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Challenges Faced by Mothers of People with Autism Spectrum Disorder

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Summary

This article aims to identify and understand the difficulties faced by mothers of individuals with Autism Spectrum Disorder (ASD) at severity level 3, who require excessive support to perform activities of daily living, academic and social activities, and to analyze how the impact of this diagnosis on the mothers' social and professional lives and the challenges they face influence their emotional well-being. The objective was to analyze the possible psychological impacts on these aspects, based on information collected from interviews, along with a review of relevant literature on the subject. The work was exploratory and qualitative, with field research and a focus on the narratives of three mothers from the participating institution, where interviews were conducted regarding data about the mother, the child, the diagnosis, and social and economic issues.

Keywords: Challenges. Mothers. Autism Spectrum Disorder.

Abstract

This article aims to identify and understand the difficulties faced by mothers of individuals with Autism Spectrum Disorder (ASD) at severity level 3, who require excessive support to perform activities of daily living, academic and social activities, and to analyze how the impact of this diagnosis on the mothers' social and professional lives and the challenges they face influence their emotional well-being. The objective was to analyze the possible psychological impacts on these aspects, based on information collected from interviews, along with a review of relevant literature on the subject. The work was exploratory and qualitative, with field research and a focus on the narratives of three mothers from the participating institution, where interviews were conducted regarding data about the mother, the child, the diagnosis, and social and economic issues.

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1. INTRODUCTION

Autism is a neurodevelopmental disorder characterized by persistent deficits in... social communication and social interaction in multiple contexts, as manifested by all that follows, currently or by previous history (AMERICAN PSYCHIATRIC ASSOCIATION, 2014, p.134). According to

ICD-11, reference data from the United States, estimates that one in 44 children She was diagnosed with the disorder 8 years ago, and that rate is growing, indicating an increase. in the frequency of diagnoses. Both the ICD (International Classification of Diseases) and the DSM (Diagnostic and Statistical Manual of Mental Disorders), organizations responsible for classification and diagnosis, they hypothesize that the 22% increase compared to 2020 is related to the expansion of diagnostic criteria, greater awareness, changes in methodology and increased real prevalence (OLIVEIRA; TRENTINI, 2023).

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The complexity of Autism Spectrum Disorder (ASD), classified in the ICD-11 as... Code 6A02 requires a comprehensive analysis that goes beyond classification and includes the environment, a Historical perspective, public policies, and the family. The intensity of this spectrum can represent potential stressors for family members, due to the diagnosis received and the care required. (SCHMIDT and BOSA, 2007). According to Smeha and Cezar (2011), the experience of family members with the A person who has the disorder and sees the world in a different way experiences... challenging.

Considering the data mentioned above, the study aimed to analyze the difficulties. challenges faced by mothers of people with Autism Spectrum Disorder (ASD) of varying severity levels. 3, a level that requires excessive support to perform activities of daily living. According to as established in the Statute of Children and Adolescents (Brazil, 1990), it is the responsibility of the family, from the community, society in general, and the Public Authorities to guarantee, as a priority, the realization of the rights of all children and adolescents related to life, health, food, education, sports, leisure, professional training, culture, dignity, respect, freedom and Family and community life. In this way, the family is one of those responsible for the care and guaranteeing the rights of children and adolescents with Autism Spectrum Disorder, being considered as a defending and promoting agent, especially mothers, who appear as the most prominent agents. active in this process.

Considering the historical construction of women, the configuration of the system in a model Patriarchal and cultural aspects mean that care is mostly provided by women (LOPES, 2019). According to Bassotto (2018), mothers play a fundamental role in this context, being the The voices of their children and their narratives are presented as a relevant resource for expressing the The experiences of these individuals. These narratives also fuel debates about the challenges of education and social inclusion, giving a voice to a part of society that It is often neglected and silenced. Despite the achievements of mothers and families for rights of people with Autism Spectrum Disorder, previously segregated in domestic environments and hospital (BASSOTTO, 2018, p.10), such as the Berenice Piana law no. 12,764 of 2012, it is observed daily challenges for people with autism and their families, especially those who They exhibit a higher degree of vulnerability and require greater support from the State for protection. of rights. This is the reality that justifies and drives this research.

