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AUTISM SPECTRUM DISORDER: CHALLENGES EXPERIENCED BY FAMILIES

TRANSTORNO DO ESPECTRO AUTISTA: DESAFIOS VIVENCIADOS PELAS FAMÍLIAS

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ABSTRACT: Autism Spectrum Disorder refers to a series of conditions characterized by some degree of impairment in social behavior, communication, and language. Objective: to identify the challenges faced by parents and/or caregivers of children diagnosed with Autism Spectrum Disorder (ASD). Methodology: qualitative, exploratory, descriptive study based on the experiences of three families with children with ASD. For data collection, a meeting was held with the families through the focus group. Data were analyzed based on discourse analysis. Results: the challenges faced by families are represented by uncertainty regarding the diagnosis of ASD and the development of their children; difficulties in accessing therapies and prejudice. Conclusion: knowledge about the challenges faced by families when diagnosed with ASD is fundamental for planning assistance with equity.

KEYWORDS: Children. Family. Autism Spectrum Disorder.

RESUMO: O Transtorno do Espectro Autista se refere a uma série de condições caracterizadas por algum grau de comprometimento no comportamento social, na comunicação e na linguagem. Objetivo: identificar os desafios enfrentados por pais e/ou cuidadores de crianças com diagnóstico de Transtorno do Espectro Autista (TEA). Metodologia: estudo qualitativo, exploratório e descritivo que parte das experiências de três famílias que possuem crianças com TEA. Para a coleta de dados, foi realizado um encontro com as famílias por meio do grupo focal. Os dados foram analisados com base na análise textual discursiva. Resultados: Os dados apontam que os desafios enfrentados pelas famílias são as incertezas frente ao diagnóstico de TEA e o desenvolvimento dos filhos; as dificuldades de acesso as terapias e o preconceito. Conclusão: o conhecimento acerca dos desafios enfrentados pelas famílias diante o diagnóstico de TEA é fundamental para o planejamento de um assistência com equidade.

PALAVRAS-CHAVE: Crianças.Família. Transtorno de Espectro Autista.

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INTRODUCTION

Autism Spectrum Disorder (ASD) refers to a series of conditions characterized by some degree of impairment in social behavior, communication, and language, and a narrow range of interests and activities that are unique to the individual and carried out repetitively.(1) Around 40% of people with ASD may present comorbidities related to up to two or more mental disorders.(2,3)

According to estimates from the Ministry of Health, there are 2 million people diagnosed with ASD in Brazil.(4) In the United States, a study carried out by the Centers for Disease Control and Prevention (CDC) in 2021 revealed increasing numbers of diagnoses, with a prevalence rate of 1 for every 36 children up to 8 years of age.(5) The rise in ASD diagnoses has also been observed in the European Union, requiring governments to increase the quality of services that serve children and their families.(6)

The receipt of an ASD diagnosis is challenging for the family, as parents tend to plan the child's entire life, idealizing healthy growth and development without interference. However, this process becomes compromised when parents are faced with realities that weaken their expectations of an "ideal" child, as is the case with the diagnosis of ASD.(7) These aspects become even more difficult when parents are unaware of the disorder, which makes them feel guilty and frustrated.

A study that described and analyzed family experiences from the moment their children were diagnosed with ASD pointed out that the socioeconomic and cultural conditions of families can directly reflect on the way they face the diagnosis due to accessibility to specialized guidance and professional resources. Furthermore, the search for knowledge on the part of the family constitutes an important tool for dealing with the demands arising from ASD.(7)

Behavioral treatment and skills training programs for parents tend to have positive effects, reducing communication difficulties and improving social behavior, enabling a better quality of life for people living with ASD as well as for their families and/or caregivers.

