

Practice and Knowledge of the Nursing Team in Primary Care Regarding Autism Spectrum Disorder: A Qualitative Study

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Theme: Health promotion, well-being, and quality of life

Contribution to the field: This qualitative research is related to the promotion of health, well-being, and quality of life. It identifies gaps in the knowledge and practice of Primary Health Care nurses regarding autism spectrum disorder (ASD) and highlights the importance of continued education to improve comprehensive care. Grounded in the holistic care model, the study shows how continuous training can strengthen the work of nurses, promoting the health, well-being, and quality of life of individuals with ASD. This approach reinforces the role of nurses as transformation agents in promoting care that is more inclusive and sensitive to patients' specific needs.

Abstract

Introduction: The growing prevalence of autism spectrum disorder (ASD) and the complexity of the care required make the knowledge of Primary Health Care (PHC) nurses crucial to the quality of care provided. **Objective:** To understand the practice and knowledge of PHC nurses regarding ASD in Pau dos Ferros, Rio Grande do Norte, Brazil. **Materials and Methods:** This was a descriptive-exploratory, qualitative study with nine nurses selected according to inclusion criteria (those with a civil service or public contract and more than one year of experience) and exclusion criteria (those on leave or vacation). Data was collected through semi-structured interviews and analyzed using the thematic content analysis technique. **Results:** Four thematic categories emerged: 1) Professional perception: PHC nurses' knowledge repertoire regarding ASD; 2) Nurses' role in providing care to people with ASD; 3) Potentialities and challenges of holistic care in PHC for ASD; 4) Continuing education as a strategy for strengthening care. **Conclusion:** The study revealed significant gaps in the knowledge and practice of PHC nurses regarding ASD, highlighting the need for continuous and specific training. The lack of training limits adequate care, particularly in the early detection and management of complex cases. The study suggests that future research should delve deeper into these issues, broadening perspectives that ensure improvements in clinical practices and the promotion of health, well-being, and quality of life.

Keywords (Source: DeCS)

Autism spectrum disorder; nursing; primary health care; qualitative research.

4 Práctica y conocimientos del personal de enfermería de atención primaria sobre el trastorno del espectro autista: un estudio cualitativo

Resumen

Introducción: la creciente prevalencia del trastorno del espectro autista (TEA) y la complejidad de los cuidados requeridos hacen que el conocimiento de las enfermeras de Atención Primaria de Salud (APS) sea crucial para la calidad de la atención prestada. **Objetivo:** comprender la práctica y el conocimiento de los enfermeros de APS de Pau dos Ferros, Rio Grande do Norte, Brasil, sobre el TEA. **Materiales y métodos:** estudio descriptivo-exploratorio, cualitativo, con nueve enfermeros seleccionados según criterios de inclusión (servidores públicos o con contrato público y más de un año de experiencia) y exclusión (en licencia o vacaciones). Los datos se recogieron mediante entrevistas semiestructuradas y se analizaron mediante la técnica de análisis de contenido temático. **Resultados:** surgieron cuatro categorías temáticas: 1) Percepción profesional: repertorio de conocimientos de los enfermeros de APS sobre el TEA; 2) Papel de los enfermeros en la atención a las personas con TEA; 3) Potencialidades y desafíos de la atención holística en APS para el TEA; 4) Formación continuada como estrategia para el fortalecimiento de la atención. **Conclusión:** el estudio reveló vacíos significativos en el conocimiento y la práctica de los enfermeros de APS sobre el TEA, destacando la necesidad de formación continua y específica. La falta de capacitación limita la atención adecuada, particularmente en la detección temprana y el manejo de casos complejos. El estudio sugiere futuras investigaciones que profundicen en estas cuestiones, ampliando perspectivas que garanticen mejoras en las prácticas clínicas y en la promoción de la salud, el bienestar y la calidad de vida.

Palabras clave (Fuente: DeCS)

Trastorno del espectro autista; enfermería; Atención Primaria de Salud; investigación cualitativa.

