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UNDERSTANDING AUTISM SPECTRUM DISORDERS AMONG THE POPULATION OF KAZAKHSTAN

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Abstract

Background: Autism spectrum disorders (ASD) associated with neurodevelopmental condition characterized with repetitive behaviors, lack of social communication. The annual increase in ASD indicates the need to increase awareness of ASD among the population in order to reduce stigma, as well as among parents of early recognition of the first symptoms of ASD. The aim of our study to identify the perception of population about ASD.

Methods: We developed a questionnaire in both Kazakh and Russian languages based on a comprehensive literature review. The survey was conducted across all regions of Kazakhstan using a Google Form, which was distributed through specialists in primary health care and parent groups with children diagnosed with ASD. A total of 410 respondents aged 18 years and above voluntarily participated in the survey. The collected data underwent statistical analyses using MS Excel and SPSS13.

Results: The survey primarily attracted participants aged 25 to 54 years. This may indicate that information about the prevalence of autism and organizations dealing with this issue is not widely disseminated among other age groups. The overwhelming majority of respondents were unaware of the prevalence of autism in Kazakhstan. This suggests that awareness about this issue remains low and requires additional education and information dissemination efforts. Despite limited awareness of the prevalence, respondents observed a growth in autism cases. This might be a sign of increasing awareness about the issue, but the lack of specific information about its scale could be a concern. Respondents also demonstrated limited knowledge about the nature of autism and organizations working in this field.

Conclusion: There is a pressing need to carry out awareness-raising initiatives among the general population regarding autism and its characteristics, as well as providing essential support to parents and caregivers of children with ASD.

Keywords: autism spectrum disorders, population, perception, Kazakhstan.

Аннотация

ПОНИМАНИЕ РАССТРОЙСТВ АУТИСТИЧЕСКОГО СПЕКТРА СРЕДИ НАСЕЛЕНИЯ КАЗАХСТАНА

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Введение. Расстройства аутистического спектра (РАС), связаны с нарушением развития нервной системы и характеризуются повторяющимся поведением, недостатком социального общения. Ежегодный

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распространения аутизма (РАС) свидетельствует о необходимости повышения информированности населения об этом расстройстве с целью снижения стигматизации и обеспечения раннего выявления первых симптомов у детей. Наше исследование направлено на выявление отношения общества к аутизму, а также на оценку уровня информированности населения о данном расстройстве.

Методы. На основе обзора литературы была разработана анкета на казахском и русском языках. Опрос проводился во всех регионах Казахстана с использованием google-формы, которая рассылалась по почте через специалистов первичного звена здравоохранения, группы родителей с детьми с РАС. В опросе добровольно приняли участие 410 респондентов в возрасте от 18 лет и старше. Статистический анализ проводился с использованием MS Excel и SPSS13.

Результаты. Опрос привлек в основном респондентов возрастом от 25 до 54 лет. Это может указывать на то, что информация о распространенности аутизма и организациях, занимающихся этой проблемой, недостаточно распространена среди других возрастных групп. Подавляющее большинство респондентов не имели представления о распространенности аутизма в Казахстане. Это может указывать на то, что осведомленность о данной проблеме остается низкой и требует дополнительного просвещения и информационной работы. Несмотря на низкую осведомленность о распространенности, респонденты отмечают рост аутизма. Респонденты также проявили недостаточную осведомленность о том, как проявляется аутизм, и об организациях, которые работают в этой области.

Вывод. Необходима реализация мероприятий по повышению осведомленности населения об аутизме и его течении, а также о том, как оказать поддержку родителям и опекунам детей с PAC.

Ключевые слова: расстройства аутистического спектра, население, восприятие, Казахстан.

Түйіндеме

ҚАЗАҚСТАН ХАЛҚЫ АРАСЫНДАҒЫ АУТИЗМ СПЕКТРІНІҢ БҰЗЫЛУЫН ТҮСІНУ

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Кіріспе. Аутизм спектрінің бұзылуы (АСБ) жүйке жүйесінің дамуының бұзылуымен байланысты және қайталанатын мінез-құлықпен, әлеуметтік қарым-қатынастың болмауымен сипатталады. Аутизмнің таралуының жыл сайынғы өсуі (рет) стигматизацияны азайту және балалардағы алғашқы белгілерді ерте анықтауды қамтамасыз ету мақсатында халықтың осы бұзылыс туралы хабардарлығын арттыру қажеттілігін көрсетеді. Біздің зерттеуіміз қоғамның аутизмге қатынасын анықтауға, сондай-ақ халықтың осы бұзылыс туралы хабардар болу деңгейін бағалауға бағытталған.

