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From the first signs to care: family pathways of children with Autism Spectrum Disorder (ASD) in the Public Healthcare System

Dos primeiros sinais ao cuidado: percursos de famílias de crianças com TEA na Rede Pública de Saúde

Desde los primeros signos hasta el cuidado: trayectorias de familias de niños con TEA en la Red Pública de Salud

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Abstract

Recognizing the challenges faced by family members is essential for effective care, as they form the main support network for the children. This study aimed to investigate the path followed by families from the perception of the first signs of developmental changes in their children to the diagnosis of Autism Spectrum Disorder (ASD) and their entry into a Psychosocial Care Center (CAPS). The method was qualitative, descriptive, and cross-sectional. Data were collected through interviews with family members or caregivers of 30 children diagnosed with ASD who were receiving care at CAPS ij in a large municipality in the State of São Paulo. Interview excerpts were transcribed for subsequent linguistic-discursive analysis of the utterances. The results showed that the first signs identified by participants were related to the process of language acquisition, such as absence of speech, lack of eye contact, and difficulty in social interaction. Other signs were linked to sensory or behavioral aspects. Most mothers (18) were the first to notice these signs, when the children were around two years old. The journey toward healthcare began with a consultation with a pediatrician at a Primary Health Care Unit, where

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Authors´contributions:
IRM: study conception; methodology, data analysis and interpretation; article writing; critical review and guidance; master's advisor of the project that originated this article.
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they expressed their concerns and suspicions. The pediatrician then referred the families for evaluation and care at CAPS or advised some to wait before a referral. Emphasizing the importance of considering family members as a key element in the care of individuals with ASD is crucial, valuing their reports so that referrals happen in a timely, appropriate, and responsible manner.

Keywords: Autism Spectrum Disorder (ASD); Family Health; Mental Health Care.

Resumo

Reconhecer os desafios vivenciados pelos familiares é essencial para a efetividade do cuidado, considerando que eles compõem a principal rede de apoio às crianças. O objetivo desta pesquisa foi investigar a trajetória percorrida pelas famílias desde a percepção dos primeiros sinais de alteração no desenvolvimento de seus filhos até o diagnóstico de Transtorno do Espectro Autista (TEA) e a entrada em um Centro de Atenção Psicossocial (CAPS). O método adotado foi qualitativo, descritivo, de corte transversal. Para a obtenção dos dados, realizaram-se entrevistas com familiares/responsáveis de 30 crianças com diagnóstico de TEA em atendimento no CAPS ij de um município de grande porte do Estado de São Paulo. Trechos das entrevistas foram transcritos para posterior análise linguístico-discursiva dos enunciados. Os resultados apontaram que os primeiros sinais percebidos pelos participantes estavam relacionados ao processo de aquisição da linguagem, como ausência da fala, falta de contato visual e dificuldade de interação. Outros sinais referiam-se a aspectos sensoriais ou comportamentais. A maioria das mães (18) foi a primeira a notar esses sinais, por volta dos dois anos de idade das crianças. O percurso até o serviço de assistência iniciou-se com consulta ao pediatra da Unidade Básica de Saúde, ocasião em que manifestaram suas queixas e suspeitas. O pediatra encaminhou para acolhimento no CAPS, avaliação e atendimento, ou orientou algumas famílias a aguardar. Ressalta-se a importância de considerar os familiares como peça fundamental no cuidado de pessoas com TEA, valorizando seus relatos para que os encaminhamentos ocorram de forma precoce e assertiva.

Palavras-chave: Transtorno do espectro autista; Saúde da Família; Assistência à Saúde Mental.

Resumen

Reconocer los desafíos vivenciados por los familiares es fundamental para la efectividad del cuidado, ya que constituyen la principal red de apoyo a los niños. Esta investigación tuvo como objetivo analizar la trayectoria recorrida por las familias desde la percepción de los primeros signos de alteraciones en el desarrollo de sus hijos hasta el diagnóstico de Trastorno del Espectro Autista (TEA) y el ingreso a un Centro de Atención Psicosocial (CAPS). Se utilizó un enfoque cualitativo, descriptivo y transversal. Para recopilar los datos, se realizaron entrevistas con familiares o responsables de treinta niños con diagnóstico de TEA asistidos en el CAPS ij de un municipio de gran tamaño del Estado de São Paulo. Fragmentos de las entrevistas fueron transcritos para su análisis lingüístico-discursivo. Los resultados indicaron que los primeros signos percibidos estaban relacionados con el desarrollo del lenguaje, como ausencia del habla, falta de contacto visual y escasa interacción social, además de aspectos sensoriales o conductuales. La mayoría de las madres (18) fue la primera en notar estas señales alrededor de los dos años de edad de los niños. El recorrido hacia la atención comenzó con una consulta al pediatra de la Unidad Básica de Salud, donde los familiares expresaron sus inquietudes. Algunos fueron derivados al CAPS para evaluación, mientras que otros recibieron la indicación de esperar. Se resalta la importancia de considerar a los familiares como parte esencial del cuidado de personas con TEA, valorando sus relatos para posibilitar derivaciones tempranas y adecuadas.

Palabras clave: Trastorno del Espectro Autista; Salud de la Familia; Atención a la Salud Mental.

Introduction

Autism Spectrum Disorder (ASD) or Autism has been the focus of study by several researchers. Since the studies of the Austrian Hans Asperger in the 1940s, it was characterized as "Infantile Autistic Psychopathy"[1]. The definition of disorders, diagnostic criteria and conceptualization have undergone changes over the years. Currently, ASD is considered by the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th edition published in 2013)[2], as a set of deficits in the areas of communication, social interaction, involving restricted and repetitive patterns of behaviors and interests.

In recent years, there has been an increase in the incidence of ASD diagnoses made in childhood, since signs of delays or changes in the development begin to manifest itself in this period. Studies, such as those by Almeida and Neves[3] and Teixeira *et al.*[4], suggest that this growth in the number of diagnoses is largely related to the greater focus of ASD in academic studies and the growing visibility of the topic in the media, which has resulted in greater public awareness. This has led to greater interest on the part of families and health professionals, directing their attention to issues related to developmental delay that may be associated with the diagnosis of ASD.

Some other factors raised as hypotheses in studies[3,4], regarding the increase in ASD diagnoses include environmental and genetic issues. In addition, subjectivity and changes in diagnostic criteria — especially those defined by the DSM-5 — also play an important role, as these criteria are based on the interpretation and evaluation of professionals.

In addition, another current reflection that has been heated up by authors such as Broderick[5] is the so-called "autism industrial complex", in which it is argued how autism has become a lucrative market for marketing, product sales, health services and capital investments, which induces cultural and political perception of the problem to generate profit. This phenomenon has social, cultural, and economic implications that are often harmful for autistic individuals and their families.

