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RESEARCH ARTICLE

Families of children with Autism Spectrum Disorder: Experiences during First COVID-19 Lockdown in Chile

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SUMMARY:
The lockdown due to COVID-19 pandemic brought a series of events that affected individuals, mostly related to mental health issues such as increased alcohol consumption, increased domestic violence and the emergence of psychiatric disorders. Children with Autism Spectrum Disorder (ASD) are particularly vulnerable, their routines were interrupted and professional help changed in this period. These situations were difficult to handle and adapt for children and their family.
This qualitative cross-sectional exploratory study examined the experience of families with ASD children who are enrolled in an ASD outpatient clinical university center in Chile during the first lockdown due to COVID-19 pandemic. Twenty individual semi-structured interviews recorded by video call were carried out by mental health professionals to parents of ASD children aged between 2 to 18 years old and were transcribed verbatim.
Using a Reflexive Thematic Analysis results display heterogeneity in the responses, with main themes related to: Information given, family changes, emotional/conductual changes in ASD children and relationship with social services. There was a balance between positive and negative perceptions. Several external family stressors increased while others disappeared during the lockdown. Both aspects should be taken into account developing more accurate services for ASD patients and their families.

INTRODUCTION

The rapid spread and high mortality rate of COVID-19 took the world by surprise. The fear of getting sick, the saturation of the health system, and the economic crisis are some of the problems that brought about an increase in stress levels in the general population. Additionally, lockdown measures were associated with a number of dramatic events, including increased alcohol consumption, increased domestic violence, and the onset of psychiatric disorders caused by extreme anxiety, depression, and post-traumatic stress (1) (2) (3). In this context, children and young people with Autism Spectrum Disorders (ASD) were a particularly vulnerable population. Tromans and collaborators investigated the main concerns during the pandemic of caregivers of these patients, highlighting the difficulty in accessing health services, the disruption of routines, the deterioration in mental health, the increase in behavioral imbalances and the over prescription of medications (4).

In Chile, the pandemic forced a decrease in outpatient health care, with only emergency cases being prioritized, and this contributed to decreased follow-up for patients with ASD. Health teams were forced to restructure their form of care, including in many places for the first time, remote medical check-ups, either by telephone or video call to avoid interrupting therapies (5); however, only one local study of the scope of these measures have been carried out in general clinical practice (6).

At the same time, the lockdown represented a major challenge for children and young people with ASD, who through a strict routine achieve greater control over their environment to obtain a level of emotional calm and minimize the occurrence of behavioral mismatches. The pandemic disrupted routines associated with attending educational and health centers and, furthermore, established a new repertoire of behaviors such as frequent hand washing and wearing a mask when leaving the house. These new elements may be uncomfortable for some children with ASD, causing adjustment difficulties for both the child and his or her family (7).

On the other hand, everyday situations, such as the movement of parents to work or attending school in person, disappeared during the confinement, generating opportunities to share with the family. Living in a pandemic period can also strengthen cohesion among members of the nuclear family to the detriment of external networks, such as the extended family or the community. In addition, increased time with caregivers may be accompanied by increased social support and can strengthen resilience (5).

The aim of this study was to describe the experience of the families of children in the ASD program at the San Joaquin Mental Health Center (CSMSJ), Pontifical Catholic University of Chile during the first lockdown period in Chile in the context of the COVID-19 pandemic.

METHODOLOGY

A qualitative, cross-sectional study was carried out. A sample of parents and/or caregivers was selected for convenience who were users of the ASD program of the CSMSJ. The children are incorporated into the ASD program after a multidisciplinary clinical evaluation with a diagnosis based on the criteria of the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (8) and evaluation results with Autism Diagnostic Observation Schedule, Second Edition. (9).

The primary caregiver of the children and adolescents was invited to participate in the study. Researchers sent invitations containing further information and consent forms via email.

Excluded from the study were children and adolescents in the process of diagnostic evaluation for the program and caregivers with any physical or mental disability that would hinder the interview by video call.

The data collection method was a 45 minutes length semi-structured interview based on a script previously prepared by the research team adapted from the Co-SPACE Study (10). The interview explored the effects of the pandemic on the mental health of children and adolescents directing the conversation towards the relevant aspects of the families' experiences during the lockdown period. The interviews were conducted from July to September 2020 (during a 4-month period of decreed confinement) by expert professionals of the ASD team via video call. The interviews were recorded with the consent of the interviewees and subsequently transcribed *verbatim*, protecting the confidentiality of the information.

