Autism Awareness of Mothers Scale (AAMS): A Study of Validity and Reliability

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Annelerin Otizm Farkındalığı Ölçeği (AOFÖ): Geçerlik ve Güvenirlik Çalışması

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Abstract
The aim of this study was to evaluate the autism awareness of mothers having typically developing children at preschool age and to investigate the validity and reliability of the Autism Awareness of Mothers Scale (AAMS). This methodological study was conducted with 136 mothers applying to a family health center in Istanbul, Türkiye. Data were collected in July-August 2021. The AAMS was a 4-point Likert-type scale and consisted of a total of 23 items. The factor structure of the scale was extracted by performing exploratory factor analysis. The median age of the participants was 32 years. Almost all the participants (91.9%) stated that they had heard the word 'autism' before. One-third of the mothers defined autism as a "social interaction problem" (33.1%). As a result of factor analysis, the AAMS had a two-factor structure, with Eigenvalues of 7.480 for Factor 1 and 4.978 for Factor 2 and explained 54.17% of total variance. The Cronbach's alpha coefficient was found to be 0.947 for AAMS (0.933 and 0.876 for subscales, respectively). According to our results, AAMS is a valid and reliable measurement tool. It can be used in Türkiye and in Turkish to determine autism awareness of mothers of typically developing preschool children.

Keywords: *Autism, awareness, mother, preschooler, scale.*

Öz
Bu çalışmanın amacı, okul öncesi dönemde ve normal gelişim gösteren çocuğu olan annelerin otizm farkındalıklarını değerlendirmek ve Annelerin Otizm Farkındalık Ölçeği'nin (AOFÖ) geçerlik ve güvenirliğini araştırmaktır. Bu metodolojik araştırma, İstanbul ilinde bir aile sağlığı merkezine başvuran 136 anne ile yapıldı. Veriler Temmuz-Ağustos 2021 tarihlerinde toplandı. AOFÖ 4'lü Likert tipinde bir ölçek olup toplam 23 maddeden oluşmaktaydı. Açımlayıcı faktör analizi yapılarak ölçeğin faktör yapısı çıkarıldı. Katılımcıların ortanca yaşı 32 idi ve tamamına yakını (%91,9) 'otizm' kelimesini daha önce duyduklarını belirttiler. Annelerin üçte biri otizmi "sosyal etkileşim sorunu" olarak tanımladı (%33,1). Faktör analizi sonucunda AOFÖ'nün özdeğerleri sırasıyla 7.480 ve 4.978 olan iki faktörlü bir yapıya sahip olduğu ve toplam varyansın %54,17'sini açıkladığı görüldü. AOFÖ için Cronbach alfa katsayısı 0,947 olarak bulundu (alt ölçekler için sırasıyla 0,933 ve 0,876). Sonuçlarımıza göre AOFÖ geçerli ve güvenilir bir ölçme aracıdır. Okul öncesi dönemde çocukları olan annelerin otizm farkındalıklarını belirlemek için Türkiye'de ve Türkçe olarak kullanılabilir.

Anahtar Sözcükler: *Otizm, farkındalık, anne, okul öncesi, ölçek.*

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Introduction

Autism spectrum disorder, also known as autism, is a common, highly inherited, and heterogeneous neurodevelopmental disorder that has underlying cognitive features and often presents with additional health problems (Lord et al., 2020). Psychiatric or neurological disorders such as hyperactivity and attention disorders, anxiety, depression, and epilepsy are common in individuals with autism, along with basic symptoms such as impairment in social communication and interaction and repetitive behaviors (Hodges et al., 2020).

Autism is associated with poor emotional control, anxiety, and impulsivity (Conner et al., 2020; McClain et al., 2017). Behavioral patterns seen in individuals with autism may lead to negative attitudes and discrimination in family/relatives, society, social environments, and school. Especially children with autism are more exposed to exclusion and bullying (Cook et al., 2020; Park et al., 2020; Terzioğlu, 2022). Studies showed that bullying can have multiple negative consequences, including damaged self-esteem, mental health problems, and higher rates of suicidal ideation in children with autism (Wainscot et al., 2008). In addition, the exclusion experienced by families with children having autism discourages the participation of the children in society and decreases the desire to seek health services of families (Ates & Rakap, 2021; Kinnear et al., 2016).

The prevalence of autism has tended to increase in recent years (Maenner et al., 2020). There are many awareness studies about autism conducted with university students (Kostiukow et al., 2020; Rakap et al., 2016), health workers (Chansa-Kabali et al., 2019), teachers (Alobaid & Almogbel, 2022; Rakap et al., 2018), and the community (Alsehemi et al., 2017; Rakap et al., 2022; Wei et al., 2022). The autism awareness of parents of typically developing children was investigated in some community-based studies (Arslan, 2023; Karabekiroğlu et al., 2009). In Arslan (2023) it was observed that the awareness of autism in parents was lower than in individuals who did not have children. Also, Karabekiroğlu et al. (2009) found elementary school teachers' autism awareness was higher than parents. However, to our knowledge, a scale measuring autism awareness of mothers having typically developing preschool children does not exist particularly in Türkiye or Turkish.

