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How parents of children with autism spectrum disorder experience the COVID-19 pandemic: Perspectives and insights on the new normal

Gulden Bozkus-Genc *, Sunagul Sani-Bozkurt

Education Faculty, Department of Special Education, Anadolu University, Eskisehir, Turkey

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ABSTRACT

Background: Considering the fact that family members necessarily spend more time together during the pandemic, this study aims to reveal the perceptions of parents with children who have autism spectrum disorder of the COVID-19 pandemic in Turkey and their experiences of the difficulties during the pandemic.

Method: A qualitative phenomenology design was used in the study. Seven mothers and one father gave their consent and participated in the study. Data were collected through semi-structured interviews and analyzed using content analysis.

Results: The results of the analysis were collected in two broad themes using 68 codes. The perspective of the parents, who evaluated the pandemic process positively in the beginning, became negative as lockdown lengthened. The issues and adverse effects of the pandemic that they most talked about were the increasing roles and responsibilities of parents, the deep impact on their mental health, and the problems experienced in distance education.

Conclusions: During this period, parents who were psychologically depressed wanted to feel that they were not alone. Parents made many suggestions and recommendations so that others would not have the same experience.

What this paper adds

This paper contributes to the surge of literature on how parents who have children with Autism Spectrum Disorder (ASD) face many unknowns, changes in responsibilities, new social situations, and mental health challenges during the lockdowns for the COVID-19 pandemic. The findings of this study are crucial to help understand the impact of future potential lockdowns on parents of children with ASD. This study also contributes valuable information to the literature by trying to understand “how their needs can be dynamically met,” exemplifying what parents can and cannot do to adapt to a global pandemic they have not experienced before. In addition, this research was conducted during the COVID-19 lockdown in Turkey and, hence, provides insights into how these parents dealt with the intricacies of supporting children with ASD during uncertain and unprecedented circumstances. These unique findings are presented in this study.

* Corresponding author.
E-mail addresses: guldenbozkus@anadolu.edu.tr (G. Bozkus-Genc), ssbozkurt@anadolu.edu.tr (S. Sani-Bozkurt).

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1. Introduction

The world began 2020 with a pandemic caused by coronavirus COVID-19, which emerged suddenly and shockingly. It is inevitable that the pandemic, which affects the whole world, has political, economic, and social effects. The pandemic, which can be considered a medical phenomenon in terms of its etiology, should also be considered a social phenomenon that has a negative effect on individuals (Karatas, 2020). The uncertainty of the global crisis has affected the lifestyle everyone in society, without exception, and especially individuals with special needs and their families, for whom it has changed ordinary needs and demands. Such a view led us to question our perceptions of what is normal (Xiao, 2021). Arguing that normal is a relative term, Bozkurt and Sharma (2020, p. i) state that “the world, and education in particular, as we know them will never be the same.” Thus, we need to develop understandings in the educational landscape that are resilient and agile. In this context, it is critical to understand the experiences of families of children with ASD in this new normal.

One of the social effects of the pandemic is, undoubtedly, the change in family lifestyle. Since the beginning of the pandemic, the United Nations Educational, Scientific, and Cultural Organization (UNESCO) estimates that 1.5 billion (91.3 %) students worldwide, from pre-school to higher education, including individuals with special needs, have stayed out of school at all levels and had no peer interaction, group activities, team sports, or access to playgrounds (Cluver et al., 2020; Narzisi, 2020; Stankovic et al., 2020; UNESCO, 2020). With the closure of daycare centers, kindergartens, and schools, which was followed by lockdowns or social restrictions, a challenging period at homes started for families and/or primary caregivers with children (Cluver et al., 2020). The necessity of the family taking an active role in the educational process as well as ensuring the care and safety of children, working remotely at home, or leaving a job have increased health and economic concerns and changed parental roles (Bozkurt et al., 2020; Cluver et al., 2020; Stankovic et al., 2020). These difficulties have increased even more for low-income families and in households with many family members (Cluver et al., 2020; Ward et al., 2020). These changes during the pandemic have increased families’ stress while reducing tolerance (Narzisi, 2020; Stankovic et al., 2020).

