

Original Research / Özgün Araştırma



Knowledge Level and Awareness of Parents with 18–36-Month-Old Children about Autism Spectrum

18-36 Aylık Çocukları Olan Ebeveynlerin Otizm Spektrum Bozukluğu Hakkında Bilgi Düzeyleri ve Farkındalıkları

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ABSTRACT

Introduction: Early diagnosis of Autism Spectrum Disorder (ASD) enables early treatment, which is a good prognostic factor for the disorder. Parents are the primary caregivers; their knowledge about ASD is crucial for early diagnosis. We aimed to examine the level of knowledge and awareness about ASD in parents and their relationship with individual factors. **Methods:** This cross-sectional study was conducted between February and July 2020 in a family health center with 340 parents with children aged 18-36 months. Participants were evaluated with a questionnaire adapted from the M-CHAT scale and DSM-V diagnostic criteria, including their sociodemographic characteristics. **Results**: 97.6% of the parents had heard of ASD before. In 32.6% parents the source of hearing autism was the media. Only 32.6% knew the right time for meaningful word production in healthy children. ASD knowledge level was higher in mothers and parents with higher education levels (p = 0.001, p < 0.001). 5.6% of the parents stated that vaccines cause ASD and 37.6% stated that they did not have information about whether vaccines cause ASD. **Conclusion:** In our study, we found that although almost all of the parents had heard of ASD before, most of them had a low level of knowledge about the language development process of a healthy child and the symptoms, causes, diagnosis and treatment process of ASD. More importantly, many of these parents with a young child were unaware of whether there was a relationship between vaccines and ASD.

Key words: Autism spectrum disorder, awareness, knowledge, family physician

ÖZET

Giriş: Otizm Spektrum Bozukluğunun (OSB) erken teşhisi, hastalık için iyi bir prognostic factor olan erken tedaviyi sağlar. Birincil bakıcılar olan ebeveynlerin OSB hakkındaki bilgi düzeyleri erken tanı için önemlidir. Ebeveynlerin OSB ile ilgili bilgi ve farkındalık düzeylerini ve bireysel faktörlerle ilişkisini incelemeyi amaçladık. **Yöntem**: Bu kesitsel çalışma Şubat-Temmuz 2020 tarihleri arasında aile sağlığı merkezinde, 18-36 aylık çocukları olan 340 ebeveyn ile gerçekleştirilmiştir. Katılımcılar sosyodemografik özelliklerini de içeren M-CHAT ölçeği ve DSM-V tanı kriterlerinden uyarlanan bir anket ile değerlendirildi. **Bulgular**: Ebeveynlerin %97,6'sı OSB'yi daha önce duymuştu. Ebeveynlerin %32,6'sında otizmi işitme kaynağı medyaydı. Sağlıklı çocuklarda anlamlı kelime üretimi için doğru zamanı sadece %32,6'sı biliyordu. OSB bilgi düzeyi annelerde ve eğitim düzeyi yüksek ebeveynlerde daha yüksekti (p = 0,001, p <0,001). Ebeveynlerin %5,6'sı aşıların OSB'ye neden olup olmadığı konusunda bilgiye sahip olmadıklarını belirtmiştir. **Sonuç:** Çalışmamızda ebeveynlerin nerdeyse hepsinin OSB' yi daha önceden duymuş olsa da birçoğunun sağlıklı bir çocuğun dil gelişim süreci ve OSB'nin semptomları, nedenleri, tanı ve tedavi süreci hakkındaki bilgi düzeyinin düşük olduğunu gördük. Küçük bir çocuğu olan bu ebeveynlerin birçoğunun aşılar ve OSB arasında bir ilişki olup olmadığı konusunda bilgi sahibi değildi.

Anahtar kelimeler: Otizm spektrum bozukluğu, farkındalık, bilgi, aile hekimi

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INTRODUCTION

Autism Spectrum Disorder (ASD) is а neurodevelopmental disorder characterized by deficiencies in social communication and interaction, repetitive behaviors, and restricted interests.1 The disorder is seen in all ethnic and socioeconomic groups from every culture. It is reported that ASD has a complex etiopathogenesis in which gene-environment interaction may lead to changes in brain development.² Advanced parental age, preterm birth, intrauterine exposure of infections, vitamin D deficiency, drug and toxic substance are among the reported environmental factors of the disorder.³ Recent data show that the incidence of ASD is increasing, and the disorder affects one in every 54 children.⁴ Changes in diagnostic criteria, increased access to experts, and increased awareness of autism in healthcare professionals and society may be responsible for this increase.5