This study is exploratory in nature, qualitative in character, and is based on a field research procedure. As discussed by Minayo (2012), a research Qualitative research is based on experience, lived experience, common sense, and action. Its objective It is about understanding and interpreting the object of study, and the author expands on the concept of understanding. such as the ability to put oneself in another's shoes. To this end, three interviews were conducted.

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These interviews were based on narratives from women who are mothers of children diagnosed with autism. interpreted from a critical perspective on the role of women and the culture of maternal guilt. Therefore, through data analysis and theoretical reflection, the aim is to reflect on the possibilities. to address the issue and, in the future, propose possible interventions.

A diagnosis of Autism Spectrum Disorder in a child can modify aspects financial and physical, mental, and social quality of life for this mother. Therefore, the present work The research problem presented was: What are the challenges faced by mothers of people... occupied with Autism Spectrum Disorder and how they influenced their demands psychological?

2. A BRIEF HISTORY OF THE RELATIONSHIP BETWEEN MOTHERS DIAGNOSED WITH AUTISM

The history of autism is linked to the blaming of mothers, especially between the decades. 40 and 60. In 1943, Leo Kanner raised the hypothesis that the etiology of the disorder was associated the cold and confrontational relationship between mothers of children diagnosed with autism, giving rise to the theory "Refrigerator mother." This was linked to the concept that the children were born "normal" and the mother herself. inflicted a psychological wound that forever damaged the child's development. Theory that This contributed to feelings of guilt among mothers and the feeling that they hadn't done enough. According to According to the author, autism was caused by mothers who did not love their children enough. (DONOVAN; ZUCKER, 2017, p. 85).

The activism of family members of autistic people has broadened research on Autism Spectrum Disorder. Autism Spectrum, moving away from the 1940s perspective and closer to neuroscience. According to the Bassotto's research (2018) shows that, over the years, there has been a notable increase in the production of works. academics who address the behavioral aspects, symptoms, causes, and issues related to learning and school inclusion. This fact can be proven by the growing number of Dissertations, theses, and articles published in the fields of health and education, available on the portals of CAPES and SCIELO. This movement contributed to reducing the blaming of mothers. autistic individuals, as it is now understood as a complex disorder encompassing genetic factors and environmental factors are multifactorial. However, there is still a physical, emotional, social and environmental overload. The economic challenges faced by mothers in relation to the demands of childcare, given that the State delegates this responsibility. to the family and, culturally, this role is fulfilled by the maternal figure. Autism has received various Nomenclatures throughout history. The first nomenclature, proposed by Kanner, was called "Autistic Disorder of Affective Contact." Kanner described this disorder as an inability children's ability to relate to others (DONOVAN; ZUCKER, 2017). Other examples of Nomenclatures include "Rett Disorder," "Childhood Disintegrative Disorder," "Asperger's Disorder" and "Pervasive Developmental Disorder Not Otherwise Specified," which includes atypical autism (AMERICAN PSYCHIATRIC ASSOCIATION, 1995).

It is currently updated by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). such as Autism Spectrum Disorder (ASD), a neurodevelopmental disorder characterized Autism is characterized by deficits in communication and social interaction in different contexts. due to rigorous changes in reciprocal social interaction and communication, as well as patterns of Restricted, repetitive, and inflexible behavior, interests, and activities. The symptoms manifested These include deficits in socio-emotional reciprocity, such as difficulties in verbal and non-verbal communication. verbal difficulties, as well as difficulties in developing, maintaining, and understanding social relationships. Individuals with ASD may present with intellectual impairment, motor stereotypies, Echolalia, idiosyncratic phrases, delayed language development, difficulty with comprehension. nonverbal language, infrequent eye contact, sensitivity to sounds, smells, textures, light, Restricted and repetitive patterns of behavior and inflexibility in changes to routine, which generates great stress from small changes (OLIVEIRA; TRENTINI, 2023).