Data were analyzed by thematic content analysis (11,12). The analysis required deductive coding based on the elements to be investigated previously defined in the interview, but also providing space through inductive coding for unexpected elements to emerge. The coding was carried out independently by four members of the research team using the QDA Miner® software. A

triangulation was subsequently carried out in which the relevance of individual encodings was discussed amongst the analysts to reach consensus. Once all the encodings were completed, they were reviewed again by a professional external to the initial research team with training in qualitative methodology to evaluate the rigor of the process and the consistency of the analysis.

This study obtained the approval of the Research Ethics Committee of the Faculty of Medicine, Pontificia Universidad Católica de Chile.

RESULTS

The sample consisted of 20 participants, with whom the theoretical saturation of responses was reached. Table 1 shows the sociodemographic characteristics of the sample.

Table 1. Socio-demographic characterization of the sample of caregivers interviewed

Cases interviewed	n: 20
Average age of child	9
- Youngest child's age	2
- Oldest child's age	18
Gender	Female (n:4) Male (n:16)
Pre-Pandemic Primary Caregiver	Mother (n:15), Father (n:6), Grandmother (n:6)
Primary caregiver during the pandemic	Mother (n:20), father (n:14)
Average age of the mother	41
Average age of the father	43
Caregiver's Educational level	University (n:9) Technical school (n:7) High School (n:4)
Residence characteristics	House with yard (n:13), Apartment with terrace (n:5), House without yard (n:2)
Families with COVID-19 (+) family member[s]	n:6

The largest group in the sample were parental primary caregivers in middle age, with higher education, residing in homes with a yard. A change in roles in caregiving was observed in which the main pre-pandemic caregivers were mothers often in the company of a grandmother, whereas during the pandemic lockdown, there was greater paternal participation and without support from grandparents.

Based on the contents of the interviews, 38 codes were identified and grouped into 12 thematic categories that at the same time were placed into 4 meta-categories (general themes).

Table 2: Codes and their density

Category	Code	N (n=20)	C/E	METACATEGORY Principal Topics
1. COVID Information	1.1. Talking to my child about COVID (and the emotions generated) 1.2. My child talks about COVID	25 9	1.25 0.45	COVID information
2. Emotions during the pandemic	2.1. Caregiver emotions 2.2. Child's emotions	44 26	2.2 1.3	
3. Positive changes in the child	3.1. Positive behavioral changes 3.2. Positive emotional Changes 3.3. Positive changes in routines 3.4. Positive changes in screen usage	17 5 16 1	0.85 0.25 0.8 0.05	Changes in the child
4. Negative changes in the child	4.1. Negative behavioral changes 4.2. Negative emotional changes 4.3. Negative changes in routines 4.4. Negative changes in screen usage	39 33 32 7	1.95 1.65 1.6 0.35	
5. Family and confinement	5.1. Positive family changes 5.2. Negative family changes 5.3. Care and nurturing 5.4. Family stress 5.5. Domestic Violence 5.6. Substance use. 5.7. Economic difficulties 5.8. Changes in diet/weight	42 26 35 62 8 16 21 16	2.1 1.3 1.75 3.1 0.4 0.8 1.05 0.8	Changes in the family group
6. Schooling and the Pandemic	6.1. Positive aspects of online schooling 6.2. Negative aspects of online schooling	20 41	1 2.05	
7. Therapies and COVID	7.1. Continuity of medical check-ups 7.2. Continuity of face-to-face therapies 7.3. Positive aspects of online therapy 7.4. Negative aspects of online therapy 7.5. Discontinuation of face-to-face therapy	4 0 11 12 16	0.2 0 0.55 0.6 0.8	
8. Social contact	8.1. Contact with family and relatives 8.1. Contact with friends	25 11	1.25 0.55	Interaction with social services during the pandemic
9. Leisure and Entertainment	9.1. Individual leisure and entertainment 9.2. Family leisure and entertainment	19 32	0.95 1.6	
10. ASD Exit Permits	10.1. Positive Experience with permit 10.2. Negative experience with permits 10.3. Did not have a certificate	12 4 3	0.6 0.2 0.15	
11. Community Support	11.1 Health support 11.2. Other Community Supports	8 9	0.4 0.45	
12. Overall Experience of ASD Families during Lockdown	12.1 Positive overall experience 12.2. Negative overall experience	21 14	1.05 0.7	
	Total	**742**	**37.1**	

The most cited codes observed in the inter-category analysis were those that made reference to *caregiver emotions* and to *positive family changes and family stress* (Table 2)

A repetitive experience of extreme negative emotions and high stress was perceived, but at the same time a reaction of reorganization of family dynamics, of more cohesion, of facing the challenge together was appreciated in several responses.