The greater visibility of ASD raises a paradox: does the increase in the number of diagnoses really reflect an increase in prevalence rates, or is it more a reflection of a change in perception and diagnostic criteria? This makes us reflect on whether we are really observing an increase in the incidence of ASD or just a better definition and recognition of the condition. Far from wanting to try to solve this issue, it is clear that this is a topic that needs to be brought up for discussion, considering its relevance as a public health issue.

According to Almeida and Neves[3] and Teixeira *et al.*[4], the increase in diagnoses does not necessarily mean an increase in the incidence rate. According to the document Guidelines for Attention to the Rehabilitation of People with Autism Spectrum Disorders (ASD) (2014)[6], this increase has a multifactorial origin, and the etiology is still unknown. This dilemma underlines the need for a more holistic approach to the theme, which is not limited to a rigid application of criteria, but which takes into account the individuality of each subject, in addition to health professionals knowing the aspects of ASD[6].

For the follow-up of these diagnosed cases, in public health, the Psychosocial Care Centers (CAPS) are the central reference services that provide part of network from health and play an important role in consolidating care for people with ASD. The CAPS emerged as an alternative to the hospital-centered and hospitalization approach, representing a change in the significant in model from care, being the first services introduced by the national mental health policy[6]. This is the first initiative in the field of mental health in the public health network, which provides a service that includes people with ASD and their families in care and assistance in a way that longitudinal.

Knowing the flow(s) of the health network allows the identification of gaps in the care process, facilitating the implementation of more effective public policies and the articulation between the different levels of care, such as basic health units, specialized centers, and mental health services[7]. In this way, it is possible to promote more continuous and quality care for children with ASD and their families, favoring the development of the child and their social inclusion.

The articulation between health services and the involvement of the family are essential for the success of the treatment. The active participation of family members directly impacts the child's evolution, as they are the main support network for these children. Thus, family participation is one of the factors that most impact the care of people with ASD. Attendance at therapies and continuity

of treatment at home are essential for positive results. In addition, family members offer emotional support, self-esteem and confidence, aspects that encourage the child to adhere to treatment[8].

The authors Givigi, Santos and Ramos[8] highlight that it is crucial that family members are informed and involved in the therapeutic process, as they are the ones who will adapt the routine to integrate the care necessary for the child's development and healthy evolution. The family, according to the authors, needs to be seen as an integral part of the therapeutic treatment, and will follow the guidelines given by health professionals on strategies to carry out meaningful interaction activities for the child and to resolve possible difficulties.

The success of the therapeutic follow-up of children with ASD and the guarantee of access to health depend not only on the health team, but also on the understanding and engagement of the family, as stated by Barros *et al*[9]. These authors also emphasize the importance of a follow-up that involves not only the child, but also their families, considering the impacts that the diagnosis can generate for them.

Therefore, it is essential to understand the trajectories of the families of children with ASD from the first complaint manifested by the family members in consultations with health professionals, to access to a health care service, since this understanding should allow a more appropriate reception. With this, it is possible to offer a more assertive and personalized treatment for individuals with ASD, considering the specific contexts of each family. In addition, it is essential to analyze the functioning of the public health network in the care of ASD cases, to ensure the most efficient management of services and the flow of the network in cases of suspected ASD.

The health team listening attentively to the family's complaint that something is altered in the course of development can guarantee referral to specialized services. Despite the advances in public mental health policies, there are still few studies that address, in depth, the path of families, from the first signs to access to diagnosis and treatment at the CAPS. Thus, the objective of this research is to verify the trajectory taken by families from the perception of the first signs of developmental alteration in their children to the diagnosis of ASD and entry into a CAPS.

Method

This article is an excerpt from a larger research entitled "The perception of family members/guardians about the diagnosis and therapeutic process of children with autism spectrum disorder" developed as a master's thesis. It had a qualitative, descriptive cross-sectional character. To obtain the data, an interview was conducted with family members/guardians of 30 children diagnosed with ASD who were being treated at the CAPS ij in the municipality of Campinas in the state of São Paulo.

The research project was authorized by the Municipal Health Department and approved by the Research Ethics Committee of the university under opinion number 6.826.043 in May 2024. To obtain the data, the researcher invited the family members who were at the CAPS reception waiting while the children were in care with the unit's professionals to be part of the research. Those who agreed to participate were directed to a room provided by the CAPS coordinator. The researcher explained the research to them, who read and signed the Informed Consent Form (ICF). After the consent of the family members, a semi-structured interview was conducted, following a script with questions about their trajectories from the perception of the first signs of alteration in the child's development to the entry into the CAPS for care.

In order to participate in the research, participants had to meet the following inclusion criteria: being a family member or guardian of the child using the CAPS, who had a diagnosis of ASD and being over 18 years old. Family members who were not legal guardians of the child, family members/guardians whose children were not diagnosed with ASD, and those children who had other disorders associated with ASD were excluded.

The interview sought to focus on the families' knowledge about the signs of alterations of children diagnosed with ASD perceived in the course of development by the families, as well as the diagnosis process and the therapies performed.

For this article, a cut was made in the data set in order to select the answers to the following questions from the interview script: What were the first signs and/or symptoms perceived in the child? What did you notice that was different about her development that caught your attention? Who noticed signs that made you suspect a disorder? Did any doctor suspect it? Any teacher? Anyone

in the family? Or you? What made you/the family seek professional help? At what age did this happen? What was the path you took to the diagnosis? Did the diagnosis occur through the public health network? How long did it take from the time you started your search for the professional until the diagnosis? What treatments have been performed so far? What do you know about them?

The excerpts from the interviews were transcribed and the data analysis followed the methodology of linguistic-discursive analysis of the utterances obtained in the participants' answers. The data obtained from the participants' answers were selected for analysis, which consisted of careful reading and interpretation of the meanings. After that, the data was organized by thematic axes. The linguistic-discursive analysis allowed the data to be analyzed in a more detailed and interpretative way.

According to the linguistic-discursive analysis, meeting the relevance criterion, some answers or excerpts of answers were used to typify the meaning of the answers that were judged to be more representative. From the analysis, the following thematic axes were reached: 1) Perceptions of family members/guardians about the signs of developmental alteration, 2) Who first noticed the signs of ASD, 3) When the first signs were perceived, 4) The path to diagnosis, 5) Assistance and therapeutic care and 6) Knowledge of family members about the children's care. In addition, it is worth noting that in the results the ages of children and adolescents will be expressed as follows: the number before the semicolon (;) indicates the year and the number(s) after the semicolon correspond to the months.

