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Autism in adults: life experiences after a late diagnosis

Autismo em adultos: relatos de vida após um diagnóstico tardio

Carla Gruber Gikovate
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Abstract

Previously considered a rare childhood disorder, autism today is a frequent diagnosis with increasing demand in all age groups, including people who were not diagnosed in childhood, but who perceive characteristics of this condition. This study, which is part of a broader research on the experience of Brazilian adults who were diagnosed with autism spectrum disorder (ASD) after 18 years, aims to explore the life stories, present and past, of this group of people. To this end, a qualitative research was carried out in which 12 participants were interviewed and the data were analyzed using the content analysis method, in its categorical aspect. Considering the objective of this work, in the analysis of the interviews, these categories emerged: *social difficulty as the central point, sensory issues, language difficulties and naivety, rigidity/repetitive behavior, and facilities/advantages that autism brought*. It was observed that social difficulties remained a central issue, even in a group of adults with mild autism, as well as sensory complaints, difficulty understanding figurative language and rigidity. Attentional hyperfocus is cited as something positive, that brings facilities to everyday life. It was concluded that the characteristics described above are present in the lives of this group of autistic people, with significant disadvantage to their daily lives.

Keywords: Autism Spectrum Disorder; Adult; Life experience.

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Resumo

Anteriormente considerado um transtorno raro da infância, hoje o autismo é um diagnóstico frequente e com crescente demanda em todas as faixas etárias, incluindo pessoas que não receberam diagnóstico na infância, mas que percebem características desta condição. Este estudo, que faz parte de uma pesquisa mais ampla sobre a experiência de adultos brasileiros que receberam diagnóstico do transtorno do espectro autista (TEA) após 18 anos, tem como objetivo explorar os relatos de vida, presentes e passados, deste grupo de pessoas. Para tal, realizou-se uma pesquisa qualitativa na qual foram entrevistados 12 participantes e os dados coletados foram analisados a partir do método de análise de conteúdo, na sua vertente categorial. Das entrevistas emergiram várias categorias de análise. Considerando o objetivo deste trabalho, serão apresentadas e discutidas as seguintes categorias: *dificuldade social como o ponto central; questões sensoriais; dificuldade de linguagem e ingenuidade; rigidez/comportamento repetitivos; e facilidades/vantagens que o autismo trouxe*. Observou-se que a dificuldade social se manteve como algo central, mesmo em um grupo de adultos com quadros de autismo leve, assim como as queixas sensoriais, a dificuldade para o entendimento de linguagem figurada e a rigidez. O hiperfoco atencional é citado como algo positivo e que traz facilidade para o dia a dia. Concluiu-se que as características descritas acima se mostram muito presentes na vida deste grupo de autistas, com significativo prejuízo para o dia a dia.

Palavras-chave: Transtorno do Espectro do Autismo; Adulto; Experiência de Vida.

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Originally described as a childhood disorder and referred to as Infantile Autism until 1987, when the revised edition of the DSM III (DSM III-R, APA 1987) was released, the concept has significantly changed over the past decades: from being classified as a disease, it became a disorder, and more recently, articles have referred to it as a condition (Bottema-Beutel, Kapp, Lester, Sasson & Hand, 2021); from something restricted to childhood, it became known as autism spectrum disorder (ASD), with no age limit and with different levels of support. Talking about autism in adults is a recent phenomenon, as noted by Howlin and Moss (2012).

An autistic adult may be someone who received a diagnosis during childhood or someone who only became aware of the diagnosis after adolescence. Conceptually, it is now understood that the social difficulties associated with autism may become more noticeable later in life, when social demands exceed the person's skill level, or when they are masked by possible learning strategies developed throughout life (APA, 2013).

Late diagnoses of autism occur in individuals with more subtle presentations, and the reverse is also true: more pronounced presentations tend to lead to earlier diagnoses (Mandell, Novak & Zubritsky, 2005). DePape and Lindsay (2016) estimated that the prevalence of autism in adults over the age of 18 is 2.21% of the population, making it a common condition.

Although the mental health diagnostic manuals — DSM (Diagnostic and Statistical Manual of Mental Disorders, now in its 5th edition) and ICD (International Classification of Diseases, currently in its 11th edition) — do not include specific criteria for diagnosing autism in adults, some guidelines have already been proposed. The UK National Institute of Health and Care Excellence (2012) suggests that a diagnostic assessment for autism in adults should be conducted if at least one of the following indicators is present: difficulty initiating or sustaining a social relationship, difficulty obtaining or maintaining employment, a history of neurodevelopmental issues, or a past (or current) need for evaluation in a mental health service. It is worth noting that there are also scales designed to identify traits of autism, such as the Autism Spectrum Quotient for adults (Booth et al., 2013), the Ritvo Autism Asperger Diagnostic Scale-Revised – RAADS-R (Ritvo et al., 2010), or ADOS Module 4 (Lord et al., 2000). It is important to emphasize that, regardless of the method of assessment (qualitative or quantitative), it is essential to understand whether there is functional impairment and what the person's developmental history was like, preferably with information from other family members, as Lai & Baron-Cohen (2015) point out.

