AWARENESS OF NURSING STAFF ABOUT AUTISM SPECTRUM DISORDER

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Abstract

Introduction. Autism spectrum disorder (ASD) are the neurological disorder characterized by the lack of social communication and interaction, as well as the limited or repetitive behavioral patterns. The prevalence of ASD has shown the increase in the world; consequently, early identification of ASD signs plays a key role in the treatment effectiveness. It is also crucial to note the importantance nurses in coordinating the care of children with ASD and their families.

Aim: to study the awareness, knowledge and experience of nurses regarding ASD.

Materials and methods. A cross-sectional study was conducted. The questionnaire, that included 19 questions on the autism awareness of children developed by Muideen O. Bakare et al was adapted. The questionnaire has been translated and adapted to Kazakh and Russian languages. The survey was conducted among nurses of the general practitioners and pediatricians of healthcare facilities that provide primary care (PHC) in Almaty.

Results. The majority of respondents in both groups had more than 11 years of work experience (44,7%). 66,7% of respondents consider ASD as a mental disorder, and approximate 9,1% of respondents interested to learn more about ASD. 70,9% of respondents know about the changes in ICD-11. Only 41,7% were aware of all methods of ASD diagnosis, and only 27,8% were aware of the modified autism screening test for children. Pediatric nurses showed more in-depth knowledge in four areas than general nurses.

Conclusion. Nurses need capacity-building training in caring for patients with ASD, especially working in teams with GPs. Healthcare managers need to prioritize the knowledge transfer trainings of nurses due to recent ASD increase and timely screening is best measure to provide effective care and treatment.

Keywords: autism spectrum disorder, PHC, awareness, nursing staff.

Резюме

ОСВЕДОМЛЕННОСТЬ СРЕДНЕГО МЕДИЦИНСКОГО ПЕРСОНАЛА О РАССТРОЙСТВЕ АУТИСТИЧЕСКОГО СПЕКТРА

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Актуальность. Расстройства аутистического спектра (РАС) - это неврологические расстройства, характеризующиеся проблемами в социальной коммуникации и взаимодействии, а также ограниченными или повторяющимися моделями поведения. Распространенность РАС в мире возросла; таким образом, их раннее выявление играет ключевую роль в эффективности лечения. Также важна роль медсестер в координации ухода за детьми с РАС и их семьями.

Цель исследования: изучить знания и опыт медсестер в области РАС.

Материалы и методы. Было проведено крос-секционное исследование. Мы адаптировали анкету, которая включала 19 вопросов о знаниях о детском аутизме, разработанную Muideen O. Bakare и соавторами. Анкета была адаптирована на казахский и русский языки. Опрос был проведен среди медицинских сестер врачей общей практики и педиатров первичной медико-санитарной помощи (ПМСП) в Алматы.

Результаты. Большинство респондентов в обеих группах имели опыт работы более 11 лет (44,7%). 66,7% респондентов считают РАС психическим расстройством и примерно 9,1% респондентов хотели бы узнать больше о РАС. 70,9% респондентов знают об изменениях в МКБ-11. Только 41,7% были осведомлены обо всех методах диагностики РАС и только 27,8% знали о модифицированном скрининговом тесте на аутизм для детей. Педиатрические медсестры продемонстрировали более глубокие знания в четырех областях, чем медсестры общего профиля.

Выводы. Медсестры нуждаются в повышении квалификации по уходу за пациентами с РАС, особенно те, кто работает с врачами общей практики. Руководителям здравоохранения необходимо уделять первоочередное внимание повышению квалификации медсестер в связи с недавним ростом числа случаев РАС, и своевременное обследование является лучшим способом повышения эффективности их ухода и лечения.

