it's a fear for us to take busses, of course, we've had concerns of contracting the disease. So, we tried to do individual training by being meticulous when she takes classes in this rehabilitation center. Other than that, of course, she's always got fear. The fear of being infected by the virus.

P3. I didn't have any problems with the training she received. Of course, there were problems from March until July last year, so she couldn't go to school, of course, we do lessons with her at home every day from time to time, so we ourselves took care of all sorts of things at home from her reading to writing studies.

P5. You know, he couldn't pronounce quite a lot of words, we did something together with him on this. For example, he texts his friend, and his mother tells me that my boy doesn't completely know how to read. She says "He sends texts, I'm reading the messages, and there's a lot of problems with his words, so that's what she's saying."

3.b. Findings regarding the problems that parents experienced with the schoolteacher of their child with special needs

The parents stated that they did not experience any problems regarding the problems their child experienced with their teacher (f=8) during the pandemic. They also stated that their teacher at the school had problems individualizing teaching (f=1) and insisted that they participate in distance education (f=1). Examples of the parents' views on this issue are given below.

P6. No, I didn't have any problems. We're very pleased, yes, she's continuing. If schools open in February, hopefully, she will start school. We didn't have any problems. She's been attending the same school for three years.

P7. He treats us like that as well, he doesn't do any activity, etc. for us, for children with special needs or my child. He treats my child just as he treats other children.

P9. We cannot join online classes. As I said, he has nothing to do with the screen. You know, they want him to join the classes. They say "let's send you activities and you do them at home." Families with children with special needs complain that

these children already have difficulty adapting to the class, and they want to set school as school and be free at home.

3.c. Findings of the problems experienced by parents with the teacher of their child with special needs in special education and rehabilitation

The parents stated that they did not experience any problems with the teacher in the special education and rehabilitation center (f=9) during the pandemic and that they had problems in that family expectations were not reflected in the individualized education program (f=1). Examples of parents' views on this issue are given below.

P6. We haven't experienced any problems. Yes, we continue our education there, but during this period, it was also closed. Likewise, we were having video-meetings with them on the internet.

E10. No, our parents are good, God bless them...

P7. They say that we should have control, for example, my child's needs and requests change in time, the school program is also involved. Because of that, I request changes in the program, or I say that I can do some of them. They do not want to accept this, they say we have special techniques, we cannot leave this up to you, we should have the control.

3.d. Findings of the problems experienced by the parents with the physiotherapist of their child with special needs

The families who continued physiotherapy stated that they did not experience any problems with the specialist working with them (f=3) during the pandemic period. Example parent views on this issue are given below.

P6. We started to receive physiotherapy when she was one and a half months old. We have been going to the same place for five years. We haven't experienced any problems.

3.e. Findings of the problems experienced by parents with other persons (school principal, bus driver, etc.) involved in the education of their child with special needs

Parents stated that they experienced no problems (f=10) with other people involved in their children's education process. Examples of parent views on this issue are given below.

E10. No, we have no problems, thank God.

4. Findings of what parents want to add regarding the difficulties they experience during the epidemic period

Regarding the additional difficulties they experienced, some parents stated that they did not have anything to add about the difficulties they had during the pandemic (f=5), they had fear of catching COVID-19 (f=3), they were unhappy due to the restriction of freedom (f=2), they were concerned about the condition of their children if they caught COVID-19 themselves (f=1) and that they had difficulties in their children's education (f=1). Examples of the parents' views on this issue are given below.

P10. We are affected and wonder if we will or will not catch the virus? If we have a little headache, we ask ourselves "I wonder if something happened?". I mean, it had a great impact on us...

P9. So, it's education. You know, financial troubles come and eventually go. My problem with my own child is related to education.

5. Findings regarding the expectations of parents with children with special needs during the epidemic process

The findings regarding parents' expectations from the classroom teacher and the state in the pandemic period are given below.

5. a. *Findings regarding the parents' expectations from their child's classroom teacher in the pandemic period*

Regarding the expectations from the classroom teacher of their children, parents stated that they did not have any expectations (f=8), they wanted them to focus on academic skills (f=1), having lessons and homework being followed up (f=1), and education should be individualized (f=1). Examples of parent views on this issue are given below.

P7. I'd like them to say: "I sent the following activities. These are the appropriate activities for your child. Please complete them." or would like them to follow up the activities, or to do an activity special to him.

P9. I do not have an expectation because we cannot study. On behalf of Berat, I do not have any expectations since we cannot study by ourselves and he cannot look at the screen.

