

Nursing in the Care of Children with Autism Spectrum Disorder

Enfermagem no Cuidado de Crianças com Transtorno de Espectro Autista

Enfermería en el Cuidado de Niños con Trastorno del Espectro Autista

Vitória Fonseca de Sousa¹, Mikaelhe Ferreira de Abreu², Renata de Moura Bubaduê³

How to cite: Sousa, VF, Abreu MF, Bubaduê RM. Nursing in the Care of Children with Autism Spectrum Disorder. 2024; 13(2): 387-96. Doi: <https://doi.org/10.36239/revisa.v13.n3.p387a396>

REVISA

1. Faculty of Science and Education Sena Aires. Valparaíso de Goiás, Goiás, Brazil. <https://orcid.org/0000-0003-2730-885X>

2. Faculty of Science and Education Sena Aires. Valparaíso de Goiás, Goiás, Brazil. <https://orcid.org/0000-0003-4437-7152>

3. Faculty of Science and Education Sena Aires. Valparaíso de Goiás, Goiás, Brazil. <https://orcid.org/0000-0001-8121-1069>

Received: 17/01/2024
Accepted: 19/03/2024

RESUMO

Objetivo: Descrever o cuidado de Enfermagem à criança com TEA e sua família. **Método:** Trata-se de uma revisão de literatura narrativa. Os artigos foram pesquisados nas bases de dados Scielo, Lilacs e Google Acadêmico. Foram utilizadas como palavras-chave: crianças, cuidado, e enfermagem Transtorno de Espectro Autista. **Resultados:** as competências e habilidades dos profissionais de Enfermagem no ambiente hospitalar vislumbram a importância da empatia, imbuído em uma visão holística para o cuidado com a criança autista. É necessário apresentar diferentes estratégias para o trato com a criança autista em suas necessidades hospitalares e assim propor o desenvolvimento de pesquisas clínicas para o aprimoramento da temática e futura usualidade no espaço hospitalar. **Conclusão:** Conclui-se que a enfermagem em seu papel interventivo urge por responsabilidade no que tange ao diagnóstico precoce do autismo. A ligação entre o enfermeiro, a criança autista e seus familiares é de suma importância para que a escuta seja qualificada e a prestação de assistência diferenciada. **Descritores:** Crianças; Cuidado de Enfermagem; Transtorno de Espectro Autista.

ABSTRACT

Objective: Descrever o cuidado de Enfermagem à criança com TEA e sua família. **Method:** This is a narrative literature review. The articles were searched in the Scielo, Lilacs and Google Academic databases. The following keywords were used: children, care, and autism spectrum disorder nursing. **Results:** The competencies and skills of nursing professionals in the hospital environment emphasize the importance of empathy, imbued with a holistic view of caring for autistic children. It is necessary to present different strategies for dealing with autistic children in their hospital needs and thus propose the development of clinical research for the improvement of the theme and future use in the hospital space. **Conclusion:** It is concluded that nursing, in its interventional role, urges for responsibility regarding the early diagnosis of autism. The link between nurses, autistic children and their families is of utmost importance for the listening to be qualified and the provision of differentiated assistance. **Descriptors:** Children; Nursing Care; Autistic Spectrum Disorder.

RESUMEN

Objetivo: Desvelar el cuidado de la salud del niño con TEA y su familia. **Método:** Se trata de una revisión bibliográfica narrativa. Los artículos se han buscado en las bases de datos Scielo, Lilacs y Google Académico. Se utilizaron como palabras clave: niños, cuidado, y enfermedad. **Resultados:** las competencias y habilidades de los profesionales de la enfermería en el entorno hospitalario ponen de manifiesto la importancia de la empatía, imbuída en una visión holística para el cuidado de los niños autistas. Es necesario presentar diferentes estrategias para el trato con el niño autista en sus necesidades hospitalarias y así proporcionar el desarrollo de investigaciones clínicas para el aprendizaje de la temática y la futura habitualidad en el espacio hospitalario. **Conclusión:** Se concluye que la enfermería en su papel intervencionista insta a la responsabilidad en cuanto al diagnóstico precoz del autismo. El vínculo entre el personal de enfermería, los niños autistas y sus familias es de suma importancia para que la escucha sea cualificada y la prestación de asistencia diferenciada. **Descritores:** Los niños; Atención em Enfermería; Trastorno del espectro autista.

