

## Eating practices and reorganization of family dynamics in children with autism spectrum disorder

Práticas alimentares e reorganização da dinâmica familiar de crianças com transtorno do espectro autista

Prácticas alimentarias y reorganización de la dinámica familiar de niños con trastorno del espectro autista

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This is a multiple case study qualitative-descriptive research, conducted in two services for children with special needs in a municipality in the Southern region of Brazil, from August 2018 to March 2019. It aimed to describe the organization of families related to the eating habits of children with Autistic Spectrum Disorder. Audiorecorded interviews were used and the analysis was carried out by the cross synthesis technique. Twenty-seven family members participated, mostly women and mothers. Two categories emerged: *Reorganization of the family dynamics of eating practices*, and *Needs, limits and potential of support networks*. There was a need of family reorganization to meet the child's condition, given the difficulties in communication and socialization that influenced the family's eating habits; participants also highlighted the limitations and the family financial condition that influenced the child's care. The impact on food does not exclusively consider the child's atypical eating characteristics, but demands the family's reorganization to understand, adapt and offer food, thus reorganizing the dynamics of families. Furthermore, there is a need for articulation between the family and the qualified support network, both formal and informal, which can contribute to positive changes.

**Descriptors:** Family; Autism spectrum disorder; Child care; Family relations; Feeding behavior.

Esta é uma pesquisa com abordagem qualitativa do tipo estudo de casos múltiplos com caráter descritivo, conduzida em dois serviços de atendimento a crianças com necessidades especiais de um município da região sul do Brasil, no período de agosto de 2018 a março de 2019, com objetivo de descrever a organização das famílias relacionada às práticas alimentares de crianças com Transtorno do Espectro Autista. Utilizou-se entrevistas audiogravadas e a análise se deu por técnica de síntese cruzada. Participaram 27 familiares com predominância de mulheres e mães. Emergiram duas categorias: *Reorganização da dinâmica familiar das práticas alimentares*, e *Necessidades, limites e potencialidades das redes de apoio*. Verificou-se a necessidade de reorganização da família para atender a nova condição da criança, frente às dificuldades de comunicação e socialização que impactaram nas práticas alimentares da família; também apontaram-se as limitações e a condição financeira familiar que influenciou no cuidado da criança. O impacto na alimentação não considera exclusivamente as características alimentares atípicas da criança, mas demanda a reorganização da família para compreender, se adaptar e oferecer os alimentos, reorganizando-se assim a dinâmica das famílias. Ademais, há necessidade de articulação da família com a rede qualificada de apoio, formal e informal que podem contribuir para as mudanças positivas.

**Descritores:** Família; Transtorno do espectro autista; Cuidado da criança; Relações familiares; Comportamento alimentar.

Esta es una investigación con un enfoque cualitativo del tipo estudio de casos múltiples con carácter descriptivo, realizada en dos servicios de atención a niños con necesidades especiales en un municipio de la región sur de Brasil, en el período comprendido entre agosto de 2018 y marzo de 2019, con el objetivo de describir la organización de las familias relacionada con las prácticas de alimentación de los niños con Trastorno del Espectro Autista. Se utilizaron entrevistas grabadas en audio y el análisis se realizó mediante la técnica de síntesis cruzada. Participaron 27 miembros de la familia, predominantemente mujeres y madres. Surgieron dos categorías: *Reorganización de la dinámica familiar de las prácticas alimentarias*, y *Necesidades, límites y potencialidades de las redes de apoyo*. Se verificó la necesidad de reorganización de la familia para atender la nueva condición del niño, frente a las dificultades de comunicación y socialización que impactaron en las prácticas alimentarias de la familia; también se señalaron las limitaciones y la condición financiera de la familia que influyeron en el cuidado del niño. El impacto en la alimentación no considera exclusivamente las características alimentarias atípicas del niño, sino que exige la reorganización de la familia para comprender, adaptar y ofrecer alimentos, reorganizando así la dinámica de las familias. Además, es necesaria la articulación de la familia con la red cualificada de apoyo formal e informal que puede contribuir a los cambios positivos.

