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Original Article

"This boy doesn't eat" – Mothers' narratives about food selectivity and autism

"Esse menino não come" – Narrativas de mães sobre seletividade alimentar e autismo

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Abstract

Introduction: Eating difficulties are increasingly present in childhood, with emphasis on food selectivity. The experience of eating together for families of children with autism and food selectivity is perceived by mothers as exhausting and stressful. **Objective:** To understand maternal representations about the food selectivity of their children with autism. **Method:** Phenomenological research carried out with mothers of children with autism and food selectivity. In-depth interviews were carried out to collect data; the interpretation was made through Thematic Analysis. **Results:** The analysis allowed the formation of five categories. The first highlighted the maternal perception of the onset of eating problems during breastfeeding and food introduction; and the main difficulties during eating. The second category addresses the diagnostic discovery and the feelings of insecurity, guilt and relief triggered. Overload of care, abandonment of occupational roles, self-questioning and strategies used to improve the child's nutrition are addressed in the third category. The fourth theme comprises the support network offered by spouses and family members, perceived as insecure, in contrast to the substantial support from other mothers in similar situations. Future fears and desires were perceived and associated with conditions of stress, depression and anxiety in the fifth category. **Conclusion:** Food selectivity causes maternal exhaustion, abandonment of occupational roles, psychological suffering and is disruptive to family daily life. Identifying signs of risk and intervening early, involving caregivers, seems to be a crucial measure of the needs of the problem. Further studies are suggested that investigate these measures.

Keywords: Food Fussiness, Autism Spectrum Disorder, Mother-child Relationships, Occupational Therapy.

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Resumo

Introdução: Dificuldades alimentares são cada vez mais presentes na infância, em destaque a seletividade alimentar. A experiência da refeição conjunta para famílias de crianças com autismo e seletividade alimentar é percebida por mães como exaustiva e estressante. **Objetivo:** Compreender as representações maternas acerca da seletividade alimentar de seus filhos com autismo. **Método:** Pesquisa fenomenológica realizada com mães de crianças com autismo e seletividade alimentar. Foram realizadas entrevistas em profundidade para coleta de dados; a interpretação foi feita por intermédio da Análise Temática. **Resultados:** A análise permitiu a formação de cinco categorias. A primeira evidenciou a percepção materna do início dos problemas alimentares durante o aleitamento e introdução alimentar; e as principais dificuldades durante a alimentação. A segunda categoria aborda a descoberta diagnóstica e os sentimentos de insegurança, culpa e alívio desencadeados. Sobrecarga de cuidados, abandono de papéis ocupacionais, autoquestionamentos e estratégias utilizadas para melhorar a alimentação da criança são abordados na terceira categoria. A quarta temática compreende a rede de apoio ofertada por cônjuges e familiares, percebida como insegura, em contrapartida ao apoio substancial de outras mães em situações semelhantes. Medos e desejos futuros foram percebidos e associados a condições de estresse, depressão e ansiedade na quinta categoria. **Conclusão:** A seletividade alimentar provoca esgotamento materno, abandono de papéis ocupacionais, sofrimento psicológico e é disruptiva ao cotidiano familiar. Identificar sinais de riscos e intervir precocemente envolvendo cuidadores parece ser medida crucial às necessidades da problemática. Sugere-se mais estudos que investiguem essas medidas.

Palavras-chave: Seletividade Alimentar, Transtorno do Espectro Autista, Relações mãe-filho, Terapia Ocupacional.

Introduction

Eating difficulties are increasingly present in childhood and have become a frequent complaint in the offices of pediatricians and other child development professionals. The literature does not present a consensus on the definition and conceptual structure of eating difficulties in childhood, with existing diagnoses being insufficient to describe the multiple factors involved (Santana & Alves, 2022; Trofholz et al., 2017; Chatoor & Ganiban, 2003), and this gap leads to difficulties in identification and appropriate professional intervention. Despite the lack of a universally accepted definition of eating difficulties, some studies show a greater frequency of food selectivity, followed by low appetite and food phobia (Okuizumi et al., 2020; Maranhão et al., 2017; Benjasuwantep et al., 2013).

The definition of the nomenclature "food selectivity" is not yet well standardized in the literature, but, in general, it is understood that it is a limited intake of a variety of foods and refusal of most new foods and nutrients that may be available as based on organic, sensory and motor issues (Oliveira & Souza, 2022; Bellefeuille, 2014). Food selectivity can happen to any child, however, it is more commonly reported in children

with developmental disorders, especially children with autism, than in typically developing children (Adams et al., 2021; Bandini et al., 2010).

