

Original Article

Perception of caregivers of preschool children with ASD on their behavior and occupational performance during the COVID-19 pandemic

Percepção de cuidadores de pré-escolares com TEA sobre seu comportamento e desempenho ocupacional durante a pandemia da COVID-19

Maene Pinheiro Silva^a , Rosangela Gomes da Mota de Souza^a , Karina Ferreira de Oliveira^b , Ana Amélia Cardoso^a , Livia de Castro Magalhães^a 

^aUniversidade Federal de Minas Gerais – UFMG, Belo Horizonte, MG, Brasil.

^bTerapeuta Ocupacional, Divinópolis, MG, Brasil.

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Abstract

Introduction: Children with Autism Spectrum Disorder (ASD) face behavioral, sensory processing, cognitive, and language challenges that affect their ability to perform activities of daily living (ADL) and necessitate access to educational, therapeutic, and health services. The COVID-19 pandemic limited access to these essential services, exacerbating the challenges faced by this vulnerable population due to imposed social distancing measures. **Objective:** To explore the perceptions of parent caregivers of preschoolers with ASD regarding their children's behavior and performance in ADL during the COVID-19 pandemic. **Method:** This cross-sectional, descriptive study utilized both quantitative and qualitative approaches, interviewing 60 caregivers of preschoolers with ASD. Participants were asked about any observed changes in their child's behavior and ability to engage in ADL during the pandemic. Child characterization involved the Autism Classification System of Functioning: Social Communication (ACSF:SC), the Pediatric Evaluation of Disability Inventory - Computer Adaptive Test (PEDI-CAT), and the Sensory Profile 2 (SP-2). Interviews were documented, with 15 recorded and transcribed for thematic content analysis. **Results:** Participants included 43 mothers, 15 couples, and two fathers, totaling 60 children, of whom 46 (76.7%) were boys aged between 3 and 5 years (mean age 53.6 ±10.18 months). Caregivers reported changes in behavior and performance in ADL, predominantly noting deterioration. Increases in stereotypic behaviors, rigidity, and hyperfocus were observed, along with decreased participation in ADL. While the presence of caregivers benefited some children, it also led to reported stress, particularly among mothers.

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Conclusion: The study found a predominant trend of deteriorating behavior and performance in ADL among children with ASD during the pandemic, based on caregiver reports.

Keywords: Social Isolation, Autism Spectrum Disorder, Caregivers, Family, Activities of Daily Living.

Resumo

Introdução: Crianças com Transtorno do Espectro Autista (TEA) podem apresentar questões comportamentais, no processamento sensorial, na cognição e na linguagem, que afetam seu desempenho ocupacional, necessitando de acesso a serviços escolares, terapêuticos e de saúde. O acesso a esses serviços esteve restrito durante a pandemia de COVID-19, tornando essa população particularmente ainda mais vulnerável às restrições sociais impostas à época. **Objetivo:** Descrever a percepção dos pais cuidadores de pré-escolares com TEA acerca do comportamento e desempenho ocupacional de seus filhos durante a pandemia da COVID-19.

Método: Estudo transversal, descritivo, quantitativo e qualitativo baseado em entrevistas com 60 cuidadores de pré-escolares com TEA. Os participantes responderam à seguinte pergunta: Você está notando alguma diferença no comportamento e desempenho da criança durante a pandemia? Para caracterização das crianças, foram utilizados o Sistema de Classificação de Funcionalidade no Autismo: Comunicação Social (ACSF:SC), o Inventário de Avaliação Pediátrica de Incapacidade – Teste Adaptativo de Computador (PEDI-CAT) e o Perfil Sensorial 2 (SP-2). Todas as entrevistas foram anotadas e 15 delas foram gravadas e transcritas. O material foi submetido à análise temática de conteúdo.

Resultados: Foram entrevistadas 43 mães, 15 casais e dois pais de crianças com TEA. Das 60 crianças, 46 (76,7%) eram meninos, com idade de 3 a 5 anos (53,6 ± 10,18 meses). Os cuidadores perceberam mudanças no comportamento e desempenho ocupacional, com prevalência de relatos de piora. Houve aumento nas estereotípias, rigidez e hiperfoco, bem como menor engajamento nas atividades cotidianas. A presença dos cuidadores beneficiou algumas crianças, mas há relato de estresse, especialmente por parte das mães. **Conclusão:** Houve variação nos relatos, com maior tendência à piora no comportamento e desempenho ocupacional das crianças com TEA.

Palavras-chave: Isolamento Social, Transtorno do Espectro Autista, Cuidadores, Família, Atividades Cotidianas.

Introduction

Because of outbreaks in various regions worldwide, the World Health Organization declared COVID-19 a pandemic in March 2020 (Organização Mundial da Saúde, 2022a). This declaration triggered the implementation of public health social measures to limit the disease's spread. These measures included wearing masks, adapting or closing schools and businesses, restricting public and private gatherings, limiting community movement and public transport use, and international travel, alongside a recommendation to stay at home (Organização Mundial da Saúde, 2022b).

The risk of illness, requiring protective confinement and social isolation, often leads to heightened stress levels for parents and caregivers. This makes epidemics or pandemics potential threats to child development, constituting an adverse childhood experience that can result in toxic stress (Araújo et al., 2021). A systematic review addressing the impact of social isolation during the pandemic on child and adolescent development revealed direct consequences of confinement, including depressive symptoms, loneliness, anxiety, sadness, and guilt, as well as a high frequency of worry, helplessness, fear, and nervousness (Almeida et al., 2021). Prolonged social isolation can affect the health of both children and adults because of increased risks of issues like sedentarism, obesity, hypertension, hypercholesterolemia, and diabetes. Moreover, isolation can impede the learning of new skills such as speaking, writing, and reading, affecting academic performance and socialization (Almeida et al., 2021).

