

Autism Spectrum Disorder: Why is It Underdiagnosed in Primary Care?

Otizm Spektrum Bozukluğu: Birinci Basamakta Neden Az Tanı Almaktadır?

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ABSTRACT

Introduction: When Autism Spectrum Disorder (ASD) is diagnosed early, successful results can be obtained with various therapies. The study was carried out to determine the knowledge and awareness of family physicians in primary health care institutions about ASD.

Material and Methods: In this descriptive cross-sectional study, 196 family physicians working in the city of Kutahya were reached between July 2021 and December 2022. A 38-item questionnaire consisting of demographic characteristics and "Knowledge on childhood autism in healthcare workers (KCAHW) questionnaire" was administered to volunteers.

Results: Of the 151 family physicians (FPs) in the study, 81.5% were general practitioners, 17.9% were FP specialists and 0.7% were other medical field specialists. Although 86.8% of the participants had received training on autism, 64.9% were determined to feel inadequate. The KCAHW score and awareness of those who followed patients with ASD, those who received theoretical training, women, and newer FPs in the profession were higher, but the awareness of only young FPs was statistically significant ($p<0,05$).

Conclusions: It was determined that FPs in primary care, the first meeting place for sick and healthy babies and children with health workers, have a lack of information about ASD; thus, they do not feel adequate.

ÖZET

Amaç: Otizm Spektrum Bozukluğu (OSB) erken teşhis edildiğinde çeşitli tedavilerle başarılı sonuçlar alınabildiği bilinmektedir. Birinci basamak sağlık kuruluşlarında çalışan hekimlerin OSB'na ilişkin bilgi ve farkındalıklarını saptamak amacıyla gerçekleştirildi.

Gereç ve Yöntemler: Tanımlayıcı kesitsel tipteki bu çalışmada, Kutahya'da görev yapmakta olan 196 Aile Hekimine Temmuz 2021-Aralık 2022 tarihleri arasında ulaşılmış ve gönüllülük esasına dayalı olarak demografik özellikler ve "Sağlık çalışanlarında çocukluk çağı otizmine ilişkin bilgiler (KCAHW) anketi"nden oluşan 38 soruluk bir anket uygulanmıştır.

Bulgular: Çalışmaya katılan 151 Aile Hekiminin (FP) %81,5'i pratisyen hekim, %17,9'u Aile Hekimliği uzmanı ve %0,7'si diğer tıp alanı uzmanlarıdır. Katılımcıların %86,8'i otizm konusunda eğitim almış olmasına rağmen, %64,9'unun kendini yetersiz hissettiği belirlendi. OSB'li hastaların takip edenlerin, teorik eğitim alanların, kadınların ve mesleğe yeni başlayan FP'lerin KCAHW skoru ve farkındalıkları daha yüksekti, ancak sadece genç AP'lerin farkındalığı istatistiksel olarak anlamlıydı ($p<0,05$).

Sonuçlar: Hastaların, sağlıklı bebeklerin ve çocukların sağlık çalışanları ile ilk karşılaşma yeri olan birinci basamaktaki Aile Hekimlerinin OSB hakkında bilgi eksikliği olduğu, kendilerini yeterli hissetmediği saptandı.

Keywords:

Autism
Awareness
Education
Family physician
Primary care

Anahtar Kelimeler:

Otizm
Farkındalık
Eğitim
Aile hekimi
Birinci basamak

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental childhood disorder in which symptoms such as impaired communication, repetitive behaviours, delay in language development, insistence on sameness, and overreaction to auditory stimuli are prominent (1). The etiology of ASD has not been understood completely yet. It is thought that genetic, environmental and epigenetic factors play a role in its etiology (2-4). It was originally thought of as a variant of schizophrenia; however, it was revealed by Leo Kanner in 1943 to be a different disorder (5). In the 1980s, the American Psychiatric Association evaluated ASD

under the title of Pervasive Developmental Disorders and reported some criteria for its diagnosis (6-8).