Prática e conhecimento da equipe de enfermagem na atenção primária sobre o transtorno do espectro autista: estudo qualitativo

Resumo

Introdução: A crescente prevalência do transtorno do espectro autista (TEA) e a complexidade dos cuidados necessários tornam o conhecimento dos enfermeiros da Atenção Primária à Saúde (APS) crucial para a qualidade da assistência prestada. **Objetivo:** compreender a prática e o conhecimento dos enfermeiros da APS de Pau dos Ferros, Rio Grande do Norte, Brasil, sobre o TEA. **Materiais e métodos:** estudo descritivo-exploratório, qualitativo, com nove enfermeiros selecionados por critérios de inclusão (concursados ou com contrato público e mais de um ano de experiência) e exclusão (em licença ou férias). A coleta de dados ocorreu por meio de entrevistas semiestruturadas, e a análise foi realizada com base na técnica de análise de conteúdo temática. **Resultados:** quatro categorias temáticas emergiram: 1) Percepção profissional: o repertório de conhecimento dos enfermeiros da APS sobre o TEA; 2) Atuação dos enfermeiros na assistência à pessoa com TEA; 3) Potencialidades e desafios do cuidado holístico na APS ao TEA; 4) Educação permanente como estratégia de fortalecimento do cuidado. **Conclusão:** O estudo revelou lacunas significativas no conhecimento e na prática dos enfermeiros da APS sobre o TEA, destacando a necessidade de formação contínua e específica. A falta de capacitação limita a assistência adequada, particularmente na detecção precoce e no manejo de casos complexos. O estudo sugere futuras pesquisas que aprofundem essas questões, ampliando perspectivas que garantam melhorias nas práticas clínicas e na promoção da saúde, do bem-estar e da qualidade de vida.

Palavras-chave (Fonte DeCS)

Transtorno do espectro autista; enfermagem; Atenção Primária à Saúde; pesquisa qualitativa.

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by deficits in communication, difficulties in social interaction, and restrictive and repetitive behaviors, which affect various domains of an individual's life, from the personal to the professional sphere (1).

Its complexity, variation in clinical manifestations, and lack of concrete causality place ASD as one of the greatest challenges in health care. Although there is consensus that ASD has a strong genetic basis, several of the genes associated with the disorder are still not fully understood. Environmental factors, such as complications during pregnancy, exposure to pollutants, and advanced parental age, are also considered significant contributors (2, 3).

In addition, studies show the prevalence of autism is increasing worldwide. The US Centers for Disease Control and Prevention reported in 2023 that the prevalence would be 27.6 per 1,000 children up to the age of eight, compared to 14.5 per 1,000 in 2012 (4). In Brazil, estimates based on these data suggest that approximately 6 million Brazilians live with ASD; however, concrete national epidemiological studies are lacking (1).

Recent studies link the high prevalence to early detection that, combined with adequate ASD management, has the potential to promote advances in social and cognitive development. They therefore emphasize that the implementation of universal developmental surveillance is regarded as a crucial strategy for improving long-term outcomes (5, 6).

Thus, in the nursing setting, the approach to patients with ASD implies humanized and comprehensive care, which requires a holistic and multidimensional approach to individuals. In this way, good care practices, along with the search for scientific knowledge, are a vital avenue for supporting these people (7).

However, international studies show that many nursing professionals are not adequately prepared to deal with autistic individuals, often relying on stereotypes or outdated information, which is reflected in less effective care and difficulty in implementing care strategies (8, 9).

Therefore, the central question of this study is: How does the practice and knowledge of Primary Health Care (PHC) nurses regarding ASD occur? To answer the question, this study sought to understand the practice and knowledge of these professionals, identifying their perceptions, strengths, and difficulties in managing patients with ASD and analyzing how these factors influence their clinical practices.

