Chapter 73

The Trajectory of Parents of Children with Autistic Spectrum Disorder in the Search for a Diagnosis

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ABSTRACT

Given the increase in diagnoses of Autism Spectrum Disorder in children and adolescents worldwide, a study is necessary to understand how these diagnoses are made. Thus, the present study aimed to investigate the age at which an Autistic Spectrum Disorder (ASD) diagnosis is made in patients of a private clinic in a city in the metropolitan area of Porto Alegre, Rio Grande do Sul state, as well as which professionals were involved in this process. Nine parents participated, being 7 mothers and 2 fathers, with ages between 29 and 62 years old, all of them were in a stable union; only one of the interviewees did not have a complete high school education. This is a qualitative study, with multiple case study design. The results were organized into categories according to the age of the children at the time of diagnosis. It is important to emphasize that most of the parents interviewed had observed atypical behavior in their children before they were 3 years old, and that communication and language impairment and delay were the earliest symptoms observed by them, followed by social behavior impairment.

Keywords: Diagnosis, Autistic Spectrum Disorder, Children, Family Trajectory.

1 INTRODUCTION

According to the new classification of the Diagnostic and Statistical Manual of Mental Disorders, DSM-5, the Autism Spectrum Disorder, whose identification acronym (ASD) is popularly used, is characterized as a neurodevelopmental disorder, indicating that the behavioral symptoms, manifestations, and indicators of the disorder are of neurological and developmental origin (American Psychiatric Association [APA], 2010). Autism or Autistic Spectrum Disorder (ASD) is a behavioral syndrome that compromises motor and psychoneurological development, affecting the child's cognition, language, and social interaction, interfering with their self-sufficiency (Posar & Visconti, 2017).

Studies conducted by Paula et al. (2011), based on international statistics, indicate that one and a half million Brazilians live with ASD. The authors also point to an estimate of sixty cases for every ten thousand births, making the Autistic Spectrum Disorder one of the most frequent childhood neurodevelopmental disorders. Backes et al. (2017) draw attention to the most recent changes in the nomenclature of autism to Autistic Spectrum Disorder (ASD), in more current publications, to refer to the class of neurodevelopmental conditions, which include autistic disorder, Asperger's, childhood disintegrative autism, and global developmental disorder not otherwise specified, also known as atypical autism.

According to Paula et al. (2011), regarding the prevalence of the Autistic Spectrum Disorder, the information comes from the United States and Europe, where there are advances in the standardization of diagnosis. According to Chamak and Bonniau (2013) the prevalence averaged two to five cases of autism in every ten thousand individuals in the late 1990s. Fombonne (2009) conducted a review of 43 research published since the period 1996 on Autistic Spectrum Disorder, concluded that the prevalence of the typical disorder is around twenty cases per ten thousand births. A more recent study, released by the World Health Organization - WHO, in 2017, points out that one child in every 160 is born with Autistic Spectrum Disorder in the world and estimates that 70 million people worldwide are part of this spectrum.

According to Teixeira (2017), the diagnosis of autism is clinical, which depends on a careful behavioral assessment of the child in the doctor's office plus an interview with the parents. During the behavioral evaluation process, some standardized screening scales for Autism Spectrum Disorder can be used. These are CARS - Childhood Autism Rating Scale; M-CHAT - Modified Checklist for Austism in Toddlers; ABC - Autism Behavior Checklist and PEP-R - Psychoeducational Profile Revised. The same author also points out that the most indicated doctors for diagnosing children with autism are psychiatrists specializing in childhood and adolescence, neurologists or neuropediatricians.

According to the Diagnostic and Statistical Manual of Mental Disorders, Autism Spectrum Disorder is defined by early impairments in social-communicative development, repetitive behaviors, and stereotyping (American Psychiatric Association [APA], 2014). Many difficulties characteristic of the disorder can be presented even in early childhood; however, several studies indicate that the vast majority of children are not diagnosed before the school period, which can cause a delay in the entry into intervention programs, as well as in specific parental guidance, according to studies by Daniels and Mandell (2014) and Noterdaeme and Hutzelmeyer-Nickels (2010).

