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WHEN MOTHERS TALK: PERSPECTIVES ON THE FIRST SIGNS OF ASD

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ABSTRACT. The goal of this research is to understand the perceptions and experiences of mothers who early identified changes in their children's development and search for a specific assessment for suspected Autism Spectrum Disorder (ASD). It is a qualitative research, with exploratory design and retrospective. Two mothers of children with characteristics suggestive of ASD participated in the study, who performed an evaluation at a Psychology Service-School in a city in the interior of the State of Rio Grande do Sul. A semi-structured interview was used for the data production. Based on the results, language impairment and social interaction were the first changes perceived by mothers. Both the first signs, such as the evaluation and the search for diagnosis, are permeated with different feelings, such as fear and worries. The mothers emphasise the importance of early assessment for development, considering their children's behavioral evolution. The implications of the study results for interventions with children with ASD and their families are discussed.

Keywords: Autism Spectrum Disorder; assessment; early diagnosis.

QUANDO AS MÃES FALAM: PERSPECTIVAS SOBRE OS PRIMEIROS SINAIS DE TEA

RESUMO. Esta pesquisa teve como objetivo compreender percepções e vivências de mães que identificaram precocemente alterações no desenvolvimento de seus filhos e buscaram uma avaliação específica para suspeita de TEA. Trata-se de uma pesquisa qualitativa, com delineamento exploratório e de caráter retrospectivo. Participaram duas mães de crianças com características sugestivas ao TEA que realizaram uma avaliação em um Serviço-Escola de Psicologia de um município do interior do estado do Rio Grande do Sul. Para a produção dos dados foi utilizada uma entrevista semiestruturada. Com base nos resultados, o comprometimento na linguagem e na interação social foram as primeiras alterações percebidas pelas mães. Tanto os primeiros sinais quanto a avaliação e a busca pelo diagnóstico foram permeados de diferentes sentimentos, como de medo e de preocupação. As mães salientaram a importância da avaliação precoce para o desenvolvimento, considerando a evolução comportamental de seus filhos. Ainda, são

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discutidas as implicações dos resultados do estudo para intervenções com as crianças com TEA e com sua família.

Palavras-chave: Transtorno do Espectro Autista; avaliação; diagnóstico precoce.

CUANDO LAS MADRES HABLAN: PERSPECTIVAS SOBRE LOS PRIMEROS SIGNOS DEL TEA

RESUMEN. Esta investigación tenía como objetivo comprender las percepciones y experiencias de las madres que identificaron cambios tempranos en el desarrollo de sus hijos y buscaron una evaluación específica por sospecha de TEA. Se trata de una investigación cualitativa con diseño exploratorio y retrospectivo. Participaron dos madres de niños con características sugestivas de TEA que se sometieron a una evaluación en una Escuela-Servicio de Psicología de una ciudad del interior del Estado de Rio Grande do Sul. Se utilizó una entrevista semiestructurada para obtener los datos. Según los resultados, el deterioro del lenguaje y la interacción social fueron las primeras alteraciones percibidas por las madres. Tanto los primeros signos como la evaluación y la búsqueda del diagnóstico están impregnados de diferentes sentimientos, como del miedo y de la preocupación. Las madres destacaron la importancia de la evaluación temprana para el desarrollo, teniendo en cuenta la evolución del comportamiento de sus hijos. Se discuten, todavía, las implicaciones de los resultados del estudio para las intervenciones con niños con TEA y sus familias.

Palabras clave: Trastorno del espectro autista; evaluación; diagnóstico precoz.

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by impairments in sociocommunicative and behavioral skills, such as repetitive and stereotyped behaviors, which limit or hinder an individual's functioning. The etiology of ASD is multifactorial and may be related to the interaction between genetic and environmental factors. However, there is no cure for this disorder (Reis et al., 2019).

