


# Impact of the COVID-19 pandemic on the eating behaviors of children and adolescents with autism spectrum disorder

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## ABSTRACT

**Introduction.** Children with autism spectrum disorder (ASD) have difficulties adapting to stressful situations, such as the COVID-19 pandemic.

**Objective.** To assess the impact of the first year of the pandemic on feeding difficulties in children with ASD.

**Population and methods.** The caregivers of children and adolescents with non-syndromic ASD (age: 2–18 years) from a neurodevelopment unit were invited to participate. Participants completed a questionnaire and the Behavioral Pediatrics Feeding Assessment Scale (BPFAS) online before and during the first year of the pandemic. A priority score (product between the average frequency and the problem) for each BPFAS item was estimated.

**Results.** Among the caregivers, 56.6% (86/152) completed the survey (mother: 74.4%); children's median age was 6.3 years (p25–p75: 4.7–8.2); 80.2% of children were males; 58.1% continued with their therapy during the pandemic; and 61.6% had behavioral problems before the pandemic. During the first year of the pandemic, children had greater behavioral problems (34.9%) and feeding difficulties (61.6%); however, 31.4% of caregivers referred improvements in feeding. There were no significant differences in the BPFAS scores before and during the pandemic. The following items obtained the highest priority scores: gets up from table during meal, does not try new food, does not eat vegetables, does not eat fruits.

**Conclusions.** A high frequency of feeding difficulties was noted during the first year of the pandemic. No differences were observed in feeding characteristics before and during the pandemic.

**Keywords:** autism spectrum disorder; behavioral assessment scale; COVID-19; restrictive diet; eating disorders; food intake disorders.

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## INTRODUCTION

Children and adolescents with autism spectrum disorder (ASD) have known feeding difficulties (FDs), which vary in frequency depending on the definition used or the type of assessment done to measure them.<sup>1–4</sup> FDs may be multiple and diverse; they include food selectivity, rejection of food based on aversions to their sensory properties, acceptance of a reduced number of foods or smaller amounts, fear of trying new food, reduced ability to feed due to impaired motor coordination, and disruptive eating patterns or schedules. All this hinders their possibility of joining the family table and attending social events, which causes behavioral problems at mealtime.<sup>1,3–6</sup>

In relation to the feeding of children and adolescents with ASD during the COVID-19 pandemic, cross-sectional studies have been conducted based on surveys administered to caregivers and different results have been observed, for example, that 20–23% of parents have had difficulties in managing the feeding of their children and that 28.1% observed greater difficulties during this period compared with the period prior to the lockdown.<sup>7,8</sup> In contrast, in another study, 49% of caregivers answered that the quality of food eaten by children and adolescents had improved during the pandemic.<sup>9</sup>

In this context, it is interesting to investigate the potential effect of the COVID-19 pandemic on the pediatric population with ASD, both on their eating behaviors and possible behavioral effects; the latter have been described in previous studies.<sup>10</sup> Our objective was to assess the impact of the first year of the pandemic on FDs in children with ASD.

## POPULATION AND METHODS

This was a quantitative, observational, analytical study of primary data obtained in participants through prospective recruitment.

All parents or caregivers of children and adolescents with ASD (aged 2–18 years) followed-up at the Unit of Neurodevelopment of Red Salud UC-Chistus, Santiago, Chile, between September and October 2020 were invited to participate. Children and adolescents diagnosed with ASD by a neurologist, a pediatrician, or a child and adolescent psychiatrist, based on the criteria of the Diagnostic and Statistical Manual of Mental Disorders, version 5 (DSM-5), were included. Children and adolescents with diseases that could be associated with FDs, such as progressive neurological diseases and Down syndrome, were

excluded due to their clinical characteristics. The informed consent was obtained before caregivers completed the questionnaire (online). The identity of children, adolescents, and their caregivers remained anonymous. The study was approved by the Ethics Committee of the School of Medicine of Pontificia Universidad Católica de Chile on July 23<sup>rd</sup>, 2020 (200617027).

