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Being sister of a person with autism spectrum disorders

Ser irmã de uma pessoa com transtornos do espectro do autismo

Be hermana de una persona con del autism spectrum disorders

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This study aimed to describe the experience of being a sister of a person with Autism Spectrum Disorders. This is a descriptive study of qualitative approach, carried out in Brasilia. Semi-structured interviews were done with seven sisters of people with autistic disorders, selected by snowball sampling. Data collection occurred from November to December 2017. Data were transcribed and submitted to thematic content analysis. Three categories were identified: The experience of perceiving the brother with Autism Spectrum Disorder; Cohabitation and family relations; and Take care of the brother with Autism Spectrum Disorder. The level of involvement in the care of the brother with autism was considered extreme by most sisters and impact on career choices, personal behaviors and early maturation. It is important to highlight the needs of health care of the sisters of people with autism because they are subject to overload and mental suffering when assuming responsibilities beyond the fraternal role.

Descriptors: Autistic disorder; Sibling relations; Family relations.

Este estudo teve como objetivo descrever a experiência de ser irmã de uma pessoa com Transtornos do Espectro do Autismo. Trata-se de estudo descritivo, de abordagem qualitativa, realizado em Brasília. Realizaram-se entrevistas semiestruturadas com sete irmãs de pessoas com transtornos autísticos, selecionadas por amostragem em bola de neve. A coleta de dados ocorreu durante os meses de novembro e dezembro de 2017. Os dados foram transcritos e submetidos à análise de conteúdo temática. Identificaram-se três categorias: A experiência de perceber o irmão com Transtorno do Espectro do Autismo; Convivências e relações familiares; e Cuidar do irmão com Transtorno do Espectro do Autismo. O nível de envolvimento no cuidado do irmão com autismo foi considerado extremo pela maioria das irmãs e impacta nas escolhas profissionais, comportamentos pessoais e amadurecimento precoce. É importante dar visibilidade às necessidades de cuidado em saúde das irmãs de pessoas com autismo, pois estão sujeitas à sobrecarga e sofrimento psíquico ao assumirem responsabilidades para além do papel fraterno.

Descritores: Transtorno autístico; Relações entre irmãos; Relações familiares.

Este estudio tuvo como objetivo describir la experiencia de ser hermana de una persona con Trastornos del Espectro del Autismo. Se trata de un estudio descriptivo, de enfoque cualitativo, realizado en Brasilia. Se realizaron entrevistas semiestructuradas con siete hermanas de personas con trastornos autísticos, seleccionadas por muestreo en bola de nieve. La recopilación de datos tuvo lugar durante los meses de noviembre y diciembre de 2017. Los datos fueron transcritos y sometidos al análisis de contenido temático. Se identificaron tres categorías: La experiencia de percibir al hermano con Trastorno del Espectro del Autismo; convivencias y relaciones familiares; y Cuidar del hermano con Trastorno del Espectro del Autismo. El nivel de implicación en el cuidado del hermano con autismo fue considerado extremo por la mayoría de las hermanas e impacta en las opciones profesionales, comportamientos personales y maduración precoz. Es importante dar visibilidad a las necesidades de cuidado en salud de las hermanas de personas con autismo, pues están sujetas a sobrecarga y sufrimiento psíquico al asumir responsabilidades más allá del papel fraterno.

Descriptores: Transtorno autístico; Relaciones entre hermanos; Relaciones familiares.

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INTRODUCTION

Autism Spectrum Disorders (ASD) are characterized by changes in behavior, language and communication, and difficulties to build and maintain social bonds, which are manifested with large individual variations, but they are generally severe, persistent and directly impact in family dynamics[1,2].

Due to the vulnerability of the person with ASD, given the high dependence of basic and specialized care, family is continually in a state of change and adaptation, and often with overloaded parents, limiting the time they could spend with the other child. In this context, many brothers seek help parents, directly looking after their brother with ASD, for example, helping in food and hygiene, but they can also sometimes contribute indirectly with home tasks[,4].