To make the diagnosis of ASD, Petersen and Wainer (2011) state that a qualified multidisciplinary team is necessary, emphasizing the difficulty of the analysis, since it is only clinical, and there are no tests, not even blood tests that corroborate the diagnosis.

As presented by DSM-5, the diagnostic criteria for Autistic Spectrum Disorder are:

Table 1: DSM-5 criteria

A	Persistent deficits in communication and social interaction: - Limitation in social and emotional reciprocity; - Limitation in non-verbal communication behaviors used for social interaction; - Limitation in initiating, maintaining, and understanding relationships, ranging from difficulties with adapting behavior to adjust to various social situations.
B	Restricted and repetitive patterns of behavior, interests, or activities, manifested by at least two of the following observed or clinical history: - Repetitive and stereotyped movements in the use of objects or speech; - Insistence on the same things, inflexible adherence to routines or ritualistic patterns of verbal and nonverbal behaviors; - Restricted interests that are abnormal in intensity and focus; - Hyper or hyporeactive to sensory stimuli from the environment.
C	Symptoms should be present in the earliest stages of development. They may not be fully manifest until social demands exceed their capabilities, or they may be masked by some learning strategies throughout life.
D	The symptoms cause clinically significant impairment in social, occupational, or other important areas of the patient's current functioning.
E	These disorders are not best explained by cognitive impairment or global developmental delay.

Source: APA (2014)

The model presented by DSM-5 includes only symptoms from two domains, one of which is related to restricted and repetitive behaviors and interests, and the other is related to deficits in social communication. The previous model made use of a third symptom related to language delay.

For Joseph et al. (2016), the diagnosis of ASD is defined behaviorally, since there are no biological markers. According to them, the assessment of the main symptoms must be multidimensional and contain the caregivers' report added to the behavioral observation of symptoms. They indicate that there are two categories to describe the methods used to assess ASD symptoms: screening measures, which are those answered by parents or caregivers of children; and diagnostic measures, which are direct observations and reports from parents to professionals trained in child development.

In order to obtain an early and reliable diagnosis, Paula et al. (2011) tells us that it is necessary to invest in continuous training and professional improvement. In order to establish a consensus between families and health professionals that the diagnosis is essential for the subject, not to label him/her as a "pathologized" person, but as a way to enable the necessary and appropriate interventions for that subject.

In a study conducted by Silva et al. (2017) with 105 parents of individuals diagnosed with Autism Spectrum Disorder in the South and Southeast regions of Brazil, it was found that the main difficulties faced by parents during the search for a diagnosis for their children were mainly the lack of qualification of the professionals in question; the need to consult several professionals in the search for confirmation; the need for numerous assessments; and the excessively lengthy process. The author also reports that, although the search for treatment was before the age of two, the confirmation of the diagnosis of ASD only occurred after the child's four years of age, on average.

A survey was conducted by Backes et al. (2017) where 136 parents of children diagnosed with Autistic Spectrum Disorder participated in 19 states in Brazil, with the majority from the following states: Rio Grande do Sul (25%), São Paulo (22.8%), and Rio de Janeiro (8.8%), with the aim of identifying the age of receipt of the child's diagnosis and its relationship with contextual and family variables. As a result of this study, it was found that children tend to be diagnosed around five years of age; there is an interval, on average, of three years between the first suspicions of the parents and the confirmation of the diagnosis.

The etiology of autism is still unclear, which often weakens the issue of diagnosis, generating uncertainties and mistrust on the part of family members. Research indicates that some genetic and neurobiological factors may be associated with ASD, such as some anatomical or physiological anomalies of the central nervous system and innate constitutional problems; psychosocial factors have also been associated as risk factors, according to (Brasil, 2013). The term autism was first used in 1911 by the Swiss psychiatrist Paul Eugen Bleuler to describe a symptom of schizophrenia defined as "detachment from reality combined with the relative or absolute predominance of the inner life" (Durval, 2011).