The "labels" often imposed by society on people with ASD represent a major challenge for family members from the moment of diagnosis to the search for interventions. When labeled, children with ASD are susceptible to more rigid clinical-pedagogical interventions that fail to consider the individual's uniqueness. (8)

Attention is also paid to the violation of human rights and discrimination, so the topic involving ASD must gain more space in the scientific community, especially due to the increase in the number of children diagnosed.(9) From this perspective, parents, teachers, and health professionals must participate in developing strategies to promote the health of children with ASD, through advice, guidance, and social support with a humanized approach, given the complexity and impact of the diagnosis on the family. (10)

Based on the above, this study aimed to identify the challenges faced by parents and/or caregivers of children diagnosed with Autism Spectrum Disorder (ASD).

METHODOLOGY

Qualitative, exploratory, descriptive study based on the experiences and understanding of the daily lives of three families with children diagnosed with Autism Spectrum Disorder. The families were recruited through the Autistic Association of a municipality located in the northwest region of the state of Rio Grande do Sul. This entity works to guarantee the rights of people with ASD.

Data were collected in August 2023 through a Focus Group (FG). Initially, eight families confirmed their participation in the activity; however, on the day the FG was held, only three families were present. Although authors such as Flick(11) suggest that the FG is made up of a minimum of five and a maximum of nine participants, in this study, even with the participation of three families, we decided to maintain the dynamics and stages of the FG, as it aims to identify participants' perceptions, feelings and ideas, enabling the understanding of different points of view and emotional processes, arising from the interaction context created.

A meeting was held, lasting 1 hour and 30 minutes. For the development of the FG, a script consisting of 2 moments was followed: in the first, a video was presented in which a father reports his love for his son with ASD; after the triggering video, the second moment began in which the mothers debated the daily challenges associated with ASD. The recording of interactions and observations was carried out by the moderators (researchers of this study). An audio recorder was appropriately placed on the table to cover as much as possible the participation of the group members. As a mechanism for stimulating and developing FG meetings, a topic guide or script with open questions was used.

To preserve anonymity, families were identified by the letter F, followed by the order in which they began their speeches, for example, F1, F2, and F3. This study was approved by the Research Ethics Committee of the institution to which it is linked, with registration number 6.226.505 and Certificate of Presentation for Ethical Assessment under number 70562123.6.0000.5354.

The discourse analysis was adopted, following the steps: identification of statements referring to the challenges faced by parents and/or caregivers of children diagnosed with Autism Spectrum Disorder (ASD); disassembling the interviews, identifying and coding each highlighted fragment, forming the units of analysis. Then, we moved on to building relationships between the aforementioned units, grouping their elements in a process called categorization.(12).

RESULTS

FROM THE SEARCH FOR DIAGNOSIS TO THE BEGINNING OF FOLLOW-UP: A LONG JOURNEY

This category highlights the numerous challenges families face in the search for a diagnosis until interventions begin. The first challenge encountered by the mothers who participated in this study was overcoming social judgments and those of their own family members, who often disregard the suspicions that were frequently raised by these mothers, as evidenced in the statements below:

> "My husband said I was going crazy, that I was imagining things, that my daughter was normal, and that I was seeing things that didn't exist." F2
>
> "Often, the family thinks you are inventing an illness, which ends up frustrating you."F3

Faced with these judgments, the mothers interviewed in this study highlight the solitary journey they faced in the search for a diagnosis because although they were certain that there were behavioral aspects and the development of their children that required investigation, such impressions were not validated by their family members.

> "Often we feel very alone. It's a walk alone."F1

> "Today I also notice this loneliness, especially in the family." F2

After overcoming the barriers related to the lack of family support, another major challenge encountered by the mothers interviewed in this study is related to feelings of fear, uncertainty, and insecurity in the face of their children's autism diagnosis. The lack of knowledge about autism spectrum disorder and what their child's life will be like following this diagnosis aroused a series of feelings, according to the speech fragments taken from the focus group presented below:

> "I couldn't even dream that it was autism, the only time I had heard of autism was in a soap opera." F1

> "The discovery is not easy. We experience grief, it takes time. When you get pregnant, you want your children to be healthy. All of this is very scary." F3

The feeling of frustration was also reported by the mothers interviewed in this study, especially because they did not want their children to be diagnosed with any condition that could hinder the full development of these children.

