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# Immigrant family perceptions of virtual therapy for young children on the autism spectrum during the pandemic

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***ABSTRACT:***

*The COVID-19 pandemic has caused major disruptions in services for young children on the autism spectrum and their families. These impacts may be particularly pronounced for immigrant families who face unique challenges. In this qualitative study, we conducted one-to-one virtual interviews with eight Persian-speaking immigrant parents of young children on the autism spectrum who were receiving in-person behavioral therapy before the pandemic but who transitioned to virtual therapy during the pandemic. Families reported that challenging behavior was more frequent with longer duration after the transition to online instruction, they were less satisfied with services, and their children may have regressed on progress made before the pandemic. Meditation, counseling, and yoga were among the coping mechanisms reported for dealing with stress. We offer recommendations for how practitioners can be responsive to family perspectives, as well as how researchers can further investigate the impacts of the pandemic that are not yet fully understood.*

**Keywords:** Autism, Family stress, Challenging behavior, ABA therapy, Virtual therapy, COVID-19 Pandemic.

## INTRODUCTION

The COVID-19 pandemic created major disruptions globally in educational services for children. UNICEF reports that 131 million schoolchildren in 11 countries missed three-quarters of their in-person learning from March 2020 to September 2021, in which 77 million (59%) missed nearly all in-person instructions (UNICEF, 2021). These educational services disruptions translated into missed learning, socialization, and communication opportunities. Moreover, the disruptions affected the psychosocial services, including services for prevention, diagnosis, and counseling (Manning et al., 2021).

The impact of the pandemic was especially challenging for young children on the autism spectrum and their families who rely on early intervention and Applied Behavior Analysis (ABA) services (American Psychiatric Association. 2022). Children on the autism spectrum have deficits in social communication, as well as restricted interests and/or repetitive behavior (Diagnostic and Statistical Manual of Mental Disorders, 5th ed, 2013). Early intervention leveraging evidence-based practices is critical for improving these outcomes (Gabbay-Dizdar et al., 2022).

CEC Standards for Evidence-Based Practices (EBP) in Special Education (2014) consist of two sections: (1) Quality Indicators (QI) whether the study has an accurate methodology, including 28 QIs in Context and Setting, Participants, Intervention Agents, Description of Practice, Implementation Fidelity, Internal Validity, Outcome Measures/Dependent Variables, and Data Analysis; 18 apply to both group comparison and single-subject studies, 6 apply to group comparison studies, and 4 are specific to single-subject studies, and (2) standards based on sound studies. (Cook et al., 2015)

The National Professional Development Center on Autism Spectrum Disorder (NPDC) team created criteria to identify a study as an EBP with three standards: (1) Two high-quality group design studies conducted by at least two different researchers or research groups, (2) Five high-quality single case design studies conducted by three different investigators or research groups and having a total of at least 20 participants across studies, and (3) Combination of evidence which is One high-quality group design study and at least

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three high-quality single case design studies conducted by at least two different investigators or research groups (across the group and single case design studies (Steinbrenner et al., 2020). Several interventions grounded in the principles of ABA have been identified as evidence-based practices for children and youth on the autism spectrum, including naturalistic interventions, discrete trial training, and positive reinforcement (Steinbrenner et al., 2020). Evidence-based practices grounded in ABA, have been shown to improve communication, social, behavioral, and adaptive outcomes for young children on the autism spectrum across multiple rigorous experimental research studies (Steinbrenner et al., 2020).

During the pandemic, families have experienced disruptions in ABA therapy and a transition from in-person therapy to virtual therapy. (Pollard et al., 2020) state that contrary to in-person ABA sessions in which the therapist delivers the intervention and works directly with the client, the focus of virtual therapy is primarily on parent training (Pollard et al., 2020). Some challenges of virtual therapy are the inability to provide physical prompts and tangible reinforcement, and difficulty to address challenging behaviors. Therefore, the success of therapy often hinges on parents doing these things under the direction of the therapist (Glaser. 1978).