Today, the primary treatment of ASD is the educational methods that aim to enhance social communication and interaction skills and reduce unwanted behavioral problems. Studies documented that ASD has a poor prognosis and many patients become caregiver-dependent in their adulthood period. On the other hand, milder disease severity, higher mental capacity, better receptive and verbal language and motor skills, and also early initiation of educational approaches are among the good prognostic factors.^{6,7,8} This impact of early educational interventions on prognosis points out the significance of early diagnosis.⁹

The diagnosis of ASD is made by an experienced child psychiatrist through clinical examination based on behavioral characteristics.¹⁰ Diagnosis can be given more easily and more accurately after the age of three when the symptoms become more evident. However, in children with ASD, it is possible to detect many symptoms at much earlier ages, such as 12-18 months.⁸ Because of this, during their routine, family physician follow-ups, assessment of social and cognitive developments of the infants and toddlers is crucial in detecting early symptoms of ASD. Various standardized scales are used to screen ASD symptoms in outpatient clinics. One of them is the Modified Checklist for Autism in Toddlers (M-CHAT), which was developed for children aged 18-36 months. This scale can distinguish children with high-risk for ASD.^{11,12} The Psychiatric Association American (APA) recommends all children to be screened for ASD between 18 and 24 months for early diagnosis.¹³ Similarly, in Turkey, according to the National Autism Screening Program, which has been put into practice with the cooperation of the Ministry of Family and Labor and the Ministry of Health, every

child under three years of age is routinely screened for ASD in primary health care services, and highrisk children are referred to child psychiatrists.

Parents are the primary caregiver of their children. They are significant in the detection of any abnormal or deviant development in their children. The lower social awareness of ASD constitutes an impediment to its diagnosis and access to treatment. However, it has been reported that the awareness and knowledge level of parents about autism is inadequate.¹⁴ Deeb's study showed that parents of children with autism spectrum disorder had medium knowledge.¹⁵ In this study, we aimed to examine knowledge and awareness about autism spectrum disorder among parents of 18-36-month-old children and the individual factors associated with them.

MATERIAL AND METHOD

Study Design and Participants

This cross-sectional, prospective study was conducted between February-July 2020 at the Kücükcekmece 4th Family Health Center in Istanbul. This study included mothers and fathers of 18 to 36 months of age children. Contact information of children who were registered in this family health center was obtained from their files. Parents were informed about this study and invited to this study via a telephone call. On their arrival at the family health centre, their verbal and written consent was obtained. Parents who were healthcare professionals, had children with autism, had a psychiatric disorder that affected their cognitive level, and were under 18 and over 50 years were not included in this study. All participants were assessed with a questionnaire, which was developed by the researchers and consisting of three sections. The first section of the questionnaire was composed of questions assessing the sociodemographic characteristics of the participant, such as age, sex and educational status. The second section included the items evaluating the knowledge and awareness level of the participant about ASD. The third section included items assessing the knowledge level of the participant about family physician/parents' responsibilities regarding ASD. The M-CHAT scale and DSM-V diagnostic criteria were utilized for the queries related to the level of knowledge and awareness of ASD in the questionnaire. The questionnaire was applied and filled in by the physician during the interview with the participant.

Ethics Statement

Ethical approval of this study was obtained by the ethics committee of the University of Health Sciences Bakırköy Dr Sadi Konuk Training and Research Hospital with the protocol code of 2020/08 and dated January 06th, 2020. The authors assert that all procedures contributing to this work comply with the ethical standards in Bakırkoy Dr. Sadi Konuk Training and Research Hospital and the Helsinki Declaration of 1975, as revised in 2008.The participants' consent to participate in this study was requested personally from each individual.

Statistical Analysis

All statistical analyses were performed using the software of Statistical Package for Social Sciences (SPSS Inc; Chicago, IL, USA), version 20.0. Analytical methods (Kolmogorov-Smirnov/Shapiro-Wilk's test) were used to assess the compliance of the data for normal distribution. In paired comparison, Man-Withney U-test was used for nonparametric numerical data, and the Student'st-test was used for parametric numeric data. Chi-square test or Fischer's Exact Test (when chi-square test assumptions were not valid due to expected lower cell counts) were used depending on where they were appropriate to compare ratios in different groups. If numerical data were not parametric, the Kruskal Wallis test was performed. Values were expressed as mean ± standard deviation, median (min-max), and n (%). The results were considered statistically significant at p<0.005.