Ключевые слова: расстройства аутистического спектра, ПМСП, осведомленность, средний медицинский персонал

Түйіндеме

АУТИЗМ СПЕКТРІНІҢ БҰЗЫЛУЫ ТУРАЛЫ ОРТА МЕДИЦИНАЛЫҚ ҚЫЗМЕТКЕРЛЕРДІҢ ХАБАРДАРЛЫҒЫ

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Кіріспе. Аутизм спектрінің бұзылуы (АСБ) - бұл әлеуметтік қарым-қатынас пен өзара әрекеттесу мәселелерімен және шектеулі немесе қайталанатын мінез-құлық үлгілерімен сипатталатын неврологиялық бұзылулар. Әлемде АСБ таралуы өсті; осылайша, оларды ерте анықтау емдеу тиімділігінде шешуші рөл атқарады. АСБ бар балаларға және олардың отбасыларына күтім жасауды үйлестіруде медбикелердің рөлі де маңызды.

Зерттеудің мақсаты: АСБ бойынша медбикелердің білімі мен тәжірибесін зерттеу.

Материалдар мен әдістері. Көлденең-қималық зерттеу жүргізілді. Біз *Muideen O. Bakare* және бірлескен авторлар әзірлеген балалар аутизмі туралы 19 сұрақтан тұратын сауалнаманы бейімдедік. Сауалнама қазақ және орыс тілдеріне бейімделді. Сауалнама Алматыда жалпы практика дәрігерлерінің медбикелері мен алғашқы медициналық-санитарлық көмек (МСАК) педиатрлары арасында жүргізілді.

Нәтижесі. Екі топтағы респонденттердің көпшілігінде 11 жылдан астам жұмыс тәжірибесі болды (44,7%). Респонденттердің 66,7% - ы АСБ психикалық бұзылыс деп санайды және респонденттердің шамамен 9,1% - ы АСБ туралы көбірек білгісі келеді. Респонденттердің 70,9%-ы ХАЖ-11 өзгерістері туралы біледі. Тек 41,7% - ы АСБ диагностикасының барлық әдістерін білді және тек 27,8% - ы балаларға арналған аутизмге арналған скринингтік тест туралы білді. Педиатриялық медбикелер жалпы медбикелерге қарағанда төрт салада тереңірек білім көрсетті.

Қорытынды. Медбикелер АСБ бар науқастарға , әсіресе жалпы тәжірибелік дәрігерлермен жұмыс істейтіндерге күтім жасау бойынша біліктілікті арттыруды қажет етеді. Денсаулық сақтау менеджерлері АСБ-ның жақында өсуіне байланысты медбикелердің біліктілігін арттыруға басымдық беруі керек және уақытылы тексеру олардың күтімі мен емінің тиімділігін арттырудың ең жақсы жолы болып табылады.

Түйінді сөздер: аутизм спектрінің бұзылуы, МСАК, хабардарлық, орта медициналық қызметкерлер.

Introduction

Autism spectrum disorder (ASD) is a disorder of the nervous system. Most often, ASD may manifest itself through impairments in social communication or interaction, in addition to restricted or repetitive behavior or interests of the individual [22]. The prevalence of ASD in world is about 0,6%, with higher rates in Australia (1,7%) and lower rates in Asia (0,4%) and Europe (0,5%) [18]. Research also shows that there are about 28,3 million cases of ASD worldwide, with 603,790 cases that are isolated cases, and 4,3 million years of life with disabilities [13].

Timely monitoring of children up to a certain age is extremely important, especially when there is an increase in ASD throughout the world. Early identification of ASD allows for effective treatment. Therefore, achieving earlier detection is possible only through screening or planning observation by a doctor and nurse in primary care facilities as well as it depends on the observation and attentiveness of parents of children with ASD [5,16,17].

Special attention should be paid to the role of nurses who can support parents or guardians of children with ASD, coordinate care, provide information on strategies for receiving care, educate parents, solve major problems related to ASD, and protect the interests of these children and their families [11]. Nurses should also coordinate care for both the child with ASD and his parents or guardians, for example, refer them to a psychologist on time or support families in important areas of family life management, meet the needs of siblings and plan for the future [6].

