Family Physicians' Awareness of Autism Spectrum Disorder: Results from a Survey Study

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Abstract

AIM: Autism spectrum disorder (ASD) is a common neurodevelopmental disorder in children. Family physicians with the first medical contact of children are among the most frequent physicians with ASD. We aimed to investigate family physicians' awareness of ASD.

METHODS: This study was carried out family physicians in between September 25-October 15, 2018. The questionnaire form on autism awareness prepared by the researcher was delivered to family physicians electronically and in printed form, and it was filled out by volunteers.

RESULTS: Forty-eight family physicians with an average professional experience of 16.9 ± 8.8 years participated in the study. A group of 66.7% of the participants had not previously received education on ASD, and 70.8% of them did not refer any child to child psychiatry with suspected ASD in the last 6 months. The participants stated that the most common clinical features in children with ASD were the inability to make eye contact (72.9%) and repetitive movements (47.9%), and 56.3% of them stated one or more features that are not observed in ASD. The compliance of the participants' answers about the clinical features observed in children with ASD with the DSM-5 criteria was determined to be 54.6 ± 18.4%. Significantly higher compliance rates were observed in the participants with education on autism and those working as a physician below 15 years.

CONCLUSION: In our study, family physicians' awareness of ASD was not found to be adequate. Education programs on autism awareness should be applied to family physicians who are probably the most frequently encountered physicians by children with ASD.

Introduction

Autism spectrum disorder (ASD) is a common neurodevelopmental disorder characterised by a permanent disruption in mutual communication and social interaction, repetitive behaviours, the field of interest or activities [1]. ASD has been thought to be developed by parental disinterest in the first years of its definition, and it has been understood to be a neurobiological disorder in the following years [2]. Also, recent studies have found many genetic disorders about ASD, and it has been found that ASD has a genetic basis [3], [4].

ASD appears to be one of the fastest increasing psychiatric disorder in children. In the current reports, its incidence has raised to 1 in 50 to 68 children [5], [6]. Among the reasons for this increase, changes in the diagnostic criteria have played an important role, but education and awareness works conducted in society have also contributed to this increase.

Current evidence indicates that interventions to increase the functionality of children with ASD are more effective in young ages and long term prognosis is better [7]. Therefore, training and awareness of healthcare professionals about ASD are crucial. In this study, we aimed to investigate autism awareness of family physicians that are probably first and most commonly contacted persons by autistic children.
Material and Methods

Study Population
The study was conducted with family physicians working in Edirne province of Turkey between September 25, 2018, and October 15, 2018. After receiving the necessary permissions from Edirne local health authority, a questionnaire form designed for the study was sent to family physicians working in Edirne province as electronic and printed documents. A total of 48 family physicians who accepted to participate between these dates were included in this study. Our study is a cross-sectional survey study, study protocol complies with the Declaration of Helsinki, and the study was approved by the local ethics committee.

Questionnaire Form
A 6-items questionnaire form for autism awareness was prepared by the researcher. This form included open-ended questions including “Specify 5 clinical features regarding autism”, “At which age are autistic patients are most commonly brought to a physician?” and “What is the most common cause of presentation to a physician in autistic patients?”. In addition to these questions, the questionnaire form also included the questions of “How many children you have referred to Child and Adolescent Psychiatry specialist within the last 6 months?”, “Have you ever received training about autism? If yes, do you think it was sufficient?” and “How many years do you work as a physician?”. To provide confidentiality of data and reliability of the study, age, gender and identity information was not involved in the questionnaire. Percentages of the five clinical features of autism stated by the responders that were involved in the ASD criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) textbook were calculated [1].

Statistical Analysis
Statistical analysis of this study was conducted using SPSS 16.0 (SPSS Inc., Chicago, IL, USA) software. Distribution of the variables was analysed with the Shapiro test. In the evaluation of the data, descriptive statistics were expressed as mean ± standard deviation, while categorical variables were given as a percentage (%). Comparison of continuous quantitative data between the two groups was made with a t-test. Correlation between the categorical variables was tested with Chi-square analysis. P < 0.05 values were considered statistically significant.