5.b. *Findings regarding the expectations of parents from the state in the pandemic period*

Regarding their expectations from the state during the epidemic period, parents stated that they did not have any expectations (f=4), requested rehabilitation centers to be inspected (f=1), demanded financial support (f=1), demanded support in finding a job (f=1), wanted the COVID-19 vaccine to arrive (f=1), wanted the number of lessons in special education and rehabilitation centers to increase (f=1), requested language and speech therapy support (f=1), parent support at home (f=1), provision of care services for the children of families infected by the virus, the precautions against the pandemic to be increased (f=1) and their children to be granted the right to repeat a grade (f=1). Examples of parent views on this issue are given below.

P7. Many students cannot attend online classes. Our child can partially join these classes; maybe two hours a week, although difficult in our country, they could have come home to teach for two hours together with the parents.

P8. I want this too, of course, I always tell this to the other parents, they stayed in the classroom last year. I think the state should give that permission again this year, I mean, these children should stay in the classroom, because they can attend very few classes and it has been almost half a term this year. They have to stay in the classroom next year. I think the right to repeat a grade should be given again next year, this is what the state can do.

As a result, parents with children with special needs stated that they were constantly locked up at home because they could not go out during the COVID-19 epidemic, and their responsibilities towards their children increased more. The responsibilities of the other members of the family towards the child with special needs have also increased. Parents also experienced problems during this period such as being dismissed, not being able to find a new job, closure of workplaces, not being able to pay the rent and the bills. Regarding the solidarity between the family members, parents stated that they supported each other morally, they shared the responsibilities towards the needs of the child with special needs, and they supported each other financially.

Regarding the educational activities of their child with special needs, the parents stated that their children experienced unwillingness to participate in distance education, could not do homework on their own, and could not continue their education due to fear of infection. Regarding the problematic behaviors of the children with special needs, parents expressed that their children exhibited aggressive behaviors, and acquired habits such as not doing what they were told, acting stubbornly, and engaging in nail biting. Moreover, parents stated that their

children with special needs could not get along with their siblings during the pandemic period and they had difficulty with personal hygiene during this period. Parents stated that they asked the state to inspect rehabilitation centers, support them financially and assist them in finding employment during the pandemic.

4. Discussion, conclusion and suggestions

The parents in the study stated that they experienced problems individually during the COVID-19 pandemic period. Studies show that parents of children with normal development also experience problems related to social interaction, physical activity and various psychological problems at home (Wang, Zhang, Zhao, Zhang & Jiang, 2020). Therefore, the parents of individuals with special needs will have more desperation and fatigue due to the behavioral problems of the child with special needs (Bell, Boyd, Tweedy, Weir, Stevenson & Davies, 2010; Maltais, Wiart, Fowler, Verschuren & Damiano, 2014). Asbury, Fox, Emre Deniz, Code and Toseeb (2020) and Mengi and Alpdogan (2020) report in their study conducted with special education teachers that parents experience various problems in their homes. According to Aishworiya and Qi Kang (2020), parents of children with special needs traditionally devote themselves to their children. During the pandemic, parents experience more problems in this struggle than ever before, because the lack of access to psychologists and therapists in the COVID-19 period negatively affects the mental health of these children, and this causes behavioral problems.

Parents stated that they experienced problems regarding the difficulties they experienced regarding other members of the family. When the literature is examined, it is seen that the COVID-19 pandemic affects both individuals and society psychologically and socially (Kundi & Bhowmik, 2020). It is normal for parents to experience psychological problems during the COVID-19 pandemic (Jiao et al., 2020). According to Brooks et al. (2020), it is stated that individuals intensively experienced post-traumatic stress disorder, anxiety, anger, depression, insomnia, and disappointment during the pandemic period. For these reasons, the stress levels of parents towards their children have increased (Cluver et al., 2020). It should be kept in mind that domestic violence is likely to increase and children are vulnerable to this issue (Bradbury-Jones & Isham, 2020). For this reason, psychological support should be provided to family members with special needs, albeit remotely, through mobile applications.

According to the results of this research, parents experience financial problems. There are findings in the literature in parallel with these research findings. According to Mengi and Alpdogan (2020), the COVID-19 pandemic affected all countries multidimensionally and economically. According to Kundi and Bhowmik (2020), economic problems will increase significantly during the pandemic process and unemployment will increase accordingly. According to Akkas Baysal, and Ocak & Ocak (2020), the COVID-19 pandemic affects our country in a multidimensional and economic way, as it does so across the world. According to Alpar (2020), people may exhibit undesirable behaviors in times of social and economic crisis. Problems experienced in economic status can also cause domestic violence. Homemakers, the unemployed or low-income families have been disturbed by the pandemic (Bozkurt, 2020). Therefore, it is recommended that the state and employers provide more support to parents who are experiencing financial difficulties.

