Original Article

doi: https://doi.org/10.1590/1983-1447.2021.20200437

Experiences of family members of children diagnosed with autism spectrum disorder

Vivências de familiares de crianças diagnosticadas com Transtorno do Espectro Autista

Experiencias de familiares de niños diagnosticados con trastorno del espectro autista

Revista Gaúcha de Enfermagem

Juliana Macêdo Magalhães[a,b,c]
Thalia Alves Rodrigues[d]
Marly Marques Rêgo Neta[e]
Carolinne Kilcia Carvalho Sena Damasceno[a,b]
Kayo Henrique Jardel Feitosa Sousa[f]
Emília Ângela Lo Schiavo Arisawa[b]

How to cite this article:
Magalhães JM, Rodrigues TA, Rêgo Neta MM, Damasceno CKCS, Sousa KHJF, Arisawa EALS. Experiences of family members of children diagnosed with autism spectrum disorder. Rev Gaúcha Enferm. 2021;42:e20200437. doi: https://doi.org/10.1590/1983-1447.2021.20200437

ABSTRACT

Objective: To describe, in the mothers' perception, the experiences lived by families in the care of children with autism spectrum disorder.

Method: Qualitative study, carried out with 20 mothers of children diagnosed with autistic disorder accompanied by an institution in Teresina-Piauí, Brazil. Semi-structured interviews were conducted between February and March 2019 and subjected to content analysis.

Results: Five central ideas related to the stages experienced by family members after the diagnosis were identified, ranging from denial to acceptance. Family members and caregivers experience feelings of sadness and mourning for the discovery of the impossibility of curing the syndrome, revealing the need for care for this family. The search for help and adaptations of the routine are constant experiences.

Conclusion: Caring for children who live with autistic disorder involves learning ranging from structural to emotional aspects, such as dealing with limitations and impossibility of cure, pointing out to the need for family care.

Keywords: Autistic disorder. Mental health. Family health.

RESUMO

Objetivo: Descrever, na percepção das mães, as experiências vivenciadas por famílias no cuidado de crianças com Transtorno do Espectro Autista.

Método: Estudo qualitativo, realizado com 20 mães de crianças diagnosticadas com transtorno autístico, acompanhadas por uma instituição em Teresina, Piauí. Entrevistas semiestruturadas foram realizadas entre fevereiro e março de 2019, e submetidas à análise de conteúdo.

Resultados: Foram identificadas cinco ideias centrais relacionadas aos estágios vividos pelos familiares após o diagnóstico, desde a negação até a aceitação. Familiares e cuidadores vivenciam sentimentos de tristeza e luto pela descoberta da impossibilidade de cura da síndrome, revelando a necessidade de cuidado para com essa família. A busca por ajuda e as adaptações da rotina são vivências constantes.

Conclusão: Cuidar de crianças com transtorno autístico envolve aprendizados que vão dos aspectos estruturais aos emocionais, como lidar com as limitações e impossibilidade de cura, apontando para a necessidade de um cuidado familiar.

Palavras-chave: Transtorno autístico. Saúde mental. Saúde da família.

RESUMEN

Objetivo: Describir, en la percepción de las madres, las experiencias vividas por las familias en el cuidado de niños con trastorno del espectro autista.

Método: Estudio cualitativo, realizado con 20 madres de niños diagnosticados de trastorno autista acompañados de una institución en Teresina-Piauí, Brasil. Las entrevistas semiestructuradas se realizaron entre febrero y marzo de 2019 y se sometieron a análisis de contenido.

Resultados: Se identificaron cinco ideas centrales relacionadas con las etapas vividas por los familiares luego del diagnóstico, que van desde la negación hasta la aceptación. Los familiares y cuidadores experimentan sentimientos de tristeza y duelo por el descubrimiento de la imposibilidad de curar el síndrome, revelando la necesidad de cuidar a esta familia. La búsqueda de ayuda y adaptaciones de la rutina son experiencias constantes.

Conclusión: Cuidar a los niños que viven con trastorno autista implica aprender que van desde los aspectos estructurales hasta los emocionales, cómo afrontar las limitaciones y la imposibilidad de cura, apuntando a la necesidad del cuidado familiar.

Palabras clave: Trastorno autístico. Salud mental. Salud de la familia.

[a] Centro Universitário Uninovafapi, Departamento de Enfermagem. Teresina, Piauí, Brasil.

[b] Universidade do Vale do Paraíba (UNIVAP), Instituto de Pesquisa e Desenvolvimento. São José dos Campos, São Paulo, Brasil.

[c] Centro Universitário Uninovafapi, Departamento de Medicina. Teresina, Piauí, Brasil.

[d] Pesquisadora autônoma. Barro Duro, Piauí, Brasil.

[e] Universidade Federal do Piauí (UFPI), Programa de Pós-Graduação em Enfermagem. Teresina, Piauí, Brasil.