ASD's prevalence is increasing in parallel with the global increase in awareness. While its prevalence was 0.04% in the 1970s, it rose to 1-2% with the increase in awareness (1,9). It is stated that its prevalence is higher in developed countries and it is observed in one in every 59-68 children (10-12). Its increasing prevalence and the fact that there is still no effective treatment increase the importance of early diagnosis of ASD because in children with ASD, successful results can be obtained with early diagnosis and treatment by special education. In fact, early diagnosis and

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treatment are considered to be among the most important prognostic factors of ASD. All healthcare professionals, especially pediatricians, child psychiatrists and FPs, have a role in the early diagnosis of ASD (13). Due to their position in primary care, the importance of FPs in the early detection and diagnosis of autism comes to the fore because when babies and children get sick, the first place of application is FPs. In addition, babies and children are regularly followed up by FPs when they are not sick. However, pediatricians and child psychiatrists mostly examine a baby and child in case of application for any reason. FPs can play an important role in diagnosing autism early, coordinating assessment and treatment, counselling parents and classroom teachers, and long-term monitoring of child's development. It is known that early diagnosis and rehabilitative factors lead to more success in treating this disease and reintegrating the individuals into society. In this study, it was aimed to investigate the education, ASD knowledge and awareness of FPs, who are actively involved in primary health care services, where infants and children first encounter the health system, and where healthy infants and children are followed up routinely.

MATERIAL AND METHODS

Study Design

Since 196 FPs in Kütahya constituted the population of this descriptive cross-sectional study and all FPs were planned to be included in the study, no sample was taken. Those who did not accept to participate in the study were not included in the study, and neither were those who filled in the form incompletely or incorrectly. The study was completed with 151 (81.6%) FPs who met the inclusion criteria. The survey was administered to FPs face-to-face or online, between September and November 2021.

Questionnaire and Evaluation

In our study, a questionnaire consisting of 38 questions involving a sociodemographic information form and the "Knowledge about childhood autism among health workers (KCAHW) questionnaire" was used to collect data. Developed by Bakare et al., it consists of 19 questions related to four areas of autism (14). The first area (A) consists of eight items and is about the deterioration in social interaction seen in children with autism. The second area (B) consists of a single item and deals with symptoms related to communication and language development. The third area (C) consists of four items showing obsessive and compulsive, repetitive and stereotypical symptoms observed in autism. The fourth area (D) consists of six items, questions whether autism is a neurodevelopmental disorder, examines possible comorbid conditions, and explores the ages at which it occurs. The possible total score that can be obtained from the questionnaire ranges from 0 to 19. Each item is answered as "yes", "no" or "I don't know". Correct answers are awarded 1 point, while other answers get 0 point. The last item questions the age of onset of autism and is scored zero for neonatal age or infancy and one for childhood. Maximum and minimum scores that can be obtained from KCAHW are 19 and 0 respectively. The average questionnaire score in the population to which the questionnaire was applied measures the level of knowledge about childhood autism in that sample. There is no cut-off value in the evaluation of

the scores obtained from the questionnaire; the higher the score, the higher the level of knowledge (14). The Turkish validity and reliability study of the scale was carried out by Özgür et al. Kuder-Richardson 21 (KR-21) shows the internal consistency of items in a scale and gives the same coefficient as Cronbach's alpha. In the study by Özgür et al., the KR-21 value was found to be 0.68 for the whole scale (15).

Statistical Analysis

As well as descriptive statistical methods (mean, standard deviation, frequency), Chi-square test was used to compare categorical data of the study. Compliance of numerical data with normal distribution was evaluated with the Kolmogorow Smirnov test. Numerical data that met the parametric test conditions were evaluated with the t-test and one-way anova, whereas the numerical data that did not meet the conditions were evaluated with the Mann Whitney-U and Kruskal Wallis tests. Significance was evaluated at the $p < 0.05$ level.

Ethics Committee

Approval from the local ethics committee, dated 30.06.2021 and numbered 2021/11-27, permission from the institution where the study and informed consent from the participants would be conducted were obtained.

RESULTS

Of the 151 FPs in the study; 82 (54.3%) were male, 123 (81.5%) were married, 123 (81.5%) were general practitioners, 27 (17.9%) were FP specialists, 1 (81.5%) 0.7) was an expert in another field. Their age was 41.87 ± 9.70 years, their professional time was 7.95 ± 4.651 years, and time in the current Family Medicine Unit (FMU) was 5.69 ± 4.284 years. FMU registered population was 2903.44 ± 857.60 and the number of daily examinations was 54.03 ± 19.28 . The number of participants with children was 114 (75.5%) (number of children: 1.65 ± 0.70). Sociodemographic characteristics and other information are given in Table 1.

