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RESEARCH ARTICLE

Experiences of Family Members of Children with Autism

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Abstract:

Introduction:

Autism spectrum disorder is characterized by the change in the behavior-interaction-communication, with different levels of impairment.

Objectives:

This study aims to describe the experiences of family members of children with autism and discuss strategies to improve the quality of life of family members.

Methods:

A descriptive, exploratory study with a qualitative approach was carried out in a self-help association for autism, located in the city of Teresina/PI, Brazil. Data collection took place in September and October 2019 through the application of a semi-structured interview. Eighteen (18) family members of children with autism in the Association of Friends of Autistic Individuals (AMA) participated in the study. Bardin's content analysis was the technique used for data analysis.

Results:

The results showed experiences of negative feelings on the part of family members who lived with autistic children, such as frustration and pain, but also positive feelings of affection and dedication and state of neutrality. The daily life of family members involved the experience of difficulties due to the care of the autistic children, in addition to the lack of information regarding different cases of autism. Therefore, it is necessary to include family members and children in support networks with the objective of making them a part of society with the help of the multidisciplinary team.

Conclusion:

The present research showed that the experiences of family members of children with autism are difficult at first, but with daily learning and interaction, they become rewarding. The study also reinforces the importance of team in the care of autistic children and highlighted the relevance of improving the family's quality of life, which can also reflect on the quality of care of that individual.

Keywords: Autism, Family relations, Nursing, Autistic individuals, Autism spectrum disorder, Hypotheses.

Article History

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1. INTRODUCTION

Autism, also known as Autism Spectrum Disorder (ASD), has its particularity in the important signs of changes in a child's communication, interaction and behavior. The symp-

toms start in the first few months of life; however, more noticeable traits are manifested around the age of three. Among the perceived signs, difficulty with speech and understanding, infrequent eye contact, and repetitive movements [1] stand out.

As a result of behavioral, interaction and language deficits, children with ASD are highly dependent on parents and caregivers. In turn, parents and caregivers may deal with the burden of physical and emotional suffering as they need to be

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fully dedicated to these children, with numerous responsibilities and overloading tasks. Thus, caregivers may experience feelings of anguish, fear of the unexpected happenings and even fear of judgment by third parties [2].

Living with autistic children can have positive and negative aspects. Among them, social isolation stands out as a negative aspect, as families are deprived of social contacts and attending certain events and gatherings due to the unexpected behavior of the child and due to fear of judgment by third parties. As a positive experience, it appears that although the family faces daily struggles in caring care for the child, feelings of affection and dedication are significantly expressed [2].

Thus, individualized care is essential to meet the needs of each autistic individual, together with family support, combined with education, leisure, and embracement, so that self-sufficiency and autonomy may be possible in the care of the autistic child [3].

Based on these considerations, the objective of this study was to describe the experiences of family members of children with autism and discuss strategies to improve their quality of life.

2. MATERIALS AND METHODS

2.1. Study Type

Descriptive and exploratory field research with a qualitative approach was developed to describe the experiences of family members of children with autism. The descriptive study is carried out to describe the characteristics of a given population or phenomenon. For this, it uses standardized data collection techniques, such as the questionnaire and systematic observation; while, the exploratory study allows greater familiarity with the problem, to explain it.

2.2. Study Participants

The participants in this research were 18 relatives of children with autism, including people who lived in the same household, irrespective of blood ties. This number was defined based on the criterion of saturation of information in the speeches. The saturation of the speeches is reached when the content of the collected material begins to be repeated so that the obtaining new information has little relevance for research.

2.3. Data Collection

For the selection process of the participants, the following inclusion criteria were considered: individuals over the age of 18, and who were family members living in the same household for at least 1 year with the autistic child. As an exclusion criterion, family members who were emotionally fragile at the time of the interview, such as crying, having lack of emotional control, high level of anxiety, or other psychological conditions that prevented the development of the interview, were excluded.

The data of this research were collected in the months of September and October 2019, through a semi-structured interview with an average duration of 20 minutes for the

interviewees to answer the questions.

The interviews were conducted in a reserved place to avoid the embarrassment of the participants, and they were identified through codes without revealing their identity. Family members were coded by the letter F and the respective number of the order of the interviews. The data collected were recorded using an advanced and comprehensive IOS smartphone device with excellent features and innovative functionality.