The 4 meta-categories (General Topics) are grouped as follows:

- COVID Information
- Changes in Children with ASD
- Family group
- Connection and Access to Social Services

Caregivers reported they attempted to deliver simple explanations regarding **information about COVID-19**, without alarm, while seeking to generate awareness for creating hygiene habits in their children, who in general responded with a sense of responsibility regarding these habits, as seen in table 3.

Table 3. Representative responses in COVID Information (Meta-category)

Category	**Code**	**Representative response**
1. COVID Information	1.1. Talking to my child about COVID	*"As a family we have tried to use what the specialists recommended by going down to their level and their type of understanding that is more concrete."* (**C10**)
	1.2. My child talks about COVID	*"He said, 'I don't want to go back because I can get sick and what happens if I bring the bug here'... he was scared because we live with grandparents here, and he's heard the news that they can suffer a lot, then he got scared."* **(C09)**
2. Emotions during the pandemic	2.1. Caregiver emotions	*"There are different moments when fear took over... many sensations that then stabilized, but then one feels other types of emotions when I want to go out, do the things I did before like shopping and walking. Of course, all those things like that give... I don't know a certain anxiety or fear or frustration, but they are moments. These 5 months we've been through different stages, emotions, moments. I have gone through everything from exhaustion, boredom, anxiety."* **(C14)**
	2.2. Child's emotions	*"He is very clear about it and is also angry with the coronavirus because his routine has changed a lot. Before he had many activities, the same routine of going to therapies and now he does not go out. He doesn't go anywhere. He complained, 'I can't go see my grandparents who are out in the country…' "* **(C12)**

Responses in the area of **Changes in Children with ASD** showed parents putting emphasis in both positive and negative changes. Within the positive changes, they reported greater autonomy in their children and the exploration of new skills (behavioral changes), changes in expressiveness, greater communication (emotional changes), greater participation in family and domestic activities (changes in routines), and hours use of screens. On the negative side, caregivers also reported increased problems with attention/ concentration, lower tolerance to frustration and greater rigidity (behavioral changes), lower capacity for emotional regulation and cases of aggressiveness (emotional changes), sleep and eating alterations (changes in routines), and the increased focus of attention towards screens. This is seen in table 4.

Table 4. Representative responses regarding changes in children with ASD (Meta-category).

Category	Code	Representative response
3. Positive changes in the child	3.1. Positive behavioral changes	*"In general she is doing super well. When we don't stress her, she is happy. She invents things... because before I did not see her playing or inventing stories. Now I see her grabbing her little stuffed animals and she starts putting together her own stories, and she plays... and even her voice changes, just like one does with her, changing the voice, and she does the same thing, which before she did not do. She was super literal."* **(C03)**
	3.2. Positive Emotional Changes	*"He's more extroverted. He was very introverted. Now he's striving to learn more things... and though he has a language and communication problem, he's communicating much better. We thought we noticed because we were more direct here, but we have received very good comments from the teachers ... who in the virtual classes ask him questions, and he answers them without problems then they themselves have been surprised.. and also he has been more participatory."* **(C02)**
	3.3. Positive changes in routines	*"We have more time to be together for lunch. At breakfast there has been more communication, more interaction. There ... with E.. amongst the family, between us with my husband and E. who talks a lot, then there has been more talking. The same with E. he suddenly interrupts. E. gets into the conversation in his own way, but he enters."* **(C06)**
4. Negative changes in the child	4.1. Negative behavioral changes	*"Yes, for him it has been complicated. He is very inattentive, very self-absorbed, as many things have been exacerbated by his autism that before went a little more unnoticed. Before he was less autistic, but now it seems he is more."* **(C10)**
	4.2. Negative emotional changes	*"These tantrums that have him uncontrolled sometimes, and sometimes he is so negative about himself: 'I will never be able to do it. I will never make it. This costs more than ten billion stars' and things like that, then it is complicated. It is exhausting to hear him talking like that all day."* **(C09)**
	4.3. Negative changes in routines	*"We started to give him sleeping medication and with that..., that's why D. had more regulated sleep. We regulated him. We also started to control the use of tablets and electronic devices."* **(C01)**
	4.4. Negative changes in screen usage	*"I don't know if addiction is the word, but he wants to spend more time with the screens and that for me is also negative, cell phones, computer. Now in my house we are not much screen-oriented, but he like seems to need that. I imagine that they leave this world a little while they use those things. I think that for me it's negative because they don't really contribute much."* **(C17)**

