

ORIGINAL ARTICLE

Teachers' experiences with autism: impact on early diagnosis and school inclusion

Experiências de professores com o autismo: impacto no diagnóstico precoce e na inclusão escolar

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ABSTRACT

The objective was to understand how the experience with autism can impact on early childhood teachers' identification of autistic traits in students from the perspective of early diagnosis and school inclusion. The methodological approach was qualitative. Ten teachers from ten Municipal Centers of Early Childhood Education located in Foz do Iguaçu, Parana, Brazil participated in the study. Data were collected through semi-structured interviews and analyzed according to content analysis, thematic modality. Two thematic nuclei emerged: "Knowledge, experiences and perceptions about Autism Spectrum Disorder" and "The teacher before the student with Autism Spectrum Disorder and investments for detection and inclusion". The conclusion was that teachers could identify signs of autism and contribute to early diagnosis, and positive experiences cooperated for accuracy in detection and school inclusion. Intersectoral and interprofessional actions should be expanded in order to provide the opportunity for user embracement and comprehensive care.

Descriptors: Autistic Disorder; Child Care; Early Diagnosis; Faculty; Mainstreaming (Education).

RESUMO

Objetivou-se compreender como a experiência com o autismo pode impactar na identificação de traços autísticos em alunos pelos professores da Educação Infantil, sob a perspectiva do diagnóstico precoce e da inclusão escolar. A abordagem metodológica foi de cunho qualitativo. Participaram do estudo dez professores de dez Centros Municipais de Educação Infantil de Foz do Iguaçu, Paraná, Brasil. Os dados foram coletados por meio de entrevistas semiestruturadas e analisados segundo análise de conteúdo, modalidade temática. Evidenciaram-se dois núcleos temáticos: "Conhecimentos, experiências e percepções sobre o Transtorno do Espectro do Autismo" e "O professor frente ao aluno com Transtorno do Espectro do Autismo e os investimentos para a detecção e inclusão". Concluiu-se que os professores são capazes de identificar sinais de autismo, contribuindo para o diagnóstico precoce e que experiências positivas cooperaram para a acurácia na detecção e para a inclusão escolar. Ações intersetoriais e interprofissionais necessitam ser ampliadas a fim de oportunizar o acolhimento e o cuidado integral.

Descritores: Transtorno Autístico; Cuidado da Criança; Diagnóstico Precoce; Docentes; Inclusão Educacional.

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How to cite this article: Couto CC, Furtado MCC, Zilly A, Silva MAI. Teachers' experiences with autism: impact on early diagnosis and school inclusion. Rev. Eletr. Enferm. [Internet]. 2019 [cited on: _____];21:55954. Available at: <https://doi.org/10.5216/ree.v21.55954>.

Received on: 11/21/2018. Accepted on: 09/24/2019. Available on: 12/31/2019.

INTRODUCTION

Autism Spectrum Disorder (ASD) or autism is a neurodevelopmental disorder of multifactorial etiology. In the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) are described the following diagnostic criteria⁽¹⁾:

- communication and social interaction impairments with possible delays in language acquisition;
- ritualized patterns of behavior and restricted interests, including: stereotyped and repetitive movements and language, attachment to routines, restricted interests, and sensory disturbances.

There is a wide variability in the expression of autistic traits involving differences in signal expression and severity levels. Autism may or may not be associated with language acquisition delays and intellectual impairment. According to international data, the estimate is that one out of every 88 individuals presents the disease⁽²⁾.

ASD has a chronic course and generally brings functional disability and interferes with autonomy for activities of daily living⁽³⁾. With early diagnosis, the appropriate multiprofessional therapy can be established since childhood and modify the critical aspects of impairment, which increases the person's chances of having relative independence and greater social insertion⁽⁴⁾.

Early diagnosis is the most impactful modifying factor of the disorder course. Research has been conducted to develop effective tools for identifying ASD in the early years of life, thereby allowing immediate therapeutic intervention⁽⁵⁾. Such effort is justified by the greater plasticity of children's brain structures in the early years of life hence, this is a more sensitive period to interventions⁽⁶⁾.

After family members, teachers are important agents involved in the suspicion of autism in young children⁽⁷⁾. Researchers in Spain pointed out that suspected autism was identified by family in 79% of cases and by education professionals in 15% of cases. In 4% of cases, the related professional was the pediatrician and in 2%, the psychologist⁽⁸⁾.

Educators' perspective regarding the identification of signs of ASD can be considered an excellent ally in early diagnosis because of their continuous contact with the same child and a more detailed observation^(9,10). Thus, attention on how these professionals understand and experience the ASD is relevant, including in relation to school inclusion.

