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Feelings of families of children with autistic spectrum disorder

Sentimientos de familias de niños con trastorno del espectro autístico**Percepções e sentimentos de famílias de crianças com transtorno do espectro autista****ABSTRACT**

Objective: To identify the perceptions and feelings of families of children with Autistic Spectrum Disorder. **Methods:** Descriptive research with a qualitative approach, had as participants the families of children with Autistic Spectrum Disorder (ASD) followed at a Rehabilitation Center in a city in Ceará, from July to September 2018. For information collection, it was applied a semi-structured interview script. The information was analyzed based on content analysis. **Results:** The following categories emerged: (1) Perceptions of family members about the child with ASD in the family and (2) Feelings of family members regarding the child with ASD. **Conclusion:** The diagnosis of ASD reveals important repercussions in the family environment. The emotional conditions of family caregivers of children with ASD interfere in the effectiveness of early intervention processes.

DESCRIPTORS: Family; Family Relations; Family Characteristics; Child; Childhood Autismo.

RESUMEN

Objetivo: Identificar las percepciones y sentimientos de las familias de niños con Trastorno del Espectro Autista. **Métodos:** Investigación descriptiva con abordaje cualitativo, tuvo como participantes a las familias de niños con Trastorno del Espectro Autista (TEA) seguidos en un Centro de Rehabilitación de una ciudad de Ceará, de julio a septiembre de 2018. Para la recolección de información se aplicó un semi- guión de entrevista estructurado. La información se analizó mediante análisis de contenido. **Resultados:** Surgieron las siguientes categorías: (1) Percepciones de los miembros de la familia sobre el niño con TEA en la familia y (2) Sentimientos de los miembros de la familia con respecto al niño con TEA. **Conclusión:** El diagnóstico de TEA revela importantes repercusiones en el ámbito familiar. Las condiciones emocionales de los cuidadores familiares de niños con TEA interfieren en la efectividad de los procesos de intervención temprana.

DESCRIPTORES: Familia; Relaciones Familiares; Composición Familiar; Niño; Autismo Infantil.

RESUMO

Objetivo: Identificar as percepções e sentimentos das famílias de crianças com Transtorno do Espectro Autista. **Métodos:** Pesquisa descritiva com abordagem qualitativa, teve como participantes as famílias de crianças com Transtorno do Espectro Autista (TEA) acompanhadas em um Centro de Reabilitação de um município do Ceará, no período de julho a setembro de 2018. Para coleta de informações foi aplicado um roteiro de entrevista semi-estruturada. As informações foram analisadas a partir da análise de conteúdo. **Resultados:** Emergiram as seguintes categorias: (1) Percepções dos familiares sobre a criança com TEA na família e (2) Sentimentos dos familiares referentes a criança com TEA. **Conclusão:** O diagnóstico de TEA revela repercussões importantes no âmbito familiar. As condições emocionais dos familiares cuidadores das crianças com TEA interferem na efetividade dos processos de intervenção precoce.

DESCRIPTORES: Família; Relações Familiares; Características da Família; Criança; Autismo infantil.

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INTRODUCTION

In Brazil, according to Law No. 12.764, Autistic Spectrum Disorder (ASD) is considered a disability and integrates the fifth version of the Diagnostic and Statistical Manual of Mental (DSM), characterized by functional impairment in the areas of communication, social interaction and behavior.^{1,2} With regard to epidemiology, according to the United Nations (UN), about 70 million people in the world are affected by ASD, and, in children, it is more common than cancer, AIDS and Diabetes mellitus.³

The child with ASD requires greater care and attention from parents or caregivers, therefore, it is believed that this will have an impact on the family, since there are many difficulties to be faced in socializing the children. In addition, the lifelong expectations that parents tend to have about their children's lives generate a set of frustrations at the time of diagnosis. Added to this, conflicts arising from the stress that parents experience, routine irritability, among others.⁴

When faced with the diagnosis of ASD, several feelings are manifested about parents and family. Among them, the loss of the idealized child, feelings of sadness, insecurity about the new reality, changes in the family routine and impotence regarding

the provision of care, which centered on the child.⁵

Understanding the series of implications that arise in the lives of parents of children with autism spectrum disorder, the dynamics of ASD, how early intervention can favorably impact development are essential points for parents that should be offered in the diagnosis or suspicion of ASD.⁶ In this perspective, the nurse assumes an important role with regard to supporting children with ASD and their families, by recognizing the most relevant points in the relationship between parents and atypical children, measures can be proposed that inform and communicate not only family members, but population in general that still barely understands what the ASD is.⁷

The discussion about ASD in the different contexts in which children are inserted, represents a need for knowledge about what is the autistic spectrum and the demystification of stereotypes, proposing new views and interpretations, through the possibilities of care and social integration of the child with ASD and their family.⁸

In this way, the ASD has been occupying the agenda of Brazilian public policies, however, it is still necessary to advance in the construction of powerful local networks that support the expanded clinic with children, organizing care so as not to overload family members or neglect their needs, prioritizing dialogue

in order to understand their perceptions and feelings.⁹

From the experience lived in the care of a child with ASD, concerns emerged regarding the little acceptance of autistic behaviors by society and by other family members, as well as an intense routine necessary for the care of children. Thus, this study aimed to identify the perceptions and feelings of families of children with Autism Spectrum Disorder.

