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It's not that I'm "abnormal". Social and emotional experiences of women with autism spectrum (AS) related to the diagnosis in adulthood

Abstract

The paper is part of a research project related to the preparation of the master's thesis of Magdalena Wala, a fifth-year student of Special Education, prepared under the scientific supervision of Dr. Sabina Pawlik. The research concerns the social and emotional experiences of women diagnosed as late as in adulthood. Compared to men, women are more likely to remain undiagnosed in childhood, thus belonging to the so-called "lost generation", i.e. people who are deprived of the opportunity to be diagnosed in childhood. One of the reasons is that women with autism spectrum (AS) have a different behavioral pattern (female autism phenotype) than men and the established diagnostic practices are focused on the basic characteristics of AS that were historically established based on the symptoms in men. The aim of the research was to learn about the social and emotional experiences of women with AS who were diagnosed in adulthood. It was associated with women's experiences before the diagnosis (related to the diagnostic process itself) and experiences after the diagnosis. The research found that women with AS in adulthood saw the value of the diagnosis in the form of increased self-knowledge, liberation from stigmatizing labels, finding their "tribe" and the possibility of receiving forms of support adequate to their condition.

Keywords: autism spectrum, female autism phenotype, diagnosis, biographical narrative interview.

Introduction

The paper presents the research on the social and emotional experiences of women with autism spectrum (AS) who were diagnosed as late as in adulthood. It is embedded in the neurodiversity paradigm, which treats autism not as a deficit or disorder but rather as an aspect of naturally occurring and desirable human variability and an essential element of identity (Straus, 2013).

Recently, there has been a significant increase in the prevalence of diagnosis of AS in adults since the diagnostic criteria have been expanded in such a way that people who may not have been diagnosed with AS in childhood or may have received a misdiagnosis can meet the current diagnostic criteria (Happé et al., 2016, p. 3469). These are usually individuals with mild symptoms who were born in the early 1990s and earlier, in whom less severe symptoms than those in autism were ignored due to the lack of diagnostic criteria (Asperger's Syndrome was included in the DSM-IV classification as late as in 1994) (Sławińska, 2014, p. 304). Women are particularly at risk of being undiagnosed or misdiagnosed. Lai and Baron-Cohen found that compared to men, women remain undiagnosed, thus belonging to the so-called "lost generation", i.e. people who were deprived of the opportunity to be diagnosed in childhood (2015).

Social and emotional functioning of women with AS

According to Sarah Hendrickx, author of *Women and girls with autism spectrum disorder: Understanding life experiences from early childhood to old age*, since the beginning of the formation of the modern concept of autism spectrum disorder, there has been a general belief that there are many more men than women among individuals with autism disorders (Hendrickx, 2015, p. 17). Currently, however, it is known that the prevalence of autism in this group of people is significantly higher than previously thought. In their research on the Scottish population, Rutherford et al. (2016, p. 630) indicated that the male-to-female ratio in childhood is 5.5 boys for one girl, while among adults it is only 1.8 men for one woman. According to Aleksandra Buchholz, this may indicate that women with AS are diagnosed much later than men (Buchholz, 2021, p. 63).

One of the reasons is that women with AS have a different behavioral pattern than men, and the established diagnostic practice is focused on the basic characteristics of AS that were historically established based on the symptoms in men. Therefore, they do not necessarily reflect the areas in which women with AS behave in a different manner than men. As a result, the diagnosis of autism in women is limited to the areas in which they are most similar to men. In turn, those who do not meet the criteria for behavioral disorders typical of