Results

Sample Characterization

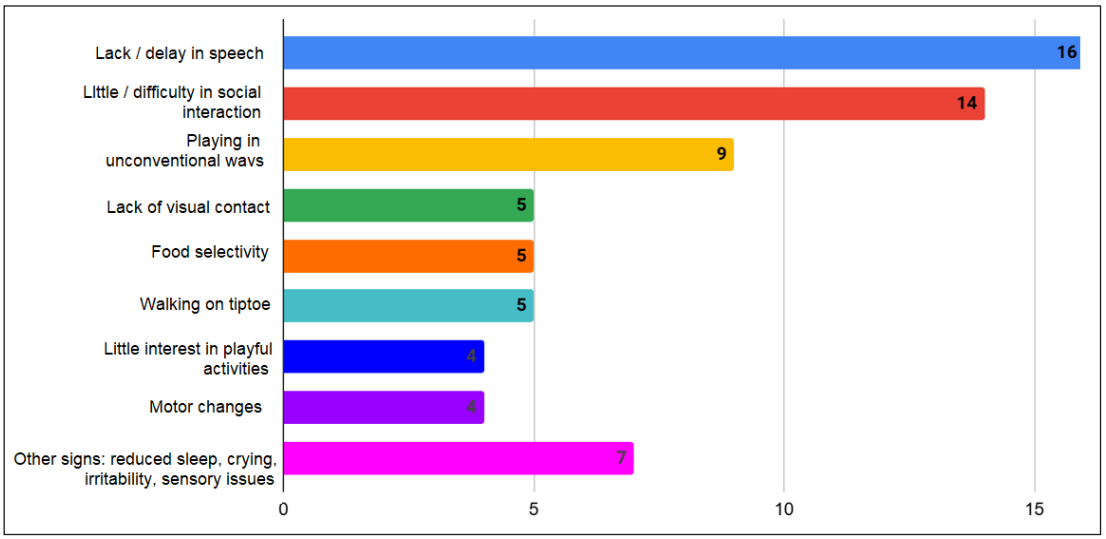
In all, 26 mothers participated in this research, constituting the majority of the participants. Regarding education, 21 participants have completed high school and in relation to profession, 9 are self-employed/merchants, 16 as housewives or unemployed, one as a production assistant, 3 as service assistants, one teacher and one retired. Ages ranged from 22 to 46 years old, with the exception of one of the participants, who is 76 years old. The mean age was 38.06 years, and most are in the age group between 34 and 45 years.

The mean age of the children was 6; 22 years old, with ages ranging from 4 years and 1 month (4; 1) to 12 years and 11 months (12; 11); and the age group from 5 years to 5 years and 11 months (5; 11) includes most children.

Family perceptions of signs of developmental alteration

The researcher asked the participants what were the first signs/symptoms/alterations that they noticed in the child's development, which caught their attention. The main signs pointed out by the families were: absence/speech delay, mentioned by 16 participants, and little/difficulty in social interaction, reported by 14 participants. The lack of eye contact, mentioned by 5 participants, and playing in unconventional ways, mentioned by 9 participants, such as lining up objects and manipulating objects that are not toys, were also pointed out as signs of alteration in the child's development.

Graph 1. Signs of ASD identified by the family

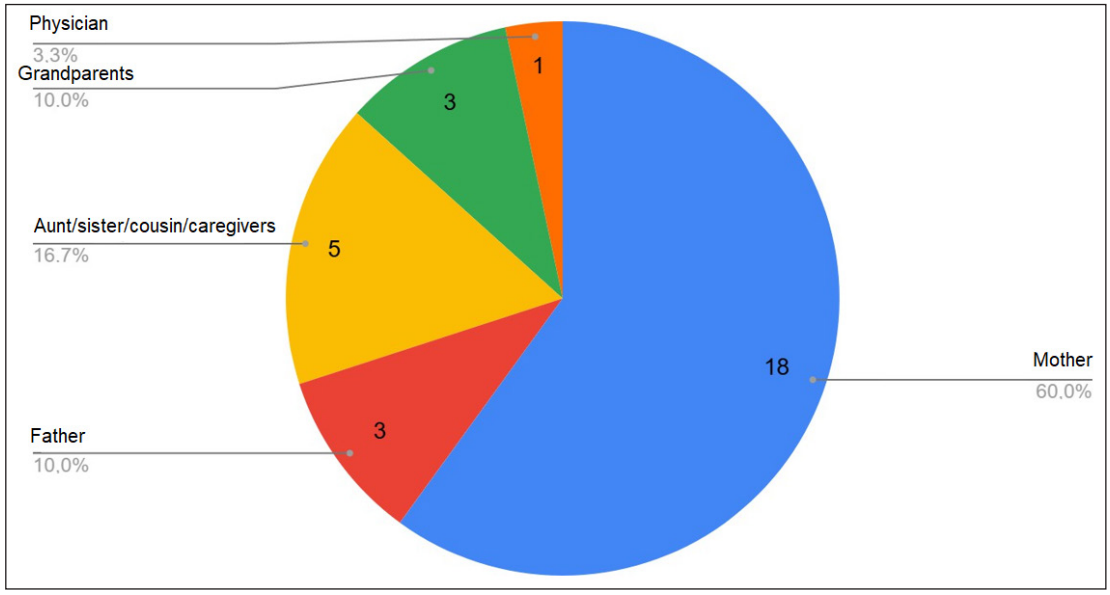


It is noted that many of the signs pointed out by most participants were related to the language acquisition process, such as the absence of speech, lack of eye contact, difficulty in interaction, mentioned by 16, 14 and 5 participants, respectively. Other signs reported refer to sensory or behavioral aspects, such as food selectivity (mentioned by 5 participants), reduced sleep (2 participants), excessive crying (7 participants), irritability or nervousness (2 participants), the habit of walking on tiptoe (5 participants), as well as discomfort with sounds, textures and lights (7 participants).

The statement of one participant exemplifies the findings: P1: “Since he was born, from a newborn, a tiny one, he has always slept little. He was always a very crying child. When he started the food introduction he didn’t eat. [...] He began not to look. He stopped talking. He just screamed and cried. He then began to walk on tiptoe. He began to have sensitivity to noise. He began to not want to leave the lights on. I didn’t want to leave. [...] And he was irritated by clothes. Then like this, then there was no like like this I said “people all possible signs”.