## Instruments

The caregiver who spent the most time with the child/adolescent was invited to complete an online questionnaire developed by the investigators in relation to the impact of the COVID-19 pandemic on children and adolescents with ASD. The questionnaire was based on Colizzi's article,<sup>8</sup> adapting its wording and adding items considered relevant by the team to cover aspects not taken into account in the original publication. An interdisciplinary panel of national experts conducted serial assessments of this questionnaire as per the modified Delphi methodology proposed by Hasson.<sup>11</sup> The Delphi panel consisted of 19 experts (1 methodologist, 1 pediatrician, 1 child psychiatrist, 2 psychologists, 2 occupational therapists, 6 pediatric neurologists, and 6 speech therapists). For the first round of consultation, 16 experts (84.2%) answered the questionnaire; all the items were considered important or very important, so they were maintained, while wording changes were made based on suggestions. For the second round, 15 experts (78.9%) answered the questionnaire; one question was eliminated because it was repeated and the wording was adjusted based on suggestions.

They were also invited to complete the Behavioral Pediatrics Feeding Assessment Scale (BPFAS). Two bilingual investigators back-translated the instrument before administering it. The BPFAS assesses FDs based on 35 items; 25 of these correspond to the eating behaviors of children and adolescents observed by their caregivers and 10, to caregivers' feelings or attitudes. For each item, the question asked about frequency (Likert scale: 1–5, from never to always) and whether it is a problem (yes = 1; no = 0).<sup>12</sup> For items whose positive answer does not imply a feeding difficulty, the answer that implies more difficulty was given the maximum score (reverse scoring). The total frequency (TF) score was estimated as the sum of the 35 items (possible value: 35–175), the total problem (TP) score was the sum of the 35 items (possible

value: 0–35); the higher the score, the higher the FD. Four subgroups were also established: frequency among children (FC) was the sum of 25 items (possible value: 25–125); frequency among parents (FP), the sum of 10 items (10–50); problem among children (PC), the sum of 25 items (0–25); and problem among parents (PP), the sum of 10 items (0–10). The following cut-off points were used to define FD: TF > 84, TP > 9, FC > 61, FP > 20, PC > 6, and PP > 2.<sup>12–14</sup> Caregivers were asked to complete the BPFAS in relation to the period before and during the first year of the pandemic.

For each BPFAS item, a priority score was estimated; this is the product between the average frequency and whether it was considered a problem. The values range between 0 and 5; the higher the value, the greater the FD. This was used to establish an item priority ranking.<sup>15</sup>

The STATA v.16 software was used for the statistical analysis. Absolute and relative frequencies were estimated for categorical variables, while average values and standard deviations (SDs) or median and interquartile range (p25–p75) were used for continuous variables based on distribution. The Shapiro-Wilk test was applied to determine whether continuous variables had a normal or skewed distribution. The internal consistency of the BPFAS was assessed using Cronbach's alpha (0.7–0.8: acceptable, 0.8–0.9: adequate; 0.9–1: superior).<sup>16</sup> The differences between the BPFAS scores were assessed using the t test or the Wilcoxon signed-rank test for dependent samples and the McNemar test. The association among variables was assessed using Spearman's correlation coefficient and the  $\chi^2$  test. A factor analysis was done to test the construct validity following the factors studied by Allen.<sup>17</sup> Significance:  $p < 0.05$ .

## RESULTS

The main caregivers of 152 children and adolescents were invited to participate; 86 (56.6%) answered. The survey was completed by the mother in 74.4% of cases.

*Table 1* shows the sample's demographic characteristics. The median age of children and adolescents was 6.3 years (p25–p75: 4.7–8.2); 69 children and adolescents (80.2%) were males; 94.2% were receiving therapy before the pandemic; of these, 58.1% continued with their therapy during the pandemic.

