SOCIODEMOGRAPHIC AND CLINICAL PROFILE OF FAMILIES AND INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

PERFIL SOCIODEMOGRÁFICO E CLÍNICO DE FAMÍLIAS E INDIVÍDUOS COM TRANSTORNO DO ESPECTRO AUTISTA

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Abstract. Autism Spectrum Disorder (ASD) imposes limitations on individuals and their families, making it necessary to understand these realities to design effective interventions. Therefore, this study aimed to survey the sociodemographic and clinical data of families and individuals with ASD in Mossoró-RN. It is characterized as a descriptive, cross-sectional, and quantitative study, through an active search on social networks and using Google Forms. After the participants had given their consent, a form was used to gather data on the socio-economic and clinical situation of the families. The target population was families with individuals diagnosed with ASD and living in Mossoró - RN. The sample was by convenience, totaling 35 individuals with ASD. Among these, 80% were male, aged between 2 and 19, and the predominant races were white and brown (45.7% each). The most common professional at the time of diagnosis was the neuropediatrician (71.4%), and the most common feeling at this time was fear (34.3%). The diagnosis was received at a late stage by the majority (42.9%), and 25.7% felt satisfied with having received it. About being monitored by health professionals, the majority reported having been (97.1%); however, this monitoring is minimally provided by the Brazilian Unified Health System (SUS) (20%). The most frequently cited day-to-day difficulties were food restrictions (65.7%) and communication (62.9%). Concerning the caregivers' data, there was a prevalence of females (97.1%), with an age range from 23 to 53 years, married (65.7%), with a high school education (40%), and who did not work (54.3%), with a monthly income of one minimum wage (40%). The urban area prevailed as their home (97.1%). Based on these results, it was possible to identify a profile of individuals and families with ASD in the city of Mossoró, highlighting the need for more targeted public policies and assistance.

Keywords: Form. Autistic Disorder. Autistic Spectrum Disorder. Collective Health. Health Profile**.**

Resumo. O Transtorno do Espectro Autista (TEA) impõe limitações para o indivíduo e família, sendo necessário conhecer ambas as realidades e traçar intervenções efetivas. Portanto, este estudo teve como objetivo realizar um levantamento de dados sociodemográficos e clínicos de famílias e indivíduos com TEA em Mossoró-RN. Caracterizou-se por ser um estudo descritivo, transversal e quantitativo, por meio de uma busca ativa nas redes sociais e utilizando o Google Forms. Após o consentimento dos participantes, foi aplicado um formulário com dados referentes à situação socioeconômica e clínica das famílias. A população alvo foram as famílias que tem indivíduos com diagnóstico de TEA e residentes em Mossoró - RN. A amostra foi por conveniência, totalizando 35 indivíduos com TEA. Destes, 80% eram do sexo masculino; com idade entre 2 e 19 anos, as raças predominantes foram branca e parda (45,7% cada). O profissional mais presente no diagnóstico foi o neuropediatra (71,4%); e o sentimento mais presente neste momento foi o medo (34,3%). O diagnóstico foi recebido de maneira tardia pela maioria (42,9%), e 25,7% se sentiram satisfeitos por ter recebido. Sobre o acompanhamento de profissionais de saúde, a maioria relatou ter (97,1%); porém minimamente esse acompanhamento se dá pelo SUS (20%). As dificuldades mais citadas no dia a dia foram as de restrição alimentar (65,7%) e comunicação (62,9%). No que se refere aos dados dos cuidadores, houve prevalência do sexo feminino (97,1%); com variação de idade de 23 a 53 anos, casados (65,7%), nível médio de escolaridade (40%) e que não trabalha (54,3%), com renda mensal de um salário mínimo (40%). A zona urbana prevaleceu como moradia (97,1%). A partir destes resultados foi possível apontar para um perfil dos indivíduos e famílias com TEA na cidade de Mossoró, despertando a necessidade de políticas públicas e assistenciais mais direcionadas.