Regarding the **Family Group** topic, both caregivers and children described intense emotions such as fear, anxiety, irritability, anguish, and increased general sensitivity. At the same time, positive changes were mentioned related to the halting of activities outside the home (including multiple medical check-ups), such as improved communication and increased parental presence. The increase in the presence of the father figure in parenting is something unusual in Chilean households; however, it also meant for caregivers an increase in both (online) work and parenting

demands. This situation, added to the economic uncertainty and the effects of prolonged confinement, would be expected to cause an increase in family stress (linked to the emotions previously described), which in turn has been linked to episodes of intrafamily verbal violence (occasional), changes in diet and weight, increases in drug and alcohol consumption and specific economic difficulties. This is seen in table 5.

Table 5. Representative responses regarding Family group (Meta-category)

Category	Code	Representative response
5. Family and confinement	5.1. Positive family changes	*"(...) the youngest tells me 'Mom, we gained something in the pandemic that now we have breakfast and lunch together' and he says we regained the love we had."* **(C01)** *"I am more attentive to her, even in therapies, because in therapies the one that helped her the most was my husband, and I went 1 to 2 times a week nothing else. The other times my husband took her. I did not always get the permits to go every day, and then we had this dynamic, and now my husband is participating a little more."* **(C16)**
	5.2. Negative family changes	*"The combination of work and family life, that there are moments that complicate the plans. What gets all mixed up is that he needs attention and there is discomfort. It has [...] happened to us more than once that we started work meetings in the morning and ended at 6 in the afternoon and throughout the day we didn't see each other. It happened to me a few days ago and there are days -- not many thank God --that I don't see them all day, being in the house, then all the plans get confused."* **(C18)**
	5.3. Care and nurturing	*"It changed. For example I do online classes and Miguel is in the house, then we are both on top of I... and also the pandemic caught us at my mother-in-law's house, so we stayed with her, and it has been good company for her actually because she was alone."* **(C11)**
	5.4. Family stress	*"But yes afterwards I get tired... like I want to sleep. I want to lie down for a while and also I have very strong headaches. I want to get off, stop the world I want to get off."* **(C10)**
	5.5. Domestic Violence	*"My reaction of rage was to hit him. I spanked him 2 times. I don't know ... I scolded him, then I exploded without thinking about it. That's what happened to me several times."* **(C16)**
	5.6. Substance use.	*"Yes...we have been drinking, and I smoke cigarettes. I smoke in the morning now, before I didn't smoke in the morning."* **(C10)**
	5.7. Economic difficulties	*"The economic issue generates a lot of stress for me. Not receiving the same money as before and having to pay the same bills and more, because with the issue that one does not have the cash flow or liquidity to the same degree. Then we use the credit cards, but that must be paid later. In the end, we only postpone the problem or make it worse. Before we didn't use these lines of credit or credit cards, but now it is the only resource that we have to live off and I wouldn't want to stop her from doing her therapies."* **(C16)**
	5.8. Changes in diet/weight	*"It has cost us to stock up on food. If there is any change of habit, it is not voluntary. For example, I don't know, the bananas are gone, and they like to eat bananas, and it is difficult to go out to buy them. We can't just go out and get more, then we have to wait until the day of shopping to eat bananas, then in that sense, it isn't a voluntary change."* **(C17)**

Finally, with regard to **Connection and Access to Social Services,** it was generally observed that community support was scarce in relation to the demands that these services have meant for the families. Among them, schooling stands out as a space that demanded more work from caregivers, although the flexibility that the online modality allowed was also valued. Regarding health services, medical follow-up and online therapy, a total pause in face-to-face therapies occurred, but the continuity of communication with the treatment team was positively valued in Table 6.

Table 6. Representative responses regarding Connection and Access to Social Services part 1 (Meta-category)

