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Original article

Untangling the Path: Challenges in Autism Diagnosis for Kazakhstani Families

Karina Nukeshtayeva [1], Bauyrzhan Omarkulov [2], Marina Lyubchenko [3], Nailya Delellis [4],
Aiman Mussina [5], Gaukhar Kayupova [6], Zhaniya Dauletkaliyeva [7]

[1] *Assistant professor of the School of Public Health, Karaganda Medical University, Karaganda, Kazakhstan.*
E-mail: nukeshtaeva@qmu.kz
[2] *Professor of the Department of Family Madicine, Karaganda Medical University, Karaganda, Kazakhstan.*
E-mail: omarkulov@qmu.kz
[3] *Professor of the Department of Neurology, Psychiatry and Rehabilitation, Karaganda Medical University, Karaganda, Kazkahstan.*
E-mail: lyubchenko@qmu.kz
[4] *Professor of the Central Michigan University, Michigan, USA. E-mail: delel1no@cmich.edu*
[5] *Professor of the Head of Department of Public Health and Epidemiology, Astana Medical University, Astana, Kazakhstan.*
E-mail: mussina.a@amu.kz
[6] *Associate professor of the School of Public Health, Karaganda Medical University, Karaganda, Kazakhstan.*
E-mail: kayupovag@qmu.kz
[7] *Dean of the School of Public Health, Karaganda Medical University, Karaganda, Kazakhstan. E-mail: dauletkalievaz@qmu.kz*

Abstract

Navigating the labyrinth of Autism diagnosis in Kazakhstan can be an arduous journey for families. The scarcity of specialized professionals, coupled with limited awareness and resources, poses significant hurdles for early identification and intervention. This study aimed to offer a comprehensive examination of caregivers' experiences in navigating the process of diagnosing autism in their children within the context of Kazakhstan.

Objective: *The overarching aim of this study is to illuminate caregivers' experiences in navigating the diagnostic journey for Autism Spectrum Disorder in Kazakhstan, shedding light on factors influencing parental decision-making and elucidating barriers faced by families seeking diagnostic support for their children.*

Methods. *This study involved a mixed interview of caregivers of children diagnosed with childhood autism, atypical autism, about difficulties in the process from initial concern about the child's development to formal diagnosis.*

Results. *On average, autism concerns emerged at 1.91 years, with specialist contact at 2.19 years. Median diagnosis age was 4.51 years, taking 2.45 years from concern. Comorbidities included Attention deficit hyperactivity disorder (16.98%), psycho-speech delay (15.09%), and mental retardation (9.43%). Satisfaction with diagnosis was low (9.43%), yet 41.5% were content. Caregivers struggled with timely diagnosis, facing awareness and support deficits from specialists and society, along with logistical and psychological challenges.*

Conclusion.*The study sheds light on the challenges faced by caregivers in Kazakhstan during the diagnosis of autism in their children. It highlights the delayed age of diagnosis, the prevalence of comorbidities, and the dissatisfaction with diagnostic assistance, underscoring the urgent need for improved access to timely and effective diagnostic services, as well as enhanced support for caregivers navigating the complexities of autism diagnosis.*

Keywords: *autism spectrum disorder, parents' experience, Kazakhstan.*

Corresponding author: Karina Nukeshtayeva, assistant professor, School of Public Health, Karaganda Medical University, Karaganda, Kazakhstan.
Postal code: M01K7G6
Address: Kazakhstan, Karaganda, Gogol street 40
Phone: +77782452740
E-mail: nukeshtaeva@qmu.kz

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Introduction

Autism spectrum disorder (ASD) is a pervasive developmental condition characterized by challenges in social interaction, communication, and repetitive behaviors, persisting across the lifespan [1]. ASD encompasses a spectrum of conditions, including autism, developmental disorders, and Asperger's syndrome [2]. Accurate diagnosis relies heavily on healthcare professionals' proficiency in identifying ASD's nuanced signs and symptoms, which typically manifest in early childhood and endure over time without remission [3]. Timely diagnosis and intervention are imperative as they facilitate early engagement in comprehensive interventions aimed at fostering social adaptation and behavioral correction, thereby enhancing the prospects for successful integration into educational, vocational, and social spheres [4,5].

