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RESEARCH

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ATYPICAL MOTHERHOOD: NARRATIVES OF A MOTHER WITH THREE CHILDREN WITH AUTISM SPECTRUM DISORDER

*A maternidade atípica: narrativas de uma mãe com três filhos com transtorno do espectro autista**Maternidad atípica: narrativas de una madre con tres hijos con trastorno del espectro autista***Thaynara Maria Pontes Bulhões¹** **Ivanise Gomes de Souza Bittencourt²** **Elizabeth Moura Soares de Souza³** **Clarice Maria Tavares Macedo Cavalcanti⁴** **Maria Eduarda Alves Porto⁵** 

ABSTRACT

Objectives: to report the experiences and narratives of a woman as a mother of three children with Autism Spectrum Disorder. **Method:** study of a qualitative nature, of the life narrative type. The research was carried out with a mother of three children with Autistic Spectrum Disorder, who was being followed up at the Riding Therapy Association of Alagoas. Data were produced from narrative interviews with a research participant. Interviews with one participant were carried out in June and July 2022, in person and individually. **Results:** it was noticed that the most recurrent health needs of the family member of the person with Autistic Spectrum Disorder are the perception of the child's vulnerability, isolation, depression and stressful events. **Conclusion:** therefore, with the investigation of the health needs of the family member and listening to the narratives of a mother, there was knowledge of the social interaction and dynamics of these people's lives.

DESCRIPTORS: Autism spectrum disorder; Family relations; Caregivers; Office nursing.

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RESUMO

Objetivo: relatar as experiências e narrativas de uma mulher enquanto mãe de três filhos com Transtorno do Espectro Autista.

Método: estudo de natureza qualitativa, do tipo narrativa de vida. A pesquisa foi realizada com uma mãe de três filhos com Transtorno do Espectro Autista, em acompanhamento na Associação de Equoterapia de Alagoas. Os dados foram produzidos a partir de entrevistas narrativas com a participante da pesquisa. As entrevistas com a participante foram realizadas nos meses de junho e julho de 2022, em momento presencial e individual. **Resultados:** percebeu-se que as necessidades mais recorrentes em saúde do familiar da pessoa com Transtorno do Espectro Autista são a percepção da vulnerabilidade do filho, isolamento, depressão e eventos estressantes. **Conclusão:** portanto, com a investigação das necessidades em saúde do familiar e escuta das narrativas de uma mãe, houve o conhecimento da interação social e dinâmica de vida dessas pessoas.

DESCRITORES: Transtorno do espectro autista; Relações familiares; Cuidadores; Enfermagem no consultório.

RESUMEN

Objetivos: relatar y discutir las vivencias y narrativas de una mujer como madre de tres hijos con Trastorno del Espectro Autista.

Método: se trata de un estudio cualitativo, narrativo de vida, descriptivo. La investigación fue realizada con una madre de tres niños con Trastorno del Espectro Autista, en seguimiento en la Asociación de Equitación Terapéutica de Alagoas. Los datos se produjeron a partir de entrevistas narrativas con el participante de la investigación. Las entrevistas a la madre participante se realizaron en junio y julio de 2022, de forma presencial e individual. **Resultados:** se percibió que las necesidades de salud más recurrentes del familiar de la persona con Trastorno del Espectro Autista son la percepción de vulnerabilidad del niño, aislamiento, agotamiento, impotencia, depresión, eventos estresantes, entre otros. Ser familiar de una persona con Trastorno del Espectro Autista es un reto y tiene un impacto significativo en la vida, trayendo consigo una gran carga de trabajo. **Conclusión:** por lo tanto, con la investigación de las necesidades de salud de la familia y la escucha de las narrativas de una madre, se tuvo conocimiento de la interacción social y dinámica de vida de estas personas, sobre sus vivencias y cómo cada evento en su existencia se refleja directamente en el curso de sus vidas, tu vida hasta ahora.

PALABRAS CLAVE: Trastorno del espectro autista; Relaciones familiares; Cuidadores; Enfermería de consulta.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects the triad of human development, consisting of communication, socialization, and behavior.¹ Parents of people with ASD are the first to notice something different in their child, which leads them to question and seek help; this is a period of uncertainty and different feelings, ranging from denial and guilt to acceptance and the search for solutions.^{2,3}

The family of the person with ASD experiences an intense and exhausting routine that affects their mental and physical health and consequently, their quality of life, resulting in high levels of stress due to caregiving and a reduction in leisure time and social participation.^{4,5}