Who first noticed the signs of ASD

Graph 2. Who noticed the signs of ASD first

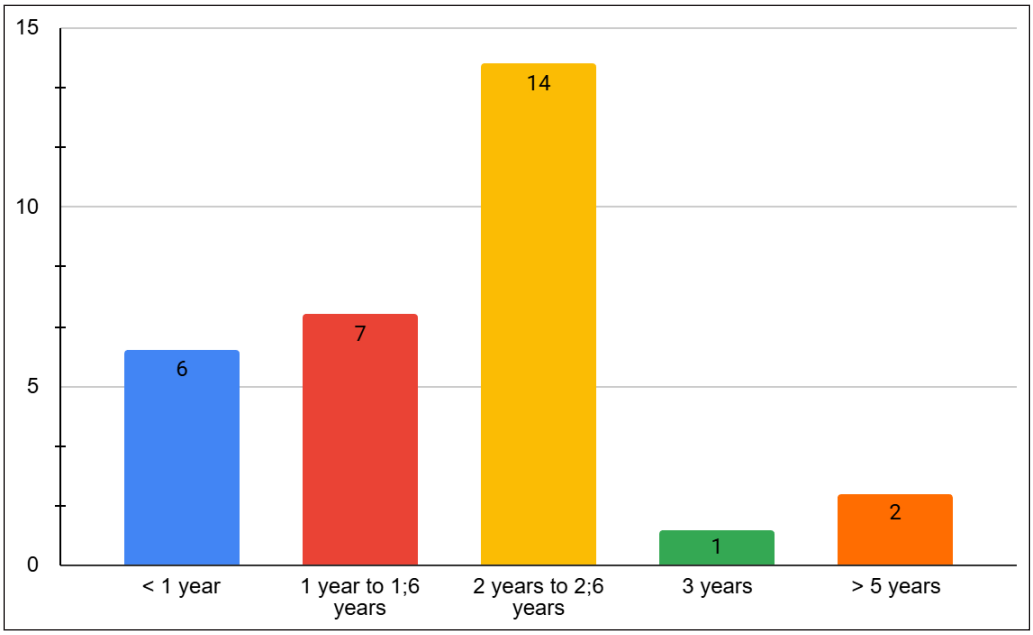


When asked who was the first person to notice the signs of ASD, the majority (18 participants), including the parents who participated in the research, answered that the mother was the first to notice the signs, pointing out that the protagonists of family care are still the mother figures. Another 5 participants answered that those who first noticed the signs were aunts, sisters, cousins, friends, neighbors who were caregivers of the children. Only one participant answered that it was the father and two others said that it was the father and mother together, the first to notice the signs. Three other participants answered that the grandparents noticed it first, because they had routine contact with the child. Only one participant reported that a psychiatrist was the first to notice the signs.

Participants reported that they notice signs of alteration in the global development of their children, but that they did not necessarily associate it with ASD. It is noted that, among 18 people who said that their mothers were the first to notice and one person who reports that the father noticed first, that is, most of the people to notice were the members of the family nucleus.

When the first signs were noticed

Graph 3. Children's age in the perception of signs



Seven participants answered that they noticed the signs of developmental alteration when the child was younger than 1 year, six participants answered that they noticed between 1 year and 1.6 years, 10 participants noticed it at 2 years, 5 participants answered that they noticed it at 2.6 years old and only one participant reports that they noticed it when the child was already older, at the age of 9. The age of perception of signs occurred mostly in early childhood. There was a high concentration of the perception of these signs in the 2-year-old age group, and only two participants differed from this pattern.

The path to diagnosis

Figure 1, below, concerns the apprehension of what, from the reports, we obtained in relation to the flow of the network in cases of suspected ASD. Fourteen participants presented similar reports regarding the trajectories they took in the flow of the public health network, which begins with the first perceptions of signs of changes in the course of the child's development, often accompanied by the perception of the school as well, when the child was already enrolled, followed by the consultation with the pediatrician of the UBS and, then, the referral to the CAPS occurs.

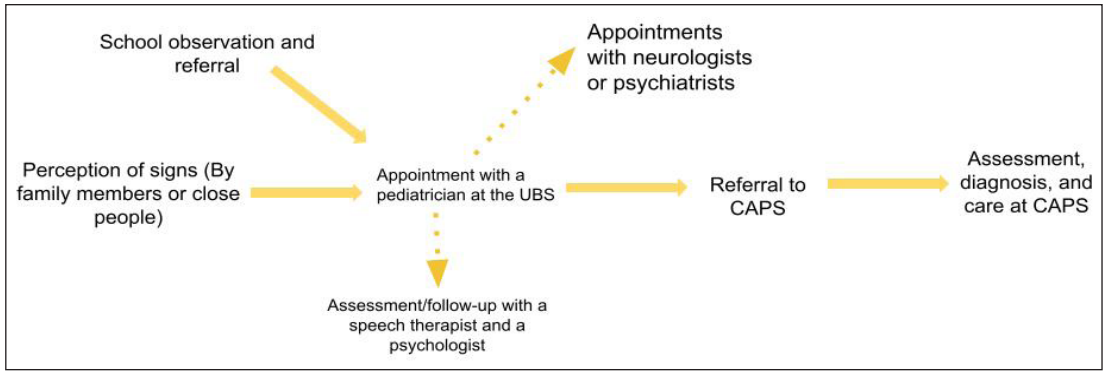


Figure 1. Flowchart of the path to the insertion of the ASD patient in follow-up in the public network

Participant P2 highlights the difficulties in this process: "It was a struggle. Because I took it to the pediatrician, I made an appointment with a pediatrician about three times. And she was denying it, saying that he had nothing, that he was too young. And I: no, he has something, he has to investigate. She: 'no, he has nothing'. Then, you let it go, you know? Then, again, I went after him to find out what he had. Then she referred them to the CAPS."

Of these fourteen participants, nine mentioned that they were also being monitored by a speech therapist and psychologist at the UBS during the period and that these professionals were also responsible for evaluating the child and discussing with the team and the UBS physician to later refer them to the CAPS or other services such as neurologists, psychiatrists or institutions such as APAE e Pestalozzi, Adacamp[1], depending on the location of the family's residence and the organization of the network flow for referrals.

At this point in the medical consultation, ten participants reported that the pediatrician asked the family to wait a little longer before making an evaluation or referrals to investigate possible diagnoses, giving time to observe if the child would develop spontaneously or by advising the child to enroll the child in school, to observe if the development would occur as expected.

Another justification for this was due to the births of children in times of pandemic; which could have hindered general development due to the social isolation that occurred. This position is controversial, because the interaction with the family has always been sufficient for the process of language acquisition and for child development. The school is responsible for formal instruction and the crèches, the care of daily life.

When, after a while, the complaints of developmental delay or alteration persist, the pediatrician in a new routine consultation was in charge of making the referral to the CAPS, as the participants' reports indicated.

In all, 20 children were diagnosed with ASD at the CAPS by the team's psychiatrist, based on the health team's assessment, as seen by the flow of the network illustrated in Figure 1. Participant P1 had the diagnosis made at APAE. Participant P3 received the diagnosis from the neurologist of the PUCC university hospital, and the other 3 received the diagnosis from professionals from the private network and through the health insurance they had.

Participants P8 and P11 report that they were matrixed by the CAPS in the UBS. The matrix support aimed to detect developmental changes in children together with the health team of the UBS and CAPS. Some families (2) also report that they were referred to other services (such as APAE e Pestalozzi) to complement the therapeutic treatments and to do more hours of therapy, in addition to the weekly hour of care at the CAPS.