RESULTS

This study was completed with 340 parents with a mean age of 34.14 ± 6.04 years. Among the participants, 274 (80.6%) were female, and 66 (19.4%) were male. The socio-demographic characteristics of the participants are presented in Table1.

Assessment of the participants concerning their ASD awareness, knowledge acquisition methods showed that 332 (97.6%) of the parents heard that there was a disease called autism. "Hearing autism" was not related to educational status and child number, but there was a significant difference between the genders. The majority of both mothers and fathers were aware of autism, but awareness of autism was higher among mothers than fathers (p<0.05). The source of hearing autism was the media in 111 (32.6%) parents. This source was the "physicians" in only 9.1% (n=31) of participants. 34.1% (n = 116) of participants had an individual with autism in their immediate circle (Table 2).

On their assessments regarding their level of knowledge about the verbal language development of a healthy child, 238 (70%) of the participants stated that the age of starting to use meaningful words started at or before the age of 1.5 years. 111 (32.6%) of the individuals who participated in the survey answered the age of using meaningful words as 1.5 years old, and 127 (37.4%) when they were 1 year old. 30% of them stated that the age of starting to use meaningful words was two years and after. In this study, 20 (5.9%) of the participants reported that the age for starting to use simple sentences was three years and later. 254(74.7%) of the participants stated that if their child's speech was delayed, they would consult a doctor immediately, and 66 (19.4%) stated that they would postpone consulting a doctor if there was a history of speech delay in their family.

We asked the participants "which symptoms led them to suspect from ASD in your children". The major symptoms were "not looking when called with his/her name" (88.3%) and "absence of eye contact" (87.4%). These were followed by symptoms of "child did not understand what other people were saying" and "child did not look at a pointed toy". Many parents stated that they would not suspect ASD in the case of the positive items, so they gave inaccurate answers for the ASD symptoms.

The number of correct responses in recognizing ASD symptoms was not correlated with the age, occupation, and number of children of the participants. However, knowledge about ASD symptoms was higher among mothers and higher educated participants (p=0.001, p<0.001).

Most of the parents did not have accurate knowledge about the cause, diagnosis, and treatment of ASD. 45.9% of the participants marked the item "It is necessary to wait until the age of three for a correct diagnosis" as true. 5.6% of the participants marked the item of "vaccines cause ASD in children" as true, and 37.6% of them marked it as "I don't know". The assessment of the participants' knowledge about the causes, diagnosis, and treatment of ASD is presented in Table 3.

Among the participants, 65.9% of them did not know that their family physicians performed autism screening tests for 18-36 months old children for early diagnosis. 97.1% of them stated that when the family physician considered it necessary to refer their children to a specialist, they would take this consultation into account and applied to a specialist.

		standard	
	Mean	deviation	
Age	34,14	6,04	
Female	33,65	5,85	
Male	36,2	6,43	
	N	%	
Age groups			
18-24 years old	22	6,5	
25-34 years old	145	42,6	
35-44 years old	160	47,1	
45-50 years old	13	3,8	
Sex			
Female	274	80,6	
Male	66	19,4	
Educational status			
Illiterate	5	1,5	
Primary school graduate	52	15,3	
Secondary school graduate	44	12,9	
High school graduate	70	20,6	
University	169	49,7	
Occupation			
Housewife	141	41,5	
Worker	40	11,7	
Architect-Engineer	6	1,7	
Self-employed	19	5,6	
Economist-Banker	5	1,5	
Teacher	66	19,4	
Financial advisor-Accountant	22	6,5	
Other	41	12,1	
Marital status			
Married	320	94,1	
Separated/Divorced	20	5,9	
Number of children			
1 child	155	45,6	
2 children	119	35	
3 children	55	16,2	
4 children and above	11	3,2	

 Table 1. Socio-Demographic Characteristics of the Participants

Table-2. Correlations between	Socio-Demographic Characteristics	of the Parents and "being heard about ASD"

	Did you hear a disease called ASD previously?		
	Yes n (%)	No n (%)	p-value
Sex			
Female	270 (98,5)	4 (1,5)	0,049 ^β
Male	62 (93,9)	4 (6,1)	
Educational status			
University graduate	168 (99,4)	1 (0,6)	$0,067^{\beta}$
Other	164 (95,9)	7 (4,1)	
Number of children			
Single child	151 (97,4)	4 (2,6)	0,999 ^β
Two children and above	181 (97,8)	4 (2,2)	

