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PRIMARY CARE PSYCHOLOGISTS' KNOWLEDGE OF AUTISM SPECTRUM DISORDERS

Lyazzat K. Kosherbayeva^{1,2}, https://orcid.org/0000-0001-8376-4345

Kuanysh K. Altynbekov^{2,3}, https://orcid.org/0000-0003-3755-0914

Laila T. Imangalieva², https://orcid.org/0009-0009-5667-5182

Nazgul S. Akhtayeva¹, https://orcid.org/0000-0002-0835-9814

Laura Kozhageldiyeva¹ https://orcid.org/0000-0003-0553-8988

Sandugash K. Kurmanalina², https://orcid.org/0000-0003-0659-1940

Aziza M. Imamatdinova¹, https://orcid.org/0000-0003-2233-4522

¹ Suleyman Demirel University, Kaskelen, Republic of Kazakhstan;

² Asfendiyarov Kazakh National Medical University, Almaty, Republic of Kazakhstan;

³ Republican Scientific and Practical Center of Mental Health, Almaty, Republic of Kazakhstan.

Abstract

Introduction. Autism spectrum disorder (ASD) is a neurological disorder with lifelong manifestations that include repetitive behaviors, limited interests, and problems in social interaction. Early detection is important for effective intervention. Parents of children with ASD often face difficulties in understanding, managing behavior, and reducing stress. Interventions in the field of cognitive behavioral and social skills are effective treatment methods that can serve as the basis for psychotherapy for children with ASD. Given these problems, providing psychological support to parents or guardians of children with ASD is crucial.

Aim of this study is to study the knowledge of primary health care (PHC) psychologists of Almaty city about Autism spectrum disorder.

Materials and methods. During the study, psychologists of the primary health care system of Almaty were interviewed to assess their knowledge about autism spectrum disorders (ASD). We have adapted an international questionnaire translated into Kazakh and Russian, consisting of 19 questions in four areas: social interaction, communication and language, obsessive and compulsive behavior, and general knowledge about RACE. 141 registered psychologists participated in the survey. Participation was voluntary and anonymous, with the assistance of the City Health Department.

Results. More than half of the respondents - 50.4% - have more than 11 years of work experience, while young professionals make up about a third of the respondents - 29.6%. The majority (84.0%) believe that ASD refers to mental and behavioral disorders (code F), although only 77.0% are aware of the changes in ICD 11. Many psychologists (45.6%) are familiar with the methods of diagnosis of ASD and a modified autism screening test for children, but most often (60.0%) they rarely work with children with ASD. The coefficient of internal consistency of the measurement results was 0.849, which indicates the high reliability of the questionnaire. The average values of the scores in various areas of the questionnaire indicate the average level of knowledge and experience of the survey participants.

Conclusion. The study highlighted the need for primary care psychologists to be trained in issues related to ASD so that they can provide effective support to parents and guardians of children with this disorder. The training should include psychological support methods aimed at helping parents accept the diagnosis and reduce anxiety and stress.

Keywords: autism spectrum disorder, PHC, awareness, psychologists.

Резюме

ЗНАНИЯ ПСИХОЛОГОВ ПЕРВИЧНОЙ МЕДИКО-САНИТАРНОЙ ПОМОЩИ О РАССТРОЙСТВАХ АУТИСТИЧЕСКОГО СПЕКТРА

Ляззат К. Кошербаева^{1,2}, https://orcid.org/0000-0001-8376-4345

Куаныш К. Алтынбеков^{2,3}, https://orcid.org/0000-0003-3755-0914

Лайла Т. Имангалиева², https://orcid.org/0009-0009-5667-5182

Назгуль C. Ахтаева1, https://orcid.org/0000-0002-0835-9814

Лаура Кожагельдиева¹, https://orcid.org/0000-0003-0553-8988

Сандугаш К. Курманалина², https://orcid.org/0000-0003-0659-1940

Азиза М. Имаматдинова¹, https://orcid.org/0000-0003-2233-4522

¹ Сулейман Демирель Университет, г. Каскелен, Республика Казахстан.

² HAO «Казахский национальный медицинский университет имени С.Д. Асфендиярова», г. Апматы. Республика Казахстан

г. Алматы, Республика Казахстан.
³ Республиканский научно-практический центр психического здоровья, г. Алматы, Республика Казахстан.