Of the participants, 131 (86.8%) received training on autism; 42 (27.8%) during medical education, 9 (6.0%) during specialization training and 99 (65.6%) during in-service training related to ASD. Of the participants, 28 (21.5%) received their last training on ASD less than two years ago, 84 (64.7%) between 2-5 years ago and 18 (13.8%) more than five years ago. Of the participants, 62 (41.1%) completed their child psychiatry internship. While 12 (7.9%) of the participants had acquaintances with autism, 52 (34.4%) followed up patients with autism. Of the participants, 53 (35.1%) thought that they were self-sufficient in autism (Table 2).

Participants got 7.08 ± 1.20 points from the first area (Area A) of the scale which questions the awareness of the deterioration in social interaction seen in children with autism, 0.92 ± 0.27 from the second area (Area B) consisting of a single item questioning awareness of symptoms related to communication and language development, 2.78 ± 0.93 from the third area (Area C) questioning the awareness of obsessive and compulsive, repetitive and stereotypical symptoms observed in autism, 3.25 ± 1.31 from the fourth area (Area D) which questions whether autism is a neurodevelopmental disorder, and 14.03 ± 2.39 points from the whole scale (Table 3).

Table 1: Sociodemographic and professional characteristics of family physicians (n=151)

Characteristics	Mean	SD
Age	41.87	9.70
Duration of Being a Family Physician	7.95	4.65
Time in the current Family Medicine Unit (FMU)	5.69	4.28
Number of Patients Examined Daily	54.03	19.28
	n	%
Sex		
Female	69	45.7
Male	82	54.3
Marital Status		
Single	28	18.5
Married	123	81.5
Status of Receiving Specialization Training		
General Practitioner	123	81.5
Family Physician Specialist	27	17.9
Specialist in Other Medical Fields	1	0.7
Total	151	100.0

Table 2: Educational characteristics of family physicians about Autism Spectrum Disorder (ASD).

Characteristics	n	%
Status of receiving training about ASD		
Received	131	86.8
Not received	20	13.2
Time since last training		
Less than 2 years	28	21.5
Between 2-5 years	84	64.7
More than 5 years	18	13.8
Child Psychiatry Internship status		
Yes	62	41.1
No	89	58.9
Considering oneself adequate for ASD		
Adequate	53	35.1
Not adequate	98	64.9
Total	151	100.0

Table 3: Knowledge about childhood autism among health workers (KCAHW) questionnaire area scores and total scale score (n=151)

Scale Area Score	Min-max	Mean±SD	%95 CI
Score of Area A	1-8	7.08±1.20	6.87-7.26
Score of Area B	0-1	0.92±0.27	0.87-0.96
Score of Area C	0-4	2.78±0.93	2.63-2.94
Score of Area D	0-6	3.25±1.31	3.03-3.46
Total Scale Score	7-19	14.03±2.39	13.62-14.45

The questions numbered A2 (n=150, 99.3%), A1 (n=146, 96.7%) and A7 (n=145, 96.0%) in the scale were the questions answered correctly by the participants at the highest rate, while C2 (n=50, 33.1%), D5 (n=52, 34.4%) and D6 (n=65, 43.0%) were those that the participants answered correctly at the lowest rate (Table 4).

It was determined that there was no statistical difference between the gender, training about ASD, occupational years, follow-up of patients with ASD and the level of ASD knowledge of the FPs participating in the study (p>0.05). It was determined that the ASD knowledge level of FPs aged 25-39 years (KCAHW score:14.49±2.19) was significantly higher than those aged 40 and over (KCAHW score:13.65±2.48) (p=0,032) (Table 5).