Changes in children with ASD are usually recognized during their first years of life (American Psychiatric Association [APA], 2014). These impairments manifest in varying degrees and forms. Some children exhibit delayed or absent language development, while others develop echolalia, monotonous intonation, and the use of jargon. They may also experience difficulties in pragmatic aspects of language, such as understanding and expressing sociocommunicative behaviors that are appropriate to the social context (Bosa & Salles, 2018; APA, 2014). Some children do not develop the ability to differentiate between their own bodies and other objects, and they have difficulty demonstrating and expressing their emotions (Duarte, 2019).

ASD can compromise a child's ability to perform age-appropriate activities and tasks. These factors increase the demand for care, and consequently, the level of dependence on parents and/or guardians (Christmann et al., 2017).

According to the Demographic Census conducted by the Brazilian Institute of Geography and Statistics (Brasil, 2012), 23.9% of the Brazilian population has some type of disability, including hearing, visual, motor, physical, mental, and intellectual. However, the number of individuals with ASD has not been measured in our country. Estimates indicate that around 600,000 people have ASD, corresponding to approximately 0.3% of the Brazilian population (Paula et al., 2017). According to statistical data from the Centers for Disease Control and Prevention (CDCP), studies indicate the prevalence of one person with autism in 54 children (CDCP, 2018).

The increase in ASD rates is partially attributed to the significant number of studies in this area, owing to new assessment and treatment methods, assistance, health policies, and societal awareness (Munayer, 2018). Cases of ASD are four times more frequent in males than in females (Paula et al., 2017).

Given this scenario, the Unified Health System (SUS) and Psychosocial Care Network (RAPS) aim to improve and enhance care for individuals with ASD and their families. Notably, Law 12764 was enacted on December 27, 2012, which established the National Policy for the Protection of the Rights of People with Autism Spectrum Disorder. This law supports individuals with ASD and guides professionals, particularly in the context of early assessment. Additionally, Brazilian Law 13146/2015, also known as the Brazilian Law on the Inclusion of People with Disabilities, aims to promote the equality and freedom of people with disabilities, seeking social inclusion and citizenship (Brasil, 2015).

Children with ASD are diagnosed through behavioral analysis or reliable, validated instruments because there are no clinical examinations that can detect the disorder (Bosa & Salles, 2018). The first characteristic is related to qualitative deviations in interaction, difficulty in establishing eye contact, and excessive crying, among other factors (Brasil, 2015). These signs usually precede speech changes and manifest differently in children (Bosa & Salles, 2018).

Impairments in joint attention (JA) are among the most robust early predictors of ASD. JA refers to the ability to intentionally engage in triadic scenes for declarative purposes (Tomasello, 2003). JA develops between 13 and 15 months of age. This is essential to the development of language and social cognition. However, changes in JA are not always identified when they appear, because they are nonverbal and subtle. Therefore, the difficulties that infants with ASD present in JA are often not noticed when they appear, or when they are noticed, they are not identified as warning signs by professionals. A Brazilian study confirmed this trend, demonstrating that although social developmental difficulties are the most likely indicators of an eventual ASD diagnosis, speech delay remains the main reason parents seek assistance (Zanon et al., 2017).

Parents seek a psychological assessment of suspected ASD for the following reasons: to confirm their suspicions, to evaluate their child's abilities and challenges after a diagnosis, or to better understand their child's behavior (Bosa & Zanon, 2016). According to the Federal Council of Psychology (CFP, 2018), psychological assessment is a structured process for investigating psychological phenomena. This process involves the use of methods, techniques, and instruments to provide information for a specific purpose. The CFP (2018) states that this process must be based on scientific psychological literature and the council's current regulations.

In this context, it is worth noting that from the moment a child is born, parents create expectations for their child's characteristics, projecting their desires and wishes onto them

(Duarte, 2019). When parents discover that their child's development differs from their expectations, their expectations and beliefs are affected. The diagnostic process is usually permeated by various feelings, and caregivers exhibit varying degrees of emotional reactions depending on their characteristics (e.g., mental health and coping strategies) and the context in which they are situated (e.g., available health services and support networks). During the assessment process, parents of children with developmental differences may experience fear, anxiety about the future, sadness, denial, anger, and feelings of helplessness (Christmann et al., 2017; Selvakumar & Panicker, 2020). Furthermore, parents' adaptation period is usually unstable, since feelings can oscillate between acceptance and rejection (Firmino et al., 2018). For this reason, providing qualified and welcoming support during this time is essential and can contribute to creating conditions for accepting the diagnosis and the process of parental mourning.