Palavras-Chave: Saúde Coletiva. Transtorno do Espectro Autista. Transtorno Autístico. Perfil de saúde. Formulário.

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INTRODUCTION

Human abilities are developed linearly and follow the individual's chronological aging process[1]. From the gestational stage onwards, the fetus is expected to develop at a certain pace, taking into account a developmental window; based on evaluations, the child who meets clinical milestones will be considered a typical child. However, some dysfunctions, which can be congenital, acquired, or inherited, with motor or mental impacts, arise to affect the natural course of development, leading to atypia, which can be physical pathologies or mental disorders[2].

From this perspective, mental disorder is defined by the Diagnostic and Statistical Manual of Mental Disorders - DSM (2014), as any syndrome that causes cognitive, emotional, and behavioral disturbances that influence the individual's biopsychosocial interactions and arise as one of the coping situations in the context of life. Among these classifications there are neurodevelopmental disorders, which emerge even before the school age of the child, presenting in specific ways, such as in learning or the performance of certain functions; or in global ways, involving multiple disorders. Other disorders involve interaction and communication difficulties and acceptance of changes in daily life, such as Autism Spectrum Disorder (ASD)[3].

ASD, formerly known as autism, now encompasses other disorders such as autistic disorder, childhood disintegrative disorder, pervasive developmental disorder, and Asperger's disorder. It is diagnosed through the perception of difficulty in communication and social interaction, associated with the maintenance of repeated and restricted patterns which cause physical, psychological, and emotional disturbance when interrupted. Even if the child's motor, communication, and interaction development is within typical standards and they still show this repetitiveness, they can be diagnosed with ASD[3].

Although these patterns exist, there are still factors that interfere with the diagnosis, such as limitations in the assessment of professionals who work with the children during the period when the signs are presented early, a shortage of specialized services, the difficulty in perceiving atypical behavioral patterns, the lack of dissemination of information about ASD, and its variety of symptom expression[4].

This diversity differentiates the severity level of the disorder, according to its need for support both in social interaction as well as in restrictive and repetitive behaviors that limit or impair daily activities.[3] Another limiting factor concerning this variety of manifestations is the scarcity of scientific publications on the subject, especially when it comes to epidemiological surveys, especially in Brazil, where the predominance of published studies is in the Southeast and South regions and is even scarcer when it comes to the Northeast region[5,6,7,8,9]. It is worth emphasizing that there is a coping process beyond the disorder, as adaptations occur in relationships and social dynamics that bring about changes in the routine and personal life of everyone involved[10].

Therefore, given this complexity, there is a need for multidisciplinary care, covering the particularities of each individual by focusing on early intervention and discussions on the subject to produce knowledge and impact the creation of social programs aimed at the public. However, to have this approach, it is necessary to know the motivating and hindering factors for the family or caregiver regarding the individuals, as well as their profile to draw up effective strategies[11,12].

This study aimed to collect sociodemographic and clinical data on children with ASD and their families in Mossoró/RN, Brazil.

MATERIALS AND METHODS

This was a descriptive, cross-sectional, and quantitative study of families with children with ASD in Mossoró, Rio Grande do Norte, Brazil. The research was carried out through an active search on the social networks of families with children with ASD. A public call was made on social media, and each family that met the criteria would receive the link via social media, or email, whichever was more convenient for the individual.

Thus, all families living in Mossoró who had a diagnosis were asked to take part in the study, both through the public call and by searching through the city's support groups involving ASD. The criteria established were: families that had a member with a defined clinical diagnosis of ASD; caregivers who were living with the individual and were directly responsible for them; of both genders; of all ages; permanently resident in Mossoró-RN; regardless of whether they were being clinically monitored. Exclusion criteria were applied to individuals who had other syndrome-causing neurodevelopmental disorders associated with ASD and duly diagnosed.

As a result, 35 families took part in the study using the convenience method.