Introduction

The care of children with ASD and their families is a complex phenomenon, which requires preparation of the nursing team in its various scenarios (hospital, outpatient clinic and primary care). Children with ASD demand health care, which includes access to information and guidance about understanding their health condition, even in relation to prognosis. The demand for atypical behaviors and aggressiveness are frequent complaints.¹

Some physical behaviors such as inappropriate stimulation of the body, flapping of the hands, smelling and touching any object, especially on the street, turning and staring at the hands, not knowing how to chew or being able to sit are situations that require a specific look at the whole.

The care of autistic children has peculiar nuances such as the preservation and respect for changes in behavior and the development of ASD. Through the behavioral observations that are carried out during the consultations, it is noticeable the need for help to the family members in dealing with the challenges, and the need for attention, identifying the weaknesses of all those involved in the health and disease process.²

The present study is justified since, although there are no statistical studies on the number of children with ASD in Brazil, the only pilot study of 2011 points out that there is one child with ASD for every 367 children. According to the World Health Organization (WHO), worldwide, one in every 160 children lives with this health condition. The Ministry of Health (MS) already provides in its legal basis, a line of care for people with autism spectrum disorder, as well as their families in the care network in the document entitled "Systematization of Nursing Care for autistic children in the hospital unit" published in 2013. Although there are some literature reviews already published on the subject, the study is not exhaustive, since it is still necessary to emphasize the importance of strong and efficient legislation that can fill the gaps in this social demand for public order.³

The present study deals with the Nursing approach to the care of children with Autism Spectrum Disorder (ASD) and aims to describe the Nursing care for children with ASD and their families.

In this context, the research problem on the agenda was the following: how should nursing act in the care of children with Autism Spectrum Disorder (ASD) in hospital units?

Method

The study is designed from the perspective of the Literature Review, which according to Gil (2002) refers to "a meticulous and broad analysis of current publications in a given area of knowledge". The research was carried out between April 16 and 30 of this year, using the following keywords: Children. Care. Nursing. Autism Spectrum Disorder. The databases used for the research were Scielo, Lilacs and Google Scholar.

Only studies in Portuguese were included, from 2012 onwards, in view of the existence of the legal framework on ASD in Brazil, through Law No. 12.764/2012.

Studies without declared authorship and that in some way did not present the role of Nursing in the Care of Children with Autism Spectrum were excluded.

Data collection took place between February and May 2023 in the Scielo, Lilacs, Google Scholar, and Pubmed databases. According to Pereira and Galvão (2014), the data extraction framework is a process that aggregates the information from the selected studies and avoids frequent return to the text of the articles. They systematize the choice of articles in line with the proposed objectives according to the theme. The selection is carried out with bases that make the texts available and the inclusion and exclusion criteria are applied, according to the study proposal.

With the selected articles, an instrument was developed to facilitate the evaluation and analysis of the data, which could provide detailed information on the studies (Chart 1). The identification variables were as follows: Title, authors, objectives, methods, completion and year of publication.

Results and Discussion

Chart 1 - Distribution of articles according to year of publication, author(s), title, design and results. Brasília, Federal District. 2023.