According to the report of participant P5, the diagnosis of ASD was made in the UBS team that includes speech therapy and psychology professionals, who discussed and evaluated the case together with the pediatrician. This participant reports that she lived in another municipality and, therefore, the UBS she attended was not in the city of Campinas It is interesting to note that in this case,

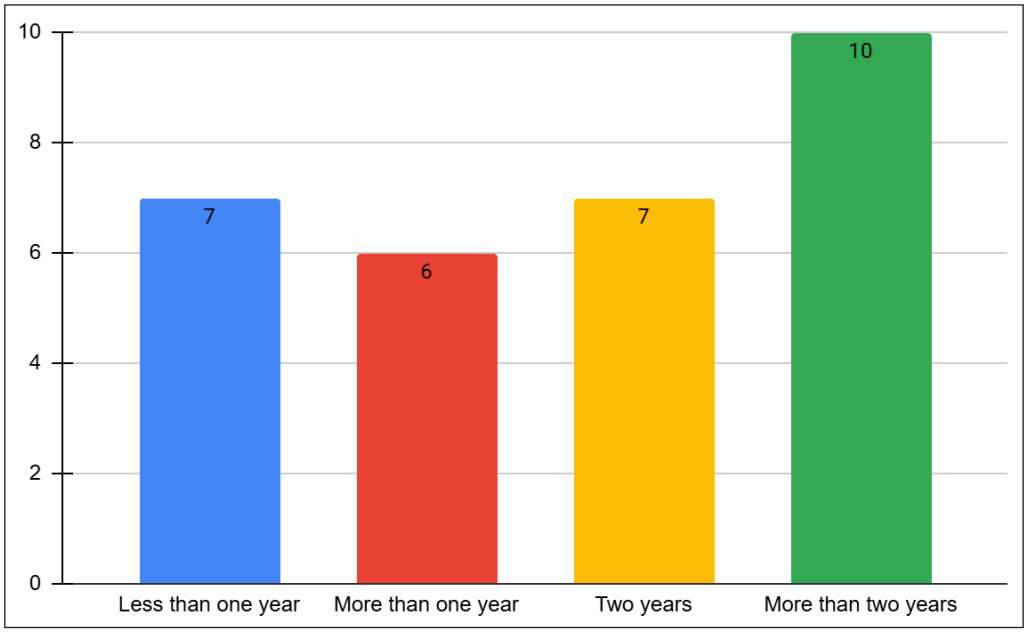
[1] Institutions that provide social assistance, education and health services for people with intellectual and multiple disabilities, including autism.

the diagnosis was made in primary care, without the need for referrals for a new evaluation.

Of the 30 participants, 5 reported that the diagnosis was made by a neurologist or psychiatrist, to whom they were referred by the pediatrician of the health plan. Four participants reported that their children were seen by a speech therapist at the UBS before being referred to the CAPS.

It can be observed that, in general, after the initial complaint, all participants had consultations with pediatricians, as they were routine consultations already scheduled or scheduled based on this complaint, and then this professional made referrals to other professionals for investigation and diagnosis of ASD.

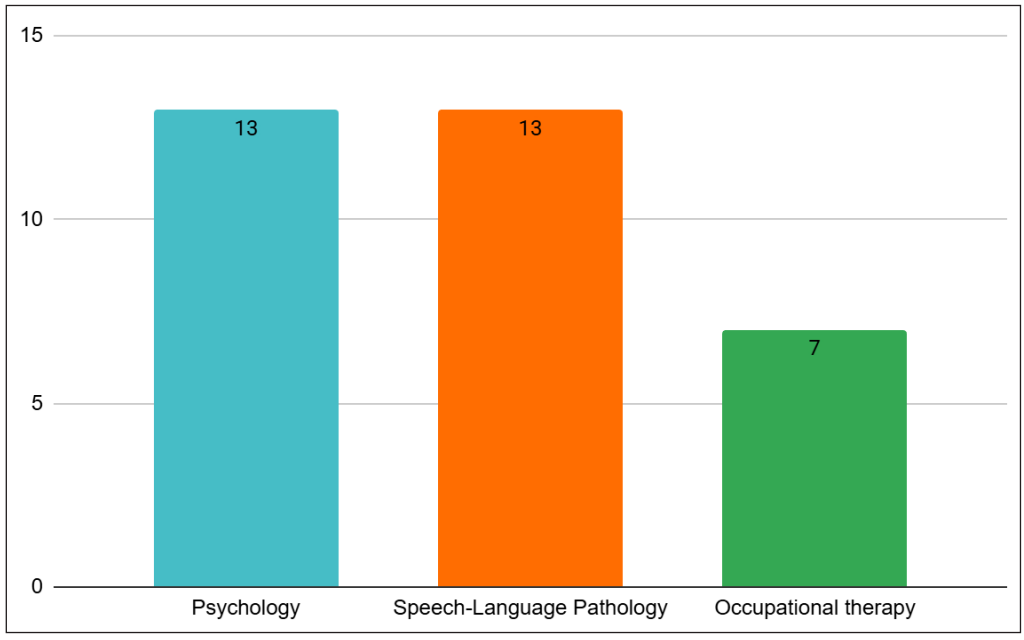
Graph 4. Time elapsed until diagnosis



It is noted that the time elapsed from the perception of the first signs to the diagnosis (of most participants) was more than one year, reaching up to two years of waiting for the diagnosis. That is, a long time considering the course of child development.

Assistance and therapeutic care

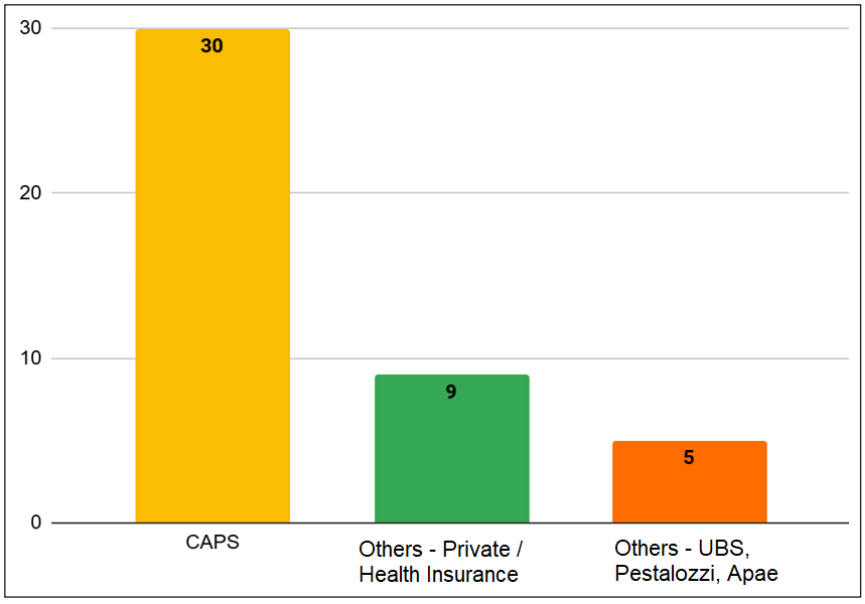
Graph 5. Professionals/Treatments mentioned that are performed at the CAPS



Most CAPS consultations are weekly (once a week) individually or in groups, according to the therapeutic project proposed by the health unit. It is known that there is a greater preference for placing patients in group care, justified by the high demand and large number of users, in addition to favoring social interaction among children. All family members participate in family groups with CAPS professionals simultaneously, while the child is being cared for by other professionals. In this sample, 25 people mention that the children's care is group and only 5 individual.