METHODS

Descriptive study with a qualitative approach. The article originated from a multicenter study entitled "Experiences of families with children with disabilities: Organization, Practices and Needs" with funding from the National Council for Scientific and Technological Development (CNPq - Conselho Nacional de Desenvolvimento Científico e Tecnológico), and was approved by the Research Ethics Committee of the Graduate Program in Nursing (UFPR) on the CAAE: 73197617.0.1001.0102, with opinion No. 2.806.799. It is linked to the Study Group on Health Vulnerability (GEVS - Grupo de Estudos em Vulnerabilidade em Saúde) of the State University of Vale do Acaraú (UVA).

The research setting was a Rehabilitation Center that provides assistance to

children with special needs, located in the municipality of Sobral, Ceará, Brazil. The participants were the 24 family members of children with ASD attended by the aforementioned service. The inclusion criteria consisted of family members of children diagnosed with ASD aged between 3 and 10 years.

Data collection was carried out from July to September 2018. The instrument applied was a semi-structured interview script consisting of questions about the daily life of family members of children with ASD.

The information was analyzed based on Bardin's framework that uses the association of qualitative methods through thematic categorical analysis.¹⁰ The

following categories emerged: (1) Perceptions of family members about the child with ASD in the family and (2) Feelings of family members regarding the child with ASD.

The study followed the ethical precepts of Resolution No. 510/16 of the National Health Council, which provides for the standards applicable to research in Human and Social Sciences whose methodological procedures involve the use of data directly obtained from the participants or of identifiable information or that may entail greater risks than those in everyday life.¹¹ Participants signed the Informed Consent Form, which informed about the risks and benefits, as well as the guarantee of anonymity.

RESULTS

In this chapter, the characterization of the participants is presented and, consequently, the analysis of the information in categories, discussed with the pertinent literature.

As for the participants, it was found that most caregivers of children with ASD were female relatives, and 11 were mothers of the children. Other degrees of kinship observed were: father (01), grandmother (01) and sister (01).

Regarding the age group, it was observed that the research members belonged to the age group of 20 to 50 years old, in which the predominant age was between 31 to 40 years old. Regarding the education of participants, about five reported having completed higher education, three incomplete high school, two complete high school, two technical level education, one incomplete primary education and the rest correspond to those with incomplete higher education.

Regarding monthly income, nine of the participants had an income between one and two minimum wages, three of them had an income of one minimum wage and two had an income above three minimum wages.

Perceptions of family members about the child with ASD in the family

It can be seen that families with children diagnosed with ASD had challenges in care. Participants reported that they did not have knowledge about the ASD and briefly described that after acquiring knowledge of the characteristics of the ASD, the care process became less exhaustive:

For me, at the beginning, everything was very new, in fact I had never even gone into the subject of knowing, understanding and from his birth I started to look for it [...] (E9)

[...] But like that, at the beginning it was a little difficult in the sense of lack of knowledge, but over time... today I have no difficulties, for me

Tabela 1 - Distribuição dos dados dos participantes da pesquisa, familiares de crianças com Transtorno do Espectro Autista, Sobral, Ceará, Brasil, 2018.

VARIÁVEIS		NO
Parentesco	Mães	11
	Pais	01
	Avó	01
	Irmão(a)	01
Sexo	Masculino	01
	Feminino	13
Idade	20 a 30	03
	31 a 40	08
	41 a 50	03
Escolaridade	Ens. Fundamental Incompleto	01
	Ens. Médio Completo	02
	Ens. Médio Incompleto	03
	Ens. Superior Completo	05
	Ens. Superior Incompleto	01
	Ens. Técnico Completo	02
Situação Civil	Solteiro	04
	Casado	06
	União Estável	02
	Divorciado	01
	Viúvo	01
Renda Mensal	1 salário mínimo	03
	1 a 2 salários mínimos	09
	Acima de 3 salários mínimos	02

Fonte: Própria dos autores (2018).

he is a normal person and for me he is not a problem, you know? I really don't have any difficulties! (E12)