Although in Brazil educators appear in the algorithm of the Ministry of Health for tracking autistic signs⁽⁶⁾, their role is little explored. This becomes clear by the lack of description of effective flows between education and health teams.

For the proper insertion of educators in care networks, there must be an understanding of their theoretical and practical experience in relation to ASD, as well as of strengths

and needs. The apprehension of this reality focused on the qualification of care networks is a poorly explored area in the literature and has significant practical implications, which justifies the performance of this study.

The aim of this study was to understand how the experience of early childhood teachers of autistic children can impact the identification of the disorder traits in students and the repercussions on school inclusion from the perspective of health care networks. The assumption is that teachers can be important agents in the recognition of early signs of autism and play a key role for the successful school inclusion.

METHODS

Qualitative study conducted with teachers of Municipal Early Childhood Education in the city of Foz do Iguaçu, Parana, Brazil. The 11 institutions elected as field of study are in the northern region of the municipality, the area with the largest number of schools.

Inclusion criteria were:

- teachers with at least three years of experience in the classroom, which enabled the selection of participants with teaching experience and teachers who graduated after the implementation of compulsory inclusive education in initial training;
- teachers of classes at higher levels than nursery, allowing direct contact with preschool students.

When more than one teacher met the inclusion criteria in each preschool, the pedagogical coordinator of each institution was asked to nominate one professional among those eligible for the study, regardless of the level of personal knowledge or experience with ASD. Thus, was selected one educator per school, thereby reaching a total of 10 participants, considering that one of the schools refused to participate in the study.

Data were collected between September and December 2016 through semi-structured interviews. They were conducted based on a script composed of participant identification data and open and guiding questions on the meaning of autism, namely: understanding about children with ASD; the teacher's experience in dealing with autistic students; the potentialities and difficulties of people with autism in daily life; and opinions on how to broaden teachers' perceptions of suspicious signs of autism.

Interviews were scheduled at a time and place of participants' choice to avoid interfering with pedagogical activities and guarantee their privacy. They had an average duration of 50 minutes, were recorded and later transcribed in full by the main researcher.

Data analysis was referenced by content analysis, thematic modality⁽¹¹⁾:

- comprehensive reading aimed at impregnation, overview and apprehension of particularities of the material generated by research;
- classification of testimonials into categories;
- identification of nuclei of meanings;
- dialogue between problematized ideas and information from other studies; and
- interpretative synthesis by seeking to articulate the study objective, the adopted theoretical-conceptual basis and empirical data.

The study was analyzed and approved by the Research Ethics Committee of the State University of Western Parana (UNIOESTE) under Opinion number 1.665.147. Participants were asked for their consent by signing the Informed Consent form according to Resolution number 466/2012 of the National Health Council. In order to guarantee the anonymity of participants, they were identified by the letter "P" for "Participant", followed by the Arabic numeral corresponding to each interview, P.1, P.2 and so on.

RESULTS AND DISCUSSION

The ten participants were female with a mean age of 39 years. The minimum age was 24 years old and the maximum was 53 years old. The average time of teaching experience was 14.3 years with a minimum of five years and a maximum of 27 years.

Regarding education, 100% of teachers (10) had completed higher education. Regarding specialization courses, 60% of teachers (6) completed or were attending a specialization course and 40% (4) had two specializations already completed. Regarding areas of specialization, 60% (6) were specialized in Early Childhood Education, 10% (1) in Special Education, 10% (1) had a postgraduate degree in Early Childhood Education and School Pedagogy, 10% (1) in Early Childhood Education and School Management and 10% (1) in Early Childhood Education and Education with Emphasis on Inclusion (considered here as specialization in Special Education). In total, 90% (9) attended or were attending a specialization course in Early Childhood Education and 20% (2) in Special Education.

Only 50% (5) of teachers reported having some direct experience with autistic individuals. In general, participants reported they acquired theoretical knowledge about ASD in courses, in-service training and informally in television programs and the internet.

From the comprehensive analysis of subjects' statements, were identified two thematic nuclei, namely: "Knowledge, experiences and perceptions about Autism Spectrum

Disorder" and "The teacher before the student with Autism Spectrum Disorder and investments for detection and inclusion", which will be discussed next.

Thematic nuclei "knowledge, experiences and perceptions about autism spectrum disorder"

Regarding the characteristic signs of ASD, most subjects highlighted children's difficulty with communication as an important element for recognizing autism. The absence of eye contact, isolation and excessive quietness of these children were the most mentioned aspects:

[...] If you are seated for very long or go to the park and do not play with the others, you are always alone, always quiet, or [...] daydreaming all the time, you know? (P.3)

We are aware it is that child, that individual who does not relate, does not talk, does not look in the eyes ... [...] We have the conception that their socialization is harder. (P.9)

The child that sits and stays there. If this is my toy, it's only mine and the only one I play with and alone. The world around does not exist. (P.10)

In ASD, verbal and nonverbal communication are impaired, as highlighted by participants. Observing nonverbal communication impairment is important, because other disorders involving delays in expressive language may be confused with ASD⁽¹⁾.