Әдістері. Әдебиеттерді шолу негізінде қазақ және орыс тілдерінде сауалнама әзірленді. Сауалнама Қазақстанның барлық өңірлерінде денсаулық сақтаудың бастапқы буынының мамандары, АСБ балалары бар атааналар тобы арқылы пошта арқылы жіберілген google-нысанын пайдалана отырып жүргізілді. Сауалнамаға 18 жастан асқан 410 респондент өз еркімен қатысты. Статистикалық талдау MS Excel және SPSS 13 көмегімен жүргізілді.

Нәтижелер. Сауалнама негізінен 25 пен 54 жас аралығындағы респонденттерді тартты. Бұл аутизмнің таралуы және осы мәселемен айналысатын ұйымдар туралы ақпарат басқа жас топтары арасында кең таралмағанын көрсетуі мүмкін. Респонденттердің басым көпшілігінде Қазақстанда аутизмнің таралуы туралы түсінік болған жоқ. Бұл берілген мәселе туралы хабардар болу төмен болып қалатынын және қосымша білім мен ақпараттық жұмысты қажет ететінін көрсетуі мүмкін. Таралуы туралы хабардарлықтың төмендігіне қарамастан, респонденттер аутизмнің өсуін атап өтеді. Респонденттер аутизмнің қалай көрінетіні және осы салада жұмыс істейтін ұйымдар туралы хабардарлықтың жеткіліксіздігін көрсетті.

Қорытынды. Халықтың аутизм және оның барысы туралы хабардарлығын арттыру, сондай-ақ АСБ бар балалардың ата-аналары мен қамқоршыларына қалай қолдау көрсету жөніндегі іс-шараларды іске асыру қажет.

Түйінді сөздер: аутизм спектрінің бұзылуы, халық, қабылдау, Қазақстан.

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Introduction

Autism spectrum disorders (ASD) associated with neurodevelopmental condition characterized with repetitive behaviors, lack of social communication. Global prevalence of ASD was 65 per 10,000[11], other research identifies pooled prevalence 0.72% [10].

Care for people with ASD is provided by a multidisciplinary team from different sectors such as health, education and social services. The lack of a single standard of care leads to the difficulty of early detection and care of patients with ASD. Given the different manifestations of the disorder and its characteristics, an individual selection and development of a treatment program together with a multidisciplinary team is required. In addition, studies show that caregivers or parents of patients with ASD are often prone to psychological distress. Therefore, in addition to the ASD patients themselves, the support of family members and caregivers is required.

Another important aspect is the awareness and public perception of patients with ASD. The annual increase in ASD indicates the need to increase awareness of ASD among the population in order to reduce stigma, as well as among parents of early recognition of the first symptoms of ASD. Various studies in this area indicate a lack of awareness of the population about ASD, for example, the public may perceive that people with ASD lack empathy and are prone to violence [6,7]. **The aim of our study** to identify the perception of population about ASD.

Methods:

Demographic variables and key guestions about the perception of ASD among population were selected based on the available published literature [4]. The questionnaire provided in Kazakh and Russian languages. The survey was conducted online using a google-form. The mailing was carried out through specialists in primary health care, parents' group with ASD children. Participants attended voluntary. The survey was conducted in all regions of Kazakhstan. Table 1 shows the number of participants by regions. The survey took participants over 18 years of age, voluntarily. The data of the researcher were also presented to provide feedback if questions arise from the survey participant. The identity of participants was not requested to ensure confidentiality. The sample size was calculated from the population with 5% accuracy, 95% confidence interval, and a 20% increase in potential loss. Initially, the sample size was estimated at 460 people, after exclusion of missing data 410 respondents included for analysis.

Statistical analyses were performed using the MS Excel and SPSS13. A descriptive analysis was performed and

variables were tested using a chi-square test. Statistical significance was determined by p-values <0.05. A comparison was made in the perception of ASD between urban and rural residents.

The study design and questionnaire were approved by the Research Ethics Committee of Suleyman Demirel University (Protocol number 6, from 6 March 2023), Almaty oblast, Kazakhstan.

Table 1. The number of participants participated in this study by regions.

Regions	N(%)
Astana city	61(14,88%)
Almaty city	130(31,71%)
Akmola region	12(2,93%)
Aktobe region	28(6,83%)
Alma-Ata's region	35(8,54%)
Atyrau region	14(3,41%)
West-Kazakhstan region	24(5,85%)
Jambyl Region	21(5,12%)
Karaganda region	10(2,44%)
Kostanay region	9(2,20%)
Kyzylorda Region	16(3,90%)
Mangistau region	4(0,98%)
Turkestan region	7(1,71%)
Pavlodar region	7(1,71%)
North-Kazakhstan region	2(0,49%)
East Kazakhstan region	11(2,68%)
Shymkent	9(2,20%)
Abay region	3(0,73%)
Zhetysu region	4(0,98%)
Ulytau region	3(0,73%)
Total	410(100,00%)

Results:

The survey involved a larger number of residents of cities compared to rural, aged 25-54 years. Among urban residents, the largest number of respondents had higher education, while among rural residents, the indicator was evenly distributed among those with secondary and secondary specialized education. The largest number of respondents had a job 61.2%, where the rate was higher among urban residents (Table 2).

The largest number of respondents noted uncertainty about the prevalence of autism (autism spectrum disorder and Asperger's syndrome) in Kazakhstan 45.9% (p=0,004), figure 1, however 53.2% respondents indicate the rise of ASD among population of Kazakhstan (p=0,005) table 3.

Table 2.

Characteristics of survey participants.

	Characteristics	Urban	Rural	Total
Gender	Male	64(20,6%)	50(50,0%)	114(27,7%)
(p<0,001)	Female	246(79,4%)	50(50,0%)	298(72,3%)
Total		310(100,0%)	100(100,0%)	412(100,0%)
Age (p<0,001)	18-24	44(14,2%)	8(8,0%)	52(12,7%)
	25-34	103(33,2%)	20(20,0%)	123(30,0%)
	35-44	101(32,6%)	25(25,0%)	126(30,7%)
	45-54	41(13,2%)	21(21,0%)	62(15,1%)
	55-64	14(4,5%)	12(12,0%)	26(6,3%)
	65-74	5(1,6%)	11(11,0%)	16(3,9%)
	75 and elder	2(0,6%)	3(3,0%)	5(1,2%)
Total	•	310(100,0%)	100(100,0%)	410(100,0%)
Level of education (p<0,001)	Higher	217(70,0%)	39(39,0%)	256(62,4%)
	Secondary special (college, etc.)	62(20,0%)	27(27,0%)	89(21,7%)
	Secondary (school)	20(6,5%)	28(28,0%)	48(11,7%)
	Incomplete secondary (school)	11(3,5%)	6(6,0%)	17(4,1%)
Total		310(100,0%)	100(100,0%)	410(100,0%)
Occupation (p<0,001)	Employed	204(65,8%)	47(47,0%)	251(61,2%)
	Unemployed	22(7,1%)	10(10,0%)	32(7,8%)
	Pensioner	12(3,9%)	20(20,0%)	32(7,8%)
	Student	27(8,7%)	12(12,0%)	39(9,5%)
	Housewife	44(14,2%)	10(10,0%)	54(13,2%)
	Other	1(0,3%)	1(1,0%)	2(0,5%)
Total		310(100,0%)	100(100,0%)	410(100,0%)

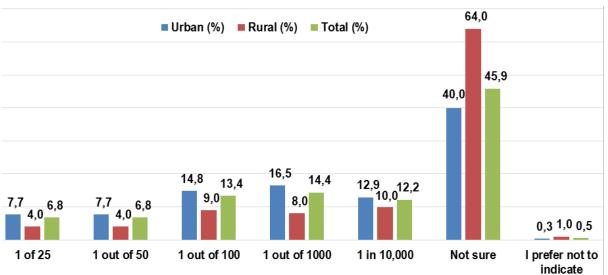


Figure 1. Public awareness of the prevalence of autism in Kazakhstan (Autism spectrum disorder and Asperger's syndrome).

