## AUTISTIC SPECTRUM DISORDER: EARLY DETECTION BY FAMILY HEALTH STRATEGY NURSES

# TRANSTORNO DO ESPECTRO AUTISTA: DETECÇÃO PRECOCE PELO ENFERMEIRO NA ESTRATÉGIA SAÚDE DA FAMÍLIA

### TRASTORNO DEL ESPECTRO AUTISTA: DETECCIÓN PRECOZ DEL ENFERMERO EN LA ESTRATEGIA SALUD DE LA FAMILIA

Yanna Cristina Moraes Lira Nascimento<sup>1</sup>
Cintia Soares Cruz de Castro<sup>2</sup>
José Leandro Ramos de Lima<sup>3</sup>
Maria Cicera dos Santos de Albuquerque<sup>4</sup>
Daniele Gonçalves Bezerra<sup>5</sup>

**How to cite this article:** Nascimento YCML, Castro CSC, Lima JLR, Albuquerque MCS, Bezerra DG. Autistic Spectrum Disorder: early detection by Family Health Strategy nurses. Rev baiana enferm. 2018;32:e25425.

Objective: to identify the role of Family Health Strategy nurses in the early detection of Autistic Spectrum Disorder in children. Method: descriptive, exploratory, qualitative research carried out in a capital city in the Northeast region of Brazil. The participants were 10 nurses who took a test to have a permanent job and work in the Family Health Strategy. Data collection took place in 2014 through individual interview, direct observation, and field diary. Thematic analysis was used, with data interpreted by the framework of the Guidelines for Rehabilitation Care of Autistic Spectrum Disorder Patients. Results: the thematic areas were: perception, strategies and interventions of nurses on symptoms and signs; difficulties related to early detection; construction of knowledge on the subject; and professionals' feelings when accompanying children with the Autistic Spectrum Disorder. Conclusion: the Family Health Strategy nurses had deficiencies in the early detection of the Autistic Spectrum Disorder in children.

Descriptors: Autistic disorder. Child care. Family Health Strategy. Early intervention (Education).

Objetivo: identificar a atuação do enfermeiro da Estratégia Saúde da Família na detecção precoce do Transtorno do Espectro Autista em crianças. Método: pesquisa descritiva, exploratória, qualitativa realizada numa capital do

Nurse. Master of Nursing. Specialist in Mental Health. Specialist in Activation of Processes of Change in Higher Education of Health Professionals. Professor of Nursing and Medicine courses at the Universidade Federal de Alagoas. Coordinator of extension projects in mental health and basic care in cooperation with the Municipal Department of Health of the Municipality of Maceió. Articulator of the Mental Health Forum of the Universidade Federal de Alagoas Nise da Silveira. Member of the Research Group on Mental Health, Alcohol and Other Drugs Austregésilo Carrano Bueno. Maceió, Alagoas, Brazil. yanna.lira@esenfar.ufal.br

Nurse. Scholarship holder of Scientific Initiation of the National Council for Scientific and Technological Development during undergraduate studies. Maceió, Alagoas,

<sup>3</sup> Student of the Nursing course at the Universidade Federal de Alagoas. Participant in the Research Group on Mental Health, Alcohol and Other Drugs Austregésilo Carrano Bueno, at the Universidade Federal de Alagoas. Scholarship holder of Scientific Initiation of the National Council for Scientific and Technological Development during undergraduate studies. Maceió, Alagoas, Brazil.

Nurse and Psychologist. PhD in Fundamental Nursing. Master in Education. Professor at the Undergraduate and Graduate Program in Nursing at the School of Nursing and Pharmacy, Universidade Federal de Alagoas. Coordinator of the Laboratory of Mental Health, Reception and Interpersonal Relationship. Leader of the Group of Research in Mental Health, Alcohol and other Drugs Austregésilo Carrano Bueno. Maceió, Alagoas, Brazil.

<sup>&</sup>lt;sup>5</sup> Biologist. PhD in Human and Experimental Biology. Master in Morphology. Professor at the Universidade Federal de Alagoas and Faculdade Estácio de Alagoas. Maceió, Alagoas, Brazil.

Nordeste, Brasil. Participaram 10 enfermeiros efetivos, concursados e em exercício na Estratégia Saúde da Família. A coleta de dados ocorreu em 2014 por meio de entrevista individual, observação direta e diário de campo. Material tratado pela análise temática, interpretado pelo referencial das Diretrizes de Atenção à Reabilitação da Pessoa com Transtorno do Espectro Autista. Resultados: foram áreas temáticas: percepção, estratégias e intervenções do enfermeiro sobre sinais e sintomas; dificuldades relatadas à detecção precoce; construção do conhecimento sobre a temática; e sentimentos dos profissionais ao acompanharem crianças com Transtorno do Espectro Autista. Conclusão: enfermeiros da Estratégia Saúde da Família apresentaram deficiências na detecção precoce do Transtorno do Espectro Autista em crianças.