In the pandemic, which can be described as a traumatic experience, individuals with ASD are clearly affected. During lockdowns, time was spent at home to maintain social distance. Interactions with schools and education centers changed completely, making it very difficult for parents to explain the situation to individuals with ASD, who may overreact and struggle to deal with changes. It is no surprise that this change was challenging for individuals with ASD, who have problems with concentration or behavior, even in one-on-one social settings. It is difficult for them to participate in distance and television-based education (UNESCO, 2020) that they have never experienced before. Socio-economic inequalities in terms of access to information and communication technologies, known as the digital divide, have become more prominent during pandemic education practices in Turkey. Moreover, there are significant differences in how much of the household budget is allocated to education (Ozer, 2020; Turkey Statistical Institute [TSI], 2019). There are also significant differences in the digital literacy skills of adults expected to support children’s distance education (TSI, 2019). When it comes to individuals with ASD adapting to distance education, parents must create a completely new routine. Lockdowns have required parents to create a new domestic and life balance. The starting point of this research is to assess what kind of balance parents have established. There is still insufficient information about the difficulties and needs of families of children with ASD during the pandemic (Bozkurt et al., 2020; Stankovic et al., 2020). It is important to assess the perceptions of parents of children with ASD in order to evaluate their changing needs and difficulties during the pandemic.

1.1. Theoretical framework

There was little or no opportunity to prepare families for the sudden move to the COVID-19. In the wake of the COVID-19 pandemic, parents have been “forced to revisit their early traditions, follow their instincts, share, and collaborate to survive” against the traumatic (Bozkurt & Sharma, 2020, p. 6). Such a view requires revisiting two important issues within the theoretical framework: These are (1) the relationship between family and traumatic experience and (2) the relationship between parental involvement in children’s education. Starting from the first issue which is the relationship between family and traumatic experience, it can be argued that trauma is not an event itself, but the body’s protective response to an event or series of events that is experienced as harmful or life-threatening. According to SAMHSA (2014) trauma is defined as “an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual’s functioning and physical, social, emotional, or spiritual well-being” (p. 7). Approaching from this perspective, trauma-informed pandemic pedagogy is pedagogical practice that keeps trauma, its prevalence, and how it affects an individual, in mind (Harper & Neubauer, 2021).

Pandemic pedagogy involves more than teaching and learning in a time of crisis; it also deals with how we conceptualize teaching and learning. Based on the view of learning ecologies, pandemic pedagogy provides the opportunity to apply asymmetric designs (e.g., teaching and learning as an emergent practice based on the needs of the learner) and to pursue pedagogical minimalism (e.g., meaningful teaching and learning for the sole purpose of teaching and learning and nothing else) (Bozkurt & Sharma, 2021). This notion leads to the second important issue within the theoretical framework: the relationship between parental involvement in children’s education. The parental involvement model (Hoover-Dempsey & Sandler, 1995) provides a lens to examine this issue. Accordingly, due to the lockdowns and other forced practices emerged with the pandemic, parents took on new responsibilities in distance learning as they became more engaged in their children’s learning experiences and adopted new pedagogical roles. As noted by Alharthi (2022), Hoover-Dempsey and Sandler’s (1995) model suggests that “parental involvement influences children’s developmental and educational outcomes through such mechanisms as modeling, reinforcement, and instruction, as mediated by the parent’s use of developmentally appropriate activities and the fit between parental activities and the school’s expectations” (p. 5). This
framework allowed the researchers to explore participants’ views by shaping semi-structured open-ended interview questions and make meaningful interpretations.

COVID-19 is not the first virus to threaten humanity nor will it be the last. It is important to track the perceptions and experiences of parents who are responsible for their children’s needs, taking care of them effectively, meeting their educational needs, protecting their future, and improving their quality of life. In this context, this study aims to reveal the perceptions of parents of children with ASD during the COVID-19 pandemic and their difficulties during the lockdowns in Turkey. We address the following questions:

1. What are parents’ thoughts and feelings about the effects of the pandemic on their lives?
2. What are parents’ perceptions and experiences regarding parenting skills?

2. Method

2.1. Research design

This study is based on a qualitative phenomenology design to reveal a common meaning based on the experiences of individuals (Creswell & Creswell, 2017). Specifically, the study focuses on the experiences, perspectives, and reactions of parents during lockdown and the restrictions intended to slow the spread of COVID-19.