According to Gadia (2006) structural anatomical changes occur in the central nervous system of the child with ASD, both in the cerebellum (hypoplasia of lobes VI and VII of the *cerebellar vermis*) and in the limbic system, observed around the 30th week of gestation, and also in the cerebral mini columnar abnormality. According to the same author, the degree of hypoplasia in autistic children may correlate with slower attention responses to visual stimuli when using a spatial paradigm of attention, corroborating with the literature regarding the cerebellum as an important factor in Autistic Spectrum Disorder.

According to Girodo et al. (2007), the etiological aspects describe autism with multifactorial causes with a strong genetic influence. It is also associated with chromosomal abnormalities, tuberous sclerosis, fragile X syndrome, cytomegalovirus, and prenatal influenza infections. The authors present in their studies the correlation between mothers who had maternal bleeding after the first trimester of pregnancy and meconium in the amniotic fluid; they also reveal the birth of children diagnosed with Autism Autism Spectrum Disorder who have a high incidence of respiratory distress syndrome and neonatal anemia.

Tuchman and Rapin (2009) point out in their research the correlation between autism and intrauterine rubella or tuberous sclerosis. The authors report some behaviors, among them, tiptoe walking and motor uncontrol, sleep-related problems or increased anxiety and interactive deficit. The authors also present in their research a correlation with neurological comorbidities such as epilepsy, hyperactivity, attention deficit, Tourette's syndrome, inadequate language, stereotyping, and changes in social skills.

Reports emerged in 1998 that regressive autism was caused by the MMR MMR vaccine or by thimerosal, a mercury-containing preservative that was used in most vaccines in the past. The attribution of autism to vaccines resulted in a reduction in immunizations, which led to an increase in the number of childhood infections. However, this hypothesis has been refuted (De Stefano, 2007; Taylor, 2006).

Silva et al. (2012) report changes in executive functions or frontal lobe functions in subjects with Autism Spectrum Disorder, demonstrating in their studies the difficulty they have in dealing with the unexpected, controlling their actions, inhibiting irrelevant responses, little flexibility to change routines, and finding strategies to solve problems. The executive functions are responsible for planning, information, and execution of activities, and the inflexibility of ASD to change and difficulty in interpersonal relationships may be associated with changes in these functions.

As mentioned by several authors above, the diagnosis of ASD triggers important changes in the family environment of individuals affected by the spectrum, due to the need for continuous monitoring that children require. Maia Filho et al. (2016) say that the diagnosis itself is an impactful situation, which may have repercussions in aspects such as changes in daily routine, readaptation of family roles, causing various effects in the occupational, financial, and interpersonal relationships spheres.

In view of the above, with a view to promoting the mental health of parents and children regarding the feelings experienced by them in the search for the diagnosis of ASD, this study aimed to identify the path taken by parents and caregivers of children with Autism Spectrum Disorder in the search for the diagnosis of their children. The main atypical behaviors observed by parents were also investigated.

2 METHODOLOGY

This qualitative research is a collective case study, which sought to understand the trajectory faced by parents in the search for their children's diagnosis. The case study is a specific process for qualitative research in which one seeks to discover what is most essential and characteristic about the situation under study (Yin, 2001). Cases are chosen because it is believed that their study will allow for better understanding, or even better theorizing, about an even larger set of cases (Stake, 2000).

Seven mothers and two fathers of children diagnosed with Autism Spectrum Disorder, according to the ICD (F84.0), and being followed-up in a multidisciplinary clinic in a city of Porto Alegre, RS, Brazil, participated in this study. The municipality was founded in 1939 and is located in the metropolitan region of Porto Alegre. Its population, according to the Brazilian Institute of Geography and Statistics - IBGE, is 348,208 inhabitants (Instituto Brasileiro de Geografia e Estatística [IBGE], 2010).