Another challenge is finding professionals who can diagnose and follow up with autistic adults in the mental health or clinical fields. The very assessment of whether or not there is functional impairment requires training and specific knowledge. Anderson & Butt (2018), in a qualitative study conducted in the United States with autistic individuals (ages 19 to 31) and their families, reported great difficulty in accessing specialized services. Similar findings were reported in England (Crane, Adams, Harper, Welch & Pellicano, 2019): interviews with 130 autistic youths revealed severe difficulty accessing mental health services.

Another important shift has occurred in scientific production: previous literature was based on data obtained from reports by parents or caregivers; Today, there is growing understanding of the topic through accounts from autistic individuals themselves. These narratives have been creating an alternative perspective, integrating autism with personal identity and focusing on the understanding of experiences, challenges, difficulties, and strengths, as highlighted by Sinclair (2013).

The autobiographical accounts of autistic adults are fundamental to a more complete and humanized understanding of the disorder, something that can be overlooked in quantitative studies (Mason, 2021). According to Mathur and Valerius (2023), the views of the foremost experts on the subject — autistic adults themselves — make it possible to explore their real experiences and needs more deeply, to value their characteristics and identity, and to allow for the development of more effective services that are better aligned with their demands. In light of this context, and the scarcity of research in Brazil on autism in adults, this study — part of a broader research project on the topic — aims to investigate the life experience narratives, both past and present, of Brazilian individuals who received an autism diagnosis after the age of 18.

Method

A field study was conducted using a qualitative methodology, based on semi-structured interviews with a group of 12 participants who received an autism diagnosis after the age of 18 and who had approached the researcher on a spontaneous basis (seeking care at a private practice) in search of an autism diagnosis. The interviews were recorded, transcribed, and analyzed using the method of content analysis, in its categorical form — in which content is organized and classified based on similarities and affinities into thematic categories.

Participants

Twelve individuals participated in this study, 6 of each biological sex, all from the middle strata of the population (according to Gilberto Velho, 1994, considering their level of education, access to private healthcare, and lifestyle). All had received a diagnosis of autism spectrum disorder (ASD) according to the DSM-5 (APA, 2013) after the age of 18 and at least 12 months prior to the study.

The participant group was composed of individuals who sought the researcher (a medical doctor specializing in autism with extensive experience in the field) on a spontaneous basis for a private consultation, with the objective of determining whether they met diagnostic criteria for autism, between 2006 and 2022. All patients who sought evaluation, were over the age of 18, and, after undergoing a qualitative clinical assessment using the official diagnostic criteria from the ICD-10 and DSM-5, met the criteria for autism spectrum disorder, were included in the study.

The qualitative clinical evaluation consisted of a detailed anamnesis, including data about developmental history from childhood (with the participation of family members when possible), observation of verbal and non-verbal linguistic abilities (such as conversational skills, narrative structure, comprehension of questions, use and understanding of symbolic language — that is, understanding of jokes and popular sayings), and the quality of eye contact. All participants signed the informed consent form.

Participants ranged in age from 21 to 44 years. Eleven of the twelve interviewees had attended higher education (six with completed degrees and five currently enrolled), and one had completed secondary education (technical course). Individuals with intellectual disability, confirmed by clinical evaluation according to the DSM-5, were excluded from the sample. This exclusion aimed to ensure that participants had the cognitive and linguistic abilities necessary to comprehend and respond to the interview questions.

All participants received their ASD diagnosis after a single, extended medical consultation (90 minutes), supplemented by written or oral reports from family members. The consultation was conducted by the researcher herself, in person for eight cases, and remotely in four cases (due to the COVID-19 pandemic). Among the participants, some had only undergone the diagnostic consultation, while others were in ongoing medical follow-up.

To present the results while preserving participants' anonymity, they were referred to as P1 through P12. Table 1 provides their sociobiographical data.

Table 1 - Sociobiographical Data of the Participants

	Biological Sex	Occupation at Time of Interview	Age at Interview (years)	Age at Diagnosis	Time between Diagnosis and Interview	Marital Status
P1	F	University Student – Social Sciences	21	20	1 year e 1 month	Single (lives with girlfriend)
P2	F	Biologist	24	22	2 years	Single
P3	F	University Student – Visual Arts	27	23	4 years	Single
P4	F	University Student – Psychology	24	22	2 years	Single
P5	F	Child Educator	41	40	1 year	Single
P6	F	Journalist	26	25	1 year	Single
P7	M	University Professor	41	33	9 years	Single
P8	M	University Student – Fine Arts	24	18	5 years	Single
P9	M	Administrator	41	23	18 years	Single
P10	M	Metallurgist	44	42	1 year e 6 months	Married
P11	M	Information Technologist	33	18	15 years	Single
P12	M	University Student - Literature	21	18	3 years e 3 months	Single

Instruments

A semi-structured interview script was used, with emphasis on the following thematic axes: life history, feelings and changes after the autism diagnosis, and identity construction. In addition to the interview, sociodemographic data were collected, as described in Table 1.