Food selectivity has recently been understood, in some rare studies, from a new perspective, which understands the role of parental perception in these difficulties, where the relationship between parents and the child, as well as care practices, can influence the management of these problems (Müller et al., 2018; Kerzner et al., 2015; Ausderau & Juarez, 2013). Parenting practices in families of children with autism are confronted with parental expectations and the child's current environmental and developmental conditions, which generates instability and parental stress (Silveira et al., 2019; Viana Neto, 2018).

Food selectivity appears as a condition that is usually serious enough to interfere with the family routine, in a way that makes the relationship between parents and children problematic (Müller et al., 2018; Santos, 2017). Studies highlight the negative impact that eating difficulties and problematic mealtime behaviors can have on mothers of children with ASD (Adams et al., 2021; Schmidt & Bosa, 2007).

Food selectivity is a condition that compromises the participation of children and mothers in their own occupations and occupational roles. The child suffers the impact of not being able to adequately perform the task of eating, while the mother finds herself unable to carry out her task of feeding. Together, mother and child, experience the challenge of participating in the co-occupation of feeding and being fed.

Occupational therapists understand that an occupation has the capacity to support or promote other occupations, just as difficulties in performing one occupation can imply difficulties in performance and participation in other occupations (Gomes et al., 2021). For example, it is possible to mention food selectivity, which challenges the occupation of eating and swallowing, as well as feeding and being fed, and can also compromise leisure occupations and social participation in family and community (Ruthes et al., 2021; Bagby et al., 2011).

The current literature on food selectivity has the majority of its productions focused on incidence and prevalence studies, as well as investigations of physiological correlations (Müller et al., 2018; Ekstein et al., 2009; Wright et al., 2007). Most studies emphasize nutritional, growth and development impacts (Santana & Alves, 2022; Magagnin et al., 2021; Molina-López et al., 2021). Few of them focus on investigating the psychological and social experiences of food selectivity for children and their families (Trofholz et al., 2017; Cunliffe et al., 2022).

Therefore, giving a voice to mothers of children with autism and understanding how they experience their children's food selectivity is essential to structure better support and effective care, through the implementation of responsive and evidence-based interventions. Thus, this study aims to understand maternal representations about the food selectivity of their children with autism.

Methodology

Phenomenology is characterized as a philosophical and methodological framework suitable for the purposes of this study, as its purpose is to explore the way in which subjects experience lived events, revealing what is covered up, hidden, to access the essence of things. It is about understanding the subject-phenomenon relationship,

rescuing meanings attributed by the subjects themselves to that specific phenomenon (Gil, 2019; Marconi & Lakatos, 2017). Beliefs, perceptions, attitudes and possibilities of representations are deepened based on the subject's perspective along with the complexity of phenomena in qualitative research, in such a way that unique opportunities arise for attributing meaning to the object of study and possible obtaining new and unexpected information (Bosi et al., 2011).

The in-depth interview, the information collection technique used, is consistent with the dimensions that support the epistemological principles of action in qualitative research. By aiming for a free interaction between the interlocutors, guided by the parameters of the object of study, the in-depth interview allows for a greater deepening of the subjectivity, perceptions, ideas, beliefs, opinions, feelings, experiences, behaviors and actions of the interviewees regarding the object of study. (Minayo & Costa, 2018).

The research was carried out in a care unit for children with autism, located in an early childhood reference center, in the city of Fortaleza – CE. The research period was from October 2023 to April 2024. The participants were mothers over the age of 18, whose children, aged between 3 and 8 years, were diagnosed with autism by a neuropediatrician, and presented complaints of food selectivity, as assessed by the interdisciplinary team (pediatrician, neuropediatrician, nurse, nutritionist, occupational therapist and speech therapist). The team evaluates children's food selectivity based on information provided by the family about the child's diet and the application of self-designed screening questionnaires.

Mothers whose children met the inclusion criteria were invited to participate in the research. Those who agreed to participate responded to the Escala LABIRINTO de Avaliação do Comportamento Alimentar no TEA (Lázaro et al., 2019). This tool aims to track children's eating behavior, and has a specific dimension for food selectivity, which was identified for all children whose mothers were interviewed, corroborating the previous assessment of the interdisciplinary team.

After this moment, the interviews themselves continued, which were carried out in person and individually, in a room suitable for that purpose. The conversations were recorded on a recorder on the interviewer's own cell phone. As this is a phenomenological research, theoretical saturation, obtained by redundancy or repetition of interview responses (Silva & Russo, 2019), was the measure used to conclude the number of participants, which consisted of 7 women.

The sociodemographic profile of the research participants was carried out in order to identify the social context experienced by the families. The seven women interviewed were aged between 26 and 42 years (average of 37 years). Regarding the level of education, only one had incomplete higher education (14.28%) and six completed high school (85.71%).

