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**COORDINATION OF CARE FOR CHILDREN WITH AUTISM IN PRIMARY CARE: PERCEPTIONS OF
FAMILIES AND PROFESSIONALS**

**COORDENAÇÃO DO CUIDADO DE CRIANÇAS COM AUTISMO NA ATENÇÃO BÁSICA: PERCEPÇÕES
DE FAMÍLIAS E PROFISSIONAIS**

**COORDINACIÓN DEL CUIDADO AL NIÑO CON AUTISMO EN LA ATENCIÓN PRIMARIA:
PERCEPCIONES DE FAMILIAS Y PROFESIONALES**

CRedit

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ABSTRACT

This article presents considerations about the processes of coordinating care for children with Autism Spectrum Disorder (ASD) in the municipality of Barão de Cocais, Minas Gerais, Brazil. ASD is a neurodevelopmental disorder characterized by impaired socialization that may present restricted or repetitive interests and activities, which affects 1 in 36 children worldwide. The objective was to identify the perceptions, needs and demands of actors involved in coordinating the care of children with ASD in the municipality of Barão de Cocais-MG. This is a qualitative research carried out between March and October 2024, which used as instruments focus groups and semi-structured interviews with health professionals and families. As a result, participants pointed out a lack of knowledge and skills necessary to deal with these patients and their families, a lack of theoretical references, inadequate referral and counter-referral flows, an absence of programmatic follow-up actions for children and their families, and precariousness in the care structure. The identified deficiencies hinder co-participation in the coordination of care by professionals and distance families from Primary Care.

KEYWORDS: Autism Spectrum Disorder; Primary Care; Organizational Capacity.

RESUMO

Este artigo traz considerações sobre os processos de coordenação do cuidado das crianças com Transtorno do Espectro do Autismo (TEA) no município de Barão de Cocais, Minas Gerais. O TEA é um transtorno do neurodesenvolvimento caracterizado por comprometimento na socialização, podendo apresentar interesses e atividades restritos ou repetitivos, que afeta 1 a cada 36 crianças mundialmente. Traçou-se como objetivo identificar as percepções, necessidades e demandas dos atores envolvidos na coordenação do cuidado de crianças com TEA no município de Barão de Cocais-MG. Trata-se de uma pesquisa qualitativa desenvolvida entre março e outubro de 2024, que usou como instrumentos o grupo focal e a entrevista semiestruturada com profissionais da saúde e familiares. Como resultados, os participantes apontaram falta de conhecimento e habilidades necessárias para lidar com esses pacientes e suas famílias, escassez de referências teóricas, fluxos de referência e contrarreferência inadequados, ausência de ações programáticas de acompanhamento para as crianças e suas famílias, e precariedade na estrutura assistencial. As deficiências identificadas obstaculizam a coparticipação na coordenação do cuidado pelos profissionais e distanciam as famílias da Atenção Básica.

DESCRITORES: Transtorno do Espectro do Autismo; Atenção Básica; Capacidade Organizacional.

RESUMEN

Este trabajo trae consideraciones sobre los procesos de coordinación de la atención a niños con Trastorno del Espectro Autista (TEA) en el municipio de Barão de Cocais, Minas Gerais, Brasil. El TEA es un trastorno del desarrollo neurológico caracterizado por una socialización deteriorada, que puede presentar intereses y actividades restringidos o repetitivos y que afecta a 1 de cada 36 niños a nivel mundial. El objetivo fue identificar las percepciones, necesidades y demandas de los actores involucrados en la coordinación de la atención a niños con TEA en el municipio de Barão de Cocais-MG. Se trata de una investigación cualitativa realizada entre marzo y octubre de 2024, que utilizó como instrumentos grupos focales y entrevistas semiestructuradas con profesionales de la salud y familias. Como resultado, los participantes señalaron falta de conocimientos y habilidades necesarias para tratar con estos pacientes y sus familias, falta de referentes teóricos, flujos inadecuados de referencia y contrarreferencia, ausencia de acciones programáticas de seguimiento para los niños y sus familias, y precariedad en la estructura de cuidados. Las deficiencias identificadas dificultan la coparticipación en la coordinación de los cuidados por parte de los profesionales y alejan a las familias de la Atención Primaria.