Procedures

Participants were contacted by the researcher via WhatsApp, with an invitation to take part in the study, along with a brief explanation of the topic and the remote format of the interviews. The interviews were conducted using the Zoom platform and were recorded for later transcription. Transcriptions were done verbatim, without corrections to sentence structure, and pauses were marked with ellipses. One interviewee (P12) reported discomfort with the "live" format and asked about the possibility of responding to the script in writing, a request that was accommodated.

The research project was approved by the Ethics Committee of the institution where the study was developed (SGOC 462687), and participants agreed to the procedure by signing an Informed Consent Form.

The data collected were processed using the method of content analysis, in its categorical form, as proposed by Bardin (2016). Content analysis is a methodological approach used to study the content of different types of material, such as texts, images, audio, and video. The categorical approach proposed by the author is one of the analysis techniques and focuses on organizing and classifying the content into thematic categories or concepts based on similarities and affinities. This was the path followed in the analysis of the material collected in this study: it began with a "floating reading" of the interview responses, without preconceptions, followed by the identification of recurring themes, the construction of thematic categories, and a deeper understanding of the underlying meaning of the analyzed content.

Analysis and Discussion of the Results

Various categories emerged from the analysis of the interviews. Considering the objective of this study — to understand the participants' life experience narratives — the following categories will be presented and discussed: social difficulty as the central point;

sensory issues; language difficulty and naivety; rigidity/repetitive behaviors; and abilities/advantages brought by autism.

Given that there is no consensus in the literature on the best way to refer to this group, this study will use interchangeably the terms: autistic person, person with autism, or simply autistic.

Social Difficulty as the Central Point

The search for an understanding of what is essential or specific to ASD is not recent. Kanner (1943), in a classic article, argued that social deficit is a primary feature of autism, although there is ambiguity regarding the cause of this deficit (is it a constitutional biological defect or a consequence of parental behavior?). Subsequent studies placed social deficits as secondary to impairments in perception, language, and cognition (Damasio & Maurer, 1978). Other influential authors (Rutter, 1983; Fein, Pennington, Markowitz, Braverman & Waterhouse, 1986), in the 1980s, returned to the assertion that in autism, the social and affective deficit is primary and specific, not secondary to cognitive impairments.

Beyond this academic discussion, in many of the narratives from participants in this study, the social aspect is referred to as the central point of their difficulties.

> The main problem was social difficulty, which had even been considered a phobia at some point, by other professionals... Especially regarding contact with the public or people outside of very close family members. I always associated [the traits] with shyness, even though I had a feeling it was “weird.” Or at the very least, different from other young people. At summer camps or courses, I was quite isolated and often mocked for some mannerism that drew attention. To this day, I have a lot of trouble socializing. Especially talking and engaging in fast-paced conversations. (P12)
>
> [still a difficulty today] Mainly social difficulties. I’m not dating or anything like that. (P9)
>
> [the greatest difficulty is] Behavior. I still can't go to places with lots of people, I can’t express my feelings, and that is really hard. My birthday is the worst day of my life, because people want to hug me and I don’t know how to retribute the same feeling, which they bring with such joy. Sometimes a friend... A few days ago, a coworker I hadn’t seen in 10 years saw me and gave me such a big smile... made that gesture... And I just said “Hi, how are you?” So this is difficult for me — it seemed like I was brushing him off, but that’s not it. I just don’t know how to reciprocate that, to convey the same thing he felt, even though I felt it too. I loved seeing him again, but I don’t know how to show it. It’s really hard for me. (P10)

These narratives describe the discomfort and tension experienced by these autistic individuals in their relationships with others, often with a tendency to blame themselves for their inability to meet the expectations of everyday social interaction. The recognition of these "failures" shapes the self-perception as someone “weird,” incapable of maintaining conversations or returning affection. The literature describes well that social difficulties may result from different impairments — either in isolation or combined — such as difficulty reading facial expressions (Yeung, 2022), poor understanding or use of verbal language, misunderstanding of nonverbal cues (Vogindroukas, Stankova, Chelas & Proedrou, 2022), lack of social experience (DePape et al., 2016), difficulty understanding (or feeling) another's perspective (Happé, 2015), and especially the challenge of integrating all of these aspects in real time during social interaction. Many late-diagnosed autistic individuals report that, although they didn't know exactly what was "wrong" with them, they always knew they were different (Leedham, Thompson, Smith & Freeth, 2020) — odd or strange — which is also well illustrated in the accounts from this study's participants:

> I always felt different from other people, and words like "weird," "different" were always used to describe me. Clearly I wasn't fighting on the same line as everyone else, but I didn't know if there was something wrong or if maybe it was just my personality. (P4)
>
> I wanted to feel less "weird." I use that term because it was what my older brother always used. He was the first to notice that I was socially awkward, and even though the term may carry a pejorative tone, I don't see it that way. Especially because I agree that, yes, I do have some odd traits and very unusual and weird moments. (P12)

The statements above point to experiences in which the individual perceives themselves as odd or strange, while simultaneously considering the possibility that these traits might be part of their essence or personality. In the interviews conducted for this study, a recurring tension was noted: whether to embrace one's peculiarities or to see them as something "out of place" that needs to be improved or corrected.