While various diagnostic tools exist, delays in obtaining a definitive ASD diagnosis often hinder prompt intervention, prolonging the unmet needs of affected children [6-11].

Factors contributing to diagnostic delays include the subtlety and variability of symptoms, limited diagnostic methodologies tailored for young children, inadequate awareness among healthcare providers, comorbidities complicating assessment, dearth of specialized facilities, and socioeconomic constraints [12].

Families navigating prolonged diagnostic processes frequently report diminished trust in healthcare professionals, leading some to pursue unvalidated treatments out of desperation [13]. Moreover, a passive "wait and see" approach by healthcare providers exacerbates parental distress, amplifying feelings of uncertainty and distrust. The toll of caregiving for a child with ASD can precipitate heightened vulnerability to mental health issues such as depression and anxiety [14].

In Kazakhstan, as in many regions globally, the prevalence of ASD is rising, though discrepancies in data integrity persist due to inconsistent collaboration among governmental entities. The Ministry of Health has noted a substantial increase in reported cases of ASD, prompting initiatives for enhanced screening technologies to facilitate early identification [15]. Official figures from the Ministry of Education indicate thousands of diagnosed cases, yet unofficial estimates suggest a much higher prevalence, indicative of systemic discrepancies [16,17]. Compounding this challenge, medical reporting practices often conflate ASD with other mental health conditions, further obscuring accurate prevalence estimates [18].

Diagnosis of ASD in Kazakhstan is restricted to psychiatrists and typically occurs after the age of four, potentially delaying access to early interventions critical for optimal outcomes. Placement of children with ASD in institutions for individuals with mental or intellectual disabilities has been commonplace, underscoring historical challenges in providing appropriate care and support [19,20].

Early research underscores caregivers' observations of early warning signs in their children, often met with hesitancy to seek medical evaluation due to perceived barriers in the healthcare system [21].

The overarching aim of this study is to illuminate caregivers' experiences in navigating the diagnostic journey for ASD in Kazakhstan, shedding light on factors influencing parental decision-making and elucidating barriers faced by families seeking diagnostic support for their children.

Material and methods

Our study involved conducting mixed interviews with caregivers of children diagnosed with childhood autism or atypical autism, focusing on the challenges encountered from the initial concerns about the child's development to receiving a formal diagnosis. The study was conducted in the period October-December 2022.

An electronic registration form created in Google Forms was distributed through neuropsychiatric dispensaries and public associations related to autism. The registration form provided informed consent, a clear description of the purpose of the study, a description of the benefits and risks of participation, and assurance that the study would be published without identifying any participants. The parents who provided consent to participate in the study completed a registration form. All participants who completed the electronic registration form were additionally sent an online form, which included information such as “Caregivers age”, “Caregivers nationality”,“Child’s Age”, “Caregivers Education”, “Contact information”, “Age of the child when the warning signs were first noticed”, “Age of the child at the first seeking diagnostic help”, “Age of the child at diagnosis”, “Satisfaction with diagnostic help” (rated from 1 to 5, where 1 - “not satisfied," 5-" satisfied”), “Satisfaction with the timeliness of diagnosis” (estimated from 1 to 5, where 1 - “not satisfied”, 5 - “satisfied”), and “Comorbidities”.

The inclusion criteria mandated a diagnosis of childhood autism or atypical autism, aligning with prevailing medical practices in Kazakhstan guided by the International Classification of Diseases-10 (ICD-10), which designates child psychiatrists as the sole authority for autism diagnosis in children.

The study was conducted in accordance with the Declaration of Helsinki and approved by the Ethics Committee of Karaganda Medical University (protocol code 2).

Fifty-three families meeting the inclusion criteria completed the electronic registration form and consented to participate. Direct participation in interviews was limited to mothers.

Following completion of the registration and online forms, interviews were scheduled at mutually convenient times. Interviews were conducted via phone, video calls, or messenger services, with consent obtained for recording. Transcription methods included manual transcription, dictaphone recording, or saving voice messages as electronic files. All audio recordings were transcribed into written text.