2.2. Participants

The maximum diversity sampling method was used to determine the study group. Maximum diversity sampling makes it possible to capture basic experiences of a phenomenon, observe the variability, and reveal a shared pattern among diverse experiences (Patton, 2002). Hence, in selecting study participants, we included children with a range of education levels who lived in homes with different income levels in different provinces. The children also vary by how much they are affected by ASD, which was assessed based on information from the parents and confirmed by the research institute where they received special education before the pandemic.

To recruit volunteers to participate in the study, we obtained phone numbers of 13 parents of children with ASD from a research institute for individuals with disabilities in Eskisehir run by a state university. After one week, two fathers did not reply to follow-up calls; two fathers and one mother declined. Hence the study includes 7 mothers and 1 father of children with ASD from various provinces in Turkey. Table 1 summarizes the demographics of the participants.

2.3. Data collection

Data were collected through semi-structured interviews. The interview form consists of four questions aimed at revealing how the pandemic affected their lives, their views on pandemic-related difficulties, and how they cope with them. Before interviews, content validity was ascertained by asking three external researchers to assess the questions’ clarity and suitability. These are professionals who do qualitative research and work with children with ASD and their families. As a result of their suggestions, one question was revised and removed. Table 2 summarizes the questions asked during the interviews.

Interviews were in September 2020 via videoconference, following the start of the gradual normalization process in Turkey. This context helps contextualize and interpret the findings of the study. By the end of May 2020, gradual normalization had started with the removal of the age restriction for curfew. This was followed by the gradual reduction of the number of pandemic hospitals and the start of normal patient admission by other hospitals, the opening of public venues such as cafes, shopping centers, and gyms, the reopening of preschools with few students for working parents (as an on-demand service), and the reopening of special education and rehabilitation centers including private and public education institutions (kindergarten, primary school, secondary school) in the last week.
of August. These changes were part of the normalization process. Most importantly, during the time when the interviews were conducted, vaccination was rare in Turkey and most of the world, which led to uncertainty, anxiety, and fear, at least in Turkey.

Before the interviews, preliminary interviews were held for approximately 15 min to familiarize research participants with the research process and confirm participation approval. Parents were informed about the purpose of the study. We planned the interview around their schedule. In order to gain their trust, the researchers assured them that their names would be kept confidential, following research ethics, and that their personal information and the personal information of their children and answers to the interview questions would be used anonymously for research purposes only. The researchers informed the parents that the interviews would be voice-recorded and obtained their permission to do this. Informed consent was obtained from all parents who participated in the study. The interviews lasted from 15–45 min.

2.4. Data analysis

Data were analyzed with the NVivo 12 program applying content analysis approach. The data were processed in five stages: (1) data organization, (2) data coding, (3) creating themes, (4) editing codes and themes, and (5) explaining and writing themes (Alase, 2017; Creswell & Creswell, 2017). Before data analysis, voice recordings were converted into text with a computer program. The researchers read each of the interview transcripts several times to obtain a general meaning. They took notes and made preliminary codes. Then, the researchers arranged the codes together and decided on the themes in light of the conceptualized data. While deciding the themes, there was disagreement on only one coding data. They reviewed and discussed disagreement once again and reached a consensus. Consequently, before reaching a full consensus on identified themes, the level of inter-coder consistency is 98.6 %. Next, researchers identified the citations that could be used as individual quotations, organized the findings, and identified themes with rich quotations. At the final stage, the data were visualized with tables and figures to make the comments clearer and more reader-friendly. The main theme and sub-themes were interpreted and direct quotations were provided to support the identified themes.

| No | Main Questions |
|----|----------------|
| 1. | Can you tell us about your thoughts and feelings on the positive aspects of the lockdown that was put in place to ensure social distance with the onset of the COVID-19 pandemic? |
| 2. | How would you describe your experiences at home during lockdown at the beginning of the COVID-19 pandemic? |
| 3. | When you think about your experiences at the beginning of the pandemic, what can you say about your parenting skills or roles and responsibilities? |
| 4. | A second wave of the pandemic is expected shortly. When you think about this possibility and another lockdown, what kind of measures do you think should be taken for you, your family, and your child? What would you recommend? |

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Table 2

Interview Questions.

| No | Main Questions |
|----|----------------|
| 1. | Can you tell us about your thoughts and feelings on the positive aspects of the lockdown that was put in place to ensure social distance with the onset of the COVID-19 pandemic? |
| 2. | How would you describe your experiences at home during lockdown at the beginning of the COVID-19 pandemic? |
| 3. | When you think about your experiences at the beginning of the pandemic, what can you say about your parenting skills or roles and responsibilities? |
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Fig. 1. Sub-themes and codes that make up COVID-19 experiences.
2.5. Quality and verification of data