**Descritores:** Familia; Trastorno del espectro autista; Cuidado del niño; Relaciones familiares; Conducta alimentaria.

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## INSTRUCTION

It is estimated that one in every 59 children is diagnosed with Autism Spectrum Disorder (ASD)<sup>1</sup>. The prevalence has increased over the years due to the expansion of diagnostic criteria, a more comprehensive definition of the disorder, as well as public and worldwide awareness of the disorder and its symptoms<sup>2</sup>.

ASD is defined as a behavioral syndrome consisting of a deficit in communication, social interaction, in association with the presence of restricted and repetitive patterns of behavior, interests or activities, and unusual responses to sensory stimuli<sup>2</sup>.

Although the formal definitions of ASD do not include sensory processing alterations, they are one of the relevant characteristics of the disorder. Such dysfunctions refer to hyper or hyposensitivity of hearing, olfactory, taste, visual and tactile sensitivity<sup>3,4</sup>. These attributes interfere in activities of daily living, and are related to food, as children with ASD start to have preferences for food taste, aroma, texture, appearance and temperature; to excess of specific foods; in addition to difficulties such as the noise generated while chewing food<sup>3,4</sup>.

Food selectivity and consequent refusal of different foods are the most common eating problems, in addition to being a recurrent concern in healthy eating practices and behaviors, as they can cause nutritional and growth deficits. The consumption of several nutrients, such as calcium, vitamin D and E, iron, zinc and fiber, is lower in children with ASD when compared to children with typical development<sup>4</sup>.

In this context, it is understood that the meal ritual is part of family routines in which the child with ASD can interfere in different ways, both by acceptability and refusal of food, by not tolerating changes in mealtime, location and, in some cases, even the use of cutlery, plates, specific glasses<sup>5</sup>.

Changes in the family's healthy eating practices and behaviors are necessary due to the important characteristics presented in ASD, resulting in an increase in the demand for care and dependence on the family, especially during meals. All of this makes it essential to pay greater attention to the planning and execution of these practices<sup>4</sup>, making family eating practices more challenging<sup>3,4</sup>.

It is noteworthy that when thinking about the child with ASD, it should be considered in a larger context, through aspects of family dynamics, so that the look becomes more comprehensive and integral in relation to the space in which it is inserted, as well as the organization of care that family members start to offer the child in their daily lives<sup>6-8</sup>. Family dynamics incorporates other aspects of daily life, such as the roles that individuals start to exercise daily and the feelings of its members, especially those directly involved in child care<sup>7,8</sup>.

In view of this, some studies<sup>7-9</sup> indicate that the work of health professionals is usually directed towards biological aspects of care, restricting attention to the child's condition, the promotion and management of symptoms, not considering the family as a care unit. Thus, this work aimed to describe the organization of families related to the eating habits of children with Autistic Spectrum Disorder.

## METHODS

This is a research with a qualitative approach of the multiple case study type with a descriptive character<sup>10</sup>. The study was conducted in two services for children with special needs in a municipality in the southern region of Brazil: an Association of Families and Friends of Children with Special Needs (*Associação de Familiares e Amigos de Crianças Portadoras de Necessidades Especiais - AFACPNE*), which offers educational and rehabilitation services, and a Center Child Neurology, which provides health care through the Unified Health System (SUS); study carried out from August 2018 to March 2019.

The following inclusion criteria were adopted: being a relative of a child with ASD between four and ten years old, living in the same house as the child and participating in their care. Family members who lived in the same house with the child were considered because they experience the care dynamics that occur in daily life. The exclusion criterion was being a minor.

The selection of children with the age group described above is justified by the fact that the diagnosis of ASD occurs more frequently at three years of age. Thus, the families of four-year-old children already experience this condition for a period of time sufficient to generate an organization for the care of the child, enabling them to respond to the object of this study. After ten years of age, children's needs start to refer to the adolescence phase, which is not the focus of this study.

Semi-structured interviews were conducted, with a script including: sociodemographic data and introductory questions; then, questions related to the experience of families involving routines and their organization in the care of children with ASD. The average duration of the interviews was 30 minutes, and they were audio recorded using a digital recorder. At the Child Neurology Center, data collection took place during scheduled outpatient visits. 48 hours before the consultation, a survey of potential participants was carried out, being pre-selected according to the inclusion criteria. On consultation days, the pre-selected family members were asked about the other eligibility criteria and their interest in participating in the study.

At AFACPNE, collection was scheduled at the institution, with each family that had shown interest in participating in the study after pre-selection, which was based on the list of children enrolled in the institution who met the eligibility criteria.