men with autism are likely to remain undiagnosed (Hull et al., 2017). Compared to men, women present with less rigid behaviors and intense interests (Duvekot et al., 2017, p. 647). Their interests are not perceived as traditionally related to AS in cultural, social, or developmental contexts (Rynkiewicz et al., 2018, p. 4). They are more interested in people and relationships than objects. Their passions are mostly associated with literature, art, languages, human or animal behavior, psychology, medicine, fashion, or cosmetics (Rynkiewicz et al., 2018, p. 12). They also present with lower deficits in play and often have better imagination and a rich world of fantasy (Rynkiewicz et al., 2018, p. 3). Compared to men, women with AS are less likely to experience externalizing behaviors such as hyperactivity, impulsivity, or behavioral problems, but they are more susceptible to internalizing problems, including anxiety, depression and eating disorders (Bargiela et al., 2016, p. 3282). According to Agnieszka Rynkiewicz et al., women are characterized by a significantly greater need to enter into social relationships, make friends and be among peers than boys or men (Rynkiewicz et al., 2018, p. 3), which is often associated with the need to adapt to social requirements and mask the difficulties that arise in interpersonal relationships (Lai & Baron-Cohen, 2015). For Hull et al. (2020, p. 306), masking is considered the primary axis of the female autism phenotype. It is a strategy aimed at hiding differences and minimizing the symptoms of autism (Buchholz, 2023, p. 187). Masking can also be an individual response to stigmatization associated with autism, resulting from the discrepancy between the natural being of people with autism and the requirements of the environment (Perry et al., 2022, p. 800). The non-obvious characteristics of female autism lead to the lack of diagnosis, or incorrect/insufficient diagnosis, thus hindering or distorting the development of normal identity understood as self-acceptance of being without the need to suppress natural aspirations (Buchholz, 2023, p. 188 after Corden et al., 2021). Women with AS who are not diagnosed do not have access to adequate forms of medical, psychological, or social support. To cope with difficulties, they use many exhausting defense mechanisms, generating low self-esteem and reducing their quality of life (Buchholz, 2021, p. 68).

Methodological note

The paper is part of a research project related to the preparation of the master's thesis of Magdalena Wala, a fifth-year student of Special Education, prepared under the scientific supervision of Dr. Sabina Pawlik. The aim was to learn about the social and emotional experiences of women with AS who were diagnosed in adulthood. The main research problem was associated with how the experiences of women with AS in adulthood were formed. Specific problems

were associated with women's experiences before the diagnosis (related to the diagnostic process) and experiences after the diagnosis.

Due to the aim and nature of the research problems, the study was embedded in a qualitative research approach (Flick, 2007). The basic technique for collecting empirical data was Fritz Schütze's autobiographical narrative interview focused on the life stories and experiences of the narrators. Its aim is to obtain from an individual an account of life or some selected stages (Kaźmierska, 2016, p. 61). In accordance with the assumptions of the technique, each interview consisted of 4 stages: the beginning of the interview, stimulation to tell the story/narration, questions (resulting from doubts arising in the narrative stage and theoretical questions, the list of which had been prepared in advance) and the end of the interview (Kaźmierska, 2016, pp. 63, 64).

The sampling was non-probabilistic. Due to the unfavorable social situation of potential narrators and their unwillingness to expose themselves, the participants were selected using the snowball method (Noy, 2008, p. 330). The target group was searched mainly through social networks. The inclusion criteria were age ≥ 18 years, biological female sex and a diagnosis of AS in adulthood. Eight narrative interviews were conducted with women aged 19 to 42.

Before the interview began, the narrators were given information about the study, including voluntary participation in the research and the possibility of withdrawing at any time. They were asked to give permission to record the interview. After the end of the interview, the recording was finished, and an informal part (casual conversation) took place as a normalizing function.

The interviews were recorded with a voice recorder and then the recordings were converted into text. The next step was the anonymization of the transcript, understood as the removal of specific information from the text (e.g. countries, towns, names, surnames, etc.) so that determining the identity of the participants was not possible. The research project was approved by the research ethics committee of the University of Silesia in Katowice (KEUS381/05.2023).

The analysis of the research material made it possible to divide it into parts, which were distinguished according to the chronological order of events in accordance with the stages of the narrators' lives. Another stage was related to coding, i.e. giving labels for assigning units of meaning to the information collected during the study (Konecki, 2005, p. 271).

Research results

Due to the specificity of the paper, it is impossible to present a complete analysis of the collected material. Therefore, we show only some selected fragments that we consider crucial in reflecting the social and emotional experiences of women with AS diagnosed in adulthood.