Materials and Methods

This is descriptive-exploratory, qualitative research, a method based on a universe of concepts, motives, beliefs, values, and attitudes that justify the products of human interpretations. Thus, it is an instrument that allows for a better understanding of behavioral phenomena according to the meanings that individuals assign to them (10, 11). This study was written following the guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ) to ensure greater rigor, reliability, and transparency in the presentation of the study (12, 13).

The setting for this research consisted of 12 PHC healthcare units in the city of Pau dos Ferros, Rio Grande do Norte, Brazil, between May and June 2023. The target population consisted of 18 nurses working in this municipality and sector, selected using the following inclusion criteria: Being a nurse with a public career or by public selection in PHC, with at least one year of experience. With this, we aimed to ensure that the professionals were familiar with local practices and approached the theme of the study. As exclusion criteria, the study did not include professionals on vacation or leave.

The approach method consisted of contacting the participants by telephone. However, due to the low response rate, an active search was conducted directly at the PHC units. During these visits, the objectives of the research were presented and, after acceptance, data collection started, with the date, location, and time set by the participants themselves. Only nine nurses agreed to participate in the study and nine withdrew.

Data collection started with the presentation of an informed consent form, voluntarily signed by the participants. Semi-structured interviews were then conducted. The script for these interviews was drafted based on the researchers' previous experiences and specialized literature and consisted of four sections: Identification (sex, race/color, place of birth), academic background, professional data, and 10 open questions to explore the nurses' practices and knowledge of ASD.

The sections were organized into three axes: Experiences of living with people with ASD, stock of available knowledge pertaining to the disorder, face-to-face relationships, and care actions. The first axis of questions covered the participants' proximity to autistic individuals; the second explored previous knowledge of ASD, including its conception, recognition of symptoms, and origin of information; and the third addressed professional practice in care, as well as challenges and suggestions for improving care. A total of nine interviews were conducted in the healthcare units, in a private room selected by the participant, so that there were no other subjects except the participant and the main researcher,

an undergraduate nursing student, who had previous training and experience in this type of data collection as a result of the activities of the research group.

With a mean duration of 10 minutes, the interviews were individually audio-recorded and then transcribed in full for data analysis. The data was then stored. The length of the interviews resulted from the fact that the professionals were not quite knowledgeable on the subject, which hindered their responses and the interview follow-up.

Of the 18 initial participants, nine withdrew from the study despite being contacted by telephone and in person for clarification. The research therefore proceeded with the remaining nine, enabling the completion of data collection. The interviews revealed themes consistently repeated, reflecting the limitation of practices and knowledge among participants. This pattern signaled a point of theoretical saturation, where no new information relevant to the categories of analysis emerged. During transcription, the absence of new findings that could contribute to the research objectives was confirmed.

The data was analyzed using the thematic content analysis technique (11), developed in four phases. In the pre-analysis phase, a preliminary reading was conducted to obtain an overview of the data and identify the seven initial themes. Then, in the content exploration phase, multiple cycles of in-depth reading were conducted to understand and identify the units of meaning and start organizing the thematic categories. The phase of result treatment, inference, and interpretation consisted of analyzing and categorizing the participants' statements, with the aim of identifying recurring patterns and structuring the information into analytical categories that reflected the main conceptions emerging from the research corpus. In this process, 54 statements were examined, from which the central themes were extracted, leading to four final categories. Finally, in the data discussion stage, the findings were contrasted and articulated with current scientific literature, providing a more comprehensive and contextualized understanding of the findings and their relevance to the field of study.

The study complied with resolutions 466 and 510 of the National Health Council. To ensure anonymity, codes were assigned to each participant, using the term "Nurse", followed by a letter of the alphabet (A, B, C, and so on), such as "Nurse A". The procedures for conducting the research were approved by the Research Ethics Committee of the Universidade do Estado do Rio Grande do Norte on March 28, 2023.

Results

Nine nurses participated in the study, representing 50% of the professionals working in the municipality. The sample included nurses aged between 25 and 48, with 77.8% of them being women.