*Table 2* shows the answers given by caregivers regarding children's and adolescents'

behavior: 53 (61.6%) mentioned their child had behavioral problems before the pandemic; 30 (34.9%), that their child's behavioral problems worsened during the pandemic; 53 (61.6%), that their child had feeding difficulties during the pandemic; and 27 (31.4%), that their eating behavior improved during the pandemic. Only 5 caregivers (5.8%) considered this was not a challenging period.

A factor analysis of the following BPFAS domains was done: food acceptance, medical/oral motor problems, and mealtime behavior. The factor analysis evidenced that the sample had a single-factor structure.

*Table 3* shows the BPFAS scores. Item 25 (has required supplemental tube feeds to maintain proper nutritional status) was eliminated from the Cronbach's alpha coefficient estimation because it maintained a null frequency answer and was not considered a problem. No significant differences were observed in the BPFAS scores before and during the pandemic. Significant differences were noted for scores considered abnormal between the TF and TP before the pandemic (McNemar  $p = 0.01$ ) and during the pandemic (McNemar  $p = 0.002$ ), as well as between the FC and PC before the pandemic (McNemar  $p = 0.001$ ) and during the pandemic (McNemar  $p = 0.004$ ).

No association was observed between the TF and TP and sex, age at diagnosis, current age, being an only child, receiving therapies before the pandemic, or language skills. No association was seen either when the difference between TF and TP was analyzed before and during the pandemic. For this analysis, the variables shown in *Table 1* were considered because they took into account the impact on the child/adolescent or their caregivers during the pandemic.

*Table 4* shows the BPFAS items, the priority score before and during the pandemic, and the priority ranking.

## DISCUSSION

This study investigates the FDs of children and adolescents with ASD as observed by their main caregivers during the first year of the COVID-19 pandemic.

Almost all participants considered this period of the pandemic was challenging or very challenging in terms of environmental changes and limitations, which is consistent with previous studies.<sup>8</sup> This may be related to a decreased access to supportive therapies, greater difficulties in autonomy and adaptation to changing routines, and increased

**TABLE 1. Demographic characteristics (n = 86)**

<b>Family characteristics</b>		
Person completing the survey, n (%)		
Mother	64 (74.4)	
Both parents	18 (20.9)	
Father	4 (4.7)	
Adults sharing the household during the pandemic, n (%)		
Both parents	47 (54.7)	
Mother and other individuals	16 (18.6)	
Both parents and other individuals	15 (17.4)	
Only the mother	4 (4.7)	
Other individuals	3 (3.4)	
Only the father	1 (1.2)	
Type of housing during the pandemic, n (%)		
House with courtyard	66 (76.7)	
Apartment with terrace	15 (17.4)	
Apartment without courtyard	4 (4.7)	
Apartment with courtyard	1 (1.2)	
Mother's current employment situation, n (%)		
Mother working from home	41 (47.7)	
Mother did not work for a salary before the pandemic	22 (25.6)	
Mother continues going out to work	10 (11.6)	
Mother did not have an employment during the COVID-19 pandemic	4 (4.6)	
Other	8 (9.3)	
Does not answer	1 (1.2)	
Father's current employment situation, n (%)		
Father continues going out to work	32 (37.3)	
Father working from home	31 (36)	
Father did not have an employment during the COVID-19 pandemic	10 (11.6)	
Does not answer	8 (9.3)	
Other	3 (3.5)	
Father did not work for a salary before the pandemic	2 (2.3)	
Household member with COVID-19 during the pandemic, n (%)	5 (5.8)	
Household member diagnosed with depression during the pandemic, n (%)	23 (26.7)	
<b>Child/adolescent characteristics</b>		
Male sex, n (%)	69 (80.2)	
Age (years), median (IQR: p25–p75)	6.3 (4.7–8.2)	
Age at diagnosis (years), median (IQR: p25–p75)	3 (2.5)	
Only child, n (%)	39 (43.4)	
Language skills, n (%)		
Fluent speaker	44 (51.2)	
Uses some phrases	20 (23.3)	
Uses some words	12 (13.9)	
Gestures	7 (8.1)	
Does not speak	3 (3.5)	
Therapy before the pandemic, n (%)	81 (94.2)	
Therapy during the pandemic, n (%)	50 (58.1)	
Attendance to educational facility before the pandemic, n (%)	82 (95.4)	
The child maintained school activities, n (%)	68 (79.1)	

n: number.