Based on the DSM-5, severity is based on impairments in social communication and patterns. of restricted and repetitive behaviors, being divided into three levels of severity and support, being divided into three levels of severity and support: 1) need for little support, 2) need 1) need for substantial support and 2) need for very substantial support. Level 1 presents difficulty. to initiate social interactions and a clear example of atypical or unsuccessful responses to social overtures. of others. People who can speak in complete sentences and engage in communication, although exhibit flaws in conversation with others and whose attempts to make friends are awkward and commonly unsuccessful. In restricted and repetitive behaviors they exhibit inflexibility. Behavior that causes significant interference with functioning in one or more contexts. Difficulty switching activities. Problems with organization and planning are obstacles to... Independence. Level 2 is characterized by a severe deficit in social communication skills. Verbal and nonverbal; apparent social impairments even in the presence of support. Person who speaks in sentences simple, whose interaction is limited to narrow special interests and which exhibits non-communication. Markedly strange verbal behavior. In restricted/repetitive behaviors, they exhibit inflexibility. behavioral problems, difficulty coping with change, or other behavioral issues. Restrictive/repetitive patterns appear frequently enough to be obvious to the casual observer and These interfere with functioning in a variety of contexts. Level 3, on the other hand, is defined by a deficit. severe impairment in verbal and nonverbal social communication skills, leading to serious difficulties. Functioning. A person with intelligible speech of few words who rarely initiates interactions and, When it does, it has an unusual approach, solely focused on satisfying needs, and reacts only to... Very direct social approaches. In restricted and repetitive behaviors, it shows inflexibility.

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Behavioral issues and extreme difficulty coping with change, or other restricted/repetitive behaviors, interfere with functioning in all areas (AMERICAN PSYCHIATRIC ASSOCIATION, 2014, p. 137).

Considering the characteristics presented in Autism Spectrum Disorder, it can be said that... to infer that people with autism face difficulties in performing activities of daily living and complex skills needed for independent living. These difficulties can range from According to severity levels 1, 2, and 3 of the disorder, these people need... Care and support throughout life. The specific characteristics of people's behavior. with autism, along with the severity of the disorder, can represent potential sources of Stress for family members. However, understanding the relationship between autism and stress Familiarity cannot be understood simply through linear, reductionist relationships between possible causes and effects. It is important to consider that various factors are involved. in this complex relationship. (SCHMIDT & BOSA, 2007).

In addition to the variable of severity level, which affects daily family life in various ways, Minatel and Matsukura (2014) discuss the difficulties faced by family members according to the individual's developmental stage. As these difficulties arise... Throughout life, transformations bring new demands for families, some of which are: similar to those faced by families with typically developing children. However, the Families with children who have special needs also face additional challenges. resulting from the characteristics of autism.

The impact that children with this diagnosis have on their families is significant. due to the time and energy required to deal with the care overload demanded by the situation. (SCHMIDT et al., 2007). The characteristics of the disorder, such as difficulty in social interaction and In the pursuit of autonomy, they result in prolonged dependence on family members and affect well-being. Social well-being of caregivers. The results of the research "Quality of life of mothers of children with "Autism Spectrum Disorder" indicates a relationship between a child's ability to interact with their peers and aspects of the mother's personal and social relationships. It is concluded, therefore, that the capacity Interaction of the individual with autism provides satisfaction to caregivers (MATTIAZZI; (HOOGSTRATEN; FEDOSSE E SANTOS FILHA, 2019). Within this context, it is hypothesized that The research found a correlation between overload and excessive caregiving demands on the mother. with her autistic son, and the psychological and emotional impact, altering her quality of life.

It becomes relevant to reach out to the mothers of autistic children in order to understand their... challenges. According to the Baresi Institute, 2012, in Brazil 78% of mothers of children with disabilities and Rare diseases are often abandoned by parents before the children reach the age of 5. This implies in a smaller support network for mothers, which can overburden them economically and emotionally.

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(LOURENÇO, 2020). In most cases, mothers face great distress when they realize the When autistic individuals see their children, they are confronted with the discrepancy between the image of... The idealized child and the reality of a child with autism, understanding the limitations of the child. They can prevent her from meeting previously established expectations. Paternal abandonment It is justified by the grief over the loss of the "ideal child," therefore "they provide very fragile support or simply abandon" (SMEHA; CEZAR, 2011).