Realizing the importance of the role of nurses, some educational institutions include a standardized role-playing game with a teenage patient with ASD, which, according to students, provides a realistic environment that cannot be obtained using static dummies or high-precision simulators [15].

However, studies show mixed results regarding nurses' knowledge of how to support children with ASD and their general awareness of ASD. Some studies indicate the need for additional training of medical personnel and medical professionals on ASD issues [4,8,9,10,20]. A similar result was obtained in a study in Kazakhstan, where a lack of knowledge of the medical staff about ASD was revealed [19].

Therefore, the **aim** of our research is to study the nurses' knowledge and experience in autism spectrum disorder in Almaty city.

Materials and methods

A cross-sectional study was conducted. To achieve our purpose we adapted the international questionnaire provided by *Muideen O Bakare et al.* [3]. This questionnaire included the studying the awareness of health professionals on ASD [3]. The authors of this questionnaire included 19 questions, which was divided to four main domains. Each domain includes one or more questions. The number of questions determines his domain scores, for example, if a domain includes eight questions, then in this domain you can score a maximum of eight points and a minimum of zero points. More detailed information about four domains is presented by *Muideen O Bakare et al.* [3]. In addition, with our project team we included questions related to the knowledge of ICD code changes (because Kazakhstan planning to implement ICD-11 in 2027) and questions included related to their job experience. The questionnaire was adapted into Kazakh and Russian languages. The external expert checked the questionnaire.

The survey was conducted among nurses of the general practitioners and pediatricians in primary health care (PHC) facilities of Almaty city. The survey was conducted through paper-based questionnaire provision to healthcare workers and online via a Google Form link. At the first stage, online version of the questionnaire was distributed. The distribution was carried out with the Almaty Public Health Department support. Due to insufficient number of respondents replied by the use that of online questionnaire, we decided to continue using paper version. All participants completed the survey anonymously, on a voluntary basis.

According to electronic system of Almaty city 1733 nurses work in PHC, of which 1614 are working in team with general practitioner doctors and 430 with the pediatric doctor. Taking into account possible errors in filling out, we increased the sample size by 20%, thereby including 373 GP nurses and 245 pediatric nurses in the study. The sample size of this study was based on the cross-sectional study design formula, hence the sample size calculation formula is:

$$n = deff \times \frac{N \cdot \widehat{p}(1 - \widehat{p})}{(N - 1)\frac{d^2}{z_\propto^2} + \widehat{p}(1 - \widehat{p})}$$

Where:
n = sample size
N= population
Deff=1 (design effect - random sampling)
p̂=0,5
d= 0,05 (desired absolute precision or absolute level of precision)
z^∝=1,96 (z- index)

Statistical analysis was performed by using SPSS13. The Kuder-Richardson Formula 20 (KR20) value was selected to examine the reliability of the questionnaire by measuring the internal consistency, where it is recommended to use binary data [2,7]. The study variables were subjected to descriptive analysis. The significance of the relationship between qualitative variables and knowledge about Autism was determined using the chi-square test (χ2). Differences in mean scale values for independent groups were calculated using Student's t-test, and a p value <0.05 was interpreted as statistically significant. The P-value is less than 0.05 as statistically significant.

The study design was approved by the Local Committee on Bioethics, Kazakhstan (Protocol No. 02.01.04, 29 February 2024).

