


## THE PROCESS OF CARE FOR PEOPLE DIAGNOSED WITH THE AUTISM SPECTRUM IN THE FIELD OF HEALTH

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### ABSTRACT

This study explores nursing care for patients with Autism Spectrum Disorder (ASD), including guidance for family members and methods that aim to improve patients' quality of life. The objective is to analyze the role of nurses in the care of patients with ASD and in guiding families, promoting the quality of life of both. Through a literature review carried out with Google Scholar sources, the study highlights the importance of nurses in caring for patients with ASD, in the early detection of signs of the disorder, and in care recommendations for family members. The results show that autism is still little discussed and understood, both by the public and by health professionals. However, the study highlights the essential role of the nursing team in supporting these patients and guiding their families. It is concluded that it is crucial for the nursing team to delve deeper into the theme, given that the nurse has a fundamental role in identifying the first signs and supporting the families, thus contributing to a better quality of life.

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## INTRODUCTION

This study highlights the importance of nurses in the care of patients with Autism Spectrum Disorder (ASD). Historically, autism has been interpreted through a psychoanalytic perspective, with an emphasis on affective and relational factors. Leo Kanner and Hans Asperger influenced early understanding of autism, but in the 1960s and 1970s, the emphasis shifted to cognitive and brain perspectives. The 1980s brought greater recognition of "Asperger's Syndrome", broadening the understanding of the autism spectrum. Autism research and understanding continues to evolve. Nurses play an essential role in providing medical, emotional, and behavioral support to patients with ASD, helping with the implementation of therapies, monitoring progress, and supporting families. (Lima *et al.*, 2014).

Autism Spectrum Disorder (ASD) has a multifactorial origin, combining genetic and environmental factors. Studies show a strong genetic influence, not a single gene responsible, but an interaction of several genes. Leo Kanner began deep research on autism in 1943, identifying it as a disorder that affects communication, social interaction, and behavior, with varying symptoms. In Paraná, Brazil, the prevalence is higher in boys (1 in 42) compared to girls (1 in 189), reflecting a global trend that continues to be studied (Feifer *et al.*, 2020).

According to the International Convention on Human Rights for People with Disabilities, it is possible to place autism in the field of disabilities, in 2012 the National Policy for the Protection of the Rights of People with Autism Spectrum Disorders (ASD) emerged (BRASIL, 2012) The individual with ASD is considered a person with a disability for all legal purposes (Souza *et al.*, 2023).

The diagnosis of autism is made by psychologists, psychiatrists and neuropsychiatrists, through the observation of symptoms and analysis of the child's development. Early diagnoses increase the chances of intervention and improvement of symptoms. The diagnosis is clinical and involves health professionals and genetics, following specific criteria established in the DSM-5. This process may include physical examinations, family medical history, laboratory tests, and genetic testing, varying according to the specific condition (Nunes *et al.*, 2009).

The nurse has a crucial role in the early detection of autism during childcare consultations, observing behaviors and characteristics indicative of ASD and knowing the diagnostic criteria. He must know when to refer the child for a specialized evaluation, such

as that of a neurologist, psychologist or neuropsychiatrist. Early detection allows for appropriate interventions and therapies earlier. Active listening is essential to understand the needs and concerns of the family and the autistic individual, using communication techniques that facilitate dialogue. Care must be systematized, respecting the peculiarities and preferences of the autistic individual. Nurses should avoid prejudice and treat autism as a neurodiverse condition. In addition, you should be prepared to use alternative communication strategies, such as gestures or images, to ensure effective communication and quality assistance. (Santos Filho *et al.*, 2020).

Careful nursing observation during the consultation is crucial to identify possible signs of autism, such as limited social interaction, atypical communication, and repetitive behaviors. The nurse should refer the child for specialized evaluation when noticing any warning signs and be up to date on the available therapeutic interventions. He also guides parents on measures to stimulate the child's development and promote their quality of life. Parental awareness is essential to seek help early. Early diagnosis and appropriate intervention make a difference in prognosis. The nurse acts as a mediator between the family and other health professionals, ensuring comprehensive care and establishing a bond of trust. (Melo *et al.*, 2017).

The nursing plan aims to care for autistic patients, focusing on reducing the risk of self-mutilation, carrying out anamnesis to understand the history and evaluate their actions. The nurse maintains regular follow-up, adjusting strategies as necessary, with the aim of providing individualized and safe care. Essential interventions include accurate assessment, guidance to parents, early stimulation, emotional support, collaboration with the multidisciplinary team, and use of distraction strategies. Building an affective bond, offering familiar objects and allowing social interaction are important. Observing the child's reaction and maintaining eye contact contributes to emotional well-being, making the care process more efficient (UNIATENAS *et al.*, 2019).

