CHAPTER 68

The omission of autistic women in research; Reasons, effects and solutions

Scrossref 🙆 https://doi.org/10.56238/alookdevelopv1-068

Cornélio Schwambach

Laura Mariano da Silva Bom Jesus Center High School

Advisor, Bom Jesus Center High School

1 INTRODUCTION

1.1 PROBLEMATIZATION

The emergence of research on autism in women is a subject that has gained traction in recent years, and the stereotype of the existence or prevalence of autism in men is increasingly dismantled in favor of an equitable view of how autism manifests itself depending on gender. But even with the academic updates, popular knowledge about autism hasn't kept up with this shift. How best to assist women who are diagnosed as autistic? And how to give them their rightful place in the history of autism after so long omitted from it?

1.2 JUSTIFICATION

The need for knowledge about autism beyond stereotypes with the goal of greater support capacity can help in early diagnosis and correct support for diagnosed children. Compassion for autistic people who do or do not seem "normal" is necessary because they are part of society itself, but we need to look at autism from a more welcoming and accepted perspective. The knowledge for the Brazilian about autism from the writing of this article proposes a new way of seeing autism not as something pathological caused by external factors but as something intrinsic to the individual and not curable, which uniquely shapes the way the person experiences the world. The article aims to show how to face autism in a way that is not prejudiced but inclusive. The autistic woman suffers from a unique kind of prejudice, and the mixture of machismo and ableism leaves her even more isolated in her experiences in contrast to the non-autistic woman and the autistic man.

1.3 HYPOTHESIS

Autism is seen with many stereotypes and is usually studied preferentially in boys, with no perspective of inclusion and help for autistic women.

1.4 GOALS

1.4.1 General

Analyze the way that autistic women are excluded from autism studies, and how this affects

1.4.2 Specific

Review specific literature on the theme developed. Propose ways of adequate support for autistic women.

Reflect on the need for a paradigm shift in knowledge related to autistic women.

2 DEVELOPMENT

2.1 LITERATURE REVIEW

2.1.1 What is Autism

Autism consists of a genetic neurodevelopmental disability, with traits consisting of difficulty maintaining eye contact, need for rigid routines, sensory sensitivities, and deficits in multiple social contexts; and predominantly in cases of autism in women, there is "masking," which is the camouflage of autistic traits by copying behaviors of non-autistic people with the aim of social integration. Because it does not have physical characteristics, such as the short neck in people with Down syndrome, it is considered an invisible disability, especially in autistic people with less severe traits or who practice masking. The term "autism" was coined by the Swiss psychiatrist Eugen Bleuler in 1911 in his book "Dementia Praecox" to name one of the main symptoms of schizophrenia, which consisted of the patient's separation from reality, and his disinterest in socialization. The word originates from the junction of the word "autos" from the Greek meaning oneself, and the suffix "ism" means a condition or state of being. His first mention in a professional setting without being a symptom of schizophrenia was made by Grunya Efimovna Sukhareva in 1926, describing the autistic characteristics his six patients shared and slowly separating autism from childhood schizophrenia; two decades before Leo Kanner and Hans Aspergers, who is most popularly known as the pioneers in the subject, and who perhaps had contact with the records of Sukhareva. One of Sukhareva's most contemporary ideas is the therapeutic school he founded, and where his six autistic patients stayed. The school offered various activities such as gymnastics, carpentry, and painting to improve the social and motor skills of the children, so that then in the future they would have the chance to attend an ordinary school. His notes are very similar to the DSM-5 (2013) record on autism according to the analysis made by Manouilenko and Bejerot (2015), even with almost ninety years of difference between the publications. Sukhareva's explanations of the children she cared for had a language that was simple to understand and also involved the patient with questions. They spoke not only of the psychological profile but also the family history of the patient, his physical profile, general examinations, his progress and diagnosis, and a summary of the case; by doing these not only behavioral tests, but Sukhareva also hypothesized that the cerebellum, basal ganglia, and frontal lobe could be the anatomical basis of childhood schizophrenia. Coincidentally, having a hypothesis far beyond his time, Sukhareva never believed in the theory of "refrigerator mothers" originated in 1949 by Leo Kanner, popularly known as the pioneer in autism studies along with Hans Aspergers, in his publication "Problems of Nosology and Psychodynamics of Early Infantile Autism.", which attributed autism to a lack of affection parental or coldness mainly coming from the mother. Even though the idea was originally Kanner's, the "refrigerator mothers" theory was popularized with Bruno Betttelheim in 1967 with his book "The Empty Fortress: Infantile Autism and the Birth of the Self," which described his experiences as a Jewish man living in Austria from 1932 to 1938; Bettelheim compared mothers of autistic children to Nazi prison guards, and the children's family environment to a concentration camp, cementing the direction of autism studies until the 1980s.

2.1.2 Ableism and misogyny

Whenever women, girls, and/or girls are mentioned in this article it refers to people designated women at birth and who were socialized as such - the inclusion of trans people in discussions about autism is essential, but this work is limited to talking about the people already mentioned. Intersectionality is a sociological concept popularized in 1989 that refers to how types of prejudice depend on each other and intersect to form unique discrimination, which in this article consists of the ableism and misogyny that affect autistic women. Because it is a unique experience for the autistic woman, the isolation of her colleagues is even more acute than with just the social difficulties that accompany the autistic in general.

2.1.3 Support and support for autistic women

The predominance of studies on autism in men, which leads to lack of knowledge about autism in women; lack of resources for autistic women because of the predominance of resources for parents of autistic children to "cope" with their child; stereotyping of autism that causes autistic characters to be almost fully represented as "geniuses" who just have problems socialization; alienation of the adult, and especially of the autistic woman about her syndrome because of the myth that autism is a "childhood disease"; lack of resources for support and diagnosis of autistic people who do not fit the more standard traits and profile of the autistic boy; ableism rooted in terms such as "mild autism", "low functioning" and "high functioning" because no autistic is equal and because the syndrome is a spectrum of traits and their intensity; numerous myths surrounding autism, such as that there are only autistic boys, that autism is caused by vaccines, that every autistic is a genius/mentally backward, and so on; equivocal diagnoses due to lack of knowledge about autism in women.

Ableism and misogyny; predominance of research by Nazi Hans Asperger who only studied autism in boys; stereotypes about autistic people who ignore autistic people who don't fit the pattern.

2.2 METHODOLOGY

The methodology used according to Gil, 2008 is classified as exploratory considering the objectives and bibliographic character, and action research considering the procedures. A literature review is a process of searching, analyzing, and describing a body of knowledge in search of an answer to a specific question. In this article, we opted for the narrative review. The narrative review does not use explicit and systematic criteria for the search and critical analysis of the literature. The search for studies does not need to exhaust the sources of information.

3 CONCLUSION

The story about autism demonstrates that boys have always been prioritized in studies, this may explain the little knowledge we have about autism in girls. Probably the lack of scientific development caused several stereotypes to be created. Many aspects in addition to the little scientific knowledge bordering on prejudice towards women, probably slowed down the knowledge about autistic girls.

Propose ways of adequate support for autistic women.

Reflect on the need for a paradigm shift in knowledge related to autistic women.

Where and why do you have all the stereotypes about autism and how best to help women who are diagnosed as autistic?

Autism is seen with many stereotypes and is usually studied preferentially in boys, with no perspective of inclusion and help for autistic women.

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