About early stimulation, the earlier a diagnosis is made, the greater the benefits for a child's intellectual and adaptive functioning. While each child exhibits unique characteristics at various stages of life, most symptoms become apparent between 12 and 24 months of age (Duvall et al., 2021) and are typically identified by caregivers or close relatives (APA, 2014; Zanon et al., 2015). While it is recognized that difficulties that characterize ASD can be identified in early childhood, studies show that many children are not diagnosed until they start school (Zanon et al., 2017).

In fact, a study of 136 parents of children diagnosed with ASD showed that Brazilian children are typically diagnosed at approximately five years of age (60.14 months on average, standard deviation, 36.56). There is usually a three-year interval between parents identifying the first warning signs and receiving a formal diagnosis (Zanon et al., 2017). These results highlight the urgent need to shorten this timeframe because of the implications of early intervention in children's development. It is also worth noting that many municipalities in the interior of Brazilian states lack professional training to perform early ASD diagnostic assessments, underscoring the importance of investing in continuing education for future professionals in this field. Therefore, it is speculated that children with ASD and their families living in smaller cities may face more challenges than those living in the capital cities, where most studies originate. Thus, research on the ASD diagnostic process involving participants from small interior cities is particularly useful. This study contributes to increased knowledge about experiences in peripheral regions and improves the conditions for assessing these cases.

An early assessment of ASD cases allows for the description of the clinical and behavioral aspects of each case, while considering their vulnerabilities and potential. Thus, an early diagnosis of ASD allows for the initiation of specialized interventions that respect the developmental needs of each child. This results in an improved prognosis, including faster language acquisition and adaptation to new social environments (Bosa & Zanon, 2016; Posar & Visconti, 2020).

However, the subtleties of the initial ASD signs, which require specific assessment, and the difficulties families experience when seeking professional help may compromise ASD diagnosis, inclusion in early intervention programs, and parental guidance during the delicate time of many elaborations. Given these circumstances, this study aimed to investigate the perceptions and experiences of mothers who identified early changes in their children's development and sought ASD assessment in a municipality in the interior of the state of Rio Grande do Sul. This study is expected to support new discussions on the early assessment of ASD and intervention strategies in this context.

Method

Design

This study is part of a larger research project titled ‘Evaluation of Children with Suspected Autism Spectrum Disorder in a Service School of Psychology,’ which aimed to investigate the assessment of children exhibiting characteristics suggestive of ASD in a service school of psychology. Additionally, we sought to understand the family and social history of the children, considering their behavioral aspects.

This study employed qualitative, exploratory, retrospective, and cross-sectional research methods. According to Flick (2009), qualitative research focuses on the meaning that participants attribute to the studied issue and requires an interpretive and naturalistic stance from the researcher.

Participants

Two mothers of children exhibiting characteristics suggestive of ASD participated in this study. Between 2017 and 2020, they underwent an evaluation of their children at the Center for Care for People with Autism Spectrum Disorder (NAPTEA) at the School of Psychology of the Educational Society Três de Maio (SETREM) and received a diagnostic report suggesting ASD. The participants are referred to as M1 and M2, and their children as B1 and B2, respectively, to protect their identities.

At the time the families sought the assessment, B1 was three years and three months old and B2 was two years and two months old; they were both boys. The mothers were 21 and 44 years old at the time of data collection. Although other family members were invited to participate, only the mothers took part in the study. B1's mother participated in the entire assessment process and research alone, as she assumed sole responsibility for her son's care. B2's father could not participate in the interview because of work obligations. However, interviews with the mothers provided broad information about their children's development and family dynamics.