DISCUSSION

ASD is a disorder with a high probability of treatment with early diagnosis, appropriate behaviour and psychological approaches. All healthcare professionals have a role in the early diagnosis of ASD. Zwaigenbaum et al. emphasize that FPs and pediatricians play a major role in diagnosing ASD (9). The role of primary health care workers, who encounter individuals with ASD most frequently after their parents, is also important. In Turkey, primary health care services have been carried out with the family medicine system since 2005. Family health workers and FPs work in family health units. Keklik et al. found the mean knowledge level for ASD to be 12.29±3.19 in their study on nurses (16). In our study, the mean score of FPs working in primary care was higher (14.03±2.38). Comparison of the two studies shows that the knowledge level of FPs is higher than that of nurses. New approaches and early diagnosis tests have been developed for early and accurate diagnosis of ASD (17-20). Although some of the children with ASD are diagnosed with these tests, it has been observed that there may be those with ASD who have a normal test result but subsequently develop ASD or whose diagnosis can be missed due to various reasons (21). Therefore, it is stated that children should be followed up regularly (22). In Turkey, infants and children are followed up by nurses or midwives at FMUs. However, it will be more appropriate for infants and children coming for follow-up to be seen by the family physician in order to make an early diagnosis of ASD.

In Turkey, FPs receive training on various subjects in the medical faculty, during the family medicine residency training process and after starting the profession. Some of this training is about ASD. It was determined in our study that 86% of the FPs received training on ASD at least once during their medical education or in their professional life. In Altay's study, 66.7% of the participants had not received any training on ASD before (23). Although the proportion of physicians who received training seemed high in our study, all of them should have received this training in order for the physicians to make the correct diagnosis of ASD. Young physicians in Turkey mostly work in primary care during their obligatory state service after graduation. Even after this period, even when they specialize, physicians may encounter infants and children with whom ASD can be diagnosed early. In their study with the parents of children with ASD, Al-Mazidi et al. found that, they were diagnosed with ASD by non-physicians

Table 4: Levels of family physicians answering correctly to Knowledge about childhood autism among health workers (KCAHW) (n=151).

Questionnaire Item	Correct answer	
	n	%
The following behaviors best describe a child with Childhood Autism:		
A1. Marked impairment in use of multiple non-verbal behaviors such as eye to eye contact, facial expression, body postures and gestures during social interaction?	146	96.7
A2. Failure to develop peer relationship appropriate for developmental age?	150	99.3
A3. Lack of spontaneous will to share enjoyment, interest or activities with other people?	134	88.7
A4. Lack of social or emotional reciprocity?	132	87.4
A5. Staring into open space and not focusing on any thing specific?	125	82.8
A6. The child can appear as if deaf or dumb?	119	78.8
A7. Loss of interest in the environment and surroundings?	145	96.0
A8. Social smile is usually absent in a child with Autism?	118	78.1
B1. Delay or total lack of development of spoken language?	139	92.1
C1. Stereotyped and repetitive movement (e.g. Hand or finger flapping or twisting)?	143	94.7
C2. May be associated with abnormal eating habit?	50	33.1
C3. Persistent preoccupation with parts of objects?	125	82.8
C4. Love for regimented routine activities?	102	67.5
D1. Autism is Childhood Schizophrenia?	96	63.6
D2. Autism is an auto-immune condition?	85	56.3
D3. Autism is a neuro-developmental disorder?	108	71.5
D4. Autism could be associated with Mental Retardation?	84	55.6
D5. Autism could be associated with Epilepsy?	52	34.4
D6. Onset of Autism is usually in, (A) Neonatal age, (B) Infancy, (C) Childhood	65	43.0

Table 5: Comparison of Autism Spectrum Disorder (ASD) knowledge level and characteristics of family physicians (n=151)

Characteristics	KCAHW score Mean±SD	P value
Age		0.032
25-39 years	14.49±2.19	
40 years and above	13.65±2.48	
Sex		0.352
Female	14.22±1.97	
Male	13.87±2.68	
Occupational years		0.370
0-5 years	14.26±2.49	
More than 5 years	13.90±2.33	
Training about ASD		0.580
Received	14.07±2.34	
Not received	13.75±2.71	
Follow-up of patients with ASD		0.406
Yes	14.25±2.29	
No	13.91±2.44	

(24). The presence of physicians with insufficient training may cause the diagnosis to be made by people other than physicians, which may lead to a delay in the diagnosis.

