https://doi.org/10.23925/2176-2724.2024v36i3e67520

Autism Spectrum Disorder: report of women who experienced a late diagnostic

Transtorno do Espectro Autista: relato de mulheres que vivenciaram um diagnóstico tardio

Trastorno del espectro autista: informe de mujeres que vivieron un diagnóstico tardío

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Abstract

Introduction: The diagnosis of ASD is a contemporary issue; however, research is focused on early diagnosis and little is discussed about reports of late diagnosis. Furthermore, including the female variable in this discussion increases the complexity of the topic. **Objectives:** Detail the late diagnosis process of autism spectrum disorder (ASD) in women, considering whether sex had an impact on this process and what were the changes in life after receiving the diagnosis. **Method:** This is a qualitative and descriptive research. Three women participated in this research who were selected from social media pages that contained personal reports on the theme of their ASD diagnosis processes. The interviews were carried out via the Google Meet Platform and in person. **Results:** The women interviewed were between 20 and 33 years old. All reported that the diagnosis was corroborated by a doctor and neuropsychological tests. Furthermore, they mentioned the gender variable as a factor correlated with their late diagnoses. Data analysis and interpretation was carried out from a linguistic-discursive position. The discussion addressed the weight of medical discourse and the effects on subjective and linguistic-discursive relationships and positions in the women interviewed from authors affiliated with the Language Clinic and Psychoanalysis.

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Authors' contributions:
AZS: conducted the data collection, article outline, methodology and critical review.
MDSGC: carried out the study design, methodological review and organization, guidance for all stages of the manuscript and writing review.
JMG: participated in the review of all steps of the paper, as well as guidelines on the axes of discussions to select the material for data collection.

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Received: 07/10/2024
Accepted: 08/12/2024

Final considerations: This research expands the possibilities for discussion that are little investigated in the literature on late diagnosis in women. This theme is constantly explored on social media and still deserves theoretical refinement based on research that considers language and subjective constitution.

Keywords: Autism Spectrum Disorder; Late diagnosis; Women.

Resumo

Introdução: O diagnóstico de TEA é um assunto contemporâneo, todavia, as pesquisas estão direcionadas para diagnóstico precoce e pouco se discute sobre os relatos de diagnóstico tardios. Além disso, incluir a variável sexo feminino nesta discussão amplia a complexidade da temática. **Objetivos:** Detalhar o processo diagnóstico tardio de TEA em mulheres, considerando se o sexo teve impacto nesse processo e quais foram as mudanças na vida após receberem o diagnóstico. **Método:** Trata-se de uma pesquisa de cunho qualitativa e descritiva. Participaram desta pesquisa 3 mulheres que foram selecionadas a partir de páginas das redes sociais que continham relatos pessoais com a temática de seus processos de diagnóstico de TEA. As entrevistas foram realizadas via Plataforma Google Meet e presencial. **Resultados:** As mulheres entrevistadas tinham idade entre 20 e 33 anos. Todas relataram que o diagnóstico foi corroborado por um médico e testes neuropsicológicos. Além disso, mencionaram a variável sexo como um fator correlacionado aos seus diagnósticos tardios. A análise e interpretação dos dados foi realizada a partir de uma posição linguística-discursiva. A discussão abordou o peso do discurso médico e os efeitos nas relações e posições subjetivas e linguística-discursivas nas mulheres entrevistadas a partir de autores filiados a Clínica de Linguagem e a Psicanálise. **Considerações finais:** Esta pesquisa amplia as possibilidades de discussão pouco investigadas na literatura sobre o diagnóstico tardio em mulheres. Essa temática é constantemente explorada em mídias sociais e ainda merece devido refinamento teórico a partir de pesquisas que considerem a linguagem e a constituição subjetiva.

Palavras-chave: Transtorno do Espectro Autista; Diagnóstico tardio; Mulheres.