The coexistence of teachers with autistic students enriched the understanding of more subtle aspects of social behavior, such as the observation on how the process of play happens in everyday life. The observation of play is relevant for the early recognition of ASD, because there is usually damage to symbolic play, the pretend play⁽¹²⁾.

For participants who reported having direct experience with ASD, the comparison with other non-autistic disorders, the different levels of severity and the wide variation between autistic manifestations were frequent findings. In addition, contact with more students with autism increased the possibility of comparing cases and brought higher quality to the description of behaviors:

[...] I noticed many levels of difference from one autism to the other ... and other disorders. [...] They are also different between them, right? [...] I thought they were the same [...] and they are not... (P.1)

[...] and the boy with Asperger is very different from the student I have now [...]. Not quite how they say... (P.2)

Aspects of inflexibility in the face of routine changes, changes in adaptive behavior, and ritualized behavioral patterns also emerged from most speeches of participants who had the opportunity to observe students with ASD:

[...] obsession for round shaped things, for wheels ... [...] or if every day she comes to my classroom, she will have that same routine. (P.1)

If I notice he cannot adapt, I escalate to the principal and try to call his mother. (P.3)

The difference between children with normal development and ASD regarding caution in new environments was observed by P.2. She highlighted the presence of this atypical disinhibition in autistic people:

Because [...] this student, I noticed something different, [on] the first day of class he already entered the classroom and he was like, not acting naughty, [...] but at no time he felt uncomfortable [...]. (P.2)

When a participant reported having experience with only one student, whether a positive, neutral or traumatic experience was a guiding thread for perceiving ASD. The first and recent experience of having a student with ASD in the classroom may be marked by traumatic impact due to the student's lack of preparation for the school environment⁽¹³⁾. P.3 even counted precisely the days when she was not attacked:

Before I had my student [...], I didn't know what autism was like, you know? [...] There are days he is sweet, but there are others when he is aggressive, like: he attacks me, I get beaten and beaten. Not now; It's been twenty-five days since he last hit me, so it's an achievement, right? [...] I have with myself this was something that hurt me a lot in the beginning of the year, thus, it stirred my emotional, and affected my home [...]. (P.3)

Traumatic experiences related to autism in the school environment provided a darker view of the disorder, accentuation of difficulties and a distortion of autistic symptomatology. Dysfunctional behavior can be considered one of the causes of frustrating experiences with ASD students that generate stress, fear, feelings of helplessness and low expectation of effectiveness as an educator⁽¹³⁾.

On the other hand, positive experiences resulted in better affective bonding, broadened participants' perception of ASD, and enabled them to transpose common sense and labels.

Even with technical knowledge gaps, in general, teachers were able to mention the main signs of ASD. Experience has allowed the observation of differences in

manifestations, contributed to a practical understanding of spectrum variability and brought a deeper apprehension of symptomatology.

Training is fundamental for increasing educators' knowledge about autistic functioning, so they can contribute to early detection, overall development and students' training.

Thus the assumption that educators are able to track students with autistic traits at schools, which is a condition highlighted in other studies^(7,14).

Thematic nuclei "the teacher before the student with autism spectrum disorder and investments for detection and inclusion"

Children with ASD may be dysfunctional in the school environment. Therapeutic investment is key for the adaptation process and expansion of behavioral repertoire⁽¹⁵⁻¹⁷⁾.

By adopting multidisciplinary therapy, children can perform functional actions and understand requests, sometimes through alternative communication models⁽¹⁷⁻¹⁹⁾ involving professionals of Speech Therapy, Psychology, Occupational Therapy, Psychopedagogy, among other areas⁽²⁰⁾. In the care network setting, the multidisciplinary team can act as a mediator between health and education by helping to identify suspected signs of ASD⁽¹⁴⁾.

Children are often "included" in the classroom without conditions to develop their cognitive and socialization potential. Teachers' rejection to have students with ASD is understandable in this scenario, but hinders both the recognition of milder cases in other students and the commitment to school inclusion⁽²¹⁾.

The role of "therapist teacher" has gained prominence in the statements of participants who had direct experience with ASD. The maladaptive behavior of autistic students obliged the prioritization of actions and routines so they could coexist, and the basic needs of students could be met.