Regarding academic training, all of them graduated after the year 2000, with 55.5% having graduated in the 2010s. Most of them (77.8%) graduated from universities in Rio Grande do Norte, and 88.9% have specializations in various nursing fields. In terms of employment, 55.5% of the nurses have permanent contracts, while 44.4% have temporary contracts.

The analyzed data enabled the delimitation of four thematic categories: 1) Professional perception: PHC nurses' repertoire of knowledge on ASD; 2) The role of nursing professionals in PHC to provide care to people with ASD; 3) The potential and challenges of holistic care in the practice of care for ASD; and 4) Continuous education as a strategy to strengthen care.

Category 1: Professional perception - PHC nurses' repertoire of knowledge on ASD

The analysis results revealed significant gaps in PHC nurses' knowledge of ASD, showing inaccurate conceptions based on stigmas. Most nurses found it difficult to clearly define ASD, limiting themselves to simplistic descriptions that associate the condition with neurological or behavioral deficits. The following statements illustrate these limited perceptions:

"I see it as a mental and psychological disorder, a matter of attention and today it is very clear." (Nurse A)

"I believe it is a neurological deficit linked to psychomotor issues." (Nurse D)

In addition, most nurses had never had the "autism" theme covered during their academic training, with only 11% reporting some specific instruction on ASD. This lack of training is reflected in the insecurity of professionals when dealing with symptoms, leading to uncertainty in identifying early signs and differentiating ASD from other disorders, such as ADHD:

"I admit that I still do not have the clinical eye to raise a hypothesis, I need to delve deeper." (Nurse A)

"No, I do not feel prepared. I hear a lot of things, but I do not really look into it. Some signs are non-specific, and during screening, it is difficult to define whether it is ASD or another disorder." (Nurse G)

This lack of clarity can lead to inaccurate diagnoses and contribute to the perpetuation of stigmas, as evidenced by the observation of behaviors that are mistakenly interpreted as indicative of ASD, reinforcing prejudice and inadequate care practices:

"He walks on tiptoe, but he talks, he pays attention [...] he does not focus, he does not sit, he does not stay on my lap." (Nurse A)

"Limited interaction, repetitive and stereotyped movements, food selectivity." (Nurse H)

Category 2: The role of nursing professionals in PHC care provided to people with ASD

Nurses recognize their key role in the early detection of signs of ASD, especially during growth and development (G&D) consultations. The practices reported show that although there is awareness of the importance of early monitoring, interventions are still fragmented and often limited due to a lack of specific training. Examples include:

“A well-performed G&D, monitored from birth to 2 years of age, is very effective because, if the nurse has a clear understanding of the developmental milestones, they can assume the diagnosis beforehand and take this approach with the parents.” (Nurse F)

“During the appointment, I noticed that the child had no interaction, no eye contact, and no response to commands.” (Nurse H)

Despite the identification of the need for a multidisciplinary approach, there is still a reduced perspective on the scope of care, with several professionals focusing their efforts only on initial identification, without moving towards effective and continuous coordination of care:

“In care, there should be a full examination and, once a diagnosis has been reached, we need to take different approaches, not to close off the diagnosis, but to induce suspicion so that the multi-professional team can refer and support us.” (Nurse H)

“The care must be greater and even more comprehensive so that the professional understands how that person perceives the world.” (Nurse E)

There is an awareness that care should be differentiated and humanized, but this approach still faces barriers, such as the lack of continuous training and the absence of a structured care model that integrates all levels of care.

Category 3: Potentialities and challenges of holistic care in ASD care practice

The complexity of holistic care for people with ASD is heightened by the difficulties of family acceptance and resistance to treatment, often witnessed in PHC settings. The nurses' statements highlight the challenges of working with families who find it difficult to accept the diagnosis and who often view ASD with prejudice, hindering treatment adherence and clinical management:

“The greatest challenge lies in parents' adherence to treatment, precisely due to concepts of ‘disease’, ‘comorbidity’, ‘problem child’, and there is this resistance to therapy adherence.” (Nurse F)

“At first, I believe that the greatest challenge is the follow-up because some parents come in already reporting, but they do not quite accept the child's condition.” (Nurse D)