Parents of children diagnosed with Autism Spectrum Disorder, defined by the presentation of a medical or psychological report with ICD (International Classification of Diseases) F84.0 and who lived with the child, were included in this study. In addition, it was essential that the children attended the multidisciplinary clinic on a weekly basis.

Interviews were conducted individually during the period in which the child remained in psycho-pedagogical care, in another room, within the clinic itself the interview was held, during the period from September to October 2018, in total seven mothers and two fathers were interviewed. Because the interviews were held in the same space as their children's care, there was cooperation from all those asked. A sociodemographic form was used to characterize the participants and a semi-structured interview script (with questions about the respondent's level of education, marital status, profession, and age). In order to obtain more information about the parents.

The participants who met the inclusion criteria were approached by e-mail and requested to a first meeting, where they received explanations about the study, its objective, as well as information related to ethical principles and, after acceptance, the individuals signed the Informed Consent Form (ICF). Next**,** the sociodemographic data sheet was applied, followed by the interview script, with an estimated average duration of 30 minutes each.

The results were analyzed in three stages, according to Bardin (2011), the first of them being the pre-analysis, where the collected material, in this case, the statements of the participating parents, were organized so that they could begin to answer the overall objective of the research, in order to elucidate the final interpretation of the study; Second stage, exploration of the material, the text was explored in a systematic way, according to the categories presented in the first stage; Third stage, the data collected were submitted to analysis, so that they could elucidate the information obtained, after which, the inferences and interpretations obtained were made.

The research was approved by the Ethics and Research in Human Beings Committee (CEP) Resolution No. 466, December 2012, of the La Salle University, under number 2,650,859 and Certificate of Ethics Presentation and Appreciation - CAAE under No. 87752218.1.0000.5307. The research participants were assured anonymity and the right to refuse participation, free of any damage, exposure, or embarrassment. The research was conducted respecting the ethical aspects provided for in Resolution No. 466/2012 of the National Research Ethics Commission (CONEP), which addresses the fundamental ethical and scientific requirements of studies involving human beings, bioethical references, aiming to ensure the rights and duties of the participant.

3 RESULTS AND DISCUSSION

The age range of the parents interviewed was between 29 and 62 years old. The sample included nine components with a predominantly female profile, seven of the total of these participants. All of them had a stable marital relationship. Regarding the level of education of the interviewees, seven had complete higher education, one had incomplete higher education, and one had incomplete primary education. Regarding the profession of the participants, two were lawyers, two declared to be housewives, one an accountant, one a psychologist, one an architect, one a psycho-pedagogue, and one a manager. As for the family income, it varied between over five minimum wages per month, with six deponents; less than three minimum wages per month, one deponent, and less than two minimum wages, two deponents.

The table below presents the participants according to age, level of education, profession, marital status, and average family income.

Table 1: Sociodemographic data of the participants

Name	Age	Respondent	Level of Instruction	Profession	Marital Status	Family Income
Ana	34	mother	upper comp.	Psychologist	Stable Union	greater than five
Maria	42	mother	upper comp.	Attorney	Stable Union	greater than five
Clara	37	mother	upper comp.	Attorney	Stable Union	less than three
Lara	29	mother	fundam. incomp.	household	Stable Union	less than two
Dora	35	mother	upper comp.	household	Stable Union	less than two
Elisa	39	mother	upper comp.	Architect	Stable Union	greater than five
John	55	father	superior incomp.	Businessman	Stable Union	greater than five
Pedro	62	father	upper comp.	Psychopedagogue	Stable Union	greater than five
Flavia	47	mother	upper comp.	Accountant	Stable Union	greater than five