[f] Universidade Federal do Rio de Janeiro (UFRJ), Escola de Enfermagem Anna Nery. Rio de Janeiro, Rio de Janeiro, Brasil.

INTRODUCTION

Autism Spectrum Disorder (ASD) is considered a syndrome of multicausal origin, as it involves several neurological, genetic, and social factors. However, the specificity of etiology is still unknown(1). In recent years, there has been a significant increase in ASD diagnoses(1). The world estimate is that 1% of the population is diagnosed with the disorder(2).

The ASD consists of a set of conditions that are characterized by a series of factors that compromise communication, language and social behavior(1–2). It is identified as a developmental disorder, as the definition is based on assessments of the individual's behavior, being determined by deficits in social communication, interaction, sensory sensitivity, motor coordination and attention levels, presenting difficulties in relation to to the effort and involvement to carry out activities(1–3).

The diagnosis usually occurs in childhood, a phase in which the syndrome's manifestations can be perceived by the alterations in the cognitive functions mentioned above(1–3). There is no cure for ASD. However, since the 1980s, there are intensive behavioral interventions that have provided relevant improvements in the development of diagnosed children, especially when combined with early detection(1–4).

After receiving the diagnosis of the disorder, the family members of these children feel distressed and helpless; therefore, they need emotional support and encouragement to care for their children. It is important that these parents receive assistance with regard to the educational role they must play, as their participation in the child's treatment is essential(5).

Family members of children with ASD are impacted by their children's diagnosis because they are afraid of their future since there are limitations in the child's development. This knowledge generates worries with the care of children when they are no longer present(6).

Most families feel fragile when receiving the diagnosis and take time to believe that their child has a problem. However, parents/caregivers realize – even before the diagnosis – that their children behave differently from other children, which is why they seek medical evaluation(3–6).

Studies indicate that the family's daily life changes, in most cases, it is necessary to stop participating in some events or even to give up leisure time due to the child's condition. The presence in certain activities – such as those involving social interaction – requires extra attention, considering that, generally, those who live with ASD have difficulty in social interaction. Thus, the scenario regarding the number of people who will be in the place must be evaluated, as well as the intensity of sound in the environment, among other points, causing, in most cases, the cancellation of participation in these leisure activities(6–8).

By knowing that the child with ASD is attached to limited and continuous activities, the family must develop a new routine that allows them to adapt to their needs. Thereby, it is important for the family to be completely in harmony with the child to deal with the frequent behavioral changes that the child may experience. A study pointed out that the grandparents of these children play an important role, as they are responsible for the care when the parents are at work, being central to their well-being(7).

Family members of the child with ASD, in most cases, are exclusively responsible for the care, without professional help. In this way, it is understood that the family also needs specific care(9), in addition to instructions and techniques to relieve stress, as the tasks that the child's caregiver assumes have an impact on their quality of life. The purpose is for the family to have a better life condition, so that it can provide more attention to the member who has ASD.

When considering the setting and aspects pointed out, the following guiding question was formulated as a starting point for the study on the subject: what are the experiences of family members of children diagnosed with ASD? From it, the objective was to describe, in the mothers' perception, the experiences lived by families in the care for children with autism spectrum disorder.

METHOD

This is a qualitative and descriptive study, developed in a public institution, located in the city of Teresina, Piauí, Brazil. This association, created in 2010, is made up of parents and professionals who seek to increase people's awareness of ASD and give support to these families. The main objective of this association is to improve the adaptability and quality of life of people with ASD, as well as their families, to minimize prejudice related to the disorder.

It was adopted as inclusion criterion to be a family member of a child diagnosed with ASD, and the exclusion criterion was less than six months of follow-up at the institution.

For the selection of participants, an intentional sampling was used, consisting of family members of children who had been diagnosed with ASD, complying with the eligibility criteria. Thus, 20 family members were listed, with no refusals and/or withdrawals.

Data collection was carried out in February and March 2019, at the study institution, through individual semi-structured interviews, recorded in audio and transcribed in full. It is noteworthy that the interviews were previously scheduled, according to the availability of the participants, and took place when the child was being attended by the association's professionals. Data collection was carried out in a private environment, with the participation of a researcher and one participant.

For this, an interview script was used that included sociodemographic characterization – age group, degree of kinship with the child, number of children, marital status, family income, residence, age of the child at the time of ASD diagnosis and cases of ASD in the family – and participants were asked to talk openly about the impact of the diagnosis of autistic disorder on their family and the daily experiences as a family member of a child with ASD.

It is noteworthy that, to verify the understanding of the questions, a pilot test was carried out with two family members of autistic children, whose interviews were excluded from the data analysis process. To stop data collection, it was adopted the criterion of recurrence of themes in the statements, which included the transcription of the interviews and the execution of repeated readings.

For content analysis, the Descending Hierarchical Classification (DHC) technique was applied, through the R interface software *pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRAMUTEQ). The following steps were observed: data preparation with transcripts and textual corpus organization in a single file; floating reading to bring researchers closer to the singularities contained in the data; and data processing through DHC. The textual corpus processing allowed to obtain a stable and definitive classification of the content into groups of text segments with similarities.