Table 1.
Main analytical categories

STAGE OF LIFE	CODES
Social and emotional experiences before diagnosis	The feeling of being weird Naughty child Education as a space of rejection and misunderstanding Building self-awareness Interest in AS Misdiagnoses
Social and emotional experiences related to the diagnosis process	Uncertainty of the diagnosis Impostor syndrome The course of diagnosis
Social and emotional experiences after the diagnosis	Affirmation and celebration Identity and belonging Explanation of the difficulties

Source: own materials

Social and emotional experiences before the diagnosis

Going back to their childhood, the narrators recalled that they often had a feeling of being different, strange, abnormal, or naughty. They felt incompatible with the surroundings. They needed to establish social relationships but could not understand why others did not reciprocate them. The comments included repetitive issues related to the experience of being misunderstood, rejected, and even encountering violence from relatives and peers. The text was literally translated from Polish into English so as not to distort the meaning. Therefore, some language inaccuracies and mistakes can be found.

> I noticed from the very beginning when I was a child that something was wrong with me… I could not establish any relationships with my peers. That is why I was bullied at school. (N5)

> My parents always had problems with me… I was naughty…I did not pay attention to them. I often did not listen to them when they talked to me, so they had to shout at me so that I could understand what was going on. I also often switched off, for example, as a child, because… I had my own world. (N1)

The participants did not have good memories of their school days. The school was not a safe place for them and education was associated with a strong fear. They experienced reluctance and even violence from other students. They also experienced a lack of understanding from teachers. Due to an intense fear of change and the lack of support from the environment, they decided to stay in an unfavorable environment.

I wanted to escape from the elementary school. I was also supposed to change school, but on the other hand, it was the fear of change in general because… this fear of changing the elementary school was probably greater than the fact that… they laughed at me, so in the end I stayed. (N3)

My teacher in my third year of high school told me to say who the subject of the poem was during Polish classes. And… I did not get these poems and their interpretations… I do not know… I told her that the author. And she later… started to get nervous, how come, saying that only a stupid person does not know that the fog was the subject of this poem and how I could be so stupid and so on. (N3)

Before the narrators were officially diagnosed, they had searched for the causes of their social difficulties. They needed to explain the causes of their difficulties and understand how they functioned and perceived the world.

I remember what struck me… I visited Wikipedia … and there were various comorbidities and comorbid disorders. And I found that I had almost all of them… all these comorbidities. Well, there were … OCD, depression, drowsiness, ADHD, different … tics and so on… It struck me that there could indeed be something to it. (N6)

Somehow, I always felt different and I always had some small things and there were so many of these small things that I felt somewhere under my skin that there was some big thing that connected them. But I never knew what it was. (N7)

One thing was connected with my stereotypes, already fixed somewhere in my head. Another thing was related to the realities that I saw not to be so dark at all. Therefore, I started reading about it. I did a basic AQ test on the Internet. [The AQ test is a screening tool in the diagnosis of AS. It can be used by adolescents and adults as well as parents on behalf of their children. It was developed by Simon Baron-Cohen with the Cambridge Autism Research Centre. The aim of the test is to quickly select people for the formal diagnostic process associated with AS.] (N7)

The study participants explored their knowledge about AS. It became a special interest for them at some point in their lives. They mentioned that their sources of knowledge were books, the Internet, groups on social networks, or self-advocate blogs. Gaining knowledge about autism led them towards their diagnosis.

Reading about autism spectrum became such a passion of mine. So strong that I wanted to spend every moment on it. In fact, I wanted to find out as much as possible … I feel fantastic that I finally found myself in something. I mean, I finally read papers that are about me, and I read books that are about me. It is beautiful because all the material about autism spectrum, especially in women, is simply a story about me. (N7)

Before the women were correctly diagnosed with AS, they had often received misdiagnoses (e.g., behavioral and emotional disorders) or insufficient diagnoses (e.g., depressive disorders, attention deficit hyperactivity disorder).

I was admitted to a psychiatric facility twice when I was in the orphanage… And that is where I was diagnosed with behavioral and emotional disorders… At the time, I thought it could have been [autism spectrum] but [it was] misdiagnosed. (N1)

I have somewhere a psychological diagnosis that was made many, many years ago because in junior high school, I may have been 12 years old when a psychologist diagnosed me with adolescent depression. (N2)

I had, so to speak, three approaches to the diagnosis in three different places. In the first one, they said that I did not have it and that I only had ADD. In another place, they said that due to my experiences in childhood, they could not clearly diagnose me. And it was in the third place that I got a final diagnosis. (N5)

Social and emotional experiences related to the diagnosis process

The diagnostic process of some women was associated with significant uncertainty and the fear mainly related to the fact that their assumptions about their condition would not be confirmed. Several narrators directly indicated that they were accompanied by the impostor syndrome (that is the feeling that they "did not deserve" a diagnosis and deceived themselves and others by wasting time and money).