The performance of nursing in the field of ASD is essential for the development and attention of these people and their families, because the nurse is a fundamental mediator in the communication between the user and the family, paying attention not only to techniques or procedures but also to the promotion of tools that guarantee support, safety, and well-being.^{6,7}

Given this, the nurse, as a therapeutic agent, seeks to understand the challenges and health needs of the family member of the person with ASD, bringing the improvement of quality of life in providing their care, to implement a care plan that helps this individual to recognize their abilities, in addition to providing security, calm and motivation.⁸

However, the experience of the family of the person with ASD is still neglected or devalued concerning their complaints and is also an insufficiently addressed issue in the health sector, including in the field of nursing, which needs more investment for professionals to be better qualified and to develop interventions that enable health promotion.^{9,7}

Therefore, this research aims to report and discuss one woman's experiences and narratives as a mother of three children with ASD.

METHOD

Study type

This is a qualitative, narrative, and descriptive study.

Study location

The scenario of the experience took place in the Association of Riding Therapy of Alagoas (AEA). The Association is in the city of Maceió-AL.

Study participants

The research was conducted with a mother of three children with ASD who was being followed up at the AEA, located in the city of Maceió-AL. This mother was invited to participate because of her experience as a caregiver of children with ASD.

The following conditions were used as inclusion criteria to participate in the research: children with ASD followed up at the

AEA, located in the city of Maceió-AL. In addition, mothers who had only 1 (one) child with ASD and/or who had children with only 6 months of registration and follow-up at the institution were excluded from the study.

The mum participating in this study was aged 43, female, married, Protestant, high school graduate. Two pregnancies, one twin, 3 children, all with complete prenatal care and cesarean in Maceió. The three children had a diagnosis of ASD and were non verbal.

Data collection

The interviews with the mother were conducted in June and July 2022, in person and individually, along with the researchers, always setting time between one and two hours for them to talk calmly, quietly, and without haste. The interviews were conducted at the AEA, always on Wednesday mornings, during the period when the children were receiving therapy with the horses. During the narrative interview, the audio recording function (on the mobile device of the researcher) was used. The trigger question for the narrative interview was: "Tell me about your whole journey as a mother of children diagnosed with an autism spectrum disorder to the present day".

From the triggering question, only listening and short notes were made on the points to be better clarified later.

Techniques to process quantitative and/or qualitative data

In this research, the narrative study method was used because it captures the personal and human dimensions of their lived and told stories.

The mother's narratives were transcribed in full, taking care to avoid any eventuality that could damage the audio files, in addition to being saved in different formats and two different accounts of the Google Drive platform. In addition, the reports written in WhatsApp were also recorded, since this mother used this means of communication as a way of reporting the difficulties and frustrations suffered in everyday life.

Ethical aspects

This research was carried out with the approval of the Research Ethics Committee of the Federal University of Alagoas and in compliance with the ethical procedures established in resolutions 466/12 and 510/16. This study was approved under opinion number 4.482.466 and CAAE number 40033720.4.0000.5013.

Once the willingness to voluntarily participate in the research had been confirmed, and to formalize this participation, the signing of the Free and Informed Consent Form (ICF) was requested in two copies. One copy was given to the participant and the other remained with the researchers.

RESULTS

The care journey of twins with ASD

The first narratives focused on the experience of caring for 14-year-old twins with ASD, the process of discovery to

the present day, and the challenges she has faced in caring for children with ASD at different times in their lives, from the boys' inclusion in school to family and social relationships.

The mother talked about how she went about conceiving and giving birth to the twins:

My pregnancy with the twins was very complicated because, in fact, at the beginning of the pregnancy, I had complications with the neighbors, I discussed a lot... And so... The boys were born in two thousand and seven, day nine of the nine of two thousand and seven.

After they were born, they spent fifteen days in the neonatal ICU, because they needed to be taking a light bath...

She also talked about her history of living with ASD and how, although her children did not play together when they were young and did not respond to her calls, this did not surprise her as a mother. The neighbors were the ones who noticed something different, and she only became suspicious when the children were 1 year old:

[...] but since then you couldn't tell anything after birth... I didn't notice anything, some neighbors who realized at four-five months, that something was strange about them, but we as parents couldn't know what they had.

But you don't know. The father didn't accept no. I didn't believe they had that diagnosis. The beginning for him was very difficult. Now I didn't, I accepted it right away.

But [my husband] has never abandoned me since the discovery of the boys' diagnosis, always present. But there are cases in which there is really abandon, but in my case not. He is in love with the boys.