During the interviews, caregivers narrated their experiences from the initial observation of warning signs in their child's development to the eventual diagnosis. Researchers posed clarifying questions to elicit detailed responses. The interview text was coded using an iterative process involving group coding and thematic analysis. The research team collectively reviewed and analyzed transcripts, assigning codes to individual members. Frequent formulations were identified and grouped into categories, which were then organized into broader themes, including "Initial concerns," "Path to diagnosis," and "Difficulties during the diagnostic period" (Table 1).

Table 1 - Themes and citation examples

Themes	Theme An exemplary citation from caregivers
Initial concerns	When my son was already more than two years old, he did not respond to his name at all, as if he did not know him.
	“Despite the fact that I read about autism and was somewhat aware, for a long time I could not accept that the fact that my child is constantly obsessed with TV and jumping in front of it is not the norm” “Up to a year and a half, she developed, like all children, even somewhere ahead of her peers, but she didn’t speak at all, and closer to 2 years, a regression began, which went so gradually that it seemed just a manifestation of character”
The way to diagnosis	“When I suspected that something was wrong with my daughter, the first thing I thought was that we need to see a neurologist”
	“When I first heard about autism on TV, I immediately began to check the information on the Internet and realized that a psychiatrist could most likely help us”
Difficulties during the diagnostic period	“At 2.5 years old, when contacting a neurologist, the doctor said that absolutely everything is fine with the child,
	as he is interested in the toys in the office. Therefore, we left completely calmed down and lost another year.”
	“When a child was diagnosed with ASD, it was a blow to me, and I fell into depression” “Everyone around me was advised to send the child to kindergarten. It was thought that communication with other children would help the development of speech. However, the problem was that due to child did not understand the addressed speech, not a single preschool accepted us.”

Descriptive statistics of the online form data were carried out.

Results

The mean age of the study participants was 36 years (SD=5.94). The national structure of the interview participants was as follows: 35 Kazakh people (66.03%), 13 Russian people (24.52%), and other nationalities, including Germans, Tajiks, and Ukrainians; there were 5 people (9.43%). Among the participants in the study, 27 people (50.94%) had higher education, 18 (33.96%) had secondary education, and 8 people (15.09%) had postgraduate education.

On average, initial concerns regarding the child's development were noted at 1.91 years of age (SD = 0.54), ranging from 1 to 3 years. The mean age at which caregivers first contacted a specialist about their child's development concerns was 2.19 years (SD=0.8). The minimum age at the first visit to the specialists was 1 year, and the maximum age was 4 years. The median age at final diagnosis was 4.51 years (SD=1.52), the maximum age was 8 years, and the minimum age was 2 years. The mean number of years that elapsed from the moment of the first visit to specialists with initial concerns until the final diagnosis was 2.45 years (SD=1.72). The minimum period was 1 month, and the maximum was 6 years.

The presence of comorbidities was observed in 22 children, 16.98% of whom had comorbidities due to attention deficit hyperactivity disorder (ADHD), 15.09% of whom had comorbidities due to psycho-speech development retardation, and 9.43% of whom had comorbidities due to mental retardation.

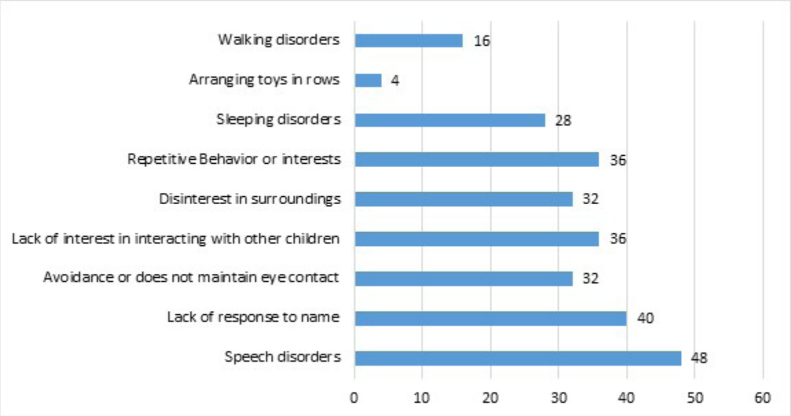

Figure 1 - Prevalence of warning signs as reported by study participants

11 study participants (20.75%) were not satisfied with the impact of diagnostic assistance, and only 5 people (9.43%) were satisfied with it. Most of the participants (22 people, 41.5%) were satisfied with the diagnosis of their children; only 2 (3.77%) were satisfied, while 16 (30.19%) of the participants were not satisfied.