Data analysis followed three main points described by the case study method<sup>10</sup>, comprising the preparation of the material, the analytical strategy and the analytical technique. The preparation of the material began with the transcription of the interviews in documents in Microsoft® Office Word format. To preserve anonymity of the participants, the reports were coded using the letter "F", which represents family, sequenced by Arabic numerals, corresponding to the order of the interview.

After transcription, the interviews were checked by the participants who chose to receive them via email or Whatsapp message, according to their preference. None of them requested changes on the content of the interview after reading it.

The analytical strategies selected for this study were: "Treating your data from scratch", which assumes that theoretical propositions are not thought, the researcher lets himself be carried away by the data based on the identified insights<sup>10</sup>; and "Development of the case description", which helps to understand the evidence of each family by grouping thematic categories and subcategories<sup>10</sup>.

The Qualitative Data Analysis Software (WebQda) was used to help organize data, making it possible to identify the categories and subcategories of this study. This software was chosen for the benefit of being an operating system, with online tools that allow interaction and sharing with other researchers during data analysis, thus providing validation of the analyzes carried out by the group of researchers<sup>11</sup>.

From this organization, the data were analyzed following the analytical technique of cross synthesis, which allows analyzing the divergent and convergent elements to cross-synthesize the cases considering general aspects of those that do not replicate. This analysis technique must be developed with strong, plausible and impartial arguments, supported by the data<sup>10</sup>.

This research was submitted to the Ethics Committee for Research Involving Human Beings according to the precepts of resolution n. 466/2012 of the National Health Council -CNS, according to the Research Involving Human Beings standards, and approved under Opinion No. 2.327.633. Participants were informed about the topic and objectives of the research and those who agreed to participate signed the Informed Consent Form.

## RESULTS

The initial pre-selection sample counted 66 potential participants: 30 were excluded for not meeting the inclusion criteria; eight did not attend the appointment or scheduled interview; and one family refused. Thus, 27 family members participated, delimited by theoretical saturation, when there was no additional information (Chart 1).

**Chart 1.** Families of children with ASD surveyed by location. Paraná, 2019.

Location	Samples (pre selection)	Excluded*	Absence to consultation or scheduled interview	Refusal	Final sample
AFACPNE	16	4	1	0	11
Child Neurology Center	50	26	7	1	16
<b>Total</b>	66	30	8	1	27

Key: \* Excluded for not meeting the eligibility criteria.

The participation of 27 family members was obtained, with a mean age of 36.59 years: 93% (n=25) were female; 89% (n=24) were the children's mothers; 52% (n=14) were married; and 37% had more than 13 years of education. The average income of the participants was R\$3,278.00, with a minimum value of R\$990.00 and a maximum of R\$20,000.00. The children's mean age was 6.29 years and they had been living with the childhood diagnosis, on average, for 2.82 years (Table 1).

**Table 1.** Characterization of family members and children with ASD. Paraná, 2019.

Respondents' gender	N	%
Female	25	93
Male	2	7
<b>Familial relationship to the child with ASD</b>		
Mother	24	89
Father	2	7
Grandmother	1	4
<b>Marital status</b>		
Married	14	52
Civil union	5	19
Single	6	22
Widowed	1	4
Divorced	1	4
<b>Years of education</b>		
Up to 5 years	3	11
Between 5 and 9 years	8	30
Between 9 and 12 years	6	22
13 years or more	10	37
<b>Family income</b>		
Up to R\$ 1,000.00	6	22
Between R\$ 1,000.00 - R\$ 2,000.00	10	37
Between R\$ 2,000.00 - R\$ 5,000.00	8	30
Over R\$ 5,000.00	2	7
No information	1	4
<b>Child's gender</b>		
Female	8	30
Male	19	70

Based on the analysis of the interviews, two thematic categories emerged: *Reorganization of the family dynamics of eating practices*, and *Needs, limits and potential of support networks*.

