Maternal existence before the care to the autistic child

Vivência materna diante do cuidado à criança autista

Existencia maternal antes del cuidado para el niño autista

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ORIGINAL

RESUMO

Objetivo: Compreender como as mães vivenciam o cuidado prestado à criança autista. **Método:** Trata-se de um estudo qualitativo, descritivo e exploratório, realizado com quatros mães de crianças autista no Instituto Psicopedagógico de Senhor do Bonfim/BA. A coleta ocorreu por meio de entrevista semiestruturada, interpretados pela analise de conteúdo. **Resultados:** Emergiram duas categorias e seis subcategorias. Evidencia-se que os cuidados com o/a filho/a autista em sua maioria ficam a encargo das mães, que recebem o diagnostico com muito sofrimento, contribuindo como um fator de sobrecarga materna. **Conclusão:** Muitas são as dificuldades enfrentadas pelas mães no cuidado ao filho autista, mas a partir da aceitação do TEA, as mães visualizam a importância do seu cuidado e o quanto contribuem para evolução da criança.

Descritores: Autismo; Criança; Cuidado; Relação mãe-filho.

ABSTRACT

Objective: To understand as the mothers lives the care rendered the autistic child. **Method:** It is Treated of a study qualitative, descriptive and exploratory, accomplished with quatros mothers of children autist in the Instituto Psicopedagógico of Senhor of Bonfim/BA. The collection happened through interview structured semi, interpreted for the it analyzes of content. **Results:** Three categories and six subcategories Emerged. It is Evidenced that the cares with o/a son / the autist in his/her majority is to the mothers', that receive him/it responsibility diagnose with a lot of suffering, contributing as a factor of maternal overload. **Conclusion:** Many are the difficulties faced by the mothers in the care to the autistic son, but starting from the acceptance of TEA, the mothers visualize the importance of his/her care and him/it all contribute for the child'sevolution.

Descriptors: Autism; Child; Care; Relationship mother-filho.

RESUMEN

Objetivo: Para comprender como las madres vidas que el cuidado dioelniño autista. **Método:** ESunestudiocualitativo, descriptivo y exploratorio, consumado conlas madres de quatros de autis/t de niñosenel Instituto Psicopedagógico del Senhor do Bonfim/BA. La recolecciónocurrió completamente la entrevista para la que Semifinal estructurada, tradujo elanaliza del contenido. **Resultados:** Trescategorías y seis subcategorias aparecieron. Es demostrado que laspreocupacionescon o / unhijo/ elautistensumayoríasuson a el(la/los/las) de las madres, que loreciben / éllaresponsabilidad diagnose conmuchosufrimiento, contribuyendo como unfactor de la sobrecarga maternal. **Conclusión:** Muchossonlos apuros enfrentado por las madres enel cuidado para elhijo autista, pero empezar de laaprobacióndelté, las madres visualizanlaimportanciasuya / su cuidado y él / él que todos aportan para laevolucióndelniño.

Descriptores: El autismo; Child; El cuidado; Relaciónmadre-hijo.

Introduction

Autism spectrum disorder (ASD) is marked by behavioral manifestations associated with deficits in communication and social interaction, repetitive and stereotyped patterns and the restriction of diverse interests and activities, which affects children since childhood.[1]

According to epidemiological studies, an aggravating increase of 1-2% in the prevalence of ASD is estimated, in comparison with the last decades.[2] In Brazil, there are still few studies that bring epidemiological data, but according to a recent survey, the margin of involvement by autism is 27.2 cases for every 10,000 inhabitants.[3]

It is during early childhood that behavioral changes arise. Initially the symptom will be delayed in language development, emerging to lack of social interest or unusual social interactions, forms of strange play and different communication. After the second phase of childhood, other behaviors are detected, in addition to the absence of games. They are usually identified from the second year of life, between 1 and 2 years of age, where it will depend on the severity of developmental delay, and can be viewed before 12 months or only from 24 months.[4]

It is important that the diagnosis is carried out with the participation of the family and the multidisciplinary team. Dividing into stages, first the interview together with the observations and after the application of other instruments, such as the criteria described in the Statistical and Diagnostic Manual of the American Psychiatric Association (DSM-V). However, this manual is divided into three criteria for diagnosing autism: (A) deficits in reciprocal social communication and social interaction; (B) repetitive and restricted pattern; (C and D) deficits that limit daily functioning.[4-5]

