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Original Article

Autism Spectrum Disorder in Primary Health Care: Challenges for multidisciplinary care

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Objective: to analyze the assistance provided to users with Autism Spectrum Disorder in a Primary Health Care Unit. **Method:** a descriptive research study with a qualitative approach. The data were collected through semi-structured interviews with professionals from the multidisciplinary team in four Primary Health Care Units and supported by Bardin's content analysis. **Results:** the evidence revealed that contact with autistic children only occurred at times such as vaccination, medication, appointments and routine exams, in addition to lack of structure for assistance. Lack of knowledge and lack of training to dialog with the autistic spectrum in Primary Health Care were presented as difficulties. **Conclusion:** identifying the autistic spectrum for early intervention promotes improvement in the child's cognition, affectivity, motor skills and behavior; however, lack of knowledge and support training of other services in the psychosocial care network resulted in challenges for the multiprofessional team's work in primary care. Thus, this study contributes to the advancement of knowledge by identifying these gaps that require intervention by managers to strengthen the continuing education of these professionals and outline strategies to ensure articulation between services in order to qualify the care provided to autistic individuals.

Descriptors: Autism; Autism Spectrum Disorder; Early Intervention; Primary Health Care.

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Transtorno do espectro autista na Atenção Primária à Saúde: desafios para assistência multidisciplinar

Objetivo: analisar a assistência aos usuários com transtorno do espectro autista em Unidade de Atenção Primária à Saúde. **Método:** pesquisa descritiva com abordagem qualitativa. Os dados foram coletados por meio de entrevista semiestruturada com profissionais da equipe multiprofissional em quatro Unidades de Atenção Primária à Saúde e subsidiados pela análise de conteúdo de Bardin. **Resultados:** as evidências revelaram que o contato com crianças autistas ocorria apenas em momentos como a vacinação, medicação, consultas e exames de rotina, além da falta de estrutura para a assistência. Desconhecimento e falta de capacitação para o diálogo com o espectro autista na atenção primária à saúde apresentaram-se como dificuldades. **Conclusão:** identificar o espectro autista para intervir precocemente promove melhoria da cognição, afetividade, motricidade e comportamento da criança, porém, a falta de conhecimento, de capacitação e de suporte dos demais serviços da rede para o cuidado psicossocial implicou em desafios para o trabalho da equipe multiprofissional na atenção primária. Assim, este estudo contribui para o avanço do conhecimento ao identificar essas lacunas que necessitam de intervenção dos gestores para fortalecer a educação continuada desses profissionais e traçar estratégias para garantir a articulação entre os serviços a fim de qualificar o cuidado as pessoas com autismo.

Descritores: Autismo; Transtorno do Espectro Autista; Intervenção Precoce; Atenção Básica de Saúde.

Trastornos del espectro autista en la Atención Primaria a la Salud: desafíos para la asistencia multidisciplinaria

Objetivo: analizar la atención a usuarios con trastorno del espectro autista en una Unidad de Atención Primaria de Salud **Método:** investigación descriptiva con abordaje cualitativo. La recolección de datos se realizó a través de entrevistas semiestructuradas con profesionales del equipo multidisciplinario en cuatro Unidades de Atención Primaria de Salud sobre la base del análisis de contenido de Bardin. **Resultados:** la evidencia reveló que el contacto con niños autistas solo se daba en momentos como vacunación, medicación, citas y exámenes de rutina, además de la falta de estructura para la asistencia. El desconocimiento y la falta de formación para el diálogo en relación al espectro autista se presentaron como dificultades en la atención primaria de salud. **Conclusión:** identificar el espectro autista para la intervención temprana promueve la mejora en la cognición, afectividad, motricidad y comportamiento del niño, sin embargo, la falta de capacitación y de soporte de otros servicios de la red de atención psicosocial derivó en desafíos para el trabajo del equipo multiprofesional de atención primaria. Así, este estudio contribuye al avance del conocimiento al identificar estas brechas que requieren la intervención de los gestores para fortalecer la formación continua de estos profesionales y delinear estrategias que aseguren la articulación entre servicios con el fin el fin de brindar atención cualificada a las personas con autismo.

Descritores: Autismo; Trastorno del Espectro Autista; Intervención Precoz; Atención Primaria de Salud.

