Health Care Providers' Awareness on Medical Management of Children With Autism Spectrum Disorder: Cross-Sectional Study in Russia

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Abstract

Background: Autism spectrum disorder (ASD) is a complex developmental range of conditions that involves difficulties with social interaction and restricted/repetitive behaviors. Unfortunately, health care providers often experience difficulties in diagnosis and management of individuals with ASD and may have no knowledge about possible ways to overcome barriers in ASD patient interactions in healthcare settings. At the same time, the provision of appropriate medical services can have positive effects on habilitative progress, functional outcome, life expectancy and quality of life for individuals with ASD.

Methods: This online survey designed research study evaluated the awareness and experience of students/residents (n=247) and physicians (n=100) in medical management of children with ASD, as well as the views and experiences of caregivers of children on the autism spectrum (n=158), all based in Russia.

Results: We have established that the Russian medical community has limited ASD knowledge among providers, and have suggested possible reasons for this. Based on the online survey of students/residents, non-psychiatric physicians and caregivers of children diagnosed with ASD, the main problems pertaining to medical management of individuals with ASD were identified, and possible problem solving solutions within medical practice were proposed.

Conclusions: Results of this study should be considered both when implementing measures to improve healthcare practices, and in developing models of effective medical management due to start in not only in Russia but also in a number of other countries.

Background

Autism spectrum disorder (ASD) is the most rapidly spreading developmental disorder [1]. The prevalence of this condition is still achieving its plateau, and the rate of its rise cannot be explained by over diagnosis only. Early intense and specific intervention for ASD leads to improved cognitive and adaptive functioning [2, 3], therefore early identification of a potential risk of autism in young children is particularly important. Pediatricians, as well as other health care providers, working with young children and families must be prepared to use surveillance and screening for ASD in their practice. In 2006 the American Academy of Pediatrics recommended screening specifically for autism during well-child preventive care visits at 18 and 24 months [4]. In Russia, a screening procedure for risk of ASD at the age of at least 24 months was approved by an order of the Ministry of Health as recently as 2019 [5].

In addition to the above, one should take into consideration that ASD is a whole-body condition that affects not only the brain but also the functioning of many organs and systems [6]. 83% of individuals with ASD are noted to have one or more non-autistic (concomitant) disorders [7]. The mortality rate of people with ASD is up to 10-fold higher than the general population [8–10]. This higher mortality usually results from comorbidities such as epilepsy, gastrointestinal and respiratory disorders [11–14]. In addition, childhood functional impairments and impairments in social reciprocity were significant

predictors of mortality [15]. Therefore, timely diagnosis, follow-up and treatment of comorbidities by specialists capable of working with this group of patients can not only improve the quality of life of children with ASD, but also help save their lives.

Methods

Participants and procedure

All participants were informed verbally, or in writing, about the purpose of the study and confidentiality of the survey. The methods described herein were approved by the Kazan Federal University Local Ethics Committee and performed in accordance with the relevant guidelines and regulations.

The medical students and residents group comprised of 247 people with an average age of 23.4 ± 2.2 years. Inclusion criteria were as follows: (1) studying in the 5th or 6th year within a medical faculty or the 1st or 2nd year of residency, (2) able to read, write, and understand Russian, and (3) residents of the non-neuropsychiatric disciplines; (4) willing and able to participate in the study. The students and residents were invited to take part in an online survey by the dean's office of their faculties between May and June, 2020.

A total of 100 Russian non-psychiatric physicians (consisting of pediatricians (50%), neurologists (34%), medical specialists – ENT-specialists, surgeons, ophthalmologists, allergists (16%)) participated in this study via the online survey between May and July, 2020, following invitations from medical faculty managements and professional associations. The professionals were relatively experienced in their professional roles: 20% had less than 5 years' experience, 21% had 5–10 years' experience, 14% had 10–15 years' experience, 11% and 34% had 15–20 years' and over 20 years' experience, respectively. The physicians were primarily pediatric specialists.

Both surveys (for students/residents or physicians) contained two sections and took approximately 5 minutes to complete (Supplement material S1). Part 1 comprised of 11-12 items on the participants' background, including basic demographics (age, location and number of years in current practice, specialty and a type of care provided) and questions relating to signs of autism, its diagnostics and comorbidities, as well as information pertaining to completion of ASD patient management educational programs and the adequacy of knowledge these courses provided. Part 2 was intended only for students/residents or physicians who have had direct practical experience with patients with ASD (in Russia students start their medical practice in the 3rd year of their studies) and summarized possible difficulties encountered in relation to diagnosis and follow-up of comorbidities and their assessment of how to overcome them.