The text segments constituting the classes generated by the DHC were submitted to the Collective Subject Discourse (CSD)(10) technique, according to the phases of identification of key expressions (KE) – which reveal the essence of the content contained in the segments – and survey of central ideas (CI), that is, the meanings referring to the set of segments included in the same class. Finally, similar CI were grouped into categories, and it was elaborated the synthesis-discourse. The interpretation and inferences of the raw data obtained with the software were performed to make sense of the words, supported by the available literature.

The study met the ethical precepts established for research involving human beings, starting after approval by the Research Ethics Committee, under the Ethical Appreciation Certificate No. 02853818500005210, as well as after reading and signing the Free and Informed Consent Form (FICF) by the participants.

RESULTS

Participated in the study twenty women, mothers of children with ASD, aged from 28 to 60 years, and who had between one and four children. Nine were married, nine single and two reported being in a stable relationship. Family income ranged from one to three minimum wages and most lived in Teresina, Piauí, Brazil. The age at ASD diagnosis ranged between 10 months and 7 years, and 65% of the mothers reported that they had no information about other cases of the disorder in the family.

The application of the IRAMUTEQ to analyze the statements recognized, in the corpus, 114 text segments, with 3,854 records of occurrences and use of 73% of the total. Through the DHC – which crosses matrices of text and word segments -, five classes originated from an axis were obtained, according to the dendrogram represented in Figure 1. As described in the figure, the corpus was initially divided into two axes and, from Axis 1, classes 1 and 4 emerged, which are correlated and sustain each other. Following, Axis 2 also branched out: on the one hand, it gave rise to Class 5; on the other hand, after a new crossing of data, it determined classes 2 and 3.

Each class is described by the most significant words (most frequent) and their associations with the class (X^2), according to Figure 2.

The presentation of the results was made according to the division and order of the DHC. The most representative KE for the set of ideas – that is, those that concentrated the signification and senses of the reports – were grouped when they referred to the same CI, thus building the CSD. In this way, the themes are presented with the respective CI and CSD.

Class 1: Experiences and knowledges of family members about autism

The central idea of Class 1 presents the words of great relevance that demonstrate the knowledge of family members after the diagnosis of ASD and the search for help in support institutions. The words were "autism", "life" and "know", which have the conceptions about the diagnoses.

> *I knew it was something that had to change in my life, I had to have more responsibility for it, because they don't have much sense of danger. Did you understand? At the age of three, I was able to talk to the pediatrician and*