The State's contribution to guaranteeing the rights of people with Spectrum Disorder Autism became particularly evident in 2012, through Law 12.764/12, known as the Law Berenice Piana. This name is a tribute to Berenice Piana, an activist mother in favor of... Regarding the rights of people with autism. The law reflects a concern for the quality of life of people with autism. with autism, ensuring them protection against any type of violence, as well as access guaranteed access to health, education, and job opportunities. Furthermore, the Law stands out. Organic Law of Social Assistance 8742/1993, which guaranteed the continuous benefit payment (BPC). - LOAS) to people with autism who face difficulties in their full participation in society, proven financial hardship and demonstration of inability to prove support for oneself and one's family (PINHEIRO, 2016).

In the daily routine they share with their autistic child, mothers end up losing their own history. and they begin to live their child's story, ceasing to find meaning or support for to explore other possibilities regarding their identity as women. The mothers of people with Individuals with autism require support and assistance throughout their journey. This includes help from caregivers and family members. and institutions can help alleviate the burden of childcare and provide support to mothers (CONSTANTINIDIS, 2018). Collecting data on this issue is necessary so that it is It is possible to disseminate information and public support networks that already exist, and to encourage capacity building. professionals to serve this audience, in addition to considering implementation strategies for policy improvements. public initiatives so that one day it will be possible to reduce these demands and improve the quality of life for these people. mothers.

3. Method

3.1 Participants

The research involved the participation of three interviewees, who were invited through A letter of invitation was sent by the director of the institution co-participating in the study. The interviewees were: selected according to the following inclusion criteria: being women and mothers of individuals diagnosed with Autism Spectrum Disorder at support levels 2 and 3, and being enrolled in the Association of Parents and Friends of Exceptional Children (APAE). Before the interviews, the

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The mothers interviewed signed the Free and Informed Consent Form (TCLE), which was Approved by the ethics committee. The informed consent form explained the study's objective, potential risks, and benefits. Those involved, as well as the confidentiality of the information. To preserve the identity of the participants, the following will be... Specific names were used: Ana, Bruna, and Daniela. The participants' ages are respectively... 55, 36, and 46 years old. A fourth interview was conducted, but due to related cultural differences... Regarding the mother's nationality, it was not possible to compare the data in this research. This issue could be... best explored in a case study.

3.2 Instruments

According to Minayo (2012), the way we respond to the object of study is directly related to the questions asked, the instruments used, and the strategies adopted for collect the data. In the case of the research in question, the field strategy employed in the instrument The operational method consisted of using sentences as a means of data collection.

For data collection, three semi-structured interviews were conducted, containing 29 questions, including questions about the mother's sociodemographic data, about the child, about the diagnosis and about social and economic aspects. The questions involve collecting data on age, sexual orientation, ethnic/racial identification, profession, education level, place of residence, routine, number of children, how many people live in the house, support network, marital status, salary income, how It included the pregnancy, the child's age, whether the child is on ongoing treatment, and how that treatment is funded. or if it is provided by the State, if the child attends school and if it is public or private, with what How often does the mother go to the doctor, whether she has psychological and psychiatric emotional problems, and whether she has suffered any type of illness. prejudice related to the child's neuroatypical condition.

3.3 Procedures

The research was submitted for ethical review by the ethics committee for research involving human subjects. from the Municipal University of São Caetano do Sul, approved as CAAE: 65515822.0.0000.5510, opinion number 5,813,789.

The research participants were invited to participate through a brochure. Information distributed by the institution's director, who invited one mother from each autistic children's classroom. APAE. The data collection interviews were conducted individually, lasting... Each session lasts approximately one hour and is conducted on-site at the institution. The analysis procedure The qualitative analysis method adopted for the development of the research was adopted, as described by Minayo. (2012).

The interviews were conducted in pairs, in a private room provided by...

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director of the institution. The questions were asked following the sequence established in the script.

The interviews were conducted using a semi-structured format and were duly recorded.

4. RESULTS AND DISCUSSION

The interviews were conducted with three mothers of individuals diagnosed with the disorder. from the autism spectrum, who were given fictitious names: Ana, Bruna, and Daniela. These mothers were invited by the institution's director. The announcement was made through an invitation letter. distributed in the students' agendas at the institution. The analysis of the data obtained from this Sampling, aspects concerning mothers will be presented and discussed in four categories, including general and specific data regarding their feelings, issues related to their children, information about the diagnosis of these children and elements related to the social dimension and The economic situation of families. It is worth noting that interpretation cannot be considered the final word. in relation to the object studied, since the meaning of a message or reality is always subject to various possibilities and options (MINAYO, 2012).

