

Perception about autism under the optics of mothers

Percepções sobre o autismo sob a ótica das mães

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RESUMO

Introdução: O transtorno do espectro autista é classificado como um distúrbio agressivo do desenvolvimento. Este compromete todo o desenvolvimento neurológico, e se caracteriza pelo desequilíbrio comportamental exposto pela inaptidão na inclusão social. **Objetivo:** Analisar as percepções e experiências emocionais de mães com filhos diagnosticados com transtornos do espectro autista. **Metodologia:** Estudo de caráter qualitativo, que teve como público alvo mães de filhos com diagnóstico de transtorno do espectro autista, participantes das APAEs. Foi realizada uma entrevista semi-estruturada gravada por gravador digital, e posteriormente transcrita. **Resultados:** Notoriamente as mães possuem dificuldades para compreender e se adaptar a realidade do filho diagnosticado de autismo. Criam expectativas e perspectivas quanto ao futuro dos filhos almejando que estes desenvolvam prioritariamente a independência. **Considerações Finais:** Obtivemos a possibilidade de compreender melhor as expectativas e as dificuldades das mães das crianças com diagnóstico de TEA. Foi encontrado idade média para o diagnóstico de espectro autista do filho entre 3 anos e 4 meses. A descoberta do diagnóstico do TEA causou importantes sentimentos prejudiciais e de não aceitação à essas mães. Surgem sentimentos negativos, afetando assim a saúde mental dessas mães e familiares.

Palavras-chave: Autismo; Psicodinâmica; Percepção.

ABSTRACT

Introduction: Autism spectrum disorder is classified as an aggressive developmental disorder. This compromises the entire neurological development and is characterized by the behavioral imbalance exposed by the inaptitude in social inclusion. **Objective:** To analyze the perceptions and emotional experiences of mothers with children diagnosed with autism spectrum disorders. **Methodology:** This was a qualitative study that had the target audience of mothers of children diagnosed with autism spectrum disorder, who participated in APAEs. A semi-structured interview was recorded by digital recorder, and later transcribed. **Results:** Notoriously, mothers have difficulties in understanding and adapting the reality of a child diagnosed with autism. They create expectations and perspectives on the future of children, aiming for them to develop independence first. **Final Considerations:** We obtained the possibility to better understand the expectations and difficulties of the mothers of children diagnosed with ASD. We found a mean age for the diagnosis of autistic spectrum of the child between 3 years and 4 months. The discovery of the diagnosis of ASD has caused important feelings of detriment and non-acceptance to these mothers. Negative feelings arise, thus affecting the mental health of these mothers and their families.

Keywords: Autism; Psychodynamics; Perception.

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INTRODUCTION

Autism spectrum disorders are intriguing, from the point of view of scientific knowledge, and have challenged the researchers who approach this subject. In terms of definition, autism focuses on a neurodevelopmental disorder, which is characterized by constant damage to social interaction, changes communication, and limits performance and interest patterns. In addition, emphasis is placed on the importance of the genetic factors of the syndrome and with research done more than fifty years ago, the origin of the syndrome remains unknown, causing difficulties in educational interventions and treatment ⁽¹⁾.

It is a situation that triggers changes in the family environment due to the accompanying conditions for the child to develop. Autism spectrum disorders make up an impact position, which can reflect directly in the daily routine, the readaptation of tasks and causes various changes in family relationships. At the time of manifestation of the disease or chronic syndrome, such as autism spectrum disorder (ASD), the family usually goes through several stages, namely: impact, denial, mourning, external focus and closure, where they are associated with complex emotions and confusing ⁽²⁾.

Since parents are the first to notice that their children exhibit behaviors that deviate from the normal pattern, their role in the diagnosis of autistic disorder is extremely important. Faced with this situation, there is a feeling of helplessness and anguish for not knowing how to help their children. The fragility of the health services, as well as professionals not being prepared to recognize autism early intensifies these feelings and ends up causing the delay or not definition of the diagnosis ⁽³⁾.