**Descritore**s: Transtorno autístico. Cuidado da criança. Estratégia Saúde da Família. Intervenção precoce (Educação).

Objetivo: identificar la actuación del enfermero de Estrategia Salud de la Familia en la detección precoz del Trastorno del Espectro Autista en niños. Método: investigación descriptiva, exploratoria, cualitativa, realizada en capital del Noreste brasileño. Participaron 10 enfermeros efectivos, concursados y en ejercicio en la Estrategia Salud de la Familia. Datos recolectados en 2014 mediante entrevista individual, observación directa y registro de servicio. Material tratado por análisis temático, interpretado por referencial de Directrices de Atención a la Rebabilitación de la Persona con Trastorno del Espectro Autista. Resultados: las áreas temáticas fueron: percepción, estrategias e intervenciones del enfermero ante señales y síntomas; dificultades informadas en la detección precoz; construcción de conocimiento sobre la temática; y sentimientos de los profesionales al trabajar con niños con Trastorno del Espectro Autista. Conclusión: los enfermeros de la Estrategia Salud de la Familia muestran deficiencias para detectar precozmente el Trastorno del Espectro Autista en niños.

Descriptores: Trastorno autístico. Cuidado del niño. Estrategia de Salud Familiar. Intervención precoz (Educación).

#### Introduction

Autistic Spectrum Disorder (ASD), which affects areas of neurodevelopment responsible for social interaction, communication and behavior, requires specific and early interventions to enhance child development, decrease the possibility of chronification, and broaden therapeutic proposals (1-2). Studies estimate that the prevalence rate of ASD is 62/10,000 with a fourfold incidence among boys (1). In Brazil, there is still no official statistical data on the prevalence of this disorder, but it is estimated that between 10% and 20% of children and adolescents suffer from mental disorders. It is considered that up to 4% of this population needs intensive treatment (3).

The symptoms of ASD appear before the age of three, and are manifested in a variety of ways, through behavioral changes, such as fear and mental confusion, low tolerance to change, difficulties in understanding social rules, inattention, impulsivity, avoidance, and self- and hetero-aggressive behaviors. Children with autism have their own responses to sensory stimuli, show resistance to pain, hypersensitivity

to touch, excessive reactions to odors, and demonstrate enchantment to specific visual stimuli. In addition, they may present poor interpersonal skills in contact with other children and even with family members<sup>(4-5)</sup>.

Family members are most likely to early notice the first changes or manifestations of autism in their child. With this possibility confirmed, and their participation in therapeutic interventions, the child is set in a situation that is favorable to the experience of a life with more autonomy<sup>(1)</sup>. To contribute with these family members and the multiprofessional teams for the health care of children with ASD in the Unified Health System (SUS, as per its acronym in Portuguese), the Ministry of Health launched, in 2014, guidelines for early diagnosis and treatment, which include the singular therapeutic project in the perspective of habilitation and rehabilitation, support and embracement to the family, follow-up flowchart, and care in the SUS network (6).

The organization of the health network in the territory, with its public and complementary

equipment at the primary care level, should prepare and strengthen the basic units with their family health teams for comprehensive, individual and collective care to children and adolescents<sup>(7)</sup>, especially in cases of children with ASD, and their families. The integrated action of basic care with several services reinforces the need for activities aimed at health promotion, prevention of diseases, and recovery and rehabilitation of health in the perspective of quality of life. For this, it is also necessary to consider the effectiveness of the matrix-based strategy of health services<sup>(8)</sup>, thus strengthening the network of psychosocial care through coordination with the Family Health Strategy (FHS).

At the FHS, it is possible to work with the perspective of health promotion and reduction of complications, following child growth and development during childcare actions. Nurses, as members of the multiprofessional team, are one of the professionals responsible for this follow-up, and should be prepared to evaluate child development in order to early detect any abnormality, and take resolutive measures to improve quality of life<sup>(9)</sup>, mainly of children with ASD and their family.

Studies conducted in the countryside of the state of São Paulo revealed that 15% of primary care professionals have already come into contact with children with ASD and their families, and that 43% of them knew how to recognize the behavioral triad that involves the disorder. However, only 10% of these professionals recognized the signs related to the manifestations in the first year of life, and although 99% of them acknowledged the need for treatment for these children, the therapies used were not clearly identified<sup>(10)</sup>.

Thus, because the FHS has, within the scope of its activities, actions aimed at monitoring children growth and development, nurses need to notice, in the childcare visit, any behavioral change that suggests ASD. Therefore, the following guiding question was adopted in the research: How do FHS nurses act at early detection of ASD in children?

The defined objective was to identify the action of FHS nurses in the early detection of ASD in children.