Results
A total of 48 family physicians with a mean professional experience of 16.9 ± 8.8 years. Of all participants, 66.7% were not trained for autism previously, 27.1% were trained, but they did not find the training sufficient, while 6.3% were trained and found the training sufficient (Figure 1). 70.8% of the participant physicians did not refer to any children suspected for autism to the child and adolescent psychiatrist, while 29.2% stated that they had referred 1 to 3 children for further investigations.

![Figure 1: Participants’ status of previous training about ASD](https://www.id-press.eu/mjms/index)

Of the participants, 48% stated the first age when families brought autistic children as 2-3 years, and a substantial part of of the participants (37%) stated this period as 4-5 years of age (Figure 2).

![Figure 2: Distribution of age of the first presentation stated by physicians in ASD patients](https://www.id-press.eu/mjms/index)

The compliance of the answers given by the participants regarding five clinical features of autism with ASD diagnostic criteria of DSM-5 was found as 54.6 ± 18.4% (median: 60%). The most commonly
stated autistic features among the five clinical features of autism by the participants were the inability to make eye contact (72.9%), repetitive movements (47.9%), delayed speech (42.9 to 47.9%), and not responding to being called (41.7%) (Table 1).

**Table 1: Distribution of the clinical features stated by physicians related to autism**

| Clinical Feature                  | n  | %   |
|-----------------------------------|----|-----|
| Inability eye contact             | 35 | 72.9|
| Repetitive movement               | 23 | 47.9|
| Delayed speech development        | 23 | 47.9|
| Not responding to being called    | 20 | 41.7|
| Restricted peer relationship      | 11 | 22.9|
| Speech disorder                   | 10 | 20.8|
| Inability to communicate          | 10 | 20.8|
| Indifference to the environment   | 8  | 16.7|
| Interest in rotating objects      | 7  | 14.6|
| Not playing with toys             | 5  | 10.4|
| Withdrawn                         | 5  | 10.4|
| Obsession                         | 3  | 6.3 |
| Preferring to have a familiar routine | 2  | 4.2 |
| Avoids physical contact           | 1  | 2.1 |
| Likes parts of the object         | 1  | 2.1 |
| Unrest in the noise               | 1  | 2.1 |
| Typical facial expression         | 1  | 2.1 |

Participants indicated multiple clinical features.

The most commonly given answers to the question about the most common causes of presentation in autistic children were delayed speech by 33.3%, inability to communicate by 18.8%, and inability to make eye contact by 14.6% (Figure 3).

![Figure 3: Distribution of the clinical findings stated by physicians as the most common cause of presentation in ASD patients](image)

Of the participants, 56.3% (n = 27) stated one or more features that are not seen in autism, when they answer the question about five clinical features seen in autistic children. The most common answers that were not specific to autism included attention deficit disorder with hyperactivity by 34.6%, learning disability by 23.1%, singing by 11.5%, and irritability by 11.5%.

Compliance of the answers regarding clinical features of autism to DSM-5 criteria was compared between the physicians who were trained (n = 16) and the physicians who were not trained (n = 32), higher rate of conformity was observed in the trained physicians (68.7 ± 19.3 vs 56.2 ± 20, p = 0.04).

According to the duration of the work of the participants, physicians with a professional experience ≤ 15 years, which the number of participants was equal (n = 25), and those with a professional experience > 15 years were compared. Conformity of the answers regarding clinical features of autism to DSM-5 criteria was significantly higher in the physicians with a professional experience ≤ 15 years (68.7 ± 18.3 vs 52.2 ± 19.7, p = 0.006).

Compliance of the answers regarding clinical features of autism to DSM-5 criteria was compared between the physicians who have referred patients to child and adolescent psychiatrist within the last 6 months, and those have not referred, higher rate of compliance was found in the physicians who have referred patients (70 ± 23.2 vs 56.5 ± 18.1, p = 0.035).