Figure 1 depicts the frequency of warning signs that alerted caregivers to potential development issues with the child. Primarily, caregivers reported speech disorders, wherein the child either exhibited delayed speech development or lacked speech entirely: “The first thing that made me think that something was wrong was when I saw the child, who was younger than my son for more than half a year, carry out such commands as, for example, “take off your hat." While my son didn’t understand me at all." Moreover, in the majority of cases, caregivers expressed concern over the child's lack of response when called by name.

All warning signs observed in the children were identified by their caregivers, who subsequently confided their concerns with relatives and friends. This sharing of apprehensions served to seek support and solicit advice on how to proceed. Remarkably, within the social circles of these families, similar unsettling symptoms were noted, notably speech delays or complete absence thereof.

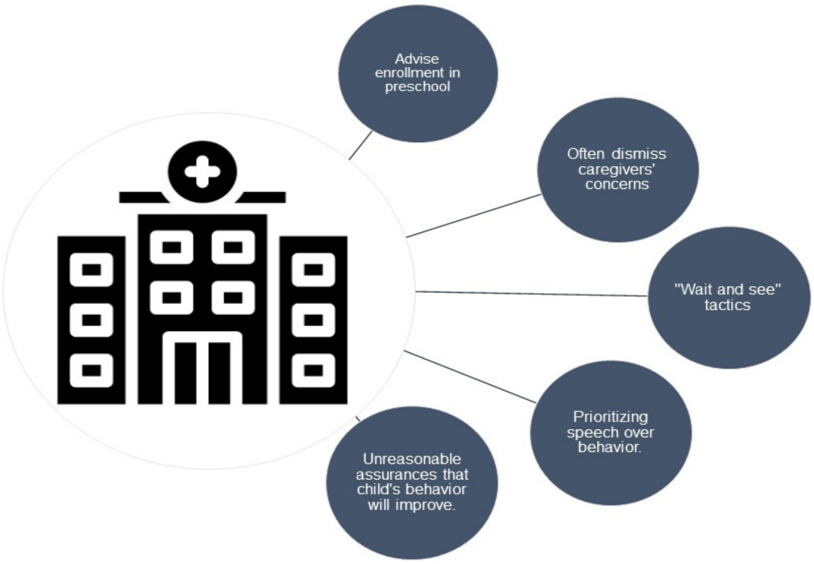

Figure 2 - Health providers' response to parents' concerns about the child's development

Nonetheless, caregivers uniformly recounted receiving reassurance and counsel advising against further action, often rationalized with statements such as, "Why label the child when everything seems fine? Perhaps he's just being a bit spoiled." The individuals around the caregivers commonly advised them to enroll the child in preschool, suggesting that exposure to other children would encourage speech development and instill discipline. Within the study cohort, caregivers perceived the child's anxious behavior as typical, while preschool staff highlighted potential developmental disorders. Despite initial advice to "Wait and See," parents proactively sought specialist input at the first inkling of concern. In determining whether their child's behavior and development were typical, parents predominantly relied on internet resources and discussions with other parents of children with developmental disorders via various messenger platforms.

Caregivers noted that despite their children undergoing routine psychophysical development screenings required for preschool enrollment, healthcare providers did not identify any alarming signs.

Caregivers primarily sought consultations from private pediatric neurologists, expressing a lack of confidence in neurologists at public primary care facilities. As one caregiver recounted, "When we visited the neurologist at our local clinic when our child was 3 years old, we were told it was premature and that the child was too young." Instead, we were advised to enroll the child in preschool." Another caregiver shared, "We were prescribed sedatives and reassured that our child, exhibiting self-harming behavior, was simply hyperactive and would outgrow it by age 7."