#### Method

An exploratory, descriptive study, using a qualitative approach, was carried out in the city of Maceió, capital of the state of Alagoas, Brazil, where nurses were the subjects. Basic health units that had FHS teams were randomly drawn to be addressed. Next, a telephone contact was made with the nurses of these units to schedule the interviews.

Ten nurses with a permanent link to these units by municipal public procurement, who also worked in the FHS, participated in the study. Nurses who were on a leave, or on vacation at the time of contact were excluded. The number of respondents followed the criterion of data saturation, understood as the moment when data starts being repeated in a certain number of interviews<sup>(11)</sup>.

Data were collected in January and February of 2014, through the triangulation of data collection with the use of the individual in-depth interview, guided by a semi-structured script consisting of questions regarding the characterization of the participants, and the view they had about children with ASD and their family.

Other data collection methods were the direct observation of the nurses' performance with children during nursing appointments in childcare, in which the students closely followed the consultation, describing what was observed in reports, in an attempt to notice if altered signs of children development suggesting autism were investigated by the nurse; also, the notes systematically registered on the field diary and guided by a script where the following was recorded: the subject addressed; date, time, location and setting of the interview; description of the behavior of the participant involved in the research; description of the activities observed in the service, in which the participant performed the work; and the researcher's comment. Data collection was carried out by two nursing students, with one of them being a scholarship holder of the Institutional Program of Scientific Initiation Scholarships (PIBIC) linked to the National Council for Scientific and Technological Development (CNPq) and the other being a collaborator.

The material produced was treated by thematic analysis (11-12). For the operationalization of the analysis, three successive stages were necessary: pre-analysis, with the preparation of the material, transcription of the recorded interviews, and thorough reading; material exploration, with coding followed by the transformation of raw data after they were cut, aggregated and enumerated; and the classification, with text writing. The Guidelines of the Ministry of Health for Rehabilitation Care of Autistic Spectrum Disorder Patients were used for analysis.

This study considered and applied the guidelines and regulatory standards for research involving human beings contained in Resolution n. 466 of December 12, 2012, and obtained approval from the Research Ethics Committee of Faculdade Estácio of the city of Alagoas, under protocol number 505.852, on December 31, 2013. These procedures guaranteed all rights of the participants once they signed a free and informed consent form.

#### Results

The nurses participating in this research had 9 to 18 years of training, had worked for 1 to 16 years at the FHS, and 50% of them reported having had contact with ASD, and identified its signs during the evaluation of growth and development of the children they followed. The content of the respondents' speeches was categorized in four thematic areas: nurses' perception, strategies and interventions on the signs and symptoms of children with ASD, difficulties related to the early detection of ASD, construction of knowledge about ASD, and feelings of professionals accompanying children with ASD.

Nurses' perception, strategies, and interventions on the signs and symptoms of children with ASD

In the participants' narratives, the perception emerged that children with ASD had difficulties interacting with other people and the environment in which they were inserted:

The person presents several traits. It is possible to be suspicious of that child who is isolated, who has no contact with anyone, sometimes not even with bis/ber mother [...] (E9).

The nurses also noticed other signs that allowed the diagnosis of ASD, such as: repetitive movements, strange and aggressive behaviors, isolation, playing differently, difficulty in sharing toys, and difficulties to sleep and breastfeed.

They are children who, in early childhood, have some difficulty in socialization and who present with repetition of body movements [...] (E5).

Children who play alone, do not share things with other children. (E6).

I believe that a child under the age of six months who has autism has difficulty coordinating sleep and breastfeeding [...] (E1).

These perceptions were confirmed in the direct observation of the nursing consultation. In this one, the professional monitors the weight, height, breastfeeding, feeding, the presence of unexpected behaviors, and assesses whether children sit without support, hold their heads in the expected time, if they observer the people around them, if they make eye contact, if they babble something, and if the transfer objects from one hand to the other.

The nurses also diverged in their perception about the cognitive ability of the ASD child. While it was stated that these children had pedagogical and neurological difficulties that hindered their learning, there was also the report of the possibility of them performing well in school life when stimulated.

I have a five-year-old daughter who is studying in a school that has special children. There is a teacher only for these children, because they have behavioral changes: sometimes they become aggressive, sometimes they are able to socialize. They cannot follow the pedagogical question; they are a little behind. (E5).

My daughter is studying in a school where there was an autistic student, and he had a very advanced degree and today he is going to college [...] (E7).

Just as school development is an important stimulus to good performance in society life, the early identification of the symptoms and signs of ASD is also crucial to the development of skills. This early diagnosis, however, according to the reports, is difficult to obtain, and a deeper and more specialized observation, with reference professionals, is necessary.

It is not so quick to realize that a child is autistic, but the sooner you discover, the sooner you intervene, the better you will get [...] (E7).