Children and adults with pre-existing psychiatric diagnoses were particularly vulnerable to the restrictions imposed during the COVID-19 pandemic (Lugo-Marín et al., 2021). Families with members who have disabilities faced unique challenges (Givigi et al., 2021) as usual support from schools, day services, or respite care was disrupted (Courtenay & Perera, 2020). Among these families, those with children with Autism Spectrum Disorder (ASD) found themselves in a particularly vulnerable position because of the constant need for therapy or school support, which was limited during the pandemic (Dal Pai et al., 2022).

ASD is characterized by persistent deficits in communication and social interaction, along with restricted and repetitive patterns of behavior, interests, and activities. These symptoms appear early in development and significantly impair social, professional, or other important areas of functioning (American Psychiatric Association, 2014). Programs for this population generally aim at improving socialization and behavior organization, with structured routines and encouragement of social interaction. Literature reviews indicate data heterogeneity regarding the pandemic's consequences for individuals with ASD (Alonso-Esteban et al., 2021; Dal Pai et al., 2022). According to some studies (Alonso-Esteban et al., 2021), the effects of social isolation on individuals with ASD are contradictory, showing cases of increased stress, anxiety, stereotypic behaviors, and challenging behaviors due to heightened emotional regulation difficulties, but also cases of decreased psychopathological symptoms, except for anxiety. Behavioral and sleep issues among children and adolescents with ASD worsened during the COVID-19 pandemic, with the most frequently observed behavioral changes being anxiety, irritability, hyperactivity, stress, aggressive behavior, and the worsening or emergence of new stereotypic behaviors.

In addition to behavioral issues, problems in sensory processing, and perceptual, cognitive, and communication skills, which are common in individuals with ASD, can affect occupational performance and restrict participation, impacting the development of these children (Beheshti et al., 2022). Regarding occupational performance, the priorities of mothers of children with ASD relate to self-care, productivity, and leisure, in that order of importance (Beheshti et al., 2022). The development of children with ASD is facilitated through supportive environments, such as schools, play, and therapies, which gradually challenge their

social skills. However, access to these environments was limited during the pandemic period (Bellomo et al., 2020). It has also been observed that the pandemic negatively affected the mental health of parents of children with ASD, who went to great lengths to better support their children because of restrictions in face-to-face education, social activities, and the support of health services and child monitoring (Yılmaz et al., 2021).

The COVID-19 pandemic slowed the gains in child health, highlighting the underinvestment in health systems and inequalities in access to these services, entrenching social inequalities, and underscoring the importance of all countries prioritizing policies aimed at children (Bhutta et al., 2022). Studies that seek to understand how the COVID-19 pandemic impacted child development can contribute to guiding preventive strategies and promoting healthy development (Araújo et al., 2021). In this context, understanding how the pandemic may have influenced occupational performance, skill acquisition, and children's behavior—to highlight the daily challenges faced by children with ASD and their families—can assist in directing public policies aimed at this population, as well as guiding professionals in helping families adapt to the post-pandemic context and other situations of social isolation. Therefore, this study aimed to describe the changes observed by caregivers of preschoolers with ASD and analyze their perceptions regarding the behavior and occupational performance of their children during the COVID-19 pandemic.

Materials and Method

This is a cross-sectional, descriptive, quantitative, and qualitative study based on interviews with caregivers of preschoolers with ASD. A secondary analysis of research data aimed to investigate the relationship between social communication, performance in activities of daily living (ADL), and sensory processing in preschoolers with ASD. This study was approved by the ethics committee of the aforementioned institution under approval number 4.197.803.

Participants and location

Participants were children aged 3 to 5 years and 11 months diagnosed with ASD and their caregivers, recruited from offices and clinics specializing in developmental disorders. Initial recruitment was conducted in person; however, because of the pandemic's progression, it became necessary to shift to online recruitment. This change enabled the inclusion of participants from various locations. Inclusion criteria for the children were: (a) age between 3 years and 5 years 11 months; (b) diagnosis of ASD made by a neuro-pediatrician or child psychiatrist, following the DSM-5 criteria (American Psychiatric Association, 2014); (c) consent from parents/caregivers to participate in the study, evidenced by signing an Informed Consent Form (ICF). Children without a physician-confirmed diagnosis of ASD were excluded.

Instruments

To characterize the participants, caregivers completed a demographic and socioeconomic questionnaire. Given the heterogeneity among children with ASD, the following instruments were used: Autism Functioning Classification System: Social Communication (AFCS:SC), Pediatric Evaluation of Disability Inventory – Computer Adaptive Test (PEDI-CAT), and Sensory Profile 2 (SP-2). Additionally, open-ended interviews were conducted to gather caregivers' perceptions of their children's behavior and occupational performance during the pandemic, which was the focus of this study.

Demographic and socioeconomic questionnaire

A questionnaire was developed by the researchers to collect information on the children's sociodemographic characteristics (age, gender, type of school, parent's education level, family configuration, etc.), birth conditions (weight, gestational age, and any relevant complications), school situation, and clinical issues (diagnosis, date of diagnosis, medication, therapies, etc.). The Brazilian Economic Classification Criteria (CCEB) (ABEP – Associação Brasileira de Empresas de Pesquisa, 2019) was utilized, classifying families into eight categories based on education level and ownership of consumer goods: A1, A2, B1, B2, C1, C2, D, and E, with A representing the highest economic level and E the lowest.

