

Parental Characteristics Affecting the Age at Diagnosis of Autism Spectrum Disorder: An Observational Cross-sectional Study

Otizm Spektrum Bozukluğu Tanı Yaşını Etkileyen Ebeveyn Özellikleri: Kesitsel Bir Gözlem Çalışması

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ABSTRACT

Objectives: Autism spectrum disorder (ASD) is a common neurodevelopmental disorder in childhood, affecting one in 68 children. Many children with ASD exhibit recognizable problems in social interactions in their first year of life. Although some mothers recognize problems earlier, the diagnosis of children is delayed due to various reasons. In this study, it is aimed to investigate the association between parental autistic traits, alexithymia and child's problematic behaviours and diagnostic delay.

Materials and Methods: A total of 80 children with ASD and their parents have been included in the study. Autism quotient (AQ), Toronto Alexithymia Scale and Aberrant Behavior Checklist were given to mothers. The socio-economic status is measured with Hollingshead-Redlich Scale.

Results: It is found that the average age of ASD diagnosis was 35.73±12.03 months and the average age that parents first noticed symptoms was 27.07±9.43 months. It is also detected that there was an average of 9.66±8.89 months delay between mothers noticing the symptoms in their children and bringing them to the child and adolescent psychiatry clinic. This difference has shown a significant positive correlation with the scores of the AQ-social skills subscale of the parents.

Conclusion: This study is important both in terms of presenting data related to the age of the diagnosis of ASD in Turkey and in terms of providing information about the diagnostic delay. Multi-centred studies with larger samples which also include data about follow-ups are required on this subject.

Keywords: Autism, parental characteristics, diagnosis, alexithymia, diagnostic delay

ÖZ

Amaç: Otizm spektrum bozukluğu (OSB), 68 çocuktan birini etkileyen, çocukluk çağıının yaygın bir nörogelişimsel bozukluğudur. OSB'li birçok çocuk, yaşamlarının ilk yılında sosyal etkileşimlerde fark edilebilir sorunlar sergiler. Bazı anneler sorunları erken fark etse de çeşitli nedenlerle çocukların tanısı gecikmektedir. Bu çalışmada ebeveynin otistik özellikleri, aleksitimi ve çocuğun problemleri davranışları ile tanısız gecikme arasındaki ilişkiyi araştırmayı amaçladık.

Gereç ve Yöntem: Çalışmaya OSB'li toplam 80 çocuk ve ebeveynleri dahil edilmiştir. Annelere Otizm Anketi (OA), Toronto Aleksitimi Ölçeği ve Anormal Davranış Kontrol Listesi verildi. Sosyo-ekonomik durum Hollingshead-Redlich Ölçeği ile ölçüldü.

Bulgular: Ortalama OSB tanı yaşının 35,73±12,03 ay, ebeveynlerin semptomları ilk fark etme süresinin 27,07±9,43 ay olduğunu bulduk. Ayrıca annelerin çocuklarındaki semptomları fark edip çocuk ve ergen psikiyatri kliniğine getirmeleri arasında ortalama 9,66±8,89 ay gecikme olduğunu tespit ettik. Bu fark, ebeveynlerin OA-sosyal beceriler alt ölçeği puanları ile anlamlı pozitif korelasyon göstermiştir.

Sonuç: Çalışmamız, Türkiye'de OSB tanısındaki yaşa ilişkin verilerin sunulması ve tanısız gecikme hakkında bilgi vermesi açısından önemlidir. Bu konuda daha geniş örneklemli çok merkezli çalışmalara ihtiyaç duyulmaktadır.

Anahtar Kelimeler: Otizm, ebeveyn özellikleri, tanı, aleksitimi, tanı gecikmesi

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Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder which appears in early childhood characterized by impairments in communication and social interaction and the presence of stereotyped or repetitive behaviors.¹ Studies have demonstrated that early and intensive intervention programs can improve social, language and cognitive abilities and adaptive behaviour in children with ASD.² ASD is a common neurodevelopmental disorder affecting one in 68 children.³ As ASD is a neurodevelopmental disorder, its signs usually develop in the first two years of life.⁴