According to the results of this research, parents stated that they experienced some health-related difficulties during the pandemic period, and similar findings are available in the literature. According to Mengi and Alpdogan (2020), the COVID-19 pandemic brings along various health problems in humans. In their study, Basaran and Aksoy (2020) stated that parents experienced various health problems during the COVID-19 pandemic. According to Goksu and Kumcak (2020), problems threatening the health of individuals during the pandemic also affect their stress and anxiety levels. For this reason, especially during the pandemic period, parents

must pay more attention to hygiene rules and activities, and psychological support should be provided to help parents relive their stress.

This research has revealed findings regarding the solidarity of family members with each other. According to NSPCC (2020), people living in the same house now spend more time together. These individuals have combined work, school, and home in the same environment. Thus, they have started to live in a small area. This situation has resulted in solidarity and cooperation in some families, and while it caused conflict in others (Ozturk, Yilmaz, Demir Erbil & Hazer, 2020). According to Kluwer (2020), it is inevitable that conflicts occur within the family, especially with the triggering of financial negativities in the household during the COVID-19 pandemic. In the process of the COVID-19 pandemic, it is an expected situation that having an individual with special needs at home, will change routines and increase stress and tension in the household. However, according to the results of this study, it is a positive finding that there is solidarity within the family.

According to the results of this research, the parents stated that they had problems with the educational activities of their children with special needs. According to the literature, Kalac, Telli and Eronal (2020) stated that, during the COVID-19 pandemic, the parents of children with special needs experienced various problems with their children's educational needs. According to Aishworiya and Qi Kang (2020) and Atli Yilmaz and Atli (2020), during the COVID-19 pandemic, the parents of children with special needs observed that their children had problems with their educational needs. In their study, Mengi and Alpdogan (2020) stated that during the COVID-19 pandemic period, "the application of distance education was very difficult for students who received special education, and in this process, students moved away from school culture and took less responsibility in the home environment; and that student who received special education could not continue the skills they acquired in face-to-face education in the distance education process". In their study, Sahin, Oz and Singin (2020) concluded that children with autism spectrum disorders had a regression in their motor skills due to lack of education. According to the results of this research, it is difficult to provide distance education for individuals with special needs in a home environment. Parents' insufficient knowledge of teaching an individual with special needs, combined with the learning problems of individuals with special needs, becomes a challenging situation for families. Parents should be provided family education through distance education.

According to the results of this study, parents stated that they had problems regarding the problematic behaviors of their child with special needs. When we look at the literature, we see difficulties specific to the population of children with special needs, according to Aishworiya and Qi Kang (2020). During the COVID-19 pandemic, these difficulties may increase and behavioral problems may be exacerbated. In their study, Mengi and Alpdogan (2020) concluded that behavioral problems of the students with special needs increased significantly during the COVID-19 pandemic. In their study, Asbury, Fox, Emre Deniz, Code and Toseeb (2020) stated that during the COVID-19 pandemic, children with special needs experienced various behavioral problems. Cacioppo, et al, (2020) and Ma, Ao, Shen, and Wang (2020) found in their study that during the COVID-19 pandemic, parents of children with special needs observed that their children experienced behavioral problems at home. The findings obtained in the current research are in accord with the findings of other studies in the literature, and it can be said that there was an increase in the problematic behaviors of students with special needs during the COVID-19 pandemic process.

According to the results of this study, parents stated that they had problems regarding the health of their child with special needs. There are parallel results with the findings of this research in the literature. According to Aishworiya and Qi Kang (2020), health problems can be observed in children with special needs during the COVID-19 pandemic and their parents take care of these health problems more. Cacioppo et al. (2020) stated that during the COVID-19

pandemic, children with special needs experienced limitations in motor skills due to being locked up at home, which negatively affected their health. Besides, the interruption of the medical care of these children will in turn affect the lives of children negatively. Mobile health personnel can be assigned for the health problems of these children.

Parents stated that they had problems with the nutritional habits of their children with special needs. There are also similar findings in the literature. Nutritional disorders are common in children with special needs, especially in children with autism spectrum disorder (Matson & Fodstad, 2009). According to Salaun Berthouze-Aranda (2011), obesity is observed in individuals with mental incompetency due to nutritional disorders. According to Spahis, Vanasse, Be'langer, Ghadirian, Grenier and Levy (2008), children with attention deficit and hyperactivity disorder also have nutritional disorders. According to the results of this study, malnutrition is a common phenomenon in individuals with special needs. In addition, children who stay at home and do not go to school are more likely to have nutritional problems.

Another finding of this study was parents stating that they had problems in communicating with their children with special needs. The literature also indicates that children with special needs experience language and communication problems. For example, it is commonly seen in children with mental disabilities (Moore-Brown & Montgomery, 2006), children with learning difficulties (Bek & Sen, 2014), and children with ASD (Diagnostic and Statistical Manual of Mental Disorders-5 [DSM-5], 2013). In parallel with these, Asbury, Fox, Emre Deniz, Code, and Toseeb (2020) stated in their study that during the COVID-19 pandemic, parents of children with special needs had communication problems with their children. According to Akcay and Basgul (2020) and Cacioppo et al. (2020), it may also cause delays in the development of communication skills of individuals with special needs during the COVID -19 pandemic.

