


## Nurses' care to children and adolescents with autism spectrum disorder

Assistência do enfermeiro(a) a crianças e adolescentes com transtorno do espectro autista

Atención del(la) enfermero(a) a infantes y adolescentes con trastorno del espectro autista

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## Descriptores

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## Abstract

**Objective:** To understand nurses' representation about the care for children/adolescents with autism spectrum disorder at Child and Adolescent Psychosocial Care Centers.

**Methods:** This is qualitative, exploratory, descriptive research, with interviews with five nurses from Child Psychosocial Care Centers. Content analysis carried out in the light of the Social Representations Theory.

**Results:** Nurses' care at Child and Adolescent Psychosocial Care Centers was represented by two thematic categories, the first being "Nurses' care for children/adolescents with autism spectrum disorder", with subcategories addressing: care with the therapeutic environment; guidelines for caregivers/relatives; case identification; and therapeutic project planning. The second category was represented as "Difficulties faced by nurses in caring for children/adolescents with autism spectrum disorder", and subcategories were represented by: slowness with which care results are achieved; challenges of articulation with family members and the educational system for continuity of care; and professional unpreparedness for care.

**Conclusion:** Nurses' care for children/adolescents with autism spectrum disorder requires knowledge for identification and assessments, individual care, in groups, for family/caregivers, and for this there are difficulties that can be overcome through the inclusion of theme in training and permanent education in health processes.

## Resumo

**Objetivo:** Apreender a representação de Enfermeiros(as) sobre a assistência a crianças/adolescentes com Transtorno de Espectro Autista nos Centros de Atenção Psicossocial Infante-Juvenil.

**Métodos:** Pesquisa qualitativa, exploratória, descritiva, com entrevista a cinco Enfermeiros(as) de Centros de Atenção Psicossocial Infantil. Realizada análise de conteúdo à luz da teoria das representações sociais.

**Resultados:** Assistência do(a) Enfermeiro(a) nos Centros de Atenção Psicossocial Infante-Juvenil foi representada por duas categorias temáticas, sendo a primeira Assistência do(a) Enfermeiro(a) a criança/adolescente com Transtorno do Espectro Autista com as subcategorias abordando cuidados com o ambiente terapêutico; orientações a cuidadores/familiares; identificação de casos e planejamento do projeto terapêutico. A segunda categoria foi representada como Dificuldades enfrentadas por Enfermeiros(as) na assistência à criança/adolescente com Transtorno do Espectro Autista, e as subcategorias foram representadas por lentidão com que os resultados da assistência são alcançados; desafios da articulação com familiares e com sistema educacional para continuidade do cuidado, e, finalmente por despreparo profissional para assistência.

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**Conflict of interest:** nothing to declare.

**Conclusão:** A assistência do(a) Enfermeiro(a) a crianças/adolescentes com transtorno do espectro autista demanda conhecimento para identificação e avaliações, cuidado individual, em grupos, à família/cuidadores e, para tal encontram-se dificuldades que podem ser suplantadas por meio da inclusão da temática em processos de formação e de educação permanente em saúde.

## Resumen

**Objetivo:** Comprender la representación de enfermeros(as) sobre la atención a infantes/adolescentes con Trastorno del Espectro Autista en los Centros de Atención Psicosocial Infanto-juvenil.

**Métodos:** Estudio cualitativo, exploratorio, descriptivo, con encuesta a cinco enfermeros(as) de Centros de Atención Psicosocial Infantil. El análisis de contenido fue realizado de acuerdo con la teoría de las representaciones sociales.

**Resultados:** La atención del(la) enfermero(a) en los Centros de Atención Psicosocial Infanto-juvenil fue representada por dos categorías temáticas, de las cuales la primera fue Atención del(la) enfermero(a) a infantes/adolescentes con Trastorno del Espectro Autista, con las subcategorías abordar los cuidados del ambiente terapéutico, identificación de casos y planificación del proyecto terapéutico. La segunda categoría fue llamada Dificultades enfrentadas por enfermeros(as) en la atención a infantes/adolescentes con Trastorno del Espectro Autista, y las subcategorías fueron demora para lograr los resultados de la atención, desafíos de la coordinación con familiares y con el sistema educativo para la continuidad del cuidado y, por último, falta de preparación profesional para la atención.

**Conclusión:** La atención del(la) enfermero(a) a infantes/adolescentes con trastorno del espectro autista demanda conocimiento para la identificación y evaluación, el cuidado individual, en grupos, a la familia/cuidadores, para lo cual se observan dificultades que pueden ser superadas por medio de la inclusión de esta temática en procesos de formación y de educación permanente en salud.