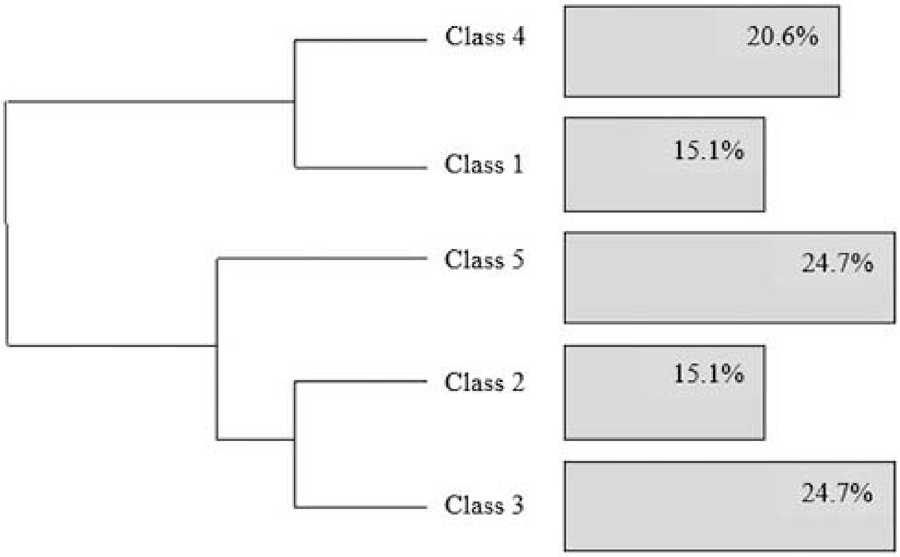
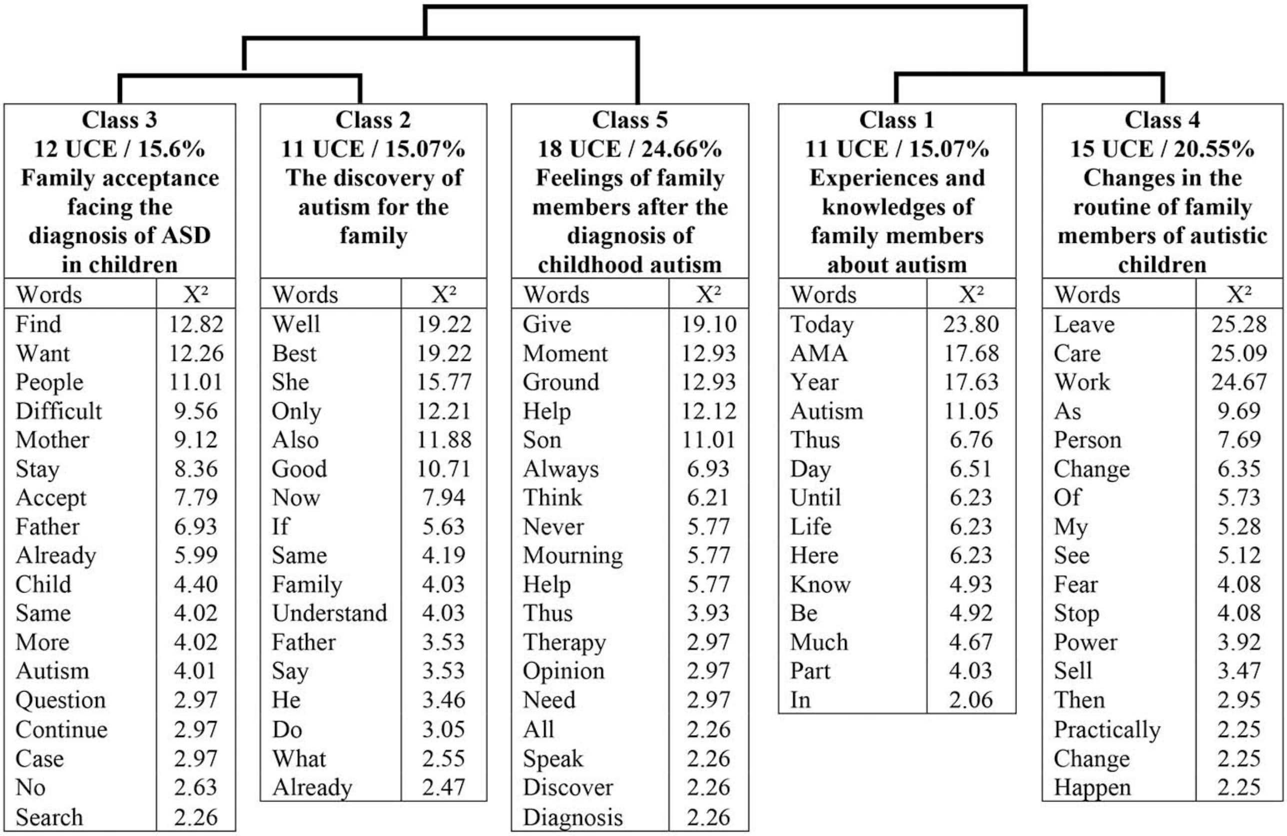


Figure 1 – Dendrogram of classes obtained from textual corpus processing. Teresina, Piauí, Brazil, 2019
Source: Research Data, 2019.



Class 3
12 UCE / 15.6%
Family acceptance facing the diagnosis of ASD in children

Words	X²
Find	12.82
Want	12.26
People	11.01
Difficult	9.56
Mother	9.12
Stay	8.36
Accept	7.79
Father	6.93
Already	5.99
Child	4.40
Same	4.02
More	4.02
Autism	4.01
Question	2.97
Continue	2.97
Case	2.97
No	2.63
Search	2.26

Class 2
11 UCE / 15.07%
The discovery of autism for the family

Words	X²
Well	19.22
Best	19.22
She	15.77
Only	12.21
Also	11.88
Good	10.71
Now	7.94
If	5.63
Same	4.19
Family	4.03
Understand	4.03
Father	3.53
Say	3.53
He	3.46
Do	3.05
What	2.55
Already	2.47

Class 5
18 UCE / 24.66%
Feelings of family members after the diagnosis of childhood autism

Words	X²
Give	19.10
Moment	12.93
Ground	12.93
Help	12.12
Son	11.01
Always	6.93
Think	6.21
Never	5.77
Mourning	5.77
Help	5.77
Thus	3.93
Therapy	2.97
Opinion	2.97
Need	2.97
All	2.26
Speak	2.26
Discover	2.26
Diagnosis	2.26

Class 1
11 UCE / 15.07%
Experiences and knowledges of family members about autism

Words	X²
Today	23.80
AMA	17.68
Year	17.63
Autism	11.05
Thus	6.76
Day	6.51
Until	6.23
Life	6.23
Here	6.23
Know	4.93
Be	4.92
Much	4.67
Part	4.03
In	2.06

Class 4
15 UCE / 20.55%
Changes in the routine of family members of autistic children

Words	X²
Leave	25.28
Care	25.09
Work	24.67
As	9.69
Person	7.69
Change	6.35
Of	5.73
My	5.28
See	5.12
Fear	4.08
Stop	4.08
Power	3.92
Sell	3.47
Then	2.95
Practically	2.25
Change	2.25
Happen	2.25

Figure 2 – Thematic structure of the classes generated by IRAMUTEQ by Descending Hierarchical Classification. Teresina, Piauí, Brazil, 2019
Source: Research Data, 2019.