Resumen

Introducción: El diagnóstico de TEA es un tema contemporáneo, sin embargo, las investigaciones se centran en el diagnóstico temprano y poco se discute sobre los informes de diagnóstico tardío. Además, incluir la variable femenina en esta discusión aumenta la complejidad del tema. **Objetivos:** Detallar el proceso de diagnóstico tardío del Trastorno del Espectro Autista (TEA) en mujeres, considerando si el sexo tuvo impacto en este proceso y cuáles fueron los cambios en la vida después de recibir el diagnóstico. **Método:** Se trata de una investigación cualitativa y descriptiva. En esta investigación participaron tres mujeres que fueron seleccionadas de páginas de redes sociales que contenían relatos personales sobre la temática de sus procesos de diagnóstico de TEA. Las entrevistas se realizaron a través de la plataforma Google Meet y de forma presencial. **Resultados:** Las mujeres entrevistadas tenían entre 20 y 33 años. Todos informaron que el diagnóstico fue corroborado por un médico y pruebas neuropsicológicas. Además, mencionaron la variable género como un factor correlacionado con sus diagnósticos tardíos. El análisis e interpretación de los datos se realizó desde una posición lingüístico-discursiva. La discusión abordó el peso del discurso médico y los efectos sobre las relaciones y posiciones subjetivas y lingüístico-discursivas en las mujeres entrevistadas de autores afiliados a la Clínica del Lenguaje y Psicoanálisis. **Consideraciones finales:** Esta investigación amplía las posibilidades de discusión poco investigadas en la literatura sobre diagnóstico tardío en mujeres. Este tema se explora constantemente en las redes sociales y aún merece un refinamiento teórico basado en investigaciones que consideren el lenguaje y la constitución subjetiva.

Palabras clave: Trastorno del Espectro Autista; Diagnóstico tardío; Mujer.

Introduction

Autism Spectrum Disorder (ASD), according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), is characterized by deficits in communication and social interaction, as well as persistent repetitive and restrictive behaviors. Symptoms usually manifest during developmental periods and can cause problems in social relationships, professional settings, and various areas of daily life[1].

There are few studies regarding the epidemiology of ASD in Brazil, but an estimate made in 2011, based on international data, suggested that 1.5 million people were affected[2]. In parallel, based on the Brazilian regions, considering the total population and a global average, it was estimated that Brazil had 1.2 million people with ASD in 2017[3].

There is discussion in the literature of a significant increase in ASD diagnoses, which have multiplied about thirtyfold worldwide since the 1960s[4]. Various reasons are explored, such as greater efficacy of protocols and legal aspects that ensure early diagnosis. An example is Law 13.438, from April 2017, which mandates the use of protocols or instruments to detect risks for psychic development in pediatric consultations.

Such diagnoses are reported four times more frequently in men than in women[1]. This data is supported by international studies indicating that 1 in 42 boys were diagnosed with ASD compared to 1 in 165 girls in 2018[5]. In Brazil, although studies are scarce, similar data can be observed in a survey from the Specialized Rehabilitation Center (CER) II at the Universidade do Estado do Pará, indicating that out of 100 patient records diagnosed with ASD, 77% were male[6].

Thus, to consider the questions about ASD statistics in men and women, various hypotheses are raised in the literature. These are not easily understood and are laden with controversies among authors. For instance, it is argued that ASD diagnoses do not account for gender differences in sociability, friendship, or emotional aspects, assuming that people with ASD have similar characteristics regardless of gender. It is suggested that ASD signs in women involve specificities and particularities that are often overlooked during the diagnostic process[7].

In alignment with this, some authors also argue about the potential social expectations based on gender, which may impact the frequency of diagnosis. For example, some behaviors are socially expected from girls, and others only from boys[8]. In summary, theorists propose the hypothesis that women might have a greater aptitude for "camouflaging" ASD traits, with reports of attempts to pretend to be something they are not in order to appear "normal."[9] This point is also observed regardless of gender, because although ASD is typically characterized by early signs, it is possible, according to the DSM-V, that it may not be recognized until social issues exceed certain limits, or it may be masked through strategies learned over time, leading many adults to suppress repetitive behaviors when in public[1]. Therefore, the complexity of this issue is evident, as well as the scarce literature on these potential differences in the timing of diagnosis.

Another point worth discussing, as it is a contemporary debate around ASD topics, is early diagnosis. It is important to highlight the risk of diagnosing a child prematurely, as even with professional support, the child could be defined under the lens of a pathology that may not be the central issue[10]. In other words, there is a risk in anticipating factors that would indicate the risk of an ASD diagnosis in very young children. Regarding risk indicators, these are behavioral signs that are often observed in only a few interactions between the professional and the child.

However, even though early diagnosis is one of the main points of discussion currently associated with ASD, it is important to note that the women in this study did not experience this contemporary discourse, as during their childhoods, early diagnosis was not widely debated. Reflecting on these aspects, this research was developed with the question of how, in the absence of this discourse during their childhoods, some women take a stance in the face of the strong contemporary discussion about ASD diagnosis.

Therefore, complementing recent studies on ASD, which emphasize early diagnosis, this research focuses on late diagnosis, specifically in women, considering the data presented above and the discussions, albeit incipient, that the literature has shown. Furthermore, there are no studies that address the significance of this statistical difference, which is notable given the numerous reports on the subject today, especially on social media. This topic remains largely invisible due to its complexity and the various factors involved.