Clinical assessment instruments

The AFCS:SC (Di Rezze et al., 2016a), translated into Portuguese (Eloi et al., 2019), was used to classify the social communication of preschoolers with ASD into five levels: Level I – initiates and maintains interaction, expands beyond their interests, but has difficulty changing topics; Level II – initiates and responds with social goals, expresses interests but has difficulties changing topics; Level III – responds to simple questions but does not sustain communication; Level IV – attempts to respond to people they know, but may not respond to strangers; Level V – communication is understood only by primary caregivers (Di Rezze et al., 2016b).

The PEDI-CAT (Haley et al., 2012; Mancini et al., 2016) described the functional status of the children, allowing classification of functional performance in four domains: everyday activities, mobility, social/cognitive, and responsibility. The normative score, with scores between 30 and 70, indicates performance within the expected range for the age group.

The SP-2 (Dunn, 2017) identifies sensory processing difficulties, strengths, and weaknesses, offering insights into daily performance and behavioral issues (Mattos et al., 2015). Average scores in the sensory processing quadrants reveal tendencies toward exploration, avoidance, sensitivity, or registration, with high scores in any quadrant associated with behavioral challenges.

Question on caregiver perceptions in the pandemic context

To gather qualitative data on caregivers' perceptions of children's behavior and occupational performance during the pandemic, we posed the following open-ended question: "Have you noticed any differences in your child's behavior and performance during the pandemic?"

Procedures

Data collection

Initially, we identified potential participants at offices, clinics, and schools serving children with ASD in two medium-sized cities in the central-west region of the state of Minas Gerais, Brazil. These cities were chosen because of professional connections that facilitated access to treatment institutions and families during the pandemic. Caregivers were approached either in person or by phone at these institutions. We explained the study's objectives and procedures, and those who agreed to participate signed an ICF. Subsequently, we scheduled face-to-face interviews. As pandemic-related restrictions intensified, we expanded our recruitment online by posting invitations on social networks and the interdisciplinary extension program's Instagram page supporting individuals with ASD. Consequently, we transitioned to an exclusively online interview format. This approach enabled us to reach families from additional regions within the state of Minas Gerais, as well as in the states of São Paulo, Rio de Janeiro, Rio Grande do Sul, Santa Catarina, Alagoas, and Sergipe. Data collection occurred between October 2020 and March 2021, coinciding with the social isolation measures in Brazil.

Face-to-face and virtual interviews were arranged at times and locations convenient for the caregivers. Each session began with a demographic questionnaire, followed by standardized questionnaires and scales, all administered by the researcher. The session concluded with a qualitative question. For online interviews, we maintained the same procedures and instruments, scheduling sessions in advance via Google Meet or another suitable video calling platform for the family (e.g., Skype or Zoom).

The first author conducted all aspects of the data collection, which lasted between one and a half to two hours. Regarding the open-ended question, initial responses were documented in writing to ensure accuracy and fidelity to the caregivers' reports, with a final check to confirm the notes accurately reflected their statements. With the shift to online interviews, we sought approval from the Ethics Committee to record responses to the open-ended question for easier documentation. After approval, the remaining 15 interviews were both noted and recorded. These recordings, along with notes from 60 interviews, were entered into an Excel[®] spreadsheet for categorization. The recordings were transcribed verbatim, including grammatical and pronunciation errors, without corrections. This compilation formed the qualitative dataset. Following each interview, we scored and interpreted the AFCS:SC, PEDI-CAT, and SP-2 questionnaires. Brief reports on the children's performances were then emailed to the parents.

Data analysis

The quantitative data, including participant characteristics and children's performance assessments, were coded, tabulated, and organized in Excel[®] spreadsheets. Descriptive analysis was conducted, calculating mean and standard deviation for numerical data and simple frequency for nominal data.

The material resulting from the interviews—notes and recordings—was transcribed and analyzed through thematic content analysis, involving the following steps: pre-analysis of the interview material through floating reading; exploration of the material to identify categories and select recording units; processing the results and constructing inferences (Campos, 2004; Minayo, 2014).

The material resulting from the interview notes was categorized into: noticed or did not notice any difference (yes/no); occupational performance; behavior; other reported aspects. The material from the recordings was analyzed considering the caregivers' perceptions of two aspects: behavior and occupational performance. In analyzing the materials from both the recorded interviews and the interviewer's notes, the Occupational Performance category was subcategorized according to the classification of occupations by the American Occupational Therapy Association (2020): Activities of Daily Living (ADL), Health Management, Rest and Sleep, Education, Play, and Social Participation. The behavior category was subcategorized based on the behavioral characteristics of individuals with ASD described in the DSM-5 (American Psychiatric Association, 2014): stereotypies, rigidity, hyperfocus, aggressive behaviors, stress, nervousness, impatience, irritability, hyperactivity, anxiety, agitation, crying, crisis, sadness, frustration, boredom, comfort, happiness, and calmness. Other aspects identified in the recorded interviews and reported by caregivers that did not fit into the previous categories included: communication, motor coordination, and screen use.