Regarding the care currently provided at the CAPS, 13 participants mentioned care with psychologists and speech therapists. Only 7 participants received care with an Occupational Therapist. Six participants cite speech therapy sessions as one of the treatments already performed previously. Seven participants did not specify which therapies and treatments they undergo in the CAPS follow-up.

Graph 6. Location of care

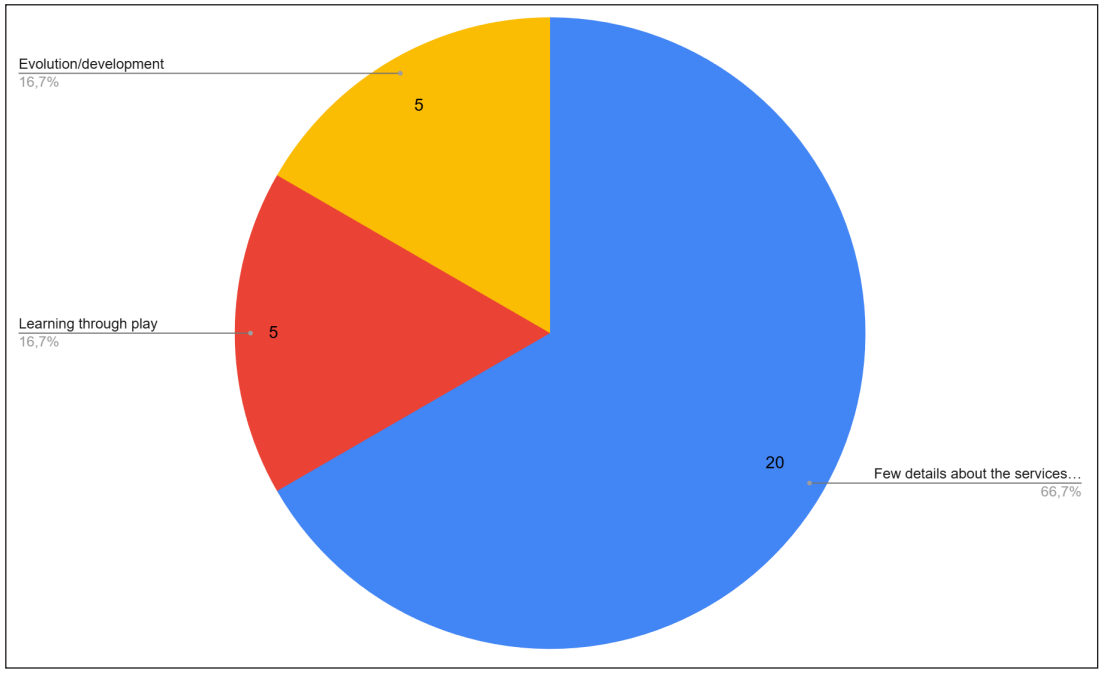


There are reports of 6 participants who say they are waiting to be called for care in other services (such as Pestalozzi, Paica and Adacamp). Another five say that the children are already being cared for in the aforementioned institutions. The children of participants P14 and P23 mention that in addition to being monitored at the CAPS, they are also monitored in a private clinic and participants P14 and P26 report that they are monitored in a clinic that follows the methodology of Applied Behavior Analysis (ABA). Three participants report that they have already been monitored by a psychologist and speech therapist at the UBS before being referred to the Caps. Six participants claim to have already undergone therapeutic care in private clinics. Participant P15 reports the desire to perform private care in clinics with the ABA methodology. Four participants were referred to other health services, such as APAE e Pestalozzi to increase the time of therapies performed, but are waiting to be called.

We see that this procedure of referring family members who are being monitored at the CAPS is common and carried out due to the low supply of care for each child in the service. Each family is served an average of one hour per week, which, considering the complexities and demands of families who have a child with ASD, is a limited time.

Knowledge of family members about the children's care

Graph 7. Information on care and treatment



It is noticeable, from the in-depth reports, that the family members do not have in-depth knowledge about the treatments already performed by their child. They do not know what happens in the sessions, as well as the purpose of therapies. The Participants report that the children have weekly sessions with a multidisciplinary team, usually with two professionals, in a group, in most cases or with some exceptions, of individual consultations.

Five participants mention the use of toys during the sessions and that children learn by playing. Another five mention that the services provided are intended to assist in the child's evolution, in their development of skills and learning. Two participants mention that they receive little information and little feedback from the professionals who care for the child about what is being done during the therapeutic sessions. In general, the family seems uninformed about the objectives of the therapeutic process and the strategies used during the sessions. However, despite this, they express recognition and emphasis on the importance of therapeutic follow-up, even without clearly knowing the objectives of the sessions.

Participant P2 explains her knowledge about the treatments: "They're teaching him to play, right? It is through play that the child learns, right? The child begins to learn things. He doesn't know how to play." It is interesting to observe the emphasis that the mother gives in her speech when she states "it is through playing that the child learns". However, it is perceived from the report that she does not include herself in the activity of playing with the child, which is delegated to the therapists.

Discussion

Based on the data presented in the previous section and in view of the objective of this research, it was possible to identify the trajectory of the families until they entered an assistance service for the care of children diagnosed with ASD. This trajectory begins with the perception of the first signs of alteration in the course of the children's

development by the mothers, who report it to the pediatricians of the UBS. The doctor is responsible for making the decision to refer the child and the family to the CAPS or request that the family wait a little longer to observe the child's development. With this, it was possible to draw a flowchart to identify the path of families with children with suspected ASD in the public health network of the municipality of Campinas.

Based on the first perception (of the mothers, for the most part), the trajectory of these families in search of a care service for the children begins. Studies[10,11] show that maternal perception is the most recurrent in the identification of the initial signs of alterations. This finding is in agreement with the findings of this study, in which 18 mothers also noticed these signs of alteration.