The nurses also report challenges in implementing a humanized approach that goes beyond technical care, requiring emotional and

interpersonal skills that are not widely developed during basic nursing training:

“It is a task that requires specific skills and competencies to perform as a result of the complexity and individual aspects of each family living with this disorder, which implies the safety of professionals in performing it.” (Nurse C)

Category 4: Permanent education as a strategy for strengthening care

Permanent education emerged as a crucial strategy for strengthening the care provided to patients with ASD in PHC. Nurses pointed to the lack of specific training as a significant barrier to effective practice and suggested the need for continuous training and encouragement from public policies to integrate ASD more consistently into PHC:

“It is necessary to train the professionals who currently work in healthcare, as this is a disorder that is becoming increasingly more common.” (Nurse A)

“Perhaps the dissemination of resources covering the disorder for reading and the municipalities providing permanent continuing education for these professionals.” (Nurse B)

“Training for all FHS [Family Health Strategy] professionals, so that the clinical perspective on traits becomes more comprehensive.” (Nurse I)

The professionals displayed an awareness that continuing education must encompass the entire multi-professional team, promoting a collaborative and integrative approach that is capable of responding adequately and inclusively to the needs of people with ASD.

Discussion

The results of this study reveal significant gaps in knowledge, especially in terms of definition, symptoms, diagnosis, and approach, as well as in the practice of PHC nurses regarding ASD, which has a direct impact on the quality of care provided. The role of nurses in this context, characterized by a comprehensive approach, which is centered on humanized care, is essential for health promotion and for the continuous follow-up of people with autism (14).

As was evidenced, the lack of in-depth knowledge regarding ASD, combined with the superficiality of nurses' conceptions of the disorder, limits their ability to intervene early and adequately. Years later, other Brazilian studies showed that although nursing professionals recognize the behavioral aspects of ASD, their knowledge of it is incomplete and fragmented (15, 16). This lack of training compromises the effectiveness of PHC, which has the duty to perform an essential role in the early detection and initial management of autistic people (17).

Another key point identified was the scant coverage of the disorder in the curricula of nursing courses, which hinders professionals from feeling prepared to meet the growing demand from patients with this condition. The literature highlights that several nursing professionals lack formal training on autism, which is crucial for improving the care and experience of these patients in the healthcare system (18, 19).

In this context, it is emphasized that inadequate academic training, combined with a lack of targeted clinical experiences, significantly compromises nurses' ability to perform their practice safely and autonomously, resulting in a lack of development of essential competencies for professional practice, affecting both confidence in clinical judgment and effectiveness in implementing adequate interventions (20).

Therefore, it is imperative that nursing training incorporates theoretical and practical approaches to autism since the limited exposure to real clinical scenarios during nurses' training significantly reduces their confidence and competence in making critical decisions and implementing adequate interventions in the management of ASD (21).

Since clinical competence is intrinsically related to exposure to practical scenarios during training, the lack of consistency in how competencies are assessed globally contributes to a significant gap between academic training and the demands of clinical practice, especially in the care of specific populations (22).

Nursing practice, as a science, requires a robust and updated theoretical basis, which is essential if the interventions performed by nurses are to be effective and based on scientific evidence. In the context of ASD, this need is heightened due to the wide variability of clinical manifestations and the impact these differences can have on patients' development and quality of life (21, 23).

Therefore, reflective approaches in nursing practice, especially in mental health care, allow professionals to apply theories in a practical and contextualized way, improving the quality of care provided and the outcomes for patients (25).

Early diagnosis and timely intervention are key to optimizing the social and cognitive development of children with ASD, leading to better outcomes in adulthood. However, the results of this study indicate that although nurses are aware of the importance of G&D appointments, they do not fully understand their responsibility in the process of early diagnosis of ASD (24).