It is a child who requires more direct care, in more details, and with specialized people [...] (E10).

It was noticeable to the interviewees that social and family issues are related to the life context of these children. Situations of precarious feeding and domestic violence interfere with the physical, neurological and psychological development of the family.

Questions of social misery involve the family, and we discovered that the brother of the child we were following bad autism. This child had dramatic malnutrition, was agitated, bit the head on the wall, and did not speak [...] (F1)

Thus, it was observed that the nurses perceived the child with ASD as that with characteristics and needs that were differentiated from the others, but it was possible to invest early in their development, to insert them in the society, with interventions being necessary.

In the follow-up of child development, nurses have the opportunity to identify dysfunctional changes. Therefore, to consider parameters to evaluate the absence of signs expected for the age was revealed as a strategy:

We follow what we know, such as the development of the child from zero to two years that we monitor. Six-montholds already sit with some support; children of seven, nine months already begin to crawl. We also test the reflex, using a parameter. When they are absent, it suggests that something is happening. (E5).

Besides the observation of dysfunctional signs during the consultation, there are reports about the need to listen to the mother's report as a strategy.

At history taking, when talking to the mother, she tells bow the child is behaving and, according to the behavior established for the age, we evaluate the development of this child ... if he/she knows his/her name, if he/she is speaking at the right age, if he/she can form sentences, if he/she has contact with the environment [...] (E8).

Regarding the procedures adopted for suspicion of ASD, some stated that they asking for an evaluation from other professionals, recognizing the need to extend care to the family.

If the child arrives and has not been diagnosed, we will refer him/her for medical consultation [...] (E8).

It is a child that requires care, not only from physicians, but from a multiprofessional team. Mainly psychologists. I think the whole family needs to be prepared to follow the child for the rest of their lives [...] (E6).

As a method of intervention, the search for assistance devices for people with ASD, specialized and reference services, such as the Child and Adolescent Psychosocial Care Center (CAPSi) was mentioned.

I would contact a psychology sector, a CAPSi [...] (E10).

But the access to these services, or even the knowledge about them, is always clear to the professionals. The lack of information interferes with the security and assertiveness of actions, making it difficult to carry out interventions directed at these children.

Difficulties related to the early detection of ASD

Among the difficulties in detecting symptoms and signs of ASD is the lack of training and dissemination of specific materials that encourage the use of facilitating instruments for the early detection of autism. The idea that the identification of signs and symptoms of ASD is not the responsibility of the nurse is also another barrier to early detection and intervention by this professional.

If we had the ability to recognize and we had access to information. (E9).

I don't know any instrument, any printed material, nothing that helps me to notice an autistic child [...] (E7).

I do not know how to attend a child with autism. And it's not even something that I have to do. I wouldn't be the adequate person to detect [...] (E6).

6

Along with these expressions, the nurses' restlessness about the lack of information and the need for spaces for training when asked about the theme was observed in the field diaries.

Another difficulty identified was the lack of protocols describing the psychosocial care network, which guides the services of reference, and the difficulties found in the search for an early diagnosis, when they need the support of other network professionals.

What we have to do is not written, because there is no protocol for it [...] (E7).

If we had an organization chart where to send the child, it would be interesting. (E6).

It is very difficult to close the diagnosis. Mothers have trouble scheduling a consultation with a psychiatrist. It is very time-consuming to appoint a consultation with a child psychiatrist [...] (E9).

In addition, many times, caregivers do not report children's behavior at home, making it difficult to perceive changes in the child's development.

We consider giving great attention to what the mother says. If the mother did not give this information about the child, it would be a problem. Because we have mothers who are disperse, and do not observe the child very much [...] (E3).

The family has a fundamental role in the whole process from identification to adherence to treatment; however, there are situations in which the family can become a risk factor for the performance of a child with ASD; especially when influenced by social stigmas, the family creates barriers that hinder the rehabilitation of the child. These barriers include the denial of symptoms, non-attendance of the child in the child care clinic, the culture of seeking the health center only when there is an illness, even religious beliefs, and disconnection from this FHS family nucleus, as well as a family environment that is unfavorable and disturbed, as reported below:

A mother of an autistic child came, but at the time she did not accept it. She resisted a lot, and then she did not show up anymore. The family needed treatment. They are evangelical, and this increased the resistance to understanding that their daughter could be autistic [...] (E7).

My difficulty would be for mothers to attend childcare because mothers only seek care when the child is sick ... If they attended the clinic, they would be identified, it might not exactly drain autism, but it will drain something out of the normal standard. But the culture is that the child goes for consultation when he/she is sick. It is necessary to demystify, with educational activities, guiding mothers since prenatal care [...] (E8).

Difficulties such as the lack of family and child monitoring since prenatal care, combined with the lack of resources necessary for effective early detection often generate insecurity in professional practice. Thus, to solve or reduce the obstacles, the construction of a technical knowledge becomes paramount.