Faced with the diagnosis, some families feel distressed and even guilty, because there is a culture of idealization of the child, and with the diagnosis there is frustration on the part of these family members. Thus, given the feeling of denial, the family starts to seek other medical evaluations before accepting the diagnosis.[6]

After diagnostic confirmation, parents are exposed to an excessive burden of activities to meet the routine of care for children with ASD. This will consequently depend on the ability of each to deal with stressors, however mothers are generally the most affected, as they are more present in the home and the main responsible for child care.[7]

Most mothers report the burden due to the absence of family members to contribute to help with the division of care with the child, and refer to the feeling of loneliness. In this way, there are difficulties and even limitations that will somehow cause a great impact on the family, since each one will overcome these challenges in their own way.[8]

We believe that studies that propose to know the experience of mothers in caring for autistic children are imperative, since most of the existing studies have the disorder itself as a central issue, and the consequences for children's cognitive development, causing a gap in the family literature in situation of ASD.

Therefore, from this study, we aim to understand how mothers experience the care provided to autistic children.

Method

This is a qualitative, descriptive and exploratory study, carried out at the Psychopedagogical Institute of Senhor do Bonfim-IPPB / APAE.

The research participants were located based on a previous screening of the number of autistic children who were attending the psychopedagogical institute, where information was provided on the days when the mothers would be at the institution. Subsequently, there was the initial contact with the participant and consequently the interview.

Participants in this study were mothers who actively act in the care of children with ASD. The inclusion criteria were to be mothers over 18 years old, living in the same house as the child and active component in care. Exclusion criteria were defined as mothers who had cognitive impairment and who were not directly linked to care.

Five children were identified. Four mothers agreed to participate in the study, all of which met the inclusion and exclusion criteria. The participants were between 32 and 38 years old during the study period; All participants are married or live in a stable relationship.

The data collection took place through a semi-structured interview, recorded with an audio recorder and are being archived by the researcher for a period of five years.

The data were analyzed using the content analysis method. According to Bardin[9], the content analysis leads to understand what is behind the words, from searches for other realities through them, all through sample messages.

This research was submitted and appreciated by the psychopedagogical institute and by the Ethics Committee of the University of the State of Bahia, CAAE n. 67245317.0.0000.0057 and Consubstantiated Opinion nº 2,152,634. Approved on: July 03, 2017.

In compliance with Resolution 466/12 of the National Health Council (CNS), the objectives of the study, its importance and other questions of the interviewees were clarified, the Free and Informed Consent Term (ICF) provided by the researcher, was then read and signed individually, prior to the interview, guaranteeing the subject's anonymity and the use of data only for the purposes of developing the study.

Results

After a careful analysis of the data, two categories emerged: “Discovering yourself as the mother of an autistic child”, whose subcategory was “The fear of discovery”, “The acceptance of the child diagnosed with autism” and “Experiencing optimism”; “Difficulties encountered in caring for the autistic child”, whose subcategories were “The social prejudice”, “Caregiving mother: Assuming multiple responsibilities.” and “The lack of financial resources”, which are presented below.

Discussion

Discovering the mother of an autistic child

Fear in the face of discovery

The family facing the diagnosis of ASD goes through countless feelings, among them is fear as a main factor. Eventually, the reason for this feeling may be due to fear of the unknown, both due to the lack of understanding of autism, as well as uncertainties about the child's future.[3]

It is noticeable in the statements the feeling of fear and uncertainty that mothers have in relation to the disease and the child's future. They wonder about the impact that autism will have on the child's daily life.

> *I had a big concern if my son was going to speak because I wanted to hear his voice.*(E2)
>
> *I looked at her and said: will he speak?.* (E3)
>
> *We are really concerned with this: how will this be?(*E4)

It is noticeable, given the statements, the difficulties felt in the face of the diagnosis and the feelings of fear and insecurity that can be correlated, often because it is a reality totally unknown to mothers, or due to the little information received about autism.[10]

> *How are you going to treat a child who was different from the one who slept and woke an autistic child? It's kind of difficult.*(E2)
>
> *As is the first child, and the only one, I have no experience.* (E4)

When diagnostic confirmation occurs, mothers have many doubts and questions, but few answers. At first, they may not be able to act on the care they need to take with the child. This happens because mothers face a divergence between the perfect baby, whom they had conceived during pregnancy, and the real child, which ends up generating a conflict of feelings.