Some mothers, when questioned about the future of their children, reveal that their goal is their independence by encouraging them to carry out day-to-day actions that have that purpose. They idealize that they be fulfilled in their love life and have a job. As they do not know the future of their children, some of these mothers are afraid of death, others believe that a family member will make a commitment to care for this autistic individual after their departure ⁽⁴⁾.

In view of this, this research intends to collect data on the situations and experiences lived by mothers with children with ASD. Based on the gathered information, professionals will have a better opportunity to reflect, seek new guidelines for the development of therapy relevant to the whole family. It will also be possible to identify difficulties and define priorities to be developed with the family of these mothers.

METHOD

This is a qualitative-exploratory research, with a descriptive approach in which it was carried out through a semi-structured questionnaire. This study was carried

out with groups of mothers of children who have children diagnosed with autism spectrum disorders from the Parents and Special Friends Associations (APAE) located in the city of Capão da Canoa and Tramandaí / RS. As participants of the study we had mothers who actively participate in groups performed in APAEs, with the aim of sharing their experiences and seeking these groups for support and coping from the diagnosis of Autistic Spectrum Disorder of the children.

Twenty mothers were interviewed, being 10 of them from APAE of Capão da Canoa municipality and 10 mothers from the municipality of Tramandaí. As criteria for inclusion: mothers with children diagnosed with Spectrum Disorders who are involved in groups in the abovementioned APAEs, and these have agreed to sign the Informed Consent Term - TCLE. The semi-structured interviews were recorded with digital recorder, and soon after they were transcribed with the minimum of interference of the researchers.

The anonymity of the participants of this study will be guaranteed, preventing judgments or preconceptions, respecting their privacy according to resolution 466/2012 of the National Health Council of the Ministry of Health ⁽⁵⁾. As an instrument of preservation of anonymity, the names of the participants were replaced by letters. For the data analysis, the Glase method was used, which aims to understand the world in which one lives, based on the subjectivities of the experiments and their individual meanings ⁽⁶⁾. For better analysis and discussion, these were divided into categories: Diagnosis and Feeling; and Difficulties and Perspectives of the Future.

RESULTS

Mothers participating in the support groups of the Association of Parents and Special Friends of the municipalities of Capão da Canoa and Tramandaí, who had children diagnosed with Autism Spectrum Disorder, were interviewed for the development of this research. The mean age of the mothers interviewed was 35.3 years, with the youngest being 22 years old and the oldest being 47 years old. Regarding the degree of study 7 (seven) had incomplete elementary education, 8 (eight) have complete education and 4 have higher education. In relation to marital status 11 (eleven) mothers are married and 8 (eight) mothers are single.

The mothers interviewed developed the following work activities: administrator, nurse, hairdresser, caretaker, artisan, makeup artist, rural extension worker, teacher, real estate brokerage and 8 (eight) housework and cleaning lady. To ensure anonymity in the users these were identified by letters and numbers at the end of each speech presented in the course of the text, as well as the names of the children involved when quoted in the

course of the text were replaced by letters. The questions asked were grouped into categories for a better analysis and discussion of the results found from the interviews transcripts.

Diagnosis and feeling:

According to the diagnostic criteria of DSM-5⁽⁷⁾, the first manifestations of ASD should appear before 36 months of age. However, empirical evidence shows that most children develop developmental problems between 12 and 24 months, with some qualitative developmental deviations occurring even before 12 months. However, some studies have shown that children with ASD rarely receive this diagnosis before the age of 5, some of which are diagnosed only when they reach school age⁽⁸⁾. In order to be able to observe and verify more clearly, we question the mothers about the age of diagnosis of their children.