Introduction

Autism Spectrum Disorder (ASD) affects areas related to neurodevelopment with early onset in the child's first years of life and chronic progression, characterized by deficits in different degrees of impairment such as: reciprocal social interaction skills, communication skills, behavior, interests, activities, and ls to develop and preserve relationships[1]. It is also considered as a "difference" in the subject's uniqueness with a worldwide prevalence of 70 cases *per* 10,000 inhabitants, with an estimate of 27.2 cases *per* 10,000 inhabitants in Brazil[2-4].

The difficulties presented by people with ASD, such as those related to establishing social relationships, much more serious deficits in relation to verbal communication, severe mental deficit, limited social interaction and inability to deal with changes require early interventions to minimize its effects and to improve functional results and quality of life[5-7].

The introduction of therapeutic measures prior to ASD progression and the identification of the first warning signs, such as lack of social gestures at 12 months old, not using meaningful single words at 18 months of age and not being interested in other children or not having spontaneous two-word phrases at 24 months, can guarantee the child's possibilities to undergo a comprehensive treatment with a view to promoting autonomy.[8-9].

For the identification of children with ASD in the context of the Unified Health System (*Sistema Único de Saúde*, SUS), something still incipient in the care context, in 2014 the Ministry of Health (*Ministério da Saúde*, MS) presented guidelines for early diagnosis and treatment with the objective of enabling integration, psychosocial rehabilitation, follow-up flowchart and welcoming in the Health Care Networks (*Redes de Atenção à Saúde*, RAS), as well as support and guidelines to the family, meeting the principle of integrality that understands man in his needs in the territory, involving the biopsychosocial issues[10].

As part of the health care network, the Primary Health Care Units (*Unidades de Atenção Primária de Saúde*, UAPS) must offer resources in the territory and prepare Family Health teams to provide comprehensive, individual and collective care to patients with ASD and their families, as the Family Health Strategy (FHS), composed of the multiprofessional team, focuses on promoting health and reducing health problems, assisting individuals from child growth and development to adolescence, through actions integrated with other network services[11].

Multidisciplinary teams must be prepared to recognize the first manifestations or behavioral changes related to ASD, combined with active listening and knowledge of the network developed by the matrix support between professionals from the Family Health Strategy (FHS) and specialist professionals from the Family Health Support Center (*Núcleo de Apoio à Saúde da Família*, NASF) and the Psychosocial Care Center (*Centro de Atenção Psicossocial*, CAPS), aiming to transform the traditional logic, together with the Psychosocial Care Network (*Rede de Atenção Psicossocial*, RAPS), through horizontal actions in the territory to assist people in psychological distress and with needs arising from the use of crack, alcohol and other drugs[12-13].

However, some types of mental disorders can be neglected in these integration approaches; among them, ASD, epilepsy, dementia and brain sequelae can be highlighted[14-15].

This reality requires priority in the scientific agenda to demonstrate the results of mental health articulation, in addition to other strategies such as training of the professionals involved, specialized reference equipment and medication flows[14-15].

In the meantime, to investigate the context of ASD in Primary Health Care (PHC), operationalization of the assistance offered at this care level and in conjunction with the RAPS; its diagnosis and early interventions are important issues to be considered for this study, which aims at analyzing the care provided to users with autism spectrum disorder in Primary Health Care units.

Method

The study is characterized as a descriptive research with a qualitative approach, developed in four UAPS that are part of the teaching-research Integrating Project (IP) between the Medical Sciences and Health School - Suprema and the Municipal Health Secretariat of the Municipal City Hall of Juiz de Fora, Minas Gerais.

The IP integrates one of the components of the curricular structure of health courses in this institution and aims at contributing to the integrated training of health professionals through the insertion of students in different communities. Each UAPS has approximately three FHS teams, comprised by a physician, a nurse, a nursing technician and community health agents, only one being a reference team for monitoring students due to lack of physical space in these places. To be part of the research, the reference team that monitors students in the field of practice was selected.

The inclusion criterion was being a reference professional for the IP that comprised the multiprofessional team. The professionals excluded were those working under an experience period, or on leave for any reason or vacation.

The field stage took place between October and December 2019, through a script for semi-structured interviews. Guiding questions comprised the script with questions directed to discuss the care provided to users with Autism Spectrum Disorder in Primary Health Care

Units. The interviews were conducted by the researchers themselves in a room reserved for this purpose, outside working hours and after prior scheduling by telephone. The participants were informed about the research theme and objectives, and each interview lasted approximately 30 minutes. The study had 20 participants.