DESCRIPTORES: Trastorno del Espectro Autista; Atención Primaria; Capacidad Organizacional.

1 INTRODUCTION

According to the Pan American Health Organization (PAHO)⁽¹⁾, Autism Spectrum Disorder (ASD) begins in childhood and follows the individual for the rest of their life. It is characterized by impairment in socialization, especially in communication and language, and may present restricted or repetitive interests and activities. New statistics released in April 2025 by the Centers for Disease Control and Prevention (CDC) of the United States of America (USA) government showed that the prevalence of ASD increased from 1 in 166 children in 2004 to 1 in 68 children during the 2010-2012 biennium, and then to 1 in 59 children in 2014. Finally, data published in March 2023 indicate that the prevalence reached 1 in 36 children in 2020 and 1 in 31 children in 2022⁽²⁾.

We must consider that Primary Care (PC) is co-responsible for the care of these children and supports the health process with the family. The family unit plays the primary role of coordinating and managing health-disease processes, promoting care adapted to the uniqueness and specificities of children with ASD, including their life history and support networks. Contact between professionals and patients must be constant and based on a horizontal approach and the democratization of decisions throughout the care process, fostering quality service delivery, valuing popular knowledge in healthcare, and reducing barriers to access.

Within this context, the present research chose the municipality of Barão de Cocais, Minas Gerais (MG) as its investigation territory. Located in the center of Estrada Real, it is 93 kilometers away from Belo Horizonte, with an estimated population of 33,232 inhabitants, according to IBGE (2021)⁽³⁾. Information provided by the Primary Care Coordination (AB) indicated that in 2022, there were 101 children in the municipality with a confirmed diagnosis of ASD, representing 1.59% of the child population. The care network for children with ASD includes a psychiatrist, two pediatricians, an occupational therapist, two speech therapists, a psychoanalyst, a nutritionist, and two physical therapists. When necessary, patients are referred for evaluation and treatment in another municipality, usually Itabira or Belo Horizonte. However, certain situations act as barriers to care coordination and create characteristics of a fragmented healthcare system, exacerbated by the recent healthcare outsourcing policy implemented by the public administration since 2018.

Thus, the objective of this research was to identify the perceptions, needs and demands of the actors involved in coordinating the care of children with ASD in the municipality of Barão de Cocais-MG.

2 THEORETICAL FRAMEWORK

Currently, ASD is primarily defined by the International Classification of Diseases and Related Health Problems (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM), created in 1952 by the American Psychiatric Association and which has become the standard for diagnosis and treatment of mental

health. Although there are differences between classifications, ASD is generally characterized by significant impairment in three main areas: language and communication, social interaction, and repetitive behavior patterns, which may include restricted interests. ASD is classified into different levels of support (Levels 1, 2, and 3), which can vary over time depending on the degree of support the individual requires to perform daily activities⁽⁴⁾.

According to a publication in the Official Gazette of the Union⁽⁵⁾, since 2012, in Brazil, people with ASD ARE considered people with disabilities, for all legal purposes, through Law No. 12,764, of December 27, 2012, when the National Policy for the Protection of the Rights of People with ASD was established. The law also highlights the guarantee of the rights to quality of life, with the maintenance of physical and moral integrity, safety, leisure and access to health actions and services that fully meet their needs, such as early diagnosis, even if not conclusive, multidisciplinary care, nutritional therapy and medication⁽⁵⁾.

Because it is a chronic condition for which there is no cure, individuals with ASD require long-term monitoring. Children and their families require multidisciplinary intervention to minimize deficits (social communication and restricted and repetitive behaviors), provide greater functional independence by facilitating learning and adaptive skills, and reduce, eliminate, or prevent behavioral problems that hinder their functional abilities. The necessary support should be provided at various levels of care, and PA is expected to be the first point of contact⁽⁶⁾.

In this sense, PC is understood as a set of individual, family, and collective health actions that involve promotion, prevention, protection, diagnosis, treatment, rehabilitation, harm reduction, palliative care, and health surveillance. Therefore, PC should be the primary entry point for patients with ASD and their families, as it is the place where care and monitoring are carried out from birth and the ideal space to identify possible delays in child development, which indicate and guide early diagnosis and referral to other points in the Health Care Networks (HCN)⁽⁷⁾.