Children were frequently diagnosed with language delay, with the focus primarily on speech initiation and development, while behavioral issues were often dismissed as a transient phase the child would eventually overcome. Ultimately, child psychiatrists were responsible for final diagnoses, despite caregivers harboring significant biases and concerns about psychiatry. As one caregiver expressed, "I was apprehensive about the potential impact on his future, such as employability," and another admitted, "I feared the possibility of my child being prescribed psychotropic medications."

However, in Kazakhstan, obtaining disability benefits, which could offset some expenses for costly interventions, necessitated a psychiatrist's evaluation, prompting caregivers to engage with them. Despite initial reservations, most caregivers found solace in receiving a definitive diagnosis, providing clarity and understanding of their child's condition. Yet, when evaluating satisfaction with the diagnostic journey and the timeliness of diagnosis, the majority of caregivers expressed dissatisfaction or remained neutral.

Figure 2 illustrates the primary challenges encountered by participants in our study while seeking diagnostic care." The primary challenge faced by caregivers was the perceived lack of acknowledgment of the severity of their situation by specialists. As one caregiver lamented, "I believe the worst mistake is to placate a mother when diligent action is required." Many specialists were found to be unaware of autism spectrum disorder (ASD), hindering their ability to provide appropriate guidance, thereby exacerbating caregivers' mistrust of the medical system. "We sought assistance, but it was not forthcoming," one caregiver expressed, reflecting on their frustration. Concerns about potential adverse effects of medications further fueled caregivers' withdrawal from seeking help.

Furthermore, parents reported a lack of support from their social circles and family members, who often dismissed their child's condition due to outward appearances of health. Additionally, the accessibility of diagnostic services was impeded by challenges associated with the child's behavior. Some caregivers found it daunting to venture outside with their children, let alone endure long waits to see healthcare providers. Private specialists were also overwhelmed, resulting in lengthy waiting lists extending for months.

The psychological well-being of caregivers emerged as a paramount concern. "My peers blame me for spoiling him, while doctors accuse me of neglecting my child and realizing the issue too late. I'm at a loss," one caregiver expressed, highlighting the emotional turmoil experienced. "It appears that parents require psychological support foremost, followed by assistance for the child. By delaying recognition of the problem, we rob the child of valuable time," another caregiver emphasized, underscoring the urgent need for holistic support.

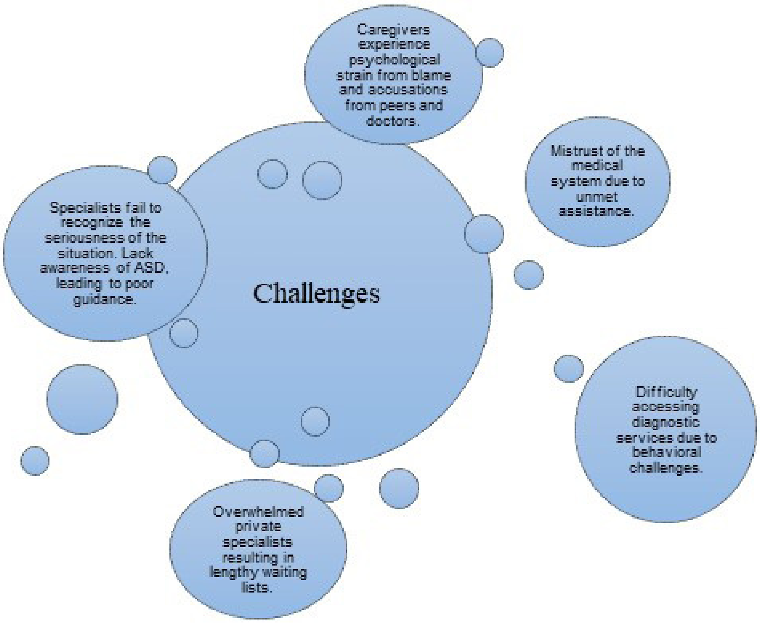

Figure 3 - Primary challenges encountered by caregivers while seeking diagnostics

Discussion

This study investigated the journey of caregivers towards the diagnosis of Autism Spectrum Disorder (ASD) in Kazakhstan and the challenges encountered. The primary issues were examined from the perspective of parents.

