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Original

Knowledge and practice of primary care nurses about autism spectrum disorder

Conhecimento e prática de enfermeiros da atenção primária sobre o transtorno do espectro autista

Conocimiento y práctica de los enfermeros de atención primaria sobre el trastorno del espectro autista

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Abstract

Objective: To evaluate the knowledge and practice of nurses from primary health care units about autism spectrum disorder. **Method:** Cross-sectional, quantitative study with 42 primary care nurses from Teresina, Piauí. A questionnaire on professional characteristics and knowledge was used. Simple frequency analyses and associations between variables were performed, adopting a maximum likelihood test with $p<0.05$. **Results:** There was a predominance of nurses aged 23 to 72 years, female (95.2%) and with more than ten years of experience (78.6%). Most (95.2%) reported insufficient knowledge during the graduation, 88.1% assisted or suspected of children with characteristics of autism spectrum disorder in childcare consultations, 85.7% did not know screening instruments and none received training from the service. Medium level of knowledge (66.7%) prevailed, but with deficits in content on characteristics and etiology. There was a statistically significant association between level of knowledge and age group ($p=0.033$). **Conclusion:** There is a need for appropriate undergraduate training and continuing education for professionals.

Keywords: Child health; Autistic disorder; Nursing.

Whats is already known on this?
Cases of autism spectrum disorder continue to grow and this clinical condition is present in childcare consultations. Knowledge is necessary for early identification of suggestive characteristics and appropriate management.

What this study adds?
It facilitates the local diagnosis of the situation; points weaknesses in assistance and gaps in graduation and the need for appropriate training and continuing education for primary care professionals.

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Resumo

Objetivo: *Avaliar conhecimento e prática de enfermeiros de unidades de atenção primária à saúde acerca do Transtorno do Espectro Autista.* ***Método:*** *Estudo transversal, quantitativo, com 42 enfermeiros da atenção primária de Teresina, Piauí. Utilizou-se questionário sobre características profissionais e conhecimento. Realizaram-se análises de frequência simples e associações entre variáveis, adotando-se teste da razão de máxima verossimilhança com p<0,05.* ***Resultados:*** *Predominaram enfermeiros com 23 a 72 anos, sexo feminino (95,2%) e com mais de dez anos de atuação (78,6%). A maioria (95,2%) referiu conhecimento insuficiente na graduação, 88,1% atenderam ou suspeitaram de crianças com características do Transtorno do Espectro Autista nas consultas de puericultura, 85,7% não conheciam instrumentos de triagem e nenhum recebeu capacitação pelo serviço. Prevaleceu nível médio de conhecimento (66,7%), porém com déficits em conteúdos sobre características e etiologia. Associação estatisticamente significativa entre nível de conhecimento e faixa etária (p=0,033).* ***Conclusão:*** *Há necessidade de formação apropriada na graduação e de educação continuada para os profissionais.*

Descritores: *Saúde da criança; Transtorno autístico; Enfermagem.*

Resumén

Objetivo*: Evaluar el conocimiento y la práctica de enfermeros de unidades de atención primaria de salud sobre el trastorno del espectro autista.* ***Método****: Estudio cuantitativo transversal, con 42 enfermeros de atención primaria en Teresina, Piauí. Se utilizó un cuestionario sobre características y conocimientos profesionales. Se realizaron análisis de frecuencia simple y asociaciones entre variables mediante la prueba de máxima verosimilitud con p<0.05.* ***Resultados****: Predominaron los enfermeros con edades de 23 a 72 años, del sexo femenino (95,2%) y con más de diez años de experiencia (78,6%). La mayoría (95,2%) refirió conocimientos insuficientes durante la graduación, el 88,1% atendió o sospechó de niños con características de trastorno del espectro autista en las consultas de puericultura, el 85,7% desconocía los instrumentos de tamizaje y ninguno recibió capacitación a través del servicio. Predominó un nivel de conocimientos medio (66,7%), pero con déficits en contenidos sobre características y etiología. Asociación estadísticamente significativa entre nivel de conocimientos y grupo de edad (p=0,033).* ***Conclusión****: Necesidad de una adecuada formación de pregrado y educación continua de los profesionales.*

Descriptores: *Salud infantil; Trastorno autista; Enfermería.*

INTRODUCTION

Child health represents a priority health care area, due to the vulnerability at this stage of life. The childcare consultation allows the nurses to evaluate the children, monitor their growth and development, identify signs of clinical suspicion, know health problems, prescribe care and guide mothers, in addition to establishing bonding, communication and interpersonal relationship.[1]