## Introduction

In Brazil, two million individuals are presumed to have autism spectrum disorder (ASD), a type of global developmental delay (GDD).<sup>(1,2)</sup> Survey using data from the Unified Health System Outpatient Information System and the Brazilian National Register of Health Establishments from 2014-2017 showed that 54.3% of GDD diagnoses were not specified, with autism being the most frequent of those specified (27.2%).<sup>(1)</sup> It is noteworthy that 70% of people with ASD may have a comorbid mental disorder, and of these, 40% with up to two or more comorbidities.<sup>(3,4)</sup>

A review study showed that individuals affected by ASD find it difficult to access care, such as the lack of services and prepared professionals, diagnostic difficulties, in addition to the lack of research on the subject, a worsened scenario in developing or emerging countries, as in Brazil.<sup>(5)</sup>

Trained professionals can contribute to the identification of signs and symptoms of ASD as well as carry out relevant interventions and necessary referrals. Thus, nurses' practice in specialized care is emphasized, which in Brazil takes place in the Child and Adolescent Psychosocial Care Centers (CAPSIJ - *Centros de Atenção Psicossocial Infanto-Juvenil*), a component of the Psychosocial Care Network (RAPS - *Rede de Atenção Psicossocial*), and also in welcoming actions in the health system, since indi-

viduals with ASD present, more frequently, medical and psychological comorbidities.<sup>(1,5)</sup>

In the review carried out, national productions addressed nurses' care for children/adolescents with ASD in primary care services with actions to identify signs and symptoms and support for family members, which was not observed considering specialized care by nurses in specialized services.<sup>(6-9)</sup> The international literature brought data consistent with the findings in the national literature, showing that nurses' role in ASD care is mostly focused on promotion and prevention in mental health. In developed countries, the literature highlighted using assessment instruments and structured care strategies in specialized services, without specifying the individual practices of the professionals involved.<sup>(10-13)</sup>

The national survey between 2014-2017, already mentioned, identified that CAPSIJ teams varied according to their type (CAPS-I-II-III) and that, in the procedures carried out, communicative practices and psychosocial rehabilitation together amounted to only 10.3% of citations, with the majority being group/individual consultations in services.<sup>(1)</sup>

Thus, the question is: How is the care provided by nurses in assisting children and adolescents with ASD in CAPSIJ?

In this context, we aimed to understand nurses' representation about the care for children/adolescents with ASD in CAPSIJ.

## Methods

This is an exploratory, descriptive, cross-sectional and qualitative study, as it was intended to seek the uniqueness of nurses' experience in assisting children/adolescents with ASD, facilitated by the qualitative approach.<sup>(14)</sup> Data collection was carried out in two CAPSIJ, in the metropolitan region, between August/October 2017, located in the municipalities, São Bernardo do Campo (SBC) and northern São Paulo (SP), industrial regions, which had as managers the same social health organization (SHO). The CAPSIJ had a total of 17 nurses.

The research was presented to SHO who informed nurses; thus, the sample was composed of five nurses who met the inclusion criteria of being graduated in nursing for at least three years, working at CAPSIJ for at least six months and being studying specialization in mental health. Being a substitute nurse not assigned to the CAPSIJ was an exclusion criterion. Participants signed the Informed Consent Form, being an intentional sample with three nurses from CAPSIJ-SBC and two nurses from CAPSIJ-SP. For ethical reasons, they were identified by the letter N followed by a number.

We respected and used the COREQ (COnsolidated criteria for REporting Qualitative report).<sup>(15)</sup> One of the researchers was a nurse at the aforementioned SHO, specialist in mental health, working in a tertiary service, interested in the subject due to her personal experience of the study's problem, and was responsible for carrying out the interviews, which were previously scheduled and carried out privately at the CAPSIJ in approximately 40 minutes. A pilot test was carried out with three CAPSIJ nurses, different from the research sites, a test that showed the triggering question adequacy to reach the objective, without the need for changes. The question was asked: How do you provide care for children/adolescents with ASD in your workplace? There was no approach of nurses with the interviewer.

The content transcribed from the recordings was validated by participants without suggestions. Content analysis,<sup>(14)</sup> data treatment strategy, followed the pre-analysis phases with in-depth read-

ing of transcripts searching the structuring nucleus, using semantic resources; afterwards, the material was explored, reconstituting participants' common organizing principles, making it possible, as a result of the analysis, to reveal the categories and subcategories that were interpreted in the light of the Social Representations Theory (SRT) in Moscovici's conception.<sup>(16)</sup> The SRT made it possible to know individuals' insertion in their environment, practical reality construction, their understanding of the world and the meanings attributed, thus the representation of the phenomenon. Data analysis was carried out by two authors, one already mentioned and a professor in the field of mental health.

After analyzing the empirical material, the first category represented by "Nurses' care for children/adolescents with autism spectrum disorder" was obtained, with subcategories: care with the therapeutic environment; and range of social interaction of individuals with autism spectrum disorder; guidance of family members and caregivers, and assistance in data collection for identification and assessment of cases and care planning. The second category was represented by "Difficulties faced by nurses in assisting children/adolescents with autism spectrum disorder", presenting as subcategories: slow and disjointed development of autism spectrum disorder patients; difficulty in articulating with family and educational system for continuity of care; and poor training for nurses' care for children/adolescents with ASD.

Approval by the Research Ethics Committee of the *Fundação ABC* school of medicine, under Opinion 09802512.0.0000.0082.333, respecting Resolutions 466/2012-510/2016, stands out.

## Results

The sample consisted of five nurses, female, between 25-28 years old, working at CAPSIJ between six months and three years, all studying specialization in mental health. During the interviews, participants identified perceptions (objectification) and described (anchoring) the care they provided, composing the structuring nucleus and

also the peripheral elements represented by the difficulties to carry it out, revealing the formation and functioning of reference systems, classifying and interpreting experiences according to SRT and Moscovici.<sup>(16)</sup> The analysis showed nurses' representations and activities' reality, mutually influencing each other as in a process.

### Nurses' care for children/adolescents with autism spectrum disorder

Nurses' representations about their assistance in the CAPSIJ were anchored in the description of the activities carried out, creating the subcategories described below.

Care with the therapeutic environment and scope of social interaction of individuals with autism spectrum disorder, a subcategory related to care, is an activity highlighted as relevant, providing coexistence and concomitant care, as shown in the speech that follows:

*Teaching social skills, for instance, teaches him to live with other children, to interact appropriately, [...] rules of limits, understand emotions, understand what he can and cannot do, what he can do in place when he is self-harming or aggressive [...]. (N2)*

Guidance activities for family members/caregivers, another subcategory of care, shows nurses' concern with continuity of care through strengthening family members/caregivers:

*Maintaining parental guidance is paramount to maintaining success in the child's improvement so that treatment, school and at home all speak the same language. (N1)*

The emphasis on observation of behavior, such as assistance, and its importance for the therapeutic project is presented in subcategory assistance in data collection for identification and evaluation of cases and care planning, as shown in the following statements:

*As nurses, I asked the mother how the psychomotor development was, the whole interview, I collected*

*this data and took it to the group and we set up the therapeutic project. (N4)*

*We nurses have a look like this in identifying these signs and symptoms that indicate the disease or disorder and the improvement or not. (N2)*

Difficulties faced by nurses in caring for children/adolescents with autism spectrum disorder made up the second category, it was unveiled while the Nurses presented the way they represented their care.

Thus, the slow and disjointed development of ASD patients is a subcategory representing one of the difficulties highlighted by nurses in caring for users and caregivers as a family/school exemplified by N5's speech:

*[...] at first, I felt the result was very slow, you do it, it regresses, then it comes back, it is a job that has to be positive [...] an autistic does this, because they know a lot about a certain subject, and restricts that subject that interests him, the difficulty is changing the subject [...] (N5)*

Difficulty in articulating with family and educational system for continuity of care, another subcategory, is related to the difficulty represented by the slow and disjointed development presented above:

*[...] then the family gets discouraged and we really need the family to continue the child's treatment, no matter how intensive it is I come every day, but what about on the weekend and at school? Everything has to integrate, and this is the difficulty, for example: treatment at CAPS plus family plus school, all speaking the same language. (N2)*

*[...] this is the biggest difficulty, the interaction we have here and the matrix that the institution is using, we go to the educational institution to discuss some cases to help the dialogue with other institutions [...] (N3)*

It is observed, through the representations of the difficulties revealed so far, that having the capacity



to provide assistance to users with ASD in CAPSIJ is flagrant; however, subcategory poor training for nurses' care for children/adolescents with autism spectrum disorder is revealed to represent difficulties for nurses, exemplified by the following speech:

*[...] now that I've been here for 3 years, I feel more prepared to do this job, at first it was complicated because we learn very little in graduation, especially in the children's area. Nursing people learn from day-to-day experience, [...] and here it's all group guidance. (N5)*

It is noteworthy that no differences were observed in the response pattern of the participants even considering different data collection sites, denoting a possible power of the findings.

## Discussion

Data collection carried out in only two CAPSIJ is a limitation for the study as well as the reduced number of participants, characteristic of qualitative studies. However, the results revealed nurses' practice in ASD and can contribute to improving pedagogical projects for bachelor's/graduate degrees in nursing and mental health policies and permanent education in health, considering ASD as a theme.

In the first category, one of the representations of assistance unveiled by the speeches evidenced subcategory care with the therapeutic environment and scope of social interaction of individuals with autism spectrum disorder, which comprises attention to individuals through adaptation and use of spaces as a care strategy, considering individuals with their needs and their surroundings.<sup>(7,8,17)</sup>

Therapeutic environment maintenance includes attention to the time spent on consultations, use of clear and assertive communication, attention to behavioral changes, physical needs, attention to comorbidities, environment organization and hygiene, attention to caregivers'/relatives' support needs, i.e., nurses appropriate the environment to carry out care, as observed in the national and international literature.<sup>(12,18,19)</sup>

The appropriate therapeutic environment for individuals with ASD should help them to develop self-esteem and self-care, encourage interaction and social reintegration, and provide comprehensive care. Nurses seek, based on a comprehensive assessment, to consider the entire spectrum of children's/adolescents' life, with the family and school environment, exploring intervention alternatives, which requires readiness and creativity.<sup>(17-19)</sup>

Also considering care with the therapeutic environment, nursing performance in the observation of behavior and interaction with children/adolescents stands out, contributing to the physical environment organization and establishing routines that can be shown on boards, panels or agendas, adapting the environment to facilitate understanding and develop children's/adolescents' independence in relation to daily routines.<sup>(20,21)</sup>

In these spaces, it is also possible to guide family members/caregivers, another subcategory related to care, which can occur during care for children/adolescents with ASD with instructions for the proper behavior management. Parents'/caregivers' preparation is of fundamental importance for continuity of care and care comprehensiveness.<sup>(9,11,20,21)</sup>

Individuals with ASD are more likely to seek medical or mental treatments than the general population. Thus, nurses will possibly come into contact with this demand and will need to carry out educational actions to strengthen family members/caregivers.<sup>(9,10)</sup>

As an example of the importance of family involvement, an American study evaluated a nursing intervention proposal in the surgical preparation of children/adolescents with ASD and their families, based on improving relationship and communication skills, with emphasis on listening to family members to establish individualized care. Significant results, regarding preparation for the procedure, were highlighted by family members involved.<sup>(12,22)</sup>

Composing the subcategory that addresses the importance of nurses' competencies to identify signs and symptoms of ASD, this professional's performance in welcoming in various services is highlighted, contributing to specific interventions and treatments as well

as to guide family members/caregivers, seeking to reduce the impacts and aversive consequences of ASD and encourage continuity and active participation in treatment of all the people involved.<sup>(4,6,8,20)</sup>

Although the participants did not objectively name specific strategies and techniques for caring for people with ASD, they cite activities that corroborate with methods of evaluation, classification and screening of child development indicators such as *Indicadores Clínicos de Risco para o Desenvolvimento Infantil* (IRDI), an instrument developed by Brazilian researchers, and the Modified Checklist for Autism in Toddlers (M-Chat), validated in Brazil, both free to use, easy to apply and that can contribute to monitoring of signs and symptoms, in addition to enabling the planning of intervention actions.<sup>(20,23)</sup>

Perhaps, the difficulty observed regarding the objective naming of specific strategies and techniques is due to the current controversy between the psychosocial rehabilitation approach developed by the CAPSIJ and specialized care defended and intended by the movement of parents with children with ASD. It is true that standardized instruments and treatments contribute, but respect for the uniqueness of each individual/family must be paramount in choosing the approach to be used.<sup>(23,24)</sup>

Instruments and accurate clinical evaluation are important in the Singular Therapeutic Project (PTS) construction<sup>(7)</sup>, which considers each individual's and family's particularities and reaffirms the indispensability of an interprofessional team and its various views, facilitating evolution documentation and leading the team to adequate care.<sup>(8,24,25)</sup>

In the results, it was possible to know the representations about the necessary care and practices advocated in the studied literature, however, arguments to support the practice are not considered by the participants, only users' needs are cited as a justification. It suggests lack of knowledge about denominations and assessment instruments, which is corroborated by the representations revealed as difficulties, therefore, in the second category, presented below.

The representation of difficulties to watch, as a second category, brought users' slow evolution as a

subcategory, and was associated with specificities of communication and social interaction, cited as constant problems of difficult clinical management, worsened when considering the various contexts of users'/families' lives. The absence and flaws in the interaction with the child/adolescent with ASD tend to aggravate and potentiate the development deficits, so it is up to the family/caregivers, education and health professionals, to act together to provide the best development. Continuity of care needs to be guaranteed, by preparing the family and the school system.<sup>(1,8,10,12,20)</sup>

Nurses, together with the team, must be committed to comprehensive care and continuity of care, through intersectoral practices, and use as a principle the care of psychosocial factors, seeking individualized and humanized care to promote quality of life and well-being both for children/adolescents and for the family and education professionals.<sup>(6,8,11,19,25)</sup>

It is recommended to look closely to perceive the nuances of global and behavioral development, as individuals with ASD tend to express themselves in an atypical way and, perceiving the evolution itself, is significantly more difficult.<sup>(5,6,11,12)</sup>

One of the main challenges is to help individuals with ASD to develop empathetic behaviors. For empathetic feelings/behaviors to occur, inferences of mental states are necessary that lead to the understanding, explanation and prediction of behaviors. Thus, the development of an empathic feeling is related to what individuals experience and perceive, allowing attributing to other individuals the same mental states in similar contingencies.<sup>(26)</sup>

Individuals with ASD are able to understand social rules and emotional expressions; however, they have difficulty identifying the contingencies in which they must present socially accepted or expected behavior.<sup>(7,8,10,26)</sup> Individuals with ASD need to develop this ability to identify, experience and project mental states to themselves and others, which can be provided from the relationship with nurses in individual or group activities.<sup>(8,13,26)</sup>

The literature points out that structured behavioral interventions for the development of these skills usually obtain positive results in the long term; however, for this to happen, it is necessary that the

multidisciplinary team is highly trained,<sup>(6-9)</sup> as children/adolescents with ASD should not be seen only as a set of symptoms that need to be remedied or resolved, but rather as someone with characteristics and a peculiar way of being in the world.<sup>(4,7,8)</sup>

According to the data obtained in the study and in line with the literature, trained professionals can identify early signs/symptoms of ASD, thus adapting the approach, assistance and relevant referrals, minimizing losses.<sup>(1,5,6,18-20,25,27)</sup>

However, the last subcategory referring to difficulties, represented by poor training to assist users with ASD, was anchored in reports that revealed that nurses' professional preparation in the sample was a result of practice, living with co-workers and taking courses promoted by the services, and not based on a formal education process. It is emphasized that being in a specialization course in mental health was an inclusion criterion for the sample, which alerts to the need to introduce the theme in nurses' training processes.

Studies show that the training of primary care professionals to suspect cases of preschool autism, associated with the development of a relationship of trust, meets parents' expectations, their needs and provides relevant referrals to children, which is decisive for case evolution.<sup>(8,9,27)</sup>

On the other hand, health and social support services, when poor, increase the stress of caregivers/relatives of children/adolescents with ASD, impacting their quality of life, which is also true when considering educational and leisure services. Thus, having professionals prepared to identify the needs of children/adolescents with ASD as well as their guardians/caregivers is of paramount importance for the welcoming and beginning of the care process, as observed in the national and international literature.<sup>(6,8,9,11,19,25)</sup>

In the discussion of the results obtained in this study, it was possible to observe that the representations of the difficulties perceived by the sample in the care for children/adolescents with ASD corroborate the literature. The representations about specialized practice in CAPSIJ in the advent of ASD were revelations, content for which further investigations are recommended.

## Conclusion

The findings of this study made it possible to understand nurses' representations regarding specialized care in CAPSIJ to children/adolescents with ASD, which requires knowledge to identify, evaluate, perform individual/group care, guidance for family-caregivers-education professionals. Difficulties are also represented that can be mitigated through educational actions both in the official training process of nurses and through permanent education in health, recommending the consideration of the ASD theme in both.

## Collaborations

Jerônimo TGZ, Mazzaia MC, Viana JM and Chistofolini DM declare that they contributed to the study design, data analysis and interpretation, writing of the article, relevant critical review of the intellectual content and approval of the final version to be published.

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