Even considering the three core diagnostic indicators for autism (persistent deficits in communication, social interaction, and restricted/repetitive patterns of behavior), in autobiographical narratives, social difficulty is often foregrounded. Temple Grandin (2020), in her book with autistic voices about being different — not worse — presents fourteen stories of autistic adults who became professionals and autonomous. Even within this group, which does not represent the majority trajectory of autistic individuals, persistent social difficulty is a common theme. Also frequently reported are bullying, loneliness, and the absence of "a shoulder to cry on," as stated by a 51-year-old veterinarian interviewed in the book.

Park et al. (2020) conducted a meta-analysis on the prevalence of bullying among students with autism, reaching 67% in this population. The risk of being bullied is significantly higher for autistic students than for those with typical development or other disabilities, and the degree of social and communication deficits is directly related to this vulnerability.

The experience of bullying and the social pointing-out (with judgment) of behaviors that diverge from the norm are often felt as painful, evoking sadness, worthlessness, and fear, as clearly identified in the following statements:

> I couldn’t notice or understand why I was so different from the others. And people kept saying I was dumb and a bunch of nonsense. At school, people noticed I was different and, instead of thinking “well, she’s just different,” no — they bashed my head in, and it hurt me a lot, I felt very different from everyone else. (P2)
>
> And people wanted to do things that, even today, are things I don’t want to do. They had this teenage maturity. It started to show in my classmates’ behavior and distanced them from me. Then I started to get a lot of bullying. Bullying because I forgot to shave my legs... Bullying because... yeah... bullying for everything. I was also kind of chubby, so there was the usual bullying for that, I wore glasses... And I closed myself off more and more into my fantasy world. And people didn’t want to hear about my fantasy world anymore. So I withdrew deeply into it. And I started reading a lot, I got addicted to books. I only wanted to read. I took books to school and kept reading. I did my homework super quickly, because I’ve always been very smart. I’d finish homework in 2 minutes and read the rest of the class. And even in college, I was bullied. Because I didn’t go to parties, didn’t drink. So I was bullied all around. I still don’t drink, still don’t go to parties. (P6)
>
> I kept those ghosts in my head and I had been bullied in high school, in my second and third years, and I was afraid of approaching people. Afraid of interacting... I think I was scared of being bullied again, so I had some difficulty expressing myself with people at college. And with that thought, it made those ghosts even worse. So, it was a lot of negative weight, really. (P9)

These narratives show how the experience of bullying seeps into the structure of the individual, affects their confidence, and amplifies a preexisting sense of inadequacy and vulnerability. Such experiences deepen social withdrawal, negative thoughts, and the search for inner alternative worlds — such as books. The suffering reported by participants points to a constant perception of being under threat, in a hostile and unpredictable world. Aligned with this picture, the high frequency of comorbid mental disorders among autistic people is well documented, with lifetime prevalence reaching 42% for anxiety disorders and 37% for depression (Hollocks, Lerh, Magiati, Meiser-Stedman & Brugha, 2019). This may reflect a biological co-occurrence between autism and psychiatric disorders or represent the psychological toll of living in a world without the same social interpretative skills as others — often accompanied by sensory processing difficulties and psychic rigidity. The perception of difference, especially when not yet named as a diagnosis, carries with it the anguish of human behavioral subjectivity, where any obvious difficulty can easily be interpreted as a choice or a lack of effort. Suffering, anxiety, and depression are heavily present in the participants’ accounts:

> I was on medication but never got better. I was always unwell, with a lot of anxiety... it felt like I was always stuck. (P1)
>
> Even though I had good grades at university, I fell into a deep depression. I didn’t want to live anymore, I saw no future for myself. It didn’t come out of nowhere, actually. If I think about it, I’ve probably had that thought since I was 12, thinking that way. But at 23, I hit my limit. (P6)

> Very painful [life before the diagnosis]. Painful in the sense of not understanding anything. (P10)

Starting from the last statement, it's possible that the lack of understanding about the reasons behind one's poor social interaction is an aggravating factor. In other words, understanding one's own difficulties from a medical perspective may enable a new kind of relationship with oneself, one with greater acceptance.

In this context, a reflection arises: to what extent could an early diagnosis of autism, along with a valid explanation for one's difficulties (as well as the possibility of therapeutic measures), relieve psychological distress, reduce vulnerability, and even prevent anxiety and depression?

Chou, Wang, Hsiao, Hu, and Yen (2020) showed that high-functioning autistic adolescents who were victims of bullying had more severe depression and anxiety than autistic adolescents who had not suffered such violence. As previously mentioned, Park et al. (2020) emphasized that deficits in social interaction and communication are directly linked to bullying in autistic individuals, making it clear that prevention and intervention in social skills are necessary to improve well-being and reduce psychiatric comorbidities.