A third of the respondents correctly indicated that a child with autism will not grow out of this condition (32.4%; p=0.029), and also about half of the respondents agree that it is difficult for people with autism to make friends 51.7% (p<0.001) and they can go in for sports 51.0% (p<0.001). In addition, 41.5% (p<0.001) do not agree that autistic

people are often prone to violence (table 3). Autism is a neurodevelopmental disease, however 42.9% consider it a mental illness, while 23.2% are unsure of the answer and 2.7% chose not to answer this question, indicating a lack of awareness among the population about ASD (table 3).

Table 3.

Public awareness of autism.

Questions		Urban	Rural	Total
A child with autism will grow out of	true	91(29,4%)	40(40,0%)	131(32,0%)
	not true	98(31,6%)	35(35,0%)	133(32,4%)
this condition (p=0.029)	not sure	116(37,4%)	22(22,0%)	138(33,7%)
	I prefer not to answer	5(1,6%)	3(3,0%)	8(2,0%)
	true	167(53,9%)	51(51,0%)	218(53,2%)
The number of autistic people is	not true	55(17,7%)	32(32,0%)	87(21,2%)
growing in Kazakhstan (p=0.005)	not sure	82(26,5%)	14(14,0%)	96(23,4%)
	I prefer not to answer	6(1,9%)	3(3,0%)	9(2,2%)
	true	134(43,2%)	42(42,0%)	176(42,9%)
Autism is a mental illness (p=0.389)	not true	91(29,4%)	37(37,0%)	128(31,2%)
Autisii is a mentai iiness (p=0.369)	not sure	77(24,8%)	18(18,0%)	95(23,2%)
	I prefer not to answer	8(2,6%)	3(3,0%)	11(2,7%)
	true	168(54,2%)	44(44,0%)	212(51,7%)
People with autism find it difficult to	not true	59(19,0%)	40(40,0%)	99(24,1%)
make friends (p<0.001)	not sure	79(25,5%)	13(13,0%)	92(22,4%)
	I prefer not to answer	4(1,3%)	3(3,0%)	7(1,7%)
	true	164(52,9%)	51(51,0%)	215(52,4%)
Autism affects everyone differently	not true	65(21,0%)	30(30,0%)	95(23,2%)
(p=0.165)	not sure	71(22,9%)	15(15,0%)	86(21,0%)
	I prefer not to answer	10(3,2%)	4(4,0%)	14(3,4%)
	true	50(16,1%)	36(36,0%)	86(21,0%)
Autistic people cannot do sport (p<0.001)	not true	165(53,2%)	44(44,0%)	209(51,0%)
	not sure	84(27,1%)	18(18,0%)	102(24,9%)
	I prefer not to answer	11(3,5%)	2(2,0%)	13(3,2%)
	true	43(13,9%)	37(37,0%)	80(19,5%)
Autistic people are often violent	not true	132(42,6%)	38(38,0%)	170(41,5%)
(p<0.001)	not sure	121(39,0%)	22(22,0%)	143(34,9%)
	I prefer not to answer	14(4,5%)	3(3,0%)	17(4,1%)

Only a third of respondents have heard of organizations related to autism, where 39.7% prevails among urban respondents compared to 20.0% in rural areas (p=0.001)

figure 2. Only 19.8% of the population know where parents of children with ASD can apply, this figure is higher among the rural population of 26.0%(p=0,071) figure 2.

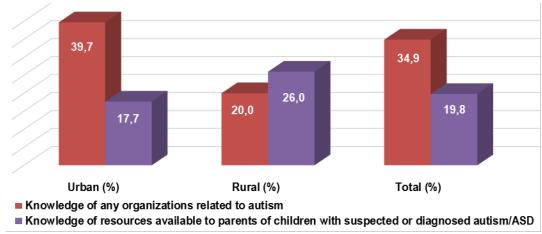


Figure 2. Knowledge of any organizations related to autism and resources available to parents with ASD children.

The largest number of respondents receive information about autism through the Internet 54.5% and TV media 26.6%. Among urban respondents, about a third received information about autism through TV media 29.4%, friends

and colleagues 26.9%, while among rural respondents through Internet resources (45.0%) and medical organizations (28.0%) table 4.