Results

The internal consistency coefficient (Kuder-Richarson reliability coefficient - KR20) of the measurements obtained from the questionnaire was 0,81. The largest number of respondents had more than 11 years of work experience (44,7%), in both groups, while the least had 6-10 years of work experience (21,3%). Only 28,3% of respondents noted that autism is a neurological disorder, whereas approximate 66,7% respondents indicate it as mental disorder. This fact may be due to that not all countries, including Kazakhstan, have moved to ICD 11. According to the existing ICD-10, autism is considered a mental illness and behavioral

disorders according to the code F. Moreover awareness of ASD was identified among 70,5% of respondents. However, about 9.1% of respondents indicated they were interested in learning more about autism, recognizing that they were not well informed about the condition. Amendments to ICD-11 were included in 2013, but full training was not carried out among medical specialists, however, the largest number of survey participants, 70.8%, were aware of these changes. It was also revealed that 13.8% of respondents would like to learn more about the changes that were included in ICD-11 in comparison with the previous version. Despite the fact that 70,9% of respondents noted that they knew the changes in ICD 11, only 23,2% were able to correctly indicate the types of ASD when detailed question were asked about the changes. Similarly with ICD 10, only 31,7% indicated the most correct answer about the types of autism (Table 1).

Table 1.

Characteristics of survey participants and general questions regarding ASD.

Questions and answers		Pediatric nurse	General Practitioners nurse	Total	P
		N(%)	N(%)	N(%)	
What is your work experience?	up to 5 years	81(33,2%)	126(34,5%)	207(34,0%)	0,123
	6-10 years	62(25,4%)	68(18,6%)	130(21,3%)	
	more than 11 years	101(41,4%)	171(46,8%)	272(44,7%)	
	Total	244(100,0%)	365(100,0%)	609(100,0%)	
Autism is:	mental illness	174(71,3%)	236(63,6%)	410(66,7%)	0,257
	neurological disease	60(24,6%)	114(30,7%)	174(28,3%)	
	educational disorder	3(1,2%)	6(1,6%)	9(1,5%)	
	Don't know	1(,4%)	6(1,6%)	7(1,1%)	
	this is not a pathology	6(2,5%)	9(2,4%)	15(2,4%)	
Do you know how Autism is coded according to ICD-10?	Diseases of the nervous system (code G)	31(12,7%)	70(19,0%)	101(16,4%)	0,103
	Mental and behavioral disorders (code F)	185(75,5%)	248(67,2%)	433(70,5%)	
	Certain conditions that arise in the perinatal period (to	7(2,9%)	17(4,6%)	24(3,9%)	
	I would like to study it in more detail, no one taught us this	22(9,0%)	34(9,2%)	56(9,1%)	
Are you aware of what changes are included in the ICD-11 Autism coding?	Mental, behavioral and neurological disorders	169(69,8%)	262(71,6%)	431(70,9%)	0,807
	Diseases of the nervous system (code 08)	31(12,8%)	51(13,9%)	82(13,5%)	
	Sleep-wake cycle disorders (code 07)	5(2,1%)	6(1,6%)	11(1,8%)	
	I would like to study it in more detail, no one taught us this	37(15,3%)	47(12,8%)	84(13,8%)	
What types of ASD (autism) do you know according to ICD-11?	ASD without intellectual disability and with mild or no speech impairment.	43(18,0%)	69(18,9%)	112(18,5%)	0,287
	ASD with intellectual disability and mild or no language impairment	19(7,9%)	44(12,1%)	63(10,4%)	
	ASD without intellectual development impairment and with speech impairment.	9(3,8%)	12(3,3%)	21(3,5%)	
	ASD with intellectual disability and speech impairment.	16(6,7%)	29(7,9%)	45(7,5%)	
	ASD with intellectual disability and lack of speech function.	16(6,7%)	10(2,7%)	26(4,3%)	
	Other specified ASD.	7(2,9%)	15(4,1%)	22(3,6%)	
	ASD, unspecified.	9(3,8%)	13(3,6%)	22(3,6%)	
	Don't know	61(25,5%)	88(24,1%)	149(24,7%)	
	there is no right answer	3(1,3%)	1(,3%)	4(,7%)	
	ASD without intellectual disability and with mild or no speech impairment.	56(23,4%)	84(23,0%)	140(23,2%)	
What types of ASD (autism) do you know according to ICD-10?	Atypical autism	72(31,2%)	120(33,8%)	192(32,8%)	0,134
	Rett syndrome	8(3,5%)	14(3,9%)	22(3,8%)	
	Other childhood disintegrative disorder	8(3,5%)	15(4,2%)	23(3,9%)	
	Hyperactive disorder combined with mental retardation	29(12,6%)	35(9,9%)	64(10,9%)	
	Asperger's syndrome	19(8,2%)	16(4,5%)	35(6,0%)	
	Other pervasive developmental disorders	5(2,2%)	24(6,8%)	29(4,9%)	
	Pervasive developmental disorder, unspecified	13(5,6%)	22(6,2%)	35(6,0%)	
	all of the above are correct	77(33,3%)	109(30,7%)	186(31,7%)	