Trustworthiness, member-checking, transferability, and auditing strategies were used to facilitate the quality of the research data and the ability to verify and authenticate the data and findings. In order to ensure validity, the opinions of the participants were objectively evaluated. To avoid misunderstandings, attention was paid to ensuring participant confirmation as much as possible during the interviews. Secondly, we stressed rich description (Alase, 2017; Creswell & Creswell, 2017). While explaining each theme in the results, we include many direct quotations and in-depth explanations. To ensure transferability, in the methods section details the steps of selecting the participants, data collection, and data analysis (Alase, 2017). To ensure the reliability of the study, the data were coded by both researchers and the themes were agreed upon. This improved the reliability of the study by providing inter-coder consistency. Reaching a consensus contributed to the consistency (Creswell & Creswell, 2017). Referring to expert opinions for data collection tools also increased the reliability of the study. Each of the study participants was informed about the risks, rights, and privacy, and their participation was completely voluntary.

3. Results

3.1. COVID-19 experiences

The main theme of COVID-19 experiences comprises two sub-themes and 49 codes. Although participants at first had positive experiences during the pandemic such as resting, spending quality time together, and making new meals, they emphasized more negative aspects as lockdowns were extended. These aspects included disruption in routines and problems with distance education. Fig. 1 provides an overview of the sub-themes and codes that make up this theme.

3.1.1. Positive aspects

As seen in Fig. 1, the positive aspects sub-theme comprises nine codes. When parents mentioned positive aspects, they highlighted spending quality time with their children and other family members, making new meals, and resting by allocating time for themselves. Notable quotations for each code are listed in Table 3.

3.1.2. Negative aspects

The negative aspects comprise eight codes (Fig. 1). Parents emphasized the changing roles and increasing responsibilities of the family, psychological reactions to uncertainty, and the health problems they faced. In particular, they drew attention to the adverse effects on their daily lives that came from problems with distance education during the pandemic. Remarkable quotations for each code are in Table 4.

3.2. COVID-19 suggestions

The main theme of COVID-19 suggestions consists of three sub-themes and 19 codes. In parallel with the changes in social life with the pandemic, parents made various suggestions to their educators, healthcare professionals, and decision-makers concerning the negative aspects of the pandemic that they have experienced with social isolation. Fig. 2 presents an overview of the sub-themes and codes for this theme.

Table 3
Codes For Positive Aspects and Citations.

| Code                        | Sample Coded Text                                                                 |
|-----------------------------|-----------------------------------------------------------------------------------|
| Resting                     | “It was a disaster that shook the world, but for parents like us who have a special situation – so to speak, running for education from one place to another like a racehorse – it felt like a resting process... We had time for each other (M1).” |
| Spending quality time       | “We started to spend more time with our father and brother. He is cooking at home. He is learning to do housework. These have become good things for us (M4).” |
| Coping with difficulties    | “Moving away from [the city] has been good for us. In the process, we went to the summer house, it is quieter, and I took them to the beach... D. loves water very much, loves the sea. He played with the soil in the garden, piled up stones, played ball, moved a little, walked... (M1).” |
| Following the pandemic rules| “Now, no one goes out without a mask. The habit of changing clothes when coming home, washing our hands and face has been established (M3).” |
| Satisfaction with distance education | “A framework was sent to us to do distance education for children with special needs. She attended some lessons with her father and some lessons with me as a family. It was very nice and productive. We didn’t have any problems (M4).” |
| Establishing social relationships at a distance | “During the lockdowns, the following things have proliferated: Look what he did this time because he could not see other people often, he met on the internet and talked on the phone very often... He has his own friends. They are usually his classmates or people I know from social media, but there may also be friends that I do not know. He’s phoning them. So, these kinds of things have increased during this troubled period (M4).” |
| Abandoning bad habits       | “I quit some of my bad habits like smoking. So, I can say that it has been very good for me (M4).” |
| Creating new interests      | “He started watching cartoons. During this period, there were cartoons that he watched regularly. And he started to like them and watched them for a long time (F2).” |
| Making new meals            | “During lockdown, we mostly started to make everything at home, like bread and pita. My son loves to eat anyway... He even told me, “Mom, you are like a restaurant owner (M4).” |
4.1. Parents

the functions of the family. In this study, some parents stated that they had more opportunities for positive interactions with their children and spend quality time with their family members, they had the opportunity to rest by taking time for themselves, and it was  