**TABLE 2. Behaviors before and during the pandemic as reported by the caregiver (n = 86)**

Behavioral difficulties before the pandemic, n (%)	
Yes	53 (61.6)
No	33 (38.4)
Severity of child's behavioral difficulties, n (%)	
Same severity	35 (40.7)
Greater severity	30 (34.9)
Lower severity	21 (24.4)
Frequency of child's behavioral difficulties, n (%)	
More frequent	31 (36)
Same frequency	30 (34.9)
Less frequent	25 (29.1)
How do you feel this period has been according to changes and restrictions?, n (%)	
Very challenging	45 (52.3)
Challenging	36 (41.9)
Unchallenging	5 (5.8)
Feeding difficulties during the pandemic, n (%)	
	53 (61.6)
Greater feeding difficulties during the pandemic, n (%)	
	40 (46.5)
My child's eating behavior improved because they are eating at home, n (%)	
Strongly disagree	13 (15.1)
Disagree	11 (12.8)
Neither agree nor disagree	35 (40.7)
Agree	6 (7)
Strongly agree	21 (24.4)
Difficulties with the autonomy of your child during the pandemic, n (%)	
	43 (50)
Greater difficulties with the autonomy of your child during the pandemic, n (%)	
	32 (37.2)
Difficulties adapting to changes in routine during the pandemic, n (%)	
	47 (54.7)
Greater difficulties adapting to changes in routine during the pandemic, n (%)	
	51 (59.3)
My child has benefited from spending more time with the family, n (%)	
Strongly disagree	1 (1.2)
Disagree	3 (3.5)
Neither agree nor disagree	9 (10.5)
Agree	23 (46.7)
Strongly agree	50 (58.1)

n: number.

**TABLE 3. Behavioral Pediatrics Feeding Assessment Scale (BPFAS) before and during the COVID-19 pandemic (n = 86)**

	Internal consistency Cronbach's alpha		Average (SD)			Abnormal score, n (%)		
	Before	During	Before	During	p	Before	During	p
Total frequency (TF)	0.84	0.84	68.2 (16.6)	67.8 (16.2)	0.73	14 (16.3)	13 (15.1)	0.78
Total problem (TP)	0.86	0.85	7.3 (5.8)	7.3 (5.7)	0.98	24 (27.9)*	26 (30.2)*	0.65
Frequency among children (FC)	0.75	0.75	48.9 (11.2)	48.6 (11.2)	0.7	12 (14)	13 (15.1)	0.79
Problems among children (PC)	0.8	0.76	5 (4)	5 (3.8)	0.97	25 (29.1)**	29 (33.7)**	0.39
Frequency among parents (FP)	0.84	0.8	19.3 (7.8)	19.2 (7.4)	0.92	34 (39.5)	32 (37.2)	0.56
Problems among parents (PP)	0.85	0.83	2.2 (2.7)	2.2 (2.6)	1	30 (34.9)	32 (37.2)	0.65*

\* Difference between TF and TP before the pandemic (McNemar p = 0.01), TF and TP during the pandemic (McNemar p = 0.002).

\*\* Difference between FC and PC before the pandemic (McNemar p = 0.001), FC and PC during the pandemic (McNemar p = 0.004).

n: number.

SD: standard deviation.