The data was collected using a form available via Google Forms, developed by the researchers. This instrument was divided into two categories of questions. The first was aimed at the main caregiver, and the second was aimed at the individual's environment and answered by the responsible caregiver. Both sections were subdivided into sociodemographic questions, such as age, gender, race, schooling, profession, and monthly income; clinical aspects, such as associated comorbidities, use of medication; family aspects, such as number of residents in the house, number of children, marital status, and other children with developmental disorders. The second category of questions dealt with the individual and covered sociodemographic, clinical, school, and social aspects.

This research was authorized by the Nova Esperança Research Ethics Committee under protocol No. 5.309.765.

RESULTS

The following results are divided into two sections, one on the individual with ASD and the other on the caregiver. A total of 48 responses were collected. Of these, 13 were excluded according to the research criteria, namely: 12 because they were not answered by the main caregiver and 1 in which the caregiver did not accept the consent terms, totaling 35 valid responses. Data on the individual with ASD was analyzed based on sociodemographic, clinical, educational, and social aspects (Table 1). The sample consisted of 35 individuals, 28 males (80%) and 7 females (20%), with a mean age of six years of age. As for race, there was a balance between whites and browns (45.7%), and the minority were self-reported by their guardians as black (8.6%). All the children were enrolled in a school at the time of the survey at different levels of education.

Table 1 – Individuals' simple frequency values and percentages.

Variables	Freq	%
Gender		
Female	07	20,0
Male	28	80,0
Age		
Mean ± standard deviation	6,0 ± 4,0	6,0 ± 4,0
Minmum – maximum	2,0 – 19,0	2,0 – 19,0
Race		
White	16	45,7
Brown	16	45,7
Black	03	8,6
Does the individual study?		
Yes	35	100,0
No	0	0,0
Education Level		
Early childhood education	09	25,7
Primary or secondary education	26	74,3

Source: Research data (2022).

Concerning the pregnancy of these individuals, Table 2 shows the mean age of the mothers of around 38 years old, all of whom said they had prenatal care and most of whom (74.3%) had used some kind of vitamin supplement during pregnancy. It is also worth noting that 54.3% reported having had some complications during pregnancy, such as urinary infection, pre-eclampsia, hypertension, vitamin deficiency, gestational diabetes, and the use of legal drugs.

Table 2 – Pregnancy simple frequency values and percentages.

Variables	Freq.	%
Did the mother have any prenatal care?		
Yes	35	100,0
No	0	0,0
Mother's age during pregnancy		

Mean ± standard deviation	38,0 ± 5,0	
Minmum – maximum	16,0-43,0	
Did the mother have any complications during her pregnancy?		
Yes	19	54,3
No	16	45,7
Did the mother use any vitamin or food supplements during pregnancy?		
Yes	26	74,3
No	05	14,3
Unknown	04	11,4

Source: Research data (2022).

Regarding receiving the diagnosis, there was a predominance of the neuropediatrician as the main professional at the time of diagnosis, a fact related to the role of this professional in this group of atypical people (Table 3). Also concerning the diagnosis process, we investigated how the family received it, in which they were mainly afraid (34.3%) and uncertain (22.8%) about the news. Therefore, the caregivers reported the importance of early diagnosis, which can be directly compared with information on the time of diagnosis, which in the majority of cases (45.7%), in this study, was late.

Table 3: Diagnosis' simple frequency values and percentages.

Variables	Freq.	%
Professional responsible for ASD diagnosis		
Neuropediatrician	25	71,4
Neurophychologist	01	2,9
Educacional psychologist	02	5,7
Child and adolescent psychiatrist	07	20,0
Which feeling best expresses your reaction at the moment of diagnosis?		
Fear	12	34,3
Uncertainty	08	22,8
Anguish	05	14,3
Surprise	02	5,7
Happiness	02	5,7
Sadness	01	2,9
Other	05	14,3
How long did it take to diagnose from the first perceptions?		
Immediately	04	11,4
Months later	15	42,9

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Satisfaction with the diagnosis		
Very unsatisfied	04	11,4
Unsatisfied	07	20,0
A little unsatisfied	01	2,9
A little satisfied	08	22,9
Satisfied	09	25,7
Very satisfied	06	17,1
Perceptions of early diagnosis		
Not important	0	0,0
Of little importance	01	2,8
Important	08	22,9
Very important	26	74,3

Source: Research data (2022).

