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RESEARCH

Prática e conhecimento dos enfermeiros sobre o autismo infantil

Practice and knowledge of nurses about child autism

La práctica y el conocimiento de las enfermeras acerca del autismo infantil

Romeika Carla Ferreira de Sena ¹, Elda Medeiros Reinalde ², Glauber Weder dos Santos Silva ³, Maura Vanessa Silva Sobreira ⁴

ABSTRACT

Objective: assessing the knowledge and practice of nurses of the Family Health Strategy about autistic disorder. **Method:** an exploratory research of a qualitative approach consisting of 15 nurses. There was used a semistructured interview. Data analysis was made by the representational analysis. It was approved by the Committee of Ethics in Research of the University of Rio Grande do Norte (CEP/UERN nº 124/11). **Results:** it became evident insecurity and fragility in nurses' knowledge about autistic disorder, because they have failed to define autism or demonstrated experience with autistic people and report the lack of training turned to the above topic. **Conclusion:** there was knowledge deficit by the nurses about infantile autism and the inexistence of practical interventions with autistic people and their families, besides not offering capabilities that address the subject. **Descriptors:** Health care, Autistic disorder, Pediatric nursing.

RESUMO

Objetivo: analisar a prática e o conhecimento dos enfermeiros da Estratégia Saúde da Família acerca do transtorno autístico. **Método:** pesquisa exploratória, com abordagem qualitativa, composta por 15 enfermeiros. Utilizou-se a entrevista semiestruturada. A análise de dados deu-se através da análise representacional, aprovada pelo Comitê de Ética em Pesquisa da Universidade do Estado do Rio Grande do Norte (CEP/UERN nº 124/11). **Resultados:** evidenciou-se insegurança e fragilidade no conhecimento dos enfermeiros sobre transtorno autístico em virtude de não terem conseguido definir autismo nem demonstrado vivência com pessoas autistas e relaram a inexistência de capacitações voltadas para o tema exposto. **Conclusão:** constatou-se déficit de conhecimento dos enfermeiros acerca do autismo infantil e inexistência de intervenções práticas realizadas com pessoas autistas e seus familiares, além da não oferta de capacitações que abordem o assunto. **Descritores:** Atenção à saúde, Transtorno autístico, Enfermagem pediátrica.

RESUMEN

Objetivo: evaluar el conocimiento y la práctica de las enfermeras de la Estrategia de Salud de la Familia sobre el trastorno autista. **Método:** investigación exploratoria, con el enfoque cualitativo, que consta de 15 enfermeras. Se utilizó una entrevista semiestructurada. El análisis de datos se realizó mediante el análisis representacional, aprobada por el Comité de Ética en la Investigación de la Universidad del Rio Grande do Norte (CEP/UERN nº 124/11). **Resultados:** se hizo evidente la inseguridad y la fragilidad en el conocimiento de las enfermeras acerca del trastorno autista porque no han logrado definir el autismo o la experiencia demostrada con las personas autistas y reportaron la falta de formación centrado en el tema. **Conclusión:** se observó un déficit de conocimiento de las enfermeras acerca del autismo infantil y la falta de intervenciones prácticas con las personas con autismo y sus familias, además de no ofrecer capacidades que abordan el tema. **Descriptor:** Atención a la salud, Trastorno autístico, Enfermería pediátrica.

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INTRODUCTION

In recent decades, public health management in Brazil has been engaged drafting, discussing and approving laws that have given more autonomy and visibility to the population living in social inequality, especially to social minorities. Today, much has been discussed about social inclusion, rights of persons with disabilities, with mental disorders, among other topics that are important for growth and development.