Sensory Issues

Although not exclusive to autism, issues related to sensory perception have gained increasing attention. In the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; APA, 2013), sensory processing peculiarities were included in the diagnostic criteria for autism spectrum disorder.

An important article on the topic was published in *Nature Reviews Neuroscience* (Robertson & Baron-Cohen, 2017), recognizing sensory symptoms as early and specific to autism, and suggesting that they may help explain, at least in part, later deficits in social communication. Atypical sensory processing could lead to avoidance of everyday situations, with consequent impacts on social and communication development.

Described by autistic individuals themselves as either heightened perception (*sensory hypersensitivity*) or reduced perception (*sensory hyposensitivity*) to external stimuli, sensory issues are highly prevalent in this group and bring daily discomfort (O'Neill & Jones, 1997). Kirby et al. (2022), in a large population study with autistic children, showed that 74% had difficulties in sensory processing. In the adult population, data is much scarcer compared to children. Tavassoli et al. (2014) also reported the presence of sensory hypersensitivity in autistic adults, compared to a non-autistic control group, with symptoms across multiple sensory domains (visual, auditory, tactile, olfactory, gustatory, and proprioceptive). As previously discussed, difficulties in reading and understanding the social world are already a major challenge for autistic individuals. This scenario can be strongly aggravated by an overwhelming influx of "misprocessed" sensory stimuli, which cause discomfort and often lead to an urgent need to modulate external stimuli — an attempt to find calm and "homeostasis" within the world they inhabit. This discomfort was clearly observed in the participants' accounts:

> I have sensory issues with hearing — I hear things very loudly. I use noise-canceling headphones a lot when I'm out on the street. I didn't used to like going outside. I once nearly passed out on the street during Carnival. I almost fainted — that was the level of it. Nowadays I use my ear protectors, right? To go out. And it's great. I feel a big difference. No, it doesn't fix everything 100%, but it helps. I have my noise-canceling gear, I use a few tactics, and hearing is one of them, right? Let me see… I also have issues with being touched by people, mainly. I can't… I struggle. My boyfriend and I only held hands after a month into the relationship. Nowadays we kiss, not with tongue, more like pecks. We take things slowly because we both have difficulty with that, you know? Which is great. I love that he's autistic too because we can go at our own pace and that's perfect, right? But yes, I do have difficulties. Sometimes people like to hug and that bothers me, you know? (P6)

> One thing that was really strong for me was realizing that I'm very sensitive to sound and that I could cover my ears, for example, when there was a loud noise. And then I found out that no, actually other people don't get bothered like I do, so I bought noise-reducing headphones, and that's how my life changed. (P4)

> I had a lot of issues with food, didn't like eating just anything, was very picky (…) I had a lot of trouble with the feeling of my feet on the floor. It made me uncomfortable, I just couldn't handle it. (P10)

> My biggest problem and discomfort is always with physical contact. Hugs, handshakes, etc. (P12)

It's not hard to understand how the sensory difficulties described above impact daily life. If something as simple as touching the floor with one's feet is experienced as intolerable, its continued impact on a person's life should not be underestimated. Atypical sensory processing alters how a person experiences the world around them, directly affecting their subjective perception of reality. Specifically considering autism, sensory stimuli are often perceived as painful and unmodulated, affecting decisions, relationships, and leaving the individual in a constant state of alert. Crane, Goddard, and Pring (2009) assessed the prevalence of sensory issues in a population of adults who received a late autism diagnosis, finding extreme discomfort in 94.44% of the sample.

Although there are now numerous publications about sensory issues in ASD, it is essential to conduct prospective studies involving autistic individuals themselves, considering the different levels within the spectrum, to better understand the natural history of these issues. Furthermore, it is urgent and necessary to investigate the extent to which therapeutic interventions (such as occupational therapy) can influence the progression of sensory issues in autism.

Understanding sensory discomfort through the narratives of autistic people is fundamental for building social practices that respect their particular way of perceiving and inhabiting the world.

Language Difficulties and Naivety

Difficulties in the domain of language (both verbal and nonverbal) are well documented in cases of ASD (Mousinho, Schmid, Mesquita & Pereira, 2021), and can vary widely in terms of severity. Considered a necessary indicator for the diagnosis of autism, language impairment gained particular emphasis in the *International Classification of Diseases*, 11th Revision (WHO, 2021), which includes five subcategories based on the presence or absence of functional language and the presence or absence of intellectual disability.

Language difficulties in ASD are not limited to whether the individual "speaks or doesn’t speak." In the literature, impairments are described in terms of *form* (morphology, syntax, and phonology), *content* (semantics), and *use* (pragmatic level) of language (Mousinho et al., 2021).