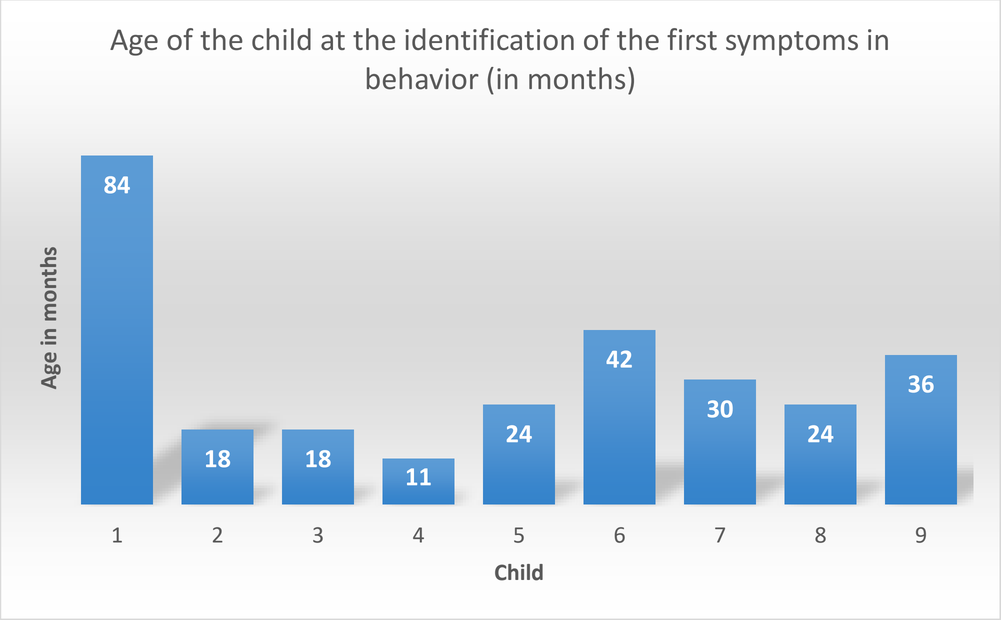
Source: Prepared by the author (2018).

The data obtained in this study show that most parents of children diagnosed with ASD (66%) noticed difficulties in the child's development before the third year of life. Research shows that most children diagnosed with ASD present atypical development from birth, but one-third of them exhibit regression of developmental milestones between 18 and 24 months of age, after an apparently typical development or in the presence of a previous developmental delay. There is still no specific biological marker (Spence & Schneider, 2009; Tuchman & Rapin, 2009).

Regarding the age of the children when the parents identified the first atypical symptoms in development, the results showed that the perception of these atypical symptoms in development tend to be perceived by the parents during the first two years of life, prevailing in this research the variation between one child at 11 months, two during the first year of life, three after reaching two years of age, two at three years of age, and one child, only, after seven years of age. Most of the children are boys, with only one girl prevailing in this study. All the children are Caucasian. According to the DSM-5 diagnostic criteria the first manifestations of ASD should appear before 36 months of age (APA, 2014).

The chart below shows the ages of the children, in months, at the time of receiving the diagnosis of Autism Spectrum Disorder.

CHART **1**: Unit distribution of the research subjects according to the age (in months) of the child in identifying the first behavioral symptoms.



Source: Prepared by the author (2018).

It was found that all the behaviors reported by the participants correspond to one of the areas compromised by the Autistic Spectrum Disorder. These were: delayed language development, impaired motor development, lack of gaze interaction, difficulties in social interaction, little flexibility to change routines, inadequate language, stereotyped and repetitive behavior, and also sleep problems. However, the delay in the development of communication and language was the symptom most frequently reported, appearing in the narrative of five interviewees. According to studies by Klin and Mercadante (2006) individuals belonging to this spectrum show less interest in relating to others, which compromises reciprocal social interaction. Regarding communication, there may be a partial deficit or complete absence of verbal communication, as well as losses in non-verbal communication. Verbal and motor stereotypes are frequent, as well as a restricted repertoire of activities and interests. According to Al-Qabandi et al. (2011) the symptoms of ASD are evident to parents when they arise in association with cognitive impairments, delays in the emergence of motor developmental milestones, speech delays, or medical problems such as epilepsy. Baghdadli et al. (2003) mention that difficulties in daily required skills and the presence of neurological problems or hearing deficits in the child are the main milestones for the recognition of this spectrum. Children who do not have language delays, on the other hand, tend to be diagnosed with ASD later in life (Fountain et al., 2011).