A total of 158 caregivers of children diagnosed with ASD were invited to participate in the online survey between April and June 2020. Attending physicians or non-profit organizations supporting individuals on the autism spectrum and their families, highlighted the study to participants. A questionnaire containing issues relating to a diagnostics procedure and the presence of comorbidities in children with ASD was

used in the study (Supplement material S2). In addition, the query items included questions on satisfaction with the quality of medical care for children with ASD and related conditions, and the difficulties that they needed to overcome in obtaining service provision.

Statistical analysis

Data obtained from the survey were imported into R 3.6.3 software (R Foundation for Statistical Computing, Vienna, Austria). Descriptive statistics are presented in absolute numbers or percentages. Qualitative analysis was carried out in relation to open-ended questions in survey. Participant responses were categorized and analyzed according to traditional methods of content analysis [16, 17].

Results

Diagnosis and follow-up of concomitant diseases (comorbidities) in individuals with ASD do involve several problems [18, 19]. Based on our findings 80.6% of physicians and 63.6% of students and residents, who had to interact with patients diagnosed with ASD in their medical practice, had difficulties in the diagnosis or follow-up of concomitant disorders for these patients. These factors also resulted in dissatisfaction with the quality of medical care for children with ASD as reported by their caregivers (Figure 1). Therefore, further consideration of the key difficulties in medical service provision and possible ways to overcome them seems to be quite important and relevant.

Limited provider knowledge

Over the past decade a large number of studies have showed moderate awareness and limited knowledge among health care providers (residents and physician) on care provision and medical management of patients with ASD [20–26]. Interestingly, these results were obtained not only in developing countries (Nigeria, Turkey), but in developed ones with long histories of researching autism and extensive experience of managing patients with ASD (United States, Canada).

In Russia, based on our data, 63.5% of students and residents indicated that they did not study the signs and symptoms of ASD and the special features of managing these patients within their university/residency educational programs. It should be noted that medical faculty curriculums do contain autism teaching; however, it is a 1.5-hour lecture course without any seminars. Therefore, it is not surprising that the majority (74.2%) of non-psychiatric physicians in Russia who conduct clinical follow-ups of patients with ASD, consider their knowledge relating to diagnostic criteria, especially early diagnosis, and on concomitant disorders and correct effective interactions with a child during an examination, to be inadequate.

According to DSM5 (Diagnostic and Statistical Manual of Mental Disorders, 5th ed.; American Psychiatric Association, 2013) behavioral markers of ASD include persistent difficulties with social communication and interaction, the presence of restricted and repetitive behaviors, interests or activities. These behavioral markers were considered by less than 50% of students/residents and physicians to be the

leading clinical signs of ASD (Table 1). At the same time 30% of the respondents added non-specific clinical signs such as mental retardation and the lack of emotional empathy as mandatory. Despite the established definitive criteria, more than 35% of respondents considered delayed speech or the lack of speech to be a leading diagnostic criterion of ASD, while ~10% of students/residents and ~20% of physicians consider limited eye contact and aggression to be mandatory clinical signs.

Table 1. Most cited clinical signs of ASD indicated by participants

<i>Clinical signs</i>		<i>Students/residents</i>	<i>Physicians</i>
DSM-5 Autism Diagnostic Criteria	Persistent deficits in social communication and social interaction	49.6%	47%
	Restricted, repetitive patterns of behavior, interests, or activities	42.5%	31%
Delayed speech or absence of speech		35.2%	43%
Limited eye contact		9.7%	21%
Aggression/self-injury		10.5%	17%
Mental retardation		17%	6%
Lack of emotional empathy		6.5%	6%
Do not know clinical signs of ASD (no answer/not a single correct answer)		17.4%	20%

As for the diagnostic criteria of ASD, healthcare providers, it is clear that they do not always have access to competent resources. The fact that some physicians and scientific schools in Russia still subdivide psychotic forms of autism and consider ASD and schizophrenia as the same entity further aggravate this problem. Early in 2020 parent and medical communities discussed new clinical guidelines on ASD, as developed by the Russian Association of Psychiatrists. The main challenge was that the clinical guidelines are unscientific and based on out dated knowledge about autism, as were approaches to its management and rehabilitation of individuals with ASD. These issues were solved, due to active participation of parent and professional communities and in July 2020 the Ministry of Health of the Russian Federation approved new clinical guidelines on the management of children with ASD. These guidelines aimed to improve the quality of care of children with ASD and will be mandatory starting from 2022; however, medical facilities have to indoctrinate their specialists on the new guidelines and had to conduct educational activities since the time of their approval.