Respondents previously answered that ASD is a psychiatric disease, however, 46.8% of nurses note that they transfer them to neurologists and only 28,9% to psychiatrists. Only 41.7% of respondents were aware of all methods for diagnosing ASD, while only 27,8% of respondents were aware of the Modified Autism Screening Test for Children (Table 2). About 70,1% of respondents rarely work with patients with ASD, while 17,4% see one patient with ASD. Nurses who see more than 5 patients in one week are 3,3% more likely to see sicker patients at home (table 2).

Table 2.

Practice of nurses in monitoring children with ASD.

Questions and answers		Pediatric nurse	General Practitioners nurse	Total	P
		N(%)	N(%)	N(%)	
If a child comes to you with a suspicion of autism spectrum disorder, which specialist will you refer him to first for diagnosis?	neurologist	119(48,8%)	166(45,5%)	285(46,8%)	0,640
	psychiatrist	67(27,5%)	109(29,9%)	176(28,9%)	
	psychologist	24(9,8%)	26(7,1%)	50(8,2%)	
	speech therapist	5(2,0%)	10(2,7%)	15(2,5%)	
	general practitioner	6(2,5%)	15(4,1%)	21(3,4%)	
	pediatrician	22(9,0%)	35(9,6%)	57(9,4%)	
	other	1(,4%)	4(1,1%)	5(,8%)	
What diagnostic tests for autism do you know?	MCHATR Modified Autism Screening Test for Children	62(25,9%)	104(29,1%)	166(27,8%)	0,409
	Autism Diagnostic Examination Scale ADOS2	17(7,1%)	31(8,7%)	48(8,0%)	
	Autism Diagnostic Interview - Revised (ADIR)	8(3,3%)	21(5,9%)	29(4,9%)	
	Psychological testing - PPO/EPO	27(11,3%)	36(10,1%)	63(10,6%)	
	ADIR test questionnaire for diagnosing autism	21(8,8%)	21(5,9%)	42(7,0%)	
	All of the above	104(43,5%)	145(40,5%)	249(41,7%)	
How many ASD patients do you work with per week?	1 patient per month	40(16,7%)	66(17,8%)	106(17,4%)	0,773
	1 patient per week	11(4,6%)	21(5,7%)	32(5,3%)	
	up to 5 patients per week	8(3,3%)	16(4,3%)	24(3,9%)	
	more than 5 patients per week	10(4,2%)	10(2,7%)	20(3,3%)	
	very rarely or I don't work	170(71,1%)	257(69,5%)	427(70,1%)	

Across four domains, pediatric nurses showed better knowledge than GP nurses (Table 3), in particular domain one as well as domain three. Other two domains like two and four had similar results (Table 3).

Table 3.

Mean scores in the four domains and mean total scores on *k*nowledge about Childhood Autism among Health Workers questionnaire.

