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ORIGINAL ARTICLE

Impact of COVID-19 pandemic confinement on the behavior of children and adolescents with autism spectrum disorder

Impacto del confinamiento en pandemia COVID-19 en la conducta de niños, niñas y adolescentes con trastorno del espectro autista

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What do we know about the subject matter of this study?

The COVID-19 pandemic has affected the personal and family functioning of autistic individuals. Determinants of child and adolescent behavior in the context of prolonged confinement are unknown.

What does this study contribute to what is already known?

It explores parental perceptions of the behavior of autistic children and adolescents during the COVID-19 pandemic confinement in order to determine risk and resilience factors and impact on different areas of individual and family functioning.

Abstract

Coronavirus disease (COVID-19) and confinement have affected access to the health system and have impacted people's mental health, particularly families of children with autism spectrum disorder (ASD). **Objective:** To investigate the perceptions of parents of children with ASD regarding benefits, positive changes, and difficulties in behavioral management at home during the first confinement due to COVID-19 in Chile. **Subjects and Methods:** We performed an exploratory cross-sectional qualitative study including 118 parents of individuals with ASD aged between 2 and 15 years. An online questionnaire, prepared by a multidisciplinary committee of national experts using Delphi methodology was applied, which contains four open-ended questions related to children's behavior (difficulties, improvements, benefits, and professional support required) during the pan-

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demic. **Results**: Parents perceived that confinement increased emotional stress for adults and children, which could exacerbate behavioral problems. The interviewees perceived improvements in child social-affective, individual autonomy, and communication skills. The family and resilience aspects, such as time-sharing that emerged during the pandemic to support children's needs, were appreciated. Parents also reported the need for professional support in behavioral and emotional management during confinement. **Conclusion**: Caregivers value the integration of the family into therapies during confinement. It is necessary to complement these results with additional studies exploring different life contexts of families with children with ASD in Chile and the impacts of long-term confinement.

Introduction

The 2019 coronavirus pandemic (COVID-19) has generated a global impact through both direct and indirect consequences. Within the latter, infection control measures, including mass confinement, are a crisis scenario from a mental health perspective, generating emotional stress exacerbated by the population's feeling of uncertainty. The literature shows that confinement is associated with increased alcohol consumption, increased reports of domestic violence, and the emergence of psychiatric disorders such as post-traumatic stress disorder and mood and anxiety disorders[1]. In this context, autistic children are particularly vulnerable, as they are more susceptible to domestic violence and caregiver neglect[2,3].

Locally, health control measures were gradually implemented, including the suspension of face-to-face academic activities and the start of online classes, limitation of mobility, and reduction of outpatient care (including mental health and neurorehabilitation services), focusing health care resources on COVID-19 cases[4,5]. These changes suddenly and drastically affected family functioning and individual routines (home confinement, suspension of face-to-face classes, implementation of online classes, frequent hand washing, and use of masks), enhancing difficulties in the management and adaptation of autistic children[6,7].

Based on the above, there is a need for research to understand the effects of social distancing on the mental health of the autistic community. The objective of this study is to explore the perceptions of a group of parents of autistic children and adolescents treated in a therapeutic center specialized in neurodevelopment conditions regarding the difficulties in managing behavior at home during the first confinement due to COVID-19 in Chile, as well as the benefits and positive behavioral changes that may have occurred during this period. Through a qualitative model, we attempted to identify risk and protective factors related to the behavior of the children studied, from the caregiver's perspective, to provide baseline evidence to guide new hypotheses and interventions in similar contexts in the future.

Subjects and Method

1. Study design and participants

Qualitative, cross-sectional, exploratory study with purposive sampling of parents of children and adolescents with a diagnosis of autism spectrum disorder (ASD), aged between 2 and 15 years, users of the Neurodevelopment Unit of the Health Network UC-CHRISTUS between January 2018 and March 2020 (N = 152). Diagnosis of ASD made by neurology or psychiatry according to DSM-5 criteria[8] and scoring above the cut-off point on the Autism Diagnostic Observation Scale, version 2 (ADOS-2)[9]. Patients with a known diagnosis of Down syndrome were excluded due to the particular family, school, social, and therapeutic challenges presented by this population.