Because of the added demands on parents, virtual ABA therapy has the potential to introduce challenges for young children on the autism spectrum and their families. Although these impacts are only beginning to be studied, researchers have reported several initial findings (Koegel et al., 2014). First, researchers have found that parental stress and emotional well-being were negatively impacted by receiving less support during the pandemic (Alhuzimi, 2021). Second, while most parents of children on the autism spectrum reported extreme or moderate stress, families who reported the greatest stress most likely were parents of preschool children (White et al., 2021) or children with the most severe autism symptomology (Manning et al., 2021). Third, parents report specific elements of virtual therapy that are very frustrating for them such as dropped calls, unclear audio, and managing technology (Wagner et al., 2021) .

On top of these better-understood issues, there are additional challenges for immigrant families of young children on the autism spectrum. Ideally, families should access early intervention when their children are two years old (Hadders-Algra, 2021). Receiving appropriate therapy is time sensitive and requires familiarity with medical system requirements, which is especially challenging for immigrant families due to cultural barriers and stressors (Khanlou et al., 2017). Language as a barrier to in-person therapy can be exacerbated by transitioning to virtual therapy. In virtual interactions, it is challenging for families who are not native English speakers to implement strategies that they would utilize during in-person sessions, such as watching body language or imitating a model (Linstead et al., 2017). These factors make immigrant families a particularly compelling focus of research (Reinert et al., 2020).

This study contributes to the research literature by focusing on the unique experiences of immigrant families of young children on the autism spectrum, and asks the following research questions:

1. How do immigrant parents perceive the impact of virtual therapy sessions during the pandemic on challenging behaviors (i.e., self-injurious behavior and aggression) of children on the autism spectrum? What do immigrant parents perceive to be the reasons for these changes in children's challenging behavior?
2. In what ways has the transition to virtual therapy contributed to the stress of families?
3. How have families coped with these stressors?

## METHOD

We were recruited from the immigrant Persian-speaking community who live in the United States and are parents to at least one child on the autism spectrum. To be included, a parent must have (a) been more than 18 years old; (b) been Persian speaking (c) had at least one child aged 2-8 years old living in their household who received in-person ABA therapy for a minimum of 10 hours/week before the pandemic, with in-person services stopping during the pandemic (Remington et al., 2007)

Ads were posted on social media and among private groups that cater to Persian-speaking immigrant parents of children on the autism spectrum (Trougakos et al., 2020). The ads were a brief description of the project, inclusion criteria, and methods to respond. As potential participants responded, they were entered into a database and encouraged to help recruit other eligible participants (Shaw et al., 2021).

Eight Irianin mothers participated in this study. One (12%) participant had a bachelor's degree, four (50%) had master's degrees, and three (3%) had a Ph.D. Before the pandemic, three parents worked in educational settings (i.e., universities, and colleges), three at tech companies, and two at offices affiliated with civil engineering companies. During the pandemic 7 out of 8 parents (88%) started working from home, and one (12%) stopped working due to problems with her son's challenging behaviors (Yi & Dixon. 2021).

**PROCEDURE AND DATA COLLECTION:** The research was conducted by one interviewer who also translated the interviews from Persian to English. All interviews were conducted individually and recorded using the Zoom for further review. Interviews ranged from 28 minutes to 92 minutes, and participants received a US$15 gift card afterward. To reduce personal bias and maintain consistency we asked the same 40 questions, which were organized into six categories: (a) Children's history and family background; (b) Types of services children received

before and during the pandemic; (c) topography, frequency, duration, and severity of challenging behaviors before and during the pandemic; (d) benefits, challenges, and the perceived impact of in-person ABA therapy sessions and virtual therapy session on children; (e) change of routines and habits in children; and (f) comparing family's satisfaction of children's progress before and during the pandemic. The parent interview also included a section focused on their stress level as well as the spousal relationship due to new challenges they faced as well as coping strategies. These parents or any community members were not involved in developing the research question, study design, measures, implementation, or interpretation and dissemination of the findings.