The discussion about assistance to people with disabilities aims to develop skills and social inclusion, given the prejudice faced in society. In this perspective, it is important to understand that disability can be defined as an injury or abnormal change, structural or functional, affecting the psychological, physiological or anatomical functions, temporarily or permanently, of individuals and could be classified as physical, visual, sensory, intellectual and mental.¹

Individuals with Autistic Disorder (TA) and, consequently, their families, suffer from prejudice and social stigma because of the disease, for it is a syndrome that affects psychoneurological development areas of the child, impairing its cognitive, social and behavioral development, interfering directly in socializing and establishing social relationships with others, making it difficult to adapt to the environment they live in. The specific behavioral characteristics of individuals with autism with the severity of the disorder, may contribute to the increased potential for family stressors.²

The professional nurse can work positively for the diagnosis and monitoring of TA, through behavioral observations of children, by consulting to analyze growth and development, but also can help parents supporting and informing them about the challenges and assistance procedures that they use in the care of children with autism.

It becomes necessary opening space for nursing assistance of the discussion the person with autism, contributing to a diagnosis of the local situation, identifying weaknesses, providing the opportunity to (re) think the professional practice. We emphasize the scarcity of bibliographical material on this theme in health, but also highlight the complexity of the issue addressed in line of the subject matter, to be coated taboos and stigmatization.

Considering the weakness in full, universal coverage and equity, mainly to the above subject, the question is: What is the practice and knowledge of nurses of the Family Health Strategy (FHS) in relation to assistance to people with autistic disorder? The study aims: To analyze the practice and knowledge of the Family Health Strategy nurses about autistic disorder.

METHOD

An exploratory study with a qualitative approach developed with 16 teams of FHS in a municipality in the State of Rio Grande do Norte, Brazil. Participants were 15 professional nurses after they meet the criteria: Inclusion - FHS effective in urban areas, linked to more than six months and who agreed to participate in the study; and exclusion - those who were on vacation or leave or acted as occupational travelers, taking a vacation or permits and refuse to participate.

Data production occurred between the months of November and December 2012 from the semi-structured interview technique, recorded in MP4 device and transferred and stored on a personal computer of one of the authors; soon after, transcribed in full and revised in Microsoft Office Word, they were sorted, classified and rearranged. It is secured and maintained the confidentiality of study participants using NFE abbreviation. Followed by the corresponding number to the subject (ENF.01 ... ENF.15), in respect for the dignity and vulnerability of defense

Data analysis was conducted through the analysis of evaluation or also known as representational analysis, which proposes an assessment of ways to opinions or behavior from the exposed reality, taking into account the direction and the intensity of the responses and judgments performed.³ Therefore, the data were organized into categories, which are subdivided according to the opinions that converged in the same direction.

This study had the research project approved by the Research Ethics Committee of the University of Rio Grande do Norte (CEP/UERN) by Opinion No 124/11 and CAAE No 0119.0.428.000-11. The research followed the legal and ethical recommendations of the National Council of Health No. 196/1996, valid for the period of submission to the CEP research proposal. However, should be informed and asserted that the resolution with guidelines and standards for research involving human subjects in force is No 466/2013 of the National Health Council.

RESULTS AND DISCUSSION

Characterization of the participants of the survey

The study subjects were characterized according to gender, age, length of service as a nurse and service time working in the FHS. The results aimed reveal the profile of the subjects studied. Concerning the sex of the participants, it was found that of the 15 nurses interviewed, 73,3% were female and 26,6% are male. With this, one can see that there is

still a great influence of the historical/cultural process of nursing in Brazil and worldwide, which is observed the prevalence of women in this profession because of the large existing considerations about the institutionalized values by Florence Nightingale.⁴

Regarding the age, it can be seen that 73,3% are between 25 and 29 years old, featuring a population of young adults, which may influence the consolidation strategy, there are changes that have occurred in recent decades in health in undergraduate programs, allowing the insertion of new ways to make health.⁵

Related to the time of working as nurses, 93,3% has been operating for between two and ten years and 6,7% is more than ten years working as a nursing professional, referring to a transformation in thinking/doing health that was the pillar basilar the Health Reform which led the organization of the Single health System (SUS), allowing the inclusion of professionals with profile facing to the health-disease as a social determinant, knowing deal with different situations in the community context.⁵

With regard to the time of service in the FHS, 86,6% have from zero to four and 13,3% are more than five years. Faced training time data with time of work, it is emphasized that the FHS is the main gateway to the professional lives of nurses, especially in inner cities and this feature is through the easy access to the type of employment contract as well by the amount of units found in the cities, demanding a greater supply of jobs.