Category	**Code**	**Representative response**
6. Schooling and the Pandemic	6.1. Positive aspects of online schooling	*"I see that A. has learned a lot with the help of her parents, perhaps this very personalized teaching for A. has served her. Because before when she was in school, we didn't sit down with the book to teach her and see what she did well. Now we sit with the book and see all the shortcomings that she has, or we give a lot of positive feedback when she does well and perhaps that has served her to want to continue studying."* **(C03)** *"The advantage of not going to school is that we avoided crises, which occurred because a colleague bothered him, because a colleague shouted in the room… that type of crisis that he had due to external factors... those we are avoiding."***(C14)**
	6.2. Negative aspects of online schooling	*" I am not a teacher, but I can help as far as that goes... Science ..I can't help with and in the humanist part neither. But I can help, and they know it, but no, I don't really like it and I also see that the children didn't like it either."***(C01)**
7. Therapies and the Pandemic	7.1. Continuity of medical check-ups	*"I still have contact by email with his neurologist, who also sees him in San Carlos and works nearby in the Sotero Del Río, so whatever happens I can go near here. He has sent me the prescriptions when I have not been able to contact Veronica who is the psychiatrist. She also sent me certificates for school."* **(C10)**
	7.2. Continuity of face-to-face therapies	-
	7.3. Positive aspects of online therapy	*"What is positive is that he likes therapy. It keeps him communicating, expressing his concerns to his psychologist who adores him, loves him, and keeps supporting him. He really feels supported in therapy and knows that for him it is necessary. Then, it is a tool for him, and he's aware of this and pays attention to what is happening with his therapy."* **(C18).**
	7.4. Negative aspects of online therapy	*"We are losing these benefits that the therapist could help us more on the face-to-face level, more behavioral, how to correct her. Of course, one becomes a co-therapist. But then it is different. I have months with this and with her and I already know how to do things, what activities, I get myself to do the didactic things that she needs. I do everything. But it is true that I am not the specialist because, then there are situations that I don't know how to handle. If it were face-to-face, she would treat her directly and correct her, without first going through me. I have to understand what she is telling me so I can apply it to my girl, and I get a bit confused."* ***(C16)***
	7.5. Discontinuation	*"They were paused from mid-March onwards, and we were going to resume the sessions in May, but my daughter got sick. Then, there we lost all contact, everything absolutely everything."* **(C17)**

	of face-to-face therapy	
8. Social contact	8.1. Contact with family and relatives	*"Communication has resumed a lot through WhatsApp, video calls...something I had lost with brothers and sisters. This pandemic has helped us to know each other. I have been more in contact with relatives, mom, brothers, ... I haven't seen my brother for 5 years and now we are back in contact."* **(C07)**
	8.2. Contact with friends	*"With friends too, more than anything else, video calls. We send videos. We like to play with these ...sending birthday greetings on videos, but that's been more than anything."* **(C18)**

Leisure was especially valued. As for the special permit (*) given for people with ASD, it was valued, but scarcely used, due to the fear of contagion. This is seen in table 6.

Table 6. Representative responses regarding Connection and Access to Social Services part 2 (Meta-category)

Category	**Code**	**Representative response**
9. Leisure and Entertainment	9.1. Individual leisure and entertainment	*"He plays all day with his little animals, organizes them, watches cartoons, jumps on the trampoline."* **(C20)**
	9.2. Family leisure and entertainment	*"We've tried on Fridays and Saturdays to get together to eat something nice and watch a movie. We've been watching series together. We've tried to have some together time. "* **(C08)**
10. ASD Exit Permits	10.1. Positive Experience with exit permits	*"Well because you notice right away that [going out] consumes energy, and with breathing another air he arrives calmer, more centered [...]. And with respect to the permit, we have been stopped only once and we had it."* **(C16)**
	10.2. Negative experience with exit permits	*"He asked me to go back home because he couldn't use the playground... the playground was closed."* **(C01)**
	10.3. Did not have a certificate	*"No, because I didn't have the certificates to prove that the children have what they have. We backtracked a bit to the previous point with D. I cannot go out just with Felipe. The truth is I have not invited him to do a little tour precisely because D. is going to see that one can go out and the other no. It's complicated. Maybe these are my own worries, and it may be that D. does not even have any interest, and that I could go out with Felipe, but I have not even tried, and besides, I don't have the certificates that prove that the children have ASD."* **(C09)**
11. Community Support	11.1 Health support	*"Yes, we got all the support in the health system. Also from now on, I have received from the Católica several emails that remind me that I have to see Dr. Jalil who is the psychiatrist of my eldest daughter. Now she will see her, [...] and they are as always attentive and giving these options that are better, not the most comfortable, but necessary, that are online."* **(C10)**
	11.2. Other Community Support	*"With regard to food and things like that, we've received care boxes from the government and from the school. A. is registered as a preferential student then this box from the Ministry of Education has arrived."* **(C05)**

(*) In Chile, the Ministry of Health created a special permit for children and adolescents who could demonstrate with a medical certificate that they have an ASD diagnosis. This permit allowed for the possibility of daily walks of limited duration, accompanied by an adult during the period of full enforced COVID lockdown. This permission was not given for other neurodevelopmental or medical conditions.

