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RESEARCH ARTICLE (ORIGINAL)

Care of Children with Autism Spectrum Disorder by Primary Health Care Nurses: Qualitative Study

Cuidados à Criança no Espetro do Autismo por Enfermeiros de Cuidados de Saúde Primários: Estudo Qualitativo

Cuidados al Niño con Trastorno del Espectro Autista por Enfermeros de Atención Primaria de Salud: Estudio Cualitativo

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Abstract
Background: The rising prevalence of Autism Spectrum Disorder (ASD) poses challenges for nursing in primary health care, where child development is monitored.
Objective: To understand primary health care nurses' perceptions of caring for children with ASD.
Methodology: A descriptive qualitative study was conducted in Portugal with 25 nurses. Semistructured interviews were analyzed using both Descending Hierarchical Classification (IRaMuTeQ) and Thematic Content Analysis.
Results: Five classes emerged: Communication and Interaction with the Child; Care Strategies for Children with ASD; Collaboration Between the Family and Health Professional; Practice and Attitudes Toward Professional Care Following Diagnosis; and Structural Barriers and the Need for Change. Communication difficulties, environmental limitations, the importance of family involvement, and gaps in professional training were highlighted.
Conclusion: Caring for children with ASD requires individualized strategies, adapted environments, and ongoing training. Structural and educational barriers limit the quality of care, underscoring the need to reorganize services and strengthen support networks for children and their families.

Keywords: autistic disorder; nursing care; primary health care; child; community health nursing

Resumo
Enquadramento: A crescente prevalência da Perturbação do Espectro do Autismo (PEA) coloca desafios à enfermagem nos cuidados de saúde primários, onde se acompanha o desenvolvimento infantil.
Objetivo: Compreender a perceção dos enfermeiros de cuidados de saúde primários sobre o cuidado à criança com PEA.
Metodologia: Estudo descritivo e qualitativo realizado em Portugal com 25 enfermeiros. As entrevistas semiestruturadas foram analisadas por meio de Classificação Hierárquica Descendente (IRaMuTeQ) e Análise Temática de Conteúdo.
Resultados: Emergiram cinco classes: Comunicação e interação com a criança; Estratégias de cuidados à criança com PEA; Colaboração entre a família e o profissional de saúde; Prática e atitude no cuidado profissional perante o diagnóstico; e Barreiras estruturais e necessidade de mudanças. Destacaram-se dificuldades comunicacionais, limitações ambientais, importância do envolvimento familiar e lacunas na formação profissional.
Conclusão: O cuidado à criança com PEA requer estratégias individualizadas, ambientes adaptados e formação contínua. As barreiras estruturais e formativas limitam a qualidade dos cuidados, reforçando a necessidade de reorganizar serviços e fortalecer redes de apoio à criança e à família.

Palavras-chave: transtorno autístico; cuidados de enfermagem; cuidados de saúde primários; criança; enfermagem comunitária

Resumen
Marco contextual: La creciente prevalencia del trastorno del espectro autista (TEA) plantea desafíos para la enfermería en la atención primaria de salud, donde se realiza el seguimiento del desarrollo infantil.
Objetivo: Comprender la percepción de los enfermeros de atención primaria de salud sobre el cuidado de los niños con TEA.
Metodología: Estudio descriptivo y cualitativo realizado en Portugal con 25 enfermeros. Las entrevistas semiestructuradas fueron analizadas mediante la Clasificación Jerárquica Descendente (IRaMuTeQ) y el Análisis Temático de Contenido.
Resultados: Surgieron cinco clases: Comunicación e interacción con el niño; Estrategias de cuidado del niño con TEA; Colaboración entre la familia y el profesional de la salud; Práctica y actitud en el cuidado profesional ante el diagnóstico; y Barreras estructurales y necesidad de cambios. Se destacaron las dificultades de comunicación, las limitaciones ambientales, la importancia de la participación familiar y las brechas en la formación profesional.
Conclusión: El cuidado de los niños con TEA requiere estrategias individualizadas, entornos adaptados y formación continua. Las barreras estructurales y formativas limitan la calidad de los cuidados, lo que refuerza la necesidad de reorganizar los servicios y fortalecer las redes de apoyo para los niños y sus familias.

Palabras clave: trastorno autístico; cuidados de enfermería; atención primaria de salud; niño; enfermería comunitaria

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Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by difficulties in communication and social interaction, as well as restricted and repetitive patterns of behavior (American Psychiatric Association, 2013). Its prevalence has increased globally, with estimates indicating that it affects approximately one in every 100 children (Zeidan et al., 2022), and it has a significant impact on daily activities and family dynamics (Ruthes et al., 2022). Given this reality, it is essential that health professionals have the knowledge and competencies required to provide qualified care to children with ASD, recognizing the need for therapeutic support that helps both children and their families overcome challenges throughout the care trajectory.

Within the pediatric population, the literature highlights multiple challenges and barriers that affect the initiation and continuity of appropriate care for children with ASD. Insufficient specialized knowledge and inadequate professional preparation undermine care quality and delay children's and their families' access to specialized services (Bonfim et al., 2023). Parents or legal guardians frequently seek diagnosis and treatment during early childhood. However, gaps in professional preparation, difficulties coordinating care across levels, and limitations in service organization ultimately compromise the care trajectory, exacerbating family stress and burden (Bradshaw et al., 2022).

Against this background, understanding how nurses perceive and experience care for children with ASD in primary health care settings is essential for identifying the strengths and weaknesses of existing practices and for informing strategies to improve professional education and public policies. Therefore, the aim of this study was to understand primary health care nurses' perceptions of the care provided to children with ASD.

Background

Caring for children with ASD requires health professionals to develop specific competencies and both theoretical and practical knowledge, as well as individualized care strategies tailored to each child's needs. However, many professionals struggle to interact with these children because of insufficient understanding of ASD's characteristics and difficulty adapting care to their individual needs (Díaz-Agea et al., 2022). In addition, families of children with ASD frequently experience emotional burden, difficulty adapting to the diagnosis, and an ongoing need for support in caring for their child (Bonfim et al., 2023; Anjos & Morais, 2021). Therefore, it is essential to improve care practices, promote the development of therapeutic relationships with children and their families, and develop more effective, individualized, and humanized care plans.

In primary health care, nurses play a central role in promoting child health, monitoring growth and development, and detecting early signs of developmental delay or behavioral changes. As the preferred entry point into the health care system, these professionals are often the first to contact children and their families. Their role is therefore critical for the early identification of signs suggestive of ASD, providing guidance for caregivers, and timely referral to specialized services (Oliveira et al., 2025). Despite the importance of this role, the literature highlights challenges in nurses' education and clinical practice when caring for children with ASD (Corden et al., 2022; Silva et al., 2025). The lack of specific protocols, difficulties in communicating with families, and the social stigma associated with autism constitute barriers to establishing inclusive, systematic, and child- and family-centered care for children with ASD and their families.

Research Question

How do nurses perceive the care children with ASD receive in the context of primary health care?

Methodology

This was a descriptive study using a qualitative approach. The study was conducted in accordance with the guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ), as recommended by the EQUATOR Network.

The study was conducted in Portugal at a higher education institution in the country's northern region. The institution is dedicated to nursing education and is integrated into a community health care network that promotes critical reflection on practices and experiences within primary health care.

The study participants were nurses enrolled in a master's program in Community Nursing, specializing in Family Health Nursing, at the aforementioned institution. Participants were selected through nonprobability convenience sampling, given that, in addition to their academic training, they were professionally active in primary health care and directly involved in Family Health Units across different regions of Portugal.

The inclusion criteria were enrollment in the master's program in Community Nursing, specializing in Family Health Nursing, and at least one year of professional experience in primary health care. Individuals who were absent from professional and/or academic activities during the data collection period were excluded. The final sample size was determined by the criterion of theoretical saturation. Data collection was discontinued when the information obtained became redundant and no new relevant elements emerged for the analysis (Nascimento et al., 2018).

Data were collected in January and February 2025. The interviews were conducted by the principal investigator, a nurse and doctoral student with experience in qualitative research. There was no prior relationship between the researcher and the participants, who were informed of the study objectives and the researcher's role before the interviews. Given her professional involvement in the field, the researcher maintained a reflexive journal throughout data collection and analysis to critically reflect

on her assumptions and monitor potential influences on the research process.

Initial contact with participants was established through a formal invitation after authorization from the program coordinator. Interviews were scheduled in advance based on participants' availability and conducted in a private location on the institution's premises to ensure privacy and confidentiality.

Data were collected using a semi-structured interview guide with open-ended questions, organized into two stages: (1) sociodemographic and professional characterization of the participants (length of professional experience, experience in caring for children with ASD, and specific training in the field) and (2) nurses' perceptions, feelings, challenges, and strategies when caring for children with ASD in primary health care.

The interviews were audio-recorded after informed consent and then transcribed verbatim in digital format. All transcripts underwent double verification to ensure the content's reliability and fidelity. To protect participants' confidentiality, each participant was assigned an alphanumeric code consisting of the letter "P" (participant) followed by a number.

The texts were organized into a corpus and analyzed using the *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ), version 0.7 alpha 2, based on R version 3.1.2. Analysis was performed using the Descending Hierarchical Classification (DHC) method, based on lexical analysis, followed by interpretation using the Thematic Content Analysis method (Bardin, 2010). Five thematic classes emerged from the analysis, along with a similarity analysis. Data analysis and interpretation were conducted reflexively, drawing on the researcher's reflexive journal entries to ensure rigor and consistency in the construction of the emerging categories.

All participants were informed of the study's objectives, procedures, and implications and signed an informed consent form. The study protocol was approved by the ethics committee of the higher education institution where the data were collected (opinion no. 047/2024).

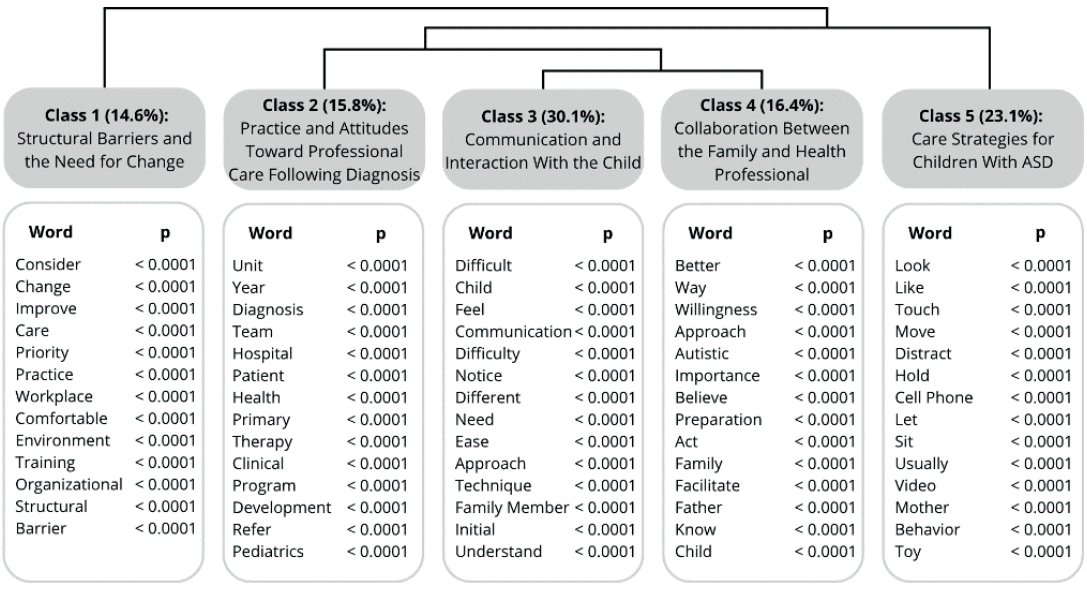
Results

Twenty-five Portuguese nurses participated in the study, the majority of whom were female (n = 24; 96%), with a mean age of 39.5 years (range 26–52 years). Most participants worked in urban settings (n = 18; 72%). All participants held a bachelor's degree in nursing, and three had specialized training in areas other than community nursing. The mean length of professional experience was 16.9 years in nursing and 5.1 years in primary health care. Most participants (n = 20; 80%) reported having previously provided care to children with ASD, whereas five (20%) had no such experience. Only one nurse reported receiving specific training in autism.

The DHC yielded five classes, with 645 text segments retained, representing 85.3% of the analyzed corpus. Based on the DHC, the textual domains were analyzed, and the classes were named according to their semantic content. This process yielded the following classes, as shown in Figure 1: Structural Barriers and the Need for Change (Class 1); Practice and Attitudes Toward Professional Care Following Diagnosis (Class 2); Communication and Interaction with the Child (Class 3); Collaboration Between the Family and Health Professional (Class 4); and Care Strategies for Children with ASD (Class 5).

Figure 1

Descending Hierarchical Classification of Nurses' Perceptions of Caring for Children with ASD in the Context of Primary Health Care



Communication and Interaction with the Child

Participants in this class reported that communication with the child is central to care and that it is essential to respect each child's individual pace and preferences. Several nurses highlighted communication difficulties, particularly with nonverbal children or those with communication limitations. In this context, parents or family members frequently assume a mediating role, helping interpret the child's needs and guiding the delivery of care. To overcome these difficulties, professionals reported using distraction strategies, including drawings, toys, videos, and music, as well as calm, therapeutic communication techniques to reduce stress and facilitate cooperation during procedures.

"Explain what was going to be done, introduce myself to the family and the child, and then try to explain to the child what was going to be done before proceeding with the procedure" (P5); "I would always ask the child how they wanted me to do it, respecting their pace" (P3); "Try to understand the child's behavior; if the child is more agitated, give them space; if they are more receptive, then communicate" (P8).

Care Strategies for Children With ASD

Participants emphasized preparing the care environment as a key factor in the success of the visit. Reducing stimuli, organizing the room in advance, and creating a welcoming environment help minimize children's sensory overload. Conversely, structural barriers, such as shared waiting rooms, cold or impersonal environments, and excessively overloaded schedules, make it more difficult to manage children with ASD and increase stress during care. Creating comfortable spaces with colors, playing objects, and adapted materials was identified as a strategy that facilitates rapport and the development of trust.

> I usually explain everything I am going to do during the child health visit. That I am going to weigh them, why I am going to weigh them, that I am going to measure them, why I am going to measure them, everything clearly. I communicate with them even though many times they don't tell me anything because they want their mother or father. (P8); "Try to find out from the parents what they like most and what their focus of attention is. If they sometimes like to draw or something like that, then we give them a sheet of paper and some colored pencils while we are trying to talk about something that engages them more, to try to establish greater proximity with the child. (P2); I tried to make the room more organized, with fewer stimuli. I kept the door closed so that no one would interrupt, so there would be no risk of someone entering abruptly and frightening the autistic child, and I tried to adapt my tone of voice to the situation. (P19)

Collaboration Between the Family and Health Professional

Professionals reported that parents actively collaborate in the care process by guiding and reassuring the child, mediating communication, and facilitating behavioral management, thereby contributing to more effective care. However, participants recognized differences among families, with some demonstrating greater preparedness while others required more continuous support, highlighting the need for individualized intervention strategies.

> I think family involvement is very important because they know the autistic child better than anyone. If it were possible to conduct a preliminary interview, it would be even better to understand what experiences they have already had, how the autistic child responds best, what strategies the parents use when they need to do something the autistic child does not like, so that we can try to adapt and use those strategies. (P25); The mother's support is very good and helps in understanding how the autistic child reacts to certain stimuli, and I know that I cannot ask for too much at once. At the same time, we need to proceed calmly and patiently so that the autistic child can accomplish what is intended, always with the mother's help. (P7); I think parents are already able to say exactly what the autistic child wants because, more than anyone else, they know their child, and I think communication with the family about what they would like us to do for their child would be easy. (P4)

Practice and Attitudes Toward Professional Care Following Diagnosis

The accounts indicate that professional practice in primary health care is strongly influenced by the organizational structure of health care units. Nurses reported that the care of children with ASD primarily occurs within a generalist care model, which limits more specific and personalized interventions. When signs suggestive of ASD are identified, professionals reported that they usually refer the child to specialized hospital services, which are considered to have a more structured approach to assessment and follow-up.

"When they are diagnosed with autism, they are followed up at the hospital. We basically also have those regular routine visits, but we don't really have many strategies, we don't know many strategies, and we could have some training" (P4); "Those therapies are provided at the hospital unit. For example, we have a psychology consultation, but for the rest, as far as therapies are concerned, we have agreements with some clinics that we refer them to and that are free of charge, but the waiting time for those clinics is much longer than for a private one, and this ends up somewhat limiting access for autistic children. They are generally referred for a psychiatric consultation at the hospital, and we have a psychologist at the health center, but the psychologist cannot meet all the needs" (P17).

Structural Barriers and the Need for Change

The accounts revealed specific challenges in performing procedures, particularly vaccination, where the child's unpredictable behavior and, at times, the need for physical restraint require additional attention. Work overload

and pressure associated with care-related performance indicators were identified as barriers that limit time for individualized care. Although professional experience contributes to greater confidence, variability among children and families requires continuous adaptation of practice. Additionally, participants reported structural, social, and organizational barriers, including a lack of appropriate spaces, limited intersectoral support, and stigma associated with autism. Conversely, they identified facilitators, namely advance planning, patience, professional flexibility, and family involvement. The accounts reveal that it is possible to provide humanized, child-centered care.

The importance of specific and ongoing training was consistently emphasized across participants' accounts and identified as essential for developing competencies in communication, behavioral management, and environmental adaptation.

"Time is a problem. Visits are limited, and we want to approach things more calmly, but we have to free up the room for another appointment" (P21);

> I think they become more stressed when they leave their environment and routine, and I think the whole health center or hospital environment already creates some stress and anxiety for them, possibly because they also associate it with less positive experiences. Therefore, they are not as cooperative. (P6); "We are the ones who have to adapt because we cannot change the entire environment because of one or two children we have in such a large population. We try to find the most suitable room whenever possible because sometimes what is possible is what gives us the best conditions. (P14)

"I think raising professionals' awareness is important because, in terms of technical competence, it is somewhat based on the experience we acquire" (P23);

> I think training on the different types of autism that exist and the different interventions that can be used in each situation is important because we often encounter new situations and new cases, and sometimes it is somewhat difficult to really respond appropriately. Often, we do not even know how to intervene. (P1)

Discussion

The findings of this study provided insight into how primary health care nurses perceive the care of children with ASD as a process requiring individualized attention, advance planning, active family involvement, and adapted communication strategies. Although nurses recognize the importance of providing humanized care tailored to each child's characteristics, they continue to face persistent challenges, particularly related to the physical environment, behavioral unpredictability, communication limitations, workload, and a lack of specific training.

Regarding communication and interaction with the child, participants reported greater difficulties when caring for nonverbal children or those with limitations in expressive communication, underscoring the mediating role of parents and other family members. Strategies such as using toys, videos, music, and calm communication techniques were identified as resources that facilitate interaction. Adopting these strategies is essential, as effective communication requires prior knowledge of the interests, preferences, and responses of children with ASD to promote their cooperation and reduce anxiety associated with care (Vilarroig et al., 2022).

Regarding care strategies, nurses emphasized the importance of reducing sensory stimuli, organizing the care environment in advance, and creating welcoming, predictable settings. In contrast, structural barriers, such as shared waiting rooms, unsuitable environments, and overloaded care schedules, emerged as factors that hinder care delivery. The literature supports the notion that sensory-adapted environments promote greater cooperation among children with ASD and reduce stress during clinical procedures, supporting the use of environmental management and individualized care practices (Bonfim et al., 2023). In addition, sensory modifications, such as reducing lighting and noise and using visual supports and augmentative and alternative communication, contribute to greater comfort and cooperation among children, particularly in more clinically demanding settings (Al-Beltagi et al., 2025).

Regarding the performance of procedures, these require additional attention because of the behavioral unpredictability of children with ASD. Scientific evidence indicates that limited time available for care and workload compromise the quality of care, affecting the experiences of both children and their families (Anjos & Morais, 2021). Procedures such as blood draws, medication administration, and vaccination are often perceived as highly stressful by children with ASD and may trigger emotional crises characterized by oppositional behavior, crying, or aggression (Al-Beltagi et al., 2025). These episodes are often intensified by excessive sensory stimuli, long waiting times, the presence of unfamiliar people, and a lack of prior preparation for the procedure, factors that may contribute to maladaptive behavioral responses (André et al., 2025). In this regard, caring for children with ASD can be a demanding and emotionally challenging experience for health professionals.

The family emerged as a central facilitator of care for children with ASD. Professionals emphasized that active parental involvement is essential because parents possess in-depth knowledge of their children's individual characteristics, preferences, and responses. Thus, the family serves as a fundamental source of support for professionals, contributing to communication, behavioral management, and the development of therapeutic relationships, all of which facilitate intervention success (Bradshaw et al., 2022).

During health care visits, parents often serve as mediators between the child and the health professional, providing relevant information about specific needs and more effective approaches. This collaboration guides the health care team on appropriate ways to communicate and engage in physical contact, particularly with nonverbal children or those with heightened sensory sensitivity (Lundholm & Stålberg, 2025).

Participants in the study placed particular importance on professional training in ASD, identifying gaps in behavioral management strategies, appropriate communication, and adaptation of the care environment. Therefore, continued and specialized training is essential to address gaps in care, improve the safety of care delivery, and promote more humanized and effective practices (Zhang & Whang, 2025).

Because ASD begins in childhood, health professionals frequently report difficulties with early detection of signs, particularly in nursing practice. In primary health care settings, where nurses are typically the first point of contact between children and families and the health care system, training for these professionals assumes a strategic role, enabling them to recognize early signs, facilitate appropriate referrals, and contribute to the timely initiation of interventions (Oliveira et al., 2025).

Scientific evidence shows that the quality of care for children with ASD depends on coordination among multidisciplinary teams, professionals' technical competence, and the value placed on the relationship with the family. This evidence calls for reorganizing care practices and strengthening care networks (Costa et al., 2023; Zhang & Whang, 2025). Understanding the context of professional care is therefore essential for designing strategies that minimize system-level limitations and promote more inclusive, integrated, and child- and family-centered care.

Regarding barriers and facilitators to care delivery, the results indicate that structural, social, and organizational factors, such as insufficient appropriate spaces, social stigma associated with autism, workload, and the absence of intersectoral support, constitute significant challenges to clinical practice. In this regard, institutional policies and training programs should incorporate not only technical training for professionals but also organizational adaptation and support for everyday clinical practice (Bonfim et al., 2023).

One limitation of the study is the inability to collect data in professionals' actual work settings, which may have affected understanding of everyday care dynamics. It is also important to note that participants were undertaking postgraduate training, which may reflect a profile with greater awareness of ASD than that observed in the general primary health care population. Therefore, the transferability of the findings to other settings should be interpreted with caution. In addition, some participants had no prior experience providing direct care to children with ASD, which may have influenced the depth of some responses. Nevertheless, the findings contribute to understanding the phenomenon under study and may inform future research in different settings and among different professional groups.

Conclusion

The study showed that caring for children with ASD in primary health care is characterized by challenges of an educational, structural, and organizational nature.

Nurses emphasized the importance of adapted environments, individualized communication strategies, and active family involvement as essential support throughout the care process. However, these health professionals also identified limitations related to available physical space, service organization, and a lack of specific training in autism.

Therefore, the study findings reinforce the need for continued investment in nursing professionals' education, structural and organizational adaptation of health care units, and the development of communication and care management strategies that promote more humanized, safe, and child-centered care for children with ASD. Additionally, strengthening coordination among primary health care, specialized services, and families is essential to building an integrated and effective care network that addresses the specific needs of children with ASD and their family contexts.

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