Medical conditions associated with ASD have been long been sufficiently studied worldwide [18, 27–35]. However, the problem of comorbidity, as well as methods of management of ASD complex behaviors, in relation to being important for effective medical care [36] are quite poorly addressed in Russian professional medical sources [37–40]. A total of 44% of physicians and 56.6% of students/residents who

participated in our survey were unable to name any of common concomitant disorders in individuals with ASD. Results from the survey to health care providers investigating the most common comorbidities in patients with ASD are given in Figure 2. Given the information available, it is not surprising that 46.2% of respondent caregivers in turn mention the lack of monitoring and correction/therapy of concomitant disorders by medical specialists for their children with ASD.

In Russia activities to make physicians aware of modern studies clarifying possible mechanisms, symptoms and consequences of comorbidities in ASD, as well as methods to overcome communication barriers, are primarily conducted by non-profit organizations supported by various grant-providing systems. Recently, as the issue is important, there are more and more professional programs aimed at advanced training for non-psychiatric physicians (mainly pediatricians and neurologists). However, these programs are not always budget-funded and provide the full-time education required, that, in our opinion, make them less available and reduces the quality of the educational program in terms of physicians being able to adequately master the topic.

We consider the limited provider ASD knowledge among the Russian medical community to be due to the following problems, to which finding solutions for is vital in order to overcome this issue: (1) the educational program intended for physicians does not provide sufficient study of ASD in the multidisciplinary context or practical skills; (2) no consensus is available in relation to diagnostic criteria of ASD and the very essence of the disorder in the medical community; (3) clinical guidelines on the management of patients with ASD based on the modern diagnostic principles and treatment approaches for this condition have been quite recently approved and it will take some time for physicians to be indoctrinated with them.

Communication barriers

Impairment in communication and social interactions are defined as the main symptoms of ASD and one of the problems encountered by physicians during diagnosis of concomitant disorders. In addition, individuals with ASD are often unable to formulate complaints and may become increasingly agitated during a physical examination [41–44]. In turn, physicians may feel uncomfortable and prefer to ascribe symptoms of concomitant diseases to "common" manifestations of autism or avoid working with patients of this category at all [45]. Therefore, patients with ASD indicate low satisfaction in patient-provider communication and low healthcare self-efficacy as a result [46–48].

The above can result from insufficient skills in examination of individuals with evident behavioral disorders, indeed this has been previously shown [24, 45]. The latter is also in line with our findings, where ~75% of students/residents and physicians related difficulties in diagnosis and follow-up of comorbidities to behavioral disorders only. At least 70% of respondents mentioned the combination of the above problem with the lack of, or failed, language ability and an inability to describe a pain/discomfort experienced and their localization. At the same time only 2% of health care providers considered that additional information on effective methods of interaction with an ASD patient during an examination was required. These findings are in line with the caregivers opinion, at least 70% of whom stated that

physicians who visit children with behavioral disorders are lacking examination skills. It has already been noted that health care providers can be unaware of the need to adjust their communication styles to be effective with patients with ASD - or are unable/unwilling to do it [49].

Many countries have started to contemplate what should be done in order to improve patient-provider communication [50–53]. In 2002, the American Board of Pediatrics began certifying developmental-behavioral pediatricians, whose activities involve diagnosis of developmental disabilities, identification of comorbidities, and the care assistance of these children. Results of the study conducted by Hansen et al. (2016) showed that the clinical practices of developmental-behavioral pediatricians allow them to complete the diagnostic evaluations for ASD and that the obtained multiple components of assessment align with existing guidelines [54]. In Russia and other countries multidisciplinary interaction is often suboptimal (it will be discussed in the following section) and physicians are often not aware of possible alternative communication methods or have no skills relating to the behavior and response during medical examination, preventive methods, or those of desensitization used in examination of individuals with ASD [55].

