

Nursing care and identifying responsibility for people with autism spectrum disorder

Assistência de enfermagem no contexto de responsabilidade às pessoas com transtorno do espectro autista

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ABSTRACT | OBJECTIVE: To analyze how nurses who provide care to people diagnosed with autism involve the interaction between the biological and social environment, in the context of responsibility. **METHOD:** Basic, exploratory, descriptive, qualitative research. Data collection took place through semi-structured interviews and analysis through thematic categorical analysis. **RESULTS:** 03 nurses, teachers, aged between 36 and 54 years old, postgraduates in pediatrics, training time of 10 to 22 years participated, and who during their professional practice took care of autistic children. Two thematic categories were created: "Responsibility for obtaining the diagnosis" and "Responsibility for therapeutic intervention". The first category emphasizes the importance of identifying signs of autism in children and highlights the collaborative role of parents and educators in recognizing early indicators of autism. The second category addresses the importance of monitoring by a qualified health professional to carry out the recommended therapies. **FINAL CONSIDERATIONS:** The responsibility for caring for autistic people in the context of diagnosis and interventions needs to be shared between parents, family, health professionals, school and society through a personalized and comprehensive approach that considers the unique needs and characteristics of each individual with autism.

KEYWORDS: Neurodevelopmental disorders. Autistic Spectrum Disorder. Nursing.

RESUMO | OBJETIVO: Analisar como as enfermeiras que prestam assistência às pessoas com diagnóstico de autismo envolvem a interação entre o ambiente biológico e social, no contexto de responsabilidade. **MÉTODO:** Pesquisa básica, exploratória, descritiva, qualitativa. A coleta de dados se deu mediante entrevista semiestruturada e a análise por meio da análise categorial temática. **RESULTADOS:** Participaram 03 enfermeiras, docentes, idade entre 36 e 54 anos, pós-graduadas em pediatria, tempo de formação de 10 a 22 anos, e que durante sua prática profissional cuidaram de crianças autistas. Foram elaboradas duas categorias temáticas: "Responsabilidade para a obtenção do diagnóstico" e "Responsabilidade da intervenção terapêutica". A primeira categoria enfatiza a importância de identificar sinais de autismo em crianças e destaca o papel colaborativo dos pais e educadores no reconhecimento de indicadores precoces de autismo. A segunda categoria aborda a importância do acompanhamento de um profissional de saúde capacitado e habilitado para a realização das terapias indicadas. **CONSIDERAÇÕES FINAIS:** A responsabilidade do cuidado aos autistas no contexto do diagnóstico e intervenções precisa ser compartilhada entre os pais, família, profissionais de saúde, escola e sociedade mediante abordagem personalizada e abrangente que considere as necessidades e características únicas de cada indivíduo com autismo.

PALAVRAS-CHAVES: Distúrbios do Neurodesenvolvimento. Transtorno do Espectro Autista. Enfermagem.

Submitted Mar. 5th, 2024, Accepted July 25th, 2024,

Published Aug. 29th, 2024

J. Contemp. Nurs. 2024;13:e5587

<http://dx.doi.org/10.17267/2317-3378rec.2024.e5587> | ISSN: 2317-3378

Assigned editor: Cátia Palmeira

How to cite this article: Silva LMF, Sandri JVA, Chesani FH, Bossardi CN, Gouvea PB. Nursing care and identifying responsibility for people with autism spectrum disorder. J Contemp Nurs. 2024;13:e5587 <http://dx.doi.org/10.17267/2317-3378rec.2024.e5587>



1. Introduction

The term 'autism' was first used in 1908 by the Swiss psychiatrist Eugen Bleuler to define individuals presenting with self-admiration and withdrawal within self. In 1943, Grey Tripplett was the first person in the world to be diagnosed with autism; his symptoms were unusual language, an unwillingness to play with other children and not responding to smiles or when called by his name.¹