Care coordination is one of the attributes of primary care, which aims to integrate different health services on the same level. It manifests itself through active participation of primary care providers in the development and monitoring of individual therapeutic projects, facilitating and organizing flows between different care aspects without losing sight of their responsibility for the comprehensive care of the patient throughout the process. To be effective, the care coordination model must consider the patient's needs, the characteristics of the professionals, and the specificities of the health system. It must also ensure adequate counter-referral and encourage matrix support processes, making appropriate changes when necessary. Thus, the coordination process does not occur in isolation or spontaneously, but through appropriate planning and coordination of work systems⁽⁷⁾.

Within the primary care setting, Family Health Team (FHT) professionals play an important role in identifying and monitoring patients with ASD. Primary care physicians and nurses are directly involved in child health and, through longitudinal monitoring, can identify developmental changes during routine procedures, through childcare visits. These professionals are among the patients' first points of contact with the healthcare system and are also the people who spend the most time with them throughout their lives, while also acting as mediators between the family and other healthcare professionals⁽⁷⁾.

3 METHODOLOGY

To achieve the proposed objectives, we used the qualitative health research approach described by Minayo (2008)⁽⁸⁾, whose main objective is to interpret the phenomenon it observes, aiming to understand the internal logic of groups, institutions and actors, regarding cultural values and representations about their history and specific themes. The universe of their investigations is everyday life and common sense experiences, interpreted and reinterpreted by the subjects who experience them.

We used focus groups and semi-structured interviews as data collection instruments. In this study, semi-structured interviews were conducted with FHT professionals involved in coordinating care as from the primary care level, in collaboration with the community assigned to the primary care unit (PCU), who agreed to participate. The purpose was to assess their perceptions regarding the monitoring of children with ASD and the role of primary care as a participant in coordinating care for this population. To obtain a more comprehensive overview, professionals with the profile of physicians and nurses from several FHT in the municipality were interviewed. The subjects involved in the Focus Group (FG) were the mothers of children with ASD in the municipality.

A previously prepared script was used to outline a brief profile of those involved in care. For professionals: age, gender, professional training, occupation, length of experience in the field, and participation in refresher courses on ASD. For family members: age, gender, education, occupation, marital status, length of time living with the child with ASD, and aspects related to the diagnostic and follow-up process. The script included guiding questions that addressed the following aspects: level of prior knowledge on the topic, perspective on public policies for treating children with ASD, the Care Network, the role of PC in monitoring children with ASD, diagnostic tools, and the FHT–family bond. The research activities were carried out between October 2022 and March 2024. The research site was the Linneu de Oliveira Lara PCU, integrated by two FHT, located at 225 Antônio Soeiro Street, Center neighborhood, in the municipality of Barão de Cocais, state of Minas Gerais (MG).

In total, three medical professionals (one male and two female) and four nurses from municipal health units participated in the interviews. The focus group included four mothers from health units. Participants in this study were selected by progressive inclusion after an initial approach to potential participants, offering all interested parties the opportunity to participate. Professionals from five of the eleven municipal health units and mothers from four of these units were interviewed. To ensure anonymity, the names of health professionals were replaced by the letters PS and the names of mothers by the letters MA, followed by the interview order number and the FG. Data analysis was performed through content analysis, using Bardin's (2016) Content Analysis as a theoretical framework⁽⁹⁾ and was developed throughout the investigation, through progressive theorizing, in an interactive process with data collection.

This article contains an excerpt from the Dissertation research presented to the stricto sensu Postgraduate Program in Professional Master's in Family Health (PROFSAÚDE), linked to the Federal University of Ouro Preto-UFOP Campus, as a requirement for obtaining the title of Master in Family Health.

The research was submitted to the UFOP Research Ethics Committee for evaluation (CAAE: 67641823.7.0000.5150), through the Plataforma Brasil, and was approved under Opinion No. 6,658,211. After approval, the process of obtaining information began through semi-structured interviews, as determined by Resolution 466/2012 regarding research involving human beings. All participants in the interviews and focus groups were duly clarified about all stages of this research and signed the Free and Informed Consent Form (FICF).

