# Knowledge levels of mothers with children aged 0-6 about autism spectrum disorder

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## ABSTRACT

**Objectives:** In this study, it was aimed to measure the level of knowledge about autism spectrum disorder (ASD) in mothers of children aged 0-6 and to determine the necessity of informative studies on this subject and the characteristics of the group that should be focused on in future studies.

**Methods:** The population of the study consisted of mothers with children aged 0-6 years who applied to the pediatric outpatient clinic. In order to measure ASD knowledge, 24 questions were created by scanning the literature.

**Results:** 388 mothers were included in the study. There was a significant difference in educational status regarding ASD knowledge score ($p = 0.042$). There was a significant difference between economic status in terms of ASD knowledge score ($p = 0.026$). Those who had heard of ASD had a significantly higher ASD knowledge score than those who had not heard of ASD ($p < 0.001$). The ASD knowledge score of those who had acquaintances with ASD was significantly higher than those who had not ($p = 0.001$). There was a significant negative correlation between ASD total score, age, and first gestational age.

**Conclusions:** Increasing the level of knowledge about ASD will enable early diagnosis and early intervention in the course of the disease and the rapid integration of individuals with ASD into society.

**Keywords:** Autism spectrum disorder, awareness, early diagnosis

**A**utism spectrum disorder (ASD) is a chronic neurodevelopmental disorder that has the potential to emerge in the first years of life. While ASD patients do not look physically different from others, their understanding, communication, learning processes, and behaviors differ. This difference has a broad spectrum [1]. While some patients can lead a near-everyday life with minimal support, others may need care.

ASD was defined separately from other childhood diseases by the American Psychiatric Association in 1980 and was classified as five diseases in 1994: Autism, Asperger's Syndrome, Atypical Autism, Childhood Disintegrative Disorder, and Rett Syndrome. However, in 2013, Rett Syndrome was excluded from this category, and all were defined as ASD based on social communication and isolated-repetitive sensory activities [2]. While one out of 59 children is diagnosed with ASD in the United States, this rate is estimated to be around 1% globally [3, 4]. It has been observed that the prevalence of ASD has

been rising in recent decades, and it has been determined that boys are at 4.2 times more risk than girls [2]. It is thought that the increasing prevalence, developing technology and facilitating access to information, and the fact that families seek to diagnose their children are compelling.

Although ASD can be identified after 1.5 years of age, the average age of diagnosis is estimated to be 3.3 [5]. It has been found that the diagnosis of children with an older brother/sister can be made earlier than those without [6]. Although there is no specific indicator or diagnostic test to be a reference, behavioral disorders such as avoiding eye contact at an early age, not spending time with peers, limited vocabulary, and the desire to comply with daily routines are valuable findings for diagnosing ASD [1]. Despite its pathogenesis is not known for sure, it is believed that factors such as lifestyle, environmental factors, genetic components, and maternal age over 40 play a role in the etiology [7].

It is crucial that awareness of ASD is kept high throughout society. Because when families have sufficient information about ASD, their awareness level will increase in order to diagnose children earlier, and they will be able to provide the necessary social conditions for the child to have a chance to lead an everyday life in addition to the professional help that the child should receive [8]. In addition, it is essential to keep the knowledge level of society high so that children with ASD and their families are accepted by society and receive the necessary social support.

This study intended to measure the level of knowledge about ASD in mothers of children aged 0-6 and to determine the necessity of informative studies on this subject and the characteristics of the group that should be focused on in future studies.

## METHODS

### Study Design
The research was undertaken as a cross-sectional and descriptive study. This study was approved by Local Ethics Committee (Decision Number: 2021/09-13, Decision Date: 16/11/2021). The study was conducted through face-to-face interviews with parents with children aged 0-6 years who were referred to the pediatric outpatient clinic. Data collection was carried out between December 2021 and March 2022. The study population consisted of mothers with children aged 0-6 years who applied to the pediatric outpatient clinic. Three hundred eighty-eight mothers were included in the study with a 95% confidence level and a margin of error of 0.05. A questionnaire form was used as a method of obtaining data, and a consent form was obtained from the participants. A questionnaire was administered to the mothers in the form of in-person interviews.