In addition to these difficulties that siblings of people with autism experience, the diagnosis is usually not explained by the family, which may compromise the living with the brother with ASD, as they are not completely instructed on the situation and behaviors of the brother[5].

Another difficulty expressed by siblings of people with ASD is the largest homestay and reduction of social interactions, who are suffering the consequences of prejudice by having a brother with autism[4].

There are several studies on the mother-child relationship with autism[6,7,8], but there are few studies with sisters of people with ASD that focus and address this population, to understand how they feel and realize coexistence and involvement in the care of the brother with TEA, since they also need care across the prioritization of attention that the sibling with autism requires from the family.

Thus, considering that the experience of being sister involves personal relationships and symbolic dimensions, that is, it is constituted, in the light of the theoretical framework of Symbolic Interactionism[9] as a interceded social phenomenon by actions, interactions, behaviors and attitudes, the following research question is presented: How is faced the experience of being sister of a person with ASD? This study aims to describe the experience of being sister of a person with Autism Spectrum Disorders (ASD).

METHOD

This is a descriptive, qualitative approach, carried out in Brasilia, capital of the Federal District, Brazil, with seven sisters of people with ASD, based on Symbolic Interaction (SI).

The SI consists of three basic premises: (a) human beings act toward the world based on the meanings that this offers; (B) such meanings come from social interaction established with others; and (c) these meanings are manipulated and modified by interpretative processes used by the person when relating to elements he is in touch[9]. Faced with the prospect of the SI and the scope of this research, it is considered that the meaning of being sister emerges from the process of interaction between the sisters and their brothers with ASD.

Inclusion criteria were: adults, adolescents or children aged at least 08 years old, who presented self-referred neurotypical development or referred by parents and/or guardians, who had at least one brother (sister) diagnosed with autism and lived in the same residence of this brother. The criteria for this age clipping considered minimally the cognitive stage of the participants in school age, to promote conduction and the interviews, but there was no participant at that age.

It was a snowball sampling, a non-probability sample used to search delicate, difficult populations to be studied, who need privacy, and it begins with documents and/or informants, called seeds, in order to locate specific people for research[10].

The Autistic Pride Movement Brazil (MOAB), a Non-Governmental Organization (NGO) non-profit that works to improve the quality of life of people with ASD and their families, announced the search for the initial seeds, which were the family linked to the NGO[11]. It is noteworthy that the sample was defined by the data saturation criterion, namely, from the data repeating in a certain number of interviews[12].

Data collection occurred from November to December 2017, through semi-structured interviews, based on a composite script by questions relating to the characterization of the participants and their siblings with ASD and the experience of being sister of a person with ASD.

The script was developed by the researchers, being previously tested. There was no need to change any of the script and the pilot interview was included in the data corpus analyzed, particularly considering the limitation of access to the target audience.

The contact between researchers and participants was initially via phone messages, to schedule the best day and time for the interviews, which were conducted in person and individually, in private environments, lasting about 30 minutes.

The interviews were recorded on digital audio device to facilitate the achievement of dialogue and prevent the loss of significant data, being subsequently transcribed in full. In turn, it was guaranteed the anonymity of participants at all stages of the process.

It is noteworthy that the data collection was initiated only after the consent of the participants by signing the Informed Consent. In the case of minor participant - only a 12- year-old teenager, it was applied the Term of Informed Assent, besides the Written Informed Consent Form facing the legal representative, who was present throughout the interview.

Data were submitted to thematic content analysis proposed by Bardin, following the steps of pre-analysis, material exploration and categorization of emerging themes of the participants’ responses, considering differences and similarities[13].

This study was approved by the Ethics Committee of the Health Sciences Faculty of the University of Brasilia, CAAE 74844917.6.0000.0030 and protocol number 2,331,709, in October 2017, being followed all ethical aspects of Resolution n. 466/2012 of the National Health Council[14].

To preserve the anonymity of the textual representation, participants’ identification was coded by the letter I, followed by Arabic number corresponding to the chronological order of interviews, results in coding: I1, I2, I3, ... I7.