Autism symptoms include difficulty interacting socially, difficulty communicating, characterized by the repetitive use of language, difficulty initiating and maintaining dialogue, behavioural problems, repetitive behaviours, interest in specific things and difficulties with imagination.² In the ICD 11, autism is divided into two main categories, people with intellectual disabilities, which in turn is divided into 4 subgroups: no functional language impairment, mild functional language impairment, impaired functional language and absence of functional language; and people without intellectual disabilities, divided into 3 subgroups: no functional language impairment, mild functional language impairment and impaired functional language.³

The current headlines about autism describe an "epidemic" of the disorder - according to data from the Center for Disease Control, in the 2000s the incidence of autism was 1 in every 150 children; by 2020 this number had risen to 1 in every 36. It is believed that this increase is linked to improved diagnostic criteria, the higher number of specialized health professionals and an improvement in the dissemination of concepts, meaning that its recorded prevalence has risen as the disorder is better understood and better support is given to those who are identified early.⁴

The prevalence of new cases makes it important for health professionals to be prepared to undertake early diagnosis and, since nurses are on the frontline of care and in a range of health situations, they need to be careful observers in order to identify signs of the presence of neurodevelopmental impairments, such as autism.

As a profession, nursing seeks to promote well-being and individual care through scientific knowledge. Nurses represent the first point of contact with health services, given that they are frequently involved in

initial assessments and in determining which of the five priority levels a patient requires.⁵

Caring for people with autism is an essential part of professional nursing development, requiring professionals to pay careful attention to the individual's needs and suffering, since communication deficits are a main feature of autism, reflecting the importance of skilled listening.⁶

Further, nurses can positively support diagnosis and follow-up, by observing children's behaviour and helping parents, providing support and information about the challenges and care procedures they can apply.⁵

It is evident that when caring for these individuals, health professionals in general, and nurses in particular, require skills, knowledge and strategies in order to provide individualized care, adjusting their activities according to the way the disorder manifests in each individual.⁶

Given this epigenetics perspective in a nurse's work for an autistic individual, the following questions arise: Is autism a disorder to be cured or an identity to be respected? Are the challenges that people with autism face related to their social context, which is unable to accept behaviour considered to be different? Our aim, therefore, is to analyse how nurses provide care to people with an autism diagnosis and how they approach the interaction between the biological and social environments, in relation to responsibility.

2. Methods

This is a basic, exploratory, descriptive and qualitative research undertaken at the Vale do Itajaí University (Universidade do Vale do Itajaí: UNIVALI) and the Pequeno Anjo Children's Hospital.

The participants were three nursing lecturers from the Nursing Course at the Vale do Itajaí University, with a history of working with children diagnosed with autism. One nurse was excluded because she was on maternity leave.

Data was collected between May and June 2022 through a semi-structured interview containing questions about how to identify the causes of

and interventions for autism, in relation to the professional's responsibility, focused on biological, social and environmental features. The interviews lasted an average of 60 minutes and were held through prior arrangement with nurses eligible to participate. One of the interviews was held at the Pequeno Anjo Children's Hospital in Itajaí, while the other two took place at the Vale do Itajaí University, their workplace.

All the interviews were recorded and participants were given the codenames P (participant) followed by a number representing the chronological order of the interview from 1 to 3 (P1, P2, P3). All participants signed an Informed Consent Form.

Following the interviews, the recorded material was transcribed verbatim, this data was then interpreted and analysed. Thematic category analysis was used to this end. This is one of the most common forms of content analysis and is used to systematically facilitate interpretation and extract meaning from interview messages.

Thematic analysis basically occurs over three stages: pre-analysis, when the documents are selected and the initial objectives of the research are reviewed. Exploration of the material, which aims to arrive at a core understanding of the content, organizing the material into categories in order to aggregate the data, and selecting categories that will provide specific details of the studied themes.⁷ Results obtained and interpretation, when the results are revealed to evidence the data obtained and where interpretation is related to scientific studies.