Participants were invited by email to answer the online questionnaire using Google Forms, during the confinement period from August to October 2020 after informed consent. This work was approved by the ethics committee of the *Pontificia Universidad Católica de Chile* (N° 200617027).

2. Instrument

A questionnaire based on the research by Colizzi et al.[10] was applied, which was modified by a multidisciplinary committee of national ASD experts according to the Delphi method to validate the content and adapt the relevance with two rounds of online consultations and a consensus of more than 80%[11]. This questionnaire collected behavioral information on autistic children during the first period of confinement due to COVID-19. The instrument consists of 56 multiple-choice questions on clinical and sociodemographic characteristics of the target population, used in a previously published paper[12], and four open-ended questions that are the ones primarily used in this study, which allowed us to explore the caregivers' perception of the

positive and negative aspects of their child's behavior in the context of the pandemic.

Question 1: What difficulty or problem with your child's behavior has been most difficult for you as parents to manage during this COVID-19 pandemic time?

Question 2: During the COVID-19 pandemic, what aspects of your child's behavior do you feel have improved?

Question 3: What aspect during the quarantine has been beneficial for your child?

Question 4: During the pandemic, what type of help would you like to access to manage your child's behavioral difficulties?

3. Data Analysis

A qualitative inductive analysis of the caregivers' written responses to the open-ended questions was conducted using a grounded theory method. All data were processed anonymously.

An expert researcher external to the leading team performed the categorization of the responses obtained to ensure confidentiality and an unbiased approach to the analysis. The analyst manually created emerging categories from the responses provided by the caregivers. The ATLAS.ti software was used to support the categorization and coding process. The categories were subjected to individual review by expert clinicians independent of each other, for thematic analysis of the content and relevance of each one of them, to reach consensus on them. The analysis was the basis for the decision to present question 4 in a differentiated form, recording the count of support requested by the respondents in the context of the COVID-19 pandemic.

Results

Of 152 participants who met the inclusion criteria, 118 (77%) participated by answering the questionnaire (Table 1). All answered the first 3 questions, while the fourth question was answered by 98%. The significant material analyzed reached 100% of the respondents' answers, ensuring information saturation and that the answers to each question began to repeat and did not allow for the formulation or consideration of new categories.

According to their characteristics, the responses to the first three questions were associated with a category (Table 2) and a particular subcategory, organizing the adult's recurrent responses to each question with a category. Subsequently, the information was cross-checked, highlighting the most recurrent contents (behaviors) by category and subcategory. After the analysis of the 10 categories, 7 concentrated most of the parents' answers, whose content reports relevant aspects related to the pandemic experience, reflecting perceptions of the children's behavioral difficulties and beneficial aspects of the confinement period in the relationship with their children. Table 3 shows the literal transcription of some of the responses provided by the participants.

1. Cognitive domain

A greater proportion of responses highlighted positive aspects of the children's cognition, perceiving improvements in responsibility and organization, sustained attention, mental flexibility, symbolic play, imagination, and interest in various activities. The interviewees perceived they had more time to share and support the children in their school challenges during the confinement. The most significant difficulties in managing the cognitive domain were related to the need for more interest in performing tasks or following orders and respecting the screen use schedule.

2. Emotional domain

In general, parents mostly perceived difficulties in the emotional area, referring to it as a challenge in school situations, the performance of daily activities, and family interactions. Responses regarding hetero-aggressive and self-injurious behaviors and difficult-to-manage emotions standed out, including anxiety, frustration, impulsivity, irritability, fear, emotional lability, and apprehension. According to the caregiver's perception, triggers for these disturbances included family arguments, change of activities, getting a negative response, frustration, and resuming school activities. Despite the unfavorable perception of this area, eleven references for improvement or benefit were detected, indicating a decrease in irritability, anxious symptomatology, and impulsivity in the child during confinement.