Regarding the marital status of the participants, four were married (57.14%), two were single (28.57%), and one was in a non-stable relationship (14.28%). Four participants had two children (57.14%) and three had a single child (42.85%). Six mothers (85.71%) were unemployed. Only one participant (14.28%) had informal employment, as a self-employed trader. The income of the study participants was based on the current value of the minimum wage in 2024, which corresponds to R$1,412,00 (one thousand, four hundred and twelve reais). The average family income is

R$1,983,85 and the majority of them (71.42%) receive Continuous Payment Benefit – BPC/LOAS.

Thematic Content Analysis was used with the aim of qualifying the subject's experiences, finding, through understanding meanings, relationships that are established beyond speech itself. Thematic Content Analysis takes place in stages: pre-analysis, exploration of the material or coding, and treatment of the results obtained/interpretation (Minayo & Costa, 2018). During the pre-analysis, a floating reading of the material was carried out to form the *corpus* and subsequent preparation of the material for exploration. Still at this stage, it was possible to formulate some thematic hypotheses.

The material exploration stage consisted of identifying registration and context units, which were grouped into thematic categories. The qualitative data analysis software ATLAS.ti was used to assist in coding and subsequent grouping of categories. The analysis process allowed the formation of five macro thematic categories: "The beginning of everything", "Perception and Diagnosis", "It's time to eat", "Family and support network" and "While the future does not come".

The research received approval from the Research Ethics Committee of the Federal University of Ceará (PROPESQ-UFC), with substantiated opinion number 6,328,770. The study participants signed the Informed Consent Form and had all rights guaranteed by Resolution no. 466/12, of the National Health Council/Ministry of Health, of December 12, 2012 (Brasil, 2012).

Results and Discussion

The organization of empirical material into registration and context units allowed the creation of five macro categories. The first of them, entitled "The beginning of everything", addresses the first signs of problems with food selectivity that were noticed early on by mothers, who observed differences and difficulties in their children during breastfeeding and food introduction. Next, we have the "Perception and Diagnosis" category, which includes the maternal search for explanations for their children's different behaviors, and the different feelings faced with the diagnostic confirmation of autism and food selectivity.

The category "It's time to eat", in third, discusses the child's feeding moments and the triggering of different feelings in mothers. Furthermore, food care demands that create overload for mothers are addressed, as they question their care for the child, at the same time as they seek strategies for the child to be able to eat.

The fourth category addresses the maternal perception of the presence of a quality support network, which is often absent even within the family nucleus. The perception of judgment due to the difficulties children have with eating is also addressed; and the support found in coexistence with other mothers who deal with children who are also selective eaters. The fifth and final category deals with what mothers think about their children's future, the consequences of food selectivity in the long term, fears, fears, but also desires, hopes and motivations.

The beginning of everything

Breastfeeding was the scene of the first feeding difficulties expressed by the children of the mothers in this study; Some managed to breastfeed their children, however, with many difficulties and particularities of the child that drew attention.

> *His diet has always been very complicated, right? First, when he was born, he didn't accept breast milk. He didn't breastfeed* [...] *And when he latched on, he sucked a little and let go quickly, right? So it didn't meet his needs, right?* [...] *He cried when I breastfed him. He kept pushing, you know?* (E3).

Some research, such as that by Jacobi et al. (2003), who carried out a longitudinal study of children from early to mid-childhood, found that children who showed food selectivity exhibited different sucking patterns, sucking less than expected, and some of them refusing to breastfeed. The scholar and researcher in the field of eating problems in childhood, Chatoor (2016), reports, in one of her productions on the subject, that many of the children monitored by her team, and who were later diagnosed with food selectivity, had, as babies, difficulties in sucking the mother's breast, with mothers giving up natural breastfeeding and adopting the use of bottles. The study by Al-Farsi et al. (2012) discusses the presence of difficulties with sucking during breastfeeding, evolving into chewing and swallowing problems, contributing to well-defined food choices, which potentially limit the establishment of a diverse food repertoire.

Some mothers had no difficulty breastfeeding their children: "*From the beginning I didn't have any problems. Neither him latching the breast nor I… giving milk. I didn't have any problems*" (E4). However, even mothers who reported being able to breastfeed their children reported difficulties in the breastfeeding process and atypical breastfeeding experiences, such as poor interaction and low reciprocity between them and their babies.

> *Breastfeeding was strange, because he breastfed and didn't look at me. And I was like 'baby, you're breastfeeding'.* [...] *He was breastfeeding, and I was talking to him, and he didn't laugh, he didn't play.* [...] *I even thought like this: 'my God, he just uses me to be his food and nothing else'* (E2).