Communication is a two-sided process, therefore it should be noted that the introduction of training on compliant physical exam and common health care procedures into the program of behavior manipulation of individuals with ASD is of importance in parallel to training medical personnel in effective cooperation skills with autistic patients [56–58]. One must assume that two-sided steps would be successful and can improve the situation.

Multidisciplinary interaction

The studies conducted showed that the work of a multidisciplinary team (medical-psychological and pedagogical follow-up) facilitates better provision of care coordination and holistic service for individuals with ASD [59–61]. Combined knowledge and competence of multidisciplinary team specialists provides optimal conditions for the successful development of a child, his/her adaptation and social interactions in the community as well as allowing them to overcome difficulties including those related to heterogeneity of disorders [55, 62, 63]. Only 2% of respondent health care providers reported having a close cooperation with psychological and pedagogical specialists and not more than 10% of physicians referred to, or recommended to, consult these specialists when identifying children with ASD. The lack of multidisciplinary interaction is evidenced by answers of caregivers of children with ASD, 41.1% of whom reported inadequate post-diagnostic support including education on evidence-based methods of ASD correction.

At the same time, given the high prevalence of concomitant diseases, the follow-up of individuals with ASD by different medical specialists is required. Margaret Bauman, a pediatric neurologist, developed the first multidisciplinary program for complex care of individuals with ASD and other developmental disorders which was called LADDERS (Learning and Developmental Disabilities and Rehabilitation Services). The developed approach, under the LADDERS project based the Autism Treatment Network medical program, is a classic model to create progressive comprehensive medical care for children with

ASD in many countries. In Russia the development of a multidisciplinary medical follow-up of children with ASD started in 2019 with an active participation of the non-profit organization the Center of Autism Problems. In this regard, there are great expectations for many pediatric physicians to become more aware of concomitant diseases, modern principles of their diagnosis and treatment approaches and to be trained in working with ASD individuals.

Need for Systemic Changes

A number of studies consider that systemic changes are required in order to improve the healthcare environment [23, 64, 65]. Investigators or health care providers suppose that medical care for individuals with ASD could be improved when implementing complex systemic changes such as additional finance promotion of medical professionals [60, 64, 65], reduced sensory load, and provision of additional methods of distraction in health care facilities [24]. Our survey demonstrated that 83.5% of caregivers of children diagnosed with ASD consider services on special follow-up of a child with ASD were required and at least 50% of the respondents mentioned that the environment (play grounds/rooms where a child can be distracted or sensory load be reduced) should be adapted for a successful health examination.

Discussion

This survey-design research study tried to clarify the main issues of medical management of individuals with ASD in Russia, including monitoring and follow-up of comorbidities, by taking opinions of both health care providers and caregivers of diagnosed children into consideration. We have also proposed possible solutions for the problem identified in present medical practice (Table 2). It should be noted that unlike a number of European countries and the USA, the care for individuals with ASD in Russia is still in its early days, and much depends upon the availability of finance and methodological support for the management of such children in the region. Nevertheless, the initiative and motivation of parents and specialists, which are usually determined by a personal relation to autism, have greatly promoted the creation of specialized care to children with ASD over the past decade ranging from evidence-based correction methods of this disorder to the implementation of a model of inclusive school and the approval of clinical guidelines on medical care of children with ASD.

Table 2. The main problems of medical management of individuals with ASD (including monitoring and follow-up of comorbidities) and possible problem solving in medical practice

No.	Problems	Problem solving
1	Difficulties in early ASD identification by primary care pediatricians and limited provider ASD knowledge in general	(1-3) Changes into the medical education program: extending the topics of child and adolescent mental health, adequate studying of ASD in a multidisciplinary context, the development of diagnostic routing protocols, training in practical skills of communication with ASD patients and their examination
2	Lack of adequate skills in examination of patients with evident behavioral disorders	
3	Poor understanding of the need to adjust communication styles to be effective with patients	
4	Lack of the proper development of competence and skills in identification, assessment and follow-up of concomitant diseases	(4-5) Conducting multidisciplinary thematic conferences and studies. Development of methodical and clinical recommendations on identification and treatment of concomitant diseases in patients with ASD with participation of a multidisciplinary working group.
5	Poor multidisciplinary cooperation of specialists	
6	Lack of specialist follow-up services for patients with ASD for successful health examination	(6-7) Changes in legal regulation of the health care system
7	Low adjustment of health care environment for patients with ASD	

Diagnostic criteria of autism have been reformed since its first description and up recently, therefore it is not surprising that there is still no consensus on diagnostic criteria of ASD and its very essence among the medical community. This factor is noted to be a great obstacle to consistent assessment and determination of the management strategy [66, 67].