3. Social-Affective domain

In this category, a positive perception of the pandemic experience was identified, reflected in the greater time shared with the family, which is perceived as a factor promoting close relationships between adults and children. Improvements standed out in aspects related to affectivity and attachment of children to their parents, valuing contact with the family nucleus, and "family time." Only seven references to handling difficult social situations for adults related to uncertainty on health and the duration of confinement were detected.

4. Communication

Parents mostly perceived that their child's communication improved during the confinement. Responses related to non-verbal communication reflected an

improvement in the spontaneous communicative intention observed, and those related to verbal language showed improvement in speech, phonetic, and pragmatic elements of language. There were no references to difficult situations to handle in this area.

5. Behavior

There was a predominance of a negative perception of confinement on children's behavior. Parents perceived difficulties related to the intensification of routines and mental rigidity, oppositional or disruptive behavior, behavioral dysregulation, and transient loss of sphincter control. There were only nine mentions of behavioral improvement or benefit in this area.

6. Personal autonomy

The overall perception of the parents was positive, reporting improvement in the individual autonomy of the children, referring to actions that they did not perform before confinement, such as dressing and going to the bathroom on their own, eating without adult help, performing manual fine motor activities, individual grooming, and self-regulation of playtime. There were only six references to difficulties in managing this domain.

7. Parental Empowerment

Parents' perception is mostly positive, stating that the pandemic favored having more time to work with their children on school issues and participate in their emotional management. Parents perceived themselves as facilitators in the emotional management of their children. Only two mentions referred to difficulties

Table 1. Sociodemographic characteristics of the sample

Characteristic	n (%)
Age in years, median (IQR)	6 (4-8)
Sex/gender: male	94 (79.7)
Age in years at diagnosis, median (IQR)	3 (2.4)
Respondent	
Mother	90 (76.3)
Both parents	21 (17.8)
Father	7 (5.9)
Children living with	
Both parents	90 (76.3)
Mother only	23 (19.5)
Father only	2 (1.7)
Other adults	3 (2.5)
Residence type	
House with garden	83 (70.3)
Apartment with backyard or garden	27 (22.9)
Apartment without backyard or garden	7 (5.9)
Other residence type	1 (0.9)
Only child	53 (44.9)
Therapy before the pandemic	110 (93.2)
Therapy during the pandemic	67 (57.3)
Mother's employment status	
Home-based telework	49 (41.5)
No pre-pandemic paid work	33 (28.0)
Face-to-face work	17 (14.4)
Other	12 (10.2)
Pandemic-related unemployment	7 (5.9)
Father's employment status	
Home-based telework	46 (39.0)
Face-to-face work	43 (36.4)
Pandemic-related unemployment	14 (11.9)
No pre-pandemic paid work	4 (3.4)
Other	11 (9.3)
Number of individuals living at home, median (IQR)	4 (3.4)

Table 2. Definition of categories evaluated with the survey

Categories	Subcategories according to respondents' answers
Cognitive Domain[a]	Mental processes of perception, memory, language, calculation, information processing, concentration, logical problem solving.
Emotional Domain[a]	Affective processes involving emotions and feelings.
Social-Affective Domain[a]	Actions including contact and interaction with parents, siblings or other relatives, but not exclusively.
Communicational Domain	Situations mentioned by parents alluding explicitly to verbal or nonverbal communication.
Behavioral Domain	Situations mentioned by parents alluding to behaviors that may have different causes: unobvious physiological or emotional maturity/immaturity or other reasons.
Personal Autonomy Domain	Referred to mentions revealing changes in the ASD child's initiative or self-management during pandemic.
Parental Empowerment Domain	Expressions showing initiatives and changes in the way parents deal with the child during the pandemic quarantine period. Not prescribed or complementary to those suggested by therapeutic team.
Feeding Domain[b]	Food intake or related habits.
Circadian Domain[b]	Situations mentioned by parents alluding to the sleep-wake cycle.
Physical Domain[b]	Body activities, physical contact, or health situation reported by parents.