Thus, the objective of this article is to detail the late ASD diagnostic process for the women interviewed. Additionally, from a linguistic-discursive perspective, which involves the position of the interviewer and interviewee, the study aims to explore whether gender had an impact on this late process and what changes occurred in these women's lives after receiving the diagnosis.

Method

The research was qualitative and descriptive, using semi-structured interviews (instrument attached, developed by the authors) conducted via Google Meet and in person. This methodology makes it possible to obtain information that approaches the subjectivity of each participant, based on their perspectives and individual, personal experiences, allowing for an understanding of the social relationships that surround them[11].

The research described here, was submitted for evaluation by the Research Ethics Committee (COMEP), of the Universidade Estadual do Centro-Oeste (UNICENTRO), adhering to the ethical and scientific requirements outlined in Resolution N.º 466/2012[12].

The participants were provided with information about the research through the Free and Informed Consent (IC). The form was read aloud to ensure they were aware of its voluntary nature and the option to withdraw from the research at any time. All information provided by the participants was used solely for this research, kept anonymous, and respecting human dignity as a requirement for conducting any research involving human subjects. Therefore, this research was only initiated after the selected participants provided their Free and Informed Consent.

Furthermore, only after the approval of the Research Ethics Committee (COMEP - 5.074.653) were the participants selected. The selection was conducted by one of the researchers through an analysis of certain social media platforms (Instagram and Twitter) where content related to the ASD diagnosis was posted. The selection criterion was that these women's posts were related to their own diagnostic process. Three women were selected, and invitations were sent via Gmail and direct Instagram messages, explaining the purpose of the research. After acceptance, one of the researchers contacted them via WhatsApp, as provided by the participants, to plan and explain how the semi-structured interview would be conducted, including aspects such as duration and scheduling based on individual availability. The interview was proposed to be conducted remotely via the Google Meet video conferencing platform, considering that the participants were from different cities, and this modality respects and complies with the sanitary measures related to the COVID-19 pandemic, which was still present during the data collection period. However, one of the participants requested that the interview be conducted in person, citing difficulties related to ASD in responding via videoconference. After obtaining approval from the UNICENTRO ethics committee for this procedure, the interview was conducted in person, following all necessary biosafety protocols.

The data analysis was grounded in a discursive approach, with a linguistic bias in which the investigator's position is always implicated when analyzing the material. The investigator's stance towards the data was proposed by Carvalho, who is affiliated with Interactionism in the field of Language Acquisition[13]. She questions scientific knowledge and the position of the investigator who distances themselves from their object of study. Supported by Milner, the author emphasizes that the investigator is a speaking subject, and when studying their own language, a return to oneself is inevitable, revealing their subjectivity[14]. The approach involves suspending prior meaning and knowledge so that the material, encountering an enigmatic but necessary strangeness to address a research question, can surprise the investigator. This stance is also shaped by the investigator's theoretical background, which is guided by a discursive network that directs the interpretation of the materials. Although Carvalho focused her research on analyzing children's speech data, this methodology is essential in qualitative research where discursive analysis is unavoidable. It is important to note that the authors of this article are aligned with the Language Clinic approach, a proposal that closely relates to Interactionism in Language Acquisition[15], which is fundamentally based on European Structuralism[16,17] and, regarding the subject, on the hypothesis of the unconscious from Psychoanalysis.

Results

Participant profiles and diagnostic process

Anna

Anna (a pseudonym) is a 20-year-old woman, a student, and runs an Instagram page where she posts content related to ASD. She mentioned that her diagnosis came as a surprise, as she had not been actively seeking it. She explained that during her adolescence, she experienced episodes of depression and anxiety, and it was during her psychiatric treatment that the possibility of ASD was first raised: *"Then, during my sessions with my psychiatrist, he… brought up the possibility that I might be autistic."*

After that, Anna had several conversations with her mother about the subject. When she returned to the doctor, she underwent tests and questionnaires, which confirmed her ASD diagnosis at the age of 15. The medical verdict was Level 1 Autism requiring support. Anna said she felt confused at the time. She added that she did not understand the purpose of the questionnaires, as she had never considered ASD before and didn't feel she fit into that category at that initial moment. In her words: *"So even though I identified with some of the criteria, I looked at it and didn't see the point… I didn't feel represented; I thought, 'No, I'm just a little strange, I'm not autistic.'"*

When asked about the professionals involved in the diagnostic process, Anna said that both a doctor and a psychologist participated.

Stella

Stella (a pseudonym) is a 29-year-old woman who works independently through Twitch, a live video streaming platform where she plays online games. Stella shared that she would like to pursue a degree in Meteorology or English Literature and even started a degree in Computer Engineering but dropped out when she realized there was no support for people with ASD. She stated that the teaching methods of the courses she researched would not be conducive to her learning.