**DATA ANALYSIS:** Data were analyzed using grounded theory. The data was codded by assigning numbers to each parent using three-step coding: In the first stage, we reviewed the interviews and provided transcripts to isolate the sections of participant responses most directly relevant to our research questions. We started our initial coding in this stage based on category identification. The second stage or intermediate coding was based on selecting a core category, by reading each transcript passage and using open coding to assign a code to a relevant participant response. Coded responses ranged from one or two sentences to several paragraphs. Next, we used axial coding strategies to identify themes and develop a set of code names and corresponding definitions addressing each of the research questions. In the final stage, we revisited the full transcripts we provided from interviews for each participant, using the framework developed in the second stage to assign a code to relevant responses both within and outside of our initially targeted interview sections.

## RESULTS

The participants were eight mothers with children on the autism spectrum, one was 2, two were 4, three were 5, one was 6, and one was 7 years old. Six were diagnosed with ASD Level 1 (i.e., requiring support) and two with level 2 (i.e., requiring substantial support; APA, 2022). All children received ABA therapy, some had occupational therapy, physical therapy, and speech therapy, and all were bilingual with Persian as their primary language. For additional details about the participants, see (Table 1)

**FIRST SIGNS OF AUTISM:** Participants had different experiences regarding the first signs of autism. Neda was concerned about her son when he turned 16 months and did not react to his father's interactions or to his own name: "when I was talking to him, he was reacting, but when his dad wanted to communicate, he had no reaction like he was not seeing him". He exhibited sensory problems, (i.e., tolerating clothes with soft fabrics), excessive interest to play with lights (i.e., turning the lights on and off), and watching the ceiling fan and washing machine. He received an autism diagnosis when he was 18 months. After starting immediate ABA services, he showed rapid improvements and started talking when he was 2 years old. Later he received an ADHD diagnosis, but no prescribed medication.

Mari noticed the first signs of autism when her son was 2 years old. He was nonverbal and had developmental delays. They received an autism diagnosis when he was 4 years old, and they started ABA at school when he was 5. Katie noticed her child's first signs of autism when he was 30 months, including no eye contact, playing alone, and sensory problems. They received an autism diagnosis when he was 35 months and started his ABA services when he was 37 months old. After this diagnosis, Katie experienced severe depression and started taking anti-depression medication. She expressed "I was in denial, was consistently asking myself: why my son?" Nazli's child was nonverbal till he was 3 years, and during infancy, he did not latch. He received an autism diagnosis at age of 3.5 years. It was very difficult for the family to accept it. Nazli said: "I could not believe he had autism. I thought he is just shy, and I did not tell anybody about it." It took 2 months for them to accept the new routine and start ABA services. Farah noticed the first signs of autism when her son was 18 months old and had a speech delay. He received his diagnosis at the age of

**Table 1**.
Description of Child's Participants.

| Participants | Child's | Child's | Autism level | Diagnosis age | Age of receiving ABA | Other services | Hours of ABA before pandemic | Hours of virtual ABA |
|---|---|---|---|---|---|---|---|---|
| **Name** | **Age** | **Gender** | | | | | | |
| **Neda** | 5.5 | male | 1 | 1 Y 6 m | 1 Y 7 m | OT, ST | 20 h/w | 10 h/w |
| **Mari** | 5.5 | male | 1 | 4 Y | 5 | ST, OT, FT | 20 h/w | 10 h/w |
| **Katie** | 7 | male | 1 | 2 Y 11 m | 3 Y 1 m | OT, PT | 40 h/w | 15 h/w |
| **Nazli** | 6 | male | 2 | 3.5 Y | 3 Y 7 m | OT | 20 h/w | 8 h/w |
| **Farah** | 4.5 | male | 1 | 33 m | 2 Y 9 m | ST, OT | 20 h/w | 5 h/w |
| **Sima** | 2.5 | male | 1 | 20 m | 22 m | ST, OT, PT | 10 h/w | 2 h/w |
| **Lili** | 5.5 | male | 2 | 3 Y | 3.5 Y | ST | 40 h/w | 15 h/w |
| **Ava** | 4 | male | 1 | 2 Y | 2 Y 3 m | OT, ST | 20 h/w | 10 h/w |
| OT = Occupational therapy. FT = Feeding therapy. ST = Speech therapy. PT = Physical therapy | | | | | | | | |