Today, impairments in social communication are considered a core feature of autism. They refer to the ability to appropriately use communication skills — including verbal language, nonverbal cues, social reciprocity, and understanding of social signals — to initiate and maintain interactions with others. Even individuals who use speech functionally may present with social communication difficulties that result in significant impairments (Vogindroukas et al., 2022). In practice, deficits in social communication in mild autism may manifest as difficulty in understanding language subtleties, abstract questions, irony, jokes, with a tendency toward literal interpretation and problems with inference. Expressively, it is common to find difficulty adjusting speech to the listener (e.g., interest, level of prior knowledge, age), impairments in turn-taking (who speaks, when, and how to switch speakers), altered prosody, and problems with the selection, maintenance, and management of conversation topics (Amato, 2022). These difficulties are often aggravated by impairments in basic social skills, such as sustaining eye contact and poor shared attention (Vogindroukas et al., 2022).

The participant sample in this study does not include any nonverbal autistic individuals (11 out of 12 interviewees had completed or ongoing higher education). Thus, this is a group of individuals with mild autism (Level 1 support, according to DSM-5), who are able to verbally describe their language difficulties as well as the impact these difficulties have on daily functioning — especially social — as seen below:

> I don't have the ability to understand people very well. I think that's the biggest one. People talk to me, and I'm left wondering whether they actually mean what they're saying. For me, it's really confusing. Sometimes, I even wanted to record all my conversations and send them to my mom so she could translate them for me, you know? Sometimes, at work, I used to send my boss's voice messages — this was at a previous job — to my mom. And I'd ask, "Does she really mean what I think she means?" And my mom would say, "No, she means something else." That happened, you know? Like, "No, that's not what you're thinking. She's saying something different." And for me, it's really difficult because I'd like to always understand what people are trying to tell me, but sometimes, what I think they're saying isn't what they mean — it's all very confusing. I can't pick up on tone of voice or anything, you know? It's harder for me to identify. I think that's the worst thing because it makes me confused and unsure if I did something right or wrong, which brings me insecurity and anxiety. (P6)

> I feel that a conversation between two "normal" people flows better than between me and a normal person. I don't know how to put it into words, but I feel like I don't quite grasp the idea of the exchange of ideas and constant speech. The "timing." (P12)

> My biggest difficulty today is with malice — people take advantage of me, and I don't even notice. I need someone else to see what's going on. There's also a thing, which I don't think is that serious, where I can't always understand irony. (P2)

The above accounts reveal the vulnerability experienced by these autistic individuals in the realm of language. The constant doubt about whether one has understood correctly, the insecurity about how to maintain a conversation, and the difficulty in grasping the subtext (ironies, intentions) render the act of communication tense, threatening, and anxiety-provoking. As previously discussed, social difficulties may stem from various impairments, alone or in combination. Communication impairments compound other difficulties (such as reading facial expressions, lack of social experience, and theory of mind deficits), creating a context of vulnerability and naivety (Trundle, Jones, Ropar & Egan, 2023). It is worth noting that social naivety impairs not only the comprehension of information and situations, but also expression and behavior in everyday social interaction, as the following statements illustrate:

> Sincerity — I'm very sincere about things. But you have to be aware of what you're saying. At work, people notice this. Even my supervisor says, "Even though you're right in what you're saying, I'm your supervisor — you need to be careful." (P10)

> I know how to start conversations and speak calmly. But my real difficulty is reading between the lines... you know, that stuff. The bigger issue is breaking routine. Because I have no filter, and when I say something without a filter, I don't feel embarrassed. So how can I explain this? It has an impact, sure. But I don't feel shame or guilt about being unfiltered. So, for me, it's normal. (P1)

> I've had to work on it a lot, but it's still hard to look people in the eye. Sometimes I look away. I even read a book to better understand what people are trying to say — *The Body Speaks*. There are things I try to stop doing, but I'm all or nothing. This issue of being overly talkative is a problem. (P5)

The experience of living without knowing whether one has understood correctly, whether one has communicated without being rude, whether one has “read” what the other person meant, or whether one is being deceived — this is part of the daily life of autistic people. A state of constant vigilance sets in: what is said, what is heard, where one looks, who is looking, what gestures are used. In this context, daily stress becomes constant, with high rates of anxiety and depression, as previously reported. As Temple Grandin once told Oliver Sacks (1995), she feels like an “Anthropologist on Mars,” trying to understand the behaviors, feelings, and expressions of the so-called “normals” of the world — and the difficulty is mutual: she is strange to the “normals,” and they are strange to her. Thus, many autistic individuals find themselves immersed in a social culture they do not master, which leads to frequent misunderstandings and suffering.

Rigidity and Repetitive Behaviors

Conceptually, repetitive behaviors are considered essential for the diagnosis of autism (APA, 2013). In the literature, we find sources in which data are collected from parents, caregivers, or teachers. More recently, however, autobiographical accounts and qualitative studies with autistic individuals themselves have emerged, bringing a new perspective to research in this area.

With the ambivalence between understanding these behaviors as part of one’s essence or as something atypical and to be eliminated, people with autism often return to this topic when speaking about their experiences. Given the limited benefits of pharmacological treatments (Zhou et al., 2021), understanding the nature of rigid and repetitive behaviors becomes indispensable in autism.