Trained and untrained physicians about autism were compared, the trained physicians were found to refer more patients within the last 6 months with the presumed diagnosis of ASD (p = 0.004). No significant difference was found between the trained and untrained participants in terms of stating the age of presentation for autism as 2-3 years. Trained and untrained physicians were compared in terms of clinical features related to autism; trained physicians more commonly stated only limited peer relationship among typical findings of ASD, while no significant difference was found in other clinical features (Table 2).

**Table 2: Comparison of some clinical variables stated by trained and untrained physicians about autism**

| Variables                          | Education (+) | Education (-) | p   |
|------------------------------------|---------------|---------------|-----|
| Age of Autism diagnosis            | 2-3           | 7 (43.7)      | 16 (56.3) | 0.68 |
|                                    | Other         | 9 (56.3)      | 16 (50)   |    |
| Patient referral within 6 months   | Yes           | 7 (43.7)      | 27 (64.4) | 0.004|
|                                    | No            | 7 (43.7)      | 27 (64.4) |    |
| Specified clinical features        |               |               |     |
| Avoiding eye contact               | Yes           | 13 (81.3)     | 22 (68.8) | 0.35|
|                                    | No            | 3 (18.8)      | 10 (31.5) |    |
| Repetitive movements               | Yes           | 8 (50)        | 15 (46.9) | 0.83|
|                                    | No            | 8 (50)        | 17 (53.1) |    |
| Delayed speech development         | Yes           | 6 (37.5)      | 17 (53.1) | 0.83|
|                                    | No            | 10 (62.5)     | 15 (46.9) |    |
| Not responding to being called     | Yes           | 8 (50)        | 12 (37.5) | 0.4 |
|                                    | No            | 8 (50)        | 20 (62.5) |    |
| Restricted peer relationship       | Yes           | 7 (43.8)      | 4 (12.5)  | 0.01|
|                                    | No            | 9 (56.3)      | 28 (87.5) |    |
| Inappropriate clinical feature      | Yes           | 9 (56.3)      | 18 (56.3) | 1   |
|                                    | No            | 7 (43.8)      | 14 (43.8) |    |

**Discussion**

Autism Spectrum Disorder is a complex, lifelong and heterogeneous neurodevelopmental disorder characterised by stereotyped and repetitive behaviors and disrupted social and communication skills [5, 6]. Whereas ASD has been etiologically linked to parent disinterest in the 1960s, today it is accepted as a neurologic disorder [2]. Many studies have been conducted in recent years about the genetics of ASD, and it has been demonstrated that
ASD has a significant genetic basis [3], [4]. In addition, there are evidence that age of parents, antenatal, prenatal and environmental factors make a contribution to the development of ASD [8], [9], [10], [11], [12].

Family physicians are the physicians found around places of family residences or the places where they can be easily reached, and to be first visited and who deliver protective healthcare services and first line diagnosis and treatment services [13]. Therefore, family physicians are the first healthcare professionals to be referred by children with ASD due to a symptom related to autism or due to any reason other than autism, especially protective healthcare services. Studies have found that first line physicians and pediatricians play a key role in the diagnosis of ASD [14], [15]. Therefore, autism awareness of family physicians is crucial for early diagnosis in children with ASD.

It was remarkable that in our study, two third of family physicians with a mean professional experience of 16.9 ± 8.8 years were not trained about ASD. Given that the incidence of ASD has been found as 1% in the current studies, it was remarkable that 70.8% of the family physicians have not referred patients suspected for ASD to the child and adolescent psychiatrists within the last 6 months [16].

An autism spectrum disorder is diagnosed with clinical findings at the presentation of the person and the history received from families. There is no pathognomonic sign or laboratory test. Therefore, to establish the diagnosis, physicians must first know clinical symptoms well, assess clinical features of the child having autism, and listen to the family carefully [17].