Our study revealed that health care providers have poor awareness of medical conditions associated with ASD. More than 50% of both physicians and students/residents were unable to name any common concomitant diseases in patients with ASD or instead described medical conditions not associated with autism. Due to active members of professional communities and experts in non-profit organizations, activities around making physicians aware of modern clinical guidelines and how to identify and treat comorbidities in patients with ASD have already started in Russia. It is expected that these activities will continue, and that health care providers will take an interest in them and follow the proven principles of diagnosis and treatment for the different comorbidities in these patients.

Improvement in medical care can have a positive effect on rehabilitation progress and quality of life for patients with ASD [68]. This issue is more and more relevant and associated with challenges to medical service provision as indicated by both healthcare providers and caregivers of children with ASD. In our opinion, the required system changes can be implemented only by changing the legal regulations of the health care system. The multidisciplinary team of specialists and active members of parent communities should be engaged in discussing proposed changes.

Conclusions

The provision of proper medical services can have a positive effect on habilitative progress, functional outcome, quality and life expectancy of individuals with ASD. In addition to primary examination, diagnostics and diagnosis, health care providers can provide important long-term medical care, support and educate families by guiding them to interventions which are effective for patients with ASD [68]. Needless to say, understanding and acknowledging the gaps in health care service provision with this population both by medical and parent communities is required for effective development of medical management in ASD. Therefore, the results of this survey should be considered when making measures to improve health care practices, and during the development of a model of effective medical management which is due to start in Russia and in a number of other countries.

Abbreviations

ASD: autism spectrum disorder; DSM: diagnostic and statistical manual of mental disorders; LADDERS: learning and developmental disabilities and rehabilitation services.

Declarations

Ethics approval and consent to participate: Informed consent was given electronically by all participants. The survey was anonymous and received ethics approval by the Kazan Federal University Local Ethics Committee (Permit Number 7, 2020). All methods were performed in accordance with the relevant guidelines and regulations.

Consent for publication: Not applicable.

Availability of data and materials: The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions: Conceived and designed the study and the analysis: MYO. Designed the survey: MYO, NIA, VVV, RCS. Collected the data: MYO, FRA. Performed the analysis: MYO. Wrote the manuscript: MYO, FRA, RCS. Reviewed the manuscript: all authors. All authors have read and approved the manuscript.

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References

1. Maenner MJ, Shaw KA, Baio J, EdS1, Washington A, Patrick M, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR Surveill Summ.* 2020;69:1–12.
2. Virués-Ortega J. Applied behavior analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose–response meta-analysis of multiple outcomes. *Clin Psychol Rev.* 2010;30:387–99.
3. Dawson G, Rogers S, Munson J, Smith M, Winter J, Greenson J, et al. Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics.* 2010;125:e17-23.
4. Council on Children With Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. *Pediatrics.* 2006;118:405–20.
5. Order of the Ministry of Health of the Russian Federation of June 13, 2019 N 396n "On amendments to the Procedure for conducting preventive medical examinations of minors, approved by order of the Ministry of Health of the Russian Federation of August 10.
6. Randolph-Gips M, Srinivasan P. Modeling autism: a systems biology approach. *J Clin Bioinforma.* 2012;2:17.
7. Hodges H, Fealko C, Soares N. Autism spectrum disorder: definition, epidemiology, causes, and clinical evaluation. *Transl Pediatr.* 2020;9:S55–65.
8. Pickett J, Xiu E, Tuchman R, Dawson G, Lajonchere C. Mortality in individuals with autism, with and without epilepsy. *J Child Neurol.* 2011;26:932–9.
9. Pickett J, Xiu E, Tuchman R, Dawson G, Lajonchere C. Mortality in individuals with autism, with and without epilepsy. *J Child Neurol.* 2011;26:932–9.
10. Guan J, Li G. Injury Mortality in Individuals With Autism. *Am J Public Health.* 2017;107:791–3.
11. Shavelle RM, Strauss DJ, Pickett J. Causes of death in autism. *J Autism Dev Disord.* 2001;31:569–76.
12. Mouridsen SE, Brønnum-Hansen H, Rich B, Isager T. Mortality and causes of death in autism spectrum disorders. *Autism.* 2008;12:403–14.