[a]Most emphasized categories of parental responses. [b]Categories with insufficient data for analysis.

Table 3. Response of parents according to survey category (Domain): positive and negative aspects perceived by respondents

Domain	Responses given by respondents (non-exhaustive list)	
	Positive aspects	Negative aspects
Cognitive	"His concentration in class is better than in face-to-face classes if I am next to him." "Since everything is online, it is a relief not to have complaints from the school." "Concentration on his homework." "Flexibility in the face of change." "I have been able to teach her what she finds difficult to understand at school."	"Her irritable behavior and lack of tolerance, she gets frustrated when she does not understand the lessons. Since these are not targeted specifically for her." "That my child understands that you can't go out in the street with the freedom and safety you used to." "Screen times." "The use of screens." "The schedules of technology use."
Emotional	"Learning to "get bored" a little." "Being more time with the whole family at home has helped her be more settled and less anxious."	"Tantrums and hitting are mainly associated with changes in television programs or something not to his liking." "He has had some episodes with disruptive behaviors, but it was difficult to control a period of breaking things." "Uncontrolled and aggressive reactions to what he doesn't like." "When frustrated, he hits his hands to his head with clenched fists or says he wants to die." "Self-harm." "Depressive symptoms, self-harm and suicidal thoughts." "That when we don't give him what he wants, he hits himself." "Anger and tantrums that come out of nowhere." "Mood swings have been greatly aggravated, as he screams, hits doors and walls." "Aggression and screaming." "Anxiety and tantrums when parents must return to work."
Social-Affective	"He is very affectionate." "The attachment with his parents." "We have more closeness; I have learned to know him more and handle him better." "He is more affectionate." "It has done her good seeing us at home; she is more playful and has developed many role-plays." "She is playing more with her younger brother of 3 years." "He is more connected with the family." "Relationship, she avoids people and relatives less." "Both parents being present and participating in his activities and routines." "Sharing more time with his parents and still accepting the confinement." "Spending more time as a family allows us to understand and get to know my son's likes and dislikes." "Spending more time with him since we both work." "Spending more time with his parents daily."	"Not letting him go out and share with other children." "He misses his grandparents a lot." "Talking into a microphone in front of peers." "Not face to face." "Becoming aware of his differences concerning his peers, seeing them all face to face on a screen." "Always sat in the first seat in front of the teacher; she did not see them." "Her anxiety about the uncertainty of the pandemic."
Communicational	"Eye contact and non-verbal communication." "He has improved speech." "Speech, her initiative, and way of interacting." "Language development (oral expression)." "Functional communication in expressing and communicating her needs and feelings." "Her communicative behavior with me (mother): she is learning to differentiate and communicate better when angry, sad or anxious." "Eye contact and language." "Communication with her family, as she has increased her word count during this time." "She has more eye contact." "Learning to communicate better, more efficiently." "Expresses emotions verbally and bodily, language is more fluent speaks in more sentences, asks more questions, tells stories."	No negative aspects
Behavioral	"Beginning of sphincter control." "Abiding by clear rules." "Sphincter control." "Gave up diapers and is also imitating a lot."	"Rigidity of behavior." "More defiant." "Maintaining routine activities." "Sphincter control." "Crying spells, lasting much longer and becoming more frequent." "Also, his oppositional behavior increased."
Personal Autonomy	"Goes to the bathroom alone and tries to get dressed." "He goes to the bathroom alone and cooperates in getting dressed. He has become more autonomous, independent." "Entertaining herself alone and doing her classes online, more independent." "Independence, eats alone, cuts and paints alone, dresses, brushes her teeth, helps at home, (making the bed, folding clothes, etc.); about three months ago, she participates alone in her classes, orders her toys, among other things." "She is self-managing in several aspects (good things and mischief)." "Waking up on her own and having her playtimes." "Self-confidence."	"Lack of autonomy." "He became more dependent; since March, he sleeps with me; he is very pampered." "He has become more dependent on us (his parents)."
Parental Empowerment	"The fact that the mother is at home has allowed me to support him more in his activities and therapies." "We have had time to work on many sensory aspects and independence." "By being at home, I can control his emotions when he cries or doesn't want to do something." "He has learned a lot with me how to read, adapted his homework for him, I look for pictures for him."	"Boredom on his part by not being able to share much with him because we are teleworking since he sees us, but we can't give him 100% attention."