Breastfeeding is widely recognized as the first social learning process for humans, which strengthens emotional ties and structures the mother-baby bond (Silva, 2020). And it is precisely because of its socio-emotional nature that the lack of reciprocity during breastfeeding indicates that something is not going well with the baby, making the mother-baby relationship unusual (Pascalicchio et al., 2021).

Reports about the onset of feeding difficulties were not limited to the breastfeeding period; in some cases, they appeared or intensified during the period of food introduction, as mentioned by interviewee E1: "*At six months I started giving soup, right? Then he ate it, but very little, sometimes when he put it in his mouth he wanted to vomit, right?* [...] *He cried when he saw food*". This data corroborates the study by Okuizumi et al. (2020), in which he investigates the origins of food selectivity and identifies food introduction as a critical period.

The moment of food introduction is marked by intense changes in the supply of new foods and the child's eating routine. It is during food introduction that learning

about what it is to eat, how to eat and which flavors belong to our culture is expanded (Favretto et al., 2021). It is expected that during food introduction some degree of normal neophobia will occur as it is an adaptive defense (Gerardo & Macan, 2022). However, the way parents recognize, interpret and deal with the child's first aversive experiences with food will make a difference in the course of future experiences, contributing to making them more, or less, selective (Chatoor, 2016).

All mothers interviewed reported that their children are resistant to eating, especially when offered new foods, especially fruits and vegetables. Among the main manifestations presented by children when offered food are physiological reactions, such as retching and vomiting.

> *Sometimes, when he put it in his mouth, he wanted to vomit, right? Then I thought, 'it's because it's starting now'. Then it passed, and over time it got worse. He didn't want to, he was angry, he wanted to vomit* (E1).

> *After a while he started, when it came to the soup, if there was even a little bit more, a lump of rice, he would start vomiting* (E4).

Mothers report children's behavioral difficulties, described as crying, restlessness and irritability during feeding times, as mentioned by interviewee E4: "*He wouldn't stay quiet, he wouldn't accept it. It was as if you... realized that the child was already suffering, you know?* [...] *He cried... And it was a cry, like that, that was inconsolable. It only stopped when I took away the food*". Studies point out the implications of food selectivity on children's behavior, favoring disruptive behaviors during meals (Lemes et al., 2023; Ausderau et al., 2019).

Another difficulty mentioned by the participants concerns problems with chewing food, limiting the child's acceptance of new foods, as reported below: "*He doesn't chew anything, nothing, nothing... he sucks until it falls apart and he swallows.* [...] *Because all life we've been trying to give H. something that doesn't fall apart, he spits it out*" (E2). The study by Lemes et al. (2023) describes a correlation between motor changes in chewing and food selectivity, sensory sensitivity and behavioral changes related to food.

The narratives of the mothers interviewed about the difficulties and differences observed in their children's nutrition inevitably led the mothers to remember other perceptions of differences in their development that currently make sense for the diagnosis of autism. All children presented some type of delay in neuropsychomotor development, the most common being speech and language delays, poor social reciprocity and motor delays.

> *When I really started to notice, it was around when he was about two, two and a half years old. I started to notice that he started to have difficulty speaking, communicating. He didn't ask for water, he just kept pointing, right?* (E5).

> *He didn't follow, everything was slow* [...] *a still look. I even wanted to know where that look he got was. Rarity, E. looked into our eyes. Very difficult* (E6).

> *K. at 3 months, 4 months, K. couldn't support his body, he was all soft. We thought that K. wouldn't even resist, because he was a soft boy, he couldn't support his neck* (E3).

Poor eye contact, low interaction in social relationships and lack of interest when called by name are considered to be indicators of risk and symptomatological expression of autism (Pascalicchio et al., 2021). Speech and language delays are the first significant signs that mothers notice, along with impairments in social interaction (Monhol et al., 2021; Carvalho-Filha et al., 2018). In addition to differences in social reciprocity and language development, there is evidence that the motor development of children with autism is below what is expected for their chronological age (Teixeira et al., 2019).

Despite the mothers' surprises and suspicions that something is not going well with their children, referral for specialized professional intervention only happened after the age of two, even though the differences were noticed and reported much earlier. Because of this, authors such as Jerusalinsky (2018) emphasize the need to consider early intervention sensitive to psychological distress in early childhood, regardless of the installation of a possible diagnosis, especially since it is a structure not decided in childhood. To achieve this, therefore, it is essential to value maternal knowledge, welcome their suspicions and strangeness when the mother believes that something is not going well with the baby.