4.1 About the mother

Three mothers of autistic individuals were interviewed; they were given fictitious names. Ana Daniela is 55 years old, Bruna is 36 years old, and Daniela is 46 years old. Two of the interviewees identify themselves as... White and one Black. Regarding marital status, one interviewee is single, one is divorced, and... One is married. However, one of them has a partner, but they don't formalize the union so as not to to lose the continuous benefit payment (BPC-LOAS), equivalent to one minimum wage.

According to Pinheiro (2016), the continuous benefit payment (BPC-LOAS) is a a right established by the Constitution that must be granted to people with autism when they They exhibit financial vulnerability and evidence of long-term limitations that make it difficult their participation in society. Therefore, only people with disabilities and senior citizens who can prove it. Those who do not have the means to provide for their own subsistence or have it provided by their family are entitled to to receive this aid, as established by law. Although the participant does not meet the requirements. Based on her account, it is possible to infer that the criteria established by law for receiving the benefit are: She chose not to formalize the union in order to benefit her son and give him a better quality of life. and the family.

Regarding education level, only one of the participants has a higher education degree. Complete. Regarding occupation, two mothers are in a relationship who work from home. performing household chores and taking care of the children, while one of them is a lawyer but works

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working from home. The change in the mother's work model was due to the difficulty of Balancing professional life and accompanying their daughter's treatment. Like other participants as well They said they had to leave their jobs due to the demands of their son's treatment. Reports are consistent with Lopes' research. According to Lopes (2019), many women end up putting aside their personal projects and jobs to dedicate themselves to the full care of their children. This results in an additional burden: while the double shift is already a reality for children. many women who work outside the home and still take care of children and household chores, for For mothers of children with disabilities, the workday is even more challenging, especially when they lack a support network.

This relationship between work and family, as planned by Constantinidis (2018), also These findings are consistent with those found in the studies by Minatel and Matsukura (2014). which indicate that the entire routine of families revolves around the child or adolescent with autism. The dynamics of the home environment, daily activities, and schedules are altered. regardless of the particularities of each family member.

Ana's family group consists of her partner, a 33-year-old daughter, and a son. 16 years old (ASD), Daniela's family consists of her husband and only daughter (ASD), and Bruna's family consists of her son. One is 15 years old (ASD) and the other is 2 years old. According to Smeha and Cezar (2011), it is identified as a form additional support from the presence of other children living with the autistic person, resulting in a Significant improvement in the development of the autistic child. However, upon analyzing the report of In the case of participant Daniela, a different situation is observed. As a single mother, she has two children. who depend on it for carrying out most of their daily activities, and reports that the birth The youngest son's condition resulted in a significant worsening of the autistic son's condition. This unique experience contradicts the authors' findings in their research. On the other hand, in the interview With Ana, she reports that her eldest daughter is a significant source of support, contributing both both emotionally and financially for the development of an autistic child.

Regarding the question about how the pregnancy went, two mothers reported that the pregnancy went well. It was a turbulent pregnancy. Participant Daniela explains that it wasn't well-planned, but that it was a pregnancy without complications. complications.

It was also asked about psychological support for the mothers, and only one has received it. which is offered by the clinic where your child receives treatment, and is covered by your health insurance.

Only one of these mothers has only one child; Ana has another daughter, 33 years old, who does not have children. He has no such disorder and doesn't live with her. Bruna has another child who is 3 years old.

The final question of the first phase consisted of an open-ended question that addressed the challenges. challenges faced by mothers of people with Autism Spectrum Disorder. All the mothers highlighted The issue of accepting the diagnosis, with Daniela specifically mentioning: "My husband

"She didn't accept the diagnosis." In this mother's words, we can identify grief for the "ideal" son, the emptiness. which represents the absence of the idealized child and the need to deal with reality. Unpredictable, unexpected, and consequently, out of control. This experience can occur before Regarding the autism diagnosis, when the mother encounters her son's peculiar behavior, facing doubts about how to act and finding it difficult to understand the situation (CONSTANTINIDIS, 2018). The data found corroborate the research by Smeha and Cezar. (2011), which points out that in this context, when a child, initially idealized, receives the With a diagnosis of autism, the parents' dreams and expectations for their child are shattered. They They noted that this child will not fully live up to their ideals and, at the same time, They will face the certainty that their lives will need to undergo changes from that moment on.