When investigating the caregivers' satisfaction with the diagnosis, most were satisfied (25.7%) or a little satisfied (22.9%). It is worth noting that although the majority reported receiving the diagnosis late, months (42.9%) and years later (45.7%), 74.3% of the caregivers described that they thought it was very important to receive the diagnosis early, indicating the desire for this diagnosis by the families, and 22.9% considered it important.

Regarding the clinical data of the individuals in the study, which involves both follow-up support within the multi-professional and health team, and their clinical conditions, it can be seen, as shown in Table 4, that the majority (60%) have no associated illnesses. Among those who had some association, allergies, food intolerances, diabetes, epilepsy, and deafness were reported.

Regarding monitoring and health coverage, only one individual was not being monitored at the time of the survey, as he had just been diagnosed. The majority had health insurance (85.7%), and about professional monitoring, 97.1% were monitored mainly by occupational therapists (94.3%), and to a lesser extent by physiotherapists (20%).

Table 4:Clinical monitoring simple frequency values and percentages.

Variables	Freq	%
Does the individual have any associated condition?		
Yes	14	40,0
No	21	60,0
Is the individual monitored by a health professional?		
Yes	34	97,1
No	01	2,9
Does the individual have health insurance coverage?		
Yes	30	85,7
No	05	14,3

Physiotherapist		
Yes	07	20,0
No	28	80,0
Physician		
Yes	23	65,7
No	12	34,3
Speech therapist		
Yes	28	80,0
No	07	20,0
Occupational therapist		
Yes	33	95,3
No	02	5,7
Psychologist		
Yes	32	91,4
No	03	8,6
Educational psychologist		
Yes	22	62,9
No	13	37,1
Physical education professional		
Yes	11	32,4
No	23	67,6
Nutritionist		
Yes	08	22,9
No	27	77,1

Source: Research data (2022).

Regarding the care provided by the Unified Health System (SUS), only 7% of the participants said the SUS monitored them, a fact that draws a lot of attention, especially due to the minimal distribution of care in the various specialties, as shown in table 5, in which only the physical education professional was not included in this care.

Table 5 – SUS professional monitoring simple frequency values and percentages.

Variables	Freq	%
Are any of these services provided by SUS?		
Yes	07	20,0
No	28,0	80,0
Physiotherapist		
Yes	01	2,9
No	34	97,1
Physician		
Yes	04	11,4
No	31	88,6
Speech therapist		
Yes	04	11,4
No	31	88,6
Occupational therapist		
Yes	04	11,4
No	31	88,6
Psychologist		
Yes	04	11,4
No	31	88,6
Educational psychologist		
Yes	0	0,0
No	35	100
Nutritionist		
Yes	01	2,9
No	34	97,1

Source: Research data (2022).

Regarding the frequency of monitoring by a health professional, 31.4% said that they were monitored at least once a week (Table 6), which reflects the routine reality of the family living with ASD daily. One fact that stands out is that 100% of the caregivers reported having some sort of difficulty in the daily care of these individuals, reflecting a reality of overload and coping for these families.

Table 6 – ASD routine-related simple frequency values and percentages.

Variables	Freq	%
How often is the individual monitored by a health professional?		
Every day	05	14,3
5 days a week	07	20,0
3 days a week	08	22,8
Once a week	11	31,4
Twice a month	02	5,7
Once a month	01	2,9
A few times a year	01	2,9
Tem dificuldades enfrentadas no dia-a-dia das pessoas com TEA?		
Yes	35	100,0
No	0	0,0

Source: Research data (2022).