### ***Reorganization of the family dynamics of eating practices***

Here are demonstrated the changes in the condition of the child diagnosed with ASD that lead to changes in family dynamics; over time, the family reorganizes to its new condition. Some families mentioned difficulty in carrying out this reorganization, thus emerging reports of instability, difficulties and anxiety, which also affect the child:

*I think the first step is to accept, organize and then the rest goes on. (F18)*

*In the beginning, until we understood what autism really was, and started to put into practice what we learned in therapy, it took some time. (F1)*

*We try to take care of his rituals. Because he needs rituals, bathing, care and food. (F1)*  
*And he knows he has a routine, like going to the doctor, so, and with it [routine] he's super well. (F13)*  
*We get lost in the day-to-day situation, I think I should have follow-up, so I can instruct myself to take care of him. (F8)*  
*It is very difficult because we are not used to it. (F20)*  
*We have to have a routine, because if we get out of the routine there, she freaks out, as she says, she doesn't accept it. (F14)*

There is an impact on the characteristics of the selective eating behavior of children with ASD, which has an influence on the child's eating habits and on the family's routine:

*In autism, there is a lot of restriction on food, they almost don't eat, now that he is eating better, but he doesn't accept much, it's very restricted, they're very annoying in this part. (F13)*  
*So, that's what she wants at the time. It has to be at that time and if there isn't what she prefers [food], we try to explain and she doesn't understand. (F14)*  
*We offer one thing, offer another, what she wants, she eats or drinks. (F20)*  
*He just likes expensive fruit, for example, he likes guava, he likes grapes, he likes strawberries, so I don't always have it to give it to him. (F8)*  
*He does food therapy, it's to initiate him, try a new fruit, he leaves there eating the fruit. So he comes home and tries it, and he wants it, and he likes it. (F1)*  
*He does have his behavioral issues at meals, as any autistic person does. But we've seen a lot of improvement after he started school. (F18)*

Furthermore, the difficulties and advances perceived in relation to communication and socialization of children with ASD and their families were highlighted. Respondents reported places and ways they seek to encourage the child's social interaction, as well as the child's daily communication progress, which are correlated with eating habits:

*It seems to my son that he is uncomfortable like this, a lot of turmoil. (F18)*  
*We go out with her to lunch at a restaurant. But everything has to be done quickly, because if she's finished eating and there isn't something there, a toy, or a playground, we have to eat quickly and leave, because she doesn't have patience. (F14)*  
*She stopped talking [...] there is no way for us to know when she is hungry, or when she is thirsty. (F20)*  
*He gets nervous, if I say "go son, say banana" [...] It's the moment I already give it, because I get nervous too, because I don't want him to cry. (F8)*  
*Even his speech is a little better, he still has difficulty, but we already understand when he asks, other people outside also understand what he says. (F13)*  
*He shows how he wants things, he doesn't show exactly what, but it's easier. (F18)*  
*After many attempts, on birthdays, he stays, sings happy birthday, behaves, something he didn't do before. (F13)*  
*We try to go out with the family, yes, restaurant [...] Rural lunch, we do a lot. (F1)*

### **Needs, limits and potential of support networks**

This category indicated elements that make up the formal network that the family seeks to promote monitoring and development of children with ASD, such as specialized health services. Also noteworthy are the restrictions in the family support network, and the potential of groups of mothers promoted by the social network Whatsapp among families experiencing the same situation:

*I am taking her to the center of the person with a disability. (F20)*  
*We seek these services [therapies], because she needs follow-up. Now in June it has been a year since she started therapy, and she has improved a lot. (F14)*  
*Today he is developing well with therapy, [...] as the number of follow-ups has increased. (F1)*  
*We were a family of four, so we shared the problem, because she is very nervous, always fighting, always hitting. (F20)*  
*My biggest difficulty in this case is being alone when he has a crisis on the street, or somewhere. (F8)*  
*I even have close relatives [...], but I don't have this help. This little way of dealing with him just me, they are a little afraid of him crying and they don't know how to calm down. (F18)*  
*I participate in a mothers group on Whatsapp. There, they post all the information. What helps me the most is the group. (F13)*

Families also explained the possibilities and limits of their financial condition that influenced the care of the child or access to social benefits:

*At home I can't even afford to buy some things for her, because I've stopped working now. (F20)*  
*There is no specific amount, they help me [family], they send it according to what they can send me [...] they help because they need it. (F8)*

*We end up not looking for this [benefits]. We end up buying the medicine he needs. (F1)*

*Thank God we have a financial condition to be able to do the therapies, pay for her plan and everything else. (F14)*

## DISCUSSION

The diagnosis of ASD causes instability in the family's organization, due to the different needs that are demanded by the new condition of the child. Establishing new routines<sup>12</sup> was identified as challenging for families. This is due to the characteristics related to the development and behavior associated with the disorder, which are correlated with the need of learning to deal with new routines and rituals of their children<sup>13</sup>.