Results

Participant profile

Caregivers of 60 children with ASD were interviewed: 43 mothers, 15 couples, and two fathers. All children had been diagnosed with ASD and had an average age of 53.6 ± 10.18 months; 46 (76.7%) were boys. Of these, 40 families were recruited in person – 23 from private clinics and 17 from public institutions for individuals with ASD. Twenty families were recruited online, residing in the states of Minas Gerais (11), São Paulo (4), and one in each of the following states: Rio de Janeiro, Rio Grande do Sul, Santa Catarina, Alagoas, and Sergipe. Most caregivers had completed higher education – 66.7% of mothers and 46.7% of fathers. The majority of the interviews (71.6%) were conducted solely with the mother present. Although the male caregivers present in the interviews accounted for 39.4% and had minimal participation in the reports, we will use the generic term “caregivers” to refer to the entire sample of parents, specifying “mothers” only in particular situations within the reports.

As recorded in Table 1, all social levels are represented, with a higher representation of families from classes A and B. Children with social communication levels III and IV predominated, representing 48.3% and 30.0% of the participants, respectively. Most of the children attended school (85%), and 34 (56.7%) were enrolled in private schools. All children participated in some type of intervention program with a specialized professional (e.g., speech therapist, psychologist, educational psychologist, or occupational therapist), and 34 (56.7%) of the children were on medication. Children with functional performance appropriate for their age according to the PEDI-CAT in all categories prevailed, but they tended to show a pattern suggestive of responses above the expected in the PS-2.

Table 1. Participant characteristics.

| Variable | Frequency (n=60) | % |
|--|------------------|-----------|
| Mother's education | | |
| Incomplete Elementary School | 2 | 3.3 |
| Complete Elementary School | 1 | 1.7 |
| Complete High School | 17 | 28.3 |
| Complete Higher Education | 40 | 66.7 |
| Socioeconomic level (CCEB) | | |
| A-B | 42 | 69.9 |
| C | 16 | 26.6 |
| D-E | 2 | 3.3 |
| Type of school | | |
| Private | 34 | 66.7 |
| Public | 17 | 3.3 |
| Not started | 9 | 15 |
| Use of medication | | |
| Yes | 34 | 56.7 |
| No | 26 | 43.3 |
| ASCF:SC Performance | | |
| Level I-II | 8 | 14.4 |
| Level III | 29 | 48.3 |
| Level IV-V | 23 | 38.3 |
| Functional performance | | |
| | Mean | SD |
| PEDI-CAT | | |
| ADV (mean ±SD) ^A | 43.48 | 8.17 |
| Mobility (mean ±SD) ^A | 52.85 | 7.3 |
| Social/cognitive (mean ±SD) ^A | 39.9 | 11.96 |
| PS-2 | | |
| Exploration | 52.10* | 15.88 |
| Avoidance | 53.05* | 16.3 |
| Sensitivity | 53.46** | 16.69 |
| Registration | 43.48* | 8.17 |

Note: *Indicates scoring “responds more than others”; **indicates scoring “responds much more than others”; DP = standard deviation; ^AOne-Way ANOVA.

Changes observed by caregivers as noted by the researcher

Table 2 presents a summary of the data obtained from the transcription of the notes taken during the interviews.

Table 2. Quantitative changes observed by caregivers during the pandemic period according to the researcher’s notes taken during the interviews.

| Parental perception | Number of Reports n (% of caregivers) | Improvement | Deterioration |
|---|--|--------------------|----------------------|
| Did not notice a difference in behavior | 7 (11.7%) | - | - |
| Noticed a difference in behavior | 53 (88.3%) | 8 | 45 |
| Occupational Performance | | | |
| ADL | 5 (9.4%) | 1 | 4 |
| Health management | 6 (11.3%) | 1 | 5 |
| Rest and sleep | 4 (7.5%) | - | 4 |
| Education | 8 (15.1%) | 2 | 6 |
| Play | 4 (7.5%) | - | 4 |
| Social Participation | 24 (45.3%) | 3 | 21 |
| Behavior | | | |
| Stereotypy | 6 (11.3%) | - | 6 |
| Rigidity | 10 (18.9%) | 1 | 9 |
| Hyperfocus | 1 (1.9%) | - | 1 |
| Aggressiveness | 7 (13.2%) | - | 7 |
| Stress | 29 (54.7%) | 1 | 28 |
| Crying | 6 (11.3%) | - | 6 |
| Happiness | 4 (7.5%) | 3 | 1 |
| Other reported aspects | | | |
| Use of screens | 5 (9.4%) | 2 | 3 |
| Motor coordination | 1 (1.9%) | - | 1 |
| Communication | 9 (16.9%) | 5 | 4 |

The seven caregivers (11.7%) who observed no changes in the performance and behavior of children with ASD during the pandemic explained this by noting their predisposition towards staying at home more and the fact that the children were not attending daycare or school before the pandemic.

In terms of Occupational Performance, particularly within the ADL subcategory, only one improvement was reported, attributed to increased interaction time between the child and their caregivers. Conversely, other caregivers reported deterioration in activities such as feeding, dressing, and bathroom use, emphasizing challenges in toilet training and discomfort with wearing masks.

Within health management, caregivers expressed concerns over the suspension of therapies, challenges in resuming appointments and initiating or adjusting medications. There were reports of skill loss, including the ability to write their names and numbers, alongside anticipated difficulties in readjusting to school. Concerning play, respondents indicated that children expressed a desire and asked to play with peers.

Social participation was the most frequently mentioned area of concern. Most reports listed the lack of contact with other children and staying at home as restrictions to the children's social participation. Some caregivers highlighted that the children did not talk about friends and that there was difficulty in going out again and interacting with other people and environments, even if, in some cases, the children were used to doing these activities before the pandemic. Caregivers who mentioned improvements in social participation referred to the fact that the children were doing well in the home environment and to the increase in attention, reciprocity, and social interaction.