β: Fischer's Exact test, * Chi-square test

Table 3. Distribution of the participants based on their knowledge on Causes, Diagnosis and Treatment of ASD			
	True n (%)	False n (%)	I don't know n (%)
1. Autism is an emotional disease; the child closes himself to the outside world since he/she does not want it; he/she can socialize if he/she wants.		128	
	98 (28,8)	(37,7)*	114 (33,5)
2. Autism is a developmental disorder; symptoms start to manifest after	179		
the first three years of age.	(52,7)*	48 (14,1)	113 (33,2)
3. The cause of autism is not clear, but genetic problems are the most	183		
significant factor.	(53,9)*	27 (7,9)	130 (38,2)
4. Vaccines lead to autism in children.		193	
	19 (5,6)	(56,8)*	128 (37,6)
5. The reason for autism is that the mother behaves her baby unfriendly		242	
and not kindly and provides poor care.	20 (5,9)	(71,2)*	78 (22,9)
6. If autism is present in a family member, the risk of developing in	12.6		
another member is higher.	136	59 (17,4)	145 (42,6)
	(40)*		
7. Child psychiatrists can diagnose Autism from the age of 18 months.	132		184 (54,1)
	(38,8)*	24 (7,1)	
8. The diagnosis of autism is made by laboratory analysis and brain			
imaging (MR, Tomography).	69 (20,3)	88 (25,9)*	183 (53,8)
9. Autism is diagnosed by an experienced specialist through clinical	254		
interview and observation.	(74,7)*	11 (3,2)	75 (22,1)

Table 3. Distribution of the participants based on	n their knowledge on Causes, Diagnosis and Treatment of ASD

10. Autism cannot be diagnosed at an early stage. Autism can only be diagnosed after the age of three, so it is necessary to wait at this age before consulting a doctor for the development of the child.	52 (15,3)	156 (45,9)*	132 (38,8)
11. Thanks to early diagnosis, the possibility of starting treatment earlier	247		
and thus amelioration in the symptoms of autism enhances.	(72,6)*	20 (5,9)	73 (21,5)
12. There is no cure for autism.		157	
		(46,2)*	115 (33,8)
12 There is an effective medication to treat the second second second		115	
13. There is an effective medication to treat the symptoms of autism.		(33,8)*	185 (54,4)
14. The most important step for treatment is that every child with autism should start special rehabilitation education as soon as the diagnosis is made.	261 (76,8)*	6 (1,7)	73 (21,5)
15. Children with autism can live independently with appropriate	229		
educational methods.	(67,4)*	15 (4,4)	96 (28,2)
16. Some special diets (e.g., gluten-free diet) provide recovery from			
autism	56 (16,5)	102 (30)*	182 (53,5)

* Correct answer

DISCUSSION

The prevalence of ASD manifests itself with lifelong communication deficits in many cases that have increased significantly in recent years. Because early treatment is a good prognostic factor in the affected children, this highlights the significance of early diagnosis.¹⁶ Early diagnosis is possible with the awareness of the disease in the health professionals and the public. The screenings applied in primary healthcare services are considerably significant for raising awareness about ASD and for referring to specialists when necessary, and hence, for early diagnosis.

In this study, we have examined the knowledge and awareness levels of ASD in parents of18-36 years of toddlers. Our findings showed that almost all of the parents heard about the existence of a disease called autism. However, their knowledge level about the symptoms, causes, diagnosis and treatment process of the disorder was low. The most significant finding of our study is that a significant portion of the parents living in Istanbul, which is Turkey's major metropolis concerning socioeconomic development level, still do not have accurate knowledge regarding the relationship between vaccines and autism. Vaccination in childhood is crucial for the child to live a healthy life. It has been clearly demonstrated in previous studies that vaccines do not lead to autism.¹⁷ In our study, 5.6% of the parents stated that vaccines caused ASD and 37.6% stated that they did not know whether the vaccines cause ASD or not. These findings regarding vaccines once again underline the necessity of providing public education about the causes of ASD and its unrelatedness to vaccines.