At the end of the interview, we asked parents to summarize the whole experience. Main responses are shown in table 7.

Table 7. Representative responses regarding Overall experience

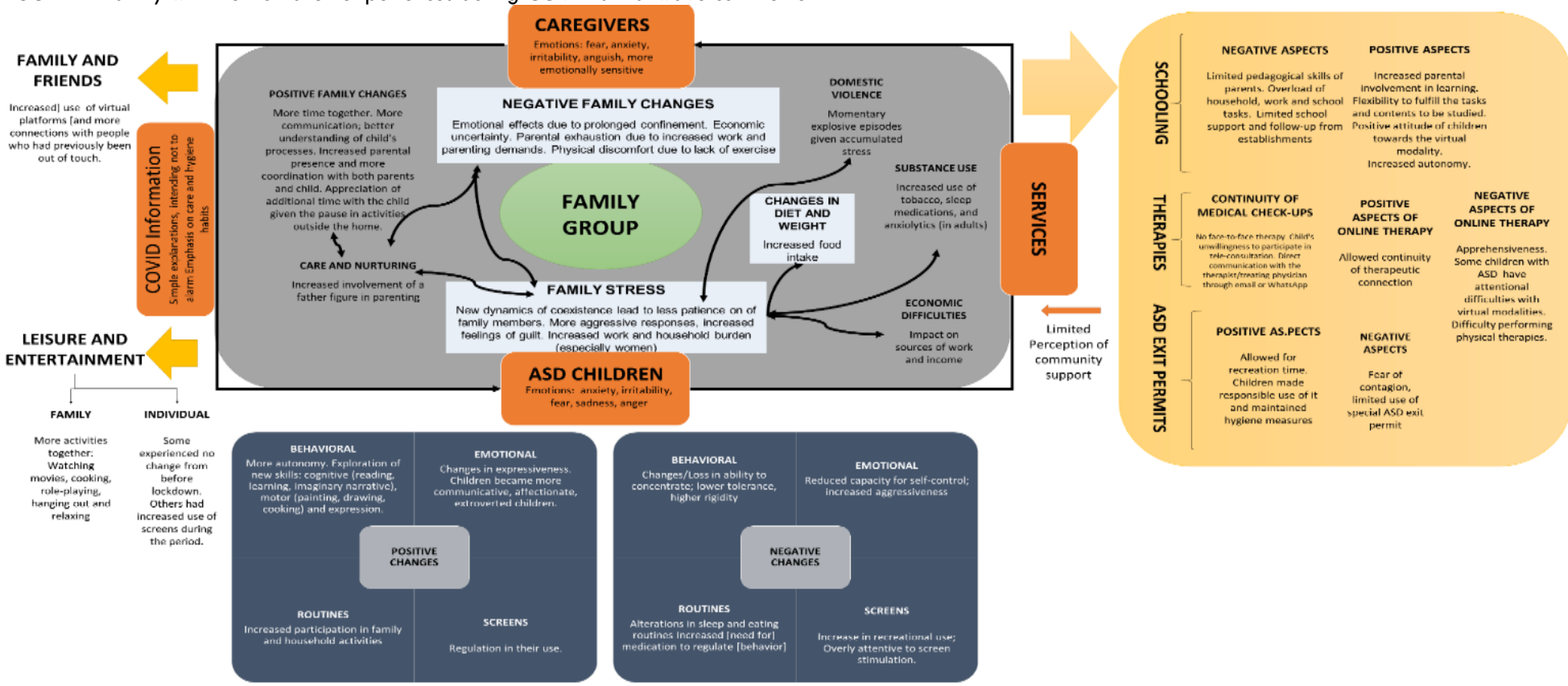
Category	Code	Representative response
12. Overall Experience of ASD Families during Lockdown	12.1 Positive overall experience	*"E. […] has matured more. We have been able to have more communication with her because we spend more time with her. Before it was my mother who spent more time with her. Now we all spend more time with her, and so we also understand her super well. Even though she does not have very fluid language, we understand her perfectly, yes in that sense...it's been great."***(C08)**
	12.2. Negative overall experience	*"Those anxieties this lockdown gives us with this pandemic are bad. Sleeping badly, being aware that the boy wakes up because he has a fright or you wake up early in the morning with the same feeling. Although before they went to school super early, in fact we get up much earlier. You notice fatigue, which is a different tiredness, which is a tiredness like in the mind then when you wake up like this, it is difficult to get going."* **(C10)**

The most cited codes observed in the inter-category analysis were those that made reference to *caregiver emotions* and to *positive family changes and family stress*.