The data were collected by means of an electronic audio recording device, an iPhone 7 device. In order to maintain greater reliability, the researchers recorded the interviews immediately after their conduction. They were then made available for reading by the participants, so that they could freely omit some information or add something that could contribute to the study proposed.

The data were evaluated from content analysis, supported by Bardin[16]. It presents three chronological nuclei: pre-analysis, from floating readings, organization and recognition of the data from the transcribed interview is performed, which will support interpretation; exploration of the material, enabling data coding and identification of the nuclei of meaning, according to the objectives proposed; and treatment and interpretation of the results achieved[16].

Based on the study objectives and on the pre-analysis of the content made, two thematic categories emerged: a) Multiprofessional assistance to users with Autism Spectrum Disorder in the Primary Health Care Unit; b) Challenges encountered by the multiprofessional team, through the care provided to users with Autism Spectrum Disorder.

Following all the legal procedures, this study was evaluated and approved by the Research Ethics Committee of the Medical Sciences and Health School - Suprema under Consubstantiated Opinion No.: 3,535,543 and CAAE 16692019.9.0000.5103. All the participants signed the Free and Informed Consent Form. There was also prior consent of the participating institution to carry out the study.

Anonymity was guaranteed by pseudonyms indicated by the letters "E" for nurses ("*Enfermeiros*" in Portuguese), "M" for physicians ("*Médicos*" in Portuguese), "ACS" for community health agents ("*Agentes Comunitários de Saúde*" in Portuguese) and "T" for nursing technicians, in the alphanumeric sequence in which the interviews were conducted (E1, E2...), (M1, M2...), (ACS1, ACS2...), (T1, T2...).

Results

The research participants were four physicians, four nurses, four nursing technicians and eight community health agents (ACSs). Each team has six ACSs in its staff, which would account for a total of 24 but, during the collection period, four were on vacation, three were on sick leave and nine did not accept to participate in the research.

Multiprofessional assistance to users with Autism Spectrum Disorder in the Primary Health Care Unit

The results highlighted the way in which the professionals reported their assistance to the user with ASD. The professionals scored technical procedures, such as vaccination, routine examinations, medication and consultations.

Our contact is more vaccine, what we can do is speed up to reduce the anxiety of the child who's seeing other children crying so that he doesn't get more agitated [...] (T1); *[...] Agent treats normal, as it's not because the child has autism that they have to be treated differently, they need to have everything, even a limit* (ACS1); *[...] usually it is to welcome, talk to the family or responsible person and really see if they have autism, here there's no structure to treat these patients, they are usually referred to some reference center, we monitor these patients through medication, vaccination, consultations and examinations if necessary [...]* (M1); *[...] We don't have a protocol or guidance for differentiated care, but we welcome, mainly the Nursing team and the idea is to listen to the user's demands [...]* (M2). *The approach is normal, as with any other user [...]* (E2). *We don't have a specific look at the approach of the autistic patient [...] But it is certainly a special patient, who has to have a different look, priority and more care* (E3). *There's no specific approach, the patient actually enters care like any other patient with mental illness or some other type of disorder* (E4).

Challenges encountered by the multiprofessional team, through the care provided to users with Autism Spectrum Disorder

The challenges faced by the multiprofessional team were related to lack of training to assist users with ASD: *Unfortunately not, the City Hall usually offers some training sessions, but in the area of autism I haven't had it yet* (E1). *No, unfortunately not. But it's a necessary thing in all the units for identification and diagnosis, it would be much easier to give a more accurate diagnosis* (M1); *No, because we have never had a training course on this* (ACS2); *I don't remember having any training about autism, it's not much talked about and even the family sometimes doesn't say, if you need to know something you don't know how to direct, have no security and avoid talking about it* (E2); *I didn't have any training, and in undergraduation it may have been mentioned, but it wasn't something to teach you, it was more superficial. And in my case I don't feel prepared to deal with this type of patient and don't even know how to deal* (E3).