I had…the impression that they would not find me to be autistic. (N6)

I was really afraid that it would turn out it was not … I mean I was really afraid that at that moment the psychologist … would directly say: "No… you are just abnormal. You have made it all up". … It was a very strong fear. (N7)

Somewhere in the back of my head … the impostor syndrome in my case was just like that … Well, I was just afraid that I would spend the money on nothing, right … It was also fine for others because denying myself and all these symptoms was and … is all the time. (N2)

Among the study participants, some were very certain of the diagnosis, and the diagnostic process was only a formality for them. The diagnosis was only a formal confirmation of being diagnosed with AS.

Was I afraid? Rather not… I rather thought … that it was more than likely. (N1)

I went for a diagnosis when I was sure I was on the spectrum. So, it was more like "Why did it last so long? Give me this paper!" (N4)

The diagnostic process was different for each narrator. There were situations when the diagnosis was made unprofessionally and resembled more the diagnosis of a child than of an adult.

Well, I had different tasks. I just got different tasks, which sometimes even surprised me. Well, for example, I had … God, yes, children have such tasks … they have to put in shapes, right, into some molds and so on … I also had a task to simply describe a picture … (N6)

In some participants, however, the diagnostic process was more age-appropriate and in line with the standards of adult diagnosis. An important part included the interviews with informants, usually a parent or parents, whose task was to provide reliable and essential information necessary to confirm the diagnosis.

> I did a test at the psychiatrist's … an Australian one? I don't know … she gave me something to fill in and later … First, my mother had it … and then I had it with a psychiatrist. Next, I had a meeting to take an IQ test. After this test, I had an appointment with a speech therapist. (N3)

Social and emotional experiences after the diagnosis

The participants willingly shared the information about the diagnosis. They did not consider it shameful. It was not regarded as a stigma or a stigmatizing attribute but rather some form of relief, explanation, and even a reason to celebrate with her loved ones in the case of one of them.

> It is nothing embarrassing for me … On the contrary, right after I got that I was on the spectrum, I generally told everyone who wanted to listen. (N4)

> When I got the diagnosis, I immediately threw a party. … I made the cake … the cake with a question mark. Now I think it is quite funny, but … it was a beautiful event. I have very good memories of it. And I did a gender reveal[1] - meaning I gathered everyone. I said, "Well, we are here because I got a psychological diagnosis" and I said, "I am autistic!" And they were all shocked. (N7)

The diagnosis gave the women a new identity, a sense of community, belonging, and not being alone with their problems. It gave access to an autistic community, where it is possible to obtain answers to crucial questions and support in difficult or crisis situations.

> I feel that many people have the same problems, and I am not alone … For a limited group of people, it is normal, and they have it too and it is cool that, for example, I do not know … I can turn to someone [and] do something to talk it over with someone. (N3)

> And also … a lot of support groups. When I have a problem, it is often better for me to consult people who are on the spectrum on how they see it than. For example … look for it in some textbooks or some other books and so on. (N1)

The diagnosis provided the participants with an answer to the source of their difficulties, which they had experienced from an early age. It set them free from the burden of being weird or abnormal. Becoming aware of the source of the problems reduced anxiety. It allowed them to accept their condition. It also gave valuable tips on how they could work on their difficulties.

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[1] Gender reveal party is a pregnancy party whose main theme is to reveal the sex of the child to family, relatives and friends.

All in all, it is nice that I got this diagnosis because I know what is wrong with me and why I stand out from everyone. It is a kind of a starting point that it OK. It is because I have this autism and as if … I can work on it to improve a little in this area, to … fit in a bit … It is not like you are … abnormal, this is a disease entity and you can work with it somehow. That was cool. (N3)

What did this diagnosis give me? Well, first of all, it gave me peace of mind … that I do not have schizophrenia, I … am simply different, right? I do not think I am worse. It is just hard for me sometimes because … I have the awareness of the existence that I am on the spectrum. (N1)

Conclusion

We conducted biographical and narrative interviews with eight women with AS who were diagnosed in early to middle adulthood to find out how their social and emotional experiences were shaped before, during, and after the diagnosis of AS.

