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BLUE WORLD: CONSIDERATIONS ABOUT AUTISM FROM THE PARENTS' UNDERSTANDING

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ABSTRACT

The diagnosis of autism, currently configured in ASD (Autism Spectrum Disorder) is becoming increasingly common among children. Autism has a long history of description and definition and what is understood today by ASD is that it is configured as a neuropsychiatric disorder that causes language impairment and socialization. OBJECTIVE: In view of the extent to which the diagnosis based on classification manuals of disorders is related to individualizing and pathologizing medical practice, this study sought to advance beyond the individualizing view and reality of child medicalization. METHODOLOGY: This is a descriptive qualitative study, where interviews were used as a data collection instrument, which took place with parents and/or caregivers of children with a diagnosis and/or diagnostic hypothesis of autism who attend the CAPS IJ in the city of Apucarana/PR, with the objective of accessing their ways of understanding what they understand by autism. RESULTS: We can observe in the family members' reports an emphasis on the aspects of pathologization and individualization of autism, which was very present in the statements and its relationship with the medical discourse. It was evidenced the crossing of medical science in the parents' discourse about autism, a fact that determines the way they understand autism, and the forms of treatment considered appropriate. FINAL CONSIDERATIONS: In this study we hope that the idea of a "blue world" as the term often used in the autism universe, which is related to the idea of a world that transforms in the face of a diagnosis, can help and contribute to the reader's concern in the face of pathologization, medicalization and individualization.

Keywords: Autism. Autism Spectrum Disorder. Critical Psychology. Psychosocial Care Center. Pathologization.

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INTRODUCTION

The Psychosocial Care Centers (CAPS) established by Ordinance/GM No. 336, of February 19, 2002, are devices that emerged from the Psychiatric Reform movement in Brazil, in the late 1980s, which, led by mental health workers, patients discharged from psychiatric hospitals and their families, denounced the precariousness of hospital conditions and the countless violence and rights violations that occurred in asylums. The movement sought to replace the psychiatric hospital as the center of mental health care, creating substitutive services, such as the CAPS. It is important to highlight Law No. 10,216, of April 6, 2001, which legally instituted the Psychiatric Reform in Brazil, guaranteeing the rights of people with mental disorders, proposing a new form of mental health care.

Among the various substitute services created, which emerged later, it is worth encompassing the Psychosocial Care Network (RAPS) of the SUS, established by Ordinance 3.088 of December 23, 2011, is the modality of CAPS i II - Child Psychosocial Care Center, the service in which this work was produced. According to the CAPS Ordinance, CAPS i II is a service intended for the care of children and adolescents with severe and persistent mental disorders, and should offer individual care, group care and therapeutic workshops, home visits and care, family care, as well as community and intersectoral activities (Brasil, 2002).

In this way, these services can come to serve children diagnosed with autism. Regarding this diagnosis, we find the first definition as a clinical picture in 1943, with the Austrian physician Leo Kanner, who, upon observing children aged 2 to 8 years with impairments in the acquisition and use of language, in development and interpersonal relationships, classified them with the so-called autistic affective contact disorder (Brasil, 2015). Another important name, Asperger, who even gave his name to the Syndrome, now framed in ASD (Autism Spectrum Disorder), began to study children with conditions similar to those Kanner had described in 1944. There are many names of those who dedicated themselves to studying autism, it should be said here that the diagnosis underwent several changes throughout the twentieth century, from the first who sought to understand and investigate childhood autism, such as the two mentioned above, to psychoanalysts who adopted a psychodynamic perspective, the cognitivists, followed by neuroscientists and psychiatrists (Brasil, 2015), and currently studies of genetics and epigenetics (Zanolla *et al*, 2015).

When we turn to the current definitions of the aforementioned dignostic, we resort to the definition given by the Ministry of Health (2016), through the document "Clinical Protocol and Therapeutic Guidelines for Aggressive Behavior in Autism Spectrum Disorder" autism is a "chronic neuropsychiatric disorder that develops in early childhood". (p. 3).

In the definition proposed by the Diagnostic and Statistical Manual of Mental Disorders (DSM – 5), a manual prepared by the American Psychiatric Association, which has great scope and clinical support in the classification of various mental disorders, ASD fits into the Neurodevelopmental Disorders, with the main characteristics for diagnosis being the deficit in communication and social interaction, patterns of restricted and repetitive behavior (DSM-5, 2014). It is important to highlight that the change in the understanding of the spectrum, in which disorders that were classified separately in the previous version of the manual are grouped, is recent and has resulted in an increase in cases that can be diagnosed with the disorder.