Our findings indicate that the mean age at final diagnosis was 54.12 months, aligning closely with the global average age at ASD diagnosis reported in a meta-analysis of 35 studies from 35 countries (50.12–70.83 months) [22].

The average duration between the initial referral to a specialist due to concerns and the ultimate diagnosis was 29.4 months, with some studies reporting periods exceeding 2 years [23]. The average age at which parents recognize their child's warning signs (1.91 years) is very close to the 1.7 years reported in a large study of parental experience in diagnosing autism in children in the United Kingdom [24].

Every fifth participant in our study was absolutely dissatisfied with the diagnostic care provided to them, and approximately 30% of participants were not satisfied with the age of diagnosis. Reducing the time that passes from the time parents first express concerns about their child's development to the time they are diagnosed with ASD is an important step toward improving the parenting experience. It is important to recognize that in some cases, clinicians are simply unable to give the child an accurate diagnostic assessment at an early stage; therefore, reassessment at regular intervals is necessary. Further research is needed to better understand how services are structured and organized to quickly and timely assess children with suspected ASD.

In our study, Attention Deficit Hyperactivity Disorder (ADHD) emerged as the most common comorbidity in children with ASD, contributing to diagnostic delays. Symptoms of ADHD may divert attention from ASD, delaying diagnosis, as anxiety symptoms are often attributed to ADHD [25].

As in other studies, parents pay the most attention to the development of the child's speech [26]. There is evidence that speech development disorders in children are a marker of increased vulnerability to the development of ASD, which suggests that both parents and medical workers should always pay attention to these kinds of complaints and not waste time waiting for the child to speak on the way to kindergarten [27].

In our study, we found that parents first turn to pediatric neurologists. Another study that presented the results of a survey of parents of children with autism in Kazakhstan reported that 73% of parents first turned to neurologists [28]. The final diagnosis was made by psychiatrists, as parents turned to them to obtain the right recommendations and conclusions for disability registration. However, research recommends a multidisciplinary approach for diagnosing ASD. It is important that these multifaceted assessments be performed by clinicians who have extensive experience in standardized testing of children and who have specific knowledge of ASD assessment [29].

Additionally, an extremely important point is to increase awareness of ASD among health providers who conduct routine screening of the psychophysical development of young children in Kazakhstan. After all, according to the results, most parents reported that no alarming symptoms were noticed during routine screenings.

When parents express their concerns during a child's examination, healthcare professionals should listen to and act on this information using ASD-specific screening rather than reassuring parents [30]. At the very least, if a waiting period is determined to be the best course of action, practitioners should establish a "wait and see" in which parents are given a certain amount of time to observe under the clear direction of the provider. If there is no improvement in development after this period, it is very important to refer such children for a comprehensive examination. Given the public health emergency posed by ASD and the long period between the first parental problems and a diagnosis of autism, there is an urgent need to improve methods for the early detection of ASD in Kazakhstan.

The small number of participants who volunteered to participate in the study is a limitation of this study. An examination of the demographics of the participants revealed that the views presented in this survey mostly reflected those of mothers with mostly college degrees. Another limitation of the sample was the small number of parents who participated in the study from various regions of Kazakhstan, preventing the reliable assessment of regional differences. Furthermore, with any self-sampling, it is impossible to determine whether the experience of those who completed the interview differed from that of nonrespondents. Those who had a particularly excellent or negative experience looking for a diagnosis for their child were more likely to complete this interview.

Conclusion

In conclusion, this study provides valuable insights into the diagnostic journey of caregivers of children with autism in Kazakhstan. It reveals significant delays in diagnosis, with caregivers encountering numerous challenges, including comorbidities, dissatisfaction with diagnostic assistance, and a lack of awareness among specialists.