> *that's where I concluded the diagnosis that she really was autistic and that's where all my struggle began and, to this day, I'm here in the autistic association, chasing and, nowadays, to me autism is nothing, because her autism is very much like those that she does not tolerate noise, crowd, fireworks noises. She doesn't like it and, to a certain extent, due to her behavior, there are days when she is great, there are days when she is terrible. So, I came to find out what it was and enroll her, I got a place here at the autistic institution and, to this day, I'm here with her and seeing more of her performance. She interacts more with children, but practically, even today, I wonder without knowing, I still don't know everything about autism.*

Class 2: The discovery of autism for the family

Class 2 speaks how the family experiences the care of the child diagnosed with ASD, which was perceived by the key expressions "best", "well", "understand" and "family". The importance of providing adequate assistance to those responsible for children with ASD is emphasized, as the family is the first environment for their socialization and seeks strength to deal with difficulties and setbacks related to ASD.

> *For us, it wasn't much of a surprise by her birth diagnosis. I accompanied my niece when she was born in the maternity ward and, as a result, the doctor that saw immediately said that she had it and that she was special. I, as an aunt, I love her dearly. So, I took my vacation to accompany her, I embraced the cause. Then I had my son and, at the age of three or two, I started to discover that he had some difficulties, I didn't really know what it was, and that was when all my struggles started. For others, he didn't speak, he gestured, he spoke in the third person, I really thought it was his age, a child of two, three years old usually has these attitudes, but it got to the point that he was growing and instead of improving, he it was getting worse. When we found out, we didn't know what it was, as time went by, we went deeper, it didn't have that much impact because we didn't know. The only thing at the beginning was the curiosity to know, when we were researching and knowing, we were acquiring and everything else. There are people who despair, we didn't have this curiosity to be able to help him because, if there are other autistic people in the family, we don't know, but my family always tried to interact to help in his treatment.*

Class 3: Family acceptance facing the diagnosis of ASD in children

Class 3 presents as central idea, through the statements, the difficult experience of the diagnosis of ASD, which alternates moments of acceptance, rejection, hope and anguish. The family seeks to better understand the disorder that affects children's lives, trying to understand the diagnosis to provide adequate treatment, knowing how to deal with it and promoting good quality of life for the child and other family members. The words of great relevance were "want", "difficult", "accept" and "continue", which demonstrated the feelings of family members after the diagnosis.

> *I think I even accepted quickly; I had that quick understanding. The mother, sometimes, gets that little pain in her heart, because we know that a lot will change; but ok, I took it. So, it's something I was working on, and I went looking for treatment. There wasn't that issue of mourning. This was more with his father, who was difficult to accept, they said the boy had nothing: he just doesn't have the patience to stay in the classroom. I didn't despair, I just wanted to know what autism is, my feeling was that I really wanted to understand. But he (the father) didn't want to admit it, he didn't even want me to wear the blouse here, saying that the boy didn't have that the people would see, he became more worried, but over time he accepted, now he exaggerates. We think it's a punishment because this happened, mainly for me, because I don't have any family support. I don't have anyone to support, I'm alone with him, so for me it was very difficult. They are seeing with another look the issue of my son who has a need and needs more help, first we have that feeling of guilt, I think every mother when she finds out, asks herself. For me, in my case, at the beginning, I felt because I wasn't prepared, because although I already had one in the family, but we never feel when it's not in our own skin. For me, I felt that was a lot difficult to accept.*

Class 4: Changes in the routine of family members of autistic children

The central idea of this class is specified by the key expressions "leave", "care", "work" and "change". Through the speeches, she addresses the experience of family members to adapt to the routine and incorporate new habits, as well as reorganizing the lifestyle, relationships, and bonds of work, which must be reassessed to allow for the care of the autistic child.

> *The change was everything, because I can't work, I only must take care of my daughter, go to school with her. For me, everything changed, because I practically live just for her. I was sad, but it was something I was really working on in my head, due to this Nursing course I took, so I was seeing the characteristics, but I couldn't say. The change was because I had to go after her treatment and leave my work behind. I worked and took my child to work, because I really don't have anyone and I couldn't do that anymore, because I had to be looking for her appointments, her treatment. At the time, I had a pharmacy, I finished the pharmacy to take care of her, as it was little and sold very little, it was just an occupation, it was better to close it down, so what changed was my routine. As she grew up, I had to stop working, because before I worked, I spent four months of maternity leave and I left her for about six months with my mother-in-law. So, what has changed is that I stopped working and live only at home now, I can't work, because when I look for someone to stay, most say they can't. I had to give up working outside the home to dedicate myself to taking care of her, because if I as a mother didn't dedicate myself fully to her, I might not see any improvement over her. I stop doing things to look at her, because I'm afraid of her running and falling into the water, I have to keep an eye on her.*

Class 5: Feelings of family members after the diagnosis of childhood autism

Class 5 has as its central idea the words of great relevance demonstrating the feelings of mothers after the diagnosis of ASD. The prevalent words and key expressions were "give", "moment", "ground" and "help", which report their conceptions about the diagnoses. It was noticed, through the speeches, that many were unaware of this disorder, or thought it would be possible to cure it, allowing the feelings of sadness and mourning to manifest.