This research rigorously followed Resolution no. 466 of December 12th 2012, which refers to the regulatory guidelines and norms for research involving humans.⁸ Approval was obtained from the Comissão Nacional de Ética em Pesquisa - CONEP (National Research Ethics Committee) under Substantiated Opinion Number: 5.395.458.

3. Results

Participant characteristics were as follows: all three were women; aged between 36 and 54; post-graduates in Pediatrics; nurses and higher education

teachers who had trained between 10 and 22 years previously. Only one worked exclusively at the university, the others had dual employment status: university, hospital or Municipal Health Department.

Our analysis provided evidence of two thematic categories: responsibility for obtaining diagnosis and responsibility for therapeutic intervention.

3.1. Category 1: Responsibility for obtaining diagnosis

When asked about the first manifestation of signs and symptoms that may support an autism diagnosis, the participants confirmed that parents and teachers observed the children's impairments early, detecting inappropriate behaviour, which may indicate the need for a diagnosis by the health service. They emphasized the importance of identifying signs of autism in children at an early age, in order to initiate appropriate therapy and support.

For example, **P2** said that both parents and teachers are capable of noticing changes in the child's behaviour, which should lead them to a health service for correct diagnosis. This underlines the collaborative role of parents and educators in recognizing early autism indicators.

[...], so the parents end up noticing these changes and can be advised to go to the health service for a correct diagnosis, [...] the school is also able to notice the changes that occur in the child, so both the parents and the teachers end up noticing these changes and can be advised to go to the health service for a correct diagnosis (P2).

Linked to the theme of early diagnosis is a personalized therapeutic approach based on the individual's age. The participants underlined the need for age-specific interventions, as noted by **P2**, in relation to specific treatment for children, as opposed to adults. This suggests that interventions must be personalized to meet individual developmental needs at different life stages. The words of **P1** further support this notion, by stressing the importance of individualized treatment to meet the specific needs of every autistic individual.

It's so important to have an early diagnosis to begin treatment, provide guidance for the family, so the family understands the process (P2).

[...] it's different when you identify a child who's two or three years old, than, for example, a child who maybe wasn't correctly or properly diagnosed in early, middle childhood [...] or as an adult [...] So I think these are very different things and that the treatments will be specific for each age group (P1).

The interviews further indicate that it is the responsibility of everyone who, either directly or indirectly, has contact with the autistic individual, in the family or social environment, for example, at school or with health professionals. Everyone should be aware of the first signs of autism neurotypes so that they can obtain a diagnosis and be referred for treatment as soon as possible.

3.2. Category 2: Responsibility for therapeutic intervention

When they discussed who is responsible for the best therapeutic intervention for autistic individuals, the nurses provided similar responses about the importance of a trained, skilled health professional who can carry out the recommended treatment for each autistic person, in an individualized manner; this is known as the Unique Therapeutic Project.

They highlighted the importance of seeking help from skilled professionals with experience working with autism. All the interviewees (**P1**, **P2** and **P3**) noted that, for an autism diagnosis, referrals should be made to professionals with the required knowledge and experience of treatment. This underlines the importance of interventions by professionals trained in ensuring effective support and care for these individuals.

[...] it has to be a health professional, they have to have treatment [...] it could be an occupational therapist, it could be a psychotherapist, a psychologist who can undertake these activities with the school. (P1)

[...] the correct process is for the patient to be referred to a qualified professional, a professional with the knowledge and background to work with autism. (P2)

[...] (the treatment) will focus on that person's needs, so you will focus on skilled listening in order to provide the appropriate treatment for that person. [...] so they can have the healthcare they need, focused on their health. It has to be individualized. (P3)

We note that, as well as therapeutic intervention with health professionals, the participants are concerned

about following up these children in school, since most of them are atypical and unique, and a therapist or psychologist is therefore needed for support at school to assist with student development.