33 months, and they started ABA and speech therapy at the same time. Sima noticed her son was walking on his toes and his vocabulary regressed when he was 2 years old: "He was not able to say "car" or "play" anymore. He was just looking at me and waiting till I guess what he wants." When he started daycare, he was able to mimic the words and use them correctly, and eventually started talking. Lili's son did not react to his name when he was 18 months, knew few words, and had repetitive hand movements. Before immigration, when he was 2 years old, he was diagnosed with sensory integration dysfunction. Hence, they focused on ST, play therapy, massage therapy, and using medication. When he turned 3, he received an autism diagnosis and started ABA, which resulted in improving his communication skills. For instance, he started responding to his name, following directions, and singing songs. When he was 3.5 years they immigrated to the United States. This change delayed starting his therapies, and he stopped talking for 6 months. He was placed in a special education class and started his ABA sessions. He received an ADHD diagnosis and started using prescribed medication, which caused nose bleeding, and made him agitated. A psychiatrist changed the diagnosis from ADHD to anxiety, and they stopped the meds before the pandemic. Another participant, Ava, noticed that when she was talking to her 20-month-old son, he did not seem to understand her. He received an autism diagnosis when he turned 2.

**IMPACT OF THE PANDEMIC ON CHILD BEHAVIORS:** Parents were asked about changes in children's challenging behavior including topography, duration, frequency, and the setting where the behavior occurred. Our bounded time was before the pandemic and during the pandemic when the services were paused or switched to virtual therapy. For an overview of challenging behaviors before and during the pandemic, see (Table 2). Neda expressed that before the pandemic her son had self-injurious behavior (SIB) at home, in the park, and Lego store. She believed that the function of his behaviors was accessing tangibles. She explained, "If we wanted to leave the park or did not buy his preferred toy, he would hit himself". Before the pandemic, he was attending Karate and swimming classes, but they were suspended during the pandemic. He showed signs of regression in socialization skills and stopped interacting with others. Neda describes "he was in his own world again and was not interested to play with anyone". His screen time increased significantly from 30 minutes to 3-4 hours per day, and this affected his sleep and eating habits. He was struggling to adjust to the new routine of staying home for a long time which resulted in throwing prolonged tantrums. Neda explained, "before the pandemic, his meltdowns were lasting for 5-10 minutes, and after the pandemic, they continued for 20 minutes." Mari's son had limited dietary options. She described him as "a picky eater who would scream or vomit if nonpreferred

**Table 2**.
Description of Changes in Behavior.

| | SIB Topography | Duration/day | | Frequency/ day | | Setting | | AGG Topography | Duration | | Frequency | | Setting | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | BP | DP | BP | DP | BP | DP | | BP | DP | BP | DP | BP | DP |
| **Neda** | Self-hitting | 5-10m | 20m | 1 | 3 | Home<br>Store<br>Park | home | - | - | - | - | - | - | - |
| **Mari** | Nail biting<br>Arm biting<br>Feet biting | 1-2m | Till it was stopped | 5 | 10-Dec | home | home | hitting | - | - | - | - | - | school |
| **Katie** | - | - | - | - | - | - | - | Throwing objects | 5s | Till stopped | 01-Feb | 06-Jul | School | home |
| **Nazli** | Nail biting<br>Arm biting<br>Feet biting | 10s | Till it was stopped | 02-Mar | 07-Aug | Alone time | In front of TV | hitting | - | 1 m | - | 01-Mar | - | transition |
| **Farah** | - | - | - | - | - | - | - | Hitting | 30 | 3-4 m | 02-Mar | 07-Aug | school | Home<br>school |
| **Sima** | Head banging | 3-4s | 15-20s | 2 | > 3 | home | home | Kicking<br>Hitting | 3 | 10 | 01-Feb | 04-May | home | home |
| **Lili** | Head banging<br>Arm biting<br>Skin scratching | 0 | 5-6s | 0 | > 2<br>>3 | home | home | Biting<br>grabbing | - | 2-3s | - | 10-12s | - | Home |
| **Ava** | Head banging | 10s | - | 04-Jun | - | Home<br>daycare | - | Throwing<br>Crashing objects | - | 2m | - | 6 | - | home |