At this time, new plans need to be drawn up, however there is the emergence of fear of not being able to face and meet the child's needs, for not having the necessary knowledge or even for not receiving support, be it professional or family.

According to Cunha[11], the feelings of uncertainty, sadness, among others are felt by caregivers when they imagine the future of their children, even though they are aware of the need for this care to continue throughout the child's life, given their abilities and limitations. Their questions and concerns are directed to those who can offer a quality of life and to their children, when they are already unable.

> *I think about the future because we imagine a future, but to see its future is complicated.* (E1)

> *I'm a little afraid, how am I going to see this future.*(E2)
>
> *It may happen that he is just as he is today his whole life(*E4)

Uncertainties are part of the expectations of the future of all people who aspire to achieve and idealize them. It is no different with mothers of autistic children, they create expectations about the future of their child, but the limitations of TEA make idealizations difficult, because in adulthood these children may still be dependent on maternal care.

Mothers experience the feeling of anguish in view of the uncertainties regarding the child's future, both because of the uncertainty of what can happen, and because of the possibility or not of the child's independence.[10]

Acceptance of the child diagnosed as autistic

When the mother goes through the acceptance process of the autistic child, the impact related to the diagnosis is reduced and stronger relationships with that child are built.[3]

> *I love my son the way he is.* (E3)
>
> *But it's good, I don't regret not having him as autistic.*(E4)

Over time mothers end up accepting and start to deal and understand more about TEA, promoting a good relationship and seeking to provide a better quality of life for their child.[12]

Until the mother believes in the improvement of the child, she goes through several moments that she integrates from the denial of the diagnosis, to the acceptance and coexistence with the singularities of the autistic child. This happens when mothers go into optimistic relationships, which have a link with the acceptance process that starts to be prioritized.

> *But, over time we adapt.* (E3)
>
> *I learned to live with it.* (E4)

It is noticeable how the interviewees bring with them the learning of living together and adapting to their children. The mother has a very important role in the child's life, acceptance enables involvement with ASD and a better understanding of the dimension that autism covers, the maternal figure is essential for the evolution of the child with ASD.[13]

Mothers begin to understand the needs of the child through the acceptance, seeking an adequate routine, bypassing the difficulties of relationships with the individuals they live with, with insertion in society, family and school.

When mothers go through the process of the child idealized for the real child, they begin to understand the importance of their role in that child's life and how necessary their care is. They will not stop loving them because they are not the son / daughter they so idealized.

Experiencing optimism

When mothers accept the diagnosis of autism and begin to deal better with the differences in ASD, they assume responsibility for care, with the aim of improving their child's development. Therefore, the more willpower to overcome difficulties, the better the prospects for the child's results.[14]

In their speeches, mothers bring with them expectations and desires about their children and the future that awaits them. Regardless of the child's differences, they yearn for them a future of personal achievements, studies, professional careers and a financial structure.

The interviewees share the same expectations and wishes regarding the future of their children. They believe in the care they provide the child, in dedication and in efforts aimed at quality of life and consequently yearn for a dignified future for their children, regardless of their condition.

> *Anything can happen, it can happen that he has a normal life like other people.*(E1)
>
> *I have no doubt that he will be someone, that he will study and go to college, that's right I have no doubt.* (E3)

Bearing in mind that the future, especially of an autistic child, is a question for the mother, it was observed in the mother E3's speech her certainty regarding the child's future. This is not only due to the care and education that this mother offers, but also to the advances in the child's development.

Facing the future of children with ASD, mothers crave their children's independence and autonomy and contribute to this in their daily lives. They seek strategies and goals to be achieved, thus assigning as models to reach their expectations.[15]

It is notorious that over time and their trajectory after diagnosis, mothers start to share optimistic thoughts, they feel more capable of caring and begin to positively visualize their actions related to care.

> *Never feel unable to take care of him.*(E2)
>
> *Privileged, as I told you, if God gave me it is because I have the capacity.*(E4)

Even in the face of various difficulties, maternal love becomes the greatest feeling for mothers, making them feel proud and pleased with each evolution in the development of their child.[8] When the real world of autism is understood, mothers feel able to care for and seek new advances in their children.