Music, especially in the form of music therapy, is a valuable nursing intervention in the care of children with Autism Spectrum Disorder (ASD), recognized since the days of Florence Nightingale. This innovative approach facilitates communication, skill development, and social interaction. The application of Dorothea Orem's self-care theory is highlighted, with strategies such as the use of images and videos to facilitate the understanding of the stages of self-care, especially suitable for children with ASD, who prefer visual stimuli. Ongoing support to families is crucial, highlighting the importance of

parental involvement in the care process to ensure continuity of practices at home. This personalized approach not only contributes to the development of autistic children's self-care skills but also emphasizes the importance of a holistic, family-centered approach to health care, serving as a model for future disciplines and promoting better outcomes for children with ASD and their families (Santos Pimenta *et al.*, 2021).

Nursing plays a crucial role in the care of people with Autism Spectrum Disorder (ASD) in various health care settings. The care offered by nursing professionals can be decisive for the acquisition and expansion of fundamental skills for an independent and autonomous life of people with autism. Nursing is a profession committed to the life and health of people in all phases of the life cycle, being essential both in public/private health and around the world. The inclusion of nursing in the line of care for people with ASD and their families in the Psychosocial Care Network (RAPS) of the Unified Health System (SUS) is highlighted as an integral and fundamental part of this approach. This highlight highlights the significant role of nursing in providing comprehensive care and promoting mental health in individuals with ASD, thus strengthening its role in the context of public health (Filha *et al.*, 2021).

The inclusion of teaching about disorders such as ASD in nursing education programs, especially in mental health disciplines, is a positive approach. This will allow future nurses to better understand the nuances of the disorder, recognize the warning signs, and understand the crucial role they play in the care of children with ASD. It is important to promote the constant updating of knowledge throughout one's professional career, given the rapid evolution in research on ASD and mental health in general. Nurses should seek opportunities for continuous learning by attending courses, seminars, and staying informed about the latest findings and best practices. Awareness of ASD can also extend beyond academic training, including awareness programs within health institutions and local communities, contributing to reducing the stigma around ASD and ensuring that families receive the necessary support (Oliveira *et al.*, 2022).

Therefore, the objective of this text is to develop more capacity and help on the part of nurses to patients with ASD, this study talks a little about the development and the extreme importance of these professionals in improving the quality of life of their patients and families.

## LITERATURE REVIEW

### AUTISM

Autism is a behavioral condition with several causes, in which child development is significantly affected (Gillbert, 1990; Rutter, 1996). The first description of this picture was made by Leo Kanner in 1943, based on eleven cases of children he observed and who shared certain characteristics: difficulty in interacting with others; severe language problems (with limited communication) and an excessive interest in constancy. This combination of characteristics was called by him early childhood autism (Kanner, 1943). For many decades, autism was previously labeled as "childhood schizophrenia."

However, in the 1970s, Rutter (1985) emphasized the importance of distinguishing between severe mental disorders that arise in childhood and psychoses that manifest later. Based on the developmental abnormalities that become evident in the first 36 months of life (according to DSM-IV/APA, 1994), the term "pervasive developmental disorders" began to be adopted from the 80s onwards (Bosa *et al.*, 2000).

### METHODOLOGIES FOR IMPROVING THE QUALITY OF LIFE OF PATIENTS WITH ASD

Assistive Technology (AT) is a crucial educational topic that offers multiple tools to reduce inequalities and improve learning for individuals with disabilities. It is especially useful for autistic children, who face challenges in social interaction, communication, and behavior. AT aims to eliminate barriers, promote autonomy, and improve quality of life for people with disabilities, disabilities, or reduced mobility. It is a multidisciplinary area that integrates technology and inclusion, creating tools to support students with special educational needs. AT is the result of technological development and is conceived in an interdisciplinary field of knowledge, which seeks to improve methodologies, strategies, and practices to increase functionality and promote the social inclusion of people with disabilities (Proença *et al.*, 2019).

There is a need for qualified care to ensure continued care in the territory, including Primary Care (PHC). This includes ensuring the rights of people with Autism Spectrum Disorder (ASD) and their families, and the importance of intersectoral networking and interaction with systems to guarantee the rights of autistic people. It emphasizes that nurses, as part of the multiprofessional team, must have knowledge about ASD, their rights and care, following the line of care stipulated by the Psychosocial Care Network (RAPS).

By being on the front line, nurses have direct contact with patients and their families, which highlights the importance of their guidance (Soares *et al.* 2021).