The thematic analysis of the data revealed, as expected, a profound change in the daily routines and lives of parents and their children with ASD. The sub-theme of suggestions for educators consists of ten codes. While the parents made suggestions for educators to  

The sub-theme of suggestions for decision-makers consists of three codes. When making suggestions to decision-makers, the parents generally preferred to abstain and shared limited information. However, they still made suggestions, emphasizing later curfews and greater sanctions. Table 7 includes the examples of notable quotations for each code.  

3.2.1. Suggestions for educators

Educators are the focal point of suggestions by parents who rapidly and adapted to an unexpected transition to distance learning in their children’s education. As seen in Fig. 2, the sub-theme of suggestions for educators consists of ten codes. Parents drew attention to controlled face-to-face education, increasing school/institutional hygiene, and social, interaction-based education. Table 5 provides examples of remarkable quotations for each code.  

3.2.2. Suggestions for healthcare professionals

During the pandemic, healthcare workers were at the forefront of the fight against the virus. As seen in Fig. 2, the sub-theme of suggestions for healthcare professionals consists of five codes. While the parents made suggestions for healthcare professionals working for public health to combat the pandemic, they focused on suggestions for accelerating vaccine studies, increasing remote counselling and remote health care services. Table 6 includes prominent examples for each code.  

3.2.3. Suggestions for decision-makers

Decision-makers take urgent and important steps to be taken regarding public health and public order. As seen in Fig. 2, the sub-theme of suggestions for decision-makers consists of three codes. When making suggestions to decision-makers, the parents generally preferred to abstain and shared limited information. However, they still made suggestions, emphasizing later curfews and greater sanctions. Table 7 includes the examples of notable quotations for each code.  

4. Discussion

In the current study, we investigate how the COVID-19 pandemic in Turkey had an impact on the lives of parents of children with ASD. The thematic analysis of the data revealed, as expected, a profound change in the daily routines and lives of parents and their children. The research questions were structured around two topics: parents’ feelings and thoughts, and parenting skills.  

4.1. Parents’ feelings and thoughts about the effects of the pandemic on their lives

It is inevitable that the pandemic has different effects on global, national, and local scales. There are still many unknowns and many sociological, psychological, and economic aspects in all layers of society. With the pandemic, significant changes have also occurred in the functions of the family. In this study, some parents stated that they had more opportunities for positive interactions with their children and spend quality time with their family members, they had the opportunity to rest by taking time for themselves, and it was entertaining to make new meals that they did not have had time to make before. One of the remarkable findings of this study is that parents of children with ASD who had creative ideas by transforming the difficult times during lockdown have managed to develop a positive perspective. In addition to these points, it can be said that abandoning some bad habits, keeping themselves busy by finding different interests, going to quieter places such as villages and summer houses away from city centers, and being in touch with their immediate surroundings helped parents keep up their spirits and motivation. As seen in the literature, difficult times are an opportunity to establish stronger social relationships and show family members’ support of each other (Cluver et al., 2020; Mumbardó-Adam...
Regarding the development of a positive perspective, in a study conducted to reveal the effects on society after the COVID-19 pandemic in Turkey, Uzun (2020) stated that family ties strengthened for half of the participants (54.5% of 5300 people) during the lockdown period. Similarly, Stankovic et al. (2020) expressed satisfaction with the increase in the mother–child–father interaction since fathers spent more time at home during lockdown in Serbia. The findings regarding the positive aspects of this study are similar to the findings of the aforementioned studies. On the other hand, the positive outlook of parents has decreased gradually due to the lengthening of the lockdown, the uncertainty of when it will end, increasing care demands of children, and the difficulty of managing and balancing work and home life.

Another negative aspect of COVID-19 experiences that parents drew attention to is the fact that mental health has been affected. Their children have become lonelier, more withdrawn, and even attempted suicide. The findings of this study, which shows that the pandemic has a truly alarming effect on the mental health of individuals with ASD and their parents, are similar to the previous results (Asbury et al., 2021; Bozkurt et al., 2020; Rose et al., 2020; Stankovic et al., 2020; Toseeb et al., 2020). For example, Stankovic et al. (2020) reported that for Serbian families, there were changes in anxiety, worry, and stress-related behaviors in children with ASD. Parents raising children with ASD face more stress than parents with typically developing children (McStay et al., 2014). Such stressful situations can affect the quality of family relationships and sometimes make patient and empathetic parenting difficult. The primary sources of stress for children with ASD and their parents are staying at home during the pandemic, not being able to go to school most of the time, and working remotely with no clarity on how long the lockdowns would last or being unable to work (Asbury et al., 2021; Cluver et al., 2020; Pelton et al., 2020; Rose et al., 2020; Stankovic et al., 2020). As a matter of fact, trauma informed pandemic pedagogy highlights that the Covid-19 pandemic has disrupted our learning ecologies by causing trauma, anxiety and stress (Bozkurt, 2021).

The final adverse effect is difficulty with online distance education (also known as ‘emergency remote education’). The Education Information Network (EIN), a learning ecosystem used in primary education in Turkey, has the live connection features of synchronous video communication. Social networks were often used to create communication channels between students with ASD, their parents,
Table 5
Codes For Suggestions for Educators and Citations.

| Code                                      | Sample Coded Text                                      |
|-------------------------------------------|--------------------------------------------------------|
| Outdoor special education                 | “At least in the summer, they could probably provide special education, for example, outdoors. Instead of putting children in small and narrow rooms. They could do table activities on the garden cushions outdoors. They could also do activities with games (M2).” |
| Live course request                       | ‘Y.A. says, ’I also want distance education.’ When [his siblings] attended online lessons, he often said, ‘I wish my teacher did live lessons, too.’ The teacher just sent the lessons as messages. He said, ‘do these pages, do these things.’ We did it and sent it, but I don’t know how effective it was (M4).” |
| Regular course monitoring                 | “They put pressure on the student to follow the lesson. He wasn’t supposed to have been interested in anything else. I saw that they were holding the students a more accountable and were not relaxed. I saw that they were more disciplined. I like that (M2).” |
| Controlled face-to-face education         | “Actually, I want the school to open; class size could be reduced and they could be divided into days. Maybe 3 days and 3 days. In our class, there are 20 people. You could divide it into 10 people: 10 people go to school for 3 days and the other 10 people go to school for 3 days. Children would at least go to school instead of staying at home. It would be 3–4 h a day without staying at school for a long time (M3).” |
| Increasing school/institutional hygiene   | “I think hygiene and precautions should be followed more carefully because the socio-economic conditions of children who go to school are very different. It is very important. There is a risk of spreading the virus there (F1).” |
| School orientation studies                | “I think they should conduct studies on how to adapt these children to school again (M2).” |
| Social interaction-based education        | “I think academic skills can be provided somehow. However, social peer communication is very important. In other words, if face-to-face education could be initiated and face-to-face education doesn’t last as long, I would like them to focus more on lessons with social content or social interaction (F1).” |
| Suspending the grade                      | “My child received education that ended halfway through second grade. My child cannot benefit much from online education. He does not watch a lot because he is distracted. For example, I was thinking this. The grade could be suspended, but only for primary school. In other words, I would like them to continue where they stopped until normalization (M4).” |
| Reducing the class size                   | “Divide the class into two. For example, my suggestion for a class of eight people, while four children are attending the Turkish lesson, four children can receive the drama lesson (M5).” |
| Maintaining distance education            | “Well, if there are such restrictions again, it would be much better to have distance education. That’s because I think children with special needs, especially, cannot keep track of everything for both personal hygiene and distance, since they cannot think in detail like us. They cannot keep track of these details. Therefore, I think it is much healthier if they have distance education (M5).” |

Table 6
Codes For Suggestions for Healthcare Professionals and Citations.