#### Construction of knowledge about ASD

In this condition, the television media influenced the interviewees regarding the reproduction of concepts and images about ASD. The internet has also been indicated as one of the sources of information, a resource for solving doubts and, thus, help in the daily routine of the profession:

All I know is what we see on TV. With autism being addressed in the soap opera, I found it interesting to follow [...] (E4).

I have never studied it. The information I have about autism is through the media. And some little things I read on the internet. (E6).

The importance of third parties, such as coworkers and family members as influencers in the construction of knowledge about ASD was also considered. In addition, the professionals themselves, sharing their experiences together.

A person from the unit has an autistic child, I noticed how this child speaks [...] (E7).

I know about autism because my daughter works in the education field with autistic children [...] (E4).

We question, discuss with the team physicians [...] (E1).

The child's booklet is also pointed out as another source of knowledge in the pages that provide information and guidance on inadequate development:

My curiosity is that if, in the child's booklet, there is a page on autism [...] (E3).

However, during the observation in some consultations, it was noticed that the most of the interviewees did not fill the page of the child's booklet intended for the early investigation of symptoms and signs of ASD.

Thus, the knowledge acquired both in the booklets, in the media, or in experiences shared have contributed to the nursing interventions that arouse some feelings.

Feelings of professionals accompanying children with ASD

It is common for the professional to feel confused, frustrated, and unable to deal with the theme, when he claims little knowledge about the subject.

It's frustrating. I felt helpless, because we were not sure bow to deal with it [...] (E1).

I feel almost incapable because of the lack of knowledge on the subject [...] (E2).

This feeling of incapacity is also perceived in the records of the field diaries, when the expression "out of normal" is used to refer to autistic children, with lack of knowledge on the subject, and the presence of social stigma being explicit. In addition, it was observed that some nurses, although they accepted to participate in the research, were limited to answer some questions, perhaps for fear of judgment or fear of exposure.

A feeling of anger was also cited, when the mother denied the child's inappropriate behavior.

At first the mother denied, this even made me angry [...] (E9).

However, feelings of well-being and enjoyment for cooperating were also cited. When they could identify the symptoms and signs of ASD and collaborate with the intervention, their feelings became of satisfaction and security.

I feel good about helping that child and family. I like to contribute to the diagnosis so that the child has better care and better quality of life [...] (E9).

I know the sooner you identify, the better. So, I would feel good, feel the best! We get very happy when we can help people. (E3).

#### Discussion

Research has shown how necessary it is for the nurses to intervene efficiently with the child who requires demanding care (13-14), and to provide support for the family, because they are the professionals that have a direct relationship with this person (13). This understanding corroborates the results of this research.

This way, the analysis of the results of this study allowed us to identify perceptions for the early detection of ASD in the nurses' performance, as well as the interventions performed by this professional, their difficulties, the way in which they constructed the knowledge on this subject, and their feelings when following a child with indications of this diagnosis.

Thus, with regard to nurses' perceptions, strategies and interventions on symptoms and signs, confirming what is mentioned in the literature, this professional considers that the child with ASD reveals intense changes in behavior and social communication, such as ritualistic behaviors, self-aggressiveness, changes in the pattern of sleep and feeding, tantrum crisis, phobia without specification, difficulties to understand reality, altered sensorial stimuli, limitations to participate in collective games, social isolation with less intense affective interactions. However, this child keeps memory capacity, which makes cognitive advances possible when there is stimulus<sup>(6,15)</sup>.

The diagnosis made in the first three years of life is essential for the development of abilities, including school development, because early therapeutic approaches increase the possibilities of positive responses due to the greater plasticity of anatomical-neurophysiological structures of the brain in that period<sup>(16)</sup>. An integrative review, which portrayed the scientific productions on nursing care for children with ASD, revealed the importance of nurses' knowledge to allow the recognition of symptoms and signs of this disorder as early as possible in the child growing and development period<sup>(17)</sup>.

However, it is common for professionals to feel insecure, unprepared for evaluating symptoms and signs, which causes delay in the diagnosis, and compromises the early identification. This leads the family and the child to consult, successively, different professionals and institutions before the ASD diagnosis is established, thereby delaying any type of intervention that contributes to the improvement of child growth and development of child growth and development to feliagnosis, treatment and follow-up of the child with ASD, as well as the recognition of their needs (17).

It should be emphasized that, in order to provide subsidies to health professionals, especially in primary care, the Ministry of Health has contributed by publishing manuals with guidelines and instructions that describe the signs that can be observed at each stage of child development, and proposes instruments that facilitate evaluation and monitoring of development, which can be used during consultations, such as: the Questionnaire of Communication Development (QDC), the Modified-Checklist for Autism in Toddlers (M-Chat), and the Preaut Signs<sup>(6)</sup>.