Within the Behavior category, 63 incidents were documented, 58 (92%) of which were negative. In the stereotypy subcategory, toe-walking, covering ears, tics, and shaking were more recurrent. Among rigidity behaviors, increased attachment to the mother, difficulty in going out and visiting new or strange places, change or lack of routine, as well as increased hyperfocus were mentioned. Regarding aggressiveness behaviors, there were reports of breaking things or threatening to destroy things, self- and hetero-aggressiveness, and screaming. Behaviors of stress, nervousness, impatience, irritability, hyperactivity, anxiety, and restlessness intensified, as well as crying, crisis, sadness, frustration, and boredom. On the other hand, reports from four mothers revealed that their children were happier, calmer, and more comfortable, and one of the children fluctuated between being happy and agitated at the beginning of isolation.

Additional reports touched on aspects like screen usage, fine motor coordination challenges, and communication. In some cases, caregivers were concerned about the increased time of screen exposure, and in others, children began to interact with cartoons and speak English influenced by videos. Regarding communication, there were both improvements and regressions. The improvement in communication was attributed to increased interaction time between the child and caregivers, with descriptions such as being more talkative, language development, and an increased vocabulary. Reduction in communication was noted in outings and pronunciation.

Caregivers' perception of their children's behavior according to analysis of recorded interviews

Most caregivers reported having noticed changes in their children with ASD's behavior, predominantly negative alterations, both in the child and in the family context, as one mother expressed:

The pandemic period had a very negative impact on our family life as a whole, but especially on P.'s development [mother of child ID01].

Regarding adverse behaviors, caregivers cited anxiety, increases in stereotypy, aggressiveness and self-harming (yelling, hitting, biting, pulling hair), sadness, agitation, irritation, nervousness, and hyperfocus.

He had a lot of anxiety [...] he used to bite his fingers and nails when he was anxious, there was a time during the pandemic when he would eat the folds of his fingers because he was so anxious [mother of child ID01].

I think he showed many more new behaviors [...] like stereotypies [...] disruptive behaviors, hitting [...] it sometimes seems like aggression. [...] and moments when he [...] became very deregulated and couldn't establish communication. Then his response was to hit or [...] scream [mother of child ID08].

Since he spent a lot of time indoors watching TV, he would only watch his favorite cartoons and those with animals, so his hyperfocus on this issue increased a lot [mother of child ID07].

And she got very sad, you know. There were days when she said: oh Mom, I'm sad, the coronavirus will never go away [mother of child ID10].

Caregivers relate the negative changes in behavior to the suspension of therapies and outings, decreased social interaction, closure of schools and daycares, need to stay only at home – sometimes with little open space, as well as deprivation of playing with other children, and sensory issues. The difficulty of balancing work and the care routine for the children was also reported.

We were in an apartment that had no open space, [...] there were no other children, no classroom rules. It ended up that there were times when I had to leave them in the living room and go to the kitchen and they started jumping on the sofa, that mess of a child who hasn't burned off energy at school, can't go out, can't go to grandma's house [mother of child ID10].

[...] I couldn't meet all his needs, right? I was working at home; his older sister was having classes. My husband kept on working, 'cause he wasn't home office, he had to go out to work [mother of child ID01].

As a way to deal with these situations, caregivers mentioned having sought professional help for assessment and to check the need to start medication and to be flexible or give in at some moments:

There were times when we had to employ various strategies so her behavior wouldn't worsen. Uh... Even giving in to some things we wouldn't like, like videos, as she spent a lot of time watching videos. We had to give in a bit because of her irritability [mother of child ID13].

We chose to start being a little more flexible [...] for my children, the neurological developmental damage and the lack of bonding with other people were much worse than the risk of exposure to the virus. [...] So even though the school hadn't resumed, in October, we went back to in-person therapy sessions, we also started to be a bit more flexible with some outings, some activities with them [...] [mother of child ID01].

Considering the caregivers who noticed positive changes in the behavior of their children with ASD, a relationship between the increased time of coexistence between child and family and the development of communication is perceived.

I noticed an improvement during the pandemic period, I think that was because she was more with us at home, right [...] I'd been working from home for a year. More time with us. I, I felt that her communication improved a lot. That was when functional speech really came [mother of child ID06].

He would get very agitated at home on the weekends. So, he learned to live with idleness. He didn't really know what to do in moments when he wasn't in directed therapy, right? [...] And when the therapies returned, after we had stopped for 5 months, we resumed in September, and then everyone really noticed a big difference. He was more ... besides being calmer, he was also more talkative [mother of child ID12].

In the account of a mother who did not notice a difference in behavior, it is possible to identify that this was a child who preferred to stay at home, who did not miss daycare, and who did not have preexisting behavioral problems. In another case, the mother reported not having noticed a difference despite changes in the routine, as she managed to circumvent the situation and the child adapted to it.

He is fine at home and he never had many behavioral issues, like, aggressiveness, or never gave me many problems. So, honestly, I didn't notice much of an issue because of the lack of daycare [mother of child ID02].

In terms of behavior, no, because I managed to deal with that deprivation, right, of ... of going out, but he had moments of ... of disrupted sleep, of ... of being a little ... a bit more restless. [...] He quickly got used to it. But really, the change in routine was very abrupt. For someone who used to go out every day, have contact with other people, to be at home just with me again, he suffered from it [mother of child ID05].