Table 7 shows that food restriction, a characteristic of ASD, is the most frequent (65.7%) difficulty, followed by communication difficulties (62.9%), social life (60%), and financial difficulties (48.6%).

Table 7 – Difficulties prevalence encountered in the daily lives of people with ASD.

Difficulties	%
(Food, enternainment) Restrictions	65,7
Communication	62,9
Social life	60,0
Financial	48,6
Repeated patterns	40,0
Speech	40,0
Motor	25,7
Coexistence	22,9
Affective	11,4

Prevalence (%)

Fonte: Dados da pesquisa (2022).

Given these difficulties, table 8 describes the fears and anxieties when it comes to sending the child to school, with the main concern being how they will be treated by their peers (40%), reflecting the prejudice by these families. Regarding support in this environment, the educational psychologist (40%) stands out compared to other professionals; however, when assessing the presence of these professionals within the school context, most mothers reported that their children did not have this type of support (60%).

Another piece of information that stands out is the absence of a classroom assistant, with 85.7% reporting that there is no support figure for their children. Furthermore, when asked about the training of teachers to deal with the challenges posed by ASD, the majority (71.4%) said that these professionals are not trained to deal with it.

Table 8 – School aspects simple frequency values and percentages.

Variables	Freq	%
Main fears and anxieties when sending children to school		
Not being at school age	04	11,4
Lack of qualified schools	02	5,7
Fear that the child will not adapt to the school	06	17,1
Fear that other children will treat them badly	14	40,0
No answer	09	25,8
Does your child have a support network at school?		
Yes	22	62,9
No	13	37,1
Educator		
Yes	14	40,0
No	21	60,0
Educational psychologist		
Yes	14	5,7
No	21	94,3
Occupational therapist		
Yes	02	8,6
No	33	91,4
Physical education professional		
Yes	03	11,4
No	32	88,6
Psychologist		
Yes	04	14,3
No	31	85,7

Classroom Assistant		
Yes	05	14,3
No	30	85,7
Are teachers trained to deal with the challenges posed by ASD?		
Yes	10	28,6
No	25	71,4

Source: Research data (2022).

The next section deals with issues relating to caregivers, in terms of sociodemographic, clinical, family, social, and engagement aspects regarding projects involving the world of ASD. Table 9 shows the sociodemographic data, in which 97.1% were female, with a mean age of 34 years old, 65.7% were married, 40% had finished high school, the majority did not work (57.1%), with a monthly income of one minimum wage (40%), and lived in the urban area (97.1%).

Table 9 – Caregiver's simple frequency values and percentages.

Variables	Freq	%
Gender		
Female	34	97,1
Male	01	2,9
Age		
Mean ± standard deviation	34,0 ± 7,0	
Minimum - maximum	23,0 – 53,0	
Marital status		
Single	10	28,6
Married	23	65,7
Divorced	02	5,7
Education		
Incomplete Primary education	01	2,9
Incomplete Secondary education	01	2,9
Complete Secondary education	14	40,0
Incomplete Higher education	06	17,0
Complete Higher education	03	8,6
Graduate school	10	28,6

Do you work?		
Yes	15	42,9
No	20	57,1
Labor regime		
I don't work.	19	54,3
CLT (Brazilian Labor Code)	13	37,1
Self-employed	03	8,6
Monthly income		
No income	03	8,6
Up until 1 minimum wage (R$ 1.100,00)	14	40,0
From 1 up to 3 minimum wages (R$ 1.100,01 - R$ 3.300,00).	11	31,4
From 3 up to 6 minimum wages (R$ 3.300,01- R$ 6.600,00).	03	8,6
From 6 up to 9 minimum wages (R$ 6.600,01 - R$ 9.900,00).	02	5,6
From 9 up to 12 minimum wages (R$ 9.900,01 - R$ 13.200,00).	01	2,9
Over 15 minimum wages (over R$ 16.500,01).	01	2,9
Residential area		
Urban area	34	97,1
Rural area	01	2,9

Source: Research data (2022).