> "The day we received my daughter's autism diagnosis, my husband left the office and went to the emergency room. He got nervous and felt sick, it was very difficult. After the diagnosis, everything had to change, my husband had already planned her entire future. He had to experience his own grief." F2

After diagnosis, the challenges encountered by children diagnosed with Autism Spectrum Disorder and their families follow. There are countless intervention possibilities for children with ASD, as they aim to stimulate the development of these children by providing greater independence in various aspects of life. However, access to therapies and follow-up with speech therapists, psychologists, and occupational therapists are not always accessible to all families, which causes concern as described in the report below:

> "The financial issue was very difficult. My daughter had to undergo several therapies. The income doesn't cover everything. The health plan didn't cover it, so it was a struggle, right? We were canceling things we had, so we could save some money, so we could pay for therapies." F2

> "There has to be greater responsibility here in the municipality. They close their eyes to some attitudes of some bodies. Health is an issue that needs to be taken more seriously." F3

FROM PREJUDICE TO EXCLUSION: LIVING WITH AUTISM SPECTRUM DISORDER

One of the most evident aspects in the speech of mothers who participated in the focus group is the exclusion and prejudice experienced daily and in various spheres of everyday life. Prejudice begins to be felt from a very early age and occurs within the family environment.

> "To this day, you know, there are people in my family who don't look for my son. I don't know if it's embarrassing because he is autistic. It seems like you can't have autism in my family, that's what I feel deep down, but whatever." F3

Prejudice and feelings of exclusion can also be felt in school environments, which, in the perception of mothers who participated in the focus group, are not yet prepared for inclusive education.

> “At school, when you enroll, it’s hard, a struggle every day. We live trying to include our daughter and make her live like others. We know that she will have difficulties and not keep up with the class, but she has to be together with the others”. F2

Still regarding the difficulties faced by children with ASD and their families, these surpass the family and school environment and are also perceived within health services that, in the mothers’ perception, are not designed to care for children diagnosed with ASD. The lack of agility in care, the waiting time, and the lack of preparation of health professionals contribute to the child’s disorganization.

> “She was hospitalized once, she turned into another child that I didn’t know about. I couldn’t control her and she cried and pushed and I tried to talk to her. We were in a semi-private room and I saw people watching and not helping. A nursing technician came in and didn’t know what to do either. I felt like that, that no one helped me.” F1

> “The hospital’s problem is even more critical. I take my daughter for a consultation and she doesn’t wait, she doesn’t know what it’s like to wait. Autistic people don’t wait and this really disorganizes them, it completely disorganizes them.” F1

Finally, the mothers stated that prejudice against children with ASD is intrinsic in society. From this perspective, families are often judged and responsible for behaviors judged as “inconvenient” by people.

> “There are times when children who scream, who cry... supermarkets, stores, they could look at autistic children with different eyes. Stores could perhaps receive some training to understand a little more about autism.”F1

> “I went to the supermarket, there was almost no one there when I went to pay, I looked to the side and where is my son? Guys, I got desperate in that market, I started calling for help and no one came to help. Their lack of empathy was difficult to deal with.” F3.

DISCUSSION

The diagnosis of Autism Spectrum Disorder is a delicate and difficult moment for the family since a child with atypical characteristics will bring changes to the family dynamics, imposing challenges and testing the limits of motherhood and fatherhood. (13) In the context of mothers with children diagnosed with ASD, the feeling of guilt is often evident and is related to guilt for having raised a child outside the standards socially considered normal.