Caregivers' perception regarding Occupational Performance

This category emerged from the relationship between occupations, the context of social isolation, and children with ASD. Regarding occupations, school activities (Education), therapies (Health Management), as well as leisure activities (Leisure), sleep (Rest and Sleep), play (Play), and social participation (Social Participation) were frequently mentioned. In addition, self-care activities (ADL) such as sanitary hygiene, dressing, eating, and feeding were mentioned.

The pandemic context changed the occupational performance of children because of the closure of schools and the transition to online classes. As a result, mothers and, in some cases, grandparents and private tutors, took on the responsibility of teaching what would be learned at school. There was also difficulty in accessing therapeutic services, parks, and other leisure places, as reported by some mothers:

And the difficulties for us to leave the house to take her to the park, she had to leave school, so, her routine changed [mother of child ID13].

He was used to going out a lot, and ... with the start of the pandemic, we had to cut those outings of his [mother of child ID11].

She began to play a lot by herself, to play, that is, to create stories with toys, all objects turned into characters, you know. In the beginning, she made a lot of reference to her classmates in these games [mother of child ID04].

I did activities with her. My mother is a teacher, so she did some online classes with her to get her used to this new reality [mother of child ID14].

Caregivers reported both difficulties and positive aspects of social isolation about Occupational Performance. The challenges faced were related to the suspension of in-person therapy sessions and classes, restrictions on participation and social interaction in the community, and changes in the routine of activities. The positive aspects refer to the increased time of family coexistence. Caregivers reported both positive and negative aspects simultaneously or changed over time, resulting in the transformation of an initially negative aspect into a positive one. The following excerpts illustrate some of the negative perceptions:

We believed a lot in therapy and school, and everything stopped. So, it generated suffering for him, and for us too. In the beginning, he was irritated because he was at home all the time, and there were no activities. And even... And it disrupted his entire routine, so it was very difficult at the beginning [mother of child ID03].

For someone who used to go out every day, have contact with other people, to be at home just with me again, he suffered from it. [...] We only went out after the therapy sessions returned. Grocery shopping was done by my husband. He would leave for work and then stop by the supermarket, taking care of everything. We stayed at home; we were literally isolated [mother of child ID05].

Caregivers for whom the pandemic context brought positive changes because of the increased time of family coexistence made reports like:

Her development improved a lot because, every day, I used to do an activity, I'd sit with her, and give her more attention [mother of child ID10].

We focused a lot on these things of, of... activities of daily living. So, like, every day we had lunch together, right, sitting at the table. So I think it improved things between us. We saw great gains during the pandemic [mother of child ID06].

Communication is essential for interaction and social participation, and it is one of the biggest challenges faced by children with ASD and their families, who report improvement or deterioration in this skill:

He regressed in the issue of speech as well. In terms of speech and communication [mother of child ID01].

I, I felt that her communication improved a lot. That was when functional speech really arose. Uh... Her reciprocity, her attention, right [mother of child ID06].

He has a difficulty [...] in generalization. So, he communicates very well here at home. He already communicated well. He already spoke complete sentences at home, at times when the school and the therapy sessions were bringing me concerns that he wasn't carrying that over. So, by having spent such a long time at home, he greatly increased his vocabulary repertoire and his word use. He managed to use them better [mother of child ID12].

A reduction in communication was observed in environments other than home, and with people outside the family.

Concerning other people, he reduced his communication a lot, so much so that upon returning to school [...] I requested a meeting with them [teachers] and then they came to me with a flood of news and things that weren't there before and they noticed after the pandemic, because he had lost his usual contact at school with the children, and became reclusive at home. I think that really affected him [mother of child ID08].

Regressions in feeding were also mentioned, with an increase in food selectivity, greater dependence on bathroom use, and worsening in motor coordination and school skills.

I also noticed that he was already going to the bathroom by himself, would lower his pants and sit on the toilet to pee, I just had to go there to clean him, but then he suddenly stopped doing that, because when the pandemic started, he was in the process of toilet training, had even finished it. [...] From one moment to the next he started to... not to do it [mother of child ID09].

His eating worsened. He already had some selectivity, but his food selectivity got even worse [mother of child ID01].

As we were at home, right, we couldn't ... everyone working from home, without being able to give him more attention, the issue of motor coordination, especially fine motor coordination was quite affected. He ... Today he can't draw lines, vertical, horizontal lines, circles, he doesn't do them, he hasn't reached that milestone yet [mother of child ID07].

And ... he had some losses regarding school skills he had already acquired. So, like, he could already write his name, then he stopped writing and then we had to bring in other professionals to our home, which isn't ... our habit in normal life, reacquiring these things that he ... lost in learning [mother of child ID15].

Sleep was affected. One of the children showed behavioral issues and problems in other areas of occupational performance. On the other hand, a mother reported success in dealing with behavior despite disrupted sleep.

His sleep became very bad [mother of child ID01].

He didn't progress as expected [...] there were moments of ... of disrupted sleep, of ... of being a bit ... a bit more restless. But, like, nothing that I couldn't manage [mother of child ID05].

Some caregivers reflected on their everyday lives and the post-pandemic consequences for their children. The overload of caregivers was highlighted because of the increase in daily activities and concerns about the developmental issues of their children resulting from the pandemic period.

[...] I couldn't meet all his needs, right? I was working at home; his older sister was having classes. My husband kept on working, 'cause he wasn't home office, he had to go out to work. So we couldn't provide all the stimuli that he needed throughout the day... [...] Even though I blocked my schedule for a while to go and stimulate him in the middle of the morning, at times of greatest agitation, even so, it wasn't enough, right? [mother of child ID01].