The findings of Homercher *et al.*[10], highlight that family perception is a key element for the early diagnosis of ASD, reaffirming the observation made by Zanon *et al*.[10], that the first signs of ASD are first noticed by those who live with the child on a daily basis, especially mothers.

Other studies on the subject explain the maternal burden in relation to children with ASD[12,13,12]. As mothers, as the main caregivers, are the first to notice the signs of developmental alterations, they also seem to be the most impacted by the lack of an early diagnosis and the scarcity of information about ASD, which can lead to emotional overload.

Among the signs mentioned by the participants as the first to be perceived are, mainly: the absence/difficulty of speech (mentioned by 16 participants), lack of eye contact (5 participants), difficulty in interaction (14 participants), in addition to playing in unconventional ways such as lining up objects, rotate the wheel of the cart. In agreement with studies by Backes, Zano and Bosa[15] and Homercher *et al.*[10], the children's manifestations in and through language are identified by family members as the first signs of developmental alterations. They don't initially link these signals to ASD, but they realize that something isn't right.

Most of the altered signs perceived by family members are related to multimodal linguistic aspects, linked to the dialogical interaction studied by Cavalcante[16] and Maldonade and Pereira[17]. Participants note that children make little use of elements such as gestures and facial expressions. It is no coincidence that, in fact, language as a constituent of the subject and that permeates all human aspects, whether social, cognitive and the individual's formation, is also the first item highlighted by family members, which draws attention to changes in the child's development.

The studies by Oliveira and Fonte[18] analyzed the acquisition of language by children with ASD and, based on the concept of multimodal acquisition, identified that elements such as gestures, eye contact and oral production form the child's triad of enunciation, evidencing the importance of considering this entire multimodal envelope in the process of language acquisition, especially in the monitoring of children with ASD.

Considering the interactionist perspective of language acquisition (which includes multimodality[17]), it was possible to observe that family members emphasize not only oral productions but also other altered dialogical and multimodal aspects, which broadens the view to detect alterations in the child's linguistic development, since it is necessary to value all their communication/interaction initiatives, that will put her in the place of a speaking subject.

Signs of developmental alteration were noticed between eight months and 2 months; 6 (two years and six months of age), showing that ASD is something that begins in early childhood. Most families (14 participants) identified signs of atypical development around the age of 2;0 years to 2;6 (two years and six months) age, especially in language and social interaction. Only participants P9 and P21 deviated from this pattern and stated that the changes were noticed when the child was 9 and 5 years old, respectively - which may indicate that there was a late perception of the signs. Studies[19,20], show that family members' perception of developmental changes in children with ASD occurs on average around 3 years of age. The results presented in this research show that the participants identified these signs on average six months earlier, than in the literature.

Taking into account the milestones of child development, it is known that between eight and 30 months of life, the child goes through a period of intense acquisitions. According to studies on human development[21,22], the 2 years of age of the child correspond mostly to the sensory-motor stage, in which the child acquires linguistic-cognitive and motor refinement skills. Regarding motor development, in this age group it is expected that the child learns to walk and later to run. At the same time, the

so-called "vocabulary explosion" occurs in the process of language acquisition, in which the lexicon increases and errors in their speech are produced, they start to experiment with new combinations of elements and structures in the language, in addition to reducing their dependence on adult speech[20,21].

It is possible to imagine that, due to this phase of development having very striking characteristics, they are more easily identified by families who have noticed the changes and absence of certain milestones. The fact that most family members perceived the signs within this time window reinforces the position that ASD is an event linked to early childhood, and shows that language is one of the most frequently affected areas, since linguistic aspects were mentioned in the answers of all participants.

In general, according to the answers of the 29 participants, after the identification of the first signs of alteration, the suspicion that something is not right in the child's development is taken by the child's close family members to the pediatric physician of the UBS in routine consultations to monitor the child, or in an appointment scheduled especially to discuss the complaint. If the suspicion is endorsed by the doctor, the child is referred to the CAPS.

At this point, it is up to the pediatrician at the UBS to evaluate and question the family to make their decision: a) to wait a little longer to wait for the child's development or b) to refer the child to a CAPS to be evaluated by the multidisciplinary team. In this study, 10 participants were instructed to wait and 4 were referred directly to the CAPS. However, those who were instructed to wait, after some time returned to the medical consultation at the UBS and, due to the prevalence of the complaint, the doctor referred them to the CAPS.

The medical advice to wait a while to observe the child's development even in the face of signs of ongoing changes is controversial. This decision goes in the opposite direction to what is stated in the literature[20,23], which points out the importance of making the diagnosis as soon as possible, in order to obtain access to care early. The delay in receiving the diagnosis may lead to delays in referrals to a service to receive the family's complaint and to initiate an appropriate follow-up. Having the diagnosis made is often a gateway to access specialized health care services.

According to Ozonoff *et al.*[24], rapid entry into a care service is considered one of the most determining factors for better prognosis in children with ASD. Postponing diagnosis can compromise access to critical therapeutic practices during the critical window of neurocognitive development.

However, studies such as Girianelli *et al.*[19], Landa and Garrett-Mayer[25] and Brentani *et al.*[26] showed that a minority of diagnoses are made early, that is, before the age of three, and the specific reasons for this are still unclear. From the data of this research, we see the same phenomenon occurring, in which the perception of the signs by the family occurred around 8 months to 2; 6, and the diagnosis was made mostly (as seen in 23 participants' responses) after more than a year of waiting, that is, the children were already over three years old.

Ribeiro *et al.*[20] also show that there is an average delay between the perception of signs (occurred when children were around 2 years old) and diagnosis (made around 5 years of age). Thus, in the authors' research, the results indicated a wait of 3 years for the diagnosis, that is, a longer time than what was found in the data presented here. The reasons given by the authors for this included the lack of adherence of pediatricians to the evaluation protocols, variation in professional experience, use of non-validated instruments, in addition to the lack of training of professionals, inadequate tools and difficulties in the doctor-family bond.

It is possible that there is a lack of knowledge on the part of medical professionals about ASD and ways to diagnose it. The literature suggests that the diagnosis should be composed of assessment instruments of multiple domains of the development, including talking to family members to consider their point of view, environmental issues and the child's health history[19,26].

This posture of "waiting a little longer", despite still being adopted by many professionals, is based on a conservative and possibly uninformed approach to the realities of ASD, as stated in the document prepared by the Ministry of Health on the line of care for the care of people with ASD and their families. The SUS psychosocial care network[6] highlights that this behavior of "waiting a little longer" can delay access to care and cause significant harm to the child.

Many doctors place the pandemic period as a determining factor for the increase in developmental delays, in which the child had the most restricted

social interactions and could not attend school. The studies carried out by Almeida, *et al.*[27] point out that the Covid-19 pandemic has in fact brought several impacts to the population as a whole, including changes in routine, learning difficulties due to the impossibility of attending school, in addition to impacts on psychological and physical health, delays in child development, globally.