However, when asked about the current inclusion of the boys in the school, she became emotional and explained that they were enrolled but that he had been fighting for two and a half years to get a room assistant to effectively include them in this environment, generating in her a lot of sadness and dissatisfaction to see his children outside the school sphere:

They are only enrolled, because they need a room assistant. I've been in this fight for two and a half years to get a room assistant.

I feel terrible. I'm emotionally drained and sad, I don't even know how I'm finding myself here because yesterday I talking to the girl collapsed because it's too overloaded" [Pause because he got emotional, and his eyes were teary].

I noticed discrimination on the part of the school for not wanting to accept the boys in this school.

She stated that there were many difficulties and that the challenges of caring for boys with ASD were immense, especially in terms of seeking rights, but that the strength to fight

was worth it. However, he reported that there was still a lot of prejudice in society, which ultimately led to a blockade and a daily struggle.

[...] the difficulties were many, because I had to run after the benefit, this whole thing, I went to the countryside, I retired my boys... The difficulties are many, and the strength of struggle that I had with the boys is gratifying, but there is always a block to this because you go out fighting for his rights and you are not welcome, you are not treated well.

She also spoke about the lack of government support and the burden:

Many kill their children and commit suicide all because of overload and the lack of support from the government and society that they do not have.

She highlighted the lack of empathy in society and the lack of attention to the needs of mothers, both in institutions and in media networks:

The lack of empathy is one of the worst, we do not have support from any institution no matter how much you are in that institution you do not have, the mother does not have support, psychological support...

When asked if the institutions that cared for and supported her twin children had done anything for her by caring for children with ASD, she said:

No. To this day it is so. What's the use of asking if it's okay... I'm not going to say it's all bad, I'm going to say it's okay. When I speak, I mean to you it's something we don't have... There was supposed to be a room where when the children were in treatment, we would be in a meeting with the social worker, to make a dynamic with other mothers.

She also talked about the importance of self-esteem for mothers and how much society should recognize this, including on Mother's Day:

The self-esteem of these mothers would be very important. At first, I took care of myself, but it was very little. Today I try to love myself more and more and it is fine with me because if I do not take care of myself or love myself how I will be able to take care of and love my children.

The care journey of the third child with ASD

From suspicion, discovery, and the daily routine of caring for an 8-year-old child with this diagnosis, this topic will cover the experience of another pregnancy and another child diagnosed with ASD. In addition to the challenges and her reality as a mother in the different areas of her life, caring for 3 children with autism.

The participant narrated the process of pregnancy and the birth of her third child, highlighting the difficulties she experienced in motherhood:

The pregnancy of my third child was super... I had nothing. It was all normal. It was the nine months of doing the prenatal everything right and the delivery also...

However, she spoke of her frustration at the closure of the diagnosis, because for her, her third child would be the brother who would help the twins:

After the diagnosis closed, I collapsed, right? Because I didn't expect it, I created a lot of expectation on top of my youngest son, because he didn't show signs at first, then in my thought, he was going to help me take care of his brothers, this was my biggest dream, my biggest expectations, this came like a bomb, I collapsed at that moment.

She also explained the difficulty of accommodating his youngest son and his siblings in a different environment, noting that he always had to seek justice:

[...] But you know, right? Here is everything, everything difficult, everything must be in court. everything is justice. If you need anything you have to go to court.

In addition, she pointed out that in addition to the difficulty of getting something for his children, and the need to seek justice, there was the obstacle of transport:

It was to be entitled to a special card because we will take from the pockets of the boys, from the salary of the boys to go up and down, with nowhere to take it. The boys don't settle for that bus noise, you know? Even when they sit down, if they are seated, they stay until the end of the trip, but if they are standing, no one gives them the place, and they panic inside a bus. If I go with their card I'm blocked, so Mom and Dad were supposed to have that card.

From the research participant's narratives, the health needs of a relative of the person with ASD were verified, who experiences numerous challenges in her daily life, which include issues ranging from the discovery of the diagnosis, and the problems associated with inclusion in school to health care, verifying that the responses explain the demands and challenges of being an atypical mother.