As Tuchman and Rapin (2009) point out, verbal and nonverbal skills are affected through the ability to communicate with others. Children who belong to this spectrum may have delayed language acquisition, regression, or total absence of language. According to the same authors, warning signs are: not babbling or pointing at 12 months, not speaking single words at 16 months, and not combining two words spontaneously at 24 months. Numerous studies point to early intervention as a key factor for clinical improvement of the autistic spectrum, offering important and lasting gains in child development (Howlin et al., 2009; Reichow, 2011). Due to brain plasticity, the early onset of intervention is essential, enhancing its positive effects.

The table below presents the symptoms observed by parents during the diagnostic search process, as well as, the percentage in which these symptoms were observed.

Table 2: Frequency of the first symptom observed by mothers of children with ASD.

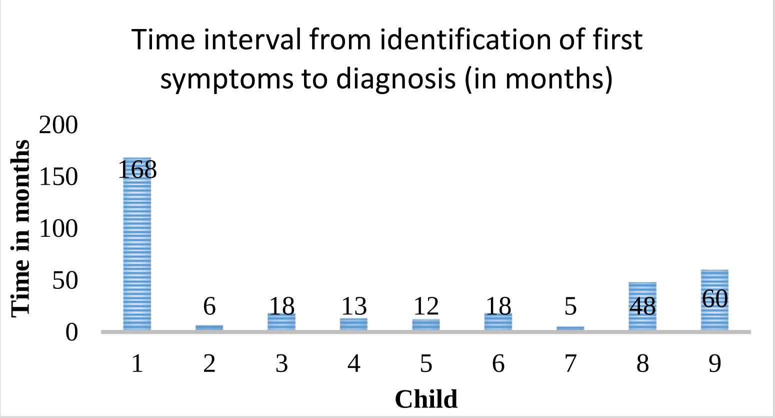
Symptoms	**Percentage (%)**
Verbal Communication Delay	56
No Social Interest	33
Difficulty in Motor Development	22
Lack of Visual Contact	22
Playing Alone	22
Repetitive Movements	22
Inappropriate Use of Image	22
Did Not Respond When Called By Name	11
Referring to Yourself in the Third Person	11
Disorganization in Routine Change	11

Source: Prepared by the author (2018).

The data collected allowed us to identify the time elapsed to obtain the diagnosis of Autistic Spectrum Disorder, from the first time a family member suspected some strange or atypical sign in the development and sought professional help until the confirmation, through the diagnosis of Autistic Spectrum Disorder, ICD F84.0. The research showed that the average time for obtaining the diagnosis in the universe explored was, on average, 38 months, with the shortest time for obtaining it, being five months, and the longest, equivalent to 168 months. According to the graph below, most children in this study obtained the diagnosis in a period of less than 20 months. It is observed that in approximately (77%) of the families, the child's ASD diagnosis took more than a year from the first symptoms, (55%) more than two years, and (33%) more than four years.

The graph below shows the time interval between the first symptoms perceived by the parents and the diagnosis of ASD issued by a specialist.

CHART 2: Unit distribution of the research subjects according to the time interval (in months) from the identification of the first behavioral symptoms and the diagnosis of ASD.



Source: Prepared by the author (2018).