What it brought me was a lot of tiredness, obviously. At home, with two children [mother of child ID12].

I gained in development because I was doing the activities, taking him to the therapy sessions and such, but some things will be difficult to recover. It will be hard to recover the psychological aspect [mother of child ID10].

Discussion

This study aimed to describe the observed changes in behavior and occupational performance of preschoolers with ASD during the social isolation period of the COVID-19 pandemic, as perceived by their caregivers. Two fathers were interviewed independently, while the vast majority of participants were mothers (71.6%), interviewed alone. In addition, 15 mothers were accompanied by the children's fathers, who participated minimally in the interviews. This discrepancy prompts a reflection on the relationship between motherhood and ASD. As discussed by Portes & Vieira (2020), mothers primarily provide basic care for children with ASD, including bathing, feeding, medical appointments, play, school tasks, and stimulating the development of reading and speech. This involvement often leads to overload, fatigue, and stress. While mothers express concerns about partners not engaging effectively in caring for children with ASD, fathers do not seem dissatisfied with this division of work (Portes & Vieira, 2020).

According to Ponte & Araújo (2022), the role of mothers of children with ASD is akin to that of care professionals, because of their near-total involvement in caregiving activities. This routine can become monotonous and burdensome, leading to fatigue,

professional life abandonment, neglect of personal interests and leisure, reduced investment in affective relationships, and neglect of other occupational roles previously held. Mothers bear the responsibility for the development of children with disabilities, dedicating themselves to an intense treatment routine, whereas fathers play a secondary role in childcare (Ponte & Araújo, 2022).

As for the caregiver profile, a significant percentage belong to socioeconomic classes A and B, with high educational levels observed. Consequently, most children (85%) attended preschool, with 66.7% enrolled in private schools. The socioeconomic and educational profile of the participants surpasses the Brazilian averages, which are 23.8% for classes A and B (Associação Brasileira de Empresas de Pesquisa, 2019) and 17.4% for higher education (Instituto Brasileiro de Geografia e Estatística, 2022). This aligns with the recruitment of most participants from private clinics. Health outcomes are influenced by social determinants of health (SDH) – a complex and interdependent set of variables related to the conditions in which people are born, grow, live, work, and age, along with the healthcare services context available in a given territory (Buss & Pellegrini Filho, 2007). Families of higher socioeconomic levels, despite facing additional economic and social costs to secure education and healthcare for children with ASD (World Health Organization, 2011), typically have access to better quality services more frequently. This may have intensified feelings of loss and helplessness regarding school closures and difficulties in accessing therapy services during the pandemic.

According to the ACSF:SC, the predominant level of communication was Level III, both in performance (48.3%) and capacity (35%). This level indicates that children initiate communication to request their needs and attempt to communicate for social purposes but do not sustain communication (Di Rezze et al., 2016b; Eloi et al., 2019).

In the PEDI-CAT, most children scored within the expected range for their age (30-70) across all domains: mobility, responsibility, social/cognitive, and ADL (Mancini et al., 2016). Although the children demonstrated age-appropriate functional performance on average, caregivers reported difficulties in daily management of communication and functional performance. These difficulties are likely associated both with the characteristics of ASD and the real need for greater support for children aged 3 to 5 years. Children in this age group are more dependent, and the care required from caregivers is more intensive, especially regarding self-care (Minatel & Matsukura, 2014).

The difficulties observed by caregivers may also relate to alterations in sensory processing, as the results from the SP-2 suggest a tendency towards a hyper-response to stimuli (Dunn, 2017). This sensory sensitivity makes these children more prone to behavioral crises, as reported by several caregivers.

The majority of caregivers identified changes in the behavior and occupational performance of their preschool-aged children with ASD associated with the pandemic, with a prevalence of negative alterations (84.9%). This finding corroborates similar studies that analyzed the perception of mothers, fathers, and caregivers about the behavior of children with ASD (Givigi et al., 2021; Stadheim et al., 2022). Givigi et al. (2021) reported changes in the behavior of children and adolescents with ASD aged 2 to 19 years, with 68.6% being negative. In the study by Stadheim et al. (2022), 92.6% of participants reported at least one negative behavioral change.

These data reveal that changes in family routine, occupational roles, and restrictions arising from the pandemic context constituted obstacles for the lives of children with ASD and their families. The abrupt changes in everyday social life, related to school closures and difficulties in accessing therapy, leisure, and play services, were significant barriers. Stadheim et al. (2022) also gathered caregiver testimonials revealing experiences of distress and concern for their children with ASD. Caregivers highlighted the disruption of family daily life and increased dependence on technology to promote continued education and access to health services, along with the longing to return to pre-pandemic life or the desire to find structure amid the barriers that emerged. These challenges were exacerbated by the ASD characteristics of their children – increased need for therapy and the emergence of maladaptive behaviors. The loss of social opportunities seemed to have negative consequences for the majority of children (Stadheim et al., 2022).

Social participation—the most cited occupation by respondents in this study—can be defined as involvement in social interactions with others. This can range from participation in family and community activities to forming friendships, including participation in peer groups, and establishing intimate relationships (American Occupational Therapy Association, 2020). People with ASD face restrictions in social participation, even in non-pandemic times, because they are often not invited to participate in other social activities with peers outside the school environment (Tanner et al., 2015). These restrictions were greater during the social isolation period related to the pandemic, which may have intensified preexisting deficits in communication and social interaction. However, changes in communication were mentioned by nine caregivers, of whom five identified improvements. Morris et al. (2021), in researching changes in social communication reported by parents of children with ASD aged 2 to 12 years, did not identify deterioration in these skills, nor that they improved after returning to school. The data suggest variations in social communication in response to the pandemic context, possibly related to the environment, family situation, and individual characteristics of the children.