The interviewees' children are between 11 and 16 years old, and at the time of diagnosis there wasn't much... There was no information or accessibility, and when treatments were found, they were very expensive. Three of them Mothers also brought up the child's aggressiveness as a challenge, Bruna says, "If he asks for something..." If you don't give him anything, he'll hit you; he wants to break things in the house, and he's 1.75 meters tall, so nobody... "Can you hold him?"

4.2 About the son

Information was also gathered about the children of the mothers interviewed. Only one Of those mothers, one had an only child; the other two mothers each had another child, but without any issues. neurological or intellectual disability.

All three were mothers of people with autism spectrum disorder level 3 help (severe). Regarding their children's needs, two of them present a significant challenge in social relationships. especially with children. Bruna says that *"He can't express his emotions, not He tolerates crying but cannot control his anger, which prevents him from socializing."* Daniela explains that Your daughter is able to socialize when she's not disorganized, but she has difficulty... Matching names with people's faces. They all tell about behavioral aspects, because Although children are able to have some autonomy in activities of daily living, for example, They refuse to do them alone. *"He knows how to bathe himself, but he won't accept it, after his brother..." The youngest one was born, and things got worse. He doesn't have the willpower to learn things, to tie his shoes. "He is very dependent on us."* (Ana). According to Smeha and Cézar (2011), the other child may do part of the support network and significantly help in improving the other autistic child's condition. However, according to From the data obtained in this mother's interview, we can observe counterpoints that diverge from what was... as observed by these authors. The youngest child, aged 2, is dependent on his mother for care. In basic terms, the fact of being a single mother significantly increases the demand. The participant also

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She reports trying to shield her son from his atypical son's crises, and expresses a feeling of fear in Regarding the possibility of him having a neurodevelopmental disorder.

Regarding the treatment offered for their son with autism spectrum disorder, two of the The mothers reported that the agreement offers specialized treatment, one with a workload of 20 hours. weekly and another with 40 hours per week, both including treatment with Analysis of Applied Behavior Therapy and a multidisciplinary team. Bruna, on the other hand, is receiving the treatment provided. According to the state, your son receives care at the Psychosocial Care Center (CAPS) in the municipality. where he lives, but explains that the turnover of professionals is very high, and this hinders the treatment is lacking continuity; he also mentioned that he had to change psychiatrists before, and this... prescribing a medication that your child had already taken and couldn't tolerate, also demonstrating a lack of internal communication. She also mentioned that her son had therapy with a psychologist every two weeks.

All the mothers explained that their children attended a municipal school before going to the... APAE, however Ana and Bruna had already enrolled their children in private schools. Bruna was Invited by the director to remove her son from there, since they were not prepared, she then needed to to go to court to get her son enrolled in APAE, which only happened when He was diagnosed with intellectual disability associated with autism.

When asked what her children were like, Ana replied, *"She's a gem, she fought hard." "For life, he's a jewel for the family, I'm very proud of him."* Bruna and Daniela also pointed out other issues. of improvement, where they explain that if the child had more support, he would be able to develop better.

4.3 About the diagnosis

According to Smeha and Cézar (2011), it is understandable that the moment of confirmation of A child's autism diagnosis is crucial for the family, especially for the mother, because, as As the primary caregiver, she will be the one who needs to dedicate herself to caring for the child.