"He ... got his diagnosis when he was eight." (M03)

"I think he was diagnosed with autism, he must have been about three and a half years, four years, two and a half years ago we started the search for the diagnosis." (M06)

"That's what I discovered, I suspected at about 4 years, but the diagnosis itself, he was already 5 years old." (M08)

"Oh, we used to spend a lot of time in the hospitals, those things, but I kind of knew it, but it took me a while. After several tests, we did a lot of things, and no doctor said anything, was normal, had nothing, but then we took the specialist right now, the neuropediatra, she already gave the autistic report there, but then with eight years, right, she was eight years old." (M14)

"She was two and a half years old." (M18)

Based on the mothers' reports, a mean age was found for the diagnosis of autistic spectrum of the child of 3 years and 4 months, the youngest being diagnosed at 20 days and the oldest at 8 years. This diagnosis was initially based on the mothers' perception of their children's behavior, focusing mainly on the issue of speech and walking development, which led to their distrust and curiosity to investigate the child's diagnosis. The early discovery of the diagnosis becomes important in the matter of the immediate possibility of interventions, of great importance, since the positive results of responses to the therapies are more relevant and effective when initiated early.

The diagnosis of ASD in a child has been described in the literature by several authors as a reason for frustration and excessive maternal stress, as well as the difficulty in communicating their desires, thus constantly experiencing such feelings. According to Malagris⁽⁹⁾ these feelings can lead to chronic stress, if much present in people's lives. In addition to the feelings of frustration commonly experienced by these mothers, several causes are associated with the predominance of maternal stress,

because they are the main caregivers of these mothers⁽¹⁰⁾. When we asked the mothers about their feelings about their children, we obtained the following reports:

"The first feeling I had when I discovered that he was autistic was ... a feeling of confusion like that, of feeling lost, not knowing what I was going to do, how it was going to be, what I was going to do, where I was going, what I was going to do, a feeling of confusion, but then it passed, it was passing, with time it was coming the acceptance and seeking help for his best treatment" (M01)

"Anguish, sadness, fear, the first feelings were these." (M06)

"It's a feeling of mourning right now, that from what we know about autism, and I did not know anything, I started to research, it's a syndrome that's going to be for the rest of my life, yeah, he's going to be autistic forever, the feeling of mourning, the first few days I cried two days, two days I cried without stopping, then I good, have to accept after that came the whole process no deaceitação. Negación in some moments that we even suspected and went through several professionals and some told me that he was not autistic, because you came to the diagnosis of truth, with confidence, moments of denial, but then I went behind, I started to go after people who also have autistic children here in capon and I started to go after treatment." (M08)

"It was concern for him in the future, in his teenage and adult life." (M19)

From the reports we can see that all the interviewees experience feelings that cause emotional damage, such as: confusion, frustration, mourning, anguish, sadness, fear, worry and even relief for the discovery of the diagnosis. Most of these feelings can shake the mental health of mothers and families, thus causing chronic stress and difficulty in accepting and dealing with one's own child. Identifying the feelings that mothers develop during the care of their children is of paramount importance so that care can also be provided to them, which are key parts in this complex process. Being able to develop a qualified listening to the mother and family allows us to provide a dignified assistance to these in their difficulties.

Difficulties and prospects for the future:

Families who have children with autism spectrum disorder experience difficulties in all aspects of daily life, difficulties begin when they try to understand what is wrong with the child, because their behavior is different from the others. For parents it is difficult to identify whether the picture that the child presents is specific to some disease or if it is only a child's own behavior⁽¹¹⁾. Mothers when questioned about the greatest difficulties encountered in their child's daily life, have reported the following:

“The biggest difficulty I see is his agitation, that he is very agitated, he has to keep looking at him all the time, I can not even sleep at times because of the agitation, but ... quiet, he is very affectionate, just have to be taking care of his fuss that he messes at everything.” (M01)

“A in everything, where you go, the way people receive you, the looks, everything ...” (M05)

“The greatest difficulties are ... one of them understands him, to know what he is saying, to satisfy also what he wants and works for development, he misses no opportunity to develop what he has, the potential that he has” (M06)

“It’s the communication, the lack of communication, this is the biggest difficulty because she cannot convey what she is feeling what she thinks, we try to guess and not always can, then it’s a very big repetition of what she says of what she conveys, she has the knowledge of a half dozen or so words, but this half-dozen words we try to have a dialogue, but we succeed, she communicates, she, very precariously.” (M12).