BP = Before pandemic. DP = During pandemic. SIB = Self-injurious behavior. AGG = Aggression

food was offered." Before the pandemic, they started a feeding program. Initially, he attended a self-contained preschool classroom and transitioned to an inclusive classroom, which Mari attributed to increased opportunities for social interaction. During the pandemic, his classes were switched to virtual, which Mari associated with an increase in challenging behavior. Likewise, during online therapy sessions, he was not comfortable sitting in front of the camera and was constantly muting himself, crying for his mother. Gradually, he developed self-confidence and started participating. His screen time increased from 1 hour to 4 -5 hours per day. Mari reported that his SIB got worse while he was watching TV. Before the pandemic, he was engaged in SIB for short periods (i.e., biting his arms and feet 5 times per day for 1-2 minutes). During the pandemic, the constant engagement in biting behavior was causing excessive bleeding, and he wouldn't stop until one of his parents physically prevented him. Before the pandemic, his favorite activities were Legos and painting, though during the pandemic he was not interested in them anymore.

Before the pandemic, Katie's child exhibited disruptive behaviors at daycare such as dumping peers' pencils, not listening to teachers, and not following school rules. Katie said that "we had to cancel camps due to his disruptive behaviors." They started ABA services when he was 37 months, and after 4 months, he started making meaningful sentences in English. He developed social skills, more awareness, joint attention, and expanded group work. The family decided to pursue intensive ABA therapy for 40 hours per week. But during the pandemic, his services were paused, then switched to virtual, and he regressed most of his social and adaptive behaviors. For instance, instead of calling his parents, he was punching the wall to get their attention. During virtual instruction, he did not like to attend online sessions or answer questions and even his handwriting regressed. His aggression worsened during the pandemic in terms of duration and frequency. Katie expressed, "before the pandemic, he was throwing objects at other people at daycare once or twice per day for almost 5 seconds, and during the pandemic, it increased to seven times per day at home and he would continue until I physically stopped him." Moreover, his favorite activities shifted from painting, Legos, and blocks to watching TV.

Nazli's child had severe receptive and expressive language deficits, processing sensory issues, and ADHD, though he did not receive any medicine. Before the pandemic, he was engaging in nail-biting behaviors, 2-3 times per day. During the pandemic, it increased to 7-8 times per day, and he would continue until he was distracted. Likewise, his daily routines such as attending athletic classes (i.e., gymnastics, swimming) were changed, and other behaviors such as socialization and following simple were regressed too. Another challenge was his sleep routine. Before turning 2 years old he did not take naps and woke up every 30 minutes at night. After starting ABA services, he developed a normal sleep routine. However, after the pause, he was awake until midnight and was waking up more frequently during the night. Nazli did not observe any regression in academic skills, though noticed a negative change in social behaviors: "He did not want to play with other children or let anyone touch him". He was more sensitive to sensory inputs, including sensitivity to lights, loud sounds, and specific fabrics. Before the pandemic, he was able to sit for a haircut, though during the pandemic, he threw tantrums and did not let his head be touched. Likewise, he regressed potty training. Before the pandemic, his favorite activity was playing with Legos and building blocks which switched to watching TV during the pandemic. Despite all these challenges, Nazli was happy to spend more time with her son and watch his speech improve.

Before the pandemic, Farah's son received ABA and speech therapies which were very effective, and his communication skills were improved. He started making sentences and expressing his needs. As Farah described "even though he was using simple words, it was clear what he was referring to. For instance, he liked massages on his back, and was saying back, to express the need". During the pandemic, his skills had a linear pattern, with no progress. Farah expressed, "he didn't learn any new skills, and his vocabulary didn't expand". Moreover, behaviorally he became more aggressive and was engaging in hitting behavior for gaining attention, tangibles, or playtime. Before the pandemic, this behavior used to occur 2-3 times per day for 30 seconds but increased to 7-8 times for 3-4 minutes during the pandemic. He did not have any change in eating habits, though he was less active during the pandemic. His screen time increased significantly from 1 hour to 4 hours per day.