Perception and diagnosis

The mothers' strangeness arising from their children's eating behaviors triggered the search for explanations, for answers that could unravel what was happening to their children, who refused to eat, or directions about what they could do about it, to change such a situation. The internet served as the main source of research and information used by these mothers, as reported by interviewee E1: "*Because I kept researching everything in relation to my son. Do you understand? And I only took it to... Which was for children who had selectivity, you know?*"

Other mothers turned to the internet as a source of information and instructions when their children were diagnosed with autism by a pediatric neurologist, and with that, for the first time, they encountered the term food selectivity and discovered that it is a condition closely associated with autism.

> *On the internet. I started to see... And on the subject of autism, within autism there are several other things. I started reading and started to understand more. Then, I started researching what was really involved in this food selectivity* (E4).

In addition to offering a name for the difficulties children had with eating, it was on the internet that mothers searched and found information from experts about autism and food selectivity to help their children overcome food selectivity.

> *So, today, I try to understand everything. Because I try to read a lot, you know? I follow a doctor who has an autistic son, understand? And I really try to understand, you know? More and more like this* (E3).

Research by Cunliffe et al. (2022) discovered that parents in positions of misunderstanding about their children's behavior often seek help and advice independently, seeking, in addition to answers to what was happening, ways to

minimize the impact of the difficulties arising from the diagnosis. Vasconcellos-Silva & Castiel (2009) report that the internet has presented itself as a valuable resource in accessing information necessary for health care, however, the dissemination of this type of information also presents risks, such as self-diagnosis, which, perhaps, may not be confirmed.

The search for and finding a diagnosis starts from discomfort in the face of differences and arrives, in some cases, at a place of meaning in the face of situations experienced that cause strangeness. For Constantinidis et al. (2018), the diagnosis allows us to name the perceived differences, at the same time that it allows us to deal with them by framing the child's different behaviors, and that, without this, mothers may feel helpless and alienated regarding their actions. The mothers in this study mentioned different feelings, such as sadness, guilt, worry and even relief upon receiving their children's diagnosis.

> *In parts, even relieved. Because before you think: 'My God, this boy is cool! You don't want to eat!'. Then you see that it's not cool. Then comes such great relief that you're like: 'Oh, my God, it was a problem! And I was forcing the animal to eat what it couldn't'* (E2).

> *I think I felt a little guilty after I found out. Because before I was angry. This child doesn't want to eat. That childish thing. I insisted a lot, shouting: "let's eat". I thought before it was like he was having a tantrum. And I pushed so hard. I insisted so much. This in a, let's say, wrong way. Then comes the guilt for us* (E4).

Interestingly, one of the mothers expressed feeling grateful for her son's food selectivity, because, according to her, it was thanks to his food selectivity that he was not interested in foods considered low in nutrition and high in calories, which could harm his health, according to the excerpt: "*And I was always grateful for some of his selectivity even in this regard, because he didn't accept those things. Understand? That helped a lot for his health*" (E3).

The concern with the consumption of foods rich in nutrients appears as a high priority for mothers of children with autism and food selectivity who participated in the research by Ausderau & Juarez (2013), since the food preferences of most children with these conditions are by low-nutrient foods, such as processed foods rich in sodium and sugar.

The discovery of food selectivity appears concomitantly with the diagnosis of autism in the reports of most mothers interviewed. It was only when they heard from the neuropediatrician that their children had a neurodevelopmental disorder that the mothers were able to explain that those difficulties with eating were called food selectivity. The fact that the mothers who make up this sample had, for the most part, heard or read about food selectivity for the first time only after the diagnosis of autism meant that many statements about their perception regarding where their children's food selectivity emerged were linked to the diagnosis of autism itself.

> *I discovered that it was food selectivity only after the diagnosis. Before that, neither a pediatrician nor anyone else came up with the word food selectivity. I only*

> *discovered selectivity, I came to understand, after the diagnosis of autism at the age of three* (E2).

Food selectivity is a multifactorial condition and can affect any child, regardless of the presence of a diagnosis, such as autism or other developmental disorders. Although children with typical development have food selectivity, there is a much higher proportion of cases in children with a developmental disorder, especially in cases of autism (Adams et al., 2021; Bandini et al., 2010; Nadon et al., 2011).

The presence of difficulties in feeding their children led mothers to seek professional help, mainly reporting their concerns to pediatricians. Mothers reported that their concerns were often not well received by health professionals.

> *When I started taking him to the pediatrician, I asked, right? I said, 'doctor, why does this boy have so much trouble eating?' Then they said, 'mom, this is from child to child.* [...] *you can't compare your son…are your five fingers the same?'* [...] *It could be that he had some difficulty, but they never ordered an investigation, right?* (E3).