Although there is still no consensus on the genesis of autism, psychiatric knowledge is one of the most used to explain what happens to the child. Biology or even Psychiatry is often used to explain a child's condition of suffering. This reflects the process of medicalization of childhood, of pathologization of life, with the unbridled attribution of diagnoses that define and enclose the subject in stigmatizing labels. For Sanches and Amarante (2014), medicalization "is a political and cultural process that transforms life experiences, reducing them to a medical rationality, pathologizing them" (p. 507). There is no way to understand the process of medicalization disconnected from that of pathologization.

Considering that this is the representation of a reality that does not occur only in this context addressed in this study, the theme of autism becomes increasingly relevant and necessary to be discussed from a critical perspective in Psychology and also in the multiprofessional team, a perspective that does not individualize the subject, but that problematizes, contextualizes and historicizes the various processes of suffering, including autism.

Thus, considering that the parents' discourse can reproduce the discourse that is placed in the social, that of biologization and pathologization, governed mainly by the medical knowledge of Psychiatry, when it comes to issues related to mental health, such as autism, this study aimed to hear what these parents have to say about autism, about what they understand about the diagnosis and what they seek with it and thus access the forms of understanding of parents and caregivers of children diagnosed or in the process of investigating the diagnosis of autism.

The realization of this research took place, from critical perspectives, proposes to advance beyond the biomedical discourse, which detaches autism from the social field, which little historicizes the phenomenon. Starting from professional defenses, the approach is directed to a place that seeks to take another look at the phenomenon, a look that expands the possibilities of a "blue world".

METHODOLOGY

The present study is a descriptive qualitative approach, which is defended by Minayo (2001) as an approach to be used when one does not want to just quantify the data and facts obtained in reality in a research. The author complements by stating that in the qualitative approach she works with the universe of meanings, motives, aspirations, beliefs, values and attitudes, which corresponds to a deeper space of relationships, processes and phenomena that cannot be reduced to the operationalization of variables.

The project was submitted to Plataforma Brasil, obtaining approval for research by the Ethics Committee of FAP (Faculdade de Apucarana) and approved under CAAE number 28954820.3.0000.5216.

For data collection, as an inclusion criterion, parents and/or caregivers of children aged 0 to 12 years who have obtained a diagnosis of autism or who are in the process of investigating this same diagnosis were selected. The selected adults were linked to the Child and Youth Psychosocial Care Center in the city of Apucarana, PR, where the children were monitored. The diagnosis was included in the children's medical records. As exclusion criteria, parents of children who presented other disorders such as comorbidities (also contained in the medical records), as well as parents of children over 12 years of age, were not selected. Parents entered in the service after the selection period were not selected.

For the selection of these parents, a search was carried out in the medical records of the CAPS IJ in question, where the data from the medical records were analyzed, and only those who fit the inclusion criteria of the research were selected. The previously selected sample consisted of parents and/or caregivers of 12 children.

After selecting the sample, the potential participants were contacted by the telephone number in the medical records to invite them to the interview. Of the 12 adults selected, it was possible to contact eight, among these, six it was possible, in the first contact, to schedule a date for the interview. Two people showed interest in participating, but with the first it was not possible to schedule and the second could not attend on the scheduled day. During the calls, the objective and content of the research were explained

The interviews would be held in the Meeting Room of the city's Municipal Health Authority, but due to the Covid-19 pandemic and social isolation guidelines, the interviews were held at CAPS IJ, which many parents already attended and accessed to take their children to psychiatric consultations, which took place on Saturdays, despite the suspension of other activities in the service, such as therapeutic groups, which took place during the week.

Six interviews were conducted, five of them with mothers and one with a father of the selected children. The interviewees signed the Informed Consent Form, which contained the objectives of the research, the risks, and the benefits. The researcher's contact was made available for any needs. The interviews were semi-structured, with guiding questions addressed during the conversation with the family members.

After the interviews, the information collected was analyzed from an exercise in the critical perspective in Psychology, using authors from Historical and Cultural Psychology for this purpose. The Historical-cultural approach emerged with Vygotsky in the post-revolutionary period of the Soviet Union, between the 1920s and 1930s, and is configured as an approach that understands the psyche from the social point of view and seeks to determine what the subject is in its social context. Vygotsky understands the human being as "an aggregate of social relations embodied in an individual" (2000, p. 33). For Zanella (2004) this statement ratifies the relationship between subject and society as inexorable, we are constituted in social contexts, which are the result of the collective organization of men.