Although studies support that ASD can be accurately diagnosed as early as 24 months of age, many children with ASD exhibit recognizable problems in social interactions in their first year of life.⁵ Many children are not diagnosed before the school age despite the signs of the disorder being identified by their parents in the first 2 years of life.⁶ Moreover, parental concerns at the age of twelve months have been found to be significantly related to independent measures of developmental status and autism symptoms. This has helped predict which infants would later be diagnosed with ASD, whereas concerns at 6 months have not found to be related.⁷ According to retrospective studies, although mothers recognize these early problems, the diagnosis of children is delayed due to various reasons, and this delay leads to miss the opportunity of early and intensive intervention.⁸

The factors related to the clinical picture could influence the time of ASD diagnosis. It is suggested that developmental regression, severe social difficulties before the age of 3, and the comorbidity of neurologic or any other psychiatric disorders are related with early diagnosis.⁹ These factors could result in earlier consultation to the clinician. In addition to these, gender might also be associated with the time of diagnosis. Some authors stated that girls were diagnosed earlier,¹⁰ while others stated that boys were diagnosed earlier.¹¹

The diagnostic delay of ASD might be due to several factors. Some environmental factors such as socio-economic status of family have been examined related to the issue. Higher levels of income and socio-economic status have been found to be related to the earlier diagnosis and intensive treatment. On the other hand, lower socio-economic status has been found to be related to the diagnostic delay, as foreseen.⁸ Even when screening can be made, delays between the first examination or parental concerns and the ASD diagnosis are common. This might arise from stigmatization due to different reasons such as the disability, lack of families' knowledge about the diagnosis and the healthcare system, communicational or authorization difficulties related to health and educational systems, long waiting periods for evaluations and geographic or transportation barriers.¹⁰

There are two significant parental traits which can interfere with the emotion recognition and the theory of mind: autistic traits and alexithymia. Both of them could influence the social relationship and face recognition.¹² Alexithymia is characterized as difficulty in identifying and describing emotions,

differentiating between feelings and bodily sensations and restricted imagination. It has been mentioned that the prevalence of alexithymia is between 5 to 13% in general population and 40 to 67% in clinical population.¹³ Several studies have suggested that alexithymia could be associated with deficits in the ability to recognize and label facial expressions of both positive and negative emotions and this could yield to problems with empathy and the theory of mind.¹⁴ Autistic traits and ASD share common genetic and biological origins and both interfere with social communication, theory of mind and emotion recognition.¹⁵ Increased alexithymia and autistic traits might interfere with parents' emotion recognition and communication. Therefore, it would be difficult to recognize the child's communication problems and this difficulty could result in delays for seeking medical advice from the child and adolescent psychiatrist. Additionally, the problematic behaviour of the child could influence the age of consulting a doctor. For example, the parents would have applied to the child and adolescent psychiatrist earlier for the children who have more serious problematic behaviours. This hypothesis is the main starting point of our study.

Although there have been several studies investigating the factors associated with the diagnostic delay of ASD, to our best knowledge none of them focused on the factors directly related to the parents themselves. In this study we aimed to examine the delay of ASD diagnosis and related factors associated with parents and the child. We aimed to investigate the association between parental autistic traits, alexithymia and child's problematic behaviours and autism diagnostic delay. We hypothesized that both autistic traits and alexithymia could interfere with the parents' emotion recognition and could be associated with diagnostic delay.

Materials and Methods

Sample and Procedure

This study has been carried out at the outpatient unit of Child and Adolescent Psychiatry Clinic, University of Health Sciences Turkey, Dr. Sami Ulus Maternity and Children's Health and Diseases Training and Research Hospital in Ankara, Turkey. The participants were included in the study between January 1st 2019 and July 1st 2019. The study started after the approval of the Keçiören Training and Research Hospital Ethical Committee (approval date: 28.11.2018, approval number: 1788). The diagnostic evaluation has been made according to the DSM-5 diagnostic criteria. A total of 80 parents, all mothers, have been included in the study. Having received medication for psychiatric disorders in the last 3 months and other medical conditions have been considered as exclusion criteria because of confounding effects on evaluation and questionnaire scores. Informed consent was obtained from all the participants.

Demographic characteristics have been recorded on the socio-demographic data form (such as child's age, special education status, family characteristics). Socio-demographic data form has

also been used to determine the age at the diagnosis and the age when mothers notice the abnormalities about communication, language, or any other area with their children. The socio-economic status has been measured with Hollingshead-Redlich scale.