in the ability to support their children due to work-related reasons.

8. Answers to Question 4

Regarding the help they would have liked to have had during the pandemic period, the interviewees cited 18 preferences, of which occupational therapy was the most mentioned, followed by child psychology, speech therapy, and psychology for parents (Figure 1). Within the specific needs, they mentioned in decreasing order support for general behavioral management, exacerbations of behavioral disturbances, and implementation of routines.

Discussion

The purpose of this study was to explore the perception of parents of autistic children regarding the management of their children's behavioral difficulties at home during confinement and to describe the benefits and positive behavioral changes during this period.

According to the categories, the main negative references mentioned by parents during this period are related to the emotional and behavioral domains. The main difficulties described were hetero-aggressive and self-injurious behaviors and difficulty in respecting the rules established by the parents, in many cases accompanied by symptoms of emotional dysregulation, irritability, and anxiety. These findings are consistent with the results of Esentürk, who hypothesized that stress and anxiety during the pandemic could increase behavioral problems in the pediatric population with ASD[13].

When analyzed by category, it is observed that parents' perceptions of difficulties in the behavioral and emotional domains of children are related to the aids they would have wanted to improve their children's behavioral management during the pandemic period (question 4).

Similar to what has been reported in the literature[14,15], the results of this study show that parent-child interaction positively impacts the development of cognitive, communication, and social-affective areas in autistic children from the caregiver's perspective. Parents during the pandemic perceived themselves as more empowered and confident in their relationship with their children, with a greater ability to solve school and communication challenges. These elements were possibly favored by the high percentage of children living with both parents, which could facilitate caregiving.

Consistent with previous studies[16,17], another positive aspect that could be observed in the parents' reports is that the external factors that generated anxiety before the pandemic (school exposure, bullying, social contact) disappeared during confinement, suggesting a benefit of the flexibility of the school schedule and balance between the online and face-to-face classes, according to the needs of each individual.

The available literature on families with autistic children shows that the disruption of routine due to confinement is associated with behavioral changes in the child and family discomfort[2,3,6,13,18]. Our interviewees' responses contrast these data showing a positive perception of family dynamics with a high valuation of the family and its ability to adapt during the