Difficulties encountered in caring for autistic children

Social prejudice

Social stigma is still seen as a difficulty to be faced by families, it is difficult to live in a society that has a strong limitation on differences, consequently they bring more harm than the TEA itself. All of this leads to the isolation of these mothers and harm that affects both the child's development and the well-being of all.[16]

Prejudice is among the most prevalent fears in the lives of these mothers. This is due to the fact that society does not understand what autism is and, as a result, there is a pre-judgment in relation to the mother and the child.

> *But so I only worry about prejudice.* (E2)
>
> *Some people say they will never get married, they will not have children, they will never do that, but nobody knows anything.*(E3)

According to Biffi et. al.[17] in his study it was observed that one of the main conflicts experienced by families is to deal with society's prejudice. It is noticeable how the lack of understanding about ASD is still an important factor for the difficulties experienced by mothers.

We observed how the fear of prejudice is well portrayed in the statements, the mothers refer to the difficulty in dealing with such feeling, the concern about the prejudice that the child will experience and how it is present in society in a certain way. All of this becomes a negative factor regarding maternal feelings.

Corroborating the above findings, Silva et. al.[18] also reaffirm in their studies that prejudice is one of the causes of social restrictions experienced by mothers, often as a result of the behavior of the autistic child.

Prejudice is very much associated with society's lack of knowledge about autism. In this case, the difficulties are present in the daily lives of these mothers, associated with common activities such as getting around to catch some transport or even staying somewhere for a certain time, becoming something stressful for these women.[13]

The daily life of mothers of autistic children is to dedicate themselves entirely to their child, using all their time in order to reduce suffering, especially in view of the prejudice experienced in society. That is why they seek to spare their children from the population's lack of understanding and intolerance.[17]

The lack of financial resources

An autistic child requires care from different health specialties. Consequently, the costs of treatments, medications and therapies are high. Therefore, the family strives to pay for these treatments. Expenses are high, but with primary purposes in advancing and improving the child's development.[5]

On the other hand, Nascimento et. al.[19], mention that SUS (Unified Health System) showed great advances after autism became accepted as a mental illness, although its support is still insufficient to fully meet its needs. It is a right guaranteed by law that the family and the autistic child are welcomed and have their treatment ensured by SUS.

The demand for care for autistic children will cause changes in family dynamics. In general, the mother becomes this main caregiver, causing abandonment of the job and a reduction in the family's income, thus leading the family to feel limited due to the needs of the child.[20]

The interviewees refer to the difficulties in associating care with work outside the home in some way. Given the needs of having to maintain the family or provide better conditions for the child, he feels that his care in relation to the child is limited in view of the real needs.

> *My care is not excellent, because we are failures, I know I could take better care if I had a better condition and didn't need to work.*(E1)
>
> *If I could afford to pay for my house without having to work outside, it would be better.* (E3)
>
> *Why having to work out, somehow, I leave a little to be desired.*(E4)

Corroborating the statements is notorious how many mothers resist to abandon their professional life and try to reconcile employment with the care of the autistic child. Bearing in mind that this double day of chores brings to these women a great overload of activities and, consequently, of stresses, without help all of this can generate damage to health.[20]

In short, when the family receives the autistic child, they necessarily need to adapt to their demands, as well as their expenses. The autistic person will need several medical consultations, therapies, medications and school, so that all this will require high expenses, so the parents, the vast majority, dedicate themselves to more hours of work, to maintain the family income.

Conclusion

Given this study, it became noticeable that the care provided by the mothers participating in the research is full of love, donation, seriousness and common sense. However, it must be considered that the trajectory that these women go through runs through insecurity in the face of the diagnosis of ASD, triggering fear in view of the excess of responsibilities and abdications that are necessary for the care provided to children with special needs.

This maternal trajectory is also very lonely, since the care for autistic children, for the most part, is entirely intended for mothers, who in addition to dedicating themselves to their child, need to find ways to remain economically, physically and emotionally and for that, the support of family members and a multidisciplinary health team is essential.

The performance of the multiprofessional team, especially nursing professionals, who assist children with ASD and their families, is essential to offer the necessary support, in view of the difficulties evidenced in the monitoring and care provided to these children, seeking, above all, to understand them. them in their singularities, and in fact meeting their real needs.

This sharing of responsibilities, as well as the involvement of the multiprofessional team in the face of ASD, was little explored in this study, so we signal that it is extremely important to carry out more studies that lead to the debate on the involvement of the multiprofessional health team in the care of children with ASD and therapeutic support. family members.

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