Children with ASD enjoy predictable environments and may feel uncomfortable if their routines are interrupted or changed. Likewise, they may have difficulties in transitioning from one activity to another, such as stopping playing to go to lunch; they may have sensory overload (smell, taste, hearing and vision), which can lead to a crisis during the act of eating and generate unexpected behavior<sup>14</sup>. These changes become part of the family dynamics and require an intense change in the caregiver's role, starting with the need to learn and understand the child with ASD, as mentioned by the mothers. Furthermore, there are many quirks that only they notice.

Eating habits are influenced by the characteristics of the disorder, because, due to communication disorders, these children may have difficulties in understanding what is happening around them, and not understanding what other people are saying. Sometimes they are unable to communicate their desires regarding food. Such characteristics can generate unwanted behavior<sup>14</sup>. That is why the mothers' responses often perceive the need to maintain the rituals and immediately attend to what the child requires to avoid a crisis. These aspects become part of the new context of families' lives.

For families, strategies are important to deal with the child's condition in the daily dynamics, as well as to identify aspects of greater difficulty in their daily lives<sup>13</sup>. Therefore, family dynamics require family members to play the role of a specialized caregiver to understand the child, provide nutrition through the transposition of barriers imposed by the disorder and, at the same time, encourage child development.

The confrontations of the families surveyed to promote the reorganization of family dynamics corroborate a study carried out in Australia with mothers of children with ASD, which pointed out that the experience of managing these routines can cost the health and well-being of mothers<sup>15</sup>.

In eating practices, selective eating behaviors of the child were identified, such as tension at meals, especially sensory ones, similar to other study<sup>16</sup>. Other investigations<sup>17,18</sup> mention that children persist in consuming the same foods, with the same textures, requiring not only types of foods, but also brands and specific moments. This restriction in the eating practices of children with ASD is perceived as idiosyncratic, which can lead the child to try to create some control and certainty regarding their peculiar characteristics in feeding<sup>19</sup>. However, they start to demonstrate challenging behaviors and chaotic routines in family dynamics.

To deal with the child's food selectivity, the families expressed strategies, such as the search for services that provide a more positive eating experience for their child through therapies focused on food, school environment and support from specialized professionals. These findings are in line with international studies<sup>17,18</sup> that recommend that it is necessary to carry out a combination of strategies aimed at the child's eating behavior, such as therapies that involve food and individualized nutrition education guidelines, to establish a balanced and adequate food plan in accordance to the needs of the child with ASD.

In addition to the context outside the home, it is important to train parents to develop tactics also during meals at home<sup>20</sup>, added here, the need for parents to learn to deal with the child on a daily basis, that is, families need to be involved in the therapeutic process.

In a study<sup>20</sup> with interventions in meals of families with children with ASD, they demonstrated that the methods used by parents led children to stay at the table, they started to interact with family members or ingested a greater amount of a preferred food in the presence of the parents. Interventions should focus on aspects of the child's selective eating behavior, such as keeping children at the table and providing a better experience of eating practices during meals with family members<sup>20</sup>.

Socialization and communication, as a result of advances and restrictions perceived in the social life of children and their families, were pointed out. Promoting the child's socialization is essential<sup>21,22</sup>, as it is in childhood that one starts to understand that there are different places and people to socialize, in addition to the family environment and, thus, relationships begin to be built, also promoting leisure activities, which are important for well-being<sup>21</sup>, and will positively impact the eating habits of this group, such as birthdays.

Aspects of the eating routine are still difficult to change for children with ASD, and positive family, social and emotional experiences in daily occupations are fleeting and generate a negative impact on the development of significant interactions and rituals related to socialization<sup>19</sup>.

Families with children with ASD tend to express greater difficulty, given the characteristics of social isolation that they present on a daily basis<sup>5,22</sup>. It is up to families to propose strategies to encourage their children's social participation<sup>19</sup>. This study showed the advances in the child's social life due to the family's attempts to encourage them to communicate and attend festive and public environments. Despite this, such activities are inserted in a context of the children's ritual, because, from the moment that eating ends, the family leaves that environment, because the situation is permeated by the fear that the child will present unwanted behavior.