However, it is not always possible to check for such symptoms if the child is not taken to a basic health unit. This occurs when the family does not perceive the dysfunctional signs in the first 24 months of life, either due to protection against social stigmas, denial or disinformation, or, in extreme cases, neglect of the child. Thus, the nurse, when conducting the nursing consultation in the infant periodically, should evaluate and monitor the growth and development of children under two years, in order to plan strategies to act according to the needs found (1.6.9).

The signs presented by the child should be evaluated and checked by the nurse along with the team, to notice changes, in the following moments: in the initial Interview with the parents or guardians; in the child's social, family, and health history taking; and in the evaluation itself of the child's development and behavior<sup>(6)</sup>.

This way, the nurse's attentive look, associated with an insightful reasoning, will guide interventions in a resolutive way. Mothers' reports help to substantiate the professional's performance in the process. It is at that moment that they expose their anxieties about their child, allowing for a channel of communication between the service and the family (3,15-16,18).

Intervening to improve the quality of life of this family is one of the roles of the nurse. The presence of stereotypes and symptoms, such as changes in sleep patterns, agitation, shouting, hetero-aggressiveness, self-mutilation and lack of social and emotional reciprocity, often lead the family to feel powerless, absorbing a high level of stress.<sup>(19)</sup>

A systematic review with quantitative, qualitative and case reports, which presented the challenges and coping strategies of families with children with ASD, confirmed the findings of this study regarding the postponement of the diagnosis, regarding the symptoms that are most related to ASD and stress<sup>(14)</sup>.

In addition to paying attention to what the family members reveal about themselves, and their child's behavior, the direct observation of the child, his/her reflexes, and the way he/she interacts in the environment is necessary for the professional's knowledge. Not only the nurse, but the whole health team needs to be instrumental in identifying changes for both ASD and any other illness or disorder. Observation is necessary, not only of the presence or absence of abilities and/or capacities, but also of the frequency and the way they occur within the context of life<sup>(6,17,20-21)</sup>.

A recent study reveals that autistic disorders may present different degrees of intensity on the child, ranging from the inability to communicate to an extraordinary intellectual ability. It also shows a high level of stress in educators, and also highlights that teachers with more experience face work with children with ASD as a challenge. In addition, this research ratifies the need for investment in school health promotion, and that nurses need to perceive the educational

environment as a context for the continuity of their interventions<sup>(15)</sup>. That is, the nurse can intervene, performing family psychoeducation, counseling for teachers, community rehabilitation, support to caregivers, actions to promote and protect the human rights of the child and the family, follow-up on regular returns, and criteria for referrals to others services<sup>(22)</sup>.

Since the first suspicions up to the correct referral, the professionals find many difficulties, such as the lack of information and training on how to behave and decide on treatment. In the daily practice of basic health units, these difficulties limit the actions of professionals, who claim that it is not their responsibility to provide care for emotions and behaviors. Thus, mental health care is only offered by those professionals who have some affinity with the area or understand, even if incipiently, the process of mental illness (16,23).

This culture that taking care of the emotions is the responsibility of professionals specialized in the mental area makes professionals even more distant from the basic units of care, as they should. However, it is necessary to keep the recommendations of SUS in mind in what regards the actions in the FHS, which should take place in a preventive way, aiming at the recovery and rehabilitation of people in a universal, comprehensive and continuous way, through humanized assistance, not excluding persons suffering from psychiatric disorders.

It is possible to notice that one of the reasons for the lack of interest of the professionals in the area may be related to the lack of stimuli during the academic training, which, at times, do not offer mental health content in the curriculum<sup>(10,23)</sup>. In addition, the lack of skills offered by services, aimed at mental health, in general or especially ASD, also limit the professional's performance. Since training must take place to enable the improvement of work activities, they can happen permanently in the daily service, in meetings rich in discussions about behavior among other professionals<sup>(23)</sup>.

Another important role that is attributed to training is the information on how the network

system works, when a situation of greater complexity is detected that needs specialized care. There is a need for interaction among specialized care centers and teams working in the FHS, to ensure better follow-up, to enable actions directed at the needs of the user, and to favor continuity of care (6,9,23), such as effective matrix-based strategy between Family Health Strategy and the CAPS.

The nurse, while providing care to the child in the various services, will search for sources to build knowledge about ASD. In some situations, the media assumes the position of starting point in the search for this knowledge. Routinely, it is in the media, such as in soap operas and documentaries, that a certain subject incites curiosity and a little more about everything that is involved in a particular subject, especially this disorder, and may arouse interest in the search for specific knowledge in other media. This way, the media contributes to the formation of professionals' knowledge. However, the contact of this professional with symptoms and signs of the disorder in the consultation has been one of the major motivations for the search for information about ASD. Uncertainty about the subject implies the need to gather information and, for this, the internet is recognized as the main source of information, because it is a universe that has much knowledge that is easily accessible. However, care should be taken to collect information from reliable sources based on scientific knowledge. The interaction with third parties who have direct contact with the reality of ASD, such as peers or family members, can also help in building knowledge about the subject.