Stella's diagnostic process occurred in 2015 when she was 22 years old. She recounted that at a certain point in her life, something happened—without being able to explain it precisely—and due to her father's concern, they sought out a neurologist: *"It was… around 2015… there was a moment in my life when my mind just crashed, seriously, I can't explain it any better than that… there was a moment when I started having panic attacks, you know… so I needed to… my dad was worried, so we went to a neurologist to see what was going on."*

From there, Stella said, the neurologist raised the possibility of autism to her and her family, leading them to seek second and third opinions, which ultimately confirmed the ASD diagnosis through a medical report: *"My diagnosis happened because I needed to see a neurologist due to my crises, and they identified certain behaviors."*

When she first heard the suspicion of autism, Stella did not doubt it; she researched the spectrum and said she understood that it fit her, even considering her childhood. Interestingly, her mother did not believe it at first and took her to a psychopedagogue for testing. According to Stella, the professional disagreed with the diagnosis.

> *Interviewer: And she said you weren't autistic, so what happened next? Were you referred back to the doctor?*
> *Stella: No…* ***she said I wasn't and that shook me****… but since two others had said I was, like… because she said I wasn't autistic, I asked her,* ***"Okay, then what am I?" and she said she didn't know…*** *so I didn't give it much importance…* ***but then I went to the one in Curitiba, and he gave the diagnosis, you know,*** *he didn't give the report, but he gave the diagnosis…* ***and my mom was with me, and then she believed it.***

This was the only interview in which doubt about the diagnostic process arose, leading to consultations with additional doctors. Stella also mentioned that she had attended a speech therapist as a child because she had difficulty producing certain phonemes.

Esme

Esme (a pseudonym) is a 33-year-old woman who works as a clinical psychopedagogue and a municipal public servant. At the age of 31, Esme was diagnosed with ASD. The situation she described is interesting, as it involves the beginning of her studies on the subject while she was pursuing a postgraduate degree. During this course, she noticed characteristics that she identified with, both in her adult life and as a child. After realizing this, Esme sought out a neuropsychopedagogue who was aligned with her research and whom she believed could assist her in exploring the diagnostic hypothesis. Esme mentioned that one of her challenges was finding a doctor capable of providing her with a diagnosis, which only became possible with the help of her postgraduate coordinator, a pediatric neurologist. She stated: *"You can't rely solely on neuropsychological tests by any means; they help but also hinder… but what really drives the diagnosis, like 90%, is the professional's eye."*

In addition to the neurological evaluation, Esme was the only one who reported undergoing a speech-language evaluation: "*She evaluated me, she noticed a speech apraxia… well, I've had speech apraxia since I was a child… I used to stutter, you know… I have echolalia… so… I still have it today…"*

Literature often correlates cases of apraxia with individuals with ASD, as well as the presence of echolalic speech. However, stuttering also falls into this list of language diagnoses that she received. She spoke about how difficult the stuttering was during her childhood, and how it affected her at school, but she says it has improved, even though she still identifies some manifestations of these issues in her current life.

Overall, what stands out in the three diagnostic processes described is the power of the medical discourse—there are no doubts, or any doubts are immediately addressed by seeking another medical opinion to eliminate any questions about the diagnosis. Another point is the presence of depression and anxiety in the periods leading up to the diagnostic process. Considering what these women narrated about the history of their diagnoses, it echoes Monteiro's[18] discussion on the diagnosis within medical standards. The author argues that medicine eliminates the individual, the singular, focusing solely on the disease. In this line of thought, she asserts that diagnoses today are identified within a clinical category, that is, solely through the exploration of symptom patterns towards a pathology: "In this stage, the disease takes the place of the patient, given the search for predictability and universality in nosographic frameworks"[18].

This conception of disease involves the view that there are internal imperfections within a body. In the excerpts from the interviews, it is possible to hear the dissatisfaction these women have with themselves, especially Esme, who is essentially self-diagnosed. It is contemporary and crucial to discuss diagnoses that happen online, often leading to self-diagnosis, where a machine lists visible signs that quickly fit into nosological frameworks, such as ASD[18]. Anna, Stella, and Esme did not report this movement of online diagnosis, but all of them began their search and confirmed the signs through online access, following characteristic patterns, as an initial mode of self-diagnosis before arriving at a medical conclusion.

Discussion

The role of gender in the diagnostic process

The participants were asked if they believed that their biological sex, the fact that they are women, had influenced their late diagnoses. All shared the same stance and described this influence from their perspectives.