Id	Title/Author	Country	Type of Study	Instruments	Results	Conclusion
A1	Sena, R; Medeiros, R; Silva, G; Sobreira, M. 2015. Nurses' practice and knowledge about childhood autism.	Brazil	Qualitative	This is an exploratory study with a qualitative approach, consisting of 15 nurses. Semi-structured interviews were used. Data analysis was performed through representational analysis, approved by the Research Ethics Committee of the State University of Rio Grande do Norte (CEP/UERN nº 124/11).	Insecurity and fragility in the nurses' knowledge about autistic disorder was evidenced because they were unable to define autism or demonstrate experience with autistic people and reported the lack of training focused on the theme exposed..	It was found that nurses had a deficit of knowledge about childhood autism and the lack of practical interventions carried out with autistic people and their families, in addition to the lack of training that addresses the subject.
A2	Dartora, D; Mendieta, M; Franchini, B. The nursing team and autistic children. Universidad e Federal de Pelotas. 2014.	Brazil	Qualitative	Qualitative, descriptive and exploratory research. The study participants were six professionals from the nursing team. Data collection took place in January 2014, through semi-structured interviews. Data analysis was carried out based on Minayo's thematic analysis, which allowed the identification of three themes: the view of nursing professionals on autism; nursing team: fear or doubt; factors that interfere in the care of autistic children.	It was observed that there is instilled in each professional a limited view of autistic children, sometimes prejudiced. Empirical knowledge overcame scientific knowledge and, as a result, care for children with autism was weakened.	The search for knowledge must be intrinsic in each professional, in order to contribute to a more qualified care.

A3	Carniel, E; Saldanha, L; Fensterseifer, L. The nurse's role in the face of autistic children. 2014.	Brazil	Qualitative	Literature review using the databases of the platforms, LILACS, Google Scholar, Bireme, as well as books. Articles from 2007 to 2020 were selected with themes related to the performance of nursing in the face of childhood autism. The results are presented in a descriptive way.	The results are presented in a descriptive way. The nurse is the basis of the autism diagnosis process, he attends to the signs and symptoms of autism, takes good care of children and their families, encourages and delivers security and tranquility to all. It is worth remembering that the treatment of autism needs to be aligned with the team	The relationship between nurses and patients with autism is very important, as patients often have difficulties in oral expression, which requires careful observation, listening and differentiated help from nurses. It is necessary to go beyond what is seen holistically, because knowing that caring is caring and paying attention to the other is the essence of human life.
----	---	--------	-------------	---	---	--

The discussion that follows addresses, at first, the epistemological nuances of Autism Spectrum Disorder, in a scenario of verses and reverses about its existence and materiality. Furthermore, it presents a reflection on the actions of nurses in observance of the multidimensional character of health, as a glimpse of a driving force in the process of care for children with ASD.

Children with Autism Spectrum Disorder (ASD)

The disease formerly known as Autism also includes Asperger syndrome and other developmental disorders not categorized by the American Psychiatric Association. To this end, the nomenclature Autism Spectrum Disorder (ASD) was introduced as a way to facilitate the study of these diseases that have characteristics in common. ASD refers, therefore, to a disorder that affects many children and implies the reduction or total annulment of social interaction and child development and must be mitigated through therapeutic interventions, since there is no cure. ASD has its onset of presentation even before the age of three and has variance between lesser and greater intensity, being a clinical manifestation of an atypical process that impairs development globally, affecting subjective experience, cognitive processes, language and behavior as a whole.⁴

The developmental disorder of a child with ASD does not refer only to a delay or an interruption of the normal developmental process, although these may be present as well, but the clinical manifestation of an atypical and harmful developmental process. Thus, the diagnosis of ASD is based on the clinical picture presented by the child. It is worth mentioning that there are no specific exams or tests, but the electroencephalogram can be a guide in the diagnosis, as well as metabolic anomalies, such as the level of serotonin in the blood.⁵

The multidisciplinary team that has in its body, Nursing, can assist in the diagnosis of this developmental disorder, as well as analyze and study each case in its particularity together, so that the actions are effective, in a detailed and enlightening way, with a view to tracing the medical, cognitive and

adaptive profile of the children and making the necessary referrals. Therefore, the autistic child needs multidisciplinary monitoring so that well-being actions are designed and essential health services are used.⁶