Regarding the clinical data of the caregivers, topics such as medication use were addressed. Although the majority (74.3%) do not use medication, the use of antidepressants (14.3%) is noteworthy, which may be reflecting the overload of these caregivers. This was also observed in the habit of sedentary lifestyles (31.4%), as shown in Table 10.

Table 10 – Caregivers' clinical data simple frequency values and percentages.

Variables	Freq	%
Medication		
None	26	74,3
Anti-hypertensive	03	8,6
Antidepressants	05	14,3
Anti-diabetics	01	2,8
Family Health Habits		
No answer	23	65,7
Illicit drug use	01	2,9
Sedentary lifestyle	11	31,4

Source: Research data (2022).

Concerning the characterization of these families, in terms of the number of people per household, the majority are made up of 3 people; in terms of the number of children, most families reported having 2 children. Regarding the relationship between family members and the individual with ASD, there was a predominant variation between regular (29%) and good (37%). As for social life, defined here as going to public places with the person with ASD, 82.9% usually went out to these places.

Table 11 - Relationship between the person with ASD and other family members simple frequency values and percentages.

Variables	Freq	%
How many people live in your household?		
02 people	05	14,03
03 people	13	37,1
04 people	10	28,6
05 pessople	03	8,6
06 people	03	8,6
07 people	01	2,8

How many children do you have?		
1 child	11	31,4
2 children	19	54,3
3 children	05	14,3
No awnser	06	17,1
How is the relationship between the person with ASD and other family members?		
Regular	10	29,0
Good	13	37,0
Very Good	06	17,0
Excellent	06	17,0
Do you often go out to public places with the person with ASD?		
Yes	29	82,9

Source: Research data (2022).

Another aspect assessed was the caregiver's engagement with groups that support ASD, society's behavior, and the parents' perception of access to ASD inclusion programs. Concerning group participation, most (51.4%) caregivers do not participate in any support group, and only one reported being active in these groups.

Table 12 - Parents' relationship with society simple frequency values and percentages.

Variables	Freq	%
Do you take part in any support groups for caregivers of people with ASD?		
Yes	17	48,6
No	18	51,4
If positive, what is your role in the support group?		
I follow their actions.	16	94,1
I volunteer and actively engage in it.	01	5,9
Do you believe that your city has inclusion policies for people with ASD?		
Yes	12	34,3

No	13	37,1
I am not aware.	10	28,6

From 0 to 5, how satisfied are you with society's behavior towards your child?

Very unsatisfied	05	14,3
Unsatisfied	11	31,4
A little unsatisfied	06	17,1
A little satisfied	10	28,6
Satisfied	03	8,6
Very satisfied	0	0,0

From 0 to 5, how satisfied are you with the accessibility level to health, education, and social services for your child?

Very unsatisfied	11	31,4
Unsatisfied	12	34,3
A little unsatisfied	02	5,7
A little satisfied	06	17,1
Satisfied	03	8,6
Very satisfied	01	2,9

From 0 to 5, how satisfied are you with the inclusion programs for your child?

Very unsatisfied	04	11,4
Unsatisfied	15	42,9
A little unsatisfied	05	14,3
A little satisfied	08	22,9
Satisfied	01	2,8
Very satisfied	02	5,7

Source: Research data (2022).

When the level of satisfaction with society's behavior towards people with ASD was assessed, 28.6% were not very satisfied. Most respondents were dissatisfied with the ease of access to health, education, and social services (34.3%) and inclusion programs (42.9%). This dissatisfaction can be explained by their lack of knowledge of these policies (28.6%) (Table 12).

DISCUSSION

ASD is a neurodevelopmental disorder whose main characteristics are repetitive patterns and restricted behaviors that affect both social and financial life and cause clinical disturbances that require intervention. It is, therefore, necessary to know these individuals and their families' realities so that effective interventions can be designed[3].