RESULTS

Characterization of participants

The survey was made up of seven female participants aged 12 to 34, average age 23 years, the majority being older than the siblings with ASD. All participants had a single male brother with ASD aged between 7 and 28 years, mean 15.6 years, that is, most of them adolescents.

As for the professional profile, one student of elementary school, four were university students, two from health area, and the other two were professionals, namely lawyers. It is important to note that three families did not have the father's presence.

From the analysis of the interviews three themes were revealed: "The experience of perceiving the brother with ASD"; "coexistence and family relations"; "to take care of the brother with ASD."

The experience of perceiving the brother with ASD

The discovery of the diagnosis by the sisters involved from natural reactions to difficulties of acceptance and suffering, which were directly influenced by the way the family, especially parents, deal and share the news with their daughters.

Most parents coped with the diagnosis naturally and demonstrated the daughters differences that siblings with ASD had and could have, which was reflected in an unassuming posture by the sisters before the autism disorder that does not define the brother to you, as he is considered first of all as a subject. It is noteworthy that when the sister was younger than the sibling with ASD, this discovery was even more naturalized, as the child of reference became the brother with ASD, as in the words:

Being the sister of my brother is like an experience whatsoever. I discovered he had autism when I was about 13, 14 years. Because it was never something talked daily for us in our home. We never labeled as autistic (I2).

I never had a shock reaction to finding out, for me, I think it was very natural anyway. Because it was what I saw every day [...]. Because he was older than me and I have no other brothers, I do not have another reference. My parents say that I had to go to school too early, just because I was not that aware of the difference. He was very hyperactive, jumped all day, climbing the windows of the apartment, he did some things like that and then I started doing that too (I7).

When the family had more difficult to accept the diagnosis and work out the meaning of this, this reaction was reflected in the face of the sisters before the discovery of the brother with ASD, characterized by reports of suffering, escape and confusion:

The day the diagnosis was closed was a day that I went to an aunt party [...]. My mother called me aside and told me, I was confused. I had a crash, there's something wrong. I cried a lot. I went to a friend's house, because I asked to go there, because I did not want to deal too much about it. I kind of ran (I3).

When we found out, my mother was shocked, my father was kind of wondering why. The family had a crisis and then got used [...] My parents explained to me. Then I get it a little. I really did not identified myself in the beginning (I4).

The sisters noticed and mentioned some characteristics of brother relating to autism, as difficulties in communication and social interaction, behavioral and motor skills changes, as well as some facilities in learning new intellectual abilities:

He does not talk, very long sentences, he talks short sentences, speak what he wants, but then, he already joins words [...]. The vocalization sometimes, of some phoneme is also different [...] he also has difficulties in motor coordination, he was not used to fall [...] but you see that he has a more disjoint type (I3).

In technology it is much more developed. He knows a lot of things, of the internet. He learned to speak English, French and Spanish all by himself! (I4).

In this context, it is emphasized that overcoming these characteristics commonly associated with the diagnosis of autism was valued by the sisters as small daily achievements of the brother with ASD:

These are things you do not notice when the child is neuro-typical, you end up noticing and giving greater value, there are small things even if you talk to someone else, the person does not understand, but I think it's really cool. Learn to appreciate the little things, an example of this was when they stopped walking on tiptoe (I1).

Coexistence and family relations

This category highlights three important interactional patterns: the interaction between the sisters with neuro-typical development and ASD; the interaction between parents and daughters with neuro-typical development and interaction between parents and children with ASD. The first highlights the interaction and coexistence among brothers, and the second along with third involves the difference between the perceptions of the participants about their relations with their parents and those with children with ASD.

The fraternal relations are permeated with companionship, love and care, and the brothers with ASD are admired by their sisters, mainly by the sensitivity and purity they show. In contrast, aggression is a common behavior in siblings with ASD, which hampers coexistence and generates many tensions in relations:

Nowadays it is difficult to be his sister. We love too much! But, sometimes it is difficult. What I like least is the aggression and these mood swings [...]. He's here with you and suddenly it hits. And he does not accept two people; if he wants to stay with me, he beats you [...] (I5).