2.4. Data Analysis

The present study was analyzed through content analysis [4], which is defined as a set of methods for the analysis of communications through systematic and objective procedures of presentation of the content of the messages.

The content analysis technique is divided into three fundamental phases. The first phase, pre-analysis, consists of an organization stage, which involves reading to select the documents that will be used to formulate hypotheses; thus, in case of interviews, these are transcribed and they constitute the corpus of the research. The second phase represents the stage of exploring the material in order to select the messages and categorize classes that bring together a group of elements of common semantics, grouping by the sense of the words. Finally, in the third phase, the results obtained are interpreted [5 - 9].

The research was approved by the Research Ethics Committee under the opinion no. 3,571,583.

3. RESULTS

The participants in this study were 18 family members of children with autism who had an association with friends of autistic individuals. Among the participants, there were people of age between 28 and 51 years and female sex predominated. The analysis of the speeches resulted in the classification of speeches into three categories.

3.1. Category 01 - Feelings Experienced by Family Members before the Diagnosis of Autism

The diagnosis of autism caused varied feelings in the family members of the child. These experiences sometimes brought negative feelings such as frustration, difficulty, denial, pain, grief and prejudice, as noted in the following statements:

[...] Parents who have a special child, whatever it is, this is something that becomes traumatizing, frustrated because you create an expectation in relation to that child (F. 01)

My experience was of difficulty because I have two children with autism and they are totally the opposite from each other (F. 11)

At first, it was complicated. I didn't want to accept it (F. 12)

[...] I received the diagnosis, it was tough; it was very painful (F. 13)

[...] There is still a lot of prejudice because

you only know how prejudice is when it is with you [...] it was not easy, I would cry, you need to have patience that you do not know where you get it from (F. 16)

[...] When you discover the diagnosis, you live as if it were a grief, because when you have a child, you think a lot of things for him, you create a lot of expectations and when you discover that the child has a problem, like autism, you feel sad and experience that period as if it were a mourning (F. 17)

On the other hand, there were also positive feelings towards the autistic child and the discovery of the diagnosis, because although the family faces a daily struggle, there are significant feelings of affection and dedication of the family members, as represented in the following statements:

It is a rich, joyful experience, but there are difficulties. [...] She is very intelligent, we believe she can have a good development in the future; her independence worries us and causes us anxiety (F. 02)

[...] the interaction is pleasant, there are difficulties related to him, but we are his partners, so for me it is a good experience as a mother (F. 03)

[...] It is gratifying because we also learn from them (F.15)

Furthermore, the study participants also reported feelings of neutrality regarding the diagnosis of children with autism. These participants believed that previous experiences of some other conditions led to the functional impairment of their children as a kind of preparation for the current situation of having a child with autism.

My son was five years old when I discovered his diagnosis; the impact was not so great because there was a diagnosis of intellectual disability. Because of that, I felt somehow prepared (F. 10)

I received the diagnosis of my son at the age of five; it was not such a big impact because I already had already received his diagnosis of intellectual disability and mental retardation (F. 14)

3.2. Category 2 - The Daily Life of Family Members of Autistic Children

This category discusses the daily lives of family members, including the difficulties that are faced. Daily interactions are particularly difficult, requiring patience and exclusive attention to the child. The level of dependence of the child sometimes

varies because it depends on the degree of autism; the greater the degree of autism, the greater the dependence.

[...] Our life today is a struggle after trying to improve each day and life becomes a little tiring; only those who have a disabled child know how tiring and stressful this can be; there are moments of crisis, lack of understanding when the child is autistic and they have a kind crying crises, impatience and you have to know how to interpret them. This is the most difficult part. Everything in life is tiring. (F. 01)

[...] at home, we bear his way; the problem is when we go out, the behavior is different, at home he has agitated behavior, when we go for a walk, he throws himself on the floor, screams, wants things his way. We have to be very patient because we really run out of patience. (F. 05)

[...] so my greatest difficulty is getting his rights respected and making people understand that he has a disorder, and because of that, he has a deficit to do some activities. (F. 07)

[...] we are trying to live with it, live with his routine. There are obstacles. (F. 08)