Care practices include caring for the environment and promoting social interaction, adapting care spaces according to the individual needs of patients with ASD. This includes attention to consultation time, clear communication, behavior management, organization and hygiene of the environment, as well as support for family members. The therapeutic environment aims to promote patients' self-esteem, self-care and social interaction, seeking comprehensive care. Nursing also guides and supports family members and caregivers, offering instructions for the appropriate management of patients' behaviors and educational support to strengthen them (Jerônimo *et al.* 2024).

## **METHODOLOGY**

The present work consists of a bibliographic review. The method used is an integrative approach that consists of a synthesis of knowledge and the incorporation of the applicability of the results of significant studies in practice with exploratory research in articles, dissertations and theses available in the health area.

Thus, the bibliographic review is indispensable for the delimitation of the problem in a research project and to obtain a precise idea about the current state of knowledge on a topic, about its gaps and about the contribution of research to the development of knowledge (Lakatos and Marconi, 2010). This is a study carried out through a bibliographic survey and based on the experience lived by the authors on the occasion of an integrative review, which will be carried out to define a profile and understand the main factors that influence the importance of nursing in the care of people diagnosed with the autism spectrum.

## **RESULTS AND DISCUSSION**

The consulted and criticized framework offers great support content to the theme addressed and focuses on quality content on nursing in the care of people diagnosed with the autism spectrum, especially methods to improve the quality of life of patients with ASD and their families and the performance and performance of nurses in front of patients with autism.

Through qualified research, it is possible to form technical-scientific knowledge about the importance of compulsory notification, in the equipping of the unified health system, in the expansion of the qualification of nursing professionals and in the



socialization of information to patients and their families. Showing that the nursing team is extremely important for patients with ASD, from the perception of the signs to the various forms of therapy that exist for motor and social improvement and even family members.

The table below lists the selected materials that contributed to the results and supported the discussion.

Chart 1: Articles searched according to theme

Databases	Title	Author	Year	Considerations
Humanities and Social Sciences in review	The historical construction of autism (1943-1983).	Lima, Rossano Cabral	2014	Analysis of the history of autism, the first cases, how the mind works, how it arrives at the diagnosis.
Jningá Magazine 57.3	Nursing care for people with autism spectrum disorder: a literature review.	Feifer, Gabrielle Palma, et al.	2020	This study highlights the importance of nursing care for patients with ASD.
UNIPAR Health Sciences Archives 27.6	The role of nursing in the care of children on the autistic spectrum.	De Souza, Katieli Oliveira, et al.	2023	It focuses on showing the role of nursing in children on the autistic spectrum, analyzes the care it has with these patients and strategies.
CuidArte, Enferm	Autism: knowledge of the nursing team.	Nunes, Sandra Cristina,	2009	Study about the importance of the nursing team's knowledge of ASD.
Psychology and Health in debate	The importance of the professional nurse in the diagnosis of autism: an integrative review of the literature.	Dos Santos Filho, Marcelo Cerilo, et al.	2020	This article reports on the importance of the nurse to the signs and diagnosis of autism.
UNIATENAS, UNIVERSITY CENTER	Strategies and nursing performance in relation to patients with autism.	arissa Da Silva	2019	It presents a descriptive study, analyzed by psychiatrist Leo Kanner, on the discovery of autism and studying it as a whole.
UNILUS Institutional Repository	Autism spectrum disorder: challenges of nursing care.	Laís Gabriele Braz, et al.	2023	This study aims to identify the challenges of nurses during the care of children with the autistic spectrum.
SciELO	Autism: brief review of different approaches.	Bosa, et al.	2000	This article examines different approaches to the study of autism: psychoanalysis, affective theory, theory of mind, neuropsychological and information processing theories.

Source: Authorship (2024)

Lima *et al*, (2019) say that since the first description of autism by Leo Kanner in 1943, conceptions about its origin and nature have changed significantly. Until the mid-1960s, the dominant view, strongly influenced by psychoanalysis, attributed autism to disturbances in early parent-infant interactions. In the 1960s, cognitivist theories emerged that sought to locate autism in the brain, a trend that became dominant in the English-speaking literature from the 1980s onwards, along with the dissemination of the concept of



"Asperger's Syndrome". This article explores this evolution in the understanding of autism between 1943 and 1983, highlighting the transition from affective-relational theories to cognitive-cerebral conceptions, in addition to considering contextual factors that influenced this change.

Feifer *et al* (2020) say that Autism Spectrum Disorder (ASD) is common in children and affects 1 in 68 individuals in Brazil. In 2016, there were 63,000 attendances of autistic children in Paraná, highlighting the need for professional training for early diagnosis and effective treatment. This study reviews the scientific production on nursing and multiprofessional care for people with ASD, analyzing articles in Portuguese published between 2007 and 2017 in the Scientific Electronic Library Online, Virtual Health Library and CAPES databases.