Sima reported that before the pandemic, her son had two episodes of head banging for 3-4 seconds per day which during the pandemic increased to 3-4 times each for 30 seconds per day. She said, "after the pause, he was more aggressive and had longer and more frequent head-banging". The topography of his aggressive behaviors was kicking and hitting 1-2 times per day for 3 seconds which increased to 4 to 5 times for 10 seconds every day during the pandemic. Another concern of hers was her son's communication skills, as he showed signs of regression. She mentioned "his interest in playing and overall, his interaction with us decreased. Instead, he preferred to watch cartoons." His favorite activities shifted from Lego, letters, and numbers to open the doors.

Lili reported that "before the pandemic, my son was on sleeping aids, and after the pause, even by using the same medication and dosage, his sleep got worse". He was frequently waking up and had difficulty falling back to sleep. Due to lack of proper sleep, he was easily getting frustrated and was prone to engage in SIB. During the pandemic, by stopping ABA services for 2 months, he experienced more sensory dysfunction. He did not let anyone touch him,

scratching his skin, and was resistant to wearing clothes. Lili explained, "sometimes I had difficulty putting clothes on him, as he was resisting to keep them on". He started exhibiting SIB including hitting his head and biting his arm. The frequency and duration of his tantrums were also increased. She did not notice any change in her child's favorite activities.

Ava's concern was about her son's social behaviors. Before the pandemic, they started ABA therapy, focused on adaptive skills for 3 hours per day, which developed his communication skills. During the pause, his skills regressed. Ava expressed, "he did not know how to show his excitement when he saw other people. He was sitting next to the window and was screaming whenever a person was passing." Another challenge was his routines. When they started virtual therapy, he could not tolerate sitting in front of the laptop, listening to the therapist, and following directions. Ava described, "virtual therapy triggered novel challenges. He was running away, jumping on the sofa, and crashing the laptop when it was time for the virtual session."

## ANALYSIS

**CHALLENGING BEHAVIOR**: By comparing the data driven from our interviews and based on the protocol of grounded theory (GT), we concluded that parents perceived increases in challenging behavior and regression of skills that coincided with the changes during the pandemic, including disruption in ABA therapy and transitions to virtual therapy. Using GT, we generated a conceptual theory that accounts for a pattern of behavior that is relevant and problematic for those involved. Our theory states that the regressed social behavior and longer electronic exposures caused fewer physical activities which resulted in some changes in sleep and eating routines.

By switching from in-person ABA therapy to virtual, 6 out of 8 families (75%) experienced more aggression from their children toward family members. (i.e., hitting others with fists, biting, kicking, grabbing, and throwing objects), 5 out of 8 families (62.5%) experienced more SIB (i.e., nail-biting, skin chewing, head banging, biting fingers, and 3 out of 8 families (37.5%) noticed developing challenging behavior outside of therapy sessions (i.e., physical aggression toward other children, tantrums, and non-compliance). Participants attributed these changes to less in-person interaction (n = 8), a change of routine in therapy sessions (n = 7), and third less patience in sitting, staying focused, and working with a computer (n = 5).

All participants observed regression in communication skills and longer exposure to electronics. Parents increased screen time during the pandemic to entertain their children. Furthermore, children's daily schedules varied. Five out of 8 families (62.5%) experienced changes in eating habits. Four out of eight families (50%) reported that their child gained weight due to eating more in front of the TV or frequent snacking. Seven out of 8 families (87.5%) reported changes in sleep routines (i.e., bedtime was shifted from 8-9 pm to 10 pm-12 am). See (Table 3) for a summary of changes in daily habits.

Two families (25%) reported that their children developed anxiety when they were asked to respond to video calls. Three out of 8 (37.5%) participants reported more concerns about the limited hours of therapy sessions. For instance, one participant with a child on the autism spectrum level 2 was able to increase ABA weekly hours from 30h/week to 40h/week before the pandemic, though after the pause it reduced to 15h/week. Nevertheless, one family (12.5%) enjoyed being part of their child's therapy session, as they gathered more knowledge about it**.**