So it could be an occupational therapist, it could be a psychotherapist, a psychologist who can undertake these activities with the school. (P1)

They need a therapist at school, because they will have a bit more difficulty following the class, [...] support therapies are essential, particularly because they have difficulties with speech. (P3)

The nurses highlight the diversity of treatment available for autistic people, which could be beneficial before labelling a child with autism. **P1** notes the importance of exploring different treatments to support the child's development and integration. This underlines the importance of holistic interventions, given the range of treatment options available to meet the unique needs of autistic individuals.

There are various types of treatments that can be applied before you actually label this child as having autistic spectrum disorder. [...] these treatments will really help them achieve greater inclusion [...] so it could be an occupational therapist, it could be a psychotherapist, a psychologist who can undertake these activities with the school. (P1)

There is a lot of discussion about intervention, which questions whether medication can enhance development and improve quality of life. First, we should note that, since autism is not a disease, there is no medical cure. Medication is used to support autistic individuals in times of crisis, when the child presents with hyperactivity, psychosis, sleep disorders or social anxiety, given that medication can support the necessary self-regulation to deal with these situations.

The efficacy of medication as a treatment option for the management of autism symptoms emerged as a significant theme in the interviews. The nurses discussed the role of medication in improving behaviour and communication skills in people with autism. **P3** noted the positive impact of medication for improving communication and behaviour, saying that medication can be a valuable component of a comprehensive intervention plan for some individuals with autism, while **P2** said that autistic behaviour

is not only managed through medication, since non-drug treatments are extremely important and relevant, and cannot be substituted with medication.

[...] medication has an effect on behavioural problems, maybe it's not only medication, maybe it's the guidance, maybe it's the handling of the situation that helped to improve it, to improve behaviour, to improve communication [...]. (P2)

[...] medication was effective, it achieved its principle and purpose, it was necessary, so it's necessary, not that every autistic child takes medication, but at some points it's necessary [...] it helped in this situation, maintaining his focus and attention, which helped him improve in communication. (P3)

4. Discussion

Our results show how these nurses view caring for people with an autism diagnosis, including in the interaction between the biological and social environment in relation to responsibility. They emphasize the need for the early identification of the signs of autism in children, and the importance of beginning appropriate treatment and support.

According to the interviews, the perception of symptoms by parents and teachers is, therefore, the first step in the diagnosis of an autistic child, and any such suspicion will initiate investigation. The earlier this is investigated, the more beneficial it will be for the child, but there are situations when the diagnosis happens during adulthood, which require distinct types of intervention. However, although the diagnosis is the most important part of the intervention, it is often neglected or ineffective, which can lead to long-term developmental damage.

In line with the above, we note that autism affects the areas of neurodevelopment that are responsible for social interaction, communication and behaviour, and, if not diagnosed and treated early, can compromise the individual's development throughout their life.⁹ Early diagnosis is therefore necessary, given that appropriate intervention measures are related to better developmental prognosis.¹⁰

Responsibility for obtaining a diagnosis is therefore a central issue, since early detection of the signs of autism relies on parents, teachers and health professionals making careful observations and having sufficient knowledge about child development. In this sense, the nurses stressed the need for health education to raise parental awareness so that these signs can be recognized as early as possible, triggering a more in-depth investigation into suspected cases. However, they noted that gaps remain in the identification of autism signs, which may delay diagnosis and the necessary intervention.

Delays in autism diagnoses limit the possibility of adaptation and reorganization, worsening symptoms, impairing the child's cognitive and social development and aggravating the clinical situation.¹¹ Autistic children and their families depend on a formal diagnosis to access specific clinical services.¹² However, in Brazil, definitive diagnosis still occurs too late, due to excessive waiting times to access specialists and tests.

There is no doubt that early diagnosis leads to effective gains in the lives of autistic people, given that it allows their potential to be recognized, before difficulties take root, since their lives can be rich and rewarding, despite not resembling the conventional ideal.

On the other hand, the responsibility for therapeutic intervention involves a multi-disciplinary and personalized approach. The interviewees noted that the effectiveness of any intervention also relies on interprofessional collaboration, since the creation of an effective treatment plan requires the integration of various perspectives and the adaptation of treatment strategies to the individual needs of each patient. Further, family participation in the development and implementation of the treatment plan is an essential component, since they know the most about the autistic child's specific issues and behaviour.

In relation to the treatment plan, it is also worth noting that the interviewees said that this should meet the needs not only of the autistic person, but also of their surrounding environment, including family, school and society.

When the participants talked about assigning an intervention to an autistic person, they noted the need to consider neurodiversity, since it is a complex issue, where the focus should remain on the more evident manifestations, such as auditory and visual sensitivity, which cause discomfort and sensory overload, leading to agitation, aggression and irritability. Interventions should, therefore, seek to promote development and reduce stereotypic behaviour, since it is believed that such measures lead to significant improvements in autism symptoms.¹⁰

Under these circumstances, the nurse's responsibilities not only include providing direct care, but also guiding and supporting families and the school community, promoting a network of robust and ongoing support, leading to a reduction in negative impacts on the autistic child's development.

Moreover, early diagnosis and any consequent reduction in symptoms are due to neuroplasticity, that is the neurone's capacity to adapt to change. It is believed that the later the diagnosis and, consequently, the later the initiation of treatment, the less neuroplasticity and the greater the difficulty in enhancing patient development.¹¹

The role and responsibility of Primary Healthcare in relation to early diagnosis is also worth analysing, given that this is where multidisciplinary care should be provided to children and their families.¹² Early diagnosis, alongside appropriate assessment, and timely and intensive intervention, improve the prognosis, while knowledge of autism is essential for successful diagnosis and, depending on the age at which the diagnosis is made, determines the form and type of therapy.¹³

It is essential for intervention strategies to be constantly reviewed and adapted in line with the patient's progress and their individual needs.

Autism approaches and interventions should concentrate on the individual's developmental capacities, addressing limitations and preventing further decline. This will enable the child to integrate into social and school environments, in line with Law 12764 of 2012, which guarantees access to education for autistic people and which should be facilitated according to their needs. Article 7 of this law states that any administrator who does not enrol students

with autism or another disability will be punished, evidence that the school is obliged to accommodate such students.¹⁴ This ensures that the student is included, rather than excluded from social life, enabling emotional, cognitive and linguistic progress.¹⁵

Common sense dictates that interventions for autistic people should uniquely and exclusively be the province of a doctor, using medication, but the fact is that, from the initial suspicion of the diagnosis, other professionals, particularly nurses, are, and will remain, involved in the entire process.

Non-pharmacological intervention is an important element in the treatment of autistic people; examples include music therapy, colour therapy and aromatherapy, all of which can be provided by trained nurses, according to the *Nursing Intervention Classification*. Animal-assisted therapies can also be provided, for example equine-assisted therapy (horses), and cynotherapy (dogs), as well as psychological interventions, occupational therapy, physiotherapy, and speech and language therapy. These should be allocated for the individual according to their Unique Therapeutic Project and aimed at patient improvement and progress.¹⁶

We know that, for successful treatment to occur, drug treatment should be complementary, given that the most commonly employed medications for the pharmacological treatment of autistic children are antipsychotics (risperidone, aripiprazole and quetiapine). On the other hand, we note that children with access to non-pharmacological treatments from a multi-professional team have a better quality of life, particularly since they do not suffer from any medication side effects.¹⁷

It is evident that therapeutic intervention should not be exclusively drug based, other therapies should be provided to support improvement. Just as clinical manifestations are unique to each individual, the treatment cannot be the same for all. For this reason, it is important for professionals to pay careful attention to the individual's needs and suffering, since communication deficits are a main feature of autism, making skilled listening even more important.⁶

As an integral part of the multi-disciplinary team, the nursing professional is responsible for assessment and childcare appointments in basic healthcare units

and can, through skilled listening, careful attention and training, identify autism neurotypes.⁵ Further, the nurse undertakes to follow up with the families of autistic patients regarding their care, answering questions, encouraging treatment and providing reassurance.¹⁸