RESULTS AND DISCUSSION

Although the invitation to participate in the interviews was extended to the parents (father and mother of the child), all interviews were conducted with only one of the parents: five with the children's mothers and one with the father. The telephone number for contact contained in the medical records, for the invitation of the interviews, was mostly for mothers. The fact that most mothers attended may demonstrate that they still occupy the place of care. Three of the mothers interviewed reported not working outside the home, they had already worked at another time in their lives, but today, they no longer do so. It is important to emphasize that these same mothers are the ones who attend with their children at the CAPS or even in other situations, other services or therapies that the child undergoes, according to them. For these families, the main financial income comes from the children's fathers, according to the mothers the fathers could not attend the interviews because they were working.

The mothers interviewed justified their stay at home by the fact that their children require "special" care, so they commit themselves to their care. The mother occupying the central place in relation to the child's care is a fact to be analyzed. The social place of women is still strongly linked to motherhood, home care and family. Badinter (1985) discusses the myth of maternal love and describes how the role of women linked to motherhood was, in fact, socially constructed throughout history. According to the author, this attachment is the result of discourses of the European State in the eighteenth century, which placed the child as a precious asset for the nation (due to its mercantile value) and delegated to women the responsibility for their care (Badinter, 1985). We reap from this same discourse to the present day. There is still idealization of the maternal role, in the delegation of domestic roles to women, in making her responsible for the primary care of the child.

It is also important to highlight that the mothers justified their condition of being at home, closer to the child, mainly because they identified their autistic children as needing special care. This refers to the fact that they identify their children's disabilities and difficulties because they are "autistic". About this, one of the mothers talks about when she discovered her son's diagnosis: ***"when we learned that he was autistic, I thought we would have the responsibility of being more than normal fathers"*** (sic). Some other statements show two mothers explaining their son's difficulties, associating them with their diagnosis: ***"because he is autistic, he can't stand to get out of the routine"*** **(sic)** ***"from autism, he has food selectivity"*** (sic).

Regarding the diagnosis of autism, although almost all parents started talking about the characteristics that their child had that fit the diagnosis (irritation, difficulty with change and preference for routine, aggressive behavior towards oneself and others, speech disorders, among others, were some of the statements that appeared), None of the interviewees was able to report what constitutes autism. The six interviewees in their entirety stated that there was no consensus on what the genesis of the condition would be. What they reported about the clinical classroom was around the characteristics of their children, which they consulted in Internet content on the subject, accessed through conversations with other parents of children who had the same diagnosis, or even through health professionals, such as doctors, speech therapists and psychologists. As an example of the latter, the following is the statement of a mother: ***"the speech therapist realized that she was just playing at ordering the toys, so she advised me to seek follow-up for autism"*** (sic).

Most of the parents interviewed turned to doctors, especially neurologists and psychiatrists, to investigate possible diagnoses for their children, and some of the parents were referred by other health professionals, who indicated the need for a specialist to evaluate the child. All six children were diagnosed as autistic by medical professionals, only one of them did not use psychotropic drugs.

Although there is still no consensus on the genesis of autism and that it is a complex diagnosis, in view of the parents' speech, it is possible to associate the attribution of the diagnosis by doctors, who are guided by the knowledge of the classification manuals, which end up labeling, framing the child, often in a light way, in a nomenclature that "explains" his behaviors, their weaknesses and difficulties. A fact that corroborates the idea of the centrality of the role of the medical professional in care was that some parents agreed to participate in the research, only because the agreed date for its performance would be on the day of the child's psychiatric consultation at the service. Some of them do not participate with their children in other activities at the CAPS besides consultations.

The centrality in the figure of the doctor represents the process of biologization and medicalization of life. From this perspective, the subject is understood from biological determinations and behaviors are explained by the classification manuals. When analyzing the process of medicalization of childhood, Sanches and Amarante (2014) emphasize how medicine has the power to regulate social life, presenting solutions of the medical clinic to problems of a social and economic nature. Still on medicalization, for Moysés *apud* Sanches and Amarante, this process ends up disregarding the subject, treating him as an object, as a biological body on which one must intervene (2014).

Regarding ASD, we have to highlight the changes that occurred in the last edition of DSM-5, from 2014, a manual commonly used as clinical support in the process of daignosticar. This new edition of the manual presents the notion of spectrum or *continuum*, with the classification from mild to severe in relation to the impairment to the subject who has the disorder. According to the manual itself, the change was established to optimize the specificity of the criteria for diagnosis, as well as to identify the ideal treatments for the due losses (2014). Most of the parents interviewed reported that their child's diagnosis was mild autism.