4 DISCUSSION AND ANALYSIS OF RESULTS

Care coordination, as a process, includes factors related to health professionals, user needs and demands, and characteristics of the health system, as outlined in the National Primary Care Policy (PNAB)⁽⁷⁾. Exploring the feelings of professionals and users and identifying through them the regional characteristics of the health system, which can act as facilitators or obstacles in the care process, was the objective of the interviews and the focus group and which were taken into consideration in the creation of the scripts.

ASD is a neurodevelopmental disorder that manifests from the first months of life. The symptomatic variability that classifies it as a spectrum sometimes hinders recognition and timely diagnosis, delaying the initiation of therapeutic interventions^(1,4). To clarify participants' understanding of the concept, key and accurate aspects of the concept of ASD were identified. For professionals, it is clear that it is a neurodevelopmental disorder with varied manifestations, especially in the area of communication.

Most professionals demonstrated, to a greater or lesser extent, knowledge of the conceptual aspects of ASD, although many still only superficially. In addition to the aspects identified as conceptual, other elements were highlighted in the participants' statements that are not part of the concept, such as: *"It's more prevalent in males. The first signs can appear in the first months of life. Diagnosis is always around three or two years of age"* (PS2), but they contribute to the perceptions of the actors involved and to the unfolding of this research.

In general, participants understand the basic concepts of the definition of ASD, however, in most cases, essential elements for diagnosis according to the World Health Organization (WHO) and the DSM-V were missing^(1,4). Only two participants identified impairments in socialization, communication, and language as core aspects. No participant mentioned the narrow range of interests and activities unique to the individual, repetitive or stereotyped movements or actions, or the presence of impairments to the individual's life as necessary elements within the diagnosis.

It is noteworthy that, although professionals understand the conceptual framework of ASD, the mothers' statements revealed difficulties in suspecting and diagnosing the condition based on the symptoms and signs presented by their children, hindering early intervention and appropriate approach, including by specialized professionals: *"Like in (son's name)'s case, I could have done it much sooner, right? The later we make the diagnosis, the more time we waste. Today, the recommendation is, you can get the diagnosis wrong, but you can't get the therapies wrong"* (M4).

One element consistent with the previous result concerns the use of tools to identify signs and symptoms of ASD during consultations. Most participants only identified the Electronic Citizen Record (PEC) of the Unified Health System (SUS) as a tool to aid in the early identification of signs of ASD. The lack of screening instruments and diagnostic methods can delay the identification of signs of ASD and, consequently, lead to a late diagnosis.

Most respondents reported using the e-SUS PEC as an aid in detecting developmental delays. On the other hand, the Child Health Record, a tool provided free of charge by the Ministry of Health, provides developmental milestones by age, as does the M-CHAT, a tool for tracking early signs of ASD and providing information on the topic for professionals and caregivers in its 7th version, which is available for free download⁽¹⁰⁾. Only one participant mentioned using the Child Health Record and M-CHAT to help assess child developmental milestones and identify warning signs and symptoms: *"Oh, I use the developmental milestones, right? Which our PEC information system, the electronic medical record, provides"* (PS1).

Clinical manifestations can appear in different areas and vary from child to child. Studies by Dias (2022)⁽¹¹⁾ and Steyer and Bosa (2018)⁽¹²⁾ indicated that the timely identification of signs and symptoms in the first months of life favors early diagnosis and, consequently, the initiation of therapeutic interventions, which is important for the development of these patients. Although the diagnosis of ASD is made through clinical evaluation and specific tests administered by trained and qualified professionals, the identification of signs and symptoms, as well as the application of screening scales, can be performed by PC professionals and even by parents and guardians themselves.

Analysis of the statements in both groups regarding diagnosis revealed that mothers generally noticed signs of ASD that were not readily identified by health professionals during follow-up appointments. These results coincide with those of Bonfim (2020)⁽¹³⁾, indicating that, in most cases, it is parents who identify changes in their children's development before they are even two years old, leading to a search for professional support.