Martínez-González, Cervin & Piqueras (2022) studied the relationship between repetitive behaviors and difficulties in social communication, showing that autistic individuals with greater impairments in social communication skills exhibit more repetitive behaviors. Handen et al. (2018), in collaboration with the Autism and Developmental Disorders Inpatient Research Collaborative (ADDIRC), demonstrated a link between repetitive and stereotyped behaviors and self-injurious behaviors. These studies offer a negative perspective on rigidity and repetitive behaviors, which is controversial, since such traits are part of the autistic essence, as can be observed in the statements below:

> One difficulty that has marked my life from the beginning is the difficulty with changes in routine and changes in general. I’m very rigid. (P1)

> I think I'm a very rigid person with myself. I love following rules, and I feel like I created very specific rules for myself. And if I didn't follow those rules, I'd catch myself, you know? I'd beat myself up, really. (P4)

> I only drink from the same mug, which must be about 15 years old... it's a green one. No one touches it. (...) "Please don't touch my mug, I'll wash it." So when I started working and they told me I'd have to follow standards, that was a huge relief for me because I memorize those, and my brain gets used to it. (P10)

In the statements above, we can see that rigidity and repetitive behaviors are part of who these individuals are — and that such traits can even bring adaptive advantages. Lai and Baron-Cohen (2015), in a key article on comorbidities and differential diagnoses in autistic adults, argue for the importance of distinguishing between obsessive-compulsive behaviors from obsessive-compulsive disorder (OCD). Generally, in OCD, the behavior brings discomfort to the individual, accompanied by self-criticism and a desire to eliminate the symptom (*ego-dystonic* pattern). In contrast, in ASD, repetitive and obsessive behaviors are often pleasurable (*ego-syntonic* pattern) and less severe than in OCD (Russell et al., 2005). Zhang, Roy, and Feng (2022) support these findings, arguing that repetitive behaviors bring pleasure and anxiety relief to autistic individuals.

Even though it is possible for someone to receive both ASD and OCD diagnoses simultaneously (Buck et al., 2014), it is important that, before labeling a behavior as pathological, a clinical evaluation should consider the individual's life context — whether there is complaint or impairment, or even benefit or relief.

Given the previously cited difficulties (social, sensory, and language-related), it is possible that repetitive behaviors offer comfort to people who live daily with the fear of the unpredictable, the pain of misunderstanding, and the distress caused by unexpected sensory stimuli. Rigidity emerges as an attempt to control the variables of the world, to predict and modulate the avalanche of complex social situations in everyday life.

To quote Temple Grandin once more: "the world needs all kinds of minds." If rigid and repetitive behavior does not bring harm or suffering to the autistic person, it should be viewed as a form of diversity — one that, at times, brings ease and benefit.

Ease and Advantages Brought by Autism

Medical diagnoses focus on what is not working or what is missing for a person to be considered "normal" — that is, similar to the average of the population. From a behavioral point of view, diagnostic criteria focus on weaknesses, symptoms, and atypical behaviors.

Attwood and Gray (1999), in a humorous approach, wrote an article creating diagnostic criteria focused on strengths (powers) associated with Asperger's syndrome (the term then used for milder forms of autism, i.e., without delays in language acquisition). They named these traits *ASPIE* — not as a diagnosis, but as a discovered talent. Drawing a parallel with the autism diagnostic criteria of the time, the authors rewrote the deficits as qualities. For example, in the case of the DSM-IV (APA, 1994), which described "failure to develop peer relationships," ASPIEs were said to show "social relationships marked by absolute loyalty, without social prejudice and with the ability to listen without judgment" — a different way of describing the same individuals, but focused on their strengths.

Following the *ASPIE* concept and the perspective that human characteristics are diverse and full of possibilities, it is important to consider that certain peculiarities of autism can bring advantages or ease in specific contexts. This point was present in the participants' accounts, as seen below:

> The hyperfocuses, for sure [are an asset]. (...) Usually, when I have hyperfocus, I get really excited and very intense about what I'm hyperfocused on, and it brings a very, very good feeling. And I like having hyperfocuses, I think it's wonderful, and we can also learn really cool things. (...) Because it's like being on drugs — your brain gets super stimulated. It brings a lot of pleasure, a lot of happiness... talking, reading, listening, and discussing that topic. And some hyperfocuses are really positive in life. I had a hyperfocus on Spanish and I was able to learn a lot. (P1)
>
> Hyperfocus for me is a good thing; it gives me a lot of concentration, a lot of willpower because of the challenges — learning something I enjoy and dedicating myself to it a lot. I think that helps a lot. (P10)

The statements above make it clear that many participants see their hyperfocuses as positive. A source of pleasure and enjoyment, hyperfocus on topics of interest allows them to learn new things, entertain themselves, stand out, and feel fulfilled — a gift amid the pressures and difficulties of daily life.

Curiously, although the participants viewed their attentional traits as strengths, the medical literature once again frames them as a "deficit." It is stated that 20–80% of autistic individuals exhibit traits of Attention Deficit Hyperactivity Disorder (ADHD), and that 28% meet criteria for both disorders (Lai et al., 2019). This negative framing was already present in the classic study by Lovaas et al. (1971), where *stimulus overselectivity* was first described as a pattern of hyperfocused attention in autistic children. The authors hypothesized that stimulus overselectivity contributed to difficulty in learning by imitation and in developing new behaviors, describing this trait as maladaptive and harmful.