In a study from India, two main features stated by pediatricians for the diagnosis of ASD were reported an an inability to make eye contact and social communication difficulties [18]. In our study also the most common feature stated by the participants was the inability to make eye contact. However, the feature stated by the participants as the most common cause of admission children with ASD to a physician was delayed speech. This result reflects that the reasons for admission children with ASD to a physician and the reasons for providing a physician to consider ASD in a child presented are different. Studies have found that the duration between onset of first symptom and referral of children with ASD to a physician by their families is longer [19]. Among the reasons for this, the most important is insufficient public awareness, recent studies show that public awareness about ASD is insufficient [20]. Other reasons include the fear of stigmatisation of the family, exposure to insensitive reactions due to misinformation of the society [19], [21]. Therefore, delayed speech and communication problems that are more regarded by families take an important place among the reason of referral to a practitioner [22].

In our study, a higher rate of responses given by the physicians with a professional experience ≤ 15 years about clinical features of ASD compared to those with a professional experience > 15 is a noteworthy finding. In a study by Sabuncuoglu et al., with family physicians, ASD scale scores were higher in physicians with longer duration of the profession. This was attributed to increased professional experience [23]. This study was conducted with family physicians residents in the education process with a median professional experience of 2-4 years and does not reflect family physicians working in the field. Similarly to our study, in their study with first-line physicians who had a mean professional experience of 14 years, Rahbar et al., found higher knowledge level about autism in the physicians with a professional experience < 5 years [24]. These results may be attributed to those physicians with longer duration in practice less follow the renewed criteria, less participate in educational activities, and experience more exhaustion.

There are data in the literature about low ASD awareness among first-line physicians [24], [25]. Also in a study from Turkey, ASD awareness of family practice residents was not found sufficient [17]. In another recent study, awareness of childhood autism of residents belonging to the non-neuropsychiatric disciplines has been moderate [26]. In our study, median conformity of ASD criteria stated by the participants to DSM-5 criteria was found as 60%, 54% of the physicians stated one or more symptoms unrelated to ASD, and 70.8% have not referred any patient suspected to have ASD, showing that autism awareness was not at the desired level also in experienced physicians working in the field. The significantly higher rate of features reported by the physicians trained for autism and those have referred patients with the presumed diagnosis of ASD within the last 6 months, supporting the necessity of ASD training in family physicians.

Symptoms begin between 0 and 3 years of life in ASD [27]. It is known that the diagnosis can be established in 2 years of age, and the American Pediatric Academy recommends screening at 2 years old [28]. However, the mean age of diagnosis was found as 5.7 in a study [29]. According to the American Centers for Disease Control and Prevention, the median age of diagnosis is 52 months [30]. Even it has been reported that more than 50% of children with ASD were diagnosed after 8 years of age [27]. In our study, about half of the physicians reported the age of the first presentation as 4 years and older. It has been shown that early diagnosis and early behavioural and social interventions in ASD significantly improved communication and social skills of these children [7], [15], [31], [32]. Therefore, awareness of family physicians on this issue was found to be insufficient.

In conclusion, our study indicated that a substantial part of family physicians was not trained
on ASD, and have not referred patients with the presumed diagnosis of ASD within the last 6 months. Conformity rate of the age of ASD diagnosis and clinical features related to ASD is not satisfactory. Awareness was significantly higher in the physicians trained in autism. Annual training programs covering early findings, clinical features, comorbidities associated with autism genetic basis and treatment program of ASD should be implements for family physicians. Also, the annual screening of children in the first 3 years may increase the rate of early diagnosis of autism.

**Study Limitations:** As the most important limitation, our study was cross-sectional and conducted with family physicians working in a single province, and some participants were relatively small. Questions of the questionnaire were prepared as open-ended by the researcher considering DSM-5 criteria to determine person specific answers, and this may cause limitation in the standardisation of some answers. Also, the number of questions was limited to provide privacy and not extend survey duration. The author proposes that questionnaires should be conducted, including more descriptive, accompanying comorbidities (such as epilepsy) about ASD. This study is a preliminary study. Further studies with larger series of participants including post-training comparisons are needed on this issue.