The SETREM Service School of Psychology is a training space that aims to promote the professional and academic development of psychology undergraduates by offering services to the local and regional community. NAPTEA was founded in 2017 in response to demands focusing on ASD. When assessing children, we used the Sistema de Avaliação da Suspeita do Transtorno do Espectro Autista - PROTEA-R (Bosa & Salles, 2018). The instrument is divided into three parts: 1) anamnesis interview, 2) Behavioral Assessment Protocol for Children with Suspected ASD, and 3) feedback interview. The protocol consists of 17 items that assess the quality and frequency of 17 behaviors characteristic of ASD in children aged 18 to 48 months with a suspected disorder (Bosa & Salles, 2018). These behaviors are divided into three categories: 1) sociocommunicative behaviors, 2) quality of play, and 3) repetitive and stereotyped body movements.

During the assessment process at NAPTEA, each session is discussed and analyzed by a team consisting of an advisor and undergraduates enrolled in basic and specific internships. The team collects data on child behavior and PROTEA-R completion. When feedback is provided to parents, necessary referrals for each child are indicated to help parents or guardians develop strategies and tools for addressing the issue.

Data production and ethical aspects

This research was approved by the Ethics Committee of the University of Passo Fundo (UPF) under the opinion number 3950690. Data were collected through semi-structured interviews with mothers ten and 13 months after their children completed the NAPTEA assessment. The interview, developed specifically for this study, consisted of ten questions aimed at analyzing the mothers' experiences with detecting changes in their children's development, as well as their perceptions of the diagnostic assessment process. The questions considered aspects related to family dynamics and children's behavioral and developmental characteristics.

After receiving authorization from the service coordinator, the researcher contacted three families who had children of preschool age (up to 42 months old at the beginning of the assessment) and were selected by convenience. Two mothers agreed to participate in the study. After signing the informed consent form and respecting all ethical precautions in research with human beings, interviews were scheduled. Due to the global pandemic caused by coronavirus, which causes the disease known as COVID-19 (Brasil, 2020), interviews were conducted on the Google Meet platform. The day and time of the interviews were scheduled according to participants' availability.

Data analysis

The interviews were transcribed in full and examined using thematic analysis (Braun & Clarke, 2006), a qualitative method that identifies themes within the data. The following procedure was used for the analysis: 1) transcription, data reading, and skimming; 2) coding of the material; 3) identification of themes; 4) analysis of inclusions in each theme and its definition; 5) naming of themes; and 6) the final analysis. Themes and subthemes were defined after data collection.

Results and discussion

Based on the analysis of the interviews, the following themes and subthemes were established: 1) first signs of ASD, which were organized into two subthemes: 1.1) changes in sociocommunicative development and 1.2) presence of restricted and stereotyped behaviors; 2) search for diagnosis, with subtheme 2.1) mourning the idealized child; 3) early assessment; and 4) post-assessment.

For the first theme, “First signs of ASD,” the statements were grouped according to the behaviors reported by the mothers regarding their children. Subsequently, subthemes were defined. The first subtheme, 1.1 Changes in Sociocommunicative Development, encompasses behavioral aspects related to language and social interactions. Mother M2 reports: “The first sign was when B2 was approximately eight months old. He would cry to ask something. I know it is normal for a child to cry, but it was too much. That started to bother me; there was something wrong.”

In the case of Mother M1, signs were observed when her child was approximately two years old. The signs were related to difficulties in social interaction, as explained in the following statement: “The first noticeable signs were at daycare. The teachers reported that he did not interact with the other children, cried a lot, and did not respond when they called him. In addition, he did not speak and was unable to form sentences.” It is worth noting from this report that B1 had difficulty using behaviors and gestures to regulate interactions with others. This behavior was reported after a speech delay was identified, suggesting that previous deficits in JA may have gone unnoticed by parents and teachers, as Zanon et al. (2015) noted.

According to APA (2014), changes in sociocommunicative development manifest clinically in ASD through persistent deficits in the emission and comprehension of verbal and nonverbal behaviors (e.g., gestures, facial expressions, and body postures) used to regulate and maintain social interactions. M1 reported that she noticed these signs but thought that the lack of interaction was just a part of his personality. She comments: “I realized my son might have difficulty when the daycare teachers said he didn't interact with other children, cried a lot, and didn't respond when they called him.”