Measures

Autism Quotient (AQ): AQ is used to measure the autistic traits. It is a questionnaire published by Baron-Cohen and contains 50 questions comprising 5 subscales of 10 questions each. Each subscale assesses a different set of skills selected from areas of social and cognitive abnormalities (such as social skills, attention to detail, attention switching, communication, and imagination) in ASD. Possible total scores range from 0 to 50. The questionnaire uses a Likert scale, ranging from “Definitely Agree” to “Definitely Disagree” to measure total AQ scores. The results slightly or strongly associated with ASD score one point, and other answers score zero, so higher scores denote higher levels of autistic characteristics.¹⁶ The reliability and validity of the AQ in Turkish was made by Kose et al.¹⁷. In the validity and reliability study of the Turkish version, the mean score of AQ has been found as 17.23 [standard deviation (SD): 4.7] among females and 18.76 (SD: 5.38) among males.

Toronto Alexithymia Scale (TAS): TAS is used to measure alexithymia traits. It’s a 20-item self-report scale, which is one of the most used scales measuring alexithymia. Alexithymia refers to people who have troubles in identifying and describing emotions and who tend to minimize emotional experiences and focus attention externally. TAS-20 has 3 subscales: Difficulty describing feelings, difficulty identifying feelings and externally oriented thinking. The total alexithymia score is the sum of the responses to all 20 items. The reliability and validity of TAS in Turkish was made by Güleç et al.¹⁸

Aberrant Behaviour Checklist (ABC): ABC is a scale designed by Aman et al.¹⁹ 1986 to measure psychiatric symptoms and behavioural disturbance. ABC has 5 domains: Irritability, agitation & crying; lethargy/social withdrawal; stereotypic behaviour; hyperactivity/non-compliance; and inappropriate speech. The reliability and validity of the ABC in Turkish was made by Sucuoğlu.²⁰

Statistical Analysis

Statistical analyses were conducted with SPSS version 22.0 (IBM Inc., Armonk, NY). Descriptive analyses have been used for frequencies of tested variables. Independent sample t-test has been used to evaluate the differences on scores between different groups. Correlation analysis has been used to examine the relations between variables. In all analyses $p < 0.05$ (two-tailed) has been determined for statistical significance.

Results

The study sample consisted of 80 children and their mothers. Thirteen of the patients were girls (16.3%) and 67 of them were boys (83.7%). The average age was 44.72 ± 19.23 months. Forty-nine of the participants were newly diagnosed, 31 of

them were attending follow-up. Among follow-up patients the average special education duration was 18.8 ± 17.41 months. While 74 of participants lived in a nuclear family, six of them lived in extended ones. After the clinical examination, intellectual disability was detected in 10 of the patients (12.5%), and 70 patients were found to have normal development (87.5%). The demographic variables are presented in Table 1, 2.

The average age of ASD diagnosis was 35.73 ± 12.03 months and the average age of mothers noticing the abnormalities about communication, language, or any other area with their children was 27.07 ± 9.43 months. There was a gap of 9.66 ± 8.89 months between the time of mothers’ concerns about their children and the diagnosis. The average age of ASD diagnosis and related data is presented in Table 3. This delay was found to be positively correlated with mothers’ AQ social skills ($r = 0.227$, $p < 0.05$) subscale in Pearson correlation analysis. There was no significant correlation between AQ total and other subscale scores, TAS total and subscale scores and the socio-economic status (Table 4).

The average age of ASD diagnosis was 29.92 ± 6.17 months among girls and 36.86 ± 12.59 months among boys. There was a significant difference between groups in terms of the average age of ASD diagnosis ($t = -3.017$, $p < 0.05$), whereas there was no significant difference in terms of the average age of mothers noticing the abnormalities about communication, language, or any other area with their children.

Table 1. Demographic and clinical characteristics

| | Mean | SD | Min | Max |
|--------------------------|-------|-------|-----|-----|
| Age (month) | 44.72 | 19.23 | 20 | 102 |
| Age of ASD diagnosis | 35.73 | 12.03 | 18 | 70 |
| Age of noticing symptoms | 26.07 | 9.43 | 9 | 54 |
| Diagnostic delay | 9.66 | 8.89 | 0 | 38 |

SD: Standard deviation, ASD: Autism spectrum disorder

Table 2. Gender distribution

| | n | % | n | % |
|---|----|------|----|------|
| Gender (female/male) | 13 | 16.3 | 67 | 83.7 |
| Patient admission (newly diagnosed/follow-up) | 49 | 61.3 | 31 | 38.8 |