In this scenario, nurses act with more autonomy; your work is more visible, it is more valued, since the competence of the nurse to integrate the FHS is established in their academic training, which equips for consultations, making diagnoses, as well as the prescription of nursing throughout the whole tour.⁶

Neurological aspects involving autism

The user with infantile autism presents several difficulties in the establishment of an early and accurate diagnosis, since this disease are observed many controversies in view of the variety of signs and symptoms with different clinical manifestations that it exposes.⁷

You can define autism as a syndrome that includes multiple etiologies and undertakes some areas of child development, interfering with their communication skills, behavior and social interrelation, and a restricted repertoire of interests and activities.⁸ This explains the multiplicity of discourses where nurses have reported the course of interviews on the concept of autism, however, in the majority of responses was observed to allocate only one feature set for autism. From the exposed concepts were extracted keywords in order to explain each of the described features.

In relation to the notice of the same about infantile autism, some stood out as a disorder of neurological origin:

The infantile autism is when your child has a neural disorder [...]. (ENF.1)

It's like a neurological, psychological disorder [...]. (ENF.2)

Autism is closely linked to neurological dysfunction. It is characterized as a disorder that affects several areas of child development, without providing an etiological definition

proven. However, the main hypothesis comes from the neurological field, have been identified by alterations in brain regions such as cerebellum, amygdala, hippocampus, and other structures. These data suggest an abnormal brain function in autistic people.⁹

With theoretical approaches from this presumption, it is confirmed that there is a delay in the maturational development of the brain and especially the parts already mentioned, as there is also a depression in Purkinje cells in children with the autistic spectrum.¹⁰

Behavioral changes and compromise in social interaction

In addition to the answers with a focus to the neurological disorders, there were some participants who reported other signs, such as aggression, difficulty in social interaction, insight, as well as the presence of stereotyped movements:

[...] so, what I know, what are the characteristics that I understood, was characteristic of aggressiveness, right? [...]. (ENF.7)

In other speeches, it is clear repetition of conceptual arguments about autism that lead to knowledge of this syndrome marked by isolation and difficulty in interpersonal relationships. The speech of various research participants; nurses address these characteristics:

[...] They are of difficult relationship; they do not play with other children. (ENF.14)

It is a disease that ends in some disorders; on the interaction with other people, in the interest in something, about the concentration of that person, the way she puts it, because she's more introspective. (ENF.15)

These mentioned features are the most observed within the usual behavior of a person with autism. Autism is a behavioral syndrome, in which the child cannot develop its interactional building skills, with a qualitative difficulty of relating and communicating common way with people, early in life.¹¹

The child begins to display a lack of spontaneous attempt to share enjoyment, as expressed in the words of one of the subjects:

The little I know about this subject is that children with autism they live in their world, huh? [...] And do things way too repetitive, huh? What they are touch, they do like that only. (ENF.07)

Thus, means that there is not a social or emotional reciprocity. Qualitative impairment in communication is accentuated by the delay or total lack of development of spoken language, and where speech is adequate, there is a marked impairment of the ability to initiate or maintain a dialogue, but also, it is common the use of stereotyped and repetitive language or idiosyncratic language.¹²

Genetic aspects of autism

Although autism etiology is totally unknown, some scholars believe that there is a close relationship between autism and possible genetic factors associated with disease, expressed by one of the interviewees:

The infantile autism it happens due the person's genetic changes [...]. (ENF.6)