I like his purity. He is very pure, you see that he has no malice at all, he is a very good person. He will be an eternal child for us, you will have the purity lifelong. (I6)

According to the perceptions of the sisters interviewed, siblings with ASD have a very high regard when the sisters give them attention, which often are absent due to the intense routine of work and/or study. In moments of interaction, activities and home leisure programs like watching shows, movies and cartoons on television, draw and play are highlighted. Only a few sisters go to walk out and go to educational events, most avoid it due to the needs that the brothers demand and prejudices that other people have in relation to ASD:

We watch series together [...] We see a lot of television [...] Going out is more complicated because a brother demand one thing and the other another demand [...]. Going out ends up being very focused to the needs of the youngest (I1).

The care with my brother is very concerned not to leave him alone, that there are not many children to play, and when there is, they do not have much patience, they are excluded. We try to take, but he does not want, because he realizes it. He becomes kind of sad [...]. So we end up playing more with him at home (I5).

Relations between the participants and their parents, in general, are considered good and involve friendship and complicity. However, the sisters realize differences between parental relationships with them and parents with siblings with ASD, who become the center of attention and parents' lives, who often overprotect children with ASD and adapt their routine to these children's:

With my mother it was always like that, the favorite one, because he is the youngest, because he was the only boy and is special, he is very overprotected by her, and up to these days, there must be someone with him when he takes a shower (I3).

I think my parents have adapted much to him. I think that he had to be more adaptable to people. [...] I think that my parents stopped their lives because of him (I7).

The coexistence of participants with the parents, particularly the mother, is often reduced due to the demands of the brother with ASD, which fall mainly on the maternal figure, which generates laments because of the lack of more frequent moments with her mother, considered rarity by the participants:

I like to go out alone with my mother, we go to the movies because I really like my mother. I just want to be with her. They are rare moments, very rare, that only happened twice [...] but to go out with my mom, I miss it (I4).

Unlike the desire for more time with their mothers, the participants do not express missing the interaction with fathers. Living with the father figure became more restricted in the reports, since the participants do not usually have much contact with the father:

With my father, I think we never did anything, me and him. Nothing, but I do not miss time with him (I3).

Taking care of the brother with ASD

This category has two subcategories "After all, we are sisters or mothers?" And "Impact on sisters' lives." The first refers to the degree of involvement in care and ambivalence of roles and feelings experienced by the sisters. The second reveals the repercussions to take care of the brothers with ASD in personal, social and professional lives of the participants.

After all, we are sisters or mothers?

The degree of involvement of the sisters in their brother's care with ASD is extreme and is reflected in the general care actions such as basic hygiene, food, medication administration and transportation.

The sisters assume the role and nourish maternal feeling from childhood for helping parents or guardians in the care of their brother with ASD. Even if they report having a healthy fraternal relation, this maternal feeling is still designed and linked to attitudes of super protective nature, which refers to an ideal desire of them to expelling and exiling the brothers with ASD in relation to real life. In general, the sisters themselves impose themselves the responsibility of taking care of the brother with ASD, but other times, the family itself is imposing this condition of caregiver:

Regarding the involvement in care, to be honest, despite being sister, I was kind of their "co-parent". I've been wanting to put my brothers in a pink bubble and let them protected there. [...] My mother always tried to get me out of this place. There was a time when we even fought [...] She always tried to get me out of this context and protect me from those thoughts that I have to help her and my brothers, and I continue because it's my thing. I put myself in this place (I1).

I help my brother a lot, when they both need to work, I look after him, I dine, bath, brush his teeth, when he has homework, sometimes I help too, so I'm kind of a second mother to him! I am extremely involved in this care with my brother [...]. Sometimes I feel a little forced. When they go out, they say: you want to go? I say: no, then they say: Oh, so you'll have to take care of your brother okay? And I get: Ok, right? (I4).

Impact on sisters' lives

The repercussions of having a sibling with ASD was referred to as an experience both positive and negative. Some sisters have reported being deprived of living full life stages such as adolescence and suspend a semester of study at the university because they have to take responsibility at an early age with his brother and therefore mature precociously:

This involvement influences a lot. Because it made me mature faster, which I did not say it was good, I do not think this is a good thing. I missed much of the end of childhood and adolescence. I was a teenager who does not come out, not only because of them, but the conditions, because they take medicine (I1).