ASD is a behavioral disorder that consists of a triad of difficulties, they are: difficulty in communication, difficulty in socializing and difficulty in using imagination. Thus, the child's development cannot fail to be stimulated, even if they present numerous behavioral difficulties, speech and communication, expression of feelings and interaction. On the contrary, greater attention should be directed to attending to the peculiarities of these children.⁷

It is important to highlight that the child with autism must have access to health, with specialized, competent and skilled care. Any and all prejudice must be barred and a broad social view must be contemplated that it is necessary to adjust to differences, since each child is a unique being, regardless of their limitations. Continuing education is of paramount importance, so that nursing professionals review their practices and expand their work repertoire, through differentiated actions and an activity aimed at more conscious comprehensive health care.⁸

The feeling of belonging needs to become real. Without it, interaction will be possible and coexistence will not be contemplated with diversity and respect in a broad way. For the inclusion process to be effective, prejudice, sometimes veiled, cannot be allowed to emphasize the "disadvantages" of autistic children, for example.⁹

ASD comprises the observation of a set of behaviors grouped into a main triad: communication impairments, difficulties in social interaction, and repetitive restricted activities. Thus, ASD is a behavioral syndrome, where the individual has difficulty in interpersonal relationships, language problems and routine. It is considered a "no-cure and severely disabling" disorder. However, contrary to what was thought a few years ago, autism no longer makes it impossible for children to learn and they can be inserted into social environments through adaptations that allow children to have their constitutional rights guaranteed.⁸

Prejudice is a health issue that needs to be worked on, directing the concern to the child's integral growth. The nurse can, in fact, be the protagonist in the process, since he will lead the process, needing to value the potential of the child with ASD by creating facilitating strategies for the child's comprehensive care.⁹

The difficulties of these children in the aspect of communication, interaction, language and behavior must be taken into account, which are typical problems of children with ASD, who also need to receive psychological help, since not all autistic children have these same difficulties, as each child is a particular universe.¹⁰

Nursing work with children with ASD

The outcome of any prognosis regarding an autistic child considers three factors: "a) the age at which he or she is diagnosed, b) the start of treatment, and c) the degree of impairment of aspects such as language, social interaction, and cognitive functioning. The more compromised, the worse the prognosis.¹⁰ Nurses without theoretical foundations will hardly be able to help both the child and the family, since without this training it is difficult to favor the process of observing symptoms and behaviors and achieve the desired quality of life for the child.¹¹

The role of nurses in relation to autistic children and their families is fundamental, since they have an important socializing role, accepting and understanding the child, as well as establishing limits, guidance and support for the family. From this perspective, the typical image of the autistic child must be deconstructed, since not necessarily all children develop the same acts of isolating themselves, swaying the body, for example. This stereotyped mental functioning is common sense, which escapes from the scientific. Nurses, in turn, need to be based on technical, scientific and humanized knowledge, so that the perception of touching the unknown and strengthening the relationship with the child's family is sharpened.¹²

It is necessary to understand the importance of nurses collecting data, an important source for raising nursing diagnoses and prescribing the necessary interventions.¹² Thus, it is important to emphasize that ASD has varying degrees of impairment, from mild autism, characterized by having a "high functioning" and generally not preventing the person from having a relatively normal and productive life, to severe degrees, in which there is a lot of impairment of cognitive functions, communication and behaviors.¹³

Doubts about the signs and symptoms of the disease generate uncertainties and fears that end up harming the work of professionals with autistic children. Of all the health professionals involved in care, the nurse has the great role of humanization. The humanized presence and the caregiver may represent to the health professional the certainty of having promoted, within their possibilities, a better quality of life and well-being for those who were temporarily under their care.¹⁴

Family care is as important as for the child and, in view of this scenario, nurses need to create intervention strategies that enable these women to be listened to, exchange experiences, share pain, suffering, so that they somehow try to alleviate their anguish and uncertainties.¹⁵ It is worth considering the following reflection:

In addition to the autistic child who needs to be properly assisted, one must look carefully at the family, especially the mother, since she is

the one who assumes the greatest responsibilities in terms of care. Given this, it is up to the professionals. Welcoming and guiding families are essential for them to put aside erroneous beliefs, and not wear themselves out with unnecessary and purposeless guilt. Taking care of family members, especially mothers, is as important as taking care of the children themselves.¹²

ASD is one of the most well-known pervasive developmental disorders, among which are several pathologies that, together, form an autistic continuum that can range from conditions that peremptorily guard mental retardation to conditions that are not associated with Asperger's syndrome". Children with ASD have a unique triad, which is characterized by difficulty and qualitative impairments in verbal and non-verbal communication, in social interactivity and in the restriction of their cycle of activities and interests.⁵ The levels of severity are:

Level 1 (mild) - Requires support Social communication: In the absence of support, deficits in social communication cause notable damage. Difficulty initiating social interactions and clear examples of atypical or unsuccessful responses to others' social overtures. May appear to exhibit reduced interest in social interactions. For example, a person who can speak in full sentences and engage in communication while failing to converse with others and whose attempts to make friends are awkward and often unsuccessful. Restricted and repetitive behaviors: Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching activities. Problems for organization and planning are obstacles to independence. Level 2 (moderate) - Requires substantial support Social communication: Severe deficits in verbal and nonverbal social communication skills; apparent social damage even in the presence of support; limitation in initiating social interactions and reduced or abnormal response to social openings from others. For example, a person who speaks simple sentences, whose interaction is limited to reduced special interests, and who exhibits markedly awkward nonverbal communication. Restricted and repetitive behaviors: Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear often enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Suffering and/or difficulty changing focus or actions. Level 3 (severe) - Requires very substantial support Social communication: Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, great limitation in initiating social interactions, and minimal response to social overtures that come from others. For example, a person with intelligible speech of few words who rarely initiates interactions and, when he does, has unusual approaches only to satisfy needs and reacts only to very direct social approaches. Restricted and repetitive behaviors: Inflexibility of behavior, extreme difficulty in dealing with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or actions.¹⁶

The specific characteristics associated with the degree of severity need to be carefully observed. The role of the nurse, therefore, is relevant and serves as a bridge of effective communication between the medical team and the family, which should never be denied.¹⁷ The professional should have "an ethical and humane posture, in addition to being clear, concise and available to questions from family members. It is important to clarify that care will be shared between the professional and the team responsible for the treatment with the family".¹⁸ There is little information about providing nursing care to autistic patients and family members.

Analyzing between the lines and with a technical and human look provides: helping the patient develop a sense of self-esteem and self-care; stimulate their ability to relate to others, emphasizing the construction of inter-relational ties with the entire multiprofessional team; help you trust people; help them return to the community with more maturity and prepared for work and life, welcoming them in an integral way, respecting their legal rights as citizens and people with disabilities, among others.

Conclusion

Among the findings of this research, it was identified that nursing plays a fundamental role in the care of children with ASD, especially its competencies and skills that must be practiced in the hospital environment; glimpsing the importance of empathy, of the holistic view for child care.

Nursing has the challenges of presenting different strategies for dealing with children with ASD in their hospital needs. Must understand the locus of difficulties in clinical practice and improve the usuality in the hospital space.

This literature review confirmed that one of the challenges of nursing in cases of ASD treatment is to find ways to make care feasible by prioritizing aspects related to child socialization and their cognitive and emotional development.

The research emphasizes the importance of the family in the process of caring for children with ASD, the role of nursing was also considered, within the context of the performance of this professional in order to avoid social aggravation of cases of children with ASD.

It is concluded that nursing in its interventional role urges responsibility with regard to the early diagnosis of autism. The connection between the nurse, the autistic child and their family members is of paramount importance so that listening is qualified and the provision of differentiated care.

Acknowledgment

This study was funded by the authors themselves.