[...] because when she got here, she used to do nothing, you know? She's been here for almost two months. She already sits, gets the pencils, she paints, she sits on the floor to play with colleagues, she sits to watch. So, her mom says she didn't use to do any of that. (P.5)

[...] I have to leave the queue here, go there, take her hand, bring her and put her first in the line, because to take her to the queue, I have to take her little hand, otherwise she'll throw herself on the floor, cry, and stay there. (P.10)

Teachers' overload with various activities brings unpleasant experiences and compromises school inclusion. The effort made to teach the child to sit, eat, pick up the pencil, obey simple orders and interact, a repertoire of behaviors worked in therapeutic environments with

appropriate techniques, should be directed to the student's pedagogical development.

This would also be teachers' expectation, especially by considering they were not prepared to manage people with ASD. Mainstreaming comes down to treatment without technique in the school environment and an inconvenient exclusion at school:

[...] if he makes something up, then he starts yelling, crying, and [...] how are you going to handle this alone? Then you have him and a group of twenty, right? [...] you end up paying attention to the others and you end up ... kind of leaving him. And then, I see that it harms the child. (P.2)

I forgot the pedagogical part [...], first I must work [...] on his socialization and his interaction, he has to feel safe in this environment, you know? (P.3)

Experiences in which children with autism evolved in the classroom, even though only in the behavioral sphere, were considered satisfactory and productive, and stimulated the search for school inclusion. Affective bonds became stronger and educators had a sense of fulfilled duty. This success was reflected in the form of understanding ASD, since the glimpse of potentialities and the delineation of difficulties were more realistically explained.

Courses, qualifications and specializations were the most frequent requests from teachers in order to expand the attention to early diagnosis. Particularly, they would like qualifications to help them deal with autistic children in the classroom. Some emphasized the importance of courses on autism funded by the Department of Education or City Hall, which they consider as minimal support to help with understanding and school inclusion:

I think we needed more training, you know? But this must be offered by the Secretariat; the course must be provided, because a few years ago we didn't hear about students with autism in class, but now the number of children is increasing. (P.2)

So, in order to deal with this autism situation, I guess I would need to have a training. [...] A clarification of what autism is, how to work in the classroom [...]. (P.10)

The health-education integration, either in terms of diagnosis or in case follow-up, is the ideal and least expensive way to articulate public health strategies, especially in the pediatric area. Integrating these social institutions allows the necessary adjustments to manage disorders such as ASD from an early age and avoid the future burden of sustaining totally dependent adults⁽²²⁾.

Intersectoriality ensures better results at community level. It is not a matter of abandoning or corrupting the specificities of professional functions, but sharing responsibilities dynamically and cultivating interfaces that dialogue between different areas⁽²³⁾.

Therefore, the need to think about practical actions for a better integration of teachers in health and social care networks with their insertion as permanent proactive agents of active voices, integrated with a functional flow allowing dialogue and the embracement of demands. Similarly, the outcome of health interventions from an intersectoral and interprofessional perspective also needs effective and continuous implementation at schools. This does not imply the creation of new structures, but rather the promotion of organization, functionality and fluidity of the connection between different areas and types of knowledge⁽²⁴⁾.

Another important measure involves the need for schools' access to health services with professionals capable of diagnosing ASD. This articulation would enable referrals of suspected cases to these services by teachers themselves as soon as children's difficulties were detected, thereby avoiding intermediate stages of referrals. Such action supported by two-way functional intersectoral practices would minimize diagnostic delays and include teachers as one of the diagnostic detection agents in the Psychosocial Care Network (Portuguese acronym: RAPS) focused on ASD⁽²⁴⁾, as theorized by the Brazilian Ministry of Health.

Matrix strategy initiatives at schools based on specialized health services, together with the joint discussion of cases would allow the continuity of comprehensive care for children with ASD^(24,25) and provide the necessary support and assistance to the pedagogical team for adequate child development and better quality of coexistence and learning.

CONCLUSION

The fundamental autistic traits were correctly pointed out by participants, regardless of their experience with the subject, which showed teachers are important support agents for the early diagnosis. This demonstrates that schools should integrate the Psychosocial Care Network focused on ASD more strongly thereby working as a point of support in screening for suspicious signals.

The emergence of situations experienced with autistic students in the classroom affected the quality of symptomatology descriptions and had greater depth when experiences were positive and diverse.

Teachers' perception of ASD is the result of an intricate web of acquired information, feelings, experiences, common sense ideas, aspirations, and personal values. Opinions about autism were not just objective information but permeated by elements of daily life in the classroom

and personal experiences (positive or not) during contact with autistic students.

The insertion of teachers in the flow of early diagnosis of ASD and school inclusion should involve support from the multidisciplinary health team at school. This approach increases the detection rates of ASD in young children and provides the opportunity of user embracement, comprehensive care and the establishment of a healthy environment for everyone at school.

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