DISCUSSION

The narratives allowed us to realize that to be a mother of children with ASD is to face the constant challenges of atypical motherhood and testify to the daily experiences of caring for a person with this diagnosis. Acceptance of this

disorder by the family is a challenge, often due to a lack of knowledge and prejudice.¹⁰

Maternity is a challenge, and it is common for mothers of children with ASD to feel guilty, fragile, and sad because they have never been taught how to care for a neurotypical child, which causes them psychological distress. The perception of the diagnosis and the first signs cause them anxiety and psychological distress, leading to a change in routine and, consequently, a total adaptation and learning process, especially in terms of communication and the mother-child relationship.¹¹

Fathers may become depressed and create a sense of overprotection and vulnerability for the individual with ASD, but mothers are more likely to experience more anxiety, loneliness, and other health needs, as culturally the mother has a greater responsibility in the love, care, and education of her children. Furthermore, in the narratives quoted by the participating mothers, it was noted that their lives were centered solely on caregiving, which supports the idea that these women normally give up their children, the labor market, and a professional career to devote themselves exclusively to this child, with a change in the organization and dynamics of the family.¹²

Nevertheless, despite the burnout, loneliness, helplessness, and lack of self-care reported by mothers of children with ASD and confirmed by the participant in this study, there is a sense of relief when they are at school.¹³

However, in several narratives, the mother reported the fear, sadness, and struggle of getting her three children into school, which caused embarrassment and distress. The inclusion of children with disabilities in school is always a challenge because, in addition to parents' concerns about their children's inclusion in mainstream education, there is also the difficulty of integrating these individuals into this environment, which is often watered down by a standardized, demanding and not at all inclusive view.¹³

Adapting to the new routine, paying attention to this person, and giving up work outside the home causes a great deal of stress, an overload of maternal work, and an enormous amount of pressure, leading to feelings of loss, sadness, and isolation,¹⁴ which are also present in this mother, who says that she is devastated, wants to disappear and feels terrible.

In addition, there is the need to pay attention to one's care, which is often forgotten due to an intense overload in daily life, with no time for leisure and self-care. Developed research, which explains "caring to care" and "self-care is not selfish", has shown that women find it difficult to delegate functions, and there is inequality within the family that contributes to women being forced to perform household chores and their children, not cooperating so that they have autonomy and time for other activities.¹⁵

In this perspective, it is important that the nurse applies the nursing process to the mother of children with ASD. It is undeniable that the family of the person with ASD needs biopsychosocial care and support, which will add essential

elements for their health promotion and psychological help. However, what we see in practice is a lack of support for these mothers, who are left to the mercy of treatment for their children, who are "forgotten", even though it is these women who need it most, due to the overwhelming demands of full-time care. The family needs therapeutic support, in which the feelings of each member of the family are clarified, and the initial challenges, main difficulties, and ways of alleviating them are identified.¹⁶

The process of adapting to the routines of children with ASD results in a change in family dynamics and relationships, which may affect social interaction with colleagues and marital conflicts. This is felt in the lives of mothers, who report distancing from friends and community life, and this complaint is a major risk for social isolation, low self-esteem, and depressed mood.

Mothers of people with disabilities report a lack of empathy from society towards them and their children, resulting from a kind of disrespect and discrimination, which leads to a decrease in the effective inclusion of these people with disabilities and to the isolation of these mothers,¹⁷ as confirmed by the participants' narratives.

However, it is necessary to point out that there are physical illnesses suffered by these mothers as a result of their life and the exhausting care they provide, which cause them symptoms such as pain, discomfort, fatigue, sleep, and impairment in other basic activities of daily living, such as self-care, which prematurely age them and cause feelings of exhaustion, loneliness, helplessness and vulnerability, which also hinder their social conviviality.¹⁸

CONCLUSION

Therefore, being a relative of a person with ASD has been found to have a significant impact on life, especially on the mother, who is the primary caregiver reported in scientific research. Being a family member/carer of this target group involves a great deal of work, often being the only job, they have. The mother is deprived of leisure, travel, and other forms of self-care, which puts her at considerable risk of distance from friends and family and social isolation, with significant consequences for her psychological and emotional life.

By investigating the health needs of the family member and listening to the narratives of the participating mothers, knowledge was gained about the social interaction and life dynamics of these people, about their experiences, and how each event in their existence was directly reflected during their lives up to the present moment.

Feelings of the vulnerability of the children, exhaustion, loneliness, depression, and, above all, the lack of attention and support from the institutions for the mothers of children with disabilities were the most frequently mentioned health needs that lead these women to a worsening of their living conditions and the deterioration of psychological factors. This further

favors the appearance of complaints, becoming a vicious circle which, if not interrupted by the attentive perception of professionals, leads to more signs and manifestations of discouragement, debilitation, and sadness.

It is believed that the theoretical/methodological approach chosen for this study creates an opening for new scenarios of production about the routine and impact of life on the family of the person with ASD, in addition to giving visibility to the performance of professionals in the care of these people.

Thus, this research was of fundamental importance, as there is a need for more studies to be carried out that cover the health of the family member of the person with ASD and produce a care plan aimed at improving care provision to ensure support, safety and well-being.

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