Anna stated that her sex was a significant factor, as the characteristics used to recognize ASD are based on male attributes, while female characteristics might be different. She believes that although there may be similarities, women should be analyzed with a different perspective. According to Anna:

> *"So, I believe that my mother might have never noticed anything U. S. (unintelligible segment) strange in my childhood because she was very attached to the criteria used to identify an autistic boy, and when you go to identify an autistic girl, you have similar criteria, but there are other things that you need to take into consideration as well, beyond what we already have in the criteria used for men, right?"*

Anna cited examples, stating that unlike boys, who tend to isolate themselves in childhood, girls often attempt forced socialization. She also mentioned that during adolescence, autistic hyperfocus is often mistaken for something that would be considered "girly." These were the two aspects that she felt were not considered during the diagnostic process for girls.

Despite this response, it is still not very clear how these characteristics fit into the signs described in the literature. There is a sense that new signs should be considered when diagnosing women. When the same question was posed to Stella, she noted that during her childhood, there were more diagnoses in boys and added another factor that could contribute to late diagnoses:

> *“Yeah… it was greater… diagnosis for men, right? Boys… not men, boys, children… but, it was in more severe types… we didn’t notice it in ourselves… we only saw diagnosis for boys, and not the mild form… we only saw levels 2 to 3 you know?”*

She also recalled that neuropsychological evaluations and test batteries were not used as frequently. Esme’s response echoed Stella’s, as she emphasized that access to and execution of this diagnosis remains superficial even today, as does the lack of trained professionals. Esme aligned with Anna’s view by stating that the signs of ASD in women are subtle, as from a young age, girls are trained to follow certain social patterns to fit in, a kind of “masking,” which Esme says is much more common in women than in men.

> *“Because the signs in women, in mild autism in women, are very subtle… because we are… we are trained from a very young age… how can I put it… to fit into social patterns, to follow social patterns, in a much more… systematic way than boys, right?… so we… our mask, masking, as they say, in female autism is much more present, it’s much stronger, so the person who is going to diagnose autism in a woman has to have a very calibrated eye… you can’t rely solely on psychometric tests, neuropsychological tests by any means, they help but also hinder… but what really drives the diagnosis, like 90%, is the professional’s eye.”*

It is also important to mention that this study did not aim to discuss the necessary differences between gender and sex, even though the former term was present in the statements of participants like Stella. The complexity of this issue was not explored in the questions that guided the interview and could not be addressed without a broad and robust discussion of the literature, a path that would diverge from the central questions of this research.

The concept of “masking” or “mask” is brought up at different points by all the interviewees. Although controversial in cognitive-behavioral literature, this masking phenomenon is discussed as a characteristic more prevalent in autistic women. As Fink[19] highlights in Bargiela’s studies, women tend to ‘pretend’ to be normal as a method of camouflage. Therefore, it would be more common for women to have a predisposition to adapt their lives to avoid showing autistic traits, thereby displaying greater social skills, which could hinder or complicate diagnosis[20]. Again, it is necessary to emphasize the complexity of this discussion. This assumption moves towards a subjective hypothesis of control over behaviors, suggesting a cognitively capable individual who can anticipate their socialization difficulties and create mechanisms to camouflage themselves. It is worth noting that this hypothesis opposes the assumption of an unconscious subject who cannot consciously predict, anticipate, or avoid a ‘type of behavior.’

Faced with the impacts of the speeches: the medical discourse

During the analysis of the interviews, both on and off the record, some statements stood out and impacted the researchers, particularly those related to the influence of medical discourse on the diagnosis of ASD. According to Clavreul, as referenced by Monteiro[18], medical discourse can be likened to one of the four discourses of psychoanalysis, the master’s discourse, which assigns meaning to signs (symptoms) and governs these signifiers. From a list of correlated signs, it is possible to identify a specific disease through a causal reasoning process. As such, this discourse is considered an “act of mastery,” commonly used and naturalized, placed in a position of power, with significant influence over those who listen to it[18]. Thus, as mentioned, regarding the erasure of the individual in a diagnostic process, even considering the discussions about symptoms, they serve solely to complete the medical discourse. In other words, “the patient speaks, but only to offer the signs of their illness. Therefore, it is a diagnosis that comes from the Other, and their speech is merely a means to obtain the signs”[18].

The interviewees’ statements indicate that once a doctor suggests the possibility of ASD to these women, there is almost no questioning of whether the diagnosis may or may not be accurate; there is simply acceptance, reflecting the weight of medical discourse upon them.

> *“During my follow-up with my psychiatrist, he… brought up this… possibility, right, that I might be autistic, and then there were several conversations with me and my mother, tests that I did, right? questionnaires, and after all that, the diagnosis came”* - ***Anna***

> *“Then the neurologist looked at me and said, ‘You might be autistic, you know,’ and then… afterward… I went to another neurologist (...) we talked and all,*

> *and he said, 'Yeah, you really are autistic,' so… that's how it was [...] I believed it, you know… I said, 'Okay'"* - ***Stella***

It's worth noting that, for Stella, another professional questioned the diagnosis, but in this case, as in others, the medical discourse was stronger in the final verdict. Drawing an analogy with contemporary times and clinical practice with children, this is something observed much more frequently, as the numbers presented in the introduction may indicate. Thus, the involvement of other professionals in this process, such as psychologists, speech therapists, or educational psychologists, is in many cases disregarded and/or completely overshadowed.