It was identified in other speeches that some interviewees have difficulties in the care process even when acquiring knowledge about ASD:

It's difficult, right... Living together, because most of us don't know how to fight with the child they have, so, how will we be living with them? That it's difficult for us to understand their things [...] (E2)
It's difficult [...] a little difficult, but I'm dealing, I'm dealing with (pause and deep breathing) I accepted as normal. There are other cases in the family with special children. (E3)

It is noted in the speeches the challenge for families in the learning process and the child's behavior:

... I didn't know what he had and I wanted to educate him like the others, take him to Mass and I wanted him to sit there like I did with my other children and I can't do it with him. So as I wanted to do it the way that is not his way, I wanted to do it my way I never could and after I found out everything became easier because I can do things with him in his time. (E2)
[...] in crises it is difficult, but sometimes I don't even think she is autistic. Only in learning, I just remember that she is autistic when studying, because I think she won't learn. (E12)

Feelings of family members regarding the child with ASD

Knowing the feelings and emotions of family members enables the performance in the care process of children with ASD, in this study we found several feelings that configure points that favor the child's performance. Among the most described by

the participants, the feeling of gratitude and joy for living with a child with ASD was identified:

But like, normal, I don't see any difference, like, no abnormality and so it gives more joy than others, intelligence is incomparable. (E9)
He talks, he walks... It's difficult, everything for him is more difficult, but I'm grateful for being autism. (E1)

Another issue mentioned in the speeches is the anxiety of participants who have neurotypical children and the new experience of motherhood and fatherhood with atypical children, it is observed that family members carry out comparisons:

[...] that even though I thought he was different, I didn't know what he had and I wanted to educate him like the other children, take him to Mass and I wanted him to stay seated, like I did with my other children and with him, I can not. (E10)
I can't say how it was, because my two boys aren't... and then this last boy was born autistic, I don't know, as a first-time mother. (E13)

DISCUSSION

Changes in the family structure in contemporary society highlight the entry of women into the labor market, their assumption of a more active role in social life and their greater contribution to the economic subsistence of the family. Consequently, the increase in the number of families in which both parents work, leading to a greater need for family tasks to be redistributed.⁶ In this context, the mother of a child with ASD experiences different stressors in the process of being a mother and primary caregiver.

A study carried out with family members of children with autism spectrum disorder in Rio Grande do Sul corroborates the above by mentioning that, given the characteristic demands of the ASD, it was mainly female figures who stopped

working to dedicate themselves fully to child care.¹²

In this context, families are faced with intense changes in their daily activities in view of the demands of the child with ASD.¹² In the study of daily experiences and demands in the context of caring for children diagnosed with autism spectrum disorder, it was identified that families organize their routine according to the child, both the home routine and the social routine.¹³

In a study on subjectivity and care in pediatric hospitalization related to the vulnerabilities of children with special needs, there is a reflection for working with children with chronic and complex health conditions, including disabilities and ASD, requiring professionals' skill and sensitivity to the recognition and interpretation of the subjectivity of the child and family.¹⁴

Another aspect to be mentioned is the financial limitation, which can be an impasse for specialized treatment as it involves monitoring with professionals from different areas, which can be costly. Furthermore, the family income thus directed could harm the needs of other members and the expenses common to the home, which could compromise leisure and other family activities. There is, therefore, a need to consider in this context financial issues and the lives of all members of the family group.¹⁵

Regarding the level of education of the participants, a relevant percentage had more years of education, which benefits the understanding of the chronic condition of ASD and the recognition of the importance of its treatment. The literature recommends that the family should seek to know the ASD after the diagnosis in order to favor the acceptance of this new condition among family members and facilitate care. Involvement in support groups is also suggested to help face challenges and share experiences, thus becoming more capable and prepared for healthy interaction.¹⁶

Although the diagnosis of ASD can represent a challenge for family members, it is observed that understanding the ASD

and the family's positive feelings for the child overcome the difficulties and impasses, through affection and lessons learned in this relationship. Thus, the emotional conditions of parents increase the effectiveness of early intervention processes.¹⁷ This evidence indicates the importance of a reciprocal look between the effects of the child with ASD on the family system and the impact of the family context on

the child with ASD due to the role of family relationships that are involved in the social and communicative processes associated with ASD.¹⁸

CONCLUSION

The diagnosis of ASD reveals important repercussions in the family environment, being attributed to the lack of knowledge

about the subject and positive feelings attributed to overcoming challenges. Thus, the emotional conditions of family members of children with ASD interfere in the effectiveness of early intervention processes. It is believed that identifying the perceptions and feelings of families of children with ASD enables a more humanized and specialized care, according to the particularities of each child and family. ■

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