In this section, the first question was about who the mothers were before the diagnosis, a She couldn't answer and spoke about having managed to be very strong after the diagnosis. The others Two mothers explained their experiences, covering academic, personal, and career aspects. Bruna brings... who was a different person, cheerful, full of dreams and hope, said that before she knew she was Pregnant at 20 years old, she had picked up the paperwork to enroll in a college in journalism, but when she was certain she was carrying a child, she became extremely happy and He said it was worth dropping out of college at that time. He also mentioned that in his During his childhood and adolescence, he had various artistic hobbies, such as dancing and singing. *"So we end up..." becoming a little bitter, because while my friends were taking their children to the playground, I was taking her to CAPS, you know? So I don't have much to tell you about going there, no.*

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It's what I experienced with him. My friend says, Elaine, you're a different person, you don't look like the same person anymore. "I'm the same, and I say it, but I'm not. I'm not. I love him too much, but my life made me do this." (Bruna). Daniela says she was in her final year of law school when she discovered the pregnant, who worked at a company, was doing an internship and finishing her final course project, then I was very tired at that time, but after she got married, it took her 7 years to get pregnant and She recounts, *"Before, our life was normal, we had a social life, we went out, we went to the movies. We enjoyed it." "I used to travel a lot, I'd wake up in the morning and we'd go somewhere to travel."* (Daniela)

They were also asked what the diagnosis meant to them, the three mothers. They brought up issues of grief, and she recounts: *"The diagnosis is like a sentence. In the beginning, you just..." You see the problems. You think you've overcome this whole disability issue because... Nobody tells you this; the morphology scan alone doesn't prepare you. Internally, we think that... The disability phase has passed after the morphological examination. When a disability is identified. In the morphological examination, you are prepared for the situation, but autism is not. The diagnosis is you. "It keeps recalculating its route. You know it's difficult, but you can't imagine how much."* (Daniela). Ana and Bruna They explain that their lives and those of their families have changed completely, requiring them to turn around and fight for... the minimum quality of life for their children.

When asked about the reaction of friends and relatives to the diagnosis, all the mothers They tell stories about the gradual distancing of these people, and how their children ended up being excluded from... celebrations and gatherings. Ana also mentions that she felt discriminated against because people didn't know dealing with her son. Bruna says that her son's father disappeared as soon as he realized his son's condition, and Daniela explains that her daughter's father also didn't accept the diagnosis very well and only understood... In fact, after a lecture with a psychologist.

There were also questions about knowledge regarding Autism Spectrum Disorder and What were the mothers' stories about him? Two of them weren't sure what it was, they only had... I had heard about special and exceptional children and Down syndrome. Daniela, however, knew a little. Ana also mentions that before her son was born, it seemed that people with autism They were hidden. Only after their children's diagnosis were they able to learn about them through... Doctors and the internet are enabling them to fight for their rights and the rights of their children.

Regarding what it's like to be the mother of a person with ASD, the three spoke about resisting and fighting for the cause. He explains: *"Besides being complicated and difficult, it's inspiring because I'm always fighting." It's become a rallying cry for me, you know? I'm always looking for things that can... to benefit him and give him a better quality of life. Right? So let's go, I didn't park because He's autistic, there's no way around it. I don't cry about it. We'll create paths by trying. "Trying, right? To improve."* (Ana)

Concerns about child development gradually appear, but never disappear.

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A diagnosis as complex as that of autism is expected. (BASSOTTO, 2018, p.31)

4.4 Regarding social and economic issues

In this category, all participants stated that they had experienced some type of prejudice. due to their child's condition. The three participants recounted moments of crisis involving their children, where they were Clearly a target of stigma, *"It happened once that he was very agitated and I was at the checkout." with a stroller, trying to calm him down. There were two ladies behind watching, and one said, "Oh dear." "Look at that father, look at the boy, if it were me I'd give him a piece of my mind right away, look at that badly behaved boy." And I said, "Oh my God, I'm this boy's mother and he's autistic, he's not badly behaved."* (Ana)

Another mother says that the comparisons are difficult to deal with and explained: *"My uncle once came... Speaking like this, oh, Marcos Mion, he treats his son super well. I said, darling, Marcos Mion He has a whole team behind him. I'm not judging. Is he a super dad? He is a super dad. That's all. That he doesn't live the reality of a poor family, you understand? A family that doesn't have... Support, there's no psychologist, no psychiatrist, no right medication, you understand? School for Gaining a fan base, a struggle, he could have been here since he was little. So, I just have to say thank you. To the father, it wasn't their fault. Do you understand? But, like, you can't compare so-and-so's story with... So-and-so. Oh, but he's also autistic. But what's his life like? And do you know what he goes through? Behind the scenes? He doesn't know either. He doesn't know if Mion is having a crisis, because sometimes people don't go to the... "The media will talk. You understand? So, this power of comparison. It kills me."* (Bruna)

Furthermore, Daniela raises the issue that people don't understand when they see a child. typical-looking person sitting in the priority seat on the bus or subway.