Введение. Расстройство аутистического спектра (PAC) — это неврологическое расстройство с пожизненными проявлениями, включающее повторяющиеся модели поведения, ограниченные интересы и проблемы в социальном взаимодействии. Родители детей с PAC часто сталкиваются с трудностями в понимании, управлении поведением и сокращении стресса. Вмешательства в области когнитивно-поведенческих и социальных навыков являются эффективными методами лечения, которые могут послужить основой для психотерапии детям с PAC. Учитывая эти проблемы, оказание психологической поддержки родителям или опекунам детей с PAC имеет решающее значение.

Цель: изучение знаний психологов первичной медико-санитарной помощи (ПМСП) города Алматы о РАС.

Материалы и методы. В ходе исследования были опрошены психологи ПСМП города Алматы, чтобы оценить их знания о расстройствах аутистического спектра (PAC). Мы адаптировали международную анкету, переведенную на казахский и русский языки, состоящую из 19 вопросов по четырем областям: социальное взаимодействие, коммуникация и язык, навязчивое и компульсивное поведение и общие знания о PAC. В опросе приняли участие 141 зарегистрированных психологов. Участие было добровольным и анонимным, при содействии городского управления здравоохранения.

Результаты. Более половины опрошенных - 50,4% - имеют опыт работы более 11 лет, в то время как молодые специалисты составляют около трети опрошенных - 29,6%. Большинство (84,0%) считают, что РАС относится к психическим расстройствам и расстройствам поведения (код F), хотя только 77,0% знают об изменениях в МКБ 11. Многие психологи (45,6%) знакомы с методами диагностики РАС и модифицированным скрининговым тестом на аутизм для детей, но чаще всего (60,0%) они редко работают с детьми с РАС. Средние значения оценок по различным областям анкеты указывают на средний уровень знаний и опыта участников опроса.

Выводы. Исследование подчеркнуло необходимость обучения психологов первичной медико-санитарной помощи в вопросах, связанных с РАС, чтобы они могли оказывать эффективную поддержку родителям и опекунам детей с этим расстройством. Обучение должно включать методы психологической поддержки, направленные на помощь родителям в принятии диагноза и снижении тревожности и стресса.

Ключевые слова: расстройство аутистического спектра, ПМСП, осведомленность, психологи.

Түйіндеме

АУТИЗМ СПЕКТРІНІҢ БҰЗЫЛУЫ ТУРАЛЫ АЛҒАШҚЫ МЕДИЦИНАЛЫҚ-САНИТАРЛЫҚ КӨМЕК ПСИХОЛОГТАРЫНЫҢ БІЛІМІ

Ляззат К. Кошербаева^{1,2}, https://orcid.org/0000-0001-8376-4345

Куаныш К. Алтынбеков^{2,3,} https://orcid.org/0000-0003-3755-0914

Лайла Т. Имангалиева², https://orcid.org/0009-0009-5667-5182

Назгуль C. Ахтаева¹, https://orcid.org/0000-0002-0835-9814

Лаура Кожагельдиева¹, https://orcid.org/0000-0003-0553-8988

Сандугаш К. Курманалина², https://orcid.org/0000-0003-0659-1940

Азиза М. Имаматдинова^{1,2}, https://orcid.org/0000-0003-2233-4522

Кіріспе. Аутизм спектрінің бұзылуы (АСБ) — қайталанатын мінез-құлық үлгілерін, шектеулі қызығушылықтарды және әлеуметтік өзара әрекеттесудегі қиындықтарды қамтитын өмір бойы көрінетін неврологиялық бұзылыс. АСБ бар балалардың ата-аналары көбінесе түсіну, мінез-құлықты басқару және стрессті азайту қиындықтарына тап болады. Когнитивті-мінез-құлық және әлеуметтік дағдыларға араласу АСБ бар балалар үшін психотерапия үшін негіз бола алатын тиімді емдеу әдістері болып табылады. Осы мәселелерді ескере отырып, АСБ бар балалардың ата-аналарына немесе қамқоршыларына психологиялық қолдау көрсету өте маңызды.

Бұл зерттеудің мақсаты Алматы қаласындағы АСБ туралы алғашқы медициналық-санитарлық көмек (МСАК) психологтарының білімін зерттеу болып табылады.