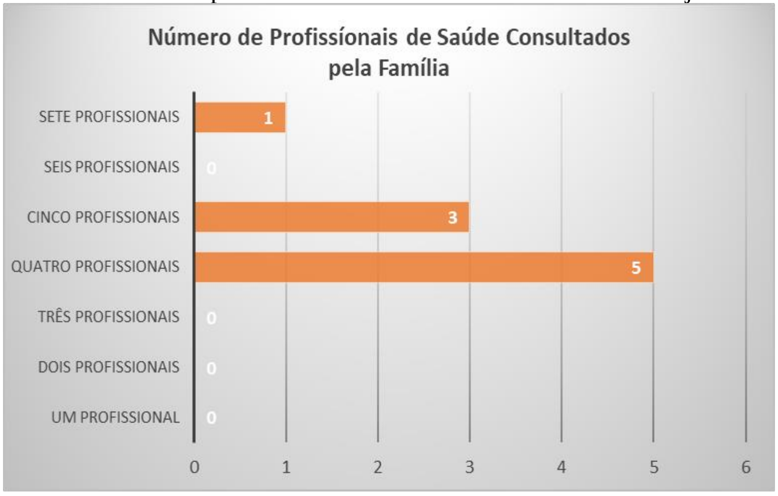
According to studies by Braga and Ávila (2004) the family is the first to notice signs and characteristics related to ASD, against 25% of health and education professionals. The sample of data collected from nine families corroborates this finding, showing that in 100% of the interviewees, the first person to identify atypical development were the family members, and these, according to three respondents, were the mother; one respondent, the paternal grandfather and another the paternal grandmother, and the other respondents claimed to be the mother and father together. As indicated in the literature, not finding a good professional who is properly qualified to guide families correctly causes the search for several health professionals, thus generating emotional distress (Passos, 2007; Favero & Santos, 2010; Goin-Kochel et al., 2006).

The present study allowed the identification of the number of health professionals to whom the children had been submitted from the time their parents suspected atypical development up to the time of the interview. The results indicate that 100% of the family members interviewed had seen four or more professionals during the path taken since the suspicion of atypical development. In the present study, one family reported having seen seven professionals since the initial suspicion of their child's atypical development, three families reported having seen five professionals along the way, and five families reported having taken their children to five different professionals.

The role of each professional is to inform parents about the typical symptoms of the spectrum, discuss the particularities of the spectrum, provide guidance on management, assist in the orientation of the most appropriate types of schools for the stimulation of adaptive behaviors and social skills, with ABA (Applied Behaviour Analysis) (Bradford, 2010). As highlighted by Schmidt et al. (2007) it is important that health professionals guide parents so that they feel able to face reality.

The chart below shows the number of professionals involved in the process of identifying the autistic spectrum disorder.

CHART 3: Number of health care professionals to which the children were subjected in this trajectory.

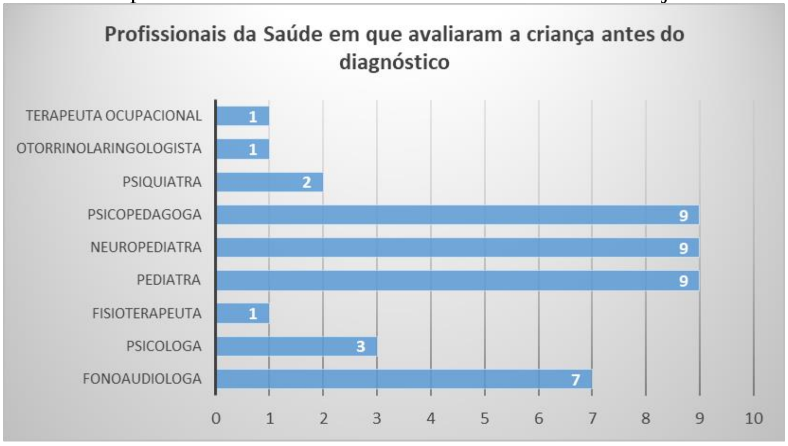


Source: Prepared by the author (2018).