> *It's the feeling I have until today is one of loneliness. If she had accepted earlier, today she would be talking. At the time I didn't feel anything because I had no idea what it was, but from that moment that I started researching and getting interested in everything that happened, but affection is essential. Is it what I did wrong? Why was my son born that way? Why did God give me a child like that? I was always very positive, from that moment on I spent a week in mourning. That week you try to walk, but it feels like you're not stepping on the ground because your thinking is all about that need, but I knew I couldn't even afford to stop and think too long because I had to act. At the time the diagnosis was given it was not as well-known as it is now. I was always in charge, so my husband and I concluded that she needed therapy treatments. In fact, I was groundless, but at no point did I think of despairing. I just thought I want God to give me a way to help my son. When the doctor told me it was the first thing that popped into my head, so I felt this feeling of despair, of mourning that people talk about. I felt that urge to do everything I could to go where I had help to help him. It was a bombshell because we never imagined, I never imagined that I would have a special child like that, because I was always very scared, I don't know why, but I was always very scared of having a special child. I felt as if the ground had opened and I entered, it's an indescribable feeling, it felt like my son had died, the son I wanted, the son I planned for me.*

DISCUSSION

Families of children diagnosed with ASD experience a dynamic process, in which members mobilize, taking active roles in face of signs, diagnosis and care, so that the interpretation of situations experienced, as well as interactions with the child, directs the actions performed by them(11).

The daily contact with the child allows mothers to identify behaviors that are different from those observed in other children they know. Although they don't know what it is, they are aware that something differs from the observed patterns, especially when this different behavior is observed after a period of normality. From this perception, the mother – as noted in the reports – begins a pilgrimage movement through offices, hospitals and health professionals, in search of answers that help to understand what is happening with the child(12).

Faced with this situation, feelings of anguish and impotence in relation to the child's health arise, as they do not know exactly what is happening or how to help them. In Brazil, the precariousness of health services, as well as the lack of experience of health professionals in early recognition of ASD, reinforces these feelings and leads to delay and uncertainty in the diagnosis(13).

Thus, it is understandable that the disclosure of the ASD diagnosis presents itself as a complex, delicate and challenging moment for the family, as well as for the health professionals responsible for this mission. The physical environment, associated with other circumstances related to the news, can interfere positively or negatively to minimize family suffering(14).

The limited availability of time, the inability to communicate and the emotional support provided by the health professional are also significant barriers to the action of diagnosing what is legally the responsibility of the physician. However, it must be considered the importance of the presence of the multidisciplinary team in this process, in order to share the questions, anxieties and needs of the family members(15).

In this context, it is essential to plan how the diagnosis will be revealed to the family, maintaining a comprehensive dialogical relationship, in order to facilitate the flow of information provided, in addition to enabling better acceptance by the family, so that it establishes the coping strategies for the child's problem(13).

The dimension of the impact of autism on the mothers participating in this study covered numerous aspects, including change and adaptation of the space, reduction in socioeconomic level, changes in future and the possibility of generating marital conflict, among others. In view of these mobilizations, it was noticed that the consequences that a permanently symptomatic member – such as the autistic one – caused to the family, becoming a relevant factor for studies(3).

This factor often leads the family to behave in a dysfunctional way, due to the constant adaptations they need to experience, and discover the best way to help the autistic child, highlighting the possibility of developing the relationship between childhood autism and stress family(16).

Because of this, ASD affects family members, generating varied feelings and responses, determining consequences for children. When experiencing the difficulties facing autism, the family presents a state of imbalance due to stressful situations, which is reflected in family relationships, affecting the emotional health of the members. Parental stress is a common situation and strategies focused on the problem or emotions are used to face it(17).

In this context, families who find themselves in special circumstances, promoters of changes in activities of daily life and in the psychic functioning of members, such as autism, are faced with an overload of tasks and special demands, which raise potentially stress-inducing situations and emotional tension. These tense situations were found in the mothers participating in this study, who demonstrated different feelings and emotions(16,17).

The burden of these mothers, due to the care of the autistic child, is also reported in a study(18) that portrays the arduous maternal struggle in the quest to assume the comprehensive care of autistic children, both at home and in the comings and goings to the services of care to the autistic child. The mother absorbs the universe of this child in such a way that she starts reporting her daily life as if it were his. This problem is particularly associated with the social construction of the role of women as caregivers, while men are the supporters of the family.