I stopped studying for a semester. To help him, taking in class and everything, because he needed. I say: I miss a semester? I pick it up later. But he losing now, in childhood? It makes a big difference. No one said that, I did it myself. I said it was because I had lost a lot of classes (I5).

However, others realize this growth as something positive, which influenced, albeit unconsciously, in the choice of profession in the health sector and specific subjects related to the theme of autism.

About the choice of my course, psychology has to do with my relation with my brother, may people asked me a lot about that! So I just stopped to think after I had already chosen [...](I2).

I would say that first time, I was not influenced by my situation to choose psychology, but when I came on to the first day of school, I sought in all matters a pro autism bias (I3).

In addition, the commitment of taking care of a brother impacts on social life, reflected in privations of living moments with friends. The loving context, what more interferes are the concerns and future impasses involving plans to set up a new independent family amid the obligations and care responsibilities with the brother with ASD:

I'm in a serious relationship and the boy talked about engagement and then I think: what do you mean, engagement? For a few years I have to look after my brothers, will you accept that? My first date was last year. Before that I had no one or I cast out everyone because I was creating a wall (I1).

DISCUSSION

The sisters of people with ASD are also affected by the diagnosis, which interrupts the idealization of a neuro-typical brother. The way the diagnosis is communicated interferes with the understanding of the disorder. In general, the diagnosis explanation is insufficient for the sister, who before the discovery feels sad to realize that the sibling with ASD is different to live with. Although the communication of diagnosis is explicit or veiled, the siblings are affected by the news of having a brother with ASD[15].

The timing of the disclosure of the diagnosis is fragile, complicated and hard for family members. Thus, the dialogue should be conducted in order to explain the disorder clearly and accurately about the causes and clinical manifestations, as this improves acceptance of the ASD by family and influence their expectations[16].

The results of this study revealed that for the younger sisters, the discovery was delayed and diagnosis, naturalized, since their benchmark for children was the brother with ASD. The age difference is directly related to the perception of sister in respect of the associated features of autism, which was evidenced in a study in which older siblings realized that the brother with ASD had an unusual development for age, while the brothers with close ages suspected the diagnosis due to differences in treatment evidenced by parents[17].

The sisters consider the brothers with ASD as a subject and build fraternal relations permeated with affection, companionship and care, corroborating another study showing that feelings of love, concern and patience are present mostly in the relations between neuro-typical brothers and brothers with ASD[18]. Even with more adversity and pressure from the families, the siblings are grateful for their relationship with their brothers wit ASD[19].

A Study investigating the effects of autism in fraternal subsystem from the perspective of adult siblings found that the siblings prefer to take care of the brother with ASD to develop jealousies and rivalries, reactions often manifested among siblings with neuro-typical development[4].

Although the sisters have a good relationship and likes the purity and sensitivity of the brother, they do not appreciate the aggression manifested by them. According to another study, the behaviors that the brothers like best are the caresses and demonstration of happiness. But they consider bad and confrontational when the brother with ASD bites, screams, makes a lot of noise and is restless[20].

In moments of interaction, home leisure activities were highlighted. Most sisters avoids going out due to the needs that the brothers demand and prejudices that other people have in relation to the diagnosis of ASD. The interaction between the brothers can be tricky, depending on the severity of ASD it becomes more difficult to play with the brother when it is a serious picture. Also, after the diagnosis, families fail to carry out some programs for fearing the behavior of the person with ASD resulting in acceptance and understanding by society, which requires planning and adaptation of social family activities[17].

Perceptions of the sisters on the relation between them and their parents and between parents and brothers, is that the brothers become the center of attention of the parents' lives. It is noteworthy that some participants reported that parents overprotect siblings with ASD and adapt to the routine of these children. Parents tend to be more tolerant and less strict with the children with disabilities in order to protect them[21].