The study found that parents observed that their children with special needs had positive relationships with their siblings. In the literature, there are research results in parallel with these findings. According to Girli (1995), siblings who show normal development develop positive friendship relations with their siblings with special needs. According to Harris and Glasberg (1994), siblings who show normal development play games, communicate with their siblings with special needs, and try to make friends with individuals with special needs. Moreover, siblings teach each other new knowledge and skills, how to live together, and reconciliation culture (Lamb & Sutton-Smith, 2014). Siblings with normal development will improve their friendships by creating a positive interaction with their siblings with special needs through leisure activities. In this way, individuals with special needs learn to live independently by acquiring the knowledge and skills required in the home and school environment without being excluded from society (King et al., 2003).

Parents stated that they observed their children with special needs had problems realizing their self-care skills. Meeting their physical needs by themselves, such as going to the toilet, getting dressed and undressed, eating, washing their hands and face, cutting nails, combing and taking care of their hair, and bathing independently is referred to as self-care skills in the literature (Cavkaytar, 2000). Problems in motor skills are observed in individuals with special needs, which cause problems in exhibiting skills such as getting dressed, combing their hair, and bathing (Chang, Chen & Huang, 2011). These self-care skills are important for individuals with special needs for them to maintain their daily lives independently or semi-independently (Cavkaytar, 2000). The results of this research have revealed the importance of providing family education to the parents of individuals with special needs during the COVID -19 pandemic on how to teach self-care skills to their children.

The parents stated that they had problems with the schoolteacher of their children with special needs and the special education and rehabilitation center in terms of individualizing

education, and the children's participation in distance education. When the literature is examined, it is seen that similar results have emerged in parallel with the findings of the present study. Kalac, Telli and Eronal (2020), in their study with parents, pointed out that parents observed "the problems related to EBA for primary school students in disability groups" regarding distance education. They expressed these problems as "connection problems in logging in and accessing the EBA system, and lack of accessibility to the EBA content; and the lack of contents that students with special needs of sight and hearing can benefit from in the EBA platform". Mengi and Alpdogan (2020), in their study conducted with special education teachers, stated that the teachers experienced problems in planning the special education needs of the students with special needs and in maintaining the education and training activities through distance education during the COVID-19 pandemic; and that the materials and assistive technologies used in special education did not serve their purpose in distance education. Kara and Alsancak (2020) expressed their opinions about the access of students with special needs to distance education as, "In the first month of the pandemic in Turkey, a lack of integration of students with special needs, in particular, to the distance education system, had limited the access of the individuals in this group to distance education and special education."

In addition to the difficulties they experienced, the parents stated that they were afraid of being infected with COVID-19, they were unhappy due to the restriction of freedom, and that they were worried about the situation of their children if they caught COVID-19 regarding the difficulties they had in the pandemic. In fact, it can be considered normal that individuals experience these emotions, undesired thoughts come to mind and daily routines change in the COVID-19 pandemic, which is experienced simultaneously around the world (Ercan, Arman, Emiroglu, Oztop & Yalcin, 2020). According to the study conducted by Goksu and Kumecek (2020), 84% of the participants stated that their anxiety increased during the COVID-19 pandemic. Similarly, Wang et al. (2020) observed in their research that people's anxiety increased during the COVID-19 pandemic. Furthermore, Duan and Zhu (2020) stated that during the COVID-19 pandemic increased stress and anxiety, and consequently mental problems such as insomnia and anger were observed in individuals.

Regarding the pandemic period, parents stated that they had various expectations from the state. Mengi and Alpdogan (2020) stated in their study that parents experienced various problems in the provision of distance education to students with special needs. Similarly, in their research, Kalac, Telli and Eronal (2020) observed problems in the provision of distance education to children with special needs. At this stage, it is thought that teachers should give more importance to the education of parents and even siblings. Considering that students with special needs spend most of their time at home, it is necessary to prepare individualized family education programs as well as individualized education programs for students with special needs. Moreover, it is difficult to provide information security in lessons offered by the video conferencing method. Legal arrangements should be made in this regard.

Since the qualitative research method was used in this study, the results obtained cannot be generalized and are limited to the views of the 10 parents who participated in the study with children with special needs. Based on these limitations, the following suggestions can be made:

- Parents with children of special needs can be provided with distance education support, financial support, and psychological support due to the problems emerging in the pandemic period.
- Further studies in which qualitative and quantitative research methods are used together can be planned with more parents with children with special needs.

- This study was carried out with parents with children with special needs, and in further studies, a single type of disability can be determined and studies can be planned with parents with a child affected by that particular disability.

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