The articles were categorized into: Health Education Strategies, Multiprofessional understanding of reality, Nurses' perception of ASD, and Nursing care and nursing processes. It was concluded that it is essential to increase the knowledge of professionals to improve early diagnoses and the quality of care, through training that promotes comprehensive care for patients and their families, improving their quality of life. For Souza, *et al* (2023), child psychiatric disorders, such as Autism Spectrum Disorder (ASD), have been increasingly perceived in health units.

ASD is a neurodevelopmental disorder characterized by persistent difficulties in communication and social interaction, as well as repetitive behaviors. In Brazil, the prevalence of ASD is about 0.3%, according to Paula *et al* (2011). The multidisciplinary team, including nurses, is essential in the treatment, assisting both patients and their families in accepting the diagnosis and adapting their lifestyle. There are no definitive pharmacological interventions for ASD, but treatment includes behavioral measures and therapies to help with social reintegration, improved motor coordination, and greater patient independence. The participation of parents and collaboration with educational entities and specialized professionals are fundamental.

Nunes *et al* (2009), in this quantitative exploratory study, investigated the nursing team's knowledge about the early signs of autism. A questionnaire with closed questions was administered to 78 health professionals in a city in the state of São Paulo. The results showed that only 15% of the professionals had had contact with autistic children and 43% could recognize the behavioral triad of autism. Although 10% knew the early signs and 99% recognized the need for treatment, the types of therapies and professionals involved

were unclear. It was concluded that the knowledge of the professionals was insufficient, suggesting the need for training courses to improve the quality of life of autistic people and their families.

Santos Filho *et al* (2020), highlights the importance of nurses in the early diagnosis of Autism Spectrum Disorder (ASD), emphasizing their role in the first contact with the child. The research, an integrative review of the literature, highlights the need for nurses to be attentive to the signs of ASD and to offer support not only to the autistic child, but also to their family. In addition, the role of the nurse in guiding family members on how to communicate and interact with the child is highlighted, thus contributing to a more effective diagnosis and to the provision of adequate nursing care.

Larissa (2019), shows a study that Leo Kanner did that identified that autism was different from schizophrenia when studying children. He noted that autism was often confused with schizophrenia and that it affected more boys. Nursing care is crucial for autistic children, who face challenges in social interaction and sensory behavior. Therapeutic treatment of autism focuses on individual and family care methods.

Moraes (2019) explains a little about the crucial performance of nurses in the care of patients with ASD to improve their quality of life, however, there is a lack of trust and adequate knowledge among nursing professionals, which can negatively affect patients and their families. The participation of nurses in autism care is still considered deficient due to the perception of lack of training. The use of the booklet of Guidelines for Attention to the Rehabilitation of People with ASD was identified as a need to deal with this complex condition.

To conclude, Bosa (2000) addresses several approaches in the study of autism, such as psychoanalysis, affective theory, theory of mind, neuropsychological and information processing theories. It highlights the main contributions and limitations of each approach. There is a call for the integration of these different domains and for research to be carried out that considers both the disabilities and the social skills of individuals with autism. This would help to recognize individual differences along the autism spectrum.

## **FINAL CONSIDERATIONS**

The study emphasizes the importance of nurses in the care of patients with Autism Spectrum Disorder (ASD). Over time, there has been an evolution in the understanding of autism, moving from a psychoanalytic perspective to more cognitive and cerebral

approaches. Today, we recognize the complexity of ASD, influenced by genetic and environmental factors, and its inclusion in the field of disabilities, as established by the International Convention on Human Rights.

Nurses play an essential role in detecting autism early during childcare appointments, referring patients for expert evaluation, and offering emotional support to families. Careful observation and regular follow-up are crucial to identify warning signs and ensure early interventions.

In addition, nursing plays a key role in the ongoing care of autistic patients, with the implementation of personalized strategies, such as Assistive Technology, and the use of innovative therapeutic approaches, such as music therapy. The promotion of inclusion and autonomy of patients, as well as support for families, are priorities in the care provided by nurses.

The literature review carried out in this study provided a comprehensive understanding of the theme, highlighting the importance of continuous training of nurses and awareness of ASD. The inclusion of autism teaching in nursing training programs is essential to ensure quality care for patients with ASD and their families.

In summary, nurses play a vital role in the care and support of patients with ASD, contributing to the improvement of quality of life and promoting a holistic and family-centered approach. The knowledge acquired in this study will serve as a basis for future research and practices in the area, always aiming at the well-being and inclusion of autistic individuals in our society.

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