The specialized services that families seek for their child's care were highlighted. Interventions aimed at early childhood development and follow-up produce favorable outcomes for individuals with ASD. Furthermore, the fact that no single intervention was universally effective for all children with ASD proved to be important in the search for different professionals to provide such care<sup>23</sup>.

Formal support was perceived; however, family support was restricted and perceived as a hindrance. Lack of support is seen as not having a person capable of caring for and understanding the child with ASD, rather than the absence of a close family. This demonstrates how much the child needs specialized support.

Some families reported receiving, through social networks, informal support from others who experience the same condition, which are perceived as important elements of support as they can share specialized information for child care with them. A study<sup>24</sup> that evaluated the support network through a social network indicated that the highest percentage of support received by families of children with ASD was about informational support, followed by emotional support. Most of the messages exchanged between participants discussed and addressed challenges and difficulties associated with caring for and raising children with ASD, as well as issues such as children's social lives and self-care routines, which corroborates the findings of this study.

Other factors perceived as barriers for the care of children with ASD involve the family's social condition, such as parental unemployment, the family's difficulty in providing food and housing, and parents' stress when caring for the child<sup>25,26</sup>.

In this study, it was mentioned that financial deficit influences the supply of food that children want, as many mothers end their professional lives to provide childcare and this reduces the family's income. These families come to depend on the financial support of other family members to promote care. However, some families reported having favorable financial

conditions. The financial condition of families is a relevant element, most of them feel an impact on their financial condition when caring for a child with complex medical conditions<sup>27</sup>.

Families seeking social support, both from professionals and services (formal) and from family and friends (informal), have a better quality of life<sup>24</sup>. However, for families to seek this care network, it is necessary to provide them with the necessary information for the care of their children with ASD<sup>25</sup>. This is an essential strategy to reduce the needs demanded by unmet children.

## CONCLUSION

The change in the health condition of children with ASD proposes a systemic change in the family that goes beyond rational care, as it requires a refined look to meet the child's needs and, at the same time, stimulate their development.

It is important for the family to establish eating practices and behaviors that minimize impacts on the child with ASD due to their atypical characteristics, such as food selectivity, difficulty in communicating and adapting to different places and environments for meals.

Coping with this new condition of life is facilitated when the family is articulated with the qualified network of formal support and information, which can contribute to positive changes in the family dynamics to meet the needs. At the same time, health professionals must perceive the family beyond the biological dimension, considering it the protagonist of the care process.

Public policies must prioritize the complex dimensions of care, and its articulation with the care network; notably, the offer of benefits that can contribute to minimizing negative impacts of the recognition of the ASD diagnosis and of this change in the daily lives of families, thus strengthening a comprehensive care for them so that they are able to offer the necessary support to children with this condition.

As a limitation of this study, the participants were predominantly mothers who were accompanying the child. It is believed that the participation of other family members who take care of the child with ASD could have enriched the identified data. The results of this research cannot be generalized, given the size of the sample and for having been selected only in a certain geographic area of the country.

Thus, it is suggested that similar investigations be replicated in other geographical areas of the country and longitudinally, as it is necessary to compare the findings in other realities, as the reorganization of care and eating practices is related to social and cultural issues, as well as to the dynamics of families.

## REFERENCES

1. Christensensn DL, Maenner MJ, Bilder D, Constantino JN, Daniels J, Durkin MS et al. Prevalence and characteristics of autism spectrum disorder among children aged 4 years — Early Autism and Developmental Disabilities Monitoring Network, Seven Sites, United States, 2010, 2012 and 2014. *Morb Mortal Wkly Rep.* [Internet]. 2019 [cited in 01 Oct 2020]; 68(SS-2):2-3. Available from: <https://www.cdc.gov/mmwr/volumes/68/ss/pdfs/ss6802a1-H.pdf>
2. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (DSM-5)* [Internet]. 5th ed. Washington, DC: American Psychiatric Publishing; 2013 [cited in 02 Oct 2020]. p. 50-9. Available from: <https://cdn.website-editor.net/30f11123991548a0af708722d458e476/files/uploaded/DSM%2520V.pdf>
3. Constantinidis TC, Silva LCS, Ribeiro MCC. “Todo mundo quer ter um filho perfeito”: vivências de mães de crianças com autismo. *Psico USF* [Internet]. 2018 [cited in 01 Oct 2020]; 23(1):47-58. DOI: 10.1590/1413-82712018230105
4. El-Kour T, Olive M, Neophytou N, Pretorius S. Nutrition and dietary considerations during treatment of autism spectrum disorder [Internet]. In: Das U, Papanephytous N, El-Kour T,