55.4% of respondents agree that parenting education can help children and parents of children with ASD. Among urban residents in comparison to rural, the largest number of respondents agree that children and caregivers of

children with ASD can be helped by educational events 61.0% (p<0.001), events organized among the population 46.9% (p<0.001) and a charitable foundation 40, 3% (p=0.042) table 4.

Table 4.

Information resource and the support path.

		Urban	Rural	Total
Resources through which people receive information	ation			
Television / media (p=0.025)	No	219(70,6%)	82(82,0%)	301(73,4%)
	Yes	91(29,4%)	18(18,0%)	109(26,6%)
Internet (p=0.030)	No	131(42,4%)	55(55,0%)	186(45,5%)
	Yes	178(57,6%)	45(45,0%)	223(54,5%)
Newspapers/ books/ magazines (p=0.001)	No	282(91,3%)	79(79,0%)	361(88,3%)
	Yes	27(8,7%)	21(21,0%)	48(11,7%)
Community (p=0.809)	No	254(81,9%)	83(83,0%)	337(82,2%)
	Yes	56(18,1%)	17(17,0%)	73(17,8%)
Madial	No	238(77,0%)	72(72,0%)	310(75,8%)
Medical organizations (p=0.300)	Yes	71(23,0%)	28(28,0%)	99(24,2%)
O-b	No	282(91,3%)	86(86,0%)	368(90,0%)
Schools/ universities (p=0.125)	Yes	27(8,7%)	14(14,0%)	41(10,0%)
Friends/colleagues (p=0.016)	No	226(73,1%)	85(85,0%)	311(76,0%)
	Yes	83(26,9%)	15(15,0%)	98(24,0%)
Did not receive information (p=0.987)	No	278(90,0%)	88(88,0%)	366(89,5%)
	Yes	31(10,0%)	12(12,0%)	43(10,5%)
Activities that can help autistic children and famil	lies			
Depart advertise (n. 40.004)	No	121(39,0%)	62(62,0%)	183(44,6%)
Parent education (p<0.001)	Yes	189(61,0%)	38(38,0%)	227(55,4%)
O	No	164(53,1%)	73(73,0%)	237(57,9%)
Community outreach training (p<0.001)	Yes	145(46,9%)	27(27,0%)	172(42,1%)
Deer summer (interreted advection) (= 0.400)	No	159(51,5%)	59(59,0%)	218(53,3%)
Peer support (integrated education) (p=0.198)	Yes	150(48,5%)	41(41,0%)	191(46,7%)
Charitable Foundation (p=0.042)	No	185(59,7%)	71(71,0%)	256(62,4%)
	Yes	125(40,3%)	29(29,0%)	154(37,6%)

Discussion

The vast majority of respondents are not aware of the prevalence of autism in the country, despite the fact that in many other countries there is an increase in it [5]. Our data are in line with other studies that found low public awareness of ASD. Melissa Rouphael et al. make a priority to increase awareness among parents, teachers and healthcare professionals [1,3,4,9]. While Alsehemi et.al. indicated that training will help to support and improve quality life of parents and families with ASD children [3]. In our study, more than half of the survey participants are not aware of ASD, and accordingly, there is a need to take measures to improve the knowledge and awareness of the population about ASD. The best tool for informing the population can be Internet resources and TV media, as well as through the nurses of medical organizations. Our data is consistent with other studies that have noted that social media is the most popular tool for disseminating information about

autism [2]. However, sources transmitted through social media must be verified from the standpoint of evidence of information [8].

It is also worth noting that despite the fact that there are various foundations in the country that provide support to parents of children with ASD, only a small number of respondents are aware of these organizations. In addition, the development of educational programs for parents and caregivers of ASDs will improve support for them, particularly in rural area. Our study shows a low need for parent education among rural participants, which may be due to their low level of interest and knowledge as well as lack of information in Kazakh languages. Ligia Antezana et al. note that rural residents need a new adaptation of existing measures, greater awareness of ASD and greater access to affordable and accessible specialized services [5]. Therefore, for rural residents, tools are needed to improve their knowledge about autism by providing information in the Kazakh language.

Conclusion: There is a need to implement activities to raise awareness among the population about autism and its course, as well as how to provide support to parents and caregivers of children with ASD. Information can be disseminated through Internet resources by developing educational programs for the population.

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