**References**

1. American Psychiatric Association (APA). *The Diagnostic and Statistical Manual of Disorders: DSM 5.* Washington, DC: Bookpoint US, 2013. https://doi.org/10.1176/appi.books.9780890425596
2. Deslauriers N. The empty fortress: infantile autism and the birth of the self. Arch Gen Psychiatry. 1967; 17 (4):510-2. https://doi.org/10.1001/archpsyc.1967.01730280126018
3. Lintas C, Persico AM. Autistic phenotypes and genetic testing: state-of-the-art for the clinical geneticist. J Med Genet. 2009; 46 (1):1-8. https://doi.org/10.1136/jmg.2008.060871 PMid:18728070 PMCid:PMC2603481
4. Alonso-Gonzalez A, Rodriguez-Fontena C, Carracedo A. De novo Mutations (DNMs) in Autism Spectrum Disorder (ASD): Pathway and Network Analysis. Front Genet. 2018; 21(9):406. https://doi.org/10.3389/fgene.2018.00406 PMid:30280067 PMCid:PMC6160549
5. Center for Disease Control and Prevention. Prevalence of autism spectrum disorder among children aged eight years – autism and developmental disabilities monitoring network, 11 sites, United States, 2010. MMWR: Surveillance Summaries. 2014; 63(2):1–21. PMcid:PMC4692457
6. Campisi L, Imran N, Nazeer A, Skokauskas N, Azeem MW. Autism spectrum disorder, British Medical Bulletin. 2018; 1:91-100. https://doi.org/10.1093/bmbld/026 PMid:30215678
7. Rogers SJ, Vismara LA. Evidence-based comprehensive treatments for early autism. J Clin Child Adolesc Psychol. 2008; 37(1): 8-38. https://doi.org/10.1080/15374410701817808 PMid:18444052 PMCid:PMC2943764
8. Sandin S, Schendel D, Magnnson P, et al. Autism risk associated with parental age at and with increasing difference in age between the parents. Mol Psychiatry. 2016; 21(5):693-700. https://doi.org/10.1038/mp.2015.70 PMid:26055426 PMCid:PMC5414079
9. Altay MA, Göker İ, Aslanova R, Bozath L, Turan N, Kaplan PB. Association between betasymptomatical tocolysis and risk of autistic spectrum disorders, behavioral and developmental outcome in toddlers. Open Access Maced J Med Sci. 2017; 5(6):730-5. PMid:29104681 PMCid:PMC5661710
10. Froehlich-Santino W, Tobon AL, Cleveland S, et al. Prenatal and perinatal risk factors in a twin study of autism spectrum disorders. J Psychiatr Res. 2014; 54:100-8. https://doi.org/10.1016/j.jpsychires.2013.03.019 PMid:24726638 PMCid:PMC4072527
11. Sveive LA, Drews-Botsch C, Harris S, Newschaffer C, Daniels J, DiGuiseppe C, Crenn LA. Windham GM Maternal and Paternal Infantility Disorders and Treatments and Autism Spectrum Disorder: Findings from the Study to Explore Early Development. J Autism Dev Disorder. 2017; 47(12):3994-4005. https://doi.org/10.1007/s10803-017-3283-1 PMid:28900768 PMCid:PMC5804352
12. Michelle Ng, Joanne G, de Montigny, Marianna Ofner, Minh T. Environmental factors associated with autism spectrum disorder: a scoping review for the years 2003–2013. Docé Health Promot Chronic Dis Prev Can. 2017; 37(1):1–23. https://doi.org/10.24095/hpcdp.37.1.01
13. Egici MT, Baydar-Artanatag A, Üstü Y, Ügürlo M. Türkiye' ve Aile Hekimliği Uygulamasına Geçişte Aile Sağlığı Elemanının Yeri. Ankara Medical Journal. 2012; 12(3):126-8.
14. Rauf, M A, Saeed, A B. Competency assurance of general practitioners-role of regulatory authority. J Pak Med Assoc. 2007; 57(11):573-4. PMid:18062529
15. Hartley-McAndrew M, Doody KR, Mertz J. Knowledge of autism spectrum disorders in potential first-contact professionals. N Am J Med Sci. 2014; 7(3):97–102.
16. Loomes R., Hull L., Mandy WP L. What is the male-to-female ratio in autism spectrum disorder? a systematic review and meta-analysis. J. Am. Acad. Child Adolesc. Psychiatry. 2017; 56:466–74. https://doi.org/10.1016/j.jaac.2017.03.013 PMid:28545751
17. American Academy of Pediatrics Committee on Children with Disabilities. The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. Pediatrics. 2001;107:1221-6. https://doi.org/10.1542/peds.107.5.1221 PMid:11331713
18. Daley CT, Sigman DM. Diagnostic conceptualization of autism among Indian Psychiatrists, Psychologists and Pediatricians. J Autism Dev Disord. 2002; 32:13-23. https://doi.org/1023/A:101749722349
19. Wang J, Zhou X, Xia W, Sun CH, Wu L, Wang J. Autism awareness and attitudes towards treatment in caregivers of children aged 3-6 years in Harbin, China. Soc Psychiatry Psychiatr Epidemiol. 2012; 47:1201-8. https://doi.org/10.1007/s00127-011-0438-9 PMid:22009414
20. Alsehemi MA, Abousaadah MM, Sairafi RA, Jan MM. Public awareness of autism spectrum disorder. Neurosciences (Riyadh). 2017; 22(3):213-215. https://doi.org/10.17712/nesy.v17i2.20160525 PMid:28678216 PMCid:PMC5946366
21. Gray DE. 'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism. Sociol Health Illn. 2002; 24:734-49. https://doi.org/10.1111/1467-9556.00316
22. Hidiroglu S, Luleci NE, Karavus M. Autism Awareness: An Overview. Recent Advances in Autism. 2016:1-10.
23. Sabuncuoglu M, Cebeci S, Rahbar MH, Hessabi M. Turkish Journal of Family Medicine & Primary Care. 2015; 9(2):46-53.
24. Rahbar MH, Ibrahim K, Assassi P. Knowledge and attitude of general physiciansregarding autism in Karachi, Pakistan. Journal of Autism and Developmental Disorders. 2011; 41(4):465-474, https://doi.org/10.1007/s10803-010-1068-x PMid:20632204
25. Lian WB, Ho SK, Yeo CL, Ho LY. General practitioners’ knowledge on childhood developmental and behavioural disorders. Singapore Medical Journal. 2003; 44(8):397-403. PMid:14700418