Table 3. Comparison of age of diagnosis between genders

| | Female | | Male | | Statistics | |
|--------------------------|--------|------|-------|-------|------------|---------|
| | Mean | SD | Mean | SD | t | p |
| Age of ASD diagnosis | 29.92 | 6.17 | 36.86 | 12.59 | -3.017 | 0.005** |
| Age of noticing symptoms | 22.92 | 5.02 | 26.68 | 9.98 | -2.032 | 0.05 |
| Diagnostic delay | 7 | 6.94 | 10.17 | 9.18 | -1.427 | 0.168 |

* $p < 0.05$, ** $p < 0.01$, SD: Standard deviation, ASD: Autism spectrum disorder

When the newly diagnosed patients and those attending follow-up were compared, it was found that the average age of diagnosis of the newly diagnosed patients (33.55±9.21 months) was significantly lower than the follow-up patients (39.19±15.02 months) ($t=-2.085$, $p<0.05$). The average diagnostic delay was 7.69±6.79 months in newly diagnosed patients and 12.77±10.86 months in follow-up ones. There was a significant difference between groups in terms of diagnostic delay ($t=-2.576$, $p<0.05$). There was no significant difference between these two groups in terms of age at which mothers noticed the symptoms. In other words, although there was no difference between the timing of the mothers of the newly diagnosed and patients who are being followed up, it can be said that the newly diagnosed group applied to the physician earlier. The related data is presented in Table 5.

Discussion

In this study, children diagnosed with autism spectrum and their families were evaluated. An average of 9.66 months delay was detected between mothers noticing the symptoms in their children and bringing them to the child and adolescent psychiatry clinic. The difference between the time of mothers' noticing the symptoms and the time of applying to the child and adolescent psychiatry clinic showed a significant positive correlation with the scores of the AQ-social skills subscale of the mothers. In other words, as the social skills problems of the parents increase, they tend to consult to the physician later. At the same time, age of diagnosis of girls was significantly lower and the age of diagnosis of patients attending follow-up visits were significantly higher. To our best knowledge, our study is the first study investigating the age at diagnosis of ASD and related parental factors in our country.

In a review published on ASD diagnosis age and related factors, the average age at diagnosis was reported to be 32-89 months. This age increases for Asperger Syndrome and is stated as 45-134 months on average.⁹ In the review, severity of ASD symptoms, developmental regression, significant social communication, and interaction problems before the age of 3, and the appearance of symptoms after normal development in the first years of life were associated with early diagnosis. Hearing loss and accompanying neurological diseases were also associated with earlier diagnosis.⁹ Similar to this review, the average age at diagnosis was 35 months in our study. Therefore, it can be concluded that the age of diagnosis of autism in our country is similar to other countries.

Some studies in the literature found the age of ASD diagnosis was not related with gender while others reported earlier diagnoses in boys or girls.^{10,21,22} It can be thought that different data obtained on this subject

Table 4. Correlations between diagnostic delay and parental characteristics

| | Diagnostic delay | AQ-social skills | AQ-attention to detail | AQ-attention switching | AQ-communication | AQ-imagination | AQ-total | TAS-Difficulty describing feelings | TAS-difficulty identifying feeling | TAS-externally oriented thinking | TAS-total | SES | ABC-total |
|------------------------------------|------------------|------------------|------------------------|------------------------|------------------|----------------|----------|------------------------------------|------------------------------------|----------------------------------|-----------|-------|-----------|
| Diagnostic delay | 0.227* | | | | | | | | | | | | |
| AQ-social skills | -0.207 | -0.205 | | | | | | | | | | | |
| AQ-attention switching | 0.058 | 0.267* | 0.047 | | | | | | | | | | |
| AQ-communication | 0.182 | 0.289** | -0.015 | 0.199 | | | | | | | | | |
| AQ-imagination | 0.192 | 0.302** | 0.278* | 0.162 | 0.278* | | | | | | | | |
| AQ-total | 0.116 | 0.654** | 0.223* | 0.593** | 0.641** | 0.602** | | | | | | | |
| TAS-difficulty describing feelings | 0.003 | 0.220* | -0.074 | 0.263* | 0.297** | 0.186 | 0.338** | | | | | | |
| TAS-difficulty identifying feeling | -0.015 | 0.075 | 0.242* | 0.226* | 0.200 | 0.260* | 0.336** | 0.620** | | | | | |
| TAS-externally oriented thinking | -0.002 | 0.136 | -0.161 | 0.018 | 0.011 | 0.009 | 0.013 | -0.229 | -0.181 | | | | |
| TAS-total | -0.010 | 0.205 | 0.061 | 0.271* | 0.264* | 0.256 | 0.389** | 0.726** | 0.855** | 0.251* | | | |
| SES | 0.036 | 0.257* | 0.002 | 0.189 | 0.190 | 0.190 | 0.332** | 0.197 | 0.221* | 0.198 | 0.324** | | |
| ABC-total | 0.132 | 0.191 | -0.086 | 0.191 | 0.148 | 0.190 | 0.227* | 0.252* | 0.236* | 0.021 | 0.275* | 0.204 | |