**TABLE 4. Behavioral Pediatrics Feeding Assessment Scale (BPFAS): children's behaviors and parents' feelings based on a priority score (n = 86)**

My child	Priority score before the pandemic <sup>a</sup>	Priority score during the pandemic <sup>a</sup>	Priority ranking <sup>b</sup>
1 Eats fruits*	1	0.75	0.75
2 Has problems chewing food	0.6	0.4	0.24
3 Enjoys eating*	0.34	0.32	0.1
4 Chokes or gags at mealtime	0.36	0.34	0.12
5 Will try new food*	1.6	1.12	1.79
6 Eats meat (beef, chicken, turkey, pig and/or fish)*	0.18	0.17	0.03
7 Takes longer than 20 minutes to finish a meal	0.56	0.81	0.45
8 Drinks milk*	0.18	0.17	0.03
9 Comes readily to mealtime*	0.44	0.42	0.18
10 Eats junky snack foods will not eat not eat at mealtime	0.36	0.36	0.12
11 Vomits just before, at, or just after mealtime	0.033	0.077	0.002
12 Eats only ground, strained, or soft food	0.4	0.18	0.07
13 Gets up from table during meal	1.28	1.75	2.24
14 Lets food sit in their mouth and does not swallow	0.36	0.34	0.12
15 Whines or cries at feeding time	0.34	0.34	0.11
16 Eats vegetables*	0.96	0.96	0.92
17 Tantrums at mealtimes	0.32	0.51	0.16
18 Eats starches (for example, potato, noodles)*	0.17	0.17	0.02
19 Has a poor appetite	0.38	0.34	0.12
20 Spits out food	0.14	0.3	0.04
21 Delays eating by talking	0.17	0.34	0.05
22 Would rather drink than eat	0.38	0.38	0.14
23 Refuses to eat meals but requests food immediately after the meal	0.36	0.36	0.12
24 Tries to negotiate what they will eat and what they will not eat	0.46	0.48	0.22
25 Has required supplemental tube feeds to maintain proper nutritional status	0	0	0
<b>The father/mother</b>			
26 I feel frustrated or anxious when I feed my child	0.66	0.66	0.43
27 I trick my child into trying some food	0.48	0.46	0.22
28 I threaten my child to get them to eat	0.34	0.34	0.11
29 I feel confident that my child is eating enough food*	0.36	0.34	0.12
30 I feel confident in my ability to manage my child's behavior at mealtime*	0.4	0.63	0.25
31 If my child does not like what I have served them, I cook something else	0.66	0.44	0.29
32 When my child refuses to eat, I forcefully put food in their mouth if necessary	0.14	0.13	0.018
33 I disagree with other adults (my partner, my child's grandparents) about how I feed my child	0.42	0.42	0.17
34 I feel that my child's eating habits are detrimental to their overall health	0.6	0.66	0.39
35 I get so angry with my child at mealtime that it takes me a while to calm down after the meal	0.14	0.14	0.02*

\* Reverse scoring.

<sup>a</sup> Priority score: product between the average frequency and whether it was considered a problem (value: 0 to 5).<sup>b</sup> Priority ranking: product between priority score before the pandemic and during the pandemic.

severity and frequency of behavioral difficulties observed in children and adolescents with ASD during the pandemic.<sup>8,10,18,19</sup>

FDs are highly prevalent in children and adolescents with ASD; the way in which they

have been measured varies: questions defined by each research team or surveys previously developed for the general pediatric population described in the bibliography.<sup>1,3–5,17,20,21</sup> In our sample, more than 60% of respondents reported

having difficulties managing their child's feeding during the pandemic and approximately 50% experienced greater difficulty managing their child's feeding during the pandemic compared to before it. Our results show a high frequency of FDs during the pandemic, which was almost double that reported by Colizzi.<sup>8</sup>

One third of the participants in our study considered that their child's feeding improved during the pandemic. The evidence in this regard is contradictory due to differences in risk and protective factors, which hinders the possibility of comparing results. A study showed that 50% of parents consider that the quality of their children's diet improved compared to before the pandemic,<sup>7</sup> while another study reported that 72% of caregivers found no change in eating behavior and that only a low percentage improved their diet during the pandemic.<sup>9</sup>