Throughout the child's follow-ups, besides the physical development, the development of social and language skills are assessed in routine controls. Accurate knowledge about the developmental milestones of early childhood is crucial for parents to follow the development of their children. In particular, language development is a concrete indicator of social development. The delay in pronouncing and using words as well as making sentences is a symptom of ASD. Speech delay in the family indicates an increased risk of ASD.¹⁸ In our study, many parents stated that a healthy child could pronounce a simple, meaningful word after the age of two and make a simple sentence after the age of three. Moreover, many participants stated that if their child had a speech delay, they would postpone consulting a doctor if there was a history of speech delay in the family. This finding suggests that the significance of speech delay, which is one of the most common symptoms of ASD, is not recognized in a substantial portion of the parents. This result of our study is in line with the findings of this study, which has been performed by Ertem et al. on 1055 mothers with children aged three and under. Researchers have revealed that mothers think that

the majority of children's developmental skills and activities can be performed over the month interval that healthy developing children can perform. They answered only 10% of the questions accurately, which were asked about their children's developmental stages.¹⁹

Our study findings related to the recognition of autism symptoms revealed that both mothers and fathers had poor knowledge about ASD symptoms. Mothers and parents with higher educational status had more knowledge about ASD symptoms. This finding suggests that every parent should be informed about ASD, but more attention should be paid to fathers and those with a lower educational level. Similar to our study, previous studies have shown that only 50% of the parents know most of the ASD symptoms, and women and mothers with many children have a more accurate view of ASD.^{14,20,21} This may be because of that, in general, mothers take more responsibility which leads to their increased knowledge of the child's physical and social development.

There is no biological marker for ASD. Diagnosis of the disorder is made by clinical assessment by an experienced child psychiatrist. It has been observed in the retrospective video recordings that children with ASD behave differently in the first years of their life. The significance of developmental follow-up and screening becomes evident at this point.^{22,23} In our approximately three-quarters of the study, participants stated that the diagnosis of autism would be made through a clinical interview with an experienced child psychiatrist, and 25.9% of them knew the diagnostic process in ASD accurately, stating that blood tests and imaging methods did not have a role in the diagnosis. However, a significant number of parents in this study do not know that child psychiatry is necessary for diagnosis. Moreover, they stated that they had no idea whether diagnostic laboratory tests and imaging techniques were necessary. Parents' lower level of knowledge on this issue may lead to delay in applying to the right authority for diagnosis. Thus, this points out the significance of informing families not only about ASD symptoms in primary healthcare services but also about the diagnosis process and referral to the right specialist. It has been determined in the clinic for their children that many parents consult physicians other than child psychiatrists, which may lead to a delay in early diagnosis and an early chance for educational treatment.

Today, accessing information is increased via technology. Television and social media have become the biggest sources of information. In a previous study, it has found that parents of ASD children obtained information about ASD mostly from the media, conferences, and other families.²⁴ Similar to this study, we showed in our study that the media was the source of information related to ASD in nearly one-third of the parents. However, the important finding was related those physicians were the source of information in the minority of parents. We had already stated that our participants had poor knowledge about symptoms, causes and diagnostic processes of ASD. They heard about ASD on TV but did not reach accurate knowledge. These findings remark that we need to work more effectively towards ASD awareness in primary healthcare centers. Family physicians can work in close contact with child psychiatrists and inform the parents about ASD in health care settings and in media programs. This would be beneficial in the early diagnosis and treatment of ASD.

Because symptoms of ASD appear before 36 months, family physicians have a significant role in the early diagnosis and treatment of the disorder. As family physicians perform routine infant-child follow-ups of the children, they are advantageous in assessing the motor and psychosocial development of the children and in detecting potential abnormalities and deviations in the early stages. It has been revealed in a recent report of the American Academy of Psychiatry that primary healthcare service physicians are more likely to encounter a child with autism.²⁵ The majority of the parents who participated in our study did not know that their family physicians performed autism screening tests for 18-36 months old children for early diagnosis. It is crucial that healthcare professionals should provide families with more clear and detailed information about how to follow up on the physical and psychosocial development of children.

CONCLUSION

Parents' knowledge level about the symptoms, causes, diagnosis, and treatment process of the disorder was low, although most of them have heard about the diagnosis of ASD. More importantly, some of these parents believed that vaccines led to autism. However, they had a child whose vaccination process was still ongoing. As family physicians working in primary healthcare services follow-up these children from their births and are in close contact with parents, the accurate information they provide about ASD would allow for early diagnosis and interventions. Hence, it would lead to an improvement in the prognosis of the disorder. We consider that it is crucial to implement media programs that are performed by doctors to expand the awareness and knowledge of families about ASD, especially pointing out the unrelatedness of vaccines and accurate diagnostic processes of the disorder.

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