*. Correlation is significant at the 0.05 level (2-tailed), **. Correlation is significant at the 0.01 level (2-tailed), AQ: Autism quotient, TAS: Toronto Alexithymia scale, SES: Socio-economic status, ABC: Aberrant behaviour checklist

Table 5. Comparison of age of diagnosis between newly diagnosed and follow-up patients

| | Newly diagnosed | | Follow-up | | Statistics | |
|--------------------------|-----------------|------|-----------|-------|------------|--------|
| | Mean | SD | Mean | SD | t | p |
| Age of ASD diagnosis | 33.55 | 9.21 | 39.19 | 15.02 | -2.085 | 0.04* |
| Age of noticing symptoms | 25.85 | 8.85 | 26.41 | 10.43 | -0.258 | 0.797 |
| Diagnostic delay | 7.69 | 6.79 | 12.77 | 10.86 | -2.576 | 0.012* |

*p<0.05, **p<0.01, SD: Standard deviation, ASD: Autism spectrum disorder

are related to issues such as socio-cultural differences and access to health services. In our study, girls were found to be diagnosed significantly earlier. This situation can be thought to be related to the social perception that boys' speech starts late and it might be "normal" in our country. A speech and communication problem noticed in girls might have prompted the parents to consult a child and adolescent psychiatrist earlier. In addition, it is possible that maturational language delay is more common in boys, which might affect the delay in diagnosis.²³

There are also different results in studies investigating the relationship between autism diagnosis age and socio-economic status. Some studies reported that higher socio-economic levels were associated with earlier diagnosis while others reported no relationship between those two variables.^{24,25} In our study, no effects of lower and higher socio-economic status could be found for age at ASD diagnosis, age at which the symptoms were noticed, and diagnostic delay. This might be related to the small size of our sample or the homogeneous and relatively lower socio-economic levels of inhabitants living in the catchment area of our hospital.

Study Limitations

There are some limitations in our study. First of all, it is a cross-sectional study and the results may not reflect causal relationships. We have not conducted an inclusion chart which describes the total number of patients who applied our clinic during the study and how many parents did not accept to participate in the study. Secondly, some of the data has been created with the information received only from the parents, which might have caused recall bias. Thirdly, because the data have been collected from a single centre, our results may not be valid for other centers and the general community.

Our study investigates the association between maternal characteristics and the diagnostic delay in ASD and presents data about the diagnostic age and the diagnostic delay in ASD in Turkey. We think that this is an important data for ASD in our country. Additionally, we have evaluated different maternal characteristics such as autistic traits and alexithymia. These are the strengths of our study.

Conclusion

As a result, this study is important both in terms of presenting data related to the age of the diagnosis of ASD in Turkey and in terms of providing information about the diagnostic delay. In addition, these data have shed light to a different perspective in

terms of examining parent-related factors. Multi-center studies with larger samples which also include data about follow-ups are required on this subject.

Ethics

Ethics Committee Approval: The study started after the approval of the Keçiören Training and Research Hospital Ethical Committee (approval date: 28.11.2018, approval number: 1788).

Informed Consent: Informed consent was obtained from all the participants.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: S.B.A., M.Ç., C.T., F.H.Ç., B.S.A., Y.I., Concept: S.B.A., M.Ç., C.T., F.H.Ç., B.S.A., Y.I., Design: S.B.A., M.Ç., Data Collection or Processing: S.B.A., M.Ç., C.T., F.H.Ç., B.S.A., Y.I., Analysis or Interpretation: S.B.A., M.Ç., F.H.Ç., Y.I., Literature Search: S.B.A., B.S.A., Y.I., Writing: S.B.A., M.Ç., F.H.Ç.

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