In contrast, in 1975, Hungarian-American psychologist Mihaly Csikszentmihalyi published a book presenting the results of his research with people without medical diagnoses, describing a mental state of full attention he called *flow*. Interviewees (athletes, musicians, artists, surgeons, chess players, etc.) described *flow* as complete immersion in what they were doing, with full attention to the task, loss of the sense of time and self-awareness, and absence of concern about outcomes. The experience can be intrinsically rewarding (*autotelic*), with pleasure arising from the activity itself, not from any external result. This *flow* state closely resembles P1's description of hyperfocus. Ashinoff and Abu-Akel (2021) define hyperfocus as a state of complete immersion in a task, in which the person ignores everything else around them — potentially leading to a *flow* state. As is often the case in the medical literature, hyperfocus is framed as a symptom, while *flow* is regarded as something positive.

Rapaport et al. (2023) conducted a qualitative study on the experience of *flow* in autistic individuals. The article clearly describes the difficulty in finding a balance between the pleasure of functioning in a state of hyperfocus and the other demands of life (including self-care), since participants reported significant difficulty in interrupting the intense and pleasurable activity they were engaged in. Part of the pleasure, they noted, was the feeling that during hyperfocus, they could be themselves — without the effort of trying to "fit" into the outside world. McDonnell & Damian (2014) also acknowledged that repetitive behaviors in autistic individuals may lead to a *flow* state, producing positive physical and psychological effects associated with a sense of fulfillment.

In this context, therapeutic programs that aim to reduce or extinguish hyperfocus may deprive autistic individuals of *flow* states, which could reduce well-being and worsen mental health — further reinforcing the importance of listening to autistic individuals about their needs. On the other hand, interventions that focus on achieving balance between time spent in hyperfocus and the demands of daily life may be greatly beneficial.

Continuing with the understanding of the strengths and advantages attributed to autism by participants, some referred to a particular way of thinking or reasoning, associated with hyperfocus, which they felt set them apart from others, as illustrated below:

> [Advantage of autism] Oh, maybe a more analytical way of thinking... but I don't know if it's really worth it compared to everything else. Hyperfocus, perfectionism, right? Dedication to work in a way, right? The desire to learn, right? (P8)

> Yes. I think that's an asset, I think I have better intellectual, cognitive reasoning... That, to me, is an advantage, right? Something associated with autism. Anyway, I do think I have better reasoning than other people. I think writing a doctoral thesis, for example, was something I did through hyperfocus — sitting down, staying focused... It wasn't something bad or exhausting. I actually enjoyed writing my thesis. (P7)

These statements highlight the participants' perception that they function in the world in a particular way. The experience of writing a thesis, far from being a burden, is described as a pleasurable and spontaneous process — revealing an *autotelic* experience with full engagement. It is also noticeable that, although the interviewees are able to recognize strengths in themselves, they often show ambivalence or doubt. It is possible that the many negative experiences accumulated throughout life have led them to question the value of their own qualities.

In the literature, other autobiographical studies also mention interest-based hyperfocus. Russell et al. (2019) interviewed 24 autistic adults to understand what they considered to be strengths or assets related to autism. Among the qualities identified were hyperfocus (cited by all participants), perseverance, attention to detail, and a particular way of processing information. The authors affirm that these traits can represent either an advantage or a disadvantage depending on the context and the person's ability to control and adapt them in daily life. Certainly, the value of the experience lies not only in its functionality but also in the way it is subjectively experienced and given meaning by the individual.

Final Considerations

This study investigated the life experiences of Brazilian adults who received an autism diagnosis after the age of 18. Although the group was small, highly educated, and demonstrated a good level of autonomy, the findings revealed the presence of various challenges that significantly impact daily life. Difficulties in social skills, fragility in understanding and using figurative language, sensory discomfort, anxiety, and depression were shown to be strongly present in the lives of these individuals.

Despite the challenges mentioned, the study also highlighted the participants' perceptions of qualities and strengths they attribute to autism. These findings demonstrate the importance of listening to and learning from autistic individuals themselves, as the perspective of those who live with this condition is fundamental and indispensable for a better understanding of their priorities and needs.

Awareness of both the difficulties and strengths present in the daily lives of autistic adults allows for the development of more realistic and effective therapeutic strategies — based on the demands and voices of the individuals themselves. In this regard, it is crucial to reflect on how to offer quality care for autistic adults in Brazil, with specialized services and trained professionals, especially within the public health system.

Finally, considering that even autistic individuals with a high level of autonomy still identify social difficulties as a central issue, and suffer from vulnerability and naivety, it becomes essential to engage in discussions on how to address these issues, including the prevention of anxiety and depression. It is crucial that society as a whole be engaged in the task of giving voice to and promoting the well-being of autistic people.

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