Материалдар мен әдістері. Зерттеу барысында Алматы қаласының алғашқы медициналық-санитарлық көмек жүйесінің психологтары арасында аутизм спектрінің бұзылуы (АСБ) туралы білімдерін бағалау үшін сауалнама жүргізілді. Біз төрт сала бойынша 19 сұрақтан тұратын қазақ және орыс тілдеріне аударылған халықаралық сауалнаманы бейімдедік: әлеуметтік өзара іс-қимыл, коммуникация және тіл, обсессивті және компульсивті мінез-құлық және нәсілдер туралы жалпы білім. Жүргізілген сауалнамаға 141 тіркелген психолог қатысты. Қалалық денсаулық сақтау басқармасының көмегімен қатысу ерікті және анонимді болды.

Нәтижесі. Сауалнамаға қатысқандардың жартысынан көбі-50,4% - 11 жылдан астам тәжірибесі бар, ал жас мамандар сауалнамаға қатысқандардың шамамен үштен бірін құрайды - 29,6%. Көпшілігі (84,0%) АСБ психикалық және мінез-құлық бұзылыстарына (F коды) жатады деп санайды, дегенмен тек 77,0% ICD 11 өзгерістері туралы біледі. Көптеген психологтар (45,6%) ASD диагностикалық әдістерімен және балаларға арналған аутизмге арналған өзгертілген скринингтік сынақпен таныс, бірақ көбінесе (60,0%) олар АСБ бар балалармен сирек жұмыс істейді.

¹ Сулейман Демирель Университеті, Қаскелен қ., Қазақстан Республикасы.

² КЕАҚ «С.Ж. аскенен қ., қазақстан Республикасы. Роспубликасы

³ Республикалық психикалық денсаулық ғылыми-практикалық орталығы, Алматы қ., Қазақстан Республикасы.

Сауалнаманың әр түрлі бағыттары бойынша бағалаудың орташа мәні сауалнамаға қатысушылардың білімі мен тәжірибесінің орташа деңгейін көрсетеді.

Қортынды. Зерттеу АСБ-на қатысты мәселелерде алғашқы медициналық көмек психологтарын оқыту қажеттілігін атап өтті, осылайша олар осы бұзылысы бар балалардың ата-аналары мен қамқоршыларына тиімді қолдау көрсете алады. Оқыту ата-аналарға диагноз қоюға және мазасыздық пен стрессті азайтуға көмектесетін психологиялық қолдау әдістерін қамтуы керек.

Түйін сөздер: аутизм спектрінің бұзылуы, МСАК, хабардарлық, психологтар.

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Introduction

Autism spectrum disorder (ASD) includes a range of neurodevelopmental disorders, which is accompanied throughout the whole life [15]. This spectrum is characterized by recurring patterns of behavior, interests, activities, and problems in social interactions. Furthermore, ASD manifests itself with behavioral and psychological problems in children [19]. Global prevalence of ASD was 0,6% [23], other research results show that 28,3 million ASD prevalent cases whereas 603,790 incident cases and 4,3 million disability-adjusted life-years [12].

Early identification of children with ASD facilitates effective early intervention, and therefore the role of medical professionals is extremely important [18]. Currently, many studies show late detection of ASD (usually at 4 age), which is associated with the absence of behavioral and psychological deviations, as well as clinical abnormalities. Thus the role of ASD screening is crucial [5,18,24]. American Academy of Pediatrics suggestes to provide screening for early detection of ASD at 18 and 24 months [18].

The first difficulty that medical specialists encounter is the ASD acceptance by parents or caregivers in their children [21,27]. The study highlights that parents or caregivers of children with ASD face three distinct challenges: understanding their children's autism, managing their children's behavior, and reducing stress caused by the behavior itself and social stigma [7]. Early recognition by parents or caregivers that their children have ASD will allow to begin effective treatment. The difficulty of ASD children caring leads to the fact that they begin to feel disadvantaged and lonely, and both physical and cognitive impairments are observed. Moreover, several studies show that parents or caregivers of ASD children are in states of anxiety or depression [9,10], thus psychological support for them is needed constantly. For this reason, health professionals must be able to develop new behavioral training strategies to help parents with ASD [15]. Effective treatments may include cognitive behavioral and social skills interventions, which can become the cornerstone of psychotherapy for people with ASD [26].