[...] My son injures himself, and it is very difficult to see that happening; the society interprets that as if an autistic person were a freak and had to be isolated from the world, because society is normal and they are not normal. This is not easy for me at all. (F. 09)

[...] Taking care of a child with special needs is not easy, we have our limitations and he has his own; we have to know how to deal with, and we need to have a lot of patience to deal with that, but there are joys, every new thing they learn it is an achievement, for us it is even more than for him, we face many obstacles for their sake. (F. 10)

[...] this is complicated because I am by myself with them and sometimes I have difficulty taking them to the treatment, to school, but we learn a lot with them and we become better as a person. (F. 11)

[...] it is not easy for you to deal with different people, with children especially it is not easy, you have to seek courage, willpower, even strength every day to deal with them because each day they have a different need, they have their routine that we cannot change. (F.15)

The daily lives of family members of children with autism are even more affected due to the lack of access to information. The constant concern with the protection and safety of the children becomes part of the life of family members,

representing a risk factor for psychological suffering.

[...] I have little knowledge about autism and I didn't want to accept it, but thanks God I managed, I accept it better now. (F.12)

[...] I learned from the internet, researching files, studying, I had to look for information to understand how to deal with my son, because it is not easy! [...] so it's very complicated for you today as a mother to deal with a child like that, if you don't have help, if you don't have guidance [...] I wanted the government to give more guidance to mothers, mainly, mothers who are not educated, those of low-income [...] we miss more lectures on autism in schools, the subject should be more disseminated (F. 16)

[...]I feel insecure due to the lack of knowledge I have about autism, I know very little, I have already watched reports and read something on the internet, but I still don't understand much about it. (F18)

3.3. Category 03 - Challenges for the Care of Autistic Children and the Social Support Network

This category exposes how parents deal with the growth and development of their children, highlighting the concern that they have in relation to the autonomy that these children will have when they come to be alone. It is worth mentioning the importance of support networks for comprehensive care, such as school inclusion and institutions that offer various activities and services to help in the child's neuropsychomotor development. They contribute to the rewarding experience of the parents to see their child's evolution. This is represented in the following lines:

[..] He started to relate well and was also studying at a regular school and at the age of four, he started to read a few words and speak (F. 03)

[..] We went after therapies and associations that could work with us and the school. He also started early in regular school, at the age of 4 and has continued since then [...] Communication is improving, as he is being followed-up by a speech therapist and has a younger sister who helps him a lot. (F. 04)

[..] *I need to accompany him everywhere, at all times and at school, because he has a mild level, SEMEC [Municipal Secretariat of Education] doesn't give me this companion, this is a big problem for me because I have to stay with him for he can't defend himself.* (F. 07)

[..] After the diagnosis, I looked for treatments

so that he could have a normal life, socialize with other children; I took him to a psychologist, speech therapist, physical therapist, so that he could have quality of life. (F. 10)

[..] He had difficulty speaking; he started to speak a little after the therapy sessions when he was almost 4 years old. (F. 12)

[..] It is a great happiness for us, he taking the first step, walking, learning to speak, each new word he learns is new for us; true it is tiring, sometimes we think we won't make it. (F. 14)

4. DISCUSSION

Based on the feelings of the family members of autistic children, it was evident that the experiences bring different feelings to the family members. Some of these feelings were negative, such as fear, anguish and denial in which they expressed difficulties in the care of children with autism, as it is an everyday struggle. But positive feelings were constantly highlighted, such as love and reciprocity between both parties, and because of such feelings, the experience became gratifying. There were also feelings of neutrality, that is, feelings that became common in daily lives of the family members.

The predominance of females guarantees multiple vulnerabilities (being a woman and being autistic), since gender equality and women empowerment are still far from reaching all women in the world, although it is part of the international community's efforts to reach Sustainable Development Goals (SDGs).

The daily lives of girls with autism can be diverse with unique feelings and perceptions. In the present study, it was observed that due to the daily contact of family members with children with autism, they were able to recognize and identify the first signs that the children presented their developmental limitations, difficulties in relation to language, lack of understanding, repetitive behaviors that become evident in the first years of life. Thus, the family is an important resource for the early identification of signs besides health professionals.

The family environment is the first in which individuals with ASD come into contact and socialize with other people. The family has the potential to be ahead of the needs of their child, thus assuming active roles in the care and development of the autistic child [10].