Although professionals seek information from a wide range of sources, many have not yet considered the instructions that the child's booklet has about ASD. It has a page with basic information that can help the professional in the identification of a possible case of autism. It carries some signs of ASD that may be associated with the child's behavior. Nurses need to be well acquainted with the instruments with which they work on a daily basis so that they can fully

exercise their role, and offer care continuously and without deficiencies (6,16).

It is understood that, faced with adverse situations, it is common that feelings of different natures, from frustration due to the difficulties found to motivation itself, encourage the professional to offer a better quality of life for the child and the family. In addition to physical, community, and material structural difficulties, the nurse suffers because feels unprepared (23). When nurses realize that their goals are not being achieved, and in the face of a disorder of little domain like ASD, they feel frustrated. They feel momentarily unable to help that child and the family who suffer with ASD. In some cases, when the family does not contribute to planning, or refuses to accept what is being addressed, nurses may see this as a devaluation of their work, and temporarily develop feelings of disgust and anger. On the other hand, motivating feelings, such as optimism and search for information about ASD, can renew the nursing care mode, guaranteeing the continued care recommended by the Unified Health System.

The findings in the scientific literature are consistent with those of this study when it comes to the need for nurses' training, the delay in the diagnosis of the child with ASD, the symptoms and signs manifested by the changes in the behavior of children with such a diagnosis, the stress experienced by the relatives, and the need to get help<sup>(13-14,17,24)</sup>. This study also contributes when it reveals the diverse feelings experienced by the nurses when accompanying these children and their relatives.

Among the limiting factors of the study, the small number of interviewees, which is not considered representative of the municipality of Maceió, stands out because it is a specific phenomenon for a given sample, and also the use of individual and specific semi-structured interviews, which could have been deepened with the use of some validated evaluation instrument that could check the impact of the actions. These limitations show the need for further research. However, the result of this

study can be considered a useful tool for the planning of policies and actions of permanent education directed to the professionals of the basic attention, especially nurses.

#### Conclusion

This study allowed the identification of nurses' perception, strategies and interventions with the child with symptoms and signs of ASD. The work in this scenario requires that this professional is able to detect this effectively, because the treatment can be initiated if ASD is early identified.

It is also worth noting that the nurses' performance in the early detection of symptoms and signs of ASD faces many difficulties, among them the lack of knowledge about the subject, the lack of academic education, and the lack of investment in permanent education, besides these professionals experiencing diverse feelings when faced with the needs of the child and their families.

Therefore, in order not to neglect or make other professional categories responsible for such intervention, the preparation of the nurse practitioner of the FHS to intervene with the child with ASD becomes indispensable. The assertive intervention of the nurse in articulating the FHS with a network, so that other services can be activated and make part of a therapeutic arrangement, is essential to start, as soon as possible, the care that allows a better quality of life for the child and the family.

In this context, stimulating permanent education actions in services for symptoms and signs, and interventions of children with ASD is essential, especially those that encourage changes in posture and nursing practices in the FHS. This way, it is possible to collaborate with the reduction of stigmas, and with actions of promotion to mental health that transform the performance of these professionals regarding ASD, and favor the best prognosis to the child and the help to the family.

#### **Collaborations:**

- 1. conception, design, analysis and interpretation of data: Yanna Cristina Moraes Lira Nascimento, Cintia Soares Cruz de Castro and José Leandro Ramos de Lima;
- 2. writing of the article and relevant critical review of the intellectual content: Yanna Cristina Moraes Lira Nascimento, Cintia Soares Cruz de Castro, José Leandro Ramos de Lima and Maria Cicera dos Santos de Albuquerque;
- 3. final approval of the version to be published: Yanna Cristina Moraes Lira Nascimento, Maria Cicera dos Santos de Albuquerque and Daniele Gonçalves Bezerra;