In this regard, at this stage it is important to provide psychological support to parents or caregivers of children

with ASD. In Kazakhstan, since 2013, the position of a psychologist has been introduced at primary health care. Considering that the prevalence of ASD is growing throughout the world, the **purpose of our** study was to investigate the knowledge of primary care psychologists of Almaty about ASD.

Materials and methods. The international questionnaire was adapted and then translated into Kazakh and Russian languages by the researchers. This questionnaire consisted of 19 questions, which were distributed across four domains: Eight questions in Part 1 are related to the impairments in social interaction of a child with ASD. For each question calculation, a maximum score of 8 and a minimum score of 0 was considered. Part 2 consisted of one question that studies the disorders in the field of communication and language development, and when calculating it was possible to obtain one point as the highest and one point as the lowest. Four questions of Part 3 study obsessions and compulsive behavior patterns of a child with ASD, where the highest score can be 4 and the lowest is 0. Part 4, that is the final domain of the questionnaire consisted of 6 questions regarding issues related to concomitant diseases and during the calculation a maximum point is 6 and the minimum score is 0. In addition to the 19 questions presented, the authors included questions regarding the study of psychologists' knowledge about to which group of diseases ASD belongs to and changes have occurred according to the ICD, etc.

The survey was conducted among psychologists of the primary health care (PHC) facilities in Almaty city. The survey was conducted on paper or online using a Google Form. The distribution was carried out with the involvement of the Almaty Public Health Department. All respondents took part voluntarily, with consent to participate, anonymously. Also, respondents had the opportunity to complete the survey at any stage of the study and ask questions to the researcher for clarification.

In accordance with this electronic system, about 141 PHC psychologists are registered. The sample size was identified as 104 respondents, but taking into account possible errors that may occur during filling out the questionnaire, we increased the sample size by 20%. In

total, our purpose was to achieve 125 respondents. To identify the sample size, we based on the cross-sectional study design formula, hence the sample size calculation formula is:

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

where:

n = sample size

N= population

Deff = 1 (design effect - random sampling)

p =0.5

d= 0,05 (desired absolute precision or absolute level of precision)

 $z^{\wedge} \alpha = 1.96$ (z - index)

For the statistical analysis, Stata 15.1 software (StataCorp, 4905 Lakeway Drive College Station, Texas 77845 USA) was used. The Kuder-Richarson reliability coefficient (KR-20) value was chosen to examine the reliability of the questionnaire by measuring internal consistency, where binary data are recommended [2,8]. The study variables were subjected to descriptive analysis.

Results.

To a greater extent of the half respondents have work experience of more than 11 years, and about third were young specialists 29,6%. The majority of the respondents indicated that ASD is a mental and behavioral disorder (code F) 84,0%. However, 77,0% of psychologists knew the changes in ICD 11 where ASD is identified as a mental, behavioral, and neurological disorder (Table 1).

Table 1.

Characteristics of survey participants and general questions regarding ASD.

	Questions and answers	N	%
What is your work experience?	up to 5 years	37	29,6
	6-10 years	21	16,8
	more than 11 years	67	53,6
	Total	125	100,0
Do you know how	Diseases of the nervous system (code G)	10	8,0%
Autism is coded according to ICD-	Mental and behavioral disorders (code F)	105	84,0%
	Certain conditions that arise in the perinatal period (to	4	3,2%
10?	I would like to study it in more detail, no one taught us this	6	4,8%
Are you aware of	Mental, behavioral and neurological disorders	94	77,0%
what changes are	Diseases of the nervous system (code 08)	5	4,1%
included in the ICD-	Sleep-wake cycle disorders (code 07)	3	2,5%
11 Autism coding?	I would like to study it in more detail, no one taught us this	20	16,4%
	ASD without intellectual disability and with mild or no speech impairment.	16	13,2%
	ASD with intellectual disability and mild or no language impairment	8	6,6%
	ASD without intellectual development impairment and with speech impairment.	4	3,3%
What types of ASD	ASD with intellectual disability and speech impairment.	16	13,2%
(autism) do you	ASD with intellectual disability and lack of speech function.	2	1,7%
know according to ICD-11?	Other specified ASD.	6	5,0%
	ASD, unspecified.	1	0,8%
	Don't know	13	10,7%
	there is no right answer	2	1,7%
	ASD without intellectual disability and with mild or no speech impairment.	53	43,8%
What types of ASD (autism) do you know according to ICD-10?	Atypical autism	26	22,0%
	Rett syndrome	4	3,4%
	Other childhood disintegrative disorder	7	5,9%
	Hyperactive disorder combined with mental retardation	14	11,9%
	Asperger's syndrome	8	6,8%
	Other pervasive developmental disorders	4	3,4%
	Pervasive developmental disorder, unspecified	3	2,5%
	all of the above are correct	52	44,1%
	MCHATR Modified Autism Screening Test for Children	33	26,4%
What diagnostic tests for autism do you know?	Autism Diagnostic Examination Scale ADOS2	11	8,8%
	Autism Diagnostic Interview — Revised (ADIR)	5	4,0%
	Psychological testing - PPO/EPO	12	9,6%
	ADIR test questionnaire for diagnosing autism	7	5,6%
	All of the above	57	45,6%