The sisters say more about their living with the mother and how they miss more close time with them than living together with their fathers, however, it must be considered that the fathers of the participants are mostly absent. There is evidence in the literature that mothers of children with ASD report that their routine is dedicated to child care with autism and they often need to abandon their profession, since the role of caregiver is usually designated by society to the woman[18]. Before the weakened family support and the absence of the father figure, the network of care support is reduced, sometimes just to the mother and the neuro-typical sibling[17].

Sisters, for helping their overburdened mothers with a brother with autism have an extreme degree of involvement in the care of their brother with ASD. The participants reported doing general care as basic hygiene, food, medication administration and transport, which is in line with other studies that have found that siblings help their brothers with ASD from infancy, even before it is necessary, and generally perform general care and hygiene, transportation and household chores to decentralize the obligations of the mother[15,17].

This involvement and increasingly responsibility in relation to basic household chores and care, in the perception of the sisters, constitute a more nurturing nature than fraternal change of role [21]. The feeling of motherhood is linked with the desire to protect the brothers with ASD and is regarded as one of the most prevalent feelings[15].

It is, thus, highlighted the playing roles historically linked to the female gender, namely the care task of caring, a careing mother, something considered inherent and innate to being a woman, so that the patriarchal imagination does not belong to the male universe, since it is due to them the detachment from the scope of tasks within the family to produce in the public sphere and get financial support for the family[22,23].

Despite the growing process of these roles transformation, the hegemonic idea of women as a place of care for children and household chores still prevails, which reflects deep gender inequality. Study of relatives of children and adolescents users of mental health services revealed that the care was predominantly performed by women, regardless of who was the family income provider, as the tendency of women to go to the labor market was not accompanied by the tendency of man taking care of domestic life, which resulted in female double journey[23].

Looking after the brother is usually self-imposed by the sisters, however, in the perception of the minority of the study participants, the family can also impose it, which is in line with other studies that show that a minority of the siblings had responsibilities imposed by parents and decided to take care of their brother because of the needs they presented[15, 21].

Being the sister of a person with ASD affects aspects such as personal behavior, career choices - courses in health and mature early, the latter in particular by the need to show themselves strong to parents, who are already very worried and occupied with the child with autism[17].

The impact of involvement in caring the brother with ASD also influences the social context by depriving friendly relations and loving, the latter being most affected by concerns about the future. The sisters of people with ASD assume that they will be responsible for their brothers in the future after the death of their parents, consisting of one of their major concerns, with the distress being diminished when there is another brother to share responsabilities[15,17].

Involvement in caring impacts on deprivation, worries about the future and even the professional choice of the sisters, and again points to a direct relation with the genre, a female identity valued by care work and responsibility in the generation and maintenance offspring with extreme devotion and self-sacrifice, attitudes so admired in the symbolic universe of a motherhood of patriarchal society[22].

CONCLUSION

This study made it possible to explore and know the sisters' experience of persons with ASD regarding the impact of the diagnosis, coexistence and involvement in their brother's care.

As a limitation of this study, it is found that the limited and restricted sample of young female participants prevents the generalization of results. It is noteworthy saying that it was not determined that the sample was composed only of female participants, however, the idea was to include participants from both genders and of different ages, but two potential male participants indicated they could not participate in the research by lack of time availability.

This limitation exposes the need for further studies to be performed with mixed sample, involving both genders, or even just with male participants to investigate and deepen the perception of being and having a sibling with ASD from gender differences.

This research can be used to aggregate technical and scientific knowledge in the field of mental health for children and youth in the nursing field, increasing the need to carry out more and more health care focused not only on the person with ASD, but also in his family, especially in siblings.

It is important that nursing highlights the needs of health care of the sisters of people with ASD, since by being extremely involved in the care and taking responsibility beyond the brotherly role, the siblings may be subject to overloads and mental suffering.

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CONTRIBUTIONS

Danielle Lourenço Ataide and **Mariana André Honorato Franzoi** participated in the design, data collection and analysis, writing and review. **Rita de Cássia Melão de Morais** and **Aline Oliveira Silveira** collaborated with critical review.

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