Risk behaviors related to ASD are often first noticed by teachers during daily and group activities in preschool, which reveal a lack of interest in and interaction with other children (Zanon et al., 2017). Teachers generally have greater knowledge than parents of the milestones of social development in childhood. Some parents pay attention to these signs and seek an assessment later, justifying it with speech delay (Bosa & Zanon, 2016). Thus, public policies and social campaigns that disseminate accessible knowledge about the early signs of ASD are important as they can motivate parents to seek specialized assessments early in a child's development.

Regarding social interaction, Mother M2 also noticed difficulties with her son: “[...] he could not interact. He couldn't look 'eye to eye,' you know.” These manifestations are believed to begin at birth and vary according to the age, developmental level, and severity of the autistic condition (Reis et al., 2019). Children with autism do not develop oral language skills because they cannot pay attention to social stimuli from the world around them. As a result, they do not learn the language through imitation of those around them (Tomasello, 2013; Zanon et al., 2015).

Both mothers detected the behaviors early and were directly related to difficulty developing joint attention (JA) skills. According to Zanon et al. (2015), JA refers to a person's interaction with objects or events through vocalizations, gestures, and eye contact. JA can appear as an initiative (IJA) or as a response (RJA) to an event.

Although some warning signs of ASD can be detected early, studies indicate a considerable time gap between identifying these characteristics and receiving a diagnosis (Paula et al., 2017). B2's parents noticed their son's difficulties but decided to seek an assessment only after watching a television advertisement about ASD. The mother said, “When B2 was two years and two months old, I watched a report about Autism Awareness Day, and we matched B2's characteristics with those presented by the interviewee. Then, we contacted the Service School.” This highlights the importance of educational campaigns and professional training for the reception and assessment of these cases.

About the presence of repetitive and stereotyped behaviors (subtheme 1.2), M2 said that B2 “[...] walked on tiptoe and had stereotypies with his hands.” Clinical and scientific evidence shows that stereotypies, both verbal (e.g., echolalia) and nonverbal (e.g., flapping, rocking), can be early indicators (red or pink flags) of autism (APA, 2014; Duvall et al., 2021).

Regarding theme 2) search for diagnosis, the mothers' statements revealed that they began searching for explanations of their children's behavior soon after their initial perceptions. In the field of multidisciplinary ASD assessment, there are few validated instruments with psychometric evidence for diagnosing ASD in Brazil, which can hinder or delay confirmation (Backes et al., 2014). However, in recent years, protocols for observing behavior through play have been developed and are now being used in ASD assessments (Seimetz, 2018). One such protocol is the Sistema de Avaliação da Suspeita do Transtorno do Espectro Autista, Revised Version (PROTEA-R) (Bosa & Salles, 2018; Steigleder et al., 2021).

In an attempt to understand their children's behavior, the mothers brought the two boys to the Service School of Psychology for evaluation. Mother M1 reported: “I sought out this service school because of a recommendation from my mother's coworker, who told me about the program. There were eight sessions with B1, and they were wonderful.” M2 found out about the service through another family and said: “I saw an interview with the mother of an autistic girl, and the service school was mentioned. My husband and I sought out an assessment, and based on the results, we suspected autism.”

Since the Service School of Psychology is a professional training space for psychology undergraduates, the assessment was carried out carefully to understand children's overall functioning in different environments. Thus, interviews were conducted with other professionals who worked with the children, and opinions were requested. A visit to the school was also conducted. At the end of the process, there is a feedback session, which is important for all families, especially parents. During this session, concerns were addressed, and behaviors observed in the child were explained. The importance of training qualified professionals to assist, recognize, and intervene with children exhibiting characteristics suggestive of ASD has been highlighted (Duvall et al., 2021; Bosa & Zanon, 2016).