When asked which professional diagnosed the child with Autism Spectrum Disorder, approximately 90% of respondents answered that it was the neuropediatrician and 10% the pediatrician who specialized in development and behavior. In studies by Bradford (2010) indicate that when symptoms are not very evident or severe, it is possible that pediatricians confuse the indicative signs of ASD with signs of some other behavior disorder or even, maladaptive behavior problems. According to Gadia et al. (2004), pediatricians are the professionals who can observe and identify symptoms even when the child is in the preschool phase, that is, from zero to three years old. For this reason, they should be able to recognize the deviations in typical development and thus guide families in case of suspicion of Autism Spectrum Disorder diagnosis. According to the report of one of the mothers interviewed, the fictitious name Dora, this is not the reality. According to her, she heard from her son's pediatrician: *"You need to be analyzed, because you have problems! You leave your child like this! Your problems affect the child [...]".* According to another interviewee, Clara, about the pediatrician's view on her son: *"He said the boy had nothing, that it was something in my head, he was two years old, he couldn't pronounce a word and the pediatrician told me that in his time he would speak [...]".* A third interviewee, Flavia, reports: *"I always knew that my son had ASD, since pregnancy. When he was born, I told the pediatrician, he said it was something in my head, that my son was healthy and that everything was fine. But, as time went by and I insisted with other professionals, the diagnosis came.* Among the interviewees, João was the one who walked the longest way in the search for his son's diagnosis, living for 14 years in doubt about which pathology had affected his son: *"[...] when he was three years old he started convulsing, the doctors said it couldn't be autism, because of the convulsions. He was treated as intellectually disabled, he was never stimulated much. A short time ago, now at 21, he was diagnosed with ASD [...]"* In the report of another father, Pedro *"I confess that I never paid much attention to the observations that my wife pointed out, for me, it was she who spoiled our son [...] we arrived at the diagnosis at her insistence"*.

The chart below shows who were the professionals involved in the process of diagnosing the autistic spectrum disorder in the case of the respondents' children.

CHART 4: Health care professionals to whom the children have been subjected in this trajectory.



Source: Prepared by the author (2018).

As shown in the graphic, the professionals most demanded by this sample were pediatricians, neuropediatricians and psychopedagogues in (100%) of the cases, followed by speech therapists with (77%,) psychologists (33%), psychiatrists with (11%) and the physical therapists, otolaryngologists and occupational therapists with (11%). All health professionals are part of the diagnostic process and must be based according to the main classification manuals, because there is a variation in the manifestation of behavioral symptoms, which is considerable due to its neurobiological heterogeneity. To favor prognosis, it is necessary to delimit the specific subgroup within the spectrum in which the subject is found. Thus, a multidisciplinary investigation is necessary, where pediatricians, psychiatrists, neurologists, psychologists, occupational therapists, speech therapists, physical therapists, and educators can work cooperatively to better understand the subject (Gadia et al. 2004).

4 FINAL CONSIDERATIONS

Through the results of this study, it can be concluded that most parents in this sample were able to recognize atypical symptoms of their children's behavior before the third year of life. The impairment in communication and language delay and development was the earliest symptom observed by them, followed by impairments in social behavior.

Based on the economic classification criteria of the Brazilian Association of Research Companies (ABEP), which makes associations between economic aspects and the level of education to identify the economic class to which the family belongs, and based on the interviewees' reports, it was observed that the families are between classes C and E. Identifying the socio-economic and educational profile of the research participants is of utmost importance, as it ensures the homogeneity of the sample, that is, families that share common characteristics trace similar trajectories. According to the specific objectives pointed out in this research, it was observed that:

a) Regarding the identification of the first symptoms of atypical behavior, identified by the parents, until the diagnostic definition of ASD, it was observed that in 66% of the interviewees the waiting time was less than three years, the longest interval identified was 14 years and the shortest was six months.

b) Regarding the health professionals involved in this diagnostic path, it was observed that children were seen by an average of four professionals. The data shows that 100% of the subjects of the study had been seen by four or more health specialists until the diagnosis was obtained, results that reflect the difficulty in finding health professionals who are qualified to guide the families, generating pilgrimage by the parents to several professionals in search of this guidance.

To conclude, it is necessary to highlight some limitations of this study, such as being based on a small and non-random sample, which did not allow for association analysis. This research, therefore, does not intend to have an end, but to enable future investigations to be proposed, with the purpose of raising data for the current national public health system in the context of care for ASD.

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