In addition to the neurological, studies show that the autistic phenotype is widely varied. Have been described both classic autism, lacking verbal communication and severe mental disabilities, as autistic with impaired sociability, presenting verbal abilities and normal intelligence.¹³

Etiological lack of autism

Throughout the interviews we saw the insecurity, fragility of knowledge, as also demonstrated the ignorance on the part of the nurses on the subject under discussion:

[...] If I'm going to tell you what I know understand what an autistic disorder is, the symptoms and what it causes, I tell you that I don't know. (ENF. 9)

With this speech, is proposed to search and investigation of the problems involved in all this lack of knowledge on the subject. This leads to think about the possible causes that induce this discourse, and at the same time do understand and comprehend this deficiency. It is clear that the subject is poorly studied in Brazil, but also there is little literature production about the subject, not getting so even professionals. There is a perception of such importance in the development of research focusing on the patient-nurse relationship and to guide the practice of nursing professionals to better serve and care for autistic patient yet.

Nursing care for autistic child

When asked about the fact assisted the person with autism, of the 15 nurses interviewed, 13 of them reported never having provided assistance to these people and had contact with an autistic child because of a discipline during graduation, however, there was no provision of any assistance to children, justifying the commitment in the interactional development that it had:

Okay, there wasn't really an assistance that we used to give at the training of collective health, we just used to lecture, these things, you know? But, so, attendance, not consultation, had contact with the child, but it was too complicated, so contact with them because they don't interact! At least the one I had did not interact. (ENF.8)

A nurse pointed out an observation:

Already. [...] but it was an observation of the basic attention even right! [...] He was well taken care of; the mother looked after him well. And I realize even biologically speaking that he is normal. (ENF.7).

Regarding the presence of autistic children or in the diagnostic process in every area of jurisdiction scope, respondent nurses all reported not having, or not recognizing any autistic child who inhabit their area. Although autism is not a very rare disease, affects about 8 to 10 thousand individuals and its highest incidence occurs in males.⁹ In the city where nurses develop their work activities, does not present a significant number of autistic, and if there are people with this syndrome, there are the following questions: Where are these people? In which health service they are met? These people have other comorbidities? If they have, where they are receiving assistance?

Safety in the provision of appropriate assistance to people with autism

When asked about the preparation of nurses in regard to the provision of assistance for people with autism, only one participant said possessing it; however, it stressed the lack of inputs and guidelines that could guide the care to the person with autism:

Prepared? I feel! Now, the big problem is here [...] has no guideline for the treatment of that patient, a flowchart, nothing that targets this patient for treatment, none of this. (ENF.5)

Three other participants said they were partially prepared. One reported:

Through specialization, a little! But, then, through referrals, even because the strategy does not offer conditions. (ENF.12)

The other participants do not feel prepared, due to lack of training, theoretical approaches and disability in the training process of the same with respect to this topic:

Don't. Because in training there was not seen the part of mental health, it was very summarized [...]. I wasn't able to taking care of autistic, could invest, participate in trainings and trainings, but at the moment to identify a child with autism, and proceed in the way that she would need today, I'm not able not. (ENF.2)

[...] in academic life is a subject that isn't much discussed in the time that I was a student by teachers, so I particularly I don't feel prepared, would have to have training, better information on the subject so that we could address better and to have a better perception when you see a person with autism. (ENF.11)

Therefore, it is essential to highlight the importance of developing scientific research that addresses on the patient-nurse relationship in order to guide the practice of nursing professionals to better serve and care for the autistic patient. Thus, the professional will realize the important role that it has, with the need for training in order to provide access to knowledge of different communication techniques and guidelines about autistic behavior, in order to facilitate the establishment of bond with the patient's family from the knowledge gained and permeated by facilitating the intervention and family interrelation.