On the other hand, based on studies on language acquisition[16,28], it is important to consider that a large social cycle is not necessary for a child's development to occur. Living with family members would be enough to guarantee interactional experiences necessary for the language acquisition process, since the family nucleus is the main source of interaction and socialization of the child in early childhood. Thus, even though the pandemic has brought impacts to the entire population, considering that this is the main causal factor to justify all developmental delays and the increase in the prevalence of ASD may be an exaggerated view, since it does not consider the home environment as the main provider for the development of minimal linguistic aspects, as it has always happened in history. In this sense, studies such as those by Cadime *et al.*[29] indicate that the pandemic has had significant impacts on child development, but reinforce that the family environment, when responsive and with quality interactions, can mitigate most of these effects, especially with regard to language.

Following the flow of the families' trajectory, after the referral of the pediatricians, the families are welcomed at the CAPS and the children are evaluated by a multidisciplinary team, which lasts about a month. From this evaluation, if the diagnosis of ASD is confirmed by the professionals, the child is inserted in a therapeutic group and the responsible family member, in family groups, which occur simultaneously with the child's care. In this study, only participants P7, P12 and P14, whose families had medical insurance, also attended consultations with psychiatrists or neurologists from private clinics and, therefore, deviated from this pattern.

It is noteworthy that the CAPS is the service that welcomes the families of children with alterations in the course of development, and the assistance (including therapeutic care) begins even before the diagnosis is concluded, showing the concern with comprehensive health care on a continuous basis. The assistance and continuous care of a health service that encompasses both the child and his family is the factor that will ensure a better quality of life[7].

Deviating from this flow, only participant P13 reported that the diagnosis was made directly at the UBS, based on observation and joint discussion between the pediatrician, the speech therapist and the psychologist of the unit. The diagnosis made at the UBS itself can bring benefits, such as the optimization of the time needed to confirm the condition, reducing the waiting period for care in other services, such as CAPS. The UBS team must be qualified to carry out assertive evaluations for effective and agile diagnosis, so that the child can have access to treatments with the shortest possible waiting time[19].

It is worth mentioning that reflection on the diagnosis is important because this will often be the determining factor for clarifying family members' doubts, for access to rights, public policies and health services. As of Law No. 12,764, of December 27, 2012, which institutes the national policy for the protection of the rights of people with ASD, their rights are ensured by the Statute of Persons with Disabilities, which guarantees access to services such as preferential vacancies, specialized monitoring in schools and the Continuous Provision Benefit (BPC). On the other hand, it is also necessary to highlight that the individual's assistance and care in health services should begin regardless of whether the child has a closed diagnosis[24,25].

Regarding the different consultations carried out for the monitoring of children and families, 13 participants mentioned that they were attended by psychologists, speech therapists and 7 mentioned consultations with occupational therapists, in addition to medical consultations and follow-up with the psychiatrist.

In general, the participants gave few details about what they know about the consultations, evidencing the families' lack of knowledge about the strategies, objectives of the sessions, materials used and other aspects of what happens during the care sessions. Few studies were found on the knowledge of families from the sessions of care with the children. However, the results of the research by Nascimento Ferreira e Rocha.[30] show that there is distance between health professionals and the family, resulting in a lack of dialogue. These authors emphasize that family members understand the importance of the multidisciplinary team's work for quality of life, however there are still difficulties in communication

between the team and the family, leading to consider that the multiprofessional work with the person with ASD is still in the construction process.

Another point highlighted by 3 participants was the desire for the child to have more hours of care, and 8 of the participants reported that the children already had care in addition to the CAPS, either in the private network or in other institutions, such as Pestalozzi and APAE, in addition to the UBS itself. Two participants expressed the desire of the family members to perform more speech therapy sessions, in order to relate the greater number of hours of speech therapy to the improvement in language development. This idea, although understandable in the context of the search for quick and tangible solutions, does not take into account the complexity of language development in children with ASD, which involves multiple variables, including the social environment, sensory stimuli, interpersonal interaction, subjectivity, and the theoretical perspective adopted by speech therapists.

With regard to speech-language pathology and audiology services, the Federal Council of Speech-Language Pathology and Audiology (in its latest version, published in 2021), in article 13 of page 22 item II – "act in common agreement, when in the simultaneous service of a client"; Thus, it does not impose restrictions for a patient to be seen in more than one service for speech-language pathology care, as long as this is carried out within the ethical principles of comprehensive care and that the professionals involved maintain adequate communication and that they know that the patient performs care with another professional, respecting access to information and the patient's decision.

In this study, it was observed that both the professionals from the UBS and the CAPS made referrals to more than one care service, as can be seen in the answers shown in graph 6, about the places of therapy. Family members report that they were referred to other places to do more hours of therapy than the one offered by the CAPS, of one hour per week. However, it is important to reflect on the impacts that multiple visits from the same family and child in different institutions can cause in the flow of the health network and in the waiting list for care, in addition to the impacts on the child and family themselves, despite considering the need for more hours of care.

The path to getting the diagnosis and care of children with ASD in the public network is permeated by challenges, which include the lack of medical knowledge and the prolonged time to get appointments, as the data from this research showed. To address these issues, it is essential to promote the continuous training of health professionals, especially in the UBS, in order to ensure more agility in the elaboration of diagnoses and more effective care. In addition, it is important to know the flow of the network in cases of ASD in order to make more assertive referrals and seek to reduce the waiting time of families for care and consultations.

Although this research provides important data on the perspective and history of families of children with ASD, the need for more studies that delve into these trajectories and give voice to these families is highlighted, in addition to other studies focusing on the initial moments of the families with the professionals of the UBS, who are the ones who will have the first contact with the initial complaints of the signs of ASD and those responsible for making the referrals to other services.

Conclusion

It is noted that family members in the nucleus closest to children with ASD are the first to notice the signs of alteration in the course of development. The first signs noticed are linked to language, such as the absence of speech, lack of eye contact, lack of social interaction. The mean age of identification of the first altered moles was around 2 years of age; that is, it is linked to the period of early childhood.

The path taken by the families until the diagnosis began with the perception of the first signs by the family, the report of the complaint in consultation with the pediatrician, who makes the decision to wait a little longer or refer them to the CAPS for reception, evaluation and assistance. The fact that doctors do not refer children with suspected ASD for evaluations right away suggests that these professionals need to be updated on the subject to take more assertive actions.

It is also necessary that family members are considered as a fundamental part of the care process for people with ASD and that they are heard and their complaints taken into account. Finally, knowing the flows of the health network allows us to identify gaps in the care process, facilitating the implementation of more effective public policies and the articulation between the different levels of

care. In this way, it is possible to promote more continuous and quality care for children with ASD and their families, favoring the child's development and social inclusion.

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