	Domain 1 (mean and SD)	Domain 2	Domain 3	Domain 4	Total
Pediatric nurse	5,66±2,39	0,69±0,46	2,69±1,36	3,29±1,34	12,32±4,17
General Practitioners nurse	5,14±2,45	0,68±0,47	2,39±1,39	3,08±1,28	11,28±4,32
P (t-test)	0,009	0,764	0,008	0,055	0,003
SD – Standard deviation					

Discussion

Our study results show insufficient knowledge of nurses in both groups about ASD. At the same time, more than half of the respondents believe that they are aware of ASD, but a detailed study of their awareness reveals a lack of knowledge. Our results are similar to other studies where, for example, a US survey of nurses in a large pediatric hospital found that only third of them (35%) had adequate strategies for caring for children with ASD [14].

Only 27,8% of respondents were aware of the Modified Autism Screening Test for Children, although this test is recommended to be used in the National Clinical Protocol (General disorders of psychological (mental) development. This clinical protocol approved by the Joint Commission on the Quality of Medical Services of the Ministry of Health of

the Republic of Kazakhstan dated July 30, 2021 Protocol No. 145 and nurses must administer it to all children aged 2 years and above. This showed that despite the mandatory character of implementation of this protocol at the countrywide, not every nurse complies with National Clinical Protocol recommendations.

A number of studies have been conducted on ASD in Kazakhstan, but the knowledge of medical personnel associated with the study was presented in one article, which identified a low understanding of ASD in the group of medical specialists. Moreover, authors, as well as the researchers of this article, were unanimous in their opinion about the need for education or training among stakeholders [15]. *Alibekova R. et al.* also revealed the presence of anxiety and stress among caregivers and parents of children with ASD in Kazakhstan [1]. As a result of the project, during which a survey was conducted among parents of children with ASD, the need of parents of children with ASD in the form of purchasing books and receiving other support services in the form of sports activities was also noted. [12]. It is not new that nurse coordination can lead to improve the delivery of integrated care. In the last two decades, the role of the nurse in Kazakhstan has been significantly transformed. There was a delegation of a number of functions from the doctor to the nurse. Across four domains, which presented before, pediatric nurses showed better knowledge of caring for children with ASD compared to GP nurses, which is most likely due to their activities with children, while GP nurses also have an adult population. This indicates the need to strengthen educational activities, particularly among GP nurses. Accordingly, they can be trained in the management of children with ASD and their parents or guardians. In primary care settings in Kazakhstan, there is a funding (stimulating component of the capitation standard) available for advanced training of local services, which includes care provided by nurses. Thus, managers should prioritize the inclusion of ASD as a main topic for future education of the nurses, especially in GP districts.

Support and encouragement of physical activity in children with ASD due to the risk of poor health outcomes may be considered as a necessary topic in nursing education. In general, by focusing on their behavioral habits, medical professionals often overlook their physical capabilities and activities. In this case, the role and training of nurses on this topic is essential in teaching children with ASD and their parents or guardians about physical development and activity. Nurses' encouragement of physical activity in children with ASD has been found to mitigate some of the negative health outcomes experienced by these individuals [21]. Perhaps nurses will need additional training in communication skills, since determining the type of spectrum of the autism in a child and finding an approach to communication with him is essential for the positive effect of treatment.

Future direction: It is important for nurses to be taught more strategies that can be used with children with ASD in the primary healthcare settings and to provide mechanisms for collaborating with other professionals to individualize strategies to meet the needs of each child as well as their parents [14]. The presented questionnaire in Kazakh and Russian can be used to study the knowledge of health workers (nurses, GP, pediatricians etc.) in rural areas, to study their knowledge gaps and develop strategies to increase the awareness of ASD. In addition, the results of the survey can help in developing an educational program, gives information for lecturer in which topics should be presented in more detail to the learning audience.

Conclusion

Our study showed the need for advanced training of nurses, in particular GP nurses, in caring for patients with ASD. This is extremely important, since in the team with the GP or pediatrician the nurse plays the role of coordinator to refer the patients and caregivers to a psychologist or other specialists. Healthcare managers need to prioritize the topic of ASD prevalence increases recently and timely screening is best measure for prompt care and treatment of children with ASD.

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