Autism awareness of preschoolers' mothers is important in ensuring that both themselves and their children show positive attitudes towards individuals with autism in their surroundings. Raising awareness about autism will allow understanding of the differences of individuals with autism and provide the right approach in social areas (Lord et al., 2020). Identifying the deficiencies in autism awareness in this population with a scale will support creating friendly surroundings in community and in schools for children with autism. Thus, the education and development of children with autism will be positively affected. This study aimed to evaluate autism awareness of mothers having typically developing children at preschool age (3-5 years) and to investigate the validity and reliability of the Autism Awareness of Mothers Scale (AAMS) developed by researchers.

Method

Study Design and Participants

This research had a methodological design. Data were collected between 1 July-31 August 2021. The study population included mothers of typically developing children aged 3-5 years (preschool children) who have applied to Sultanbeyli No. 3 Family Health Center in İstanbul Province of Türkiye. Mothers having a child with autism, having worked or are

working at a special education institution related to autism, having graduated from a child development school, and having worked or are working at a child development institution were excluded from the study. In addition, among the healthcare workers, the study did not include mothers who were neurologists, child neurologists, psychiatrists, child psychiatrists, and psychologists. Of the 150 mothers who applied to the concerned Family Health Center during the data collection period and met the eligibility criteria, 136 agreed to participate in the study (participation rate: 90.7%).

Data Collection Tool

A questionnaire form was used as a data collection tool in the study. The questionnaire consisted of 4 sections and was made up of 35 questions. The data collection tool was applied to the participants using the face-to-face interview method by experienced researchers. In the sociodemographic section, which was the first section of the questionnaire, there were four questions about the participants' age, number of children, educational level, and occupation. The second section consisted of five multiple-choice questions about having heard the word 'autism' before, the most appropriate definition for autism, autism prevalence, the age of onset of autism symptoms, and sources of information about autism. The third section of the questionnaire consisted of three questions about mothers' general experience of autism, namely whether the mothers have met an individual with autism, the presence of an individual with autism in their social circle, and the presence of an individual with autism in their families.

The Autism Awareness of Mothers Scale (AAMS) developed by researchers was the fourth section of the questionnaire. The AAMS was a 4-point Likert-type scale and included 23 questions in total. The scores could range from 23 to 92, and high scores were expected to indicate a high level of awareness of childhood autism.

Statistical Analysis

Data for sociodemographic characteristics, general knowledge about autism, and general experience of autism were presented with frequencies, medians, and interquartile ranges (IQR). The construct validity was evaluated by principal component analysis (orthogonal varimax rotation) for the AAMS. The sampling adequacy for factor analysis was measured with the Kaiser-Meyer-Olkin (KMO) value. The Barlett Test of Sphericity was used to evaluate the appropriateness of the data for factor analysis. Internal consistency was evaluated with Cronbach's alpha coefficient, item-total correlations, and mean inter-item correlations. In addition, the correlations between AAMS and subscales were evaluated with Spearman's correlation coefficient.

The distribution of AASM scores of the participants' characteristics was assessed by univariate analyzes. The normality of the distribution of the data was investigated by histogram graphs, the Kolmogorov-Smirnov test, and the Shapiro-Wilk test. In the case of non-normal distribution, the Mann-Whitney U test was used if the independent variable had two groups, and the Kruskal-Wallis test was used if the independent variable had three groups. IBM SPSS Statistics, version 23 program was used in the analysis of the data. For all statistical analyzes, p value of <0.05 was considered as statistically significant.

Research Ethics

Ethics committee approval for this study was obtained from the Ethics Committee of Marmara University Health Sciences Institute with the date of 18.02.2019 and number of 68. The research permission was granted by the Istanbul Provincial Health Directorate,

Health Services Presidency. Written informed consent was obtained from all participants. All procedures performed in this study comply with the ethical standards of the institutional and national research committee and the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Results

Sociodemographic Characteristics

The median age of the participants was 32 years (IQR=28-37 years), and half were between 31-40 years old (50.4%, n=68). Most of the mothers were housewives (66.7%, n=90), and 55 (39.0%) had two children. Approximately one-third of the participants were high school graduates (31.6%, n=43). Eighty-four mothers (65.1%) had met an individual with autism so far, 18.2% (n=24) had an individual with autism in their social circles, and 4.4% (n=6) had an individual with autism in their families (Table 1).

Table 1. Sociodemographic Characteristics of the Participants

Variable	F	%
Age (years)		
21-30	55	40.7
31-40	68	50.4
≥41	12	8.9
Number of children		
1	36	26.5
2	53	39.0
3	30	22.0
4+	17	12.5
Educational level		
Illiterate	2	1.5
Literate	7	5.2
Primary school	24	17.6
Elementary school	28	20.6
High school	43	31.6
University or higher	34	25.0
Occupation		
Healthcare worker	6	4.4
Teacher/educator	9	6.7
Hairdresser, tradesman, banker	12	8.9
Housewife	90	66.7
Other	18	13.3

General Knowledge about Childhood Autism

Almost all participants (91.9%, n=125) stated that they had heard the word 'autism' before (Table 2). When asked about the most appropriate definition for autism, the most common answer given by mothers was "The basic feature is social interaction" (33.1%, n=43). Other answers to this question were "It is kