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Original Article

Perception of primary care nurses regarding the care for families of children with autism spectrum disorder*

Percepção de enfermeiros da Atenção Primária sobre cuidados às famílias de crianças com espectro autista

Percepción de los enfermeros de Atención Primaria sobre los cuidados a las familias de niños con espectro autista

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Abstract

Objective: To understand the perception of nurses regarding the challenges experienced in caring for families of children with autism spectrum disorder in Primary Care. **Method**: Descriptive research with a qualitative approach, involving nine nurses working in Primary Care units in Foz do Iguaçu, Paraná, Brazil. Interviews were conducted, and data were analyzed using Content Analysis with a Thematic approach, in August and September 2023. **Results**: Thematic categories emerged: The family of a child with Autism Spectrum Disorder in the perception of the nurse; Challenges of the Unified Health System in providing individualized care for children with this disorder; Importance of professional training and education. **Conclusion**: In the nurses' perception, families experienced feelings of insecurity, stress, and anxiety, facing challenges such as lack of training and a shortage of specialized professionals, fragmented care, weak articulation between Primary and specialized care, and lack of infrastructure and supplies.

Descriptors: Community Health Nursing; Nursing Care; Mental Health; Autism Spectrum Disorder; Family Relations

Resumo

Objetivo: compreender a percepção dos enfermeiros sobre os desafios experienciados no cuidado com as famílias de crianças com transtorno do espectro autista na Atenção Primária. **Método**: pesquisa descritiva de abordagem qualitativa, com participação de nove enfermeiros atuantes em unidades de Atenção Primária de Foz do Iguaçu, Paraná, Brasil. Realizam-se entrevistas, dados analisados por Análise de Conteúdo na vertente Temática, em agosto e setembro de 2023. **Resultados:** emergiram as categorias temáticas: A família da criança com Transtorno do Espectro Autista na percepção do enfermeiro; Desafios do Sistema Único de Saúde para o atendimento singular da criança com esse transtorno; Importância da formação e capacitação profissional. **Conclusão:** na percepção dos enfermeiros, as famílias experimentaram sentimentos de insegurança, estresse e ansiedade, enfrentaram desafios como falta de capacitação e escassez de profissionais especializados, fragmentação do cuidado, fragilidade na articulação da Atenção Primária e especializada, e falta de estrutura e insumos.

Descritores: Enfermagem em Saúde Comunitária; Cuidados de Enfermagem; Saúde Mental; Transtorno do Espectro Autista; Relações Familiares

Resumen

Objetivo: comprender la percepción de los enfermeros sobre los desafíos experimentados en el cuidado de las familias de niños con trastorno del espectro autista en Atención Primaria. **Método:** investigación descriptiva de enfoque cualitativo, con la participación de nueve enfermeros que trabajan en unidades de Atención Primaria de Foz do Iguaçu, Paraná, Brasil. Se realizaron entrevistas y los datos fueron analizados mediante Análisis de Contenido en la vertiente Temática, en agosto y septiembre de 2023. **Resultados:** surgieron las categorías temáticas: La familia del niño con Trastorno del Espectro Autista en la percepción del enfermero; Desafíos del Sistema Único de Salud para la atención individualizada del niño con este trastorno; Importancia de la formación y capacitación profesional. **Conclusión:** en la percepción de los enfermeros, las familias experimentaron sentimientos de inseguridad, estrés y ansiedad, y enfrentaron desafíos como la falta de capacitación y escasez de profesionales especializados, fragmentación del cuidado, fragilidad en la articulación entre la Atención Primaria y especializada, y falta de estructura e insumos.

Descriptores: Enfermería en Salud Comunitaria; Atención de Enfermería; Salud Mental; Trastorno del Espectro Autista; Relaciones Familiares

Introduction

Over the years, the definition of autism has broadened, encompassing Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) under the term "Autism Spectrum Disorder" (ASD).[1] Individuals with this neurodivergence exhibit verbal and non-verbal language as means of communication in social interaction and show impairments in their ability to develop, maintain, and understand relationships. Additionally, repetitive behaviors and restricted patterns of interests and activities are present.[2]

In the last 50 years, there has been an increase in the number of ASD diagnoses worldwide.[3] In the United States, the Autism and Developmental Disabilities Monitoring (ADDM) Network tracks the prevalence of ASD in eight-year-old children using medical and educational records. In 2020, the average rate was 27.6 per 1,000 children, meaning 1 in 36 eight-year-olds was diagnosed with ASD, a figure 3.8 times higher in boys than in girls. These numbers vary by race, family income, and the average age at first diagnosis, with the median age being 49 months. Among these children, 38% are also identified with intellectual disabilities. These figures represent an increase from previous estimates.[4]

This increase may be related to greater awareness of the condition, implementation of diagnostic criteria, and improved reporting.[3] Consequently, it is crucial for healthcare professionals to possess the competencies and skills necessary to provide quality care to individuals with this disorder.[5]

Neurodevelopmental disorders can be classified as ASD, Attention Deficit/Hyperactivity Disorder (ADHD), motor disorders, among others. Neurological impairments include issues such as cerebral palsy, epilepsy, brain tumors, traumatic injuries, and more. Therefore, neurological disorders are considered primary causes of childhood morbidity among chronic diseases.[6]

The diagnosis of ASD is based on the criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V)[1] and is typically made in childhood when the manifestations of the spectrum can be identified through changes in cognitive functions. While ASD has no cure, behavioral interventions identified since the 1980s have shown to improve the development of diagnosed children, especially when combined with early detection.[7]

Collaborative action in Primary Care aims to achieve quality in service delivery within the support network involving patients, families, caregivers, and the community, and can be defined as service delivery based on multidisciplinary comprehensiveness.[8] Thus, the intervention plan for individuals with ASD should be interprofessional, encompassing various health and education professionals such as doctors, psychologists, nurses, nutritionists, social workers, and others to meet the unique needs of each individual. In this process, it is essential to consider the family a crucial element, as they can provide valuable information and set priorities related to the child's development.[9]

Generally, it is during early childhood that parents or guardians seek diagnosis and treatment. The lack of preparation, integration between professionals from different levels of care (primary and specialized), or management problems can contribute to impairing, delaying, or fragmenting the entire care process, as well as increasing the risk of causing emotional stress for the caregivers seeking care. Parents of individuals with ASD report experiencing overload, isolation, and rejection during the diagnosis and intervention process.[9]

The involvement of the family in promoting the mental health of children, including those with ASD, has received increasing attention in recent years. The role of the family is increasingly recognized as essential in the emotional and psychological development of children. The family is seen as a space where the construction of feelings and the expression of psychic challenges that affect all its members occur.[10]

Moreover, the approach to thematization in border regions is influenced by several factors, such as ethnic differences, access to health resources, the availability of qualified professionals, and public policies aimed at mental health. Given this context, it is important to consider the needs and challenges faced by the families of people with ASD, as each border region and community has its own unique characteristics to ensure comprehensive health actions.[11]

In this scenario, the interventions of nurses and other healthcare team members assist in supporting and adapting the families involved in this complex process. Family nursing identifies the harm that illness causes to families and analyzes their demands, needs, vulnerabilities, and suffering.[6,10]

With this understanding, this study aimed to understand the perception of nurses regarding the challenges experienced in caring for families of children with autism spectrum disorder in Primary Care.

Methods

This is a descriptive study with a qualitative approach. The Consolidated Criteria for Reporting Qualitative Research (COREQ) were used as a guide to refine the presentation of the report.[12]

The study setting included Primary Health Care (PHC) units in Foz do Iguaçu, Paraná (PR), a city in the tri-border area with Paraguay and Argentina, which has 33 health centers/basic units registered in the National Registry of Health Establishments.

These are organized into five health districts: North, Northeast, East, West or Central, and South. The study encompassed eight health units: three in the North district, one in the Northeast, one in the East, one in the West, and two in the South. The selection of units was based on the availability of nurses.

PHC performs a set of individual, family, and community health procedures involving promotion, prevention, reception, diagnosis, treatment, harm reduction, palliative care, and health surveillance. These practices are developed through integrated care and qualified management, carried out by a multidisciplinary team assigned to a population marked by territory, where these teams assume sanitary responsibility. Thus, it is considered the main entry point to the Unified Health System (SUS) and the integration center of the entire Health Care Network (HCN), guided by the principles of universality, accessibility, care, comprehensiveness, humanization, and equity.[13]

Data collection was carried out through interviews conducted by the principal researcher, using a semi-structured script, from August to September 2023, with nurses working in PHC. A software tool on a cell phone and a notebook was used to record and back up the interviews, with authorization for recording. The average duration of the interviews was 20 minutes, held in the PHC unit in a private location, with only the interviewer and interviewee present.

The instrument used in this research consisted of a characterization form for the individuals, in addition to the semi-structured interview script. The instrument underwent a pilot interview and did not require corrections, as indicated in the results. Participants signed the Informed Consent Form and the voice recording authorization form.

The identification form was organized with sociodemographic characterization variables: sex, age, date of birth, marital status, education, undergraduate degree, postgraduate degree, professional experience, duration of practice, and current workplace. The interview script included 11 questions in two sections: one for understanding the context and another for identifying the needs of professionals to assist families of children with ASD. The questions addressed the nurse's routine and their perception of the challenges experienced in their daily work with families of children with autism spectrum disorder.

The inclusion criteria for the participants were nurses working in PHC for more than six months at the health unit. Nurses on medical leave or vacation were included. The criterion to include nurses with more than six months of service was based on the relationship that the professional establishes with the user over time.

Nurses who met the inclusion criteria were contacted by phone and informed about the research objectives and data collection methods, allowing them to decide freely whether or not to participate. If they agreed, the interview was scheduled at a time and place chosen by the professional. This strategy aimed to reduce any discomfort for the nurses.

A total of nine nurses participated in the research. The interviews were stopped using the data saturation technique. This method allows identifying the need to include new participants or not. The sample was related to the guiding question and objective, articulating with the chosen and interviewed participants.

The interviewees were designated by the letter "N" for Nurse, followed by the numerical order of the interviews: N1, N2, N3, and so on.

The interview data were transcribed in full in a Microsoft Word document and subjected to Thematic Content Analysis.[14] This analysis aimed to show, through the participants' statements, their perceptions of the challenges experienced in caring for families of children with ASD in Primary Care in the municipality of Foz do Iguaçu, PR.

The data analysis involved several steps: pre-analysis, where the material was first organized through reading and then a precise reading to begin organizing the data; material exploration, where statements were highlighted, starting the categorization of the main ideas found, transforming raw data into excerpts; data processing and interpretation, separating by identified thematic categories, and later observing the agreement, solidity, and occurrence of any subcategory to construct an interpretive and coherent analysis.[14] These data are illustrated in Table 1. The theoretical foundation was based on the National Policy for the Protection of the Rights of Persons with ASD,[15] as well as the National Primary Care Policy.[13]

Table 1 - Example of the matrix used for analyzing empirical material

Theme	Meaning (core meaning)	Contextualization	Excerpts from the Statements
Importance of professional training and education	Lack of professional preparation	The professional reports that they do not have sufficient knowledge to guide parents and children with ASD	Personally, speaking for myself, I don't have enough knowledge to be guiding a mother and father who have an autistic child [...] (N4)

In accordance with Resolution No. 466, of December 2012, the research was approved by the Research Ethics Committee involving Human Subjects, under opinion No. 6.225.517 and CAAE No. 70722623.7.0000.8527, on August 8, 2023, ensuring confidentiality and anonymity to the participants.

Results

Nine nurses participated in the study, ranging in age from 27 to 52 years old, with eight women and one man. All had postgraduate degrees, with two specializing in ASD. The length of service at the unit varied from six months to 10 years. Data on the characteristics of the participants are presented in Table 2.

Table 2 - Characteristics of the nurses participating in the study. Foz do Iguaçu, Paraná, Brazil, 2023

Codename	Age (years)	Length of Service (years)	Postgraduate Degree	Specialization in ASD
E1	27	4	Yes	Yes
E2	42	10	Yes	No
E3	26	6 months	Yes	Yes
E4	33	6 months	Yes	No
E5	35	2	Yes	No
E6	52	2	Yes	No
E7	47	10	Yes	No
E8	27	2	Yes	No
E9	30	4	Yes	No

After the data analysis process, three thematic categories emerged regarding the nurses' perceptions of ASD: the family of the child with ASD in the nurse's perception; challenges of the SUS in providing individualized care for the child with ASD; and the importance of professional training and education.

The Family of the Child with ASD in the Nurse's Perception

Nurses perceived the families of children with ASD as lonely, with daily doubts and insecurities about their child's care. They also identified the absence of a support network that could welcome and support the families in their journey of caring for the child.

> *[...] she said: "my husband goes out, he doesn't talk, he doesn't speak to me at home, but he can still work." At least there is the income to help her take care of him [...] and the child [...]. (E6)*
> *[...] I think there also needs to be a support network for this family member [...]. (E7)*
> *Sometimes there is no family support [...]. E8)*

The experiences of family members or caregivers can create challenging situations in the care, diagnosis, and treatment of the child. These situations can trigger stress, anxiety, insecurity, changes in family routine, denial, anger, doubts, and anxieties within these families, as highlighted by the nurses' statements.

> *[...] I notice that the family has a lot of difficulty accepting and understanding when they get a diagnosis [...] it changes the parents' routine a lot. Until they can adapt to the child's routine or adapt the child's routine to theirs [...] I notice that they first experience denial [...]. (E5)*
>
> *The mother becomes anxious [...] mothers have many doubts. Especially when the diagnosis is recent, then I run after it, ask for help [...]. (E6)*
>
> *[...] generally what they mention is fatigue, stress, they request a referral to psychology [...] the main issue is the lack of knowledge about the disease [...] since it is very broad, people have a lot of difficulty [...]. (E8)*
>
> *[...] with the family member, it's a bit more difficult because of the issue of punishing the family member [...] not accepting the diagnosis [...]. (E9)*

This theme revealed that nurses recognize that the family of a child with ASD lacks a support network and experiences feelings of insecurity, stress, and anxiety.

Challenges of the SUS in Providing Individualized Care for the Child with ASD

This theme was identified through the analysis of core meanings, which highlighted the fragility in access to health services, the performance of the HCN in dealing with ASD, and the structure of PHC units.

According to the nurses, the families of children with ASD faced difficulties in accessing healthcare, as evidenced in the statements:

> *[...] They mostly have issues regarding access to services; it's a family that needs the SUS, they cannot afford private therapies [...]. (E1)*
>
> *[...] one difficulty we have in this neighborhood is that it is very far away, and the care for these children is provided at the Specialized Rehabilitation Center, which is on the other side of the city. The difficulty I notice for some parents is really, really related to logistics [...]. (E5)*
>
> *[...] they have difficulty with transportation sometimes to go to appointments, one said: "I'm not taking them because I can't afford it" [...]. (E6)*
>
> *[...] there is also a lack of accessibility [...] there needs to be a bit more decentralization of access [...]. (E9)*

Regarding the nurses' perception of the functioning of the HCN, they mentioned difficulties in organizing waiting lists and their progress in specialized services, the lack of a specific protocol, and a well-defined flow.

> *[...] therapy in the SUS is very slow, the waiting list is very slow, this is their biggest barrier [...] I think strengthening the specialized care service is really needed [...]. (E1)*
> *[...] when we refer this child, there is no flow [...] there are no schools that are also trained. So, is everything bad, is everything lacking for this child? (E3)*
> *The difficulty, the delay in being called from the waiting list, not just for this type of diagnosis, but for many other diseases [...]. (E4)*
> *Yes, there is a lack of a specific care protocol for people with autism [...]. (E9)*

The factors that weaken the reception and care of the family were also listed by the nurses and included workload, lack of time, inadequate physical structure, and lack of professional support for the care of these children.

> *[...] more structure is needed too because look at the room, it's completely neutral [...] it is not cozy or welcoming for the child [...] the biggest barrier is time, I can't spend more time or give more attention to this child [...] we have very little support from the service, if we have any doubts, there is no one to ask [...]. (E1)*
> *[...] a room specifically for children [...] some structure [...] something playful [...] the patients wait outside [...] I think there should also be support [...] we would need support from a social worker, for example [...]. (E7)*

The challenges of the SUS in providing individualized and humane care for children with ASD, from the nurses' perspective, were related to the structuring of the HCN in the municipality, which hinders access to specialized services, as well as the adequate structure in PHC units for individualized care, including working conditions.

Importance of professional training and education

The participants pointed out insecurity in managing individuals and family members as a result of the need for knowledge, given the lack of preparation to identify and characterize the disorder, approach and manage the family, clarify doubts, develop active listening, and offer support for their demands.

> *[...] we follow up in pediatric care, and the child is diagnosed [...] we already feel a bit lost [...], and now, how is pediatric care going to be [...]. (E3)*
> *Personally, speaking for myself, I don't have enough knowledge to guide a mother and father who have an autistic child [...]. (E4)*
> *[...] I know about it, but I don't know in-depth, I don't feel comfortable, prepared for a situation [...] here in our area, in our coverage area. There are some, you know? But as far as I remember, really remember, it's one child [...]. (E7)*

The lack of training, as well as the unavailability of specialists in the unit, was highlighted in the statements as a difficulty in attending to family members. In the professionals' perception, without the necessary knowledge, care became weakened because they did not feel qualified to meet the families' and patients' needs comprehensively.

> *[...] how are you going to handle this child [...] attend to them [...] if you don't have knowledge? [...] there are no trained professionals to attend to this child in both the basic and specialized [network] [...]. (E3)*
> *Because we really don't know [...] I also include myself in this because we don't know how to deal with it, what to do [...]. (E7)*
> *[...] there is a lack of professionals, specialists in adequate quantities [...]. (E9)*

The nurses recognize their weaknesses in attending to families and children with ASD and emphasize the importance of professional training to provide the necessary support and promote effective care.

Discussion

This study explored the perceptions of nurses regarding the challenges experienced in caring for families of children with ASD in PHC. The results highlighted perceptions about the family of the child with this disorder, the challenges of the SUS in providing individualized health care for these children, and the importance of professional training and education.

A weakened support network for these families was identified, a situation that negatively impacts the treatment and development of these children. When this network is fragile or even absent, the challenges faced by both the families and the nurses are concerning for health. Without it, families are subjected to misinformation, emotional and physical overload, social isolation, denial, among others, creating barriers that hinder the nurse's work process.[16-17]

It is the family's right to have access to information that aims to assist in the diagnosis and treatment of their children with ASD, as described in the National Policy for the Protection of the Rights of Persons with ASD, provided by Law No. 12.764, of 2012.15 Furthermore, Law No. 13.438/2017 included in the Statute of Children and Adolescents the obligation for the SUS to assess risks to the psychological development of children up to 18 months, using specific protocols in pediatric consultations. To this end, numerous follow-up consultations are recommended until the child is two years old, followed by annual consultations.[18-19]

The child's health booklet, used in pediatric consultations, is an important tool for monitoring and guiding child development, including risk prevention and health promotion. In the presence of any developmental risks, the child should be referred for evaluation and treatment by a multidisciplinary team, including referrals to specialized services.[20]

Particularly for individuals with ASD, Law No. 13.977, established in 2020, known as the Romeo Mion Law, marked a significant advancement through the creation of the Identification Card for Persons with ASD. This card ensures priority and specialized attention in public and private services, especially in health, education, and social assistance.[21] In 2023, Law No. 14.624 introduced the use of a sunflower lanyard to indicate individuals with invisible disabilities, expanding recognition and inclusion.[22]

Therefore, professionals from various fields need evidence-based knowledge to support families and enhance individualized care for the population with ASD. Families often deal with feelings of grief, sadness, and guilt that, combined with a lack of knowledge, can worsen the denial related to the diagnosis and delay the initiation of necessary stimulation for children with ASD, as shown by a review study conducted by researchers from the state of Santa Catarina, Brazil.[23]

The family environment is fundamental for the physical, psychosocial, and cognitive development of children with autism spectrum disorder, as it provides security and stability. Thus, the family is considered the first line of support and the most present throughout life. In this context, family members and caregivers play a crucial role for individuals who require care, being responsible for meeting fundamental needs, offering affection, providing emotional support, and promoting socio-cognitive and psychosocial skills. When the support network is solid, the family tends to feel more capable and resilient in assisting the child on this journey, minimizing developmental delays.[24]

Therefore, it is essential for nurses to identify and assess this support network for families, as the involvement of caregivers in the diagnostic and treatment process is crucial for promoting the child's healthy development. A study conducted in Campinas indicated that nurses can only develop a personalized therapeutic plan with knowledge and, from there, create a trusting relationship with family members, ensuring they have expanded access to professionals to ask questions and be understood about their lived experiences.[25]

After receiving the diagnosis of the disorder, family members may feel stressed, anxious, insecure, and have difficulty reorganizing routines, compounded by feelings of denial, anger, doubts, and concerns about the prognosis and treatment of their child, evidenced by emotional deprivation. Therefore, it is crucial that PHC professionals are trained and prepared to provide this support and know how to care comprehensively for people with ASD and their families.[23]

A study with families of patients with ASD from northeastern Brazil showed that nurses must pay attention to the care demands of the family, in addition to advising and providing support in a way that encourages and inspires confidence so that they can raise their autistic children as appropriately as possible.[26] To meet the needs of their children, parents and guardians should find support from Primary Care professionals.

Given this context, it is highlighted that the family of an individual diagnosed with ASD is at risk of having higher levels of stress, depression, and difficulties adapting to the new routine, as shown by a review conducted by researchers from the United Kingdom.[27] Another study from the city of Porto, Portugal, identified that this scenario makes the nurse's job even more challenging since such situations can influence interaction and care.[28] Feelings of guilt, stress, isolation, and denial can hinder the implementation of interventions proposed by nurses. Isolation can lead to a lack of information and increased stress, while denial can be one of the biggest challenges for nurses, as not recognizing the diagnosis prevents timely interventions from being offered.[17]

ASD is not a disease but a condition; there is no cure, but many early interventions can improve a person's quality of life and reduce their level of support needed throughout life. This highlights the importance of interaction between healthcare professionals, patients, and families, based on humanization and empathy.[28]

Regarding the challenges of the SUS in caring for children with ASD, the following were listed: fragility in accessing health services, structural difficulties, and issues with the flow and protocols of primary and specialized care. This scenario highlights the difficulty in practically implementing policies related to individuals with ASD.[15] The lack of integration in the PHC network hinders family access and reveals deficiencies in the referral and counter-referral system. This situation contradicts clause III of Article 3 of Law No. 12.764, of 2012, which emphasizes the importance of ensuring access to health practices, comprehensively addressing health needs.[13]

Despite advances in integrating people with autism into society, it is still necessary to consider that this population is subject to various prejudices due to a lack of information and the characteristics of the disorder. Other challenges remain, such as difficulties in diagnosis, inadequate spaces for accessing people with autism, a shortage of trained professionals, a reduced number of technologies, and a lack of physical infrastructure, as shown by a study conducted by Indian researchers.[29] Consequently, both families and individuals with ASD face obstacles in obtaining access and treatment, highlighting the urgency of increasing awareness on the subject. This not only drives a change in attitudes toward disability but also ensures the dissemination of knowledge to challenge and overcome existing paradigms.[30]

Regarding competence and specialization in the subject, along with the need to ensure an adequate number of professionals in the network, these are crucial for promoting an appropriate approach and correct management of patients. The lack of knowledge directly impacts the confidence and preparedness of these professionals to provide individualized care. It became evident, in the perception of the professionals, their insecurity in providing healthcare to families and their children with ASD.

The lack of knowledge and experience among nursing professionals results in fragile care for children with ASD. This leads to the absence of specific follow-up to understand the signs of ASD through the comprehension of human behavior. However, it was observed that nurses understand and acknowledge the need for improvement but perceive a lack of structure and support from academic training, resulting in professionals with knowledge gaps in providing specialized care and continued assistance. There is no shortage of specific care protocols for people with autism; what is lacking is the training, updating, and ongoing education of health teams.

To support the family throughout this process, it is essential for professionals to undergo training and development to enhance their professional competence. Additionally, it is crucial to consider each child with ASD according to their unique characteristics, requiring continuous and long-term training.[23] In this context, the nurse's role as a team leader is highlighted, promoting ongoing education and their role in matrix support within the HCN.

In the scope of PHC actions, it is necessary to emphasize the role of family health teams in preventing and supporting the child and their family, with attention to the weaknesses in diagnosing and ensuring individualized care at this level of health attention so they are not merely referred to another specialized unit. Primary Care needs to practically transform this reality, which is often only described in policies and protocols.

The limitation of the study was related to the focus on a single category of professionals, considering that the care of families and children with ASD requires a multidisciplinary approach, making it necessary to expand to other specialties within PHC.

Nonetheless, the study demonstrates to nurses the importance of family-centered care and its contributions to the management and best practices for treating individuals with ASD. Another point of emphasis was the importance of including the topic in the training of professionals across various health fields.

Conclusion

This study aimed to understand and explore the perception of nurses regarding the challenges in caring for families of children with ASD in PHC. The care was perceived as insecure, fragmented, and facing challenges in fully implementing the National Policy for the Protection of the Rights of Persons with ASD.

The main difficulties identified were centered on the lack of training, fragmentation of care, shortage of specialized professionals, weak coordination between Primary and Specialized Care, and lack of structure and supplies. It is important to emphasize the need for training, the adjustment of workflows, and specific protocols for each municipality, considering their different realities, demands, and challenges.

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