In basic healthcare units and hospitals the screening and care provided during hospitalization are largely undertaken by nurses, who establish a close relationship with the patients; it is this relationship that allows them to perceive signs before the medical team does. In basic healthcare, the nursing team is one of the teams responsible for supporting and defining every autistic patient's Unique Therapeutic Project, which aims to direct care according to their needs and those of their family. Generally, this care involves a multidisciplinary team that provides a plurality of approaches and views. Normally, the multidisciplinary team consists of a psychologist, a speech and language therapist, an occupational therapist, an educational psychologist, nutritionists, nurses and doctors whose aim is to provide progressive improvements to the patient's quality of life.

Finally, parental responsibility was another feature of the interviewees' discourse, in which they pointed out that the family is an important resource for identifying the manifestation of autism characteristics in early childhood. The parents' participation in this diagnosis and intervention was evidenced. The school's responsibility, as a social environment and in the context of inclusion, the development of skills, the identification of symptoms and in helping the family, was also described as indispensable.

All parents need support and guidance in bringing up their children and often ask for help. Generally, children need sensitive and accepting parents or caregivers, who stimulate their development. The need to develop social and communication skills with other people is not categorically different for autistic children, although it may be expressed differently.¹⁹

Issues related to diagnosis and intervention using specific treatments, according to the autistic child's needs and age, as well as the role of health professionals in the various therapeutic approaches and in medication, underline the complex and multifaceted nature of support for autistic individuals. These reflect the importance of a personalized and comprehensive approach to intervention, which

takes into consideration the unique characteristics of each autistic individual.

The low number of nurse participants is a study limitation, although the majority of nurses who met our criteria did respond.

5. Final considerations

Through the nurses' narratives, the study demonstrated the importance of obtaining an autism diagnosis at the earliest possible time, although this is not always possible, leading to late referrals and consequently late access to therapeutic interventions. The nurses recognized that responsibility for an autistic child is shared between the family, school and health professionals and they pointed out that interaction with the biological environment occurs as a result of the condition of the autism itself and the need for family and social support, so that the autistic individual can develop according to their capacities, maximizing their potential, through appropriate and individualized management, and enabling the social environment to recognize their neurodiversity. Being autistic is therefore an integral part of their identity, since it is something that cannot be cured but can be respected.

Nurses are essential to this development, since they have the capabilities required for early identification and provide support to families, assist in and even carry out therapeutic interventions, monitoring the neurodevelopment of autistic individuals and intervening when necessary. In short, the nurse plays an essential role in caring for autistic people, significantly contributing to early diagnosis and therapeutic intervention. A nurse's presence and work are therefore essential to ensuring adequate and personalized care for individuals with autism.

Finally, there is a need for greater scientific and media investment in information about autism, not focused on the conventional hegemonic clinical paradigm, but on understanding that neurodiverse people exist in society, just as neurotypical ones do. This information should reflect a vision that neurodiverse people can live harmoniously in the same social environment. Similarly, expanding public and private assistance so that families have support and guidance to better care for their autistic loved ones is a goal to be achieved.

Acknowledgements

We would like to thank the Conselho Nacional de Desenvolvimento Científico e Tecnológico - CNPq (National Council for Technological and Scientific Development), which funded the grants awarded to the authors.

Authors' contributions

Silva LMF, Sandri JVA participated in drafting the research proposal, data collection, qualitative data analysis and interpreting the results. Chesani FH, Bossardi CN, Gouvea PB participated in the design of the research question and the methodological design. All the authors have reviewed and approved the final version and are in agreement with its publication.

Conflicts of interest

No financial, legal or political conflicts involving third parties (government, private company or foundation, etc.) were declared for any aspect of this work (including, but not limited to, grants and funding, participation in advisory boards, study design, drafting of the manuscript, statistical analysis, etc.).

Indexers

The Journal of Contemporary Nursing is indexed in the [DOAJ](#) and the [EBSCO](#).



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