Following the assessments at the Service School of Psychology, mothers began to seek answers and ways to help their children. Mother M1 emphasizes that “[...] she breathed autism and spent the whole day looking for information on how to work with and develop her child.” Mother M2 asserts: “I always try to understand his behavior. I look for suitable professionals and teach things that, sometimes, they don't have the patience to teach at school.”

According to Pinto et al. (2016), when considering the mourning of an idealized child (subtheme 2.1), it is observed that families have difficulty accepting the loss of the idealized child. This mourning process is permeated by feelings of fear and anguish. The interviewees' statements revealed feelings of fear and denial when they received the assessment results. One interviewee said, “[...] Deeply, I wanted to believe that it was not true because we always have hope, right? I was shocked because I had imagined it, but hearing it from a professional was shocking” (M1). Christmann et al. (2017) also report that the fear of prejudice is one of the feelings expressed in interviews: “It wasn't a cold shower; it was hot water. It was horrible to know that B2 could have autism” (M2). Receiving an assessment result and hearing something one does not want to hear can cause discomfort and destabilization. Interviewee M1 stated, “When I was going to the last assessment session, I told myself, ‘I am not going to cry,’ but when I received the results, I broke down. I could not hold back the tears” (M1).

A diagnostic assessment generates changes in family dynamics, as family members must cope with ambiguous feelings and an unknown reality. However, during this period, it is important to understand more than just the diagnosis's name, as knowledge of it favors adaptation, coping mechanisms, and prognostic perspectives (Pinto et al., 2016).

Maia et al. (2016) emphasize that healthcare professionals should welcome parents who receive an ASD diagnosis for their child. This allowed parents to experience the stages of mourning for the child they had envisioned. Therefore, diagnostic assessment should be understood as a process. The feedback interview is especially important for parents (Bosa & Salles, 2018). Following the PROTEA-R guidelines, the study participants received a final diagnosis and referral for early stimulation and prognosis based on the potential of each child.

Regarding theme 3, early assessment expanded the possibilities of habilitation, rehabilitation, and adaptation (Zanon et al., 2017). Thus, the earlier a diagnosis is made, the greater the chance of achieving positive treatment outcomes, since the early stages of life are a critical period for interventions (Brasil, 2014). However, some aspects may delay the diagnosis of ASD. For example, there is a lack of specific exams, qualified professionals, and multidisciplinary teams, especially in interior regions. There is also a lack of acceptance of disability by the family, even with all clinical evidence. These points reflect the reality of the interviewees and possibly of other families (Pinto et al., 2016).

Mother M1 reports: “B1 does not have a definitive diagnosis. We are undergoing monitoring and exams with a speech therapist and neurologist, but we do not have a definitive diagnosis.” Mother M2 explained the situation with B2: “We started genetic testing in Porto Alegre, but the results were inconclusive. We needed to redo the test with a different technique, but the pandemic prevented us from doing so.”

Lack of diagnosis can hinder the development of children with ASD. Some obstacles that contribute to this include the lack of qualified professionals who can recognize symptoms. Mother M2 states: “[..] We often questioned the two pediatricians who treated him. We talked about our suspicions and concerns, but they always told us that there was nothing wrong and that every child develops at their own pace.” M2 also emphasizes: “[...] We realized that B2 had stalled in his development, so we asked for a speech therapist's support. She didn't think it was necessary yet, but at the end of the treatment, she agreed because we asked so many questions.”

Recognizing atypical behaviors and social difficulties in children, visiting doctors' offices and hospitals, postponing the diagnostic process, and establishing a treatment plan are often sources of concern and suffering for parents. Studies show that families facing special situations that drastically change their daily lives are overwhelmed by tasks and demands, which can trigger emotional exhaustion and psychological problems, including depression and anxiety (Selvakumar & Panicker, 2020). It is worth mentioning that parents' mental health can interfere with the quality of care they provide to their children, which can impact child development.

A trained multidisciplinary team is essential for the diagnosis of ASD, a requirement that is regrettably unmet in certain cities within the interior regions of the states (Zanon et al., 2017), as highlighted in this study. However, it is important to acknowledge that a delayed formal diagnosis of ASD does not preclude children from receiving interventions that are vital for fostering their independence and adaptation (Duvall et al., 2021).