References

1. Fávero-Nunes MA, Santos MA. Depressão e qualidade de vida em mães de crianças com transtornos invasivos do desenvolvimento. *Revista Latino-América de Enfermagem* 18(1). Jan – fev 2010.
2. Sena R, Medeiros R, Silva G, Sobreira M. Prática e conhecimento dos enfermeiros sobre o autismo infantil. 2015.
3. Camargo SPH, Rispoli M. Análise do comportamento aplicada como intervenção para o autismo: definição, características e pressupostos filosóficos. *Revista Educação Especial, Santa Maria*, v. 26, n. 47, p. 639-650, set./dez. 2013.
4. Santos SA. Transtornos Globais do Desenvolvimento TGD procedimentos e encaminhamentos. Departamento de Educação Especial Diretoria de políticas e tecnologias educacionais. Curitiba ,2016.
5. Brasil. Ministério da Saúde. Departamento de Atenção Especializada e Temática. Linha de cuidado para a atenção às pessoas com transtornos do espectro do autismo e suas famílias na Rede de Atenção Psicossocial do Sistema Único de Saúde / Ministério da Saúde, Secretaria de Atenção à Saúde, Departamento de Atenção Especializada e Temática. – Brasília: Ministério da Saúde, 2015.
6. Mercadante MT, Gaag RJV, Schwartzman JS. Transtornos invasivos do desenvolvimento não-autísticos: Síndrome de Rett, transtorno desintegrativo da infância e transtornos invasivos do desenvolvimento sem outra especificação. *Revista Brasileira de Psiquiatria*, 28(supl. I), S12-S20. 2006.
7. Mello AMSR. Autismo: guia prático. 5 ed. São Paulo: AMA. Brasília: CORDE, 2007.
8. Cunha E. Autismo e incluso: psicopedagogia práticas educativas na escola e na família/ Eugênio Cunha. Rio de Janeiro: Wak Ed., 2009.
9. Batista, MSB et al. Relatos de experiência de saberes profissionais, Interdisciplinares e transversais na área da Saúde. 1. ed. Aracaju, SE: Criação Editora, 2022.
10. Klin A. Autismo e síndrome de Asperger: uma visão geral. Yale University School of Medicine. USA, 2006.
11. Carniel E, Saldanha L, Fensterseifer L. A atuação do enfermeiro frente à criança autista. 2014.
12. Dartora D, Mendieta M, Franchini B. A equipe de enfermagem e as crianças autistas. Universidade Federal de Pelotas. 2014.
13. Velloso R, Duarte C, Schwartzman J. Evaluation of the theory of mind in autism spectrum disorders with the Strange Stories. *Arq. neuro psiquiat.* 2013.
14. Barbosa C, Couto F, Gomes R, Emmerick V, Xavier Z. Atuação do

enfermeiro frente aos modelos substitutivos no tratamento aos portadores de transtornos mentais. *Littera Docente & Discente em revista*. 2012.

15. Smeha L, Cezar P. A viv ncia da maternidade de m es de crian as com autismo. *Psicol estud*. 2011.

16. Da Silva Mesquita,  gila Thalia et al. A assist ncia de enfermagem prestada   crian a autista. *Sa de em Foco: Temas Contempor neos - Volume 1*, 2017.

17. Schmidt C, Bosa C. A investiga o do impacto do autismo na fam lia: revis o cr tica da literatura e proposta de um modelo. *Intera o psicol*. 2003.

18. Silva MMC. Diagnosticando o transtorno autista: Aspectos fundamentais e considera es pr ticas. *Psicologia: Ci ncia e Profiss o, Bras lia, DF*, v. 29, n. 1, p. 116-131, 2009.

Correspondent Author

Vit ria Fonseca de Sousa
Acre St., Court 02. Lots 17/18 n/n. ZIP: 72876-241-
Setor de Ch cras. Valpara so de Goi s, Brazil.
vitoria.sousa127viih@gmail.com