**Table 3**.
Change in Habits.

| | Sleeping habits | | Eating habits | | Physical activity | | Screen time/d | |
|---|---|---|---|---|---|---|---|---|
| | **BP** | **DP** | **BP** | **DP** | **BP** | **DP** | **BP** | **DP** |
| **Neda** | Normal | difficulty falling asleep, longer awakeness | Normal | Eating more | active | Moderate | 30m | 3-4h |
| **Mari** | Normal | longer awakeness, waking up late | Limited food | More limited | active | Moderate | 1h | 4-5h |
| **Katie** | Normal | Late and light sleep, longer awakeness | Normal | Normal | active | Not active | 2h | 6h |
| **Nazli** | Normal | frequent waking up | Normal | Excessive hunger | active | Moderate | 1h | 4h |
| **Farah** | Normal | longer awakeness, waking up late | Normal | Normal | active | Moderate | 1 | 4h |
| **Sima** | Normal | Normal | Normal | Contingent on TV | active | Moderate | 0 | 5h |
| **Lili** | Sleep aids | frequent waking up | Normal | Normal | active | Moderate | 1h | 4h |
| **Ava** | Normal | Late sleep | Normal | Frequent snacking | active | Moderate | 0 | 4h |

Active: more than 2 hours. Moderate: 1-2 hours of physical activity. Not active: physical activity less than 1 hour. BP: Before the Pandemic. DP: During the Pandemic.

**Table 4**.
Pandemic Related Difficulties.

| | Financial difficulties | Mental problems | Coping strategies |
|---|---|---|---|
| Neda | Lost her job | Anxiety, depression, fighting with the spouse | Counseling |
| Mari | Decreased income | Depression | Counseling |
| Katie | Lost her job | Depression | Anti-depressant medicine, weekly counseling |
| Nazli | Stopped working | tiredness | Counseling, Meditation |
| Farah | Decreased income | Depression | Yoga |
| Sima | Decreased income | Anxiety panic attacks | Melatonin for sleep, counseling |
| Lili | Decreased income | Anxiety Depression | Counseling |
| Ava | Decreased income | Depression, guilt, shame | Counseling, Yoga |

**OTHER PANDEMIC-RELATED STRESSORS:** In addition, we asked parents about other pandemic-related stressors. The themes are reported in (Table 4). A recurring theme was the loss of income or a change in working schedules. Many families indicated that they had a daily job routine pre-pandemic. They emphasized the importance of having a fixed income to structure their life and maintain their children's therapy sessions. One participant reported losing her job, and another had to quit her job to be able to stay with her child as a primary caregiver. Some families expressed that these financial hardships and having the whole family stay together made them more insecure and caused more tension between the parents, which negatively affected the children's well-being. This study revealed that immigrant parents with young children on the autism spectrum suffer from depression, and felt overwhelmed by working from home, dealing with children's therapy sessions, and their challenging behaviors. Hence, they expressed they needed to adjust their daily routines.

**COPING STRATEGIES:** Parents described needing to develop coping strategies to deal with the new difficulties directly related to the pandemic. These strategies were using a counselor, meditation, and yoga practices. All the participants who used counseling as a coping strategy described it as a very effective way to express their concerns with a third party without being judged. They strongly recommended using a counselor if feeling overwhelmed. It is more important for immigrant families as they don't have the help of family and a circle of friends. In some cultures, people are hesitant of using anti-depression medication as it is taboo or a sign of being mentally ill, though it is better to break the taboo and follow the path that helps them feel better. Likewise, yoga and meditation, helped them to control their mind and control the rush of unpleasant thoughts. They mentioned it was a few minutes that they could call "me-time", as they tried to free their mind and put the stresses aside.

## DISCUSSION

The COVID-19 pandemic has been disruptive to everyone but has had an especially negative impact on the lives of children on the autism spectrum and their families (Oomen et al., 2021). These families often depend on ABA therapy that promotes prosocial behavior and reduces maladaptive behaviors (Yi & Dixon, 2020). During the pandemic, families experienced less access to ABA therapy or transitioned from in-person to virtual services. These changes have posed challenges for families, and these challenges may be exacerbated for immigrant families who encounter additional cultural and language barriers (Yu et al., 2020). In this study, we interviewed immigrant parents of children on the autism spectrum who transitioned to virtual therapy services. We focused on parents' perceptions of their child's challenging behavior, its impacts on the family, and family coping strategies during the pandemic. Even though virtual therapy was challenging, parents felt that having the option for virtual therapy was better than not having any therapy at all. Parents experienced increased stress in their daily lives and needed some coping techniques. They mostly considered meditation and counseling as effective coping mechanisms to deal with the new situation. These findings extend the literature regarding how the COVID-19 pandemic has impacted young children on the autism spectrum and their families in several ways.