13. Woolfenden S, Sarkozy V, Ridley G, Coory M, Williams K. A systematic review of two outcomes in autism spectrum disorder - epilepsy and mortality. *Dev Med Child Neurol*. 2012;54:306–12.
14. Bilder D, Botts EL, Smith KR, Pimentel R, Farley M, Viskochil J, et al. Excess mortality and causes of death in autism spectrum disorders: a follow up of the 1980s Utah/UCLA autism epidemiologic study. *J Autism Dev Disord*. 2013;43:1196–204.
15. Smith DaWalt L, Hong J, Greenberg JS, Mailick MR. Mortality in individuals with autism spectrum disorder: Predictors over a 20-year period. *Autism*. 2019;23:1732–9.
16. Tempski P, Bellodi PL, Paro HBMS, Enns SC, Martins MA, Schraiber LB. What do medical students think about their quality of life? A qualitative study. *BMC Med Educ*. 2012;12:106.
17. Siqueira MAM, Gonçalves JP, Mendonça VS, Kobayasi R, Arantes-Costa FM, Tempski PZ, et al. Relationship between metacognitive awareness and motivation to learn in medical students. *BMC Med Educ*. 2020;20:1–10.
18. Tye C, Runicles A, Whitehouse AJO, Alvares GA. Corrigendum: Characterizing the Interplay Between Autism Spectrum Disorder and Comorbid Medical Conditions: An Integrative Review. *Front Psychiatry*. 2019;10.
19. Liu J, Chen LL, Shen S, Mao J, Lopes M, Liu S, et al. Challenges in the Diagnosis and Management of Pain in Individuals with Autism Spectrum Disorder. *Rev J Autism Dev Disord*. 2020.
20. Carbone PS, Murphy NA, Norlin C, Azor V, Sheng X, Young PC. Parent and Pediatrician Perspectives Regarding the Primary Care of Children with Autism Spectrum Disorders. *J Autism Dev Disord*. 2013;43:964–72.
21. Broder-Fingert S, Ferrone CF, Giauque A, Connors SL. Residents' Knowledge and Comfort With Caring for Children With Autism Spectrum Disorder. *Clin Pediatr (Phila)*. 2014;53:1390–2.
22. Esegbe EE, Nuhu FT, Sheikh TL, Esegbe P, Sanni KA, Olisah VO. Knowledge of Childhood Autism and Challenges of Management among Medical Doctors in Kaduna State, Northwest Nigeria. *Autism Res Treat*. 2015;2015:1–6.
23. Muskat B, Burnham Riosa P, Nicholas DB, Roberts W, Stoddart KP, Zwaigenbaum L. Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals. *Autism*. 2015;19:482–90.
24. Zwaigenbaum L, Nicholas DB, Muskat B, Kilmer C, Newton AS, Craig WR, et al. Perspectives of Health Care Providers Regarding Emergency Department Care of Children and Youth with Autism Spectrum Disorder. *J Autism Dev Disord*. 2016;46:1725–36.
25. Kalb LG, Stuart EA, Mandell DS, Olfson M, Vasa RA. Management of Mental Health Crises Among Youths With and Without ASD: A National Survey of Child Psychiatrists. *Psychiatr Serv*. 2017;68:1039–45.
26. Hidiroglu S, Lüleci NE, Karavus M, Tanrioer O, Bayar ES, Karavus A. The awareness of childhood autism among residents of neuropsychiatric and other disciplines of a research and training hospital in Istanbul, Turkey. *J Pak Med Assoc*. 2018;68:247–51.