Addressing these systemic challenges requires a multifaceted approach, including expanding training programs for diagnosticians, enhancing public awareness campaigns, and improving the availability of affordable services nationwide. By fostering a more inclusive and supportive environment, Kazakhstan can strive towards ensuring that every child receives the timely diagnosis and support they deserve.

Conflict of interests. The authors declare no conflicts of interest.

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Жолды ашу: Қазақстандағы отбасылар үшін аутизм диагностикасының қиындықтары

Нукештаева К.Е. [1], Омаркулов Б. К. [2], Любченко М.Ю. [3], Nailya Delellis [4], Мусина А.А. [5],
Каюпова Г. С. [6], Даулеткалиева Ж.А.[7]

[1] Қоғамдық денсаулық мектебінің ассистент-профессоры, Қарағанды медицина университеті, Қарағанды, Қазақстан. E-mail: nukeshtaeva@qmu.kz

[2] Отбасылық медицина кафедрасының профессоры, Қарағанды медицина университеті, Қарағанды, Қазақстан. E-mail: omarkulov@qmu.kz

[3] Неврология, психиатрия және реабилитология кафедрасының профессоры, Қарағанды медицина университеті, Қарағанды, Қазақстан. E-mail: lyubchenko@qmu.kz

[4] Орталық Мичиган университетінің профессоры, Маунт Плезант, Мичиган, АҚШ. E-mail: delel1no@cmich.edu

[5] Қоғамдық денсаулық және эпидемиология кафедрасы меңгерушісі, Астана медицина университеті, Астана, Қазақстан. E-mail: mussina.a@amu.kz;

[6] Қоғамдық денсаулық мектебінің қауымдастырылған профессоры, Қарағанды медицина университеті, Қарағанды, Қазақстан. E-mail: kayupovag@qmu.kz

[7] Қоғамдық денсаулық мектебінің деканы, Қарағанды медицина университеті, Қарағанды, Қазақстан. E-mail: dauletkalievaz@qmu.kz

Түйіндеме

Қазақстандағы аутизмді диагностикалау лабиринтінде шарлау отбасылар үшін қиын жол болуы мүмкін. Арнайы дайындалған мамандардың аздығы, науқастардың хабардарлық деңгейінің төмендігі, ерте анықтау және араласу үшін айтарлықтай кедергілер тудырады.

Бұл зерттеудің негізгі мақсаты – Қазақстандағы аутизм спектрінің бұзылуының диагностикалық жолы туралы ата-аналардың тәжірибесіне жарық түсіру, ата-аналардың шешім қабылдауына әсер ететін факторларға ден қою және диагностикалық қолдау іздеген отбасылар және балалары үшін кездесетін кедергілерді түсіну.

Әдістері. Бұл зерттеу балалық шақтағы аутизм, атипті аутизм диагнозы қойылған балалардың ата-аналарымен баланың дамуы туралы бастапқы алаңдаушылықтардан ресми диагнозға дейінгі үдерістегі қиындықтар туралы аралас әдіспен анықтауға бағытталған сұхбаттарды қамтыды.

Нәтижесі. Зерттеу тобында аутизм проблемалары орташа алғанда 1,91 жаста, ал маманға жолдама 2,19 жаста пайда болғаны белгілі болды. Диагноз қойылғанда орташа жас 4,51 жасты құрады. Қосымша ауруларға зейін тапшылығының гиперактивтілігінің бұзылуы (16,98%), ақыл-ойдың артта қалуы (15,09%) және ақыл-ойдың артта қалуы (9,43%) жатады. Диагнозға қанағаттанушылық деңгейі біршама төмен (9,43%), дегенмен респонденттердің 41,5% диагноз қою сапасына қанағаттанған екені анықталды. Қамқоршылар мамандар мен әлеуметтік ортаның хабардарлығы мен қолдауының жетіспеушілігіне, сондай-ақ логистикалық және психологиялық қиындықтарға тап болып, дер кезінде диагноз қоюдың кешігуімен күресуде.