- editors. *Autism 360°*. Cambridge: Academic Press; 2020 [cited in 01 Jul 2021]. p. 329-38. DOI: <https://doi.org/10.1016/B978-0-12-818466-0.00018-6>
5. Poulain JP, Proença RPC, Diez-Garcia RW. Diagnóstico das práticas e comportamento alimentares: aspectos metodológicos. In: Diez-Garcia RW, Cervato-Mancuso AM, organizadoras. *Mudanças alimentares e educação nutricional*. Rio de Janeiro: Guanabara Koogan; 2016. p. 149-63.
6. Factor RS, Ollendick TH, Cooper LD, Dunsmore JC, Rea HM, Scarpa A. All in the family: a systematic review of the effect of caregiver-administered autism spectrum disorder interventions on family functioning and relationships. *Clin Child Fam Psychol Rev*. [Internet]. 2019 [cited in 02 Oct 2020]; 22:433–57. DOI:10.1007/s10567-019-00297-x
7. Hennel S, Coates C, Symeonides C, Gulenc A, Smith L, Price AMH, et al. Diagnosing autism: contemporaneous surveys of parent needs and paediatric practice. *J Paediatr Child Health* [Internet]. 2016 [cited in 19 Mar 2021]; 52(5):506-11. DOI: <https://doi.org/10.1111/jpc.13157>
8. Oliveira EN, Silva AMP, Ribeiro MA, Lopes RE, Queiroz IFR, Furtado JPRX, et al. A dinâmica familiar diante da pessoa com transtorno do espectro autista. *Rev Pesq Saúde* [Internet] 2017 [cited in 19 Mar 2021]; 18(3):151-6. Available from: <http://www.periodicoseletronicos.ufma.br/index.php/revistahuufma/article/viewFile/8783/5904>
9. Molteni P, Maggiolini S. Parents' perspectives towards the diagnosis of autism: an Italian case study research. *J Child Fam Stud*. [Internet]. 2015 [cited in 19 Mar 2021]; 24(4):1088-96. DOI: <https://doi.org/10.1007/s10826-014-9917-4>
10. Yin RK. *Estudo de caso: planejamento e métodos*. 5ed. Porto Alegre: Bookman; 2015. 320p.
11. Machado ALG, Vieira NFC. Use of webQDA software on qualitative nursing research: an experience report. *Rev Bras Enferm*. [Internet]. 2020 [cited in 12 Oct 2020]; 73(3):e20180411. DOI: 10.1590/0034-7167-2018-0411
12. Bagatell NJ, Cram M, Alvarez CG, Loehle, L. Routines of families with adolescents with autistic disorders: a comparison study. *Can J Occup Ther*. [Internet]. 2014 [cited in 09 Oct 2020]; 81(1):62–7. DOI: 10.1177/0008417414520691
13. Chavez AE. Parent negative and positive impacts: reciprocal associations between child behaviors and parenting experiences in families of children with autism spectrum disorder [Internet]. [dissertation]. Boston, MA: University Of Massachusetts Boston; 2019 [cited in 01 July 2021]. 65p. Available from: [https://scholarworks.umb.edu/masters\\_theses/574/](https://scholarworks.umb.edu/masters_theses/574/)
14. Sharma R, Ghimire S, Dhungel KU. Autism and food selectivity. *J Med Sci*. [Internet]. 2020 [cited in 12 Apr 2021]; 8(1):64-74. DOI:10.3126/jmcjms.v8i1.31560
15. McAuliffe T, Thomas Y, Vaz S, Falkmer T, Cordier R. The experiences of mothers of children with autism spectrum disorder: managing family routines and mothers' health and wellbeing. *Aust Occup Ther J*. [Internet]. 2019 [cited in 09 Oct 2020]; 66(1):68-76. DOI: 10.1111/1440-1630.12524
16. Waizbard-Bartov E, Yehonatan-Schori M, Golan O. Personal growth experiences of parents to children with autism spectrum disorder. *J Autism Dev Disord*. [Internet]. 2019 [cited in 09 Sep 2020]; 49:1330-41. DOI:10.1007/s10803-018-3784-6
17. Sharp WG, Burrell TL, Berry RC, Stubbs KH, McCracken CE, Gillespie SE, et al. The autism managing eating aversions and limited variety plan vs parent education: a randomized clinical trial. *J Pediatr*. [Internet]. 2019 [cited in 09 Sep 2020]; 211(1):185-92. DOI: 10.1016/j.jpeds.2019.03.046
18. Curtiss SL, Ebata AT. The nature of family meals: a new vision of families of children with autism. *J Autism Dev Disord*. [Internet]. 2019 [cited in 15 Sep 2020]; 49(2):441–52. DOI: 10.1007/s10803-018-3720-9