27. Barton M, Volkmar F. How commonly are known medical conditions associated with autism? *J Autism Dev Disord.* 1998;28:273–8.
28. Xue Ming, Brimacombe M, Chaaban J, Zimmerman-Bier B, Wagner GC. Autism Spectrum Disorders: Concurrent Clinical Disorders. *J Child Neurol.* 2008;23:6–13.
29. Bolton PF. Medical conditions in autism spectrum disorders. *J Neurodev Disord.* 2009;1:102–13.
30. Kang V, Wagner GC, Ming X. Gastrointestinal Dysfunction in Children With Autism Spectrum Disorders. *Autism Res.* 2014;7:501–6.
31. McElhanon BO, McCracken C, Karpen S, Sharp WG. Gastrointestinal Symptoms in Autism Spectrum Disorder: A Meta-analysis. *Pediatrics.* 2014;133:872–83.
32. Muskens JB, Velders FP, Staal WG. Medical comorbidities in children and adolescents with autism spectrum disorders and attention deficit hyperactivity disorders: a systematic review. *Eur Child Adolesc Psychiatry.* 2017;26:1093–103.
33. Bozzi Y, Provenzano G, Casarosa S. Neurobiological bases of autism-epilepsy comorbidity: a focus on excitation/inhibition imbalance. *Eur J Neurosci.* 2018;47:534–48.
34. Neumeyer AM, Anixt J, Chan J, Perrin JM, Murray D, Coury DL, et al. Identifying Associations Among Co-Occurring Medical Conditions in Children With Autism Spectrum Disorders. *Acad Pediatr.* 2019;19:300–6.
35. Madra M, Ringel R, Margolis KG. Gastrointestinal Issues and Autism Spectrum Disorder. *Child Adolesc Psychiatr Clin N Am.* 2020;29:501–13.
36. Blinova NA, & Pyrina IV. The role of a nurse in the work of a multi-professional team in the provision of medical care to children with autism. *Omsk Psychiatr J.* 2019;2:11–3.
37. K. A. Natarova, A. V. Semke EVG. Autism spectrum disorders (clinical-dynamic, regional and family aspects). 2012.
38. Kelmanson IA. Sleep disturbances in children with autistic spectrum disorders. *Zhurnal Nevrol i psikhiatrii im SS Korsakova.* 2015;115:102.
39. Morozov SA. On the Issue of Comorbidity in Autism Spectrum Disorders. *Autism Dev Disord.* 2018;16:3–8.
40. Belousova ED, Zavadenko NN. Epilepsy and autism spectrum disorders in children. *Zhurnal Nevrol i psikhiatrii im SS Korsakova.* 2018;118:80.
41. Evans DW, Canavera K, Kleinpeter. FL, Maccubbin E, Taga K. The Fears, Phobias and Anxieties of Children with Autism Spectrum Disorders and Down Syndrome: Comparisons with Developmentally and Chronologically Age Matched Children. *Child Psychiatry Hum Dev.* 2005;36:3–26.
42. White SW, Oswald D, Ollendick T, Scahill L. Anxiety in children and adolescents with autism spectrum disorders. *Clin Psychol Rev.* 2009;29:216–29.
43. van Steensel FJA, Bögels SM, Perrin S. Anxiety Disorders in Children and Adolescents with Autistic Spectrum Disorders: A Meta-Analysis. *Clin Child Fam Psychol Rev.* 2011;14:302–17.