Consequently, it is evident that there is a lack of knowledge among psychologists regarding the types of ASD in accordance with ICD 10 and ICD 11, which indicates the need for training in the future (Table 1). About

45,6% of the respondents are aware about the types of diagnostic methods of ASD and 26,4% of them knew Modified Autism Screening Test for Children tool for ASD diagnosis (Table 1). The majority of psychologists noted

that they rarely work with children with ASD (60,0%), while 16.8% face them once a month. 12.8% of psychologists see one patient once a week, while 9.6% see more than 5

patients a week, which is most likely due to their work in another ASD support centers, not only at PHC facilities (Figure 1).

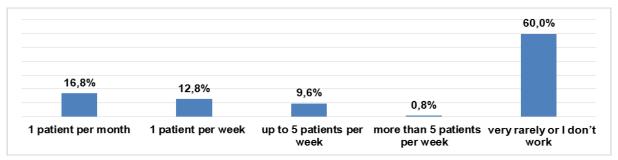


Figure 1. Number of ASD children psychologist work with per week.

The internal consistency coefficient (Kuder-Richarson reliability coefficient - KR20) of the measurements obtained from the questionnaire was 0.849. For domain 1 of 8 questions, the average value was 6,03±2,59, while for domain 2, which consisted of 1 question, the average was

 0.72 ± 0.45 . The third domain consisted of 4 questions, where the average was scored 2.83 ± 1.51 , while the fourth domain of 6 questions achieved 3.1 ± 1.21 . Thus, out of 19 questions, the average value was revealed to be 12.68 ± 4.36 representation (Table 2 and Table 3).

Mean scores in the four domains and mean total scores on knowledge about Childhood Autism among Psychologists.

Table 2.

Mean ± and Standard deviation	Domain 1	Domain 2	Domain 3	Domain 4	Total
Score	6,03±2,59	0,72±0,45	2,83±1,51	3,1±1,21	12,68±4,36

 $\label{eq:Table 3.} \mbox{ General correlation of items of the questionnaire "Knowledge about autism spectrum disorder among primary care psychologists".}$

Questions	Domain			
Domain 1				
1. Significant impairment in the use of multiple nonverbal behaviors such as eye-to-eye contact, facial expression,				
body posture, and gestures during social interactions? 2. Inability to establish relationships with peers, development appropriate for age?				
2. Inability to establish relationships with peers, development appropriate for age?				
3. Lack of desire to share spontaneous joy, interest or activity with other people?				
4. Lack of social or emotional interaction?				
5. Staring into an open space without focusing on anything in particular?	0.7530*			
6. Does the child appear to be deaf or mute?	0.6822*			
7. Loss of interest in the environment and what is happening around?	1.0000*			
8. Is social smiling usually absent in a child with autism?	0.8186*			
Domain 2				
Delay or complete lack of development of spoken language?				
Domain 3	0.7934*			
Stereotypical and repetitive movements (for example, clapping hands or curling fingers)?				
2. May be associated with abnormal eating habits?	0.7905*			
3. Constantly preoccupied with the details of objects?	0.8548*			
4. Do you like monotonous routine activities?	0.7448*			
Domain 4	0.5294*			
1. Is autism a childhood schizophrenia?	0.3234			
2. Is autism an autoimmune disease?	0.5263*			
3. Is autism a neurodevelopmental disorder?	0.0878			
4. Can autism be associated with mental retardation?				
5. Can autism be associated with epilepsy?				
6. The onset of autism usually occurs in childhood.				
*- p values demonstrate a statistically significant correlation. The total score was dichotomized according to the median.				