These gaps in knowledge hinder the use of specific care technologies, culminating in challenges for the applicability of the public policies in the area:

[...] I think that there should be a specialized person to receive them and assist them by helping in the welcoming, [...] (T1); *The family members themselves very often think that in the health unit there's no way to give this diagnosis, and have this fear of bringing the autistic patient and until the referral we don't receive*

any feedback, there's no such counter-referral and it would be easier to monitor this patient and adhere to the treatment (M1); *The challenge is actually to offer an adequate place with trained professionals to receive these patients, because it's not enough for you to have access, and when you follow up there's no adequate professional or someone who will conduct the case* (E2); *Learning how to offer this differentiated care, knowing how to deal [...] we usually also deal with the companion and we don't have the ability, dialog on how to conduct the case, I think it's a disorder that is left aside, but we need training and to learn how to deal with it* (M2); *[...] the challenge is that we know how to direct better, where they have to go, what they have to do, give the necessary guidelines to the parents* (E3); *[...] generally we also deal with the companion and don't have the ability to dialog and how to conduct the case, I think it's a disorder that is left aside (M3); How we will take care of this person here, if some crisis comes up and they need some care that is specific to psychiatry. We have an autistic child who suffered a full burn, and it's difficult to deal with, we don't have this ability to deal with autistic patients* (T3).

Discussion

Most of the professionals who participated in this research do not have knowledge about ASD and assist these users through technical procedures common to the routine assistance in the UAPS. When inserted in the service of the UAPSs surveyed, these professionals faced challenges to assist users with ASD and their family members. Such assistance is characterized by little dialog, lack of training and lack of knowledge about the light care technologies in Primary Health Care, resulting in difficulties to understand the duties of the multiprofessional team in the face of this care demand.

Lack of training and of knowledge regarding the mental health policies that support health care to users with ASD and their family members interfered in the conduction of care that initially lacked, on the part of the multiprofessional team, the theoretical and practical direction of psychosocial rehabilitation.

The National Primary Care Policy aims at care integrality, placing the subjects as the protagonist of their own care. In this sense, multiprofessional health teams have been assigned the role of investigating the ASD signs for early identification and assistance in consonance with the mental health policies for the inclusion of these users and their family members in the field of biopsychosocial care, considering that users with ASD and their family members have common assistance needs in Primary Health Care[17].

Early identification of ASD occurs during the visit of the child to the UAPS seeking the professionals' assistance in procedures such as vaccination, medication, examinations or consultations, as shown in the results. These meetings between family/user with ASD and professionals must take place through overcoming the reductionism of the biomedical model, whose focus on ASD is predominantly aimed at the pathology and at cognitive, motor and behavioral deficit, as well as to the child's general disability[18].

However, the importance of the specialized multiprofessional team of the Children's Psychosocial Care Centers (*Centros de Atenção Psicossocial Infantil*, CAPSi) in this collaborative care process must be considered, in order to share the questions, anxieties and needs of the family members who are established at the time of diagnosis[18-19].

It is important to understand the need to expand the information beyond knowledge about ASD, since acceptance and management can occur from the increase in knowledge by the teams and also regarding the treatment modalities and prognostic perspectives, aiming at expanding dialog between care and integrality[14-19].

Although this is a multifactorial syndrome that requires a specialized approach, it is indispensable to emphasize the importance of early diagnosis in Primary Health Care (PHC). In a systematic review regarding formal screening of ASD in young children with (16–40 months old), a Positive Predictive Value (PPV) was verified for early identification in 50%[20]. Regarding screening for the identification of other developmental conditions, the PPV increased to 95%, which suggests contributions to evaluate improvements in aspects such as the child's cognition, affectivity, motricity and behavior, as well as guarantees for the improvement of neurodevelopment in childhood[21-22].

The professionals who participated in the study revealed difficulties regarding the management of patients with ASD, as well as training needs. In fact, there is still a weakness in terms of knowledge and professional training with regard to the diagnostic practices and the implementation of interventions[23-24]. On the other hand, caution must be exercised as to the diagnosis, since it cannot be determined on the basis of only one screening instrument[25].

Other barriers that compromise care efficacy are related to lack of care coordination and to lack of time and guidelines in the practice, in addition to the deficit in the professionals' qualification to work with ASD and more investment in the production of the care provided to the person in mental distress in primary care[26-27]. In this context, it is perceived that the physician still cannot establish an adequate dialogical relationship with the person with ASD and their family[28]. It is therefore understood that, if the way of communicating the diagnosis is not considered an important aspect in the care process, this fact may generate tension and emotional conflicts on the part of patients and family members at the time of discovery[29].

From the perspective of the importance of society understanding and knowing the policies that involve the guarantee of the rights of people with ASD, which include quality of life and the right to comprehensive care at all health levels as essential, the National Policy for the Protection of the Rights of People with ASD stands out. This policy was Instituted by Law No. 12,764 of December 27th, 2012, which mentions the aspects that define ASD and highlight the rights of citizenship, physical and moral integrity, safety, leisure, multiprofessional team care, nutritional therapy and medications[30-31].

To promote alignment between the fields of rehabilitation and psychosocial care for the qualification of the multiprofessional team to assist people with ASD under the SUS, from 2013 on, the Ministry of Health created two work guides for the care of users with ASD, the first being the Guidelines for care and rehabilitation for people with ASD and the second referring to the document entitled "Care Line for the Care provided to People with Autism Spectrum Disorders and their Families in the Psychosocial Care Network of the SUS", which recognizes autism in the field of psychosocial care[31].

Based on the premise that ASD can be seen by the field of psychosocial care, through matrix support, the CAPSi can offer specialized support to the FHS teams for the management of ASD and the establishment of counter-referrals between the teams[32] as pointed out by the professionals investigated for better conduction of the cases.

Identification of signs and symptoms of clinical risk in ASD requires specialized interprofessional assistance to perform robust standard diagnoses and permanent health education actions with the UAPSs, as this complexity level is the main gateway of the person with ASD to the SUS[25-32].

Within the SUS scope, people with ASD require approaches that provide them with expansion of autonomy and that take into account their uniqueness and rights since, in the FHS, the professionals may be able to perform effectively and significantly in the itinerary of psychosocial rehabilitation of people with ASD, as well as that of their family members[26].

In the performance of the multidisciplinary team by the FHS, the ACSs, especially, have a fundamental participation in the early recognition of ASD, as their perspective of action integrates the first contact of health care with the families, performing preventive, rehabilitation and curative care actions; and it is also necessary that they have knowledge about the promotion of actions in health[14].

From the perspective of ASD, it is important to point out that the health care policy guides that, when trained, the ACSs are able to assess the children in their living environment, using it as a work tool for the monitoring and surveillance of child development, which provides an opportunity for the global assessment of the person in their biopsychosocial aspects[27].

It is necessary to offer a training and encouragement program from the competent bodies, so that the multiprofessional team can provide effective care centered on the patient with ASD. Knowledge makes it possible to strengthen the health support network in the elaboration of individualized therapeutic plans, with quality therapies and appropriate interventions, aiming not only at recovery, but at quality of life and respect as part of the treatment.

The combination of various approaches with the theoretical foundation and systematization of actions to face the demands foreseen in the public health policies avoids care fragmentation and the challenges faced by the team, in addition to contributing to the understanding of the reality imposed by spontaneous demand with equality and quality.

In this sense, we understand that the offer and guarantee of the professionals' access to qualification programs is not enough, but the understanding of all the stages of the strategies aimed at the early identification of ASD and the measures that seek to assess the effectiveness of these actions.

Study limitations

One of the study limiting factors was the fact that the family members were not heard regarding the assistance to ASD in PHC, as well as the specialized professionals of the CAPSi, with regard to the matrix support among the teams of the specialized services and the FHS teams. This fact made it impossible to know all the strategies and behaviors of the professionals involved in the RAS, in addition to the meanings for the family members, their doubts and positions regarding the ASD.

Final considerations

This study evidenced the assistance provided by the professionals from the multiprofessional team on the management of patients with ASD in the UAPS and the main challenges in providing assistance to those individuals. Among the impasses that fragment the assistance provided by the multiprofessional team in the UAPSs, there is lack of knowledge for the management of these users and their family members, lack of training and knowledge about specific care technologies that involve the applicability of public policies in the area for the early identification of ASD in Primary Health Care regarding improvements in the child's cognition, affectivity, motricity and behavior.

Development of this research made it possible to identify that, in the UAPSs, herein taken as a research space, the multiprofessional team is not prepared to assist

patients with ASD due to their low level of knowledge, as well as it is unable to establish welcoming strategies for their family members. Fragmentation in the care provided by the interdisciplinary team to the patients with ASD and their family members is related to lack of knowledge about ASD, resulting from the lack of training aligned with the need for knowledge about the mental health policies, which exerts a negative impact on the use of the specific care technologies.

From the above, it is evidenced that the performance of the multiprofessional team in the UAPSs needs governmental attention, as there are delicate issues that reflect on the assistance provided by the team, which, even without understanding and knowing ASD, assumes the responsibility of psychosocial care, without the support of the other care network services in the development of an articulated work. The investment in professional training and qualification of the health team professionals is emergent, aiming to stimulate continuing education based on technical and scientific knowledge, to qualify multiprofessional assistance for people with ASD and their family members in the UAPSs.

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