The DSM-5 has been the target of several criticisms, mainly because it establishes this idea of the spectrum, which expands the possibility of diagnoses for a disorder. Making a criticism of psychiatric manuals, Martinhago and Capone (2019) point out that in these manuals, "the definitions of mental disorders are formulated arbitrarily, due to their pragmatic, clinical or research usefulness" (p.7). The authors, based on other scholars in the area, also develop the idea that for Psychiatry, with its knowledge that constructs diagnostic manuals, there is little confrontation with the conception that mental disorders are socially constructed.

As a counterpoint to this medical and biologizing look that stigmatizes, individualizes and creates a pathological look, from a critical perspective of action in Psychology, it is necessary to look at the child far beyond that. We have to look at its history, and at the history before it. The diagnoses of mental disorders are products of a social construction and this perspective is adopted when we use the historical-cultural approach to explain the most diverse phenomena. In a critique of traditional psychology, which often, like medical knowledge, individualizes and stigmatizes the various forms of suffering. Zanella (2004) proposes the approach inaugurated by Vygotsky as of another order, an order that understands the human being as the result of biological, anthropological, psychological and essentially cultural aspects. We can think of autism as a manifestation of suffering from these aspects, understanding that no human phenomenon can be explained from just one bias. We are not purely biological beings, we are products of a history, in a certain sociocultural context. The classifications contained in manuals such as the DSM, which do not give much history to the diagnoses, serve as support for a logic that individualizes and labels the subject as having a disorder, a diagnosis.

It is not possible to determine who a child is, or what he is capable of, or what his potentialities are through the lens of a disease manual. And this is a path that many professionals who evaluate and care for children tend to take, given the hegemony of this discourse. In this regard, Merlleti (2018) states that "the technical-scientific discourse, allied to contemporary ideas about childhood, tends to take the child as a describable, predictable, adaptable and controllable object, disregarding what would make him or her unique" (p. 146). Hence the importance of the professional's critical and ethical view of not adhering to the social mandates of the diagnosis, which standardize and classify the child (2018).

At the CAPS IJ in question, there was a great demand for care for children with the diagnosis or characteristics of ASD, including children referred for evaluation who had been "pre-diagnosed" by teachers, for example. A "walking on tiptoe" aroused the concern of teachers attentive to the diagnosis. It was an important fact observed in this study that many mothers, fathers or caregivers seek the CAPS IJ in order to obtain the diagnosis of ASD for their child.

It is necessary to understand the child beyond the perspective of the pathology in which we live. This demonstrates how much one looks at the child through the supposed diagnosis he carries. Two of the interviewees emphasized the need for professionals from CAPS and even from other services, which they attend, such as schools, to specialize in the study of autism ***"there is a lack of knowledge and specialization so that you professionals can know how to work with autistic people"*** (sic)). This fact can demonstrate the relationship they establish with the diagnosis, for them, the diagnosis and the specialized therapy associated with it are the only possibility, two of the parents mention ABA for example. ABA (applied behavior analysis) is an intervention method widely associated with the treatment of ASD, especially in the United States (Camargo and Rispoli, 2013). This may reflect the fact that the child is seen from the dignostic he carries, for these parents mentioned, it is necessary to know specifically about autism so that the professional can intervene on the child. One of these parents emphasizes the need for the CAPS IJ in question to have specialized professionals, which does not occur.

The CAPS as a health service, which emerges in the midst of the ideals of the Psychiatric Reform, of the Anti-Asylum Struggle, should be a reference service for care in freedom, for multiprofessional care that aims at understanding the subject as a multidetermined being. It should not be in favor of pathologization and excessive medicalization, which enclose that little subject in labels that determine their lives. This is the reality we live with, but it is necessary to go beyond it. It is necessary to create a Health Care Service that welcomes diversity and the most varied ways of existing. Given the importance of thinking about the subject beyond a diagnosis or "label" that can determine who he is from a view of the other, it is necessary the interaction of the multiprofessional team and especially the psychologists working in child and adolescent mental health on the front line, to discuss the position in which this subject is placed and to advance beyond it.

The diagnosis of autism becomes responsible for saying a lot about the child, for representing to the family how to behave in front of that child who suffers. The family is organized based on the diagnosis, hence the idea of the "blue world" often arises, an idea often present when the issue of autism is addressed, the search for rights, claims, dialogues with society. The "blue world" is a world defined through the lens of diagnosis. The family turns to the child based on the diagnosis he carries, a world that turns blue.

If before receiving the diagnosis most parents had never had contact with it, they knew little or nothing about autism, from the attribution of the diagnosis, it is a guiding reference for the parents, and this was present in their statements, especially when they narrated about changes that had to be made in their lives from the attribution of the diagnoses.