A lot of expectations are attached with the family when it comes to provide care to the child. When it is found that a child is affected by ASD, expectations can be higher and they change the family's psychodynamics. There is no standard behavior before the diagnosis; each family reacts differently [11].

In this context, the challenges of care are translated into physical and emotional burdens on family members, due to the fact that the condition of the child generates different needs. The burden is related to the concern for the child's future, the difficulty of social interaction, the financial situation, scarcity

of activities available for their leisure time, in addition to late diagnosis and the difficulty of dealing with the symptoms which bring feelings of guilt and anguish [12].

The moment of diagnosis of autism is a striking and stressful moment for the family, as different expectations emerge permeated by a series of mixed feelings. Furthermore, the birth of a child and a new member of the family is associated with a lot of plannings, and with the diagnosis, everything desired or imagined for that new being is vanished.

It is noticed that there is a lack of awareness among families regarding the diagnosis of autism and what this disorder really is and what are its symptoms. The lack of information further increases negative feelings and hopelessness about the prognosis.

Individuals with autism are little understood by society due to the fact that little information on the condition is disseminated. Such lack of empathy can bring a different or even distorted view of what autism really is, and this lack of information can reflect negatively on the inclusion of these children in society [13].

Therapeutic resources for the care of children with autism are necessary, such as support networks that can be essential foundations in the treatment, including schools, the family and the network of professionals in the education and health arena. Such networks may contribute to improvements, as they are followed up by speech therapists, occupational therapists, psycho-pedagogues, social workers, physical educators, among others who can compose this network [14].

Thus, the difficulty of family members was observed in having access to the support networks that could involve their children in various activities and modes of assistance. They found support from the Association of Friends of Autistic Individuals (AMA), which facilitates in providing venues for different activities such as occupational therapy and psychology, in addition to providing an exchange environment, as these family members meet and exchange experiences, talk about their main difficulties, fears, anxieties and comfort each other.

Inclusion must take place for both the children and families, because when family members get to know about the diagnosis of autism and start a new phase in relation to care, they end up socially isolating themselves, especially because they get too busy caring for the child and meeting all the needs and also because of the child's behavior, which is sometimes unreasonable and judged by others, causing fear of going out in public places [2].

Thus, there must be a comprehensive health network and services, also targeting family members and caregivers. Various services such as psychology and social work could be integrated so as to benefit both [3].

Another strategy to improve the quality of life of family members within support institutions for children with autism is the promotion of conversation wheels with these family members to expose their doubts and share their experiences with other families. These activities would also strengthen the bond with the health professionals as it contributes to focused

listening.

Nurses within the multidisciplinary team have the function of keeping parents informed and providing information so that they can understand autism. They must evaluate the degree of the disease as well as the feelings towards the reality experienced [15]. In addition, nurses assist through nursing consultations in the early diagnosis of autism, thus contributing to better treatment of these children.

The limitations of this study are related to the refusal on the part of some family members to participate in the research, as it is a broad field for research, with a large number of family members. Thus, there is a need for complementary studies on the theme because there is still a lack of studies reporting the experiences of family members of children with autism.

CONCLUSION

The feelings of the family members of the children with autism were diverse, ranging from negative feelings such as frustration, pain, denial, and difficulty, to positive feelings such as joy, dedication, love; there were also feelings of neutrality because the children had already been associated with other health conditions. In relation to the daily routine of family members of children with autism, there are difficulties. It is a daily struggle, requiring full dedication on the part of the family. There is, however, daily learning and the routine brings a significant improvement to this relationship and to the quality of care, shaping the quality of life and the treatment. The support networks are extremely important in the children's life, as they introduce them to society through activities of various types such as occupational therapy and psychology. It is also important to reintegrate the families of these children into society for the improvement of the quality of life and care for these children.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This research was approved by the Research Ethics Committee under the opinion no. 3,571,583.

HUMAN AND ANIMAL RIGHTS

This study complied with ethical and scientific guidelines concerning research involving human subjects according to the Brazilian National Health Council Resolution No. 466/2012.

CONSENT TO PUBLICATION

Informed consent was obtained from the interviewees.

AVAILABILITY OF DATA AND MATERIALS

The authors confirm that the data supporting the findings of this study are available in the article.

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Not applicable.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest of financial or other nature.

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