A repetitive experience of extreme negative emotions and high stress was perceived, but at the same time a reaction of reorganization of family dynamics, of more cohesion, of facing the challenge together was appreciated in several responses.

The final product of this article is the concept map of **Figure 1**, which is a schematic representation of the most relevant aspects that emerged from the narratives regarding the experiences of families with ASD children during COVID-19 confinement. This scheme attempts to integrate the main codes collected from the responses of the parents and the main topics grouping them as sets and showing how they interrelate.

FIGURE 1: Family with ASD children experiences during COVID´s first wave confinement



DISCUSSION

This qualitative study shows that in general, parents perceived both positive and negative aspects of the pandemic and confinement in their homes during lockdown. Importantly, despite the difficulties of this period, parents with young children or adolescents with ASD experienced positive changes in family dynamics and witnessed favorable changes in areas of their child's development and behavior, and in their children's abilities to express themselves emotionally. In addition, team members observed that some changes that were implemented in an improvised manner during the period of lockdown were actually beneficial for some of our patients.

The increase in behavior problems and symptoms of anxiety suffered by children and adolescents due to confinement have been cited in the international and Chilean scientific literature. Some studies have highlighted that children with ASD are more vulnerable to confinement (15). In ours, parents reported that adapting to the changes required by lockdown was slow and that there were difficulties in installing new routines. The vast majority of children had difficulty falling asleep; many had to initiate pharmacological treatment for this purpose and others needed dose adjustment of previously indicated treatments. Sleep disturbances and the use of unprescribed medication was reported in other studies as well (16,17).Being forced to stay at home also generated difficulties on the part of caregivers in handling the use of screens, with parents reporting a significant increased focus on the stimulation provided by electronic devices, such as the PC, cell phones and video games.These challenges were also described in a study that interviewed parents to explores the experience of their children with autism during the lockdown, where many children exhibited an increase in ritualized behavior, bursts of anger and difficulties to fall asleep. This was also attributed to the discontinuity of their routines, recommending parents to help their children re-establishing new ones. (18)

In the parents' account, several comments on the benefits of this period of lockdown also stand out. Most relevant were having more family time and also recognizing the importance of sharing quality time among all the members of the household. This may be associated, in part, with parents positively appreciating the break they were given from having to transport their children to therapy sessions and the reduced academic demands. Parents mentioned a pre-pandemic daily routine overloaded with transporting their children to therapy sessions, to school, to work and other obligations, which left little free time for children and for enjoying shared family time. Evidence shows that travelling from place to place is associated with increased stress (19) whereas the confinement required by pandemic measures removed this risk factor from daily life.

Enjoying more family time might also foster children's social and cognitive development especially if part of this time is devoted to the interaction between the child and his or her parents (20). Interviewees frequently noted that they had more time to share and talk with the family, which gave family members more insight and a better understanding with respect to the processes of each. Likewise, greater communication and involvement between parents was mentioned, favoring for some a better parental coordination and a feeling of greater self-efficacy on the part of the main caregiver (4). There was a strong perception that confinement allowed the development of greater autonomy for the child with respect to the performance of domestic chores and self-care. This improvements were also found in other studies, where the authors believe this can be explained by having parents around to provide reminders (21). It is also relevant that the parents highlighted an improvement in communication with the child as well as noticing greater development of the child's verbal language. This could be explained by more cognitive stimulation on the part of parents towards their children or perhaps by greater parental attention to their children's development. (22). Along the same idea, it is interesting to note that despite the lack of support from the external network (the absence of external caregivers such as the grandmother or uncles) that could generate more family stress, (23) this was compensated by the greater presence of the father figure in the home with greater participation in parenting tasks. In Chile the presence of the father in children's upbringing is limited and exceptional (24). There was a high appreciation that the greater presence of the father allowed more possibilities for activities to be enjoyed together with the whole family. Most of these moments included activities such as watching movies or series together, cooking as a family, performing role-playing, among others mentioned. Recent publications underline that spending more time with the family members help in maintaining social development, reduce maladaptive behavior and benefit the general adjustment to stress (16).

This study was conducted during the fourth month of the first lockdown period in Chile. At this point, family stress was mainly due to the health situation, but also to economic uncertainty and job instability. All interviewees were affected by unemployment or

a lower family income. Working mothers were the most affected, as described in other studies (25, 26) both by the feeling of an overload in domestic functions and by the risk of unemployment. Reconciling the responsibilities involved in parenting and working was a strong stressor for them. These mothers reported having, on some occasions, less patience with their children, but there was little allusion to episodes of psychological violence between the parents. We can hypothesize that there may have been a bias in reporting, as this is a sensitive topic that perhaps caregivers would not talk about openly in a survey or study. Parents also did not report increased use of alcohol or substances but referred to increased use of non-prescribed anxiolytics.