Is doubt a possibility in the face of a medical diagnosis?

The questions asked during the interview led to other issues, and this is how the participants expressed their views on how others reacted to their diagnoses. These responses were marked by the characteristic presence of anxiety in these women when minimally challenged about the fact that they are autistic.

> *"So, I didn't know how they would react, right? If they would start saying, 'Oh, all of a sudden Anna* ***started being autistic****, doing this and that,' when in* ***reality I always did those things, but I masked it*** *so people wouldn't notice… and … yeah… with… time it got easier, but at first,* ***not everyone believed it****… there were many ableist comments, but people learned over time."* – ***Anna***.

> *"But yeah… my family didn't accept the autism well.* ***They denied it for a long time****… like, it was only this year that they slowly started to give support, being more open… but still… still not really (...)* ***And then autism came and… it's a disability, right?****… and they didn't want to admit that there was someone in the family with it (...) so my family is very much like that, you know… so my relationship with my family is quite complicated… I thought it was just psychological, but it made me think that it has a bit to do with it,* ***because I'm different, and they don't know how to handle it, I don't know, they don't want to deal with it.****"* – ***Stella***.

The bolded terms, that stand out, suggesting a possible interpretation of this "before and after" of autism, a division that is clear in many of the statements from the three interviewees, while simultaneously referring to something that has always been there: *"I always did that" [...] "because I'm different."* Even in this ambiguity, for them, there is no possibility of discussing their ASD diagnosis with others, or even with themselves (about themselves), but there is confidence and affirmation that it is real, and there can be no other possibility. In light of this, the question that arises when listening to and reflecting on how to receive these statements, even offstage during the reading of the materials, would be to discuss what these women see in this diagnosis; what is it about this diagnosis that finally gives Anna, Stella, and Esme the feeling that they are part of something. Or yet, another question: what would be so difficult for them to handle outside of this diagnosis? These are points we do not intend to answer, but they are pertinent questions, considering Monteiro's[18] discussion, at one point in her work states, "In the past, to achieve equality, one had to die; today, it's enough to be ill." The effect cannot be ignored that it is through autism that these women identify with themselves and open up to certain experiences, even though they are always imposed by certain "limits" that involve being on the autism spectrum.

In any case, it is interesting to think that these women's stories with autism are marked by a late diagnosis**.** The time for some identification process was short, but it seems that once established, there is no room for other possibilities or discourses. There is a desire to be accepted as they are, to be seen as equal, based on what each of them understands as autism, which until then did not exist in their lives or the lives of their families.

It is important to remember that these women to understand themselves as autistic use the criteria described in the DSM-V; they recognize themselves within these standards, therefore, they are autistic. This includes their own questioning about the need for new criteria to be included in the manuals to address the differences that, for them, exist for women. The erasure of the individual is also found in this aspect; the uniqueness of each of these women within these frameworks is obliterated. It would be important to consider the singularity of each symptom since, in medical knowledge, the individual is merely a sample of the disease, and what is brought by them, (symptoms) only matters as data[18].

It is crucial to emphasize that this research does not aim to agree or disagree with these diagnoses. Moreover, if we observe some excerpts from the participants' statements, they list signs that, from a medical discourse, fit within the autism spectrum. At this point, it is impossible not to refer to Lacan's text. In a discussion about speech and language, the author points out that there are paradoxes of language, one of which is the possibility of hearing alienation. In the author's words:

> "The third paradox of the relationship between language and speech is the subject who loses their meaning in the objectifications of discourse. [...] For there lies the deepest alienation of the subject of scientific civilization, and it is this that we first encounter when the subject begins to speak of themselves [...] To give an exemplary formulation of this, we could not find a more pertinent ground than the use of current discourse, noting that the 'this is me' of Villon's time has transformed into the 'it's me' of modern man"[21].

In the interviewees' self-reflections, the effect is that medical discourse prevails and takes control of this body-language, creating an alienation that imposes a discourse leaving no room for doubt or different modes of subjectivity. The fact is that it is within this identification with the autism spectrum that the entire discursive network of these women is embedded.