The care of an autistic child requires a lot of parents or caregivers, knowing to understand, being patient, having attention are some of the strategies to be able to deal with this duty that in its path has many difficulties, from the reports it is realized that there is still prejudice and lack of understanding about TEA by society. Various difficulties are reported, and besides difficulties due to external pressures, society still has a great deal of difficulty living with differences, which becomes the main conflict suffered by the relatives of the autistic child, which is prejudice.

The literature describes that the mothers’ greatest concern about the future of the autistic child is related to the need for responsibility for the autistic child, but at the same time they seek the independence of the child and encourage actions in the daily life of the child⁽¹²⁾. With the reports about the expectation about the future of the children, they follow the line:

“Look, at first I did not believe he could be independent, have a profession, but today with all the help I have with professionals, with acquaintances who do not even have the AMA group right now, we can to join them enough to help them in everything, so now I’m believing that he can have the future better, kind of suddenly getting a job, you know, if it’s independent, through a lot of fighting that we’re running after, right, if they dedicate to go behind, help of professionals, they can, yes.” (M03)

“Well, I ... I do everything I can do today, at the moment he has, he’s having the necessary treatments like that ... That I can pay obvious right, he has an extracurricular support, private psycho-pedagogue, which is where he learns most, that at school it is very difficult for him to learn. Because I do not have great expectations and

at the same time I dream of his autonomy, my main objective is that he has the maximum of autonomy possible, that’s right...” (M08)

“The only thing I want, that she is happy, no matter what she will know, if she will know how to read if she will not read, if she will study if she is, just be happy, and she is a joyful child, a happy child, what she has, what she can do, because she is now looking for her independence, she is dynamic, she is the holy diva, she likes to draw, she likes to paint, she likes to write although she is not literate., some letters she writes, she likes to watch videos, dance, not much because of the motor, that now began to be developed the fine motor at the age of fourteen only the fine motor began to develop, so the important thing for us is only that she is happy.” (M12)

“A grown man, a hard-working, well-educated man, his family having his wife, his children, and serving God in the first place, which is what I am trying to take God’s way, fulfill my dream, touching one, an instrument inside the church, with his family and his son, is my greatest desire, if God fulfills this desire he does not have to do anything else.” (M19)

It can be noticed from the reports that the experience of motherhood, while having an autistic child, becomes a complex and challenging experience for women, once they meet the unexpected and unknown, about the future there are some expectations, however many uncertainties, and because of this, some mothers end up having more difficulties planning for their future and even the autistic child.

CONCLUSION

From this research it was observed that children with autism were diagnosed with an average age of approximately 3 years, an age considered to be common in the literature. Early diagnosis generates a possibility of planning and use of educational services for the best development of this child and supports the demands of families.

The discovery of the diagnosis of ASD has caused important feelings of detriment and non-acceptance to these mothers. This fact has a direct reflection on the daily life and the family context, as well as the expectation of the child the mothers face a feeling of frustration. Negative feelings arise, thus affecting the mental health of these mothers and their families, which ends up generating an acceptance that is often late, which may affect the development of the child and the mother and child relationship. It was noticed that some changes in the routine, especially on the part of the mothers occurred with all interviewed, mainly regarding the difficult socialization of the child and acceptance by the society.

The difficulties of the child's relationship and interaction often lead these mothers to no longer go out with their children, avoiding social environments, especially to avoid demonstrations of prejudice towards the child and their behavior. Although the mothers cannot predict the future of the children, it was noticed that the majority of

the mothers aim at the independence and happiness of this child. And that despite the limitations of these children, all have some kind of educational and therapeutic support, although very fragile, contribute to the development, in order to reach their independence and acceptance in society in the future.

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