Furthermore, the testimonies analyzed show that, although the questions addressed ASD comprehensively, the participants' reports were mostly focused on childhood. This suggests a limitation in the perception of professionals, who tend to restrict their experi-

ences and knowledge of the disorder to just this stage of development, ignoring the needs of autistic adolescents and adults.

Such a narrow focus can compromise the continuity of care, contrary to the guidelines of the *Diagnostic and Statistical Manual of Mental Disorders* 5 (26), which emphasizes not only the importance of early diagnosis but also the need for continuous monitoring throughout the life cycle, since the needs of individuals with ASD change significantly, especially in the transitions to adolescence and adulthood.

Recent studies highlight the importance of a comprehensive approach to providing care for individuals with ASD, especially to prevent the exacerbation of conditions such as anxiety and depression. A study published in *Psychological Medicine* revealed that adults with this condition, when they do not receive adequate support for comorbidities such as anxiety disorders and depression, tend to experience a significant worsening in their quality of life (27).

From this perspective, permanent education, highlighted by the participants as a pressing need, emerges as a key strategy for training nurses to address the complexity of ASD in PHC. Continuing education programs that include specific training on ASD are essential for developing interpersonal skills that improve communication with autistic patients and their families, recognizing that understanding behavioral and emotional nuances can contribute to more effective care (28, 29).

However, it should be noted that the need for training and continuing education may differ between newly qualified professionals and those with more experience. Therefore, these programs should be structured with each learning profile in mind, guaranteeing the scope and relevance of the training for each reality.

The results also highlighted the resistance of families towards diagnosis and treatment, identified by nurses as a significant obstacle to practice. The literature suggests that adequate communication between healthcare professionals and families can improve treatment adherence and reduce the emotional burden on caregivers (30).

In this sense, empathetic communication can improve patient and family satisfaction, increase treatment adherence, and reduce anxiety. Nurses who are able to perform active and empathetic listening contribute to patient and family satisfaction, leading to greater trust in the healthcare team and better adherence to the care plan, which is particularly relevant in complex settings, such as the treatment of chronic or long-term conditions (31).

Thus, this study stands out by addressing the practice and knowledge of nurses in PHC, exploring not only the identification of

early signs, but also the challenges of holistic care, professional perception of the disorder, and barriers to permanent education. It therefore complements the existing literature (32, 33) by highlighting how training gaps impact care and what the specific demands of nurses in PHC are, contributing to the improvement of educational strategies and professional training policies focusing on ASD.

Future research could expand this discussion by comparing varying regional contexts and researching the effectiveness of training programs segmented according to the time of experience of professionals.

This study has some limitations that should be considered. The small sample size, restricted to a single region of Brazil, may limit the generalizability of the findings to other PHC realities. In addition, socio-economic and structural factors can influence the knowledge and practice of nurses in various contexts, which suggests the need for research with larger samples distributed across different regions of the country. Despite this, qualitative research is important as it can transfer the knowledge presented from a local context to similar contexts and even to global reflections.

Future research could also expand the analysis to other Latin American countries, which would allow comparisons between healthcare systems and strengthen the understanding of the demands on the education and training of professionals in the care of people with ASD.

Conclusions

As a qualitative and exploratory research, the study provides initial findings on the gaps in knowledge and practice among PHC nurses regarding ASD, highlighting the importance of continuous training for more inclusive and informed practices. It was found that the lack of permanent education and specific training limits the performance of these professionals in providing care to people with ASD, hindering early identification and adequate management of the demands of this population.

Therefore, the findings of this study highlight the need for further research into the continuing education and nursing practice of professionals providing care to people with ASD. Future studies could provide a more robust basis for the implementation of improved clinical practices, contributing directly to the promotion of health, well-being, and quality of life, as well as strengthening PHC and nursing as transforming agents in the construction of a more inclusive healthcare system that is sensitive to the specific needs of this population.

Furthermore, to deepen the knowledge of the training needs and care strategies for people with ASD in PHC, it is suggested that

additional studies should be conducted that explore other perspectives and contexts that can provide important support for broader and more targeted care practices.

Conflicts of interest: none declared.

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