First, children on the autism spectrum are resistant to changes in routine. The interviews showed that parents felt their children exhibited more challenging behavior as a direct result of changes in therapy routines. These changes included having no direct in-person connection, therapists' different ways of delivering instruction and reinforcement and sitting for a long time in front of the screen for therapy purposes. Furthermore, shifting a mother's role from parent to therapist caused tension in child-parent relationships. Other factors related to increased challenging behaviors were children staying home, missing their extracurricular activities (gym, soccer, etc.), spending more time engaged with screens and electronic devices, and experiencing changes in sleep routines.

Second, the results of this research highlighted the psychological burden of the pandemic on families who have young children with autism and shed light on how the COVID-19 pandemic caused more stress in these families lives.In this study, all interviewed parents, except one, experienced increased stress in their daily life, due to this change of service, financial struggles, and dealing with an increase in their children's challenging behaviors.

Participants mentioned they tried a range of new coping strategies to handle the related stress. They used some technics like meditation to cope with the stress, although some struggled more and received counseling services, even referred to a psychiatrist for depression treatments. Due to lockdowns parents spend substantially more time with their children and were thus able to implement the interventions throughout their daily life. On the other hand, although parents reported that they made significant gains in their therapy skills, and some were more satisfied to be a part of their children's therapy program, it is unknown whether parent-implemented ABA services would lead to similar outcomes as therapists implemented ABA.

**IMPLICATIONS FOR PRACTICE:** Based on the results of this study, we make two recommendations for ABA providers, technical assistance providers, and parents. Both recommendations are not only applicable in the context of the pandemic, as the COVID-19 crisis has exposed and exacerbated issues that preceded and will outlast the pandemic. First, we recommend that therapists take proactive steps to empower families to be active in therapy during in-person sessions. This has multiple advantages; including enabling parents to support therapy outside of sessions, and putting families in a better position to support virtual therapy should a transition be necessary again in the future. When supporting immigrant families to actively participate in therapy sessions, we recommend looking for cultural differences and trying to fit into the family routines. To overcome the language barrier, we recommend using simple words, and less jargon. This will motivate the families to communicate with the therapy team. Second, we recommend that parents think about their health and well-being, which has a direct impact on their ability to support their child. This involves assessing their psychological health and stress levels and seeking help if needed by talking to a counselor or trusted friend or identifying an activity to reduce stress such as yoga or meditation**.**

**LIMITATIONS AND DIRECTIONS FOR FUTURE RESEARCH:** This study had several limitations. First, our sample size was small with 8 participants. Second, our participants were all Persian, and had young boys on the autism spectrum. Hence, conclusions from this study might not be generalizable to other cultures or other genders. In future studies, researchers might recruit families from diverse cultures and ensure that every gender is represented. Third, the data was collected through virtual interviews with the parents; hence, parents' perceptions of their children's behavior might be impacted by other unrelated stressors. In future studies, researchers might interview multiple respondents or gather data through live observation.

## CONCLUSION

The COVID-19 pandemic has created special circumstances in which parents of children on the autism spectrum experienced a new level of discomfort in their lives. This stress was partially related to the novel approaches to implementing required therapies. Virtual therapies and eliminated in-person therapy caused a change of routine in children's life and increased their challenging behaviors. Parents reported a decrease in social skills, an increase in disruptive behaviors, and longer daily exposure to electronics. This burden was particularly greater for immigrant families. Findings from this study highlight the challenges of immigrant families of young children on the autism spectrum. In many ways, the pandemic exacerbated challenges that already existed for these families in terms of communication and cultural barriers and points to new opportunities to study how to overcome these challenges both during and after the pandemic.

## CONFLICT OF INTEREST

Hereby, we confirm that we have no known conflict of interest to disclose.

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