Қорытынды. Зерттеу Қазақстандағы заңды өкілдердің өз балаларындағы аутизмді диагностикалау кезінде қандай қиындықтарға тап болатынын көрсетеді. Қиындықтар диагностиканың кешіктірілуін, қосымша аурулардың таралуын және диагностикалық көмекке қанағаттану деңгейінің төмендігі секілді тұстарды қамтыды. Дер кезінде жүргізілген және тиімді диагностикалық қызметтерге қолжетімділікті жақсартудың өзекті қажеттілігін көрсетеді. Сондай-ақ аутизм диагностикасының күрделі мәселелерін зерттейтін қамқоршыларға қолдауды күшейтеді.

Түйін сөздер: аутизм спектрінің бұзылуы, ата-ана тәжірибесі, Қазақстан.

Распутывая путь: трудности диагностики аутизма для семей в Казахстане

Нукештаева К.Е. [1], Омаркулов Б. К. [2], Любченко М.Ю. [3], Nailya Delellis [4], Мусина А.А. [5],
Каюпова Г. С. [6], Даулеткалиева Ж.А.[7]

[1] *Ассистент-профессор Школы общественного здоровья, Медицинский университет Караганды, Караганды, Казахстан. E-mail: nukeshtaeva@qmu.kz*

[2] *Профессор кафедры семейной медицины, Медицинский университет Караганды, Караганды, Казахстан. E-mail: omarkulov@qmu.kz*

[3] *Профессор кафедры неврологии, психиатрии и реабилитации, Медицинский университет Караганды, Караганды, Казахстан. E-mail: lyubchenko@qmu.kz*

[4] *Профессор Центрального университета Мичигана, Маунт Плезант, Мичиган, США. E-mail: delel1no@cmich.edu*

[5] *Заведующая кафедрой общественного здоровья и эпидемиологии, Медицинский университет Астана, Астана, Казахстан. E-mail: mussina.a@amu.kz*

[6] *Ассоциированный профессор Школы общественного здоровья, Медицинский университет Караганды, Казахстан. E-mail: kayupovag@qmu.kz*

[7] *Декан Школы общественного здоровья, Медицинский университет Караганды, Караганды, Казахстан. E-mail: dauletkalievaz@qmu.kz*

Резюме

Преодоление сложностей диагностики аутизма в Казахстане представляет собой значительное испытание для семей. Недостаток квалифицированных специалистов, ограниченная осведомленность и нехватка ресурсов создают серьезные препятствия для своевременного выявления расстройства и начала вмешательства.

Цель исследования: изучить опыт родителей, проходящих процесс диагностики расстройства аутистического спектра в Казахстане, определить факторы, влияющие на принятие решений семьями, и выявить основные барьеры, с которыми они сталкиваются в поиске диагностической помощи для своих детей.

Методы. Исследование включало проведение полуструктурированных интервью с родителями детей, которым были поставлены диагнозы детский аутизм и атипичный аутизм. Интервью касались трудностей, которые родители испытывали от момента возникновения первых подозрений относительно развития ребенка до получения формального диагноза.

Результаты. Средний возраст, когда родители впервые начали беспокоиться о развитии своих детей, составил 1,91 года, а обращение за профессиональной помощью происходило в 2,19 года. Диагноз же ставился в среднем в возрасте 4,51 года. Среди сопутствующих заболеваний были выявлены синдром дефицита внимания и гиперактивности (16,98%), задержка психоречевого развития (15,09%) и умственная отсталость (9,43%). Только 9,43% родителей выразили удовлетворенность процессом постановки диагноза, в то время как 41,5% остались довольны полученной помощью. Родители сталкивались с множеством препятствий, среди которых были недостаточная осведомленность и поддержка со стороны специалистов и общества, а также логистические и психологические трудности.

Выводы. Данное исследование подчеркивает серьезные проблемы, с которыми сталкиваются семьи в Казахстане при диагностике аутизма у своих детей, включая поздний возраст постановки диагноза и высокую распространенность сопутствующих расстройств. Оно также акцентирует внимание на неудовлетворенности родителей качеством диагностической помощи и необходимости улучшения доступа к своевременным и эффективным услугам, а также усиления поддержки родителей в процессе диагностики.

Ключевые слова: расстройства аутистического спектра, родительский опыт, Казахстан.