44. Raymaker DM, McDonald KE, Ashkenazy E, Gerrity M, Baggs AM, Kripke C, et al. Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism*. 2017;21:972–84.
45. Zerbo O, Massolo ML, Qian Y, Croen LA. A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System. *J Autism Dev Disord*. 2015;45:4002–14.
46. Bruder MB, Kerins G, Mazzarella C, Sims J, Stein N. Brief Report: The Medical Care of Adults with Autism Spectrum Disorders: Identifying the Needs. *J Autism Dev Disord*. 2012;42:2498–504.
47. Cheak-Zamora NC, Yang X, Farmer JE, Clark M. Disparities in Transition Planning for Youth With Autism Spectrum Disorder. *Pediatrics*. 2013;131:447–54.
48. Nicolaidis C, Raymaker D, McDonald K, Dern S, Boisclair WC, Ashkenazy E, et al. Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership. *J Gen Intern Med*. 2013;28:761–9.
49. Nicolaidis C, Raymaker DM, Ashkenazy E, McDonald KE, Dern S, Baggs AEV, et al. “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. *Autism*. 2015;19:824–31.
50. Brown AB, Elder JH. Communication in autism spectrum disorder: a guide for pediatric nurses. *Pediatr Nurs*. 2014;40:219–25. <http://www.ncbi.nlm.nih.gov/pubmed/25929112>.
51. Mason D, Ingham B, Urbanowicz A, Michael C, Birtles H, Woodbury-Smith M, et al. A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *J Autism Dev Disord*. 2019;49:3387–400.
52. Clark LA, Whitt S, Lyons K. Improving Communication Between Health Care Providers, Families, and Children with Autism Spectrum Disorder: The Linked Program. *J PeriAnesthesia Nurs*. 2019;34:889–99.
53. Casagrande K, Ingersoll BR. Improving Service Access in ASD: A Systematic Review of Family Empowerment Interventions for Children with Special Healthcare Needs. *Rev J Autism Dev Disord*. 2020.
54. Hansen RL, Blum NJ, Gaham A, Shults J. Diagnosis of Autism Spectrum Disorder by Developmental-Behavioral Pediatricians in Academic Centers: A DBPNet Study. *Pediatrics*. 2016;137 Supplement:S79–89.
55. Nesterova AA, Aysina RM, Suslova TF. A positive socialization model for children with autism spectrum disorders (asd): comprehensive and interdisciplinary approaches. Part 1. Foreign models of teaching social skills to children with asd. *Educ Sci J*. 2016;:145–55.
56. Slifer KJ, Avis KT, Frutchey RA. Behavioral intervention to increase compliance with electroencephalographic procedures in children with developmental disabilities. *Epilepsy Behav*. 2008;13:189–95.
57. Cuvo AJ, Reagan AL, Ackerlund J, Huckfeldt R, Kelly C. Training children with autism spectrum disorders to be compliant with a physical exam. *Res Autism Spectr Disord*. 2010;4:168–85.

58. Orellana LM, Martínez-Sanchis S, Silvestre FJ. Training Adults and Children with an Autism Spectrum Disorder to be Compliant with a Clinical Dental Assessment Using a TEACCH-Based Approach. *J Autism Dev Disord*. 2014;44:776–85.
59. Carbone PS, Behl DD, Azor V, Murphy NA. The Medical Home for Children with Autism Spectrum Disorders: Parent and Pediatrician Perspectives. *J Autism Dev Disord*. 2010;40:317–24.
60. Warfield ME, Crossman MK, Delahaye J, Der Weerd E, Kuhlthau KA. Physician Perspectives on Providing Primary Medical Care to Adults with Autism Spectrum Disorders (ASD). *J Autism Dev Disord*. 2015;45:2209–17.
61. Morris R, Muskat B, Greenblatt A. Working with children with autism and their families: pediatric hospital social worker perceptions of family needs and the role of social work. *Soc Work Health Care*. 2018;57:483–501.
62. Howes OD, Rogdaki M, Findon JL, Wichers RH, Charman T, King BH, et al. Autism spectrum disorder: Consensus guidelines on assessment, treatment and research from the British Association for Psychopharmacology. *J Psychopharmacol*. 2018;32:3–29.
63. Hassan MM, Mokhtar HMO. Investigating autism etiology and heterogeneity by decision tree algorithm. *Informatics Med Unlocked*. 2019;16:100215.
64. Fenikilé TS unn., Ellerbeck K, Filippi MK, Daley CM. Barriers to autism screening in family medicine practice: a qualitative study. *Prim Health Care Res Dev*. 2015;16:356–66.
65. Kuhlthau KA, Warfield ME, Hurson J, Delahaye J, Crossman MK. Pediatric provider's perspectives on the transition to adult health care for youth with autism spectrum disorder: Current strategies and promising new directions. *Autism*. 2015;19:262–71.
66. Lord C. A Multisite Study of the Clinical Diagnosis of Different Autism Spectrum Disorders. *Arch Gen Psychiatry*. 2012;69:306.
67. Verhoeff B. Autism in flux: a history of the concept from Leo Kanner to DSM-5. *Hist Psychiatry*. 2013;24:442–58.
68. Myers SM, Johnson CP. Management of Children With Autism Spectrum Disorders. *Pediatrics*. 2007;120:1162–82.

Figures

Figure 1

Quality evaluation of medical care provision in different medical facilities as reported by caregivers of children diagnosed with ASD (in %).

Figure 2

Most cited medical conditions associated with ASD indicated by participants (in %).

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