The study by Aguiar & Pondé (2020) addresses similar professional conduct, in which there was difficulty on the part of professionals in welcoming, clarifying and guiding parents regarding the difficulties and doubts raised about their children's development. Data from research by Visani & Rabello (2012) suggest a lack of contact and possible insecurity among early childhood doctors with early signs of obstacles in the baby's development. For Pascalicchio et al. (2021), such conduct occurs not because of a lack of sensitivity or negligence, but because of a belief that the presence of signs of developmental risk implies closing a diagnosis, thereby losing the precious benefit of early intervention.

The lack of mention by professionals to parents about the existence of a selective food condition, clearly presented by children, raises questions about the level of knowledge that these professionals have about food selectivity itself, and whether they are sensitive to identifying signs risk, which leads to specialized referral for early intervention.

"It's time to eat"

The interviewees' narratives about eating times with their children permeate various feelings, such as anxiety, hope and frustration, which are triggered even before the meal itself, even during the choice and preparation of the food.

> *But then, when I go to give him food, I already have that grip* [hands closed over his chest] *that he won't accept.* [...] *Do you understand? I'm anxious right now* (E1).

> *I feel hopeful* [...] *then when it's time to do it I really get that excitement. And when you see that it doesn't work, then frustration comes. It's frustrating. We go with expectations. Now it will work. Now he will want it, it will work. And no. It does not work* (E4).

The literature confirms these reports with other studies that indicate the existence of an overload of stress and anxiety in mothers of children with autism and who have food selectivity (Cunliffe et al., 2022; Adams et al., 2021). Furthermore, the mothers interviewed in the present study feel insecure about their roles and question their care abilities in the face of their children's refusals.

> *I felt frustrated, right? I felt frustrated. Like, I was like... My God, am I doing something wrong? Am I not knowing how to take care of my son? I felt that way* (E1).

Adams et al. (2021) point out data from the maternal experience of feeding a child with autism, and highlight that mothers experience feelings of guilt for feeling unable to adequately care for their children with autism, and highlight the negative impact that the phenomenon of food selectivity has on with mothers, who often consider mealtimes to be chaotic and stressful. Cunliffe et al. (2022) report that the feeling of low self-efficacy is very common among mothers of children with autism and who have difficulties with eating, leading to higher incidence rates of anxiety and depression in these women.

Insecurity extends to other demands of the child, not only food selectivity, but which include the characteristics of autism, as reported in the following excerpt: "*Living with his autism... because you don't understand, right? Like, a different world that I had to deal with. I cried a lot... because I didn't know how to help*" (E6). Sadziak et al. (2019) deal with the particular suffering of mothers of children with autism due to the lack of knowledge and skills when it comes to caring for their children, and that mothers may not feel like high-quality women, as they experience sadness, regret and endless feeling of guilt.

Fatigue appears closely associated with the feeling of guilt for not knowing how to deal with the child's difficulties, both food and autism-related. The provision of continuous and systematic childcare, crossed by anguish, doubts and questions about this care, places these mothers in a vulnerable situation for developing symptoms of parental exhaustion (Sadziak et al., 2019). Furthermore, the routine centered on the child's needs leads these women to abandon their desires, dreams and plans, losing their own identity and living their child's story (Monhol et al., 2021), as said by Fadda & Cury (2019, p .6): "It's taking care of each other by neglecting oneself."

> *It's about paying attention. It's always being ready there. It's so much that, sometimes, I end up forgetting to be a woman, to be myself, to just be a mother* (E5).

The readjustment of these mothers' daily lives in terms of caring for their autistic children and the condition of food selectivity also includes the abandonment of a professional life and other occupations (Pascalicchio et al., 2021; Monhol et al., 2021), as mentioned interviewee E1: "*He only eats with me, so if he ate properly, ate alone and everything, I could be working, you understand?*".

Still regarding meal times, the interviewees make adaptations to their eating routine, in order to take into account their children's needs, in an attempt to ensure that the child eats within the expected minimum, as reported by interviewee E5: "*So, I already know the type of things he already eats. So I often don't waste much time. Do you understand?*

Offering other things..." Trofholz et al. (2017) state that picky eating affects the general eating environment at home in such a way that mothers develop an adaptive stance towards their children's picky eating behaviors, preferring to offer foods that are certain to be accepted by the child.

Mothers seem to be groping for mechanisms that guarantee their objective of feeding their children. They often follow their intuitions, but they also seek knowledge about managing food selectivity and its spectral characteristics, in which each child presents particular difficulties and strengths.