The study showed that women had struggled with difficulties in everyday life before the diagnosis without knowing the source. Lack of awareness of the autistic etiology of their behaviors meant that they used labels taken from the "non-autistic" world to explain them, defining themselves as strange, naughty, abnormal, or mismatched. They considered their behavior pathological, which had an impact on the formation of a constructive image of themselves (Buchholz, 2021, p. 62).

Before obtaining a final diagnosis, women strongly needed to know and understand the reasons for their differences. They had searched for the explanation of their difficulties in the available literature, Internet sources and social media. Before they were given a proper diagnosis of AS, they had been exposed to incorrect and insufficient diagnoses. According to Sarah Bargiela et al., the phenomenon of misdiagnoses reflects specific features of the female phenotype, which are not captured by gender-insensitive diagnostic tools and features of diagnostic systems in a particular country (Bargiela et al., 2016, p. 3290).

Before the diagnostic process, the narrators had been afraid that they would not be given the diagnosis, they had misjudged their difficulties and had overinterpreted the behavior. They were accompanied by the impostor syndrome as a negative consequence of long-term masking (Buchholz, 2023, p. 188). Obtaining a formal diagnosis was a breakthrough for them (Pawlik, 2019). They accepted it with relief and even satisfaction. Paradoxically, the diagnosis did not mean another labeling for them. It was seen as a release from the label they had previously had (being strange, abnormal or defective) (Buchholz, 2021; Pawlik, 2019). Due to the diagnosis, women gained a sense of belonging. They found their "tribe" (Buchholz, 2021, p. 62, after Campbell, 2018). It gave them access to an autistic community where it is possible to obtain answers to questions and

support. The diagnosis also proved helpful in the process of unmasking, i.e. taking control over the masking strategy, which in turn supports the formation of authentic identity.

To conclude, women pay high social and emotional costs related to not being diagnosed or misdiagnosed, which limits the chances of receiving early medical, psychological, or social support for this group of people (Buchholz, 2021, p. 69). It also deprives them of the opportunity to benefit from the identification with a group of people with similar characteristics. Women with a late diagnosis of AS definitely see the value of the diagnosis in the form of increased self-knowledge, liberation from stigmatizing labels, finding their "tribe" and the possibility of receiving forms of support adequate to their condition.

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To nie jest tak, że jestem „nienormalna". Doświadczenia społeczno-emocjonalne kobiet z zaburzeniami ze spektrum autyzmu związane z diagnozą w dorosłości

Streszczenie

Prezentowane badania stanowią część projektu badawczego związanego z przygotowaniem pracy magisterskiej Magdaleny Wali, studentki V roku Pedagogiki specjalnej, przygotowanej pod opieką naukową dr Sabiny Pawlik. Dotyczą doświadczeń społeczno-emocjonalnych kobiet, które swoją diagnozę otrzymały dopiero w dorosłości. Kobiety częściej niż mężczyźni pozostają w dzieciństwie niezdiagnozowane, należąc do tzw. „pokolenia straconych", czyli osób pozbawionych możliwości otrzymania diagnozy w dzieciństwie. Jedną z przyczyn takiego stanu rzeczy jest fakt, że kobiety w spektrum autyzmu reprezentują odmienny od mężczyzn profil behawioralny (tzw. żeński fenotyp autyzmu), a ustalone praktyki diagnostyczne koncentrują się na podstawowych cechach zaburzeń ze spektrum autyzmu, które zostały historycznie ustalone na podstawie objawów pojawiających się u mężczyzn. Badania miały na celu poznanie doświadczeń społeczno-emocjonalnych kobiet w spektrum autyzmu, które swoją diagnozę otrzymały w dorosłości. Odnoszą się do doświadczeń kobiet poprzedzających diagnozę, tych, które wiążą się z samym procesem diagnostycznym oraz doświadczeń po otrzymaniu diagnozy. Ukazały, że kobiety, u których zdiagnozowano autyzm w dorosłości dostrzegają wartość otrzymanej diagnozy w postaci wzrostu samowiedzy, wyzwolenia ze stygmatyzujących etykiet, odnalezienia „swojego plemienia" i wreszcie możliwości otrzymania adekwatnych do ich kondycji form wsparcia.

Słowa kluczowe: zaburzenie ze spektrum autyzmu, fenotyp autyzmu u kobiet, diagnoza, wywiad biograficzny.