These aspects are influenced by the social construction of gender, in which men are linked to the economic and political sphere of life, while women assume responsibility for the private sphere of the home, thus, caring for children becomes entirely their responsibility.(14)

When diagnosing a child with ASD, authors highlight that parents usually react to the unknown with feelings of denial, anguish, sadness, and disbelief, as this moment constitutes a milestone in a new cycle. The search for knowledge and social acceptance of children with ASD is a major challenge for parents and caregivers.(15) A study carried out in the national literature highlights that mothers of individuals with ASD often manifest clinical symptoms of stress, depression, and anxiety.(15)

Still, concerning the family context, the authors state that families need to change their routines, and with this, financial difficulties arise, the need to do informal work or overtime, or even the abandonment of work, mainly by the mother. As a result, marital problems arise due to the difficulty of finding time for the relationship, and sometimes, shame, the feeling of failure and the father's insecurity end up motivating the couple's separation.(14)

From this perspective, care for children with ASD must be extended to the family, as it is common for families to pay greater attention to their children's inadequacies and not pay attention to their children's potential and abilities. Focusing on a child's potential requires a greater proportion of attention, tolerance, persistence, and discipline. Parents' lack of knowledge sometimes leads to overprotection of these children, impairing even more the development of social skills.(16-17)

Studies indicate that social support and emotional support offered to families are important, as they help them to meet the needs of children with ASD, alleviating suffering, anxiety, and stress, contributing to family strengthening, and promoting well-being.(18-19)

Regarding legal aspects, according to Laws 12.764/2012 and 13.146/2015, autistic people are considered for legal purposes to have a disability, thus both aim to guarantee the rights of these people and among them early diagnosis, multidisciplinary care and access to medicines and nutrients, ensuring priority status both in the SUS (free of charge) and in the private network.(20-22) However, states and municipalities are not always able to guarantee comprehensive health care for people with ASD.

In Brazil, one of the biggest challenges is to make society aware of its responsibility in the management of public policies, focusing on the demands arising from the child and youth population, especially those belonging to the most vulnerable groups. It is imperative to establish the relationship between the set of social needs and effective practice in line with the rules established by the Federal Constitution and the Statute of the Child and Adolescent.(23)

Many children diagnosed with ASD are victims of prejudice in various contexts. In the school environment, many children can be seen as aggressive and incapable of socializing and learning, which can often be used as a justification for not accepting these children in a regular school.(24)

Regarding the care of children with ASD in health services, a study reveals the lack of preparation for assistance given the difficulty of these professionals in understanding the world of the autistic person, communicating with the child, establishing trust, and creating a bond.(8) Some difficulties were also highlighted in European Union countries, including the delay of some professionals in addressing the initial concerns expressed by the country and, consequently, the delay in diagnosis.(6)

Given the complexity of ASD and the challenges the condition imposes on the parents/caregivers of these children, it is necessary to understand ASD in depth within its uniqueness, thus health professionals can more assertively provide comprehensive health care.(8)

Finally, regarding the social representation of children diagnosed with ASD, a study with university students showed that the words evoked to represent a child with autism were difficulty, isolation, illness, and disability. Social representation can interfere with the self-esteem of these children, as they may perceive their lives to be limited to social categorizations and stereotypes.(25) Situations of contempt and rejection constitute factors that negatively interfere with rights such as access to education, religion, health, leisure, and well-being.(26).

CONCLUSION

The present study aimed to identify the challenges faced by parents and/or caregivers of children diagnosed with ASD. From the reports of research participants, despite there being specific legislation that deals with the rights of people with autism, society, in general, has difficulties in accepting them.

In addition to social prejudices that make the lives of children with autism and their families difficult, prejudice is also manifested by those who should welcome the child, such as health and education professionals, who, sometimes, make it difficult for children with autism to enter regular schools, contributing to the stigmas associated with ASD.

In this way, studies willing to uncover the nuances that permeate the daily lives of people living with ASD and their families must be developed. In practice, these studies can contribute to reducing prejudice related to the disorder, as well as supporting the development of public policies aimed at promoting health and social equity.

Similar studies should be encouraged because, in isolation, such results highlight the reality of a small number of mothers immersed in a regionalized and punctual culture. As a whole, studies involving this topic can contribute to reducing prejudice, stigmatization, and social injustices routinely experienced by the population living with ASD and their families.

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