Family and support network

The support network theme was very present in the interviewees' speech. When it comes to the social support network, highlighting the figure of the father, mothers brought different reports about sharing childcare responsibilities. Some fathers are present and collaborate with the care practices carried out by mothers. Others, even though they live with the child, do not provide direct care for them; and, still, there are parents completely absent from the child's life.

> *I think the same way as me. He's a lot like me. And I'm more into teaching him too. So he's on the same wavelength as me too. I think that's it* (E4).

> *His father has no patience. Because his father, he ate a spoonful, 'Oh, he doesn't want any more, no. Because he already swallowed. It's because he doesn't want to anymore, no'* [...] *then his father: 'No, no. I don't have patience'* (E7).

Research on maternal *burnout* pointed to the involvement of parents in their children's education and the sharing of responsibilities with the mother of the child with disabilities as an important protective factor (Sadziak et al., 2019). The study by Machado et al. (2022) found that parents of children with autism had higher levels of parental and marital stress in conflicts related to raising the child, and that mealtimes and child feeding were a factor influencing marital stress.

The findings of Silveira et al. (2019) show that the presence of a spouse does not necessarily imply a positive factor, as these women often still feel overwhelmed with their daily work, having little support from others. The burden of one of the spouses, almost always the mothers, combined with the lack of parental support, can be considered stressors that generate feelings of insecurity, negatively influencing the mental health of mothers (Machado et al., 2022; Monhol et al., 2021; Carvalho-Filha et al., 2018).

The family, in addition to the figure of the father, also appears in narratives linked to the theme of support network. In general, support from the maternal family is more present in the lives of mothers of children with autism, with maternal grandmothers occupying a prominent place in this support, as mentioned by interviewee E1: *"So my only support network is his grandmother, right? Because she helps me a lot. My support is her."* However, most reports permeate the feeling of judgment on the part of the family itself, which blames the mothers for the child's eating difficulties. Furthermore, the

participants report the perception of a disauthorization of their care practices, mainly coming from grandmothers.

> *What affects is... I'll also tell you a problem that weighs heavily: the family. Then the frustration increases even more, because no one knows what we are going through at home. Because it's very painful not to know what your child wants to eat. And still be judged* (E7).

Family support is understood as a generator of security and a protective factor against maternal stress in a study that compared mothers with and without family support. Mothers who identified that they have a family support network, that their family members respect their decisions, their privacy, feel more emotionally welcomed and demonstrate less stress (Faro et al., 2019). However, support is found within social circles with other mothers of children with autism. The support and friendship of others in the same situation becomes invaluable for these mothers.

> *I have received a lot of support from here. I have received a lot of support from the girls, who are also part of here, the mothers of the other children, to exchange experiences* (E2).

The involvement of mothers in activities and associations of parents for children with disabilities is seen as an important support network that enables personal connection and a sense of belonging through identification with other mothers who have similar experiences, from which mutual support can emerge. and exchange of experiences (Sadziak et al., 2019). Similarly, the study by Pascalicchio et al. (2021) found that mothers consider the welcoming felt when talking to other mothers going through the same situations as an essential support network.

Formal support, highlighted in this context as the support offered by health professionals who accompany autistic children and their families, also appears in the interviewees' statements. Mothers express a desire to be guided by these professionals regarding what they should or should not do to improve their child's nutrition, as mentioned in the following excerpt: "*As they will be with S. frequently, they may be able to sort of guide us in the right way. In a way that makes him accept food better*" (E4).

In addition to mothers' interest in teaching strategies and guiding care practices, there is a desire to understand what actually happens to the child, to understand the mechanisms that lead the child to not want to eat. And that, based on this understanding, it would be easier to deal with the difficulties that the child presented, being able to reorient the actions taken.

> *I would like to participate in a lecture so that someone can explain to us what happens in an autistic child's palate when he starts to put food like this, different. I'm curious to know what it's like. It would be cool* (E6).

Regarding this place of support, Winnicott (2023) highlights the importance of professionals positioning themselves as yet another, but no less important, facilitating environment for the child. And this would only be possible with empathetic listening,

systematic monitoring of each mother-child binomial, and encouraging maternal security and self-confidence, after all, mothers are the true experts of their children.

Until the future arrives

The mothers interviewed, when talking about their children's eating routine, expressed fears and fears regarding their future eating habits. The fear of death and the belief that only they are capable of adequately caring for their child emerge in the speech of these women.

> *My fear is that, because he has this selectivity…. I won't always be there to give him just what he wants, do you understand?* (E1).

> *And when I die, my God in heaven, who will have the patience to cook his food the way I do? To give him that food, understand?* (E2).