As a way to objectify behavioral eating problems, we used the BPFAS,<sup>12</sup> which is a psychometrically robust instrument that assesses FDs. This survey covers different domains and is useful in clinical practice due to its ease of application and interpretation of the results by the evaluator.<sup>22</sup>

The BPFAS has been used in observational studies in which children and adolescents with ASD obtain high scores, which translates into a higher frequency of FDs when compared to controls. An association has been observed between a higher frequency of FDs and greater severity and higher frequency of social communication difficulties, repetitive or restrictive behaviors, behavioral problems, and sleep disorders.<sup>5,17,20</sup> Our results show no association between the different BPFAS scores and the study variables. Although families describe difficult or more difficult times in the face of all the changes experienced during the pandemic, we found no significant differences between BPFAS scores before and during the pandemic.

In 2013, Dovey established cut-off points to define the presence of FDs for frequency and problem scores, which have been used extensively in the bibliography.<sup>12,20,23</sup> In relation to these scores, Peverill found that 34.8% of studied pediatric ASD patients had FDs in terms of FC, twice as high than the value observed in our study.<sup>20</sup>

When comparing our results with those of other studies in which the BPFAS was administered to children and adolescents with ASD, the characteristics of our sample include a

lower TF score than that reported and a FC score similar to the one described.<sup>5,17</sup>

An interesting finding, but which we did not observe in other publications, is that there was a significant difference when comparing the percentage of abnormal scores between TF and TP, and FC and PC. It was twice as high when answering whether it was a problem rather than if it was frequent, in response to the same questions; i.e., it is highly believed to be a problem despite the fact that it is not a FD that occurs with a high frequency.

Based on priority rankings, it was observed that the higher frequency was related to items "gets up from table during meal" and "takes longer than 20 minutes to finish a meal"—both referring to difficulties at mealtime, consistent with what has been described in other publications—,<sup>1,5,24,25</sup> as well as other items related to food acceptance, such as trying new food and a lower consumption of fruits and vegetables.<sup>5,26–28</sup> Another item with a high score in the priority ranking was "I feel that my child's eating habits are detrimental to their overall health," a common concern among caregivers given the food selectivity typical of children and adolescents with ASD, which leads to them having a smaller range of food or preparations options for their consumption.<sup>1,3–5,26,28</sup>

In 2021, the Aut-Eat Questionnaire about FDs was published, which includes different domains and was developed based on a case-control study specifically focused on people with ASD.<sup>28</sup> To date, there are no studies available that compare the consistency between that questionnaire and the BPFAS.

One of our findings is that the FDs observed in this study were related to mealtime, and it is worth noting that none of the children and adolescents in our sample required a nasogastric tube to support enteral feeding, which is consistent with what has been described in the bibliography.<sup>5</sup>

One of the limitations of this study was that the back-translation of the BPFAS was done without a prior pilot test. In addition, the answers were collected at a point in time at the beginning of the pandemic, which may have been affected by memory or perception and may not necessarily represent what occurred throughout the entire period. Our sample was relatively small and selected by convenience; therefore, the results do not necessarily reflect the reality of the national population. Lastly, we did not obtain information about clinical follow-up.

The main strengths of this study lie in the fact

that all children and adolescents have a specialist diagnosis and that the use of a standardized and validated survey on FDs in children and adolescents with ASD allows comparing the results with those of other studies. The main contribution of this study is that it provides information on the eating behaviors of children and adolescents with ASD during the first period of lockdown due to the COVID-19 pandemic.

To conclude, in the first year of the COVID-19 pandemic, caregivers of children and adolescents with ASD perceived greater FDs, although there were no differences in the BPFAS scores before and during the pandemic; priority scores were higher for items typical of the FDs observed in children and adolescents with ASD. ■

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