Regarding the demographic profile, the data from this study corroborates the literature, which points out that 80% of individuals diagnosed with ASD are male.[6] Likewise, the study by De Lima Reis[7] et al. (2019), shows a prevalence of 77% of boys compared to girls and raises the hypothesis of the Y chromosome being involved in this condition, in which specific genes linked to this chromosome may show a greater tendency to develop the disorder.

As for age variability, a minimum of two years and a maximum of nineteen years old were compatible with the profile of De Lima Reis et al.[7] (2019), in which the data collected through the survey showed a minimum age of one year old and a maximum of between seventeen and twenty years old. Regarding race, the data from this research corroborates the study by Tomazelli and Fernandes[8] who studied individuals with developmental disorders, in which the brown and white races are more prevalent in cases of ASD.

Regarding the level of education, in agreement with this study, De Lima Reis et al.[7] (2019), pointed out that the most frequent education level found was elementary school education, which can be explained by the beginning of the literacy phase when the first developmental and interaction signs are observed, as well as being intrinsically linked to late diagnosis.

Regarding the pregnancy data, the results are similar to the study by Maia et al.[13], in which the mothers' ages ranged from 25 to 35 years old. In the study by Fezer et al.[9], the age ranged from 21 to 38 years old, which shows a similar mean age.

As for pregnancy complications, the literature is in line with this study, which presented gestational diabetes, hypertension, and pre-eclampsia as the main ones. Fezer et al.[9], in a documental study, pointed to factors such as bleeding, prematurity, low birth weight, and asphyxia. In this case, the authors also point out that their results are inconclusive since many of the data were not included in the patients' records. However, in general, this diversity may be related to the mothers' context, as well as the intrinsic factors of the women's health.

As for supplementation during pregnancy, the study by Maia et al.[13] looked at the relationship between folic acid intake and the occurrence of ASD, since folic acid is used to reduce neural tube formation defects and some studies hypothesize that the mother's high folate intake could be a triggering environmental factor due to the level of this vitamin in the bloodstream of these children.

Concerning the professional who made the diagnosis, De Lima Reis et al.[7] agree with the results obtained in this study and also point out that the most frequently cited professionals responsible for the diagnosis were the neuropediatrician and the child and adolescent psychiatrist. The epidemiological profile study makes it clear that these professionals, due to their specialty and clinical profile, conduct the diagnosis and then refer the patient to other professionals for intervention.

The parents' reaction at the time of diagnosis was also discussed, with the most common feelings being fear and uncertainty, which corroborates the study by Pinto et al.[14] who report these feelings of frustration, insecurity, fear, and hopelessness upon discovering the diagnosis of ASD. Further substantiating this discussion, Aguiar and Pondé[15] describe the moment as a devastating shock, describing it as the worst moment experienced by parents.

FINAL REMARKS

This study points to an ASD profile of male children aged between 2 and 19 years old, most of whom are of school age, attending elementary or middle school. All the mothers had prenatal care, with complications during pregnancy. The professionals who diagnosed the disorder were varied, but the neuropediatrician stood out. The vast majority had professional support, especially occupational therapists and psychologists.

As for the profile of ASD caregivers, the majority were women, aged between 23 and 53, married, living in urban areas, and with high school qualifications. It was observed that most of them did not work and that the average monthly income was one minimum wage.

The most common daily difficulties were dietary restrictions and communication difficulties. Although all the children studied, many caregivers reported anxiety when it came to sending their children to school because of their relationships with their peers and because they felt that the professionals were not prepared to receive their children.

There were limitations to the study in terms of sample size, which also reflects the population's lack of awareness of the relevance and impact that this type of study may have on the care process and the creation of public policies. Among the data, it is striking how little assistance the Unified Health System (SUS) provides to this specific population, even in the face of the high need for clinical support. It is suggested, based on the survey of these difficulties, that further studies be carried out to outline the profile and reality of this group, to strengthen discussions and search for effective strategies that enable understanding of the issue and the creation of public policies to meet the needs of this population.

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