In this study, it can be observed that there were several parents who mobilized themselves in relation to knowing about the diagnosis, consulting specialists on the subject, participating in events related to autism, but these characteristics were not present in the statements of most parents. Only one of them reported getting involved in seeking theoretical knowledge from experts about autism.

Another characteristic addressed in the statements of three of the interviewees was the parents' claim for the rights of children with autism, which was a discourse present in the CAPS IJ in question, such as parents who resorted to the service to obtain their child's diagnosis, as a way to access some benefits. Some speeches addressed this issue. One of the mothers said she was looking for her son's rights, who according to her, was discriminated against precisely because he was autistic, at the school he studied. It came up in the speech of a father that it is necessary for people, society in a broad way, to know autism to be able to respect, not to discriminate. One of the mothers is looking to get the social security benefit for her daughter (because she is autistic) so that she no longer works and dedicates herself to her care. Here we have autism that calls on parents to act in the sense of claiming rights, in the search to bring autism to the broader debate and discussion.

In the city where this research takes place, there is the AMAA (Association of Parents and Friends of Autistic People of Apucaranenses) which is configured as an NGO. The first AMA (Association of Friends of the Autistic) founded in Brazil was in São Paulo and dates back to 1983. In this city, AMAA works as an articulator of the debate with various spheres in relation to autism. None of the parents interviewed actively participates in the association in the city, although all of them know and have contact with people who participate. Some of the interviewees reported participating in the association's whatsapp group, one of the parents cited the need to value AMAA, which he sees as a great power for the broader discussion with society on the subject of autism.

In the city of Apucarana, there were a series of rights conquered for the autistic child. There is the Municipal Autistic Identification Card (CMIA), law No. 102/2018 that reserves one percent of parking spaces to serve people with ASD in public and private establishments. There is also Law 22/2018 that declares the Association of Parents and Friends of Autistic Apucaranenses – AMAA to be of Public Utility. The parents interviewed did not mention these laws and rights, despite addressing the concern with the issue of autism and ensuring dignified conditions of care and equality for their children.

The interviewees are generally parents, attentive to the diagnosis, interested in seeking qualified professionals and services to attend to their children, their demands and difficulties, parents who have been transformed and who have transformed much of their lives from the diagnosis given by doctors, professionals whom they place as essential for care. Their discourses outlined much of what is seen in the reality of pathologization, stigmatization and labeling of subjects based on the disorders they carry, which "explain" their ways of suffering.

FINAL CONSIDERATIONS

The theme chosen for the project arose from professional and observational questions. What generates concern is the attribution of individualizing diagnoses, especially ASD, diagnoses that enclosed little subjects in labeled places, in diagnoses that "explained" the subject's difficulties and the medicalization of the supposed disorders.

In addition to the various existing explanatory theories, we chose to start from another place, from an analysis that understands the subject beyond the label of the individualizing diagnosis.

Considering the theoretical, technical, historical limits, among many others, it is believed that the realization of this research proposed precisely to advance beyond the individualizing understandings of autism, that given by traditional medical and psychological knowledge, from a perspective that does not standardize, does not forge adaptations, but considers psychic diversity and welcomes demands despite a diagnostic classification.

Listening to the parents of children who "carry" this diagnosis in this research proved to be an important part of knowledge and approximation of the research theme, of apprehension of the forms of understanding and discourses that are so unique, but that speak from a broad context, determined historically, politically and economically.

It is important to highlight that the results of this research, when addressing how much the parents' discourse reflects the biomedical and pathologizing view, are not configured as a criticism of the understanding that parents have about their children, about the diagnosis of autism. It is necessary to take a critical and broader look at this issue.

Although this study is reduced to a small sample of parents, it is believed that it represents much of what can be found elsewhere, that is, the hegemony of medical knowledge, of biologizing knowledge, as if these could be able to explain the complexity of the human being, his relationships (the most diverse) and their consequences, and even from the historical panorama (we are historical beings) products and producers of what we live. It is hoped that the presentations made in this research will serve as reflections, suggestions or even ideas for future work and research.

Some excerpts were generated from the discourses of the interviewed parents and throughout the realization of this research. The idea of a "blue world" as the term is often used in the universe of autism, which is related to the idea of a world that transforms in the face of a diagnosis, we hope from this research to be able to contribute to the reader's restlessness in the face of pathologization, medicalization and individualization. May we welcome the difference and the different ways of being in the world of each child. May the blue world be one of many blues, of many shades, varieties and possibilities.

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