The importance of nursing care to people with autism

The link between the nurse, the autistic person and their family becomes of paramount importance, since in the play of nursing work is denoted a careful look, devoid of prejudices, attentive to the needs of others and their suffering, as that in most cases there will have a speech by the autistic, fitting to the nurse listening and providing differentiated service. You must read between the lines, look beyond what is visible to the eye, because care knowledge implies worry, pay attention to the other, and this, the essence of human life.

This differentiation of care implies a multidisciplinary care whose purpose qualify care, through guidance to families about autism, creating treatment plans that address the uniqueness of each child or patient, so you can provide a better quality of life everyone involved. In the speeches of the participants, we could notice a constant concern with these details that deserve attention to be given adequate support:

[...] even because the child with autism, more than anyone, needs multiprofessional care. (ENF.04)

Thus, everything is a detail, everything you have to understand. It's not the same thing. An autistic child she will not say: Oh! It hurts here! Ah! I'm with it! Ah! I'm with it, do not! You have to create methods to realize that [...]. (ENF.8)

Thus, it is suggested to nurses and deepen research on the subject, to prepare studies in order to create specific care and nursing interventions for these people and their families, and try to provide a better quality of life, but also, plan actions aimed at the inclusion of the same in society, encouraging family members to actively participate in this rehabilitation process.⁷

Nurses' competence to design and conduct a therapeutic environment, as they are the professionals who spend more time in contact with patients in relation to other professionals in health.⁷ Among the main objectives of the therapeutic environment we have: help the patient developing a sense of self-esteem and self-care; enhancing its ability to relate to others, giving emphasis on building ties with interrelational whole multidisciplinary team; helping you to trust people; helping you return to the community with more maturity and prepared for work and life, welcoming the paid up, respecting their legal rights as citizens and people with disabilities, among others. Thus, subjects reported the following:

[...] we need to stay together, both the person who has autism, and their families, helping to identify problems according to which each presents. Make the environment favorable so he can grow and develop right? Being included right in the society as a person who has in case the autism, but that can be inserted into normal, you may have a normal life, I believe it is the role of the nurse's together, but helping him and his family. (ENF.10)

Yes, for the nurse, especially from the FHS, he builds a bond with the community, with users who come, so that family is very important to have that accompanies that meet all the history, then the nurse goes is directly related to all of this, right? [...]. (ENF.13)

Therefore, the nurse is able to provide necessary support for children with autism, but also understand the people with special needs as part of the world, which should not be

omitted for fear of obstacles. These must be faced with perseverance, because it is clear the importance of the aid and participation of nurses in the process of prevention, promotion and rehabilitation, promoting better quality of life for these patients and their families.

CONCLUSION

Given the results, one can see a great lack of knowledge of nurses of this research about childhood autism, given the few characteristics reported for the same about this pathology. This can be understood by the fact that autism has a wide variety of signs and symptoms as well as its various etiologies. However, the results also make it clear that the curricular grids of nursing area little work the theme, or do not expose.

It is noteworthy that, during the interviews, there were not cited any action taken by them that addressed the said issue, despite being much discussed during the talks the importance of planning actions that meet the needs of children and their families. And with that, he was missing a clearer fashion, to list such shares.

It is also seen as a gap in the study have not been measured and evaluated the Health Care Networks (RAS) within primary care, primarily the Person to Care Network with Disabilities, since the same priority care lines which organizes actions and services offered to the target audience, since the RAS on the person with disabilities was implemented in 2011.

The constant search for knowledge and updates, as well as the development work that will contribute to knowledge, encourages the realization of permanent and continuing education in health that makes the subject approach, since autism is gaining more visibility because the understanding that it is a syndrome that leads to social exclusion, leading to a degrading development deficit in important areas of cognition and learning.

Finally, it is important to note that when caring for an autistic must also consider the family and the community in which it is inserted, worry in the deconstruction of preconceptions and formulation of new concepts and better quality of life hopes why being a nurse is caring know, cherish and produce new forms of knowledge/nursing.

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