^{*-} p values demonstrate a statistically significant correlation. The total score was dichotomized according to the median These questions were correlated with the total score for each item (low or high) using tetrachoric analysis.

Discussion

Every year there is an increase in identified cases of children with ASD, and early acceptance of this diagnosis by parents facilitates the process of treatment and rehabilitation. The results of the study showed that parental skills of discernment and acceptance of the diagnosis of ASD in their children allow the effective implementation of intervention programs so, the parents - ASD children communications are upgraded [6]. Research as systematic review and meta-analysis showed that implemented interventions to the parents of ASD children had the implications as the promoted responsiveness and positive effect on the relationship between parents and children. However, the above-mentioned research reflected limited effect on stress of parents [11]. Consequently, psychologists' function at PHC is crucial as they are the key providers of psychological support to parents and caregivers of ASD children. For example, a randomized clinical trial examined the effects of a brief group program of acceptance and commitment therapy designed for parents of autistic children, youth, and adults. This study suggests that this therapy may help improve some aspects of the mental health of parents of children with autism [17]. Accordingly, PHC psychologists' knowledge in this area is critical for providing quality care.

Rachel A Rhoades and co-authors found that pediatricians, compared with other doctors, identify children with autism at an earlier age. The typical age at which autism is diagnosed (4 years 10 months) is frequently too late for children to fully benefit from early interventions. While the majority of experts, particularly developmental pediatricians, offer educators extra insights into early childhood autism (ASD), there exists a notable subset who do not. This might suggest an inadequacy in readiness for the diverse range of behavioral traits associated with autism. Parents commonly seek outside sources for ASD information. To enhance early detection and diagnosis of autism, it is advised that all medical professionals undergo specialized training, followed by guiding caregivers on evidence-based interventions [22]. Other research notes the importance of the training school psychologists about ASD, who also have limited knowledge in this area [16]. In Uganda, a study found that clinical psychologists, psychiatrists, psychiatric residents and pediatric nurses scored the highest on sociodemographic characteristics and childhood autism, while psychiatric nurses and clinical social workers scored the lowest [20]. A similar study conducted in China found that a significant number of doctors had misconceptions about the diagnosis and treatment of ASD. Often, studies note that doctors believe in the existence of effective drug therapy, and thus the disease is curable [13].

Early recognition of autism spectrum disorders (ASD) contributes to more timely diagnosis, which can speed up access to necessary and effective interventions. Since primary care psychologists are often the first professionals to be contacted by families concerned about possible ASD in their children, it is imperative that they have in-depth knowledge about this condition. This ensures that any gaps in understanding are eliminated [7,17]. Delays in diagnosis can lead to delays in interventions, which potentially worsens the prognosis for the child. After a diagnosis of

ASD, parents should be provided with support and guidance on empirically proven services and treatments. Therefore, improving the process of early diagnosis and referral is a top priority. There are several factors contributing to delayed diagnosis. Specialists may be hesitant to diagnose ASD due to concerns about a strong emotional reaction from parents, fears of the negative impact of labels, or hopes for self-resolution of symptoms. In addition, some medical professionals feel that they do not have enough training to accurately assess ASD. A study conducted in France showed that pediatricians often underestimate concerns about race due to a lack of knowledge. Also, a survey of families whose members have been diagnosed with ASD revealed that 33% of doctors spontaneously recommended non-traditional methods of treatment that do not have reliable empirical support. These data indicate a lack of knowledge among doctors about certain aspects of ASD and empirically proven treatment methods, which may lead to the loss of important opportunities for early intervention and referral to appropriate specialists [11,12,13]. Parents who receive a diagnosis of ASD without proper information may turn to other sources, such as the Internet, which may contain inaccurate or misleading information. Despite their potential value, these sources can be overloaded and confusing due to the large amount of information available. Although primary care physicians diagnose ASD in children a year earlier than psychiatrists and psychologists, a study published in the journal Autism showed that from 2004 to 2019, the likelihood of being diagnosed with ASD by primary care physicians decreased annually. This discrepancy requires further research to improve the effectiveness of diagnosis in children with ASD. Early diagnosis of ASD is key to initiating treatment during critical periods of development. Early intervention often improves long-term outcomes by eliminating underlying problems and providing the necessary support to improve quality of life. Primary care physicians play a vital role in early diagnosis, as they constantly monitor a child's development from infancy. However, the diagnostic tools necessary for the diagnosis of ASD require careful preparation and are often available only in specialized centers [22].