It is worth noting that there are other modes of diagnosis. Movements from other fields, such as Psychoanalysis and the Language Clinic, reflect on alternative approaches to addressing the diagnostic process. Arantes[22], when explaining the distinction between a language-based diagnosis and a medical one, argues that the former cannot be marked by the cause-and-effect relationship and does not rely on this clinical conception but opens possibilities for the unpredictable and the singular. In this direction, a "change in perspective should necessarily imply a transformation in the analysis/interpretation of the material—it should shift the therapist from the position of the 'spokesperson' of knowledge"[22]. Furthermore:

> "Many centuries were needed for Medicine to conquer its object and thus reach the 'recognize/explain' that are definitive of diagnosis in its field. Freud's decisive gesture founded a different discursivity and redefined 'diagnosis' in Psychoanalysis. Thus, we see that the conquest of the object is a gesture that precedes the circumscription of the diagnostic instance. In fact, the lesson these fields of knowledge teach us is that the definition of diagnosis requires considering the specificity of what is in focus in different clinics—it requires a commitment to the phenomenon that is being questioned"[22].

Evidently, the necessary differences imposed by these fields mean that the professional's perspective and position will define the diagnostic process. Alongside Psychoanalysis, a structural diagnosis is theorized. Maleval[23], a psychoanalyst, advocates for the hypothesis of autism as a structure rather than a nosology. For the Language Clinic, the issue of structure is also important, but it calls for a diagnosis rooted in language and based on language. It is through the clinician's attentive listening to the speaker's relationship with their own speech, and the speech of others that one can be affected by the movements of language, and possible disruptions in speech, which may indicate a structural diagnosis.

The inability to speak about oneself and the lack of personal engagement in their words

An interesting effect in the interpretation of the transcribed materials was that in response to certain questions, Anna, Stella, and Esme found it difficult to engage with their own narratives—they struggled to speak about themselves without tying their identity to ASD. Consider the following excerpts:

> *"It's the way I**… it's the way I communicate… today, with the diagnosis, I know it's the autistic way, right?**… of communicating, that I was very logical, I was very sincere, you know, I was very rational about things, you know, like… and also, I was very literal… [...] because neurotypicals usually think that autistics are rude, right?…"* - **Stella**

> *"**Self-knowledge is a very powerful thing**, and it was from that point that I began to empower myself **as an autistic woman**…"* - **Anna**

> *"I always say… even… **I'm lucky that my hyperfocus became autism**, so…"* - **Esme**

Maleval[23] had already noted a tendency among autistics to write "in the name of autistics." The author mentions the writing of an autistic person: "Autism is a way of being. It is pervasive, it occupies the entire experience, every sensation, perception, thought, emotion, every aspect of life"[23]. In other words, this seems to be a recurrent pattern—a stance, it's worth noting, that was assumed later in life by these women.

At times during the interviews, one can sense a position in language that describes events with little or no subjective involvement. As Maleval[23] noted, "The autistic person who seeks to communicate guides themselves toward a language that would describe facts, without needing to interpret them." The author questions the engagement of voice in cases of high-functioning autistics and states: "They resolve this through factual language [...] the use of the signifier is erased in favor of the sign"[23].

In brief, the relationship these individuals have with the sign and signifier is because the autistic person relies on the sign but does not engage in signification[23]. There would, therefore, be a constant and rigid way of dealing with language. We do not want to assert that this is the case for the interviewed women, as we've already stated that the aim of this article is not to support or refute their diagnosis but rather to problematize the effects of the discursivity of their words and identifications. On the other hand, it is impossible to ignore that there are moments when their words produce a sign effect and slide into a mere description of facts, as in the following excerpts:

> *So, I think I responded a bit with what I just said and… also… I think that… physically, right? it was physically… emotionally, neurotypicals can't handle the… the truth… I find this very annoying… like, you… you can't just come and say it, you have to find a way… keep finding ways to speak more softly, I don't know, you know… this annoys me a bit! Especially because I don't know how to do that, I don't know how to keep finding ways… every time I needed to, I would ask my psychologist "how do I do this" and then she would explain and I could do it… but… this… this… this makes me anxious! I… I don't like it, you know?… can you understand why? –* ***Stella***.

> *"Yeah… I have a business partner, in our company... who talks like this, she's autistic too, she... it was me who diagnosed her, actually with 34 years old... yeah... she says that the phrase that defines us is "this doesn't make sense" (laughs) the phrase we use the most, it's… it annoys me this need people have to keep talking, talking, talking about their life to others... it annoys me the fact that people want to live... things... immoral or illegal... but I don't... I don't... I don't try to fix this because that's up to each person, right, I know my place... it annoys me... it's stressful situations, right... the tone of people's voices to me is extremely stressful, there are voices of people that I can't stand, I don't stay near... I don't even stay near, I leave... understand... and it's not... volume, it's frequency, it's the timbre of the noise... -* ***Esme***.