Mothers develop particular mechanisms to cope with their children's food selectivity, and with this they develop an exclusive relationship with the child, in which they come to believe that only they are capable of understanding and meeting the child's demands (Fadda & Cury, 2019). The fear of death arises, generating feelings of anxiety and concern about the future, when imagining the possibility of children not being treated well when in your absence (Pascalicchio et al., 2021; Fadda & Cury, 2019; Machado et al., 2018).

The fear that the child will present a worsening of food selectivity was also mentioned in the speech of some interviewees, and appears associated with the fear that the child may develop a disease, due to their nutritional status, as mentioned: "*Also, the question is whether we know what it will be like from now on. The health issue. I don't know what his health will be like*" (E3).

The realization of the difficulties presented by the child and the prospect of a possible worsening leads these mothers to develop sick emotional and psychological states. Anxiety is very present in the interviewees' statements, corroborating other studies on atypical maternal experiences and the development of anxiety and depression (Cunliffe et al., 2022; Adams et al., 2021; Pascalicchio et al., 2021).

> *I felt, therefore, in a very big bind.* [...] *like that thing that was suffocating me inside, you know? There were days when I couldn't sleep because I kept crying, right? Already imagining what it would be like, since I'm very much like that, thinking about it in the future. What will the future be like, do you understand?* (E1).

The future for these women is also understood from the perspective of desire and hope. The interviewees express a desire for change in relation to their children's diet, as in the following report: "*I really want him to eat like other children. Eat a banana, eat a fruit, understand?* (E3). Mothers learn to resize their expectations regarding the future of their child with autism and their own future, however, they continue to dream, even simpler dreams, but that understand the child's differences (Kütük et al., 2021; Constantinidis et al., 2018).

> *I don't expect him to eat everything. But I wanted him to eat only what was necessary for his body. It doesn't have to be all fruits. But it was the most important. The one that had the most important vitamin for his body, right?* (E4).

Motivation appears associated with statements about future perspectives. Despite recognizing the burden that caring for children and the condition of food selectivity brings to their lives, it is in the children themselves that mothers see the motivation to continue.

> *My motivation is when I look at my son and I see that he needs me. Because even with all the difficulties he has, I feel frustrated, I have to be there firm and strong to take care of him. This is my motivation* (E1).

The establishment of a bond with the real child, different from the one initially idealized, based on the emotional investment in the child and the thought of how it can really be, and not how it could have been, is perceived as fundamental for both the acceptance and appreciation of the child and to face the difficult aspects of the current situation (Machado et al., 2018).

Conclusion

The themes revealed based on the interviewees' statements show that, in addition to a restricted dietary repertoire, there are several intertwined factors that include maternal feelings in relation to childcare, which involve not only food. Furthermore, there is an overload of the mother's occupational role, which interferes with the performance of other occupations and roles, leading to maternal exhaustion and emotional suffering.

The precocity of problems with selective eating raises the importance of early identification and intervention, and at the same time questions professional knowledge regarding this phenomenon. Studies that could evaluate the understanding of health professionals, especially those in primary care, about the condition of food selectivity, are relevant to the knowledge regarding how, or not, the investigation of early signs of food selectivity and intervention in yes. The interdisciplinary team plays a relevant role in this investigation, especially the occupational therapist, in understanding and intervening in human occupational performance, their occupations, roles and daily lives, as well as the mastery of sensory functions, and the relationship between food selectivity and sensory changes.

Support network contributions are also raised, with the understanding of the lack of a substantial support network on the part of the interviewees. Other studies can investigate the perception of coping with selectivity when there is a quality support network, which includes not only family support, but formal support. Studies aimed at understanding children's own perceptions about their selective eating would be welcome and would bring unprecedented contributions to the literature, which, in turn, could contribute to the approach of this phenomenon, as well as the investigation of the contributions of interventions for food selectivity that are family centered. This is because this study highlighted family involvement, especially mothers, in managing food selectivity.

Finally, food selectivity negatively impacts the child's health and development, at the same time as it infringes maternal emotional suffering, being disruptive to family daily life. There is a scarcity of studies on food selectivity, especially the understanding of social, emotional aspects and occupational performance, despite the diversity of investigation possibilities that ask to be carried out.

This study brought contributions about maternal experiences regarding the food selectivity of their autistic children. However, there is no exhaustion of these statements, since these women in the daily life of being a mother of an autistic child with food selectivity brings the emergence of meanings that are configured as a normative rupture of this motherhood. In other words, a discontinuity in the linear trajectory expected by this woman who became a mother.

The maternal parental role in this context is only possible with care in support networks that can offer the mother self-confidence and development of skills in caring for her child. Therefore, reflect on support networks that can fill the gaps with protective factors and spaces that promote human interactions with the exchange of knowledge and experiences that are necessary between mothers, the professional team and the community.

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