In general, the knowledge of psychologists who participated in our research shows an understanding of ASD, perhaps this is due to the fact that the largest number had more than 11 years of work experience. However, there is a need for training particularly among young professionals. It is important to note that the transition to ICD 11 also requires training of medical specialists in its correct interpretation, including among psychologists, where our research also revealed insufficient understanding of the types of ASD. The need for training of healthcare professionals as well as medical students was noted by several studies, including Kazakhstan [4.14.22.25], A study conducted by Ahlers and his colleagues found that additional training in autism screening leads to a reduction in the time required for diagnosis and a reduction in financial costs for families. This finding highlights the importance of effective screening and early diagnosis of autism to improve treatment outcomes and support for children with this disorder. Additional training for screening specialists can increase their ability to recognize early signs of autism, which will allow for faster initiation of necessary support and intervention activities. Faster diagnosis also allows families to access resources and services faster, which reduces their financial burden and facilitates the process of seeking help. Thus, investing in autism screening training may prove to be a beneficial step both for society as a whole and for individual families facing this disorder [1,14].

The results of our study have revealed the need for training primary health care psychologists in the field of autism spectrum disorders (ASD). This training allows them to better support and advise parents and caregivers of children with ASD, providing them with the necessary help and assistance. Special attention should be paid to the development of psychological support methods that will help parents cope with their child's diagnosis and reduce anxiety and stress levels. This may include learning practical skills such as communicating effectively with parents, understanding their emotional needs, and providing information about available resources and support in the community. These efforts are aimed at creating a more friendly and supportive environment for families facing the challenges of ASD and contribute to improving the quality of life of children and their loved ones.

Conclusions.

Our study revealed the need to train primary care psychologists about ASD, which will enable them to provide appropriate support and assistance to parents and guardians of children with ASD. Features of training should include methods of psychological support, allowing parents of children with ASD to accept their diagnosis, as well as reduce the level of anxiety and stress.

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Contact information:

Lyazzat Kosherbayeva – Head of the Project - Researcher, SDU University, Kaskelen, Republic of Kazakhstan and Head of the Health Policy and Management, Kazakh National Medical University, Almaty, Republic of Kazakhstan, Professor, PhD, Email: kosherbaeva.l@kaznmu.kz, Phone: + 7 7475697834;

Altynbekov Kuanysh - General Director of the Republican Scientific and Practical Center of Mental Health, Almaty, Republic of Kazakhstan, PhD, E-mail: altynbekov.kuanysh@kaznmu.kz, Phone: +7(727) 2724832;

Imangalieva Laila - Lecturer at the Department of Health Policy and Management, Kazakh National Medical University, Almaty, Republic of Kazakhstan, MSC, imangalieva.l@kaznmu.kz;

Akhtayeva Nazgul – Researcher, SDU University, Kaskelen, Republic of Kazakhstan. PhD, Associate professor. E-mail: akhtaeva_nazgul@mail.ru, Phone: +7 777 247 0074;

Laura Kozhageldiyeva - A Researcher, SDU University, Kaskelen Republic of Kazakhstan. MSC. E-mail: laurahealthprojects@gmail.com, + 7 701 746 5276;

Kurmanalina Sandugash - 1st year PhD student of the educational program "Public health", Asfendiyarov Kazakh National Medical University, Almaty, Republic of Kazakhstan, E-mail: s.kurmanalina@mail.ru; Phone: + 7 7017191038

Imamatdinova Aziza - Researcher, SDU University, Kaskelen, Republic of Kazakhstan and 1st year PhD student of the educational program "Public health", Asfendiyarov Kazakh National Medical University, Almaty, Republic of Kazakhstan, Email: azizaimamatdinova0@gmail.com Phone: +77020249250.

Corresponding author:

Aziza İmamatdinova, 1st year PhD student of the educational program "Public health", Asfendiyarov Kazakh National Medical University, Almaty, Republic of Kazakhstan. https://orcid.org/0000-0003-2233-4522

Postal address: Republic of Kazakhstan, Almaty, A10A9B6 Aksai-1, 24

E-mail: azizaimamatdinova0@gmail.com

Phone: +77020249250