Another aspect is that all the interviewees mention that they deal with their emotions, as well as those of others, differently. Based on Maleval's hypothesis, the relationship with the sign produces these effects; he states: "The primacy of the sign in the thinking of autistics has major consequences for their treatment. It creates an obstacle to spontaneous learning aligned with affections."[23] In the interviews, one can read:

> *I deal differently because emotions are always very subjective so I can never accurately answer a question that involves my feelings or the feelings of another person -* ***Anna***

> *What I'm feeling is… I have… I have an explanation, you know, I seek an explanation for everything -* ***Stella***

> *But… I am a very rational person… very rational… so even when I come across a situation involving feelings, I… I am able to analyze it… I… I can put myself in someone else's shoes, yes I can… but what people call empathy, that is, trying to feel the pain of another, this is impossible… this is not empathy… this biologically chemically does not… it does not make the slightest sense… so as for my own feelings, how do I deal with them… I don't deal very well because I am a person who does not talk about my feelings, I don't like it… -* ***Esme***

Additionally, it is noteworthy how they bring up an issue of identification with Asperger's Syndrome and a certain complaint regarding contemporary changes in terminology. In this context, there would be high functioning, with greater abilities for social adaptations, specific interests, and behaviors, without cognitive or language impairments[24]. However, the DSM-V removes this category from its manual and reallocates it within Autism Spectrum Disorder[24].

> *I received the diagnosis of being an autistic person level 1 support… that until the end of this year we'll still call Asperger's Syndrome but starting next year it will all be under Autism Spectrum Disorder –* **Anna**.

> *I don't know if it was much because... because back then there wasn't (US) to diagnose Asperger's, right?... back then it was Asperger's... - **Stella**.*

There is a discomfort regarding this change in nomenclature. It's interesting to think that these women believe in their ASD diagnosis, but they have a greater identification with Asperger's Syndrome. Therefore, it should be noted that the points highlighted and discussed are the effects of a position affiliated with the Language Clinic, which has substantial connections with Psychoanalysis. This background guided the reading and interpretation of the materials.

Final considerations

From the discourse of the interviewees, it is evident that the weight of medical discourse plays a significant role in the diagnosis, which is clinical, it is worth noting, but does not allow for questioning, either from Anna, Esme, and Stella, or others; such questioning is even considered a position of prejudice. The effect on the reading of the materials is that the responses are influenced by a discursive position of "being ASD." Similarly, the interviewees claim that ASD in women has peculiar characteristics that are seldom discussed during the process, raising the issue they have exposed on their own social networks about how gender can be a factor in impeding early diagnosis. Furthermore, it is only recently that there is more ease and accuracy in diagnosing ASD in milder cases.

A central issue, which was of extreme relevance during the reading and analysis of the data, is how this diagnosis seems important to them, as it is through it that they feel complete and find themselves as subjects. This label, they say, liberates them, places them in a position to (finally) be who they are, and belong somewhere. Questions arise from this, however, beyond the issues and significant discussions of how this diagnosis is made, it is essential to listen to these women, or rather, to truly hear their voices. If these are the effects that an ASD diagnosis has on them, this is essential and must be considered. In this regard, a poignant autobiographical book by a woman with an ASD diagnosis state:

> "What began as research for the book turned into a journey of self-discovery (...) By seeking and finally obtaining my diagnosis (at thirty-four years old), the heroine of this book was able to be born. (...) I knew her intimately because she came from my heart. I no longer had to censor my ideas to make them socially acceptable, something I had been unconsciously doing for years. And this freedom allowed me to find my voice. I had been using the writing style of others, trying to be something different. When I wrote this book, I became myself, and I have continued to be since then, without the slightest weight on my conscience."[25]

Therefore, we consider that this research opens a range of discussion possibilities that are underexplored in the literature on late diagnosis in women. This theme is constantly explored on social media and still deserves due theoretical refinement from research that considers language as determinant and constitutive and problematizes the diagnosis from a structural point of view, rather than merely as a checklist of signs aimed at closing a nosological framework.

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INTERVIEW SCRIPT

1) Full Name:

Date of Birth: ___/___/___ Age:

Address:

Education Level:

Profession:

2) Tell me about your diagnostic process.

3) At any point during the diagnostic process, did you have the participation of a speech therapist?

4) Do you think your gender influenced the delayed diagnosis?

5) In your childhood, did you feel different or out of the norm?

6) Do you feel that you handle emotions differently than more logical/rational matters?

7) At any point in your life, did something about others (people) distress you?

8) How do others (people) usually affect you?

9) How is your relationship with close people, friends, family, and with not-so-close people? (e.g., friends of friends).

10) What changed in your life after the diagnosis?