Other negative factors experienced by parents were related to aspects of housing conditions. Frequently mentioned was the limited space for the family with everyone sharing the same environment (27). It was also noted the little private space for parents, which interfered with family dynamics (28). This was documented in other studies where families living in smaller households reported greater negative effects on their quality of life during the lockdown, suggesting that the social and physical environment in which families live may play an important role in the ability of autistic individuals and their families to cope with lockdown restrictions (29).

Although the literature specialized in education refers to the damages caused by the absence of face-to-face classes (11) our study shows that parents of children with special educational needs lived some aspects positively in the incorporation of online classes. The presence and now constant family coexistence allowed greater parental involvement in the learning process; they reported being more aware of the strengths and weaknesses of their children, which led to being able to support them in the most appropriate way, based on the particular needs they observed. One positive aspect noted in relation to this was the possibility of adapting the academic schedules according to the motivation and mood of the children, which allowed the parents to better guide the learning process. Other benefits described in online learning are personalized education, self-paced learning and enhanced time management skills (30). This led us to question which learning modality might be most suitable for ASD children in terms of the rigidity of schedules and the academic calendar.

On the other hand, there were many references to the complexities of online schooling where the greatest difficulties for parents were related to Internet connection problems, not having specific pedagogical skills for the online modality, and not having enough support or guidance from the school. Overall, parents experienced both challenges and benefits with regards to virtual learning. Even though studies in this area have increased, there is still not enough information on the effectiveness or efficacy of the virtual classroom provided by educators during the lockdown (16).

One worrying fact that stood out in the parents' responses was the limited continuity of treatments and face-to-face therapies, which had mostly been discontinued. Some children maintained an online intervention, but parents reported there was less therapeutic benefit with telemedicine compared to face-to-face therapies. According to the data from this study, the transition from face-to-face care to online interventions was difficult and slow. After four months of lockdown, the children remained without organized therapeutic support and without a clear perspective of when traditional interventions would be resumed. No explicit negative consequences regarding discontinuation of therapy could be described, but it should be considered that the lockdown process was only in its fourth month at the time of this study. Although the assessment of telemedicine and online therapies was not positive in general, the possibility of maintaining direct contact with the therapeutic team through the different platforms (video calls, online calls, emails, among other means) was valued. The interruption of face to face therapies, which was experienced worldwide, lead to less occupational, language and physical therapy for ASD children (31,32).

Finally, the daily exit permit offered by Ministry of Health was an exclusive benefit for a small number of people, including children with ASD. Despite being well valued, it was little used, which brings into question the implementation of public policies like this one. More communication with families about the use of this permit would likely have been beneficial.

STUDY LIMITATIONS

Given the exceptional phenomenon of study and the little international information regarding the mental health consequences in adolescents and young children especially in ASD populations, it is difficult to compare results; however, recent studies reflect experiences similar to those described in our study in other parts of the world. There are also self-report and memory biases in questionnaire-interview interactions, which can result in under-reporting issues such as domestic violence or situations about the family that may increase stigma.

The survey was conducted in the first COVID outbreak in Santiago and over the course of the first four months of quarantine. It is possible that responses are influenced by the time and timing of each family's confinement. Finally, we do not have information on the different levels of clinical severity of the patients involved in this study, which may interfere with and make it difficult to compare the experiences of each family during the pandemic.

CONCLUSION:

Despite the difficulties of living in a time of pandemic, parents were able to see this confinement period as an opportunity to spend more quality time with their family. What stands out is the perception that this period of confinement, with greater parental supervision, improved the sense of self-efficacy, which positively stimulated the emotional and cognitive development of children and was reflected above all by greater autonomy of ASD children in their homes. The confinement also resulted in a greater presence of the father in the home, which was positively valued by the family and generated a greater closeness of the father with his children. Working mothers were the most affected because they had the added pressure of juggling work with household chores and childcare. On the other hand, the positive aspects of online schooling suggest the importance of organizing face-to-face classes in a more flexible way and taking into account the moments of the day of greatest alertness of children with ASD.

Finally, this study made it possible to visualize the need and benefits of having multidisciplinary protocols for online intervention adapted to support children with ASD and their families. These protocols must have specific therapeutic objectives, agreed upon with the parents that can be implemented in a timely manner.

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