| Code                                      | Sample Coded Text                                      |
|-------------------------------------------|--------------------------------------------------------|
| Accelerating vaccine studies              | “I’m waiting for Turkey’s health authorities to initiate vaccination in Turkey in the same way as in other European counties and the US or bring the vaccine from elsewhere and administer it (F1).” |
| Prioritizing the vaccine                  | “The vaccine is mentioned. So, if there is such a thing, I think that our children or children with chronic diseases should be vaccinated first (M4).” |
| Home health care service                  | “Well, for autistic children, it could be ensured that certain doctors are assigned to control children in such a way at home. I think this can be done. Because we are not talking about the general public, we are talking about children with autism, and they are special children. Therefore, if such a service is provided, it would be good for both families and children (M2).” |
| Remote counselling service                | “In terms of health, for example, there could be a psychological counsellor to whom we can talk and who can relax the child. So instead of always going to the doctor, there could be a person who could answer our questions… We sometimes have very depressing days in those troubled times. There should be services that could provide us with psychological support. There should be a number so I could call whenever I need to (M3).” |
| Remote health care service                | “Let me explain that lockdown period. The many times we got sick, we called our doctor on the phone, and he was very helpful. He helped us without going for a visit. So, I think that doctors can help in this way, without patients going to the hospital (M2).” |

Table 7
Codes For Suggestions for Decision-Makers and Citations.

| Code                                      | Sample Coded Text                                      |
|-------------------------------------------|--------------------------------------------------------|
| Secure internet use                       | “It has been recently shown on TV that TikTok is very harmful. I think our government should take measures regarding this. Young children should not be allowed to use such services. For example, some applications could be banned… They also watch horrible things on there. I cannot watch him all the time. Or access to them could be blocked (M2).” |
| Stretching curfew                         | “I was very sorry about this… Do you remember, special permission was given for children to leave the house since they were very bored at the beginning of the COVID pandemic. The permit was for people under 18, but there are children over 18. They didn’t do anything for them, nor was anything said. There are also autistic or spastic children at the age of 40. The people who looked after them were usually their parents. Their grandmothers, and so on. They could take children out; a study could have been done with them (M3).” |
| Increasing the sanctions                  | “The lockdown must be tighter. Thinking about these children, students… They were set free. They were let loose. I think that doctors can help in this way, without patients going to the hospital (M2).” |

…
teachers, and school administrators from pre-school to higher education. Although the continuity of education was ensured to some extent, there were common problems such as children not being able to stay in front of the screen for a long time and being unable to follow the lessons. Additionally, problems related to the internet, infrastructure, and digital competence weakened the motivation and belief in the effectiveness of online distance education. Some parents emphasized that face-to-face education was more effective for their children with the slogan “Interaction with peers, not with the screen!” They are very concerned about the gap between their children, who are already behind academically, and their peers has opened significantly. Distance education is experienced differently by each parent (Pikulski et al., 2020; Singh, 2020; Stankovic et al., 2020). This result is similar to the problems reported by a study of online emergency remote education, which provided a global perspective on the fact that education has been interrupted due to the COVID-19 pandemic in 31 countries and for 62.7% of the global population (Bozkurt et al., 2020). This shows that the trends in Turkey are similar.

The technological devices used for entertainment and recreation before the pandemic transformed into learning tools for distance education. This new use has not been easily accepted for educating children (Reich et al., 2020). The effort to keep students who do not have the habit of self-study in front of the screen under the pressure of adults has triggered the emergence of various problematic behaviors. These include closing oneself in the room, tantrums, and nail-biting; children experiencing difficulty spending their free time and not being able to express themselves sufficiently have resorted to violence (e.g., breaking a TV, kicking doors) or even have attempted suicide (e.g., throwing themselves off the balcony). In the literature, it is stated that these individuals can express the effects of being socially isolated and having difficulty in establishing distance social relationships in different ways (Pelton et al., 2020; Wright et al., 2020). Moreover, families have felt very alone and intensely helpless in dealing with problematic behaviors during the pandemic (Alexander et al., 2020; Courtenay & Perera, 2020; Rose et al., 2020; Stankovic et al., 2020). Social media has played an important role in creating an environment where parents who feel lonely can share their problems and exchange information. Social media has brought together parents, educators, students, administrators, and non-governmental organizations on common ground for cooperating and supporting each other in sharing materials, generating new knowledge, and creating support communities (Bozkurt et al., 2020; Waddingham, 2020).