19. Marquenie K, Rodger S, Mangohig K, Cronin A. Dinnertime and bedtime routines and rituals in families with a young child with an autism spectrum disorder. *Aust Occup Ther J*. [Internet]. 2011 [cited in 15 Sep 2020]; 58(3):145–54. DOI:10.1111/j.1440-1630.2010.00896.x
20. Ausderau KK, John B, Kwaterski KN, Nieuwenhuis B, Bradley E. Parents' strategies to support mealtime participation of their children with autism spectrum disorder. *J Occup Ther*. [Internet]. 2019 [citado em 15 set 2020]; 73(1): 7301205070. DOI: 10.5014/ajot.2019.024612
21. Hilton C, Ratcliff K, Hong I. Trajectory of leisure participation among children with autism spectrum disorders from childhood through adolescence. *Am J Occup Ther*. [Internet]. 2019 [cited in 15 Sep 2020]; 73(4):7311520425. DOI: 10.5014/ajot.2019.73S1-PO3042
22. Degrace B, Smith J. Family social participation in young children with autism: phenomenological analyses. *Am J Occup Ther*. [Internet]. 2019 [cited in 15 Sep 2020]; 73(4):73115051591. DOI: 10.5014/ajot.2019.73S1-PO6008
23. Maw SS, Haga C. Effectiveness of cognitive, developmental, and behavioural interventions for autism spectrum disorder in preschool-aged children: a systematic review and meta-analysis. *Heliyon* [Internet]. 2018 [cited in 09 Oct 2020]; 4(9): e00763. DOI: 10.1016/j.heliyon.2018.e00763
24. Roffeei SHM, Abdullah N, Basar SKR. Seeking social support on Facebook for children with Autism Spectrum Disorders (ASDs). *Int J Med Inform*. [Internet]. 2015 [cited in 21 Oct 2020]; 84(5):375-85. DOI: 10.1016/j.ijmedinf.2015.01.015
25. Burke MM, Rios K, Garcia M, Sandman L, Lopez B, Magaña S. Examining the perspectives of Latino families of children with autism spectrum disorder towards advocacy. *Exceptionality* [Internet]. 2018 [cited in 09 Oct 2020]; 27(3):201-14. DOI:10.1080/09362835.2018.1433041
26. Karpur A, Lello A, Fraizer T, Dixon PJ, Shih AJ. Health disparities among children with autism spectrum disorders: analysis of the National Survey of Children's Health 2016. *J Autism Dev Disord*. [Internet]. 2019 [cited in 09 Oct 2020]; 49(4): 1652-64. DOI: 10.1007/s10803-018-3862-920
27. Mooney-Doyle K, Lindley LC. The association between poverty and family financial challenges of caring for medically complex children. *Nurs Econ*. [Internet]. 2019 [cited in 21 Oct 2020]; 37(4)198-212. Available from: <https://go.gale.com/ps/anonymous?id=GALE%7CA599442207&sid=googleScholar&v=2.1&it=r&linkaccess=abs&issn=07461739&p=AONE&sw=w>

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**Victoria Beatriz Trevisan Nobrega Martins Ruthes** and **Verônica de Azevedo Mazza** contributed to the design, collection and analysis of data, and writing and reviewing. **Mariana Borba Ribeiro** participated in the design, collection and analysis of data and writing. **Gisele Weissheimer** contributed to the writing and reviewing. **Cibelly Aliny Siqueira Lima Freitas** contributed to the reviewing.

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