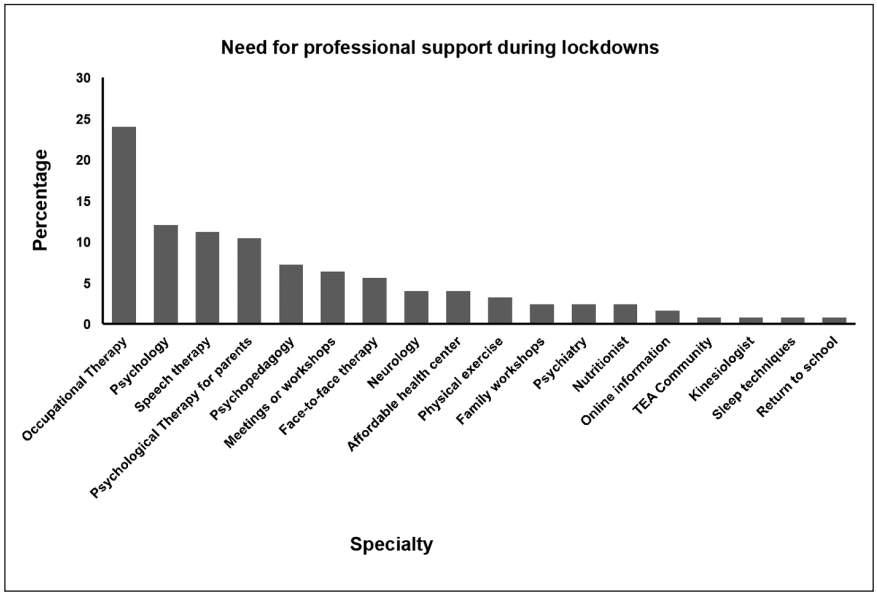

Figure 1. Relative frequency of caregivers' perception of the need for professional support during lockdowns.

pandemic. It is clear from the reports that because of the confinement, there were spaces for family sharing, behaviors favoring the autonomy of children in daily life activities, and that the parents took advantage of this time to support them in school and emotional aspects. However, no specialized external support to strengthen parenting skills was reported, which probably has repercussions on the need for therapeutic counseling expressed by the caregivers, specifically in behavior management.

A relevant aspect to highlight is the perceived lack of time to interact with the children before the pandemic due to work obligations and commuting routines, which was highlighted by the confinement. Parents state that the quarantine period gave them more family time to carry out activities with their children, improve communication between members, and support their children's needs. According to the analysis of the categories, parents attribute to the time shared with their children during the quarantine a role as a favoring factor in the improvement of cognitive, emotional, socio-affective, behavioral, communicational, and personal autonomy-related aspects. These findings complement a previous study in which parents of autistic children value family-child interaction in physical activities as a support for children's social development[13].

Approximately half of the children evaluated discontinued neurodevelopmental therapy during confinement. Interviewees report occupational therapy support as the main professional need, suggesting parental prioritization of therapeutic interventions focused on organization and behavior management. Occupational therapy is perceived as a significant support for the emotional well-being of children and parents, reducing emotional stress in the latter and helping them to better manage their behavior. This finding is consistent with previous studies concerning caregiver support and well-being needs[14,16]. Therefore, it is likely that, for families with autistic children, online occupational therapy care focused on counseling caregivers during confinement is an effective intervention tool for behavioral difficulties and improves family functioning[17,19,20]. Additionally, in periods without confinement, online interventions could reduce the commuting time required by parents to take their child to a professional, maintain treatment in cases with limited mobility, and improve adherence. It could be positive to include therapeutic sessions remotely to the usual face-to-face interventions[10,16,20].

The main limitations of this study are related to the application of the questionnaire during a specific period of the COVID-19 pandemic in Chile, and it may be possible that the caregivers' perceptions may change over time. Due to the nature of the survey, it was not possible to provide feedback on the individualized results to the participants. The researchers are from neurodevelopmental and mental health units, so the focus of the questions is primarily clinical; however, the categories assessed were generated by an external researcher distant from the data, based on literal transcriptions of responses provided by parents. Although data on socioeconomic factors were not collected, we obtained data on the type of residence, which could approximate this dimension, but it is still a limitation. We also did not investigate the specific effect that schooling before the pandemic may have had on the users evaluated.

Although online surveys on health issues usually have a relatively low response rate[21], a strength of our study is that over 75% of the participants answered the 4 questions proposed. In addition, the questionnaire was administered at a time when the participants had already experienced confinement for a continuous period of months, which lends credibility to our findings.

It is necessary to complement the information obtained with additional studies exploring different realities of families of autistic children in our country.

Conclusions

Parents of autistic children generally perceived a higher frequency of emotional dysregulation and disruptive behaviors in their children during the period of confinement. However, they report positive changes including increased time-sharing, parental empowerment, and progress in areas of child autonomy development and communication. Given our findings, family time should be considered in the planning of interventions for autistic children, both at the health and school levels.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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