It was possible to identify a feeling of guilt towards their son in the statements of the three women. interviewees. Participants 1 and 3 reported feeling guilty about getting pregnant. Ana She reported feeling guilty for not having planned for it and for not being able to provide treatment. better for the child. In Daniela's speech, one can observe guilt for insisting on having children, since The husband didn't want to. Bruna, on the other hand, blames herself for having had a relationship with her son's father, and feels this She feels guilty when she talks to her about this issue.

Regarding the question about what it means to be a good mother, mother 1 and 3 responded with sentences 1 and 3. I don't know what it means to be a good mother; I think we can't be good mothers. The second mother replied that the most important thing is to have patience, and recounts that she often needs to reinforce this. Inappropriate behavior, even if unintentional, leads to *"So, being a good mother is about passing on..." "Sometimes, I get the urge to correct them so I don't get hit."* (Bruna). Daniela brings also that one of the reasons for not considering oneself a good mother is needing to work, because that way she doesn't She is able to spend more time with her daughter, in order to better support her treatment.

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Regarding the emotional, financial, and social changes, two mothers shared that they stopped... One had to work, and the other had to request a mission from a company and work from home to succeed. reconciling treatment, care, and expenses related to health insurance and medication, which add up to approximately R$1,880.00. Socially, the three pointed out changes, since they only go out with the They have children and need to take care of them almost 100% of the time. The emotional aspect was also highlighted: *"And you have..." I need to be strong, so I think emotionally I pretend to be strong and I need to believe that I am strong.* (Daniela)

Regarding the support network, it was possible to perceive a great difficulty among the three participants. because they can only count on two people to help take care of the child, when They need, for example, to go to the doctor, but they all have reservations about asking for this help, because they feel... that these people are already overburdened.

Regarding the issue of monthly income, a large discrepancy was observed among the participants, because Ana's income is approximately R$7,000.00, since her partner is retired, but still Bruna works at the company, while she only has R$1,300.00, as she is unemployed and surviving on handouts. With only her son's LOAS benefit, Daniela has approximately R$3,500.00, because She and her husband are self-employed lawyers.

The last point regarding the socioeconomic issue was whether their children were registered with... CadÚnico and if they received any social benefit or collection of the LOAS benefit, they all had the Registration was open, but one person did not receive the benefit. Ana managed to get the benefit for her son because she did not register. Married by law, since it is only given to those who have families who cannot support themselves. Bruna says who quickly obtained the benefit because she is a single mother and does not have a job. Daniela, on the other hand, says who is unable to apply because her husband has a CNPJ (Brazilian tax ID).

5. FINAL CONSIDERATIONS

The results indicate that these women, mothers of children with level 3 ASD, They accumulate the pain of the fall from the "ideal child" and of abandonment, along with the emotional overload. which especially affects the mother, who will be responsible for dealing with all these issues, particularly with regard to the child's behavioral aspects and aggressiveness, it is understood which in most cases are women who are on the front lines, fighting to ensure that their children receive dignified treatment, often neglecting their own needs. in the background.

The psychological demands of mothers of autistic children collected by this sample included guilt for pregnancy and child development, and anxiety regarding cognitive advancements in son. Faced with their son's diagnosis, all participants report distress at the lack of

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Information and access to education in an inclusive way, both in public and private schools.

Collecting data on this issue will help to understand the needs of this audience. in order to think about implementing improvements in public policies so that one day it will be possible to reduce these demands and improve the quality of life for these mothers. We emphasize the importance of The fourth interviewee, who presented her demands and difficulties from the perspective of another country... Latin America. This being an important point for the analysis of future studies that will enable... new meanings regarding the subject in question.

Finally, it is important to emphasize the questions and concerns about the challenges. The challenges faced by mothers of autistic children do not end with this study. It is worth highlighting that... The importance of future research on autism through other approaches, not just Regarding the challenges faced by Brazilian mothers at support level 3.

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