### Questionnaire Form
In order to measure ASD knowledge, 24 questions

**Table 1. Sociodemographic characteristics of the participants**

| | Data |
|---|---|
| **Age (years), Mean ± SD** | 27.7 ± 5.8 |
| **Educational status, n (%)** | |
|   Middle school and below | 182 (49.6) |
|   High school | 135 (34.8) |
|   University | 71 (18.3) |
| **Spouse's educational status, n (%)** | |
|   Middle school and below | 126 (32.5) |
|   High school | 189 (48.7) |
|   University | 73 (18.8) |
| **Economical situation, n (%)** | |
|   Good | 179 (46.1) |
|   Moderate | 127 (32.7) |
|   Bad | 82 (21.1) |
| **First gestational age (months), Mean ± SD** | 22.4 ± 3.1 |
| **Number of children, Mean ± SD** | 1.8 ± 1.1 |
| **Number of children aged 0-6, Mean ± SD** | 1.2 ± 0.4 |
| **The state of hearing about autism spectrum disorder, n (%)** | |
|   Yes | 234 (60.3) |
|   No | 154 (39.7) |
| **Do you know anyone with autism spectrum disorder?, n (%)** | |
|   Yes | 150 (38.7) |
|   No | 238 (61.3) |

were created by scanning the literature. Those who answered the questions correctly were given 1 point, and those who gave wrong answers and said they had no idea were given 0 points. The ASD knowledge level of those who answered more than half of the right questions (13 or more) was accepted as high.

## Statistical Analysis

Analyzes were conducted using the SPSS (Statistical Package for Social Sciences; SPSS Inc., Chicago, IL) 22.0 software package. In the study, descriptive statistics are displayed as n and % values in categorical data and mean±standard deviation (Mean±SD) values in continuous data. Chi-square analysis (Pearson Chi-square) was carried out to compare categorical variables between groups. The Kolmogorov-Smirnov test evaluated the conformity of continuous variables to normal distribution. Student t-test was used for the comparison of paired groups. One Way ANOVA analysis was performed to compare more than two variables. The Pearson correlation test was used to examine the relationship between continuous variables. The statistical significance level in the analysis was assumed to be $p < 0.05$.

## RESULTS

Three hundred eighty-eight women were enrolled in the study. The mean age of the women was $27.7 \pm 5.8$ years (min = 20-max = 55). The education level of 182 (46.9%) women was secondary school or below, 135 (34.8%) were high school graduates, and 71 (18.3%) were university graduates. Education level of 126 (32.5%) spouses in secondary school or below, 189 (48.7%) are high school graduates, and 73 (18.8%) are university graduates. The economic status of 179 (46.1%) of the women is favorable, 127 (32.7%) of

**Table 2.** Comparison of ASD knowledge score according to educational status, economic status, hearing about ASD, and acquaintance with ASD

| | | Total score Mean ± SD | *p* value |
|---|---|---|---|
| **Educational status** | | | |
| | Middle school and below | $8.7 \pm 3.5^a$ | **0.042**[*] |
| | High school | $9.3 \pm 4.0^{a,b}$ | |
| | University | $10.0 \pm 4.5^b$ | |
| **Spouse's educational status** | | | |
| | Middle school and below | $9.2 \pm 4.2$ | 0.968[*] |
| | High school | $9.2 \pm 3.7$ | |
| | University | $9.1 \pm 3.9$ | |
| **Economical situation** | | | |
| | Good | $9.7 \pm 4.5^a$ | **0.026**[*] |
| | Moderate | $8.9 \pm 3.3^{a,b}$ | |
| | Bad | $8.4 \pm 2.7^b$ | |
| **The state of hearing about autism spectrum disorder** | | | |
| | Yes | $9.7 \pm 4.1$ | **< 0.001**[**] |
| | No | $8.3 \pm 3.4$ | |
| **Do you know anyone with autism spectrum disorder?** | | | |
| | Yes | $10.0 \pm 3.5$ | **0.001**[**] |
| | No | $8.7 \pm 4.0$ | |

*One Way ANOVA analysis, **Student t test was applied. [a,b]Group from which the difference originates

them are moderate, and 82 (21.1%) of them are bad. The mean first gestational age of the mothers was 22.4 ± 3.1 months (min = 18-max = 36). The mean number of children of the mothers was 1.8 ± 1.1 (min = 1-max = 8), and the mean number of children aged 0-6 years was 1.2 ± 0.4 (min = 1-max = 3). Of the mothers, 234 (60.3%) had heard of ASD, and 150 (38.7%) had acquaintances with ASD (Table 1). The mean ASD total knowledge score of the mothers was 8.2 ± 3.6, and the median score was 18 (min = 0-max = 22).

There was a significant difference in educational status regarding ASD knowledge scores ($p = 0.042$). This difference was due to the difference between those who graduated from secondary school and below and those who were university graduates. It was determined that the scores of those who graduated from university were higher. There was a significant difference between economic status in terms of ASD knowledge score ($p = 0.026$). This difference was due to the difference between those with good economic status and those with bad economic status, and it was determined that the scores of those with good economic status were higher.

Those who had heard of ASD had a significantly higher ASD knowledge score than those who had not heard of ASD ($p < 0.001$). The ASD knowledge score of those who had acquaintances with ASD was significantly higher than those who had not ($p = 0.001$). (Table 2). There was a significant negative correlation between ASD total score, age, and first gestational age (Table 3).