Although 41.1% of the participants in our study had a child psychiatry internship during their medical education and specialization training, only 27.8% received training on ASD. The rate of those who did child psychiatry internships can be considered low. However, it is remarkable that the rate of those who received ASD training was lower than those who received a child psychiatry internship, which shows that ASD education had been neglected during medical education and residency training, including child psychiatry. It was seen in our study that FPs received training on ASD mostly as in-service training (65.6%). In their study in Pakistan, Imran et al. suggested that physicians fail to diagnose ASD due to the developmental, cognitive and emotional characteristics of ASD and the presence of various misperceptions, therefore, in-service training should be emphasized (25). The importance of in-service training cannot be denied, but it is seen that there is a great lack of medical faculties and institutions providing specialist training.

According to our study, about seven out of ten FPs had not received any training on ASD during their medical education. Similarly, about eight out of ten FPs who were family medicine specialists had not received ASD training during their residency training. These show that ASD is ignored both in medical faculties and during residency training. In addition, although the level of knowledge of FPs who received training is higher than those who did not, the lack of statistically significant difference raises questions about the quality and method of education given to FPs. The fact that ASD training

is not done continuously may also cause this result. In fact, only 21.5% of the FPs received ASD training in the last two years. Therefore, Altay emphasizes that annual trainings on ASD should be organized (23). According to our study, although the prevalence and awareness of ASD has increased worldwide, no difference was found in our study group in the ASD knowledge level. In our study group, the time spent in the profession did not affect the level of ASD knowledge, which makes us think that there has not been a positive change in ASD training in medical education and specialty education. In the study conducted by Imran et al. in Pakistan, they concluded that the frequency and experience of encountering people with ASD increased with the increase in professional years, and this facilitated diagnosis (25). Consequently, only one third of the FPs participating in our study thought that they were self-sufficient in ASD. Awareness of ASD and other mental illnesses was found 41.5% in Van't Hof et al.'s study with FPs. The rate is quite low in both studies. Van't Hof et al. reported that this inadequacy causes delays in the diagnosis of ASD (26).

In Altay's study, the participants stated that the most common clinical features in children with ASD were inability to make eye contact (72.9%) and repetitive movements (47.9%) (23). In our study, however, FPs scored lower in the fourth area, which specifically questions whether autism is a neurodevelopmental disorder, examines comorbid conditions, and investigates the age at which it occurs. The three most common wrong answers to the scale items show that FPs had a lack of knowledge about abnormal eating habits, epilepsy co-diagnosis and the onset time of ASD. The content of the trainings can be adapted according to the items that show FPs' lack of knowledge.

Another factor affecting the early diagnosis of ASD by FPs is related to the time allocated to the patient. The World Medical Association states that the time to be allocated per patient should be at least 20 minutes for the qualified delivery of health care and good medicine. Zwaigenbaum et al. state that FPs should ask the family

about their concerns about ASD each time they meet with babies and should follow the children who apply more carefully (9). In our study, nearly half of the FPs examine more than fifty patients a day; therefore, it is not possible for the family physician to allocate twenty minutes per patient. The family physician may not find enough time to participate in the follow-up of infants and children. In this case, even if awareness level of the family physician is sufficient, diagnosis of ASD may be delayed. The high number of patients shortens the time that the family physician will devote to his patient and his own education, not only preventing the early diagnosis of ASD, but also leading to overlooking many important diseases.

Limitations of the Study

The strength of this study is that it is one of the few studies on this subject in our country. The limitation of the study is that it is single-centred and descriptive cross-sectional type.

CONCLUSION

The increasing frequency of ASD has made it an important public health problem. Since the etiology of ASD is unknown, primary prevention measures cannot be effective in preventing the disease. Therefore, the importance of early diagnosis as a secondary preventive measure is increasing. According to our study, there is a lack of information about ASD in FPs working in primary care, which is the place where sick and healthy infants and children first meet with healthcare professionals. FPs are also aware of this situation and do not feel sufficient. As a result, ASD should take place sufficiently during medical education, especially in pediatrics, family medicine, public health and child psychiatry internships. ASD should definitely take place in the process of specialization training such as family medicine and pediatrics. At the same time, it is crucial that FPs be given regular training seminars and renewal trainings on ASD throughout their professional lives. Particular attention should be paid to the areas of lack of knowledge of FPs in this and similar studies.

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