26. Hidiroglu S, Lüleci NE, Karavus M, Tanriover 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(2):247-251. PMid:29479101

27. Venkat A, Jauch E, Russell WS, Crist CR, Farrell R. Care of the patient with an autism spectrum disorder by the general physician. Postgrad Med J. 2012; 88(1042):472-81. https://doi.org/10.1136/postgradmedj-2011-130727 PMid:22427366

28. Johnson CP, Myers SM, American Academy of Pediatrics Council on Children with Disabilities. Identification and evaluation of children with autism spectrum disorders. Pediatrics. 2007; 120(5):1183-1215. https://doi.org/10.1542/peds.2007-2361 PMid:17967920

29. Shattuck PT, Durkin M, Maenner M, et al. Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. Journal of the American Academy of Child & Adolescent Psychiatry. 2009; 48(5):474-83. https://doi.org/10.1097/CHI.0b013e31819b3848 PMid:19318992 PMCid:PMC3188985

30. Centers for Disease Control and Prevention. Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2014. MMWR Surveillance Summaries. 2018; 67(6):1-23. https://doi.org/10.15585/mmwr.ss6706a1 PMid:29701730 PMCid:PMC5919599

31. Fombonne E. Epidemiology of autistic disorder and other pervasive developmental disorders. J Clin Psychiatry. 2005; 66(Suppl 10):3-8. PMid:16401144

32. Långh U, Hammar M, Klintwall L, Bölte S. Allegiance and knowledge levels of professionals working with early intensive behavioural intervention in autism. Early Interv Psychiatry. 2017; 11:444-50. https://doi.org/10.1111/eip.12335 PMid:27060473