#### References

- Zanon RB, Beckes B, Bosa CA. Identificação dos primeiros sintomas do autismo pelos pais. Psic Teor Pesq. 2014 mar;30(1):25-33.
- American Psychiatric Association. Manual diagnóstico e estatístico de transtornos mentais: DSM-5. 5a ed. Porto Alegre: Artmed; 2014.
- Elbert M, Lorenzini E, Silva EF. Mães de crianças com transtorno autístico: percepções e trajetórias. Rev Gaúcha Enferm. 2015 mar;36(1):49-55.
- 4. Ramírez GR. Trastorno del espectro del autismo. Diagnostico. 2014 set;53(3):142-8.
- Carvalho FA, Paula CS, Teixeira MCTV, Zaqueu LCC, D'Antino MEF. Rastreamento de sinais precoces de transtorno do espectro do autismo em crianças de creches de um município de São Paulo. Psicol Teor Prat. 2013 ago;15(2):144-54.
- Brasil. Ministério da Saúde. Diretrizes de autismo à reabilitação da pessoa com Transtornos do Espectro do Autismo (TEA). Brasília; 2014.
- Damasceno SS, Nóbrega VM, Coutinho SED, Reichert APS, Toso BRGO, Collet N. Saúde da criança no Brasil: orientação da rede básica à Atenção Primária à Saúde. Ciênc Saúde Coletiva. 2016;21(9):2961-73.
- Arantes LJ, Shimizu HE, Hermann EM.
   Contribuições e desafios da Estratégia Saúde da Família na Atenção Primária à Saúde no Brasil: revisão de literatura. Ciênc Saúde Coletiva. 2016;21(5):1499-509.

- Andrade RD, Santos JS, Pina JC, Silva MAI, Mello DF. A puericultura como momento de defesa do direito à saúde da criança. Ciênc Cuid Saúde. 2013 dez;12(4):719-27.
- Nunes SC, Souza TZ, Giunco CT. Autismo: conhecimento da equipe de enfermagem. CuidArte Enferm. 2009 dez;3(2):134-41.
- Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 12a ed. São Paulo: Hucitec; 2010.
- Bardin L. Análise de conteúdo. Reimpressão. Brasil: Edições 70; 2014.
- Nogueira MAA, Rio SCMM. A família com criança autista: apoio de enfermagem. Rev Port Enferm Saúde Mental. 2011 jun;5:16-21.
- Gomes PTM, Lima LHL, Bueno MKG, Araújo LA, Souza N. Autism in Brazil: a systematic review of family challenges and coping strategies. J Pediatr. 2015;91(2):111-21.
- 15. Cappe É, Poirier N, Boujut É, Nader-Grosbois N, Dionne C, Boulard A. Autism spectrum disorder and evaluation of perceived stress parents and professionals: Study of the psychometric properties of a French adaptation of the Appraisal of Life Event Scale (ALES-vf). Encephale. 2017 Aug;43(4):321-5.
- Jendreieck CO. Dificuldades encontradas pelos profissionais da saúde ao realizar diagnóstico precoce de autismo. Psicol Argum. 2014 jun;32(77):153-8.
- 17. Sousa AMBS, Sousa CS. Produções científicas sobre os cuidados de enfermagem às crianças com Transtorno do Espectro Autista (TEA). Rev Cient Multidisc Núcleo Conhecimento. 2017 abr;2(1):387-406.
- 18. Gorlin JB, McAlpine CP, Garwick A, Wieling E. Severe childhood autism: the family lived experience. J Pediatr Nurs. 2016 Dec;31(6):580-7.
- Bonis SA, Sawin KJ. Risks and Protective Factors for Stress Self-Management in Parents of Children with Autism Spectrum Disorder: An Integrated Review of the Literature. J Pediatr Nurs. 2016 Nov-Dec;31(6):567-79.
- 20. Souza RS, Ferrari RAP, Santos TFM, Tacla MTGM. Atenção à saúde da criança: prática de enfermeiros da saúde da família. Rev Min Enferm. 2013 jun;17(2):331-9.

- 21. Reis HIS, Pereira APS, Almeida LS. Características e especificidades da comunicação social na perturbação do Espectro do Autismo. Rev Bras Ed Esp. 2016 set;22(3):325-36.
- 22. Organização Mundial da Saúde. MI-mhGAP Manual de Intervenção para Transtornos Mentais, Neurológicos e por Uso de Álcool e outras Drogas para os serviços de atenção a saúde não especializados: Programa de Ação para reduzir as lacunas em saúde mental. Genebra; 2015 (Impresso no Brasil).
- 23. Sena RCF, Reinalde EM, Silva GWS, Sobreira MVS. Práticas e conhecimentos dos enfermeiros sobre o autismo infantil. J Res Fundam Care. 2015 set;7(3):2707-16.
- 24. Ebert M, Lorenzini E, Silva EF. Mães de crianças com transtorno autístico: percepções e trajetórias. Rev Gaúcha Enferm. 2015 mar;36(1):49-55.

Received: January 20, 2018

Approved: March 12, 2018

Published: May 23, 2018



The Revista Baiana de Enfermagem use the Creative Commons license – Attribuition -NonComercial 4.0 International. https://creativecommons.org/licenses/by-nc/4.0/

This article is an Open Access distributed under the terms of the Creative Commons (CC BY-NC). This license lets others remix, adapt and create upon your work to non-commercial use, and although new works must give its due credit and can not be for comercial purposes, the users do not have to license such derivative works under the same terms.