A study published by Keehn (2023)⁽¹⁴⁾ in the journal *Pediatrics*, in the USA, concluded that "community-based Primary Care physicians who receive specialized training can make accurate diagnoses of ASD in most cases". The study, conducted with 126 children aged 14 to 48 months, assessed the agreement on the categorical diagnosis of ASD between a trained clinician and specialist physicians, resulting in an 82% accuracy rate. The importance of studies of this type lies in the possibility of expanding access to diagnosis given the growing number of ASD cases in recent years and the need for early intervention. In Brazil, where there is a shortage of specialized professionals, training physicians working in PA appears to be a promising solution to facilitate access.

When exploring the level of knowledge about ASD among professionals, two agreed that it was average, while the majority (five) indicated that it was low or shallow. Professionals highlighted this lack of knowledge as a problem in the management of children with ASD and their families, often recommending specialized care as a regular monitoring resource. Regarding the topic, one participant reported: *"Pretty basic,*

unfortunately, right? Because at the Medical School we don't have anything as focused as this, right? I had it in neuropsychiatry, we had a little" (PS3).

The difficulties highlighted by professionals do not go unnoticed by patients and family members, who point to the perceived lack of knowledge about ASD experienced in the health units they attend as a hindrance in creating bonds and seeking care: *"And the difficulty is that no one realizes autism, right? [...] It's an invisible disability. No one knows. The majority, like, ninety percent everywhere, including within a health unit, for sure" (MA3).* This has a negative impact on the coordination capacity of professionals, the longitudinality of care, and the comprehensiveness of care for children and their families.

International and national studies referenced by Rezende (2020)⁽¹⁵⁾ in an article that explores knowledge about ASD among PC professionals, indicate very low levels of knowledge among these professionals. The author identifies deficiencies in the knowledge of PC professionals and highlights the need for educational programs for this group. The deficiencies identified in these studies could be related to problems in academic training, as highlighted by Marques et al. (2021)⁽¹⁶⁾ and Souza (2020)⁽¹⁷⁾, who found that undergraduate medical students did not receive sufficient guidance on ASD during their academic training and, consequently, in their professional practice they lack clarity about how to manage the disorder.

When exploring the care and referral workflows after a suspected diagnosis, all participants agreed on the need to refer patients to other professionals in the HCN, highlighting, in order of mention: speech therapists, pediatrics, neuropsychiatry, psychology, psychiatry, nutrition, and occupational therapy. A fragmented view of the management of cases by the PC team and a lack of awareness of the need for assessment by a multidisciplinary team were observed, as well as other network aspects that can assist in the monitoring of children with ASD and their families. It was possible to identify that some HCN aspects are unknown or little used by professionals when it comes to monitoring patients with ASD and their families.

All interviewees highlighted the need for specialized evaluation for the child, but none mentioned offering support, shelter, or psychological counseling to the family during the process. There is no consensus among professionals regarding referral processes and there is a lack of follow-up routines, which reaffirms the participants' reports about the scarcity of theoretical frameworks they are familiar with and the need to create municipal protocols for addressing ASD: *"So, usually here at the unit where I see it happening, the family already arrives with this suspicion, right?! So we evaluate it, see if it truly fits, and then I make the referral" (PS2).*

Another aspect identified as a fault was the lack of specialists and counter-referrals, as well as poor communication between professionals at different levels of care, in addition to the lack of matrix support, which hinders care coordination and comprehensive monitoring. The lack of communication and fragmentation of care among the different actors has proven to be a negative aspect of the monitoring of children with ASD in the municipality: *"So it's actually a flaw in our unit, even within the system, right? Since*

the municipality doesn't offer it with the regularity they need, many go to the private sector. So we end up losing some contact" (PS1).

The same assessment was made by families who cite the lack of municipal resources and inconsistent treatments as reasons for staying away from health care facilities. Children with ASD require specialized early intervention and systematic care, preferably by a multidisciplinary team that can create an individualized and shared treatment plan⁽⁶⁾. In this regard, the mothers identified deficiencies in the public system, which proved incapable of guaranteeing the recommended care. All participants limited their follow-up at the UBS to vaccinations or consultations for acute needs. No leadership positions were identified in the care processes, nor were preventive or regular care actions directed at children with ASD and their families: *"The OT [occupational therapist] went on maternity leave, and there was a very long gap, a very long time for her to return. And [child's name] could have lost many of his skills during that time (...) so I had to take him to the private sector" (MA3).*

There must be interaction and information sharing among professionals from different categories within the HCN, always with family participation. All actors must participate in the creation and monitoring of the Singular Therapeutic Plan (STP), and the PC must coordinate the care processes, always respecting the autonomy of the patient and their family, who will always have a voice in command and decision-making power over health actions⁽⁷⁾.