In this conjuncture, mothers, slowly, lose their own history and identity, because they start to live for their children. Therefore, they seek support to raise a child with ASD at the Friends Association of the Autistic (*Associação de Amigos dos Autistas* – AMA) and the Parents and Friends's Association of the Exceptional (*Associação de Pais e Amigos dos Excepcionais* – APAE), which work by providing spaces for exchanging experiences and support, so that caregivers can talk about daily difficulties, feelings, frustrations, in addition to clarifying doubts and seeking advice from professionals working in these services. With this, they acquire a sense of security and motivation to move forward with the daily battle of raising autistic children in the best way possible(19).

It is in this context that nursing gains space for action, both regarding care for the child and for the family, in particular mothers, who, at this moment, are fragile, needing support and guidance about the direction to be taken.

Nursing professionals must pay attention to the singularities of individuals and their respective needs, providing comprehensive and quality care – which meets all the care demands of autistic individuals and families –, contributing to the strengthening and expansion of relational ties. The nurse involved, due to the competence in caring for the patient and his family, is a professional capable of inserting himself in home care and contributing to the organization of family dynamics.

The family demands care provided by professionals from different areas. However, it is observed that each professional works within their own assignment, in isolation, despite belonging to the same treatment team. Thus, the support offered reveals fragmented, discontinuous and out of proportion to cover all the family's needs.

Each family has needs, whose weaknesses to be covered are related to its own dynamics. It is necessary to understand the family, its structure, and its functioning, and it is up to the professional to discover, through consultations and narratives – as well as by understanding the home environment – how its organization occurs, in addition to relationships and resilience. In this sense, home visits can be part of family care planning, as they reveal issues that the office space/health institution does not cover(20).

The limitations of this study are related to the number of interviewees and the location of the study – a single unit –, which restrain the generalization of the findings. However, the results are considered reliable, as they reflect similar conditions found in research with greater scope and highlight the need for further studies involving the topic, as there is still a lack in this regard.

CONCLUSION

This study evidenced the impact of the diagnosis and the effects on the family relationships of children with ASD. From the results, it was possible to notice that the disclosure of the ASD diagnosis had important repercussions in the family context, in the concerns attributed to the mothers, as well as in the ability to understand the peculiarities of the syndrome and the important need for help to children. The study emphasized the routine changes observed in the work of these women, in the experience and living to reconcile childcare and support themselves financially.

In this way, it was highlighted the importance that the necessary clarifications are provided, the doubts and anxieties of the mothers involved at that time are minimized and that health professionals – including the nurse – know how to implement acceptance strategies and provide solid support in the dissemination of information.

It is highlighted the relevance of the present study, considering that the results obtained emphasize the perception of the woman – mother of a child diagnosed with ASD – about the disorder and their experiences in this care, raising directions for future research.

Finally, it is believed that the findings will contribute to the search for actions aimed at education and support for the caregiver family of individuals with ASD, both by nursing professionals and other professionals in the health area. The study also allows for reflections on the importance of providing appropriate care to these women, through a holistic view, without specifically focusing on the patient with ASD, but also focusing on their caregivers.