ASD knowledge level was high in 70 (18%) mothers and low in 318 (82%) mothers. It was observed that the level of knowledge was high in 12.4% of those with secondary education and below, 20% with high

**Table 3. Correlation of ASD knowledge score with age, gestational age and number of children**

| | Total score | |
|---|---|---|
| | r | *p* value[*] |
| Age | -0.127 | 0.012 |
| First gestational age | -0.117 | 0.021 |
| Number of children | 0.017 | 0.743 |
| Number of children aged 0-6 | 0.040 | 0.438 |

*Pearson correlation analysis was applied.

school graduates, and 28% with a university degree. This difference was found to be statistically significant ($p = 0.01$). ASD knowledge level was high in 23.7% of those with good economic status, 18.4% with moderate, and 3.9% with poor economic status. There was a significant difference between economic status and ASD knowledge level ($p = 0.001$).

Twenty-two point six percent of those who had heard of ASD and 11% who had not heard of ASD were found to have a high level of ASD knowledge, and a significant difference was found between them ($p = 0.004$). ASD knowledge level was high in 24% of those who had acquaintances with ASD and 14.3% of those who had not, and a significant difference was found between them ($p = 0.015$).

## DISCUSSION

Determining the level of knowledge about ASD is essential not only for the individual with ASD and his/her immediate environment but also for society in general. Early diagnosis of the disease will provide early support for the development of the individual with ASD. It will enable the individual to adapt to family life and the social order more quickly. ASD does not only affect individuals. The implementation of the individual's daily routines and conditions, such as sleep disorders, can affect the whole family.

For this reason, preparations for this disease group should target the ASD-affected community, which includes individuals with ASD, as well as their families and the immediate affected environment. In this study, 24 questions were asked to determine the knowledge level of the participants, but the participants were able to answer 8.2 of these questions correctly on average. The level of knowledge is considered relatively low. In a study conducted with 339 parents in Pakistan in 2018, it was found that the knowledge level of the participants about ASD was low in parallel with our study [8]. On the other hand, the public's knowledge level was high in studies conducted in the United States of America, Australia, and Saudi Arabia [2, 9, 10]. In order to increase the level of knowledge, it is recommended to provide parents with short-term training in pairs. In a study conducted in India, informative training on ASD was organized for parents, and a significant increase was observed in the knowledge levels of

the participants after the training [8].

In this study, the ASD knowledge levels of those who heard about ASD and had contact with individuals with ASD were significantly higher than those who did not hear about ASD and did not know anyone with ASD. In a study conducted in Australia, the level of knowledge of those who had contact with individuals with ASD was significantly higher than those who did not [9]. In a study in Pakistan in which families with children with ASD and health professionals were not evaluated, the level of knowledge of participants who heard about ASD was significantly higher than those who did not [8]. Previous research supports our study. Again, in a study conducted with 1054 participants in Australia, it was stated that the factor affecting knowledge level the most was spending time with individuals with ASD [11]. It is thought that individuals who have heard of ASD and know people with ASD have researched this area and obtained information about ASD from mass media, such as social media or television, in their daily lives [2].

In this study, when the level of knowledge was measured according to education level, it was determined that university graduates had a significantly higher level of knowledge than other education levels. In a study conducted in Australia with 478 participants, a correlation was found between educational status and the level of knowledge [9]. In a study conducted in Saudi Arabia with 500 participants, the knowledge level of master's/doctorate graduates was significantly higher than other education groups [2]. Previous studies show that there is a correlation between the level of education and the level of knowledge about ASD in general.

When the income status of the family and the level of knowledge about ASD were examined, it was observed in our study that participants with a good income had a higher level of knowledge than participants with poor income. In a study comparing the knowledge levels of ASD in America and China, a correlation was found between the economic situation and knowledge levels in China [12]. Likewise, the level of knowledge of those with good economic status in Pakistan was significantly higher than those of the middle and lower classes [8].

Although no significant correlation was detected between the level of knowledge and age in the literature, it was observed in this study that the level of knowledge declined with increasing age. This situation makes accessing informative channels (social media, television, etc.) challenging as age increases and adaptation to technology decreases.

## CONCLUSION

Based on previous studies and the results of this study suggests that the ASD knowledge level of those who have not encountered individuals with ASD may be insufficient. For this reason, in order to increase the ASD knowledge level of the public, it is necessary to use social media actively, to include informative programs about ASD through channels such as television/radio, and to organize training that is easy to reach, especially for parents and prospective parents. Increasing the level of knowledge in ASD will enable early diagnosis and early intervention in the course of the disease. This will enable the rapid integration of individuals with ASD into society.

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