When asked about patient and family monitoring in primary care, all professionals interviewed stated that they do not carry out scheduled follow-up activities for this population group, limiting care to acute needs. Similarly, no follow-up or family guidance programs were mentioned as treatment support. Planning health actions from primary care onwards must be universal and equitable, meeting the needs of all users⁽¹¹⁾. Failure to implement programmatic actions for these groups violates the principles of the SUS and violates users' rights, while also jeopardizing the comprehensive and longitudinal treatment of patients with ASD: *"There's no such scheduled follow-up for these patients. We don't even usually receive counter-referrals, right? So it's really just from referral onward. We don't have a schedule" (PS2).*

During the interviews, it was noted that FHT professionals do not take the expected protagonism as collaborators with families in coordinating the care of children with ASD within the HCN. No case discussion processes or participation in STP were mentioned, and most presented themselves as identifiers and referrals in situations of suspected or confirmed diagnosis, without actually taking an active role in the care of this group.

The professionals' lack of knowledge about the HCN reference points, the lack of well-defined service flows and programmatic care actions, as well as the absence of municipal protocols in Barão de Cocais-MG, were aspects highlighted by the interviewees. The identified difficulties act as obstacles in the care of these children and their families, hindering the development of bonding relationships, and hindering the desired outcome of PC as the HCN's organizer.

There is a lack of resources to ensure efficient care across the network, reinforcing the need for a trained, organized, and systematized multidisciplinary team as a solid foundation for effective care and interventions. Another aspect worth pointing out is that there is still a scarcity of studies on the role of primary care professionals in coordinating the care of patients with ASD. This highlights the need to improve access to care and reduce some of the current barriers faced by many families of children with ASD, highlighting the importance of training for primary care professionals⁽¹⁸⁾.

Little is discussed about the multidisciplinary approach to care and monitoring for patients with ASD, given its recent inclusion in the field of mental disorders. It is essential that professionals from all health areas work as a team to provide comprehensive support to children and their families. The SUS should ensure comprehensive care for all families, with primary care as the gateway and coordinator of the HCN. A study by Maciel (2020)⁽¹⁸⁾ indicates the inexperience of the multidisciplinary primary care team in identifying, monitoring, and supporting patients and their families.

5 CONSIDERATIONS

This research has identified that there are important challenges regarding professionals, families and the structure of the regional health system, which undermine the co-participation of AB professionals in coordinating care with families in the HCN in Barão de Cocais-MG. The detailed analysis highlights difficulties in diagnosis and follow-up by FHT professionals, including specialized care professionals, who, in the view of family members, are unable to make a timely and early diagnosis, despite having theoretical knowledge of the signs and symptoms of ASD. Professionals point to a lack of knowledge and skills necessary to deal with patients with ASD and their families as challenges, often due to ineffective undergraduate programs in addressing ASD.

Linked to this, the absence of municipal clinical protocols, the lack of matrix support and the lack of diagnostic assessment tools that support the management of ASD cases, starting from PC, reinforces the need for Health Education programs on the topic. Difficulties in effective communication and in the professional ability to guide families, combined with the lack of family support and guidance programs, reinforce families' feelings of invisibility, making them feel distant from the care processes. In addition, the lack of programmatic actions aimed at patients with ASD and their families, and professionals' lack of knowledge on the topic, distances users from FHT and hinders the creation of bonding relationships, demanding changes in work systems that encompass inclusive agendas and humanized support spaces.

The identified deficiencies highlight the need for a comprehensive and coordinated approach to improve diagnosis, treatment, and support for individuals with ASD and their families within the Municipal Health System. This may involve implementing clear protocols, professional training, improving communication between different levels of care, and greater attention to family needs. Limitations are manifested in the current impossibility of addressing the determinants related to administrative and organizational resources identified in this research, such as the scarcity of human and structural resources that hinder the effective

participation of PC professionals in care coordination, who depend on the coordination and management of the public administration.

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