REFERENCES

1. Sociedade Brasileira de Pediatria. Departamento Científico de Pediatria do Desenvolvimento e Comportamento. Manual de Orientação: transtorno do espectro do autismo. Rio de Janeiro: Sociedade Brasileira de Pediatria; 2019 [cited 2020 Sep 30]. Available from: https://www.sbp.com.br/fileadmin/user_upload/21775d-MO_-_Transtorno_do_Espectro_do_Autismo___2_.pdf
2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. DSM-5. Washington (DC): American Psychiatric Association; 2013.
3. Carvalho Filha FSS, Silva HMC, Castro RP, Moraes Filho IM, Nascimento FLSC. Coping e estresse familiar e enfrentamento na perspectiva do transtorno do espectro do autismo. Rev Cient Sena Aires. 2018 [cited 2020 Sep 25];7(1):23-30. Available from: http://revistafacesa.senaaires.com.br/index.php/revisa/article/view/300
4. Gomes CGS, Souza DG, Silveira AD, Oliveira IM. Intervenção comportamental precoce e intensiva com crianças com autismo por meio da capacitação de cuidadores. Rev Bras Educ Espec. 2017;23(3):377-90. doi: https://doi.org/10.1590/s1413-65382317000300005
5. Merlleti C. Autism in question: diagnostic historicity, clinical practice and parents' narratives. Psicol USP. 2018;29(1):146-51. doi: http://doi.org/10.1590/0103-656420170062
6. Correa B, Simas F, Portes JRM. Socialization goals and action strategies of mothers of children with suspected autism spectrum disorder. Rev Bras Educ Espec. 2018;24(2):287-302. doi: https://doi.org/10.1590/s1413-65382418000200010
7. Desiningrum DR. Grandparents' roles and psychological well-being in the elderly: a correlational study in families with an autistic child. Enferm Clin. 2018;28(1 Supl.):304-9. doi: https://doi.org/10.1016/S1130-8621(18)30175-X
8. Jaswal VK, Dinishak J, Stephan C, Akhtar N. Experiencing social connection: a qualitative study of mothers of nonspeaking autistic children. Plos One. 2020;15(11):e0242661. doi: https://doi.org/10.1371/journal.pone.0242661
9. Morris R, Muskat B, Greenblatt A. Working with children with autism and their families: pediatric hospital social worker perceptions of family needs and the role of social work. Soc Work Health Care. 2018;57(7):483-501. doi: https://doi.org/10.1080/00981389.2018.1461730
10. Lefevre F, Lefevre AMC. Discourse of the collective subject: social representations and communication interventions. Texto Contexto Enferm. 2014;23(2):502-7. doi: https://doi.org/10.1590/0104-07072014000000014
11. Mapelli LD, Barbieri MC, Castro GVDZB, Bonelli MA, Wernet M, Dupas G. Child with autistic spectrum disorder: care from the family. Esc Anna Nery. 2018;22(4):e20180116. doi: https://doi.org/10.1590/2177-9465-ean-2018-0116
12. Segeren L, Fernandes FDM. Correlation between verbal communication of children with autism spectrum disorders and the level stress of their parents. Audiol Commun Res. 2016;21:e1611. doi: https://doi.org/10.1590/2317-6431-2015-1611
13. Pinto RNM, Torquato IMB, Collet N, Reichert APS, Souza Neto VL, Saraiva AM. Infantile autism: impact of diagnosis and repercussions in family relationships. Rev Gaúcha Enferm. 2016;37(3):e61572. doi: https://doi.org/10.1590/1983-1447.2016.03.61572
14. Nobre DS, Souza AM. Experiences of parents and/or caregivers of autistic children in a psychological service. Rev Baiana Enferm. 2018;32:e22706. doi: http://doi.org/10.18471/rbe.v32.22706
15. Machado MS, Londero AD, Pereira CRR. Tornar-se família de uma criança com transtorno do espectro autista. Contextos Clín. 2018;11(3):335-50. doi: https://doi.org/10.4013/ctc.2018.113.05
16. Maia FA, Almeida MTC, Oliveira LMM, Oliveira SLN, Saeger VSA, Oliveira VSD, et al. Importância do acolhimento de pais que tiveram diagnóstico do transtorno do espectro do autismo de um filho. Cad Saúde Colet. 2016;24(2):228-34. doi: https://doi.org/10.1590/1414-462X201600020282
17. Ishtiaq N, Mumtaz N, Saqulain G. Stress and coping strategies for parenting children with hearing impairment and autism. Pak J Med Sci. 2020;36(3):538-43. doi: https://doi.org/10.12669/pjms.36.3.1766
18. Biffi D, Ribeiro VR, Mellos A, Pereira LD, Manzoni FD. Perception about autism under the optics of mothers. Rev Enferm Atual In Derme. 2019;87(25 Suppl.). doi: https://doi.org/10.31011/reaid-2019-v.87-n.25-art.222
19. Guareschi T, Alves MD, Naujorks MI. Autismo e políticas públicas de inclusão no Brasil. J Res Spec Educ Needs. 2016;16(s1):246-50. doi: https://doi.org/10.1111/1471-3802.12286
20. Rocha KB, Conz J, Barcinski M, Paiva D, Pizzinato A. A visita domiciliar no contexto da saúde: uma revisão de literatura. Psicol Saúde Doenças. 2017;18(1):170-85. doi: http://doi.org/10.15309/17psd180115

Authorship contribution:

Conceptualization: Juliana Macêdo Magalhães, Thalia Alves Rodrigues.
Investigation: Juliana Macêdo Magalhães, Thalia Alves Rodrigues, Emília Angela Lo Schiavo Arisawa.
Methodology: Juliana Macêdo Magalhães, Thalia Alves Rodrigues.
Formal analysis: Juliana Macêdo Magalhães, Thalia Alves Rodrigues, Marly Marques Rêgo Neta, Carolinne Kilcia, Carvalho Sena Damasceno, Kayo Henrique Jardel Feitosa Sousa, Emília Angela Lo Schiavo Arisawa.
Project administration: Juliana Macêdo Magalhães.
Writing-original draft: Juliana Macêdo Magalhães, Thalia Alves Rodrigues.
Writing-review & editing: Juliana Macêdo Magalhães, Thalia Alves Rodrigues, Marly Marques Rêgo Neta, Carolinne Kilcia, Carvalho Sena Damasceno, Kayo Henrique Jardel Feitosa Sousa, Emília Angela Lo Schiavo Arisawa.

The authors declare that there is no conflict of interest.

Corresponding author:

Kayo Henrique Jardel Feitosa Sousa
E-mail: kayohenriquejardel@hotmail.com

Associate editor:
Rosana Maffacciolli

Received: 11.19.2020
Approved: 04.06.2021

Editor-in-chief:
Maria da Graça Oliveira Crossetti