In the current study, we identified an increase in irritability, stereotypies, tics, aggressiveness, hyperactivity, anxiety, and difficulties returning to social life, corroborating data from similar studies (Mutluer et al., 2020; Stadheim et al., 2022). Mutluer et al. (2020) observed significant changes in behaviors related to ASD before and during the pandemic, including increases in irritability, lethargy/social withdrawal, stereotyped behavior, hyperactivity, inappropriate speech, aggressiveness, and hypersensitivity. Sleep problems were also reported, characterized by a reduction in sleep duration, difficulty falling asleep, nighttime awakenings, and challenges in returning to sleep (Huang et al., 2021). Stadheim et al. (2022) noted that children with ASD exhibited increasing or new behaviors, such as nervous breakdowns, aggressiveness, self-harming, property destruction, elopement, and the use of inappropriate language, posing challenges for parents who reported decreased patience and difficulties in reaching agreements with their children.

The majority of children experiencing a decline in sleep quality also exhibited behavioral issues and/or difficulties in occupational performance. The prevalence of sleep problems in children with ASD ranges from 44% to 83%, compared to 11% to 37% in typically developing children (Malow & McGrew, 2008).

Hypotheses regarding the causes of sleep problems in ASD include non-adherence to sleep routines, difficulties transitioning between activities, communication challenges, sensory issues, hyperactivity, inattention, anxiety, and mood disorders. Sleep disturbances can exacerbate behavioral issues in individuals with ASD, increasing caregiver stress and negatively impacting family quality of life (Mazzone et al., 2018).

Echoing the findings of Cardy et al. (2021), we observed an increase in screen time exposure. Consequently, parents often experience emotions such as guilt, frustration, worry, and relief, with guilt being more prevalent among parents of children with ASD (Cardy et al., 2021). This can contribute to heightened stress in parent-child relationships.

Lastly, the majority of reports from this study indicate a deterioration in the performance of ADL. This finding contrasts with the study by Stadheim et al. (2022), where parents noted improvements in self-care skills, such as toileting, tooth brushing, bathing, and dressing, attributed to increased parental involvement. Additionally, some children improved in completing household tasks, such as preparing snacks/meals and other chores. This discrepancy may be due to differences in the ages of the participants, as Stadheim et al. (2022) focused on children and adolescents with ASD aged 3 to 18 years, not just preschoolers.

Studies on how the behavior of children with ASD impacts their caregivers' lives reveal significant everyday challenges. Even before the pandemic, mothers reported seldom having time for self-care, often because of problems in finding reliable childcare or the perceived burden it places on others (Estanieski & Guarany, 2015). Many mothers, adapting to their children's conditions, often sideline their occupational roles, resulting in high levels of stress, low quality of life, and poor occupational performance due to difficulties in seeking or maintaining employment and engaging in leisure activities and social interaction. These data, in line with mothers' reports in this study, underscore the urgent need to discuss the low involvement of fathers in childcare, which could enable the creation of more comprehensive support strategies for families (Estanieski & Guarany, 2015).

Data from Kalb et al. (2021), obtained during the initial months of the pandemic, reveal significant psychological distress among caregivers of children with Autism Spectrum Disorder (ASD). This emphasizes the urgent need for targeted support and highlights the importance for physicians, researchers, and policymakers to prioritize the mental health of these caregivers in situations of social isolation, similar to those experienced during the pandemic. Indeed, the results of this study show the necessity to understand both how the pandemic impacted the development of children with ASD and the repercussions on the mental health of caregivers so that appropriate policies for this population can be implemented in the context of pandemics.

A strength of this study was the detailed accounts given by caregivers, who provided detailed observations of their children's behavior, both changes and consistencies, often using technical language. This highlights the power of clinical practice focused on the family's needs and studies that elucidate perceptions of their own experiences. However, a limitation was that the sample consisted of caregivers with a socioeconomic profile above the Brazilian average, limiting the data's generalizability. Families with higher purchasing power have greater access to services

and social goods that favor children's development, whose interruption was a focus of parental concern. Considering that all children, regardless of socioeconomic level, have access to school and some form of intervention, the global issues revealed here are not restricted to certain socioeconomic levels. Another limitation is that this study was planned before the emergence of COVID-19, leading to unexpected adjustments to the pandemic context, such as online data collection, but which allowed us to bring to light the caregivers' experiences and perceptions regarding how the pandemic impacted their children's development.

Conclusion

The COVID-19 pandemic impacted everyone's life. Caregivers identified changes in the behavior, occupational performance, and social communication of their children with ASD – some of these were positive, but the majority of reports reveal suffering for both caregivers and children. These results unveil aspects of the person-environment-occupation relationship and lead us to reflect on the importance of family-centered care, which broadens the care perspective beyond managing the child's specific issues. In pandemic contexts, like the one experienced, or where there is greater social isolation, it is important to create support structures for families to minimize suffering and reduce adverse effects on the development of children with ASD. It is suggested that future studies investigate whether caregivers' perceptions of the behavior, occupational performance, and social communication of children with ASD are influenced by factors such as socioeconomic and educational level.

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Author's Contributions

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Corresponding author

Lívia de Castro Magalhães
e-mail: liviacmag@gmail.com

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