Although these signs of the disorder were perceived early, both mothers expressed the belief that they should have pursued assessment and started treatment earlier to enhance their son's quality of life. Mother M1 reports: “I think we took B1 for treatment a little late, and today we have to try to ‘catch up’ for what we lost [...].” M2 concurred, stating: “[...] When one reaches a certain age, it becomes difficult to develop certain things. With B2, I think it was even later.” Mothers' concerns regarding the initiation of interventions for their children were valid. In early life, the brain is highly plastic and forms new connections in response to educational stimuli. This is associated with an improved long-term prognosis (Bosa & Zanon, 2016; Posar & Visconti, 2020).

Regarding theme 4, post-assessment, the professionals currently working on developing their children are educators, psychologists, speech therapists, and the entire team at the Association of Parents and Friends of Exceptional Children (APAE). Multidisciplinary care is important for socialization and integration because needs are interconnected. “Before we started treatment at APAE, he didn't point, didn't have joint attention, and didn't respond to his name” (M2). Mother M1 states: “[…] today, B1 is interacting with other children and becoming more independent. Even though I want him all to myself, he needs to be with other people.” M1's statement revealed the importance of early intervention in developing her son's independence. Studies show that early intervention has positive and significant effects on children's development (Brasil, 2014). M1 also states, “[…] today, he can form sentences and ask for what he wants.”

By seeking out the Service School of Psychology, mothers were able to gain insight into their children's behavior and refer themselves to other professionals. Even without a definitive diagnosis, they seek resources to help their children progress and improve their quality of life. This demonstrates the importance of the feedback interview, which was conducted in accordance with PROTEA-R System guidelines (Bosa & Salles, 2018). Parents must actively participate in the assessment process in order to understand their children's difficulties and potential. In addition to systematically evaluating subtle aspects of the child's development, professionals must help parents reflect on the recommended behavioral and educational therapies for each case to promote the integral development of individuals with ASD.

Final considerations

Through this research, we gained an understanding of the perceptions and experiences of mothers who identified early changes in their children's development, and sought a specific assessment of suspected ASD. Through interviews, we learned that the initial signs, assessment, and search for a diagnosis were permeated by feelings of concern and fear. However, in their reports, the mothers emphasized the importance of development and adaptation for themselves and their children.

The mothers' statements revealed that traits related to difficulties in sociocommunicative skills (communication and social interaction) were the initial signs that prompted them to seek assistance in understanding their children's behavior. The mothers reported detecting symptoms in early childhood but had difficulty accepting the condition and suspected an ASD diagnosis in their children. Studies that present red flags for ASD, public policies, and informative and educational campaigns on the importance of early ASD identification are useful in raising awareness of ASD characteristics and encouraging families to seek specialized help (Brasil, 2015; Duvall et al., 2021). It was also noted that there is a lack of qualified professionals, especially in the medical field, to assess suspected ASD in the studied context (the interior of the state of Rio Grande do Sul), which often causes dissatisfaction and stress for families who sometimes need to travel to large centers for consultations and exams.

In this context, it was possible to understand the importance of specialized services, such as the Service School of Psychology, since it receives and guides the family according to the child's needs and, in addition, provides tools that guide and help with this issue. However, it is worth mentioning that the team of this service does not have professionals from other specialties, such as those in the medical or speech therapy areas, who could have contributed to the accuracy of the assessment, confirmation of the early diagnosis of ASD, and guidance for the parents.

Despite the mourning experienced by these mothers, the assessment provided an important opportunity for them to seek treatment and intervention for their children. This contributed to children's development, replacing the initial feelings reported, and showing acceptance and coping with reality. Thus, numerous questions remain concerning this topic, which were not addressed in this study. The limitations of this study include the participation of only two mothers and the inability to interview them in person due to the pandemic, which would have allowed for greater interaction between the researcher and participants. New research focused on the diagnostic process in small cities is important for integrating family members, teachers, and professionals in the area to provide more benefits to people with ASD.

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