In Turkey, as in the rest of the world, parents of children with ASD believe in the necessity of finding a vaccine and vaccination to get the pandemic under control. They state that children with chronic diseases and special needs should be given priority in vaccination. Another point emphasized by parents is that they need remote services to be able to consult for non-emergency illnesses or routine checks during lockdown, and especially for psychological support. Thus, Turkey’s Ministry of Health, which has not remained indifferent to such demands, has developed a remote visual inspection service application named the “Tele-health System” to reduce virus transmission and ensure that individuals at risk can access healthcare services without threatening public health (Ministry of Health, 2020). It is very encouraging that the study participants and families in similar situations have contributed to the development of such an application. Another point emphasized by parents is that they think that the sanctions applied during the pandemic are not sufficient and they recommend that decision-makers apply stricter sanctions. It is thought that this recommendation originates from the belief that the pandemic will end if the high level of attention they have shown during the pandemic is exhibited by everyone despite longing for old routines.

4.2. Parents’ perceptions and experiences regarding parenting skills

The changing roles and greater responsibilities of parents during the pandemic are another finding that should be emphasized. Extraordinary situations such as epidemics do not have a homogeneous effect on society. Every social layer or group feels their effects differently (Bozkurt et al., 2020). The injustice experienced in the family in terms of gender roles in Turkey has come to the fore once again with the pandemic (Budak & Küçükse, 2018). The workload of mothers has increased enormously. They must continue their professional life online in addition to the tasks mothers have traditionally been responsible for such as raising children, meeting the needs of their spouses and children, and maintaining the order of the house. During the pandemic in Turkey, women’s workload has increased four times more than men’s (United Nations Development Programme, 2020). This trend, which is not specific to Turkey, agrees with previous research showing that lockdowns have increased responsibilities of parents (Asbury et al., 2021; Bozkurt et al., 2020; Rose et al., 2020; Stankovic et al., 2020; Toseeb et al., 2020).

One of the most important effects of the global epidemic has been the change in the way of teaching and learning, that is, education. As a result of the closure of schools, students switched to distance education that requires home supervision. Parents suddenly had to take on a professional role as an educator in order to supervise or support their children at home and, most importantly, to ensure education continuity (Bozkurt et al., 2020; Tarbox et al., 2020). Thus, the World Bank aptly describes parents as the first-line responders for children’s survival, care, and learning (Devercelli, 2020). Students with ASD who stayed away from education for a long time or who could not obtain sufficient proficiency with online education needed more family support. The parental involvement literature has introduced that some parents took on new responsibilities in distance learning as they became more engaged in their children’s learning experiences, while others struggled with distance learning as it placed more pressure on them (e.g., Garbe et al., 2020). Studies in other countries and Turkey show that most parents could not allocate enough time to their children due to limited internet access, lack of knowledge with technological devices, difficulties in access to information, work intensity, and the presence of other children (Courtenay & Perera, 2020; Goldschmidt, 2020; Özer, 2020; Rose et al., 2020). Very few parents could turn this situation into an opportunity (Stankovic et al., 2020). Varying support levels led to inequality among students, which was an additional burden put on parents’ shoulders (Bozkurt et al., 2020; UNESCO, 2020). It is not easy to manage this process and ensure the continuity of learning in a crisis environment for parents who are trying to establish a sustainable balance between work and home even in normal times.
4.3. Limitations and implications

The study is limited to eight parents who have children with ASD. The severity of diagnosis may directly or indirectly impact parental satisfaction or dissatisfaction with caregiving. In this regard, one of the limitations of this study is a lack of information regarding the children with ASD’s verbal disabilities, diagnosis and determining their level of ASD severity and level of functionality. In an attempt to minimize the effect of wealth on parental dynamics, more detailed information about child characteristics should be reported in future research. In this study, there was an unbalanced ratio of female to male parent participants (7:1). New research could address this. Each parent went through different experiences and emotional states during quarantine so data collection from phone interviews might not be representative of all those different states for all families and children. This study aimed to explore parents’ perceptions through different lockdown experiences, but it would have been beneficial to understand the children with ASD’s perspectives on the pandemic. Future research could use longitudinal methods to understand the impact of pandemics on parents, children with ASD, and sibling dynamics. In addition to these issues, comparative experimental studies with control groups, including individuals with different disabilities and parents, could be carried out. When evaluating the findings, it should be considered that the data were collected in one country and different results may emerge depending on the cultural context in other countries. In line with this limitation, further studies in different cultural contexts could be planned.

CRediT authorship contribution statement

Gulden Bozkus-Genc: Study administration, Conceptualization, Methodology, Validation, Investigation, Data collection and analysis, Writing-original draft, Visualization, Resources.

Sunagul Sani-Bozkurt: Validation, Data collection and analysis, Writing-review & editing.

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