It is important that nurses are trained and have knowledge about the main changes that affect child development, including Autism Spectrum Disorder (ASD). The early detection of the clinical signs of ASD favors the diagnosis and this leads to significant advantages for the children's development, minimizing losses.[2]

ASD consists of an alteration of neurodevelopment, characterized by restrictive, repetitive and stereotyped behaviors, which vary in lesser or greater intensity, in addition to difficulties in interaction and social communication. To enhance child development and minimize such symptoms, specific and early conduct is necessary.[3]

Children diagnosed with ASD need multiprofessional monitoring. In this context, nursing care is of great relevance in the provision of care that will contribute to improving quality of life, promoting child development, facilitating access to information and directing essential health services.[4]

However, despite the important role of nurses, it is a subject little addressed in the curriculum of the undergraduate nursing course at universities, causing professionals to have little proficiency in assisting this public.[5]

Such fragility in academic training reflects in professional performance, as many children fail to be properly evaluated, leading to the late identification of signs and symptoms and interventions that could minimize the functional losses caused by ASD.[6]

Given the above and the scarcity of studies related to the theme, the following guiding question was delimited: What is the knowledge and practice of nurses working in primary care on ASD? Thus, this study aimed to evaluate the knowledge and practice of nurses working in primary care units about ASD.

METHODS

This is a descriptive, cross-sectional study with a quantitative approach. The study population consisted of 69 nurses, a number equivalent to the number of nurses working in the primary health care units (PHCU) of the northern region of the municipality of Teresina, Piauí. A non-probabilistic sampling was established, for convenience, adopting as inclusion criteria, acting in the Family Health Strategy (FHS) and performing childcare consultations. In turn, the exclusion criteria were PHCU located in rural areas,

professionals who were on vacation, time off or sick leave during the data collection period. This resulted in a sample of 42 nurses.

Data collected from May to June 2022 through a self-administered instrument by the nurses in their office with only the presence of the researcher, which was collected after complete filling, in order to avoid bias from a possible consultation of the professionals to theoretical references.

The questionnaire was structured in two parts: the first addressed information on professional characterization and the second part included the evaluation of knowledge about ASD, consisting of 21 statements for which the nurses indicated whether they were true or false. It is noteworthy that the instrument that evaluated knowledge was prepared according to the precepts of the Manual: Guidelines for Attention to the Rehabilitation of People with Autism Spectrum Disorders.[7]

Each question was assigned one point, so that the score of the instrument ranged from 0 to 21 points, having as cohorts established for the classification of the level of knowledge: regular level - less than or equal to 11 points (less than or equal to 50%); medium level - from 12 to 16 points (51% to 80%) and high level - greater than or equal to 17 points (greater than or equal to 81%).[8]

The data collection instrument that evaluated knowledge about ASD was previously validated by specialists in the field of child health and mental health, obtaining a general content validity index (CVI) of 0.90 of agreement on the items of the questionnaire regarding the relevance and clarity of each item.

Data organized in Excel and analyzed using the PASW Statistics for Windows Software (SPSS) version 20.0. For the associations between the variables, the maximum likelihood test was used, considering the analyses as statistically significant when $p < 0.05$.

Research approved by the Research Ethics Committee (REC) of the State University of Piauí (SUPI) according to Resolution 466/2012 of the National Health Council, under opinion 5.361.620 and CAAE 57823122.8.0000.5209.

RESULTS

Table 1 shows the social and professional characterization of the participants. There was a predominance of females (40; 95.2%), aged 40 to 59 years (25; 59.5%), with specialization (33; 78.6%) and experience of more than ten years in the Family Health Strategy (33; 78.6%).

As for the knowledge acquired at undergraduate course about ASD, (25; 95.2%) of the professionals considered it insufficient, although (41; 97.6%) considered it to be an important topic that should be better worked on. All were unanimous (42; 100.0%) when they had never received training on ASD offered by the service.

Table 1. Distribution of nurses according to sociodemographic characteristics and professional training, Teresina - PI, Brazil, 2022 (N= 42)

Variables	N	%
Sex		
Female	40	95.2
Male	2	4 8
Age group (years)		
23 – 39	10	23.8
40 – 49	10	23.8
50 – 59	15	35.7
60 – 72	7	16.7
Academic degree		
Specialization	33	78.6
Master/PhD	9	21.4
Time working in the FHS (years)		
Up to 5	6	14.3
6 to 10	3	7.1
More than 10	33	78.6
Knowledge acquired at undergraduate course about ASD		
Yes	2	4. 8
No	40	95.2
It is important to address ASD during the undergraduate course		
Yes	41	97.6

No	1	2. 4
Received training		
Yes	-	-
No	42	100.0

Source: Research data, 2022.

Regarding professional practice, Table 2 shows that nurses (37; 88.1%) have already attended or suspected children with signs indicative of ASD in childcare consultations. On the other hand, (41; 97.6%) mentioned that the service does not have protocols for tracking/screening ASD signals and (36; 85.7%) do not know specific instruments for early detection of these manifestations.

Most nurses (38; 90.5%) mentioned feeling little or no security to act in assistance regarding the identification of clinical warning signs for ASD. The conduct mentioned when identifying children with these signs was referral to the team physician or specialist.

Regarding the strategies used to identify changes in child development, only one nurse (2.3%) mentioned using a specific screening instrument for ASD. Most of them emphasized listening to the parents' reports (34; 80.9%) along with observing the child (33; 78.5%).

Table 2. Distribution of nurses according to practice in childcare consultations and screening of warning signs for Autism Spectrum Disorder, Teresina – PI, Brazil, 2022 (N= 42)

Variables	N	%
Assisted or suspected of children with ASD manifestations		
Yes	37	88.1
No	5	11.9
ASD Signal Screening Protocols		
Yes	1	2. 4
No	41	97.6
Knows an instrument for screening ASD signals		
Yes	6	14.3
No	36	85.7
Uses educational material in consultations		
Yes	21	50.0
No	21	50.0
Feels confident to identify signs of ASD		
Yes	4	9.5
No	21	50.0
Little	17	40.5
Conduct in the face of the identification of warning signs for ASD		
Medical referral of the team physician or specialist	42	100.0
Strategies for identifying changes in child development*		
Instrument for the screening of ASD signals	1	2. 3
Child's Observation of Signs of Alteration	33	78.5
Reports of parents, for evaluation of signs of developmental problems	34	80.9
Developmental milestones as described in the child's health booklet	31	73.8

Source: Research data, 2022.

*More than one of the options was marked by the research participants.

As for the evaluation of knowledge about ASD, Table 3 shows the number of correct answers to the questions by nurses. The questions with the highest rate of correct answers ranging from 81.0% to 95.2% corresponded to items 1, 3, 5 to 7, 9, 16 and 19, which dealt with communication, epidemiological aspects, etiology, routines and therapeutic resources of ASD. Questions 2, 4, 8, 11, 15, 17, 18 and 21 had the lowest rates of correct answers, from 23.8% to 61.9%. These were related to content on concepts, clinical manifestations, drug treatment and etiology.

Table 3. Distribution of correct answers of nurses regarding knowledge about Autism Spectrum Disorder, Teresina – PI, Brazil, 2022 (N= 42)

Questions	N	%
1. Children with ASD should be considered disabled persons for legal purposes (T)	34	81.0
2. ASD encompasses neurodevelopmental changes, conditions that are inserted in the same degree of impairment (F)	15	35.7
3. ASD has a higher incidence in female children (F)	38	90.5
4. Specific characteristics of ASD can be identified in the neonatal period (F)	26	61.9
5. Children with ASD can present from the complete absence of speech to apparently adequate language but with particularities (F)	34	81.0
6. The etiology of ASD is associated with multiple factors, including genetic, biological and environmental factors (T)	35	83.3
7. The child with ASD has absences of facial expressions aimed at communication (T)	38	90.5
8. The child with ASD may show exacerbated or decreased sensitivity to sensory stimuli (T)	10	23.8
9. Children with ASD have difficulty modifying their diet (T)	36	85.7
10. Children with ASD may be prone to echolalia (T)	32	76,2
11. Children with ASD tend to explore objects and their functions (F)	15	35.7
12. Children with ASD may have associated intellectual disability (T)	31	73.8
13. In the child with ASD usually the direction of the smile is diffuse, not directed to the other, without identifiable reason or the child does not smile (T)	33	78.6
14. Modified Checklist for Autism in Toddlers (M-CHAT) is an ASD screening instrument (T)	32	76.2
15. There are specific medications for ASD (F)	25	59.5
16. ASD symptoms such as insomnia, aggressive behaviors and stereotypes can be mitigated with the use of psychiatric medication (T)	36	85.7
17. Children with ASD show intense manifestation of displeasure when faced with ritualized routines in their daily lives (F)	20	47.6
18. A common characteristic of children with ASD is to demonstrate attention and social reciprocity to maternal and family speech (F)	18	42.9
19. Medication is the main therapeutic resource for the person with ASD (F)	40	95.2
20. Interest in make-believe games and imitation games are present in children with ASD (F)	30	71.4
21. Perinatal infections, prematurity and birth asphyxia are among the possible environmental causes of ASD (T)	-16	38.1

Source: Research data, 2022.

Regarding the classification of the level of knowledge, table 4 shows that the majority (28; 66.7%) of the professionals had medium level of knowledge, which corresponded to the correct answer of 12 to 16 questions (51% to 80%). Only eight (19.0%) nurses had a high level of knowledge.

Table 4. Level of knowledge of nurses about Autism Spectrum Disorder, Teresina - PI, Brazil, 2022 (N= 42)

Level of knowledge	N	%
Regular level	6	14. 3
Medium Level	28	66.7
High level	8	19.0

Source: Research data, 2022.

Table 5 shows a statistically significant association between the level of knowledge and age group (p= 0.033), observing that the level of high knowledge prevailed among younger professionals (40%). The medium level of knowledge was more frequent among nurses with master's/PhD degrees (77.8%) and with less time working in the Family Health Strategy (FHS) (83.3%).

Table 5. Association of nurses' level of knowledge about Autism Spectrum Disorder related to social and professional variables, Teresina - PI, Brazil, 2022 (N= 42)

	Regular N (%)	Medium N (%)	High N (%)	p
Age group (years)				**0.033**
23 – 39	-	6 (60.0)	4 (40.0)	
40 – 49	-	8 (80.0)	2 (20.0)	
50 – 59	3 (20.0)	10 (66.7)	2 (13.3)	
60 – 72	3 (42.9)	4 (57.1)	-	
Academic degree				0.698
Specialization	5 (15.2)	21 (63.6)	7 (21.2)	
Master/PhD	1 (11.1)	7 (77.8)	1 (11.1)	
Time of FHS				0.185
Up to 5	-	5 (83.3)	1 (16.7)	
6 to 10	-	1 (33.3)	2 (66.7)	
More than 10	6 (18.2)	22 (66.7)	5 (15.2)	

Source: Research data.
p of the Maximum Likelihood Ratio test

DISCUSSION

By indicating a high percentage of care or clinical suspicion of children with ASD manifestations in childcare consultations, this study demonstrates how much this clinical condition is present in primary care services. On the other hand, nurses do not feel totally confident in caring for these children, and there are still gaps related to the knowledge deficit.

Research shows that the number of cases of autism spectrum disorder continues to grow, making it a challenge for professionals who will provide care to these children.[9]

This problem begins in professional training itself. This study showed that most professionals reported not having obtained sufficient knowledge about ASD, despite the theme having been judged as relevant, corroborating other studies that point to the deficit of knowledge on the subject among nursing undergraduates. This is the case of the study carried out at the University of Brasília in which all participants mentioned that they had not acquired sufficient knowledge about this theme during their undergraduate studies and more than 90% mentioned that they were not sure how to work with this public.[10]

This deficit of knowledge about ASD was identified not only in nursing, but also in courses such as physical education, psychology or medicine.[11] This raises the question of whether undergraduate courses, in general, deal with subjects such as ASD still in the context of training health professionals with relevance.

In a survey of medical students at the University of Alabama in the United States, more than 85% of participants rated their general knowledge about ASD as scarce and were unfamiliar with sensory problems that are often present in this audience. It was also pointed out that didactic and clinical training was insufficient to acquire skills for early diagnosis.[12]

Given the prevalence and complexity of ASD, addressing it still in the academic training of nurses, as well as other students in the health area, is important for them to acquire more proficient means of providing qualified care.[11] Therefore, given the identification of the difficulties presented by the participants of this research and the results pointed out in other studies, it is essential to pay greater attention to this theme in undergraduate studies.

Knowledge about ASD is necessary to identify and recognize, early, the first characteristics of alteration during the period of growth and development of the children. Among the factors that hinder early management is the lack of training offered by the service to the team and the dissemination of specific materials that facilitate detection. The idea that the identification of signs and symptoms suggestive of ASD is not the responsibility of the nurses, it also becomes another barrier to early detection and appropriate conduct by this professionals.[13]

In the present study, all nurses mentioned that they had not received training on the subject and most reported that the service did not use protocols or screening instruments to detect ASD signs. Only a few nurses mentioned knowing instruments to screen these signs and only one reported using it as a strategy to identify changes.

A similar result is observed in a research with nurses from the FHS of Santa Catarina, which showed that professionals did not perform screening using specific instruments for ASD signs. The way professionals evaluated the signs of developmental risk was usually through observation, parents' reports and the children's portfolio that shows the developmental milestones according to age.[14]

On the other hand, a study that screened the signs of childhood autism by primary health care nurses using the instrument called M-CHAT revealed that 20.45% of the children had clinical characteristics suggestive of ASD, and they were referred to the specialist to obtain an adequate diagnosis.[15]

It is noteworthy that, to provide subsidies to health professionals, especially in primary care, the Ministry of Health published manuals with guidelines and instructions on the signs observable at each stage of children development and proposes facilitating assessment instruments that can be used during consultations. Among the instruments for screening ASD indicators, the Modified Checklist for Autism in Toddlers (M-Chat) stands out, adapted and validated in Brazil, and can be applied by any health professional.[7]

In this context, the screening of suspected signs of ASD becomes fundamental as a public policy, as it would be the initial step to identify children at risk, whose follow-up would allow the referral for early diagnosis and interventions, which would favor the development of these children.[5] Therefore, the screening of ASD signs performed by the nurse in the childcare consultation is fundamental for child health.

Regarding the level of knowledge, although most have shown medium level, important deficits are observed in some specific questions regarding the suspicion of clinical manifestations of ASD, concepts and etiological factors, which can impact the care provided.

According to, in a study carried out with nurses from the FHS of the North of Santa Catarina on indicators for ASD screening, they demonstrated doubts and difficulties in describing about ASD, concepts and causes.[14] Another study carried out with nurses from the FHS of ABC Paulista pointed out the insecurity and fragility of the knowledge and practice of nurses. Most had difficulties in defining ASD and describing its characteristics.[16] Similarly, in a study with nurses from Turkey, gaps in knowledge regarding the classification of ASD were observed.[17]

Research carried out in Italy showed that nurses had basic knowledge about ASD and that those older and with more experience in pediatrics or living with children with ASD had higher knowledge scores.[18] A different result was obtained in the present study in which the level of high knowledge was observed more frequently among younger professionals, which may be related to the most recent training and the inclusion of this theme in class content.

As for the conduct observed in the practice of the nurses participating in the research, all mentioned that in the face of suspicious cases, they refer the child to the team physician and specialized services.

In this context, the importance of the work of the multidisciplinary team in the early identification and care of children with ASD is highlighted. It is important for primary care professionals to develop intersectoral actions, maintain articulation with other network services as a possibility to enrich diagnoses, share interventions and contemplate the diversity and particularities of each person with ASD and his family.[13]

Therefore, this intersectorality guides the therapeutic monitoring of the person with ASD and relates among the care actions, to the psychosocial care network, mainly, the children's Psychosocial Care Centers (CAPS), which are mental health services aimed at caring for children and adolescents with mental disorders.[19]

As a limitation, it is pointed out that the research occurred with a certain number of units in a Brazilian city, making it difficult to generalize. Thus, it is possible that its findings are different or similar to other cities. Therefore, it is suggested to expand this research involving other locations, as well as not only nurses, but other team professionals to identify deficiencies and promote training on this topic. Also, it would be relevant to carry out studies aimed at implementing training with professionals and evaluating their impact on knowledge.

The findings of this research contribute to a diagnosis of the local situation, help to identify weaknesses and provide the opportunity to (re) think about professional practice, aiming at improving care.

CONCLUSION

According to the results obtained, there is a need for training and awareness offerings on the subject in the academic and professional spheres. Many professionals do not feel adequately prepared to provide assistance due to the little contact with the subject at undergraduate course and the lack of training offered by the services. However, it is essential that nurses acquire knowledge about ASD that enables early identification, referral of suspected cases and provision of adequate care to children with ASD and their families.

There is a need for appropriate training during graduation on ASD and continuing education for primary care professionals, since this is the preferred gateway to SUS.

CONTRIBUITIONS

Conception or design of the study: Aguiar ASC, Almeida DSM, Data collection: Almeida DSM, Analysis and interpretation of data: Aguiar ASC, Almeida DSM, Almeida PC, Writing of the article or critical review: Aguiar ASC, Almeida DSM, Veloso LUP, Carvalho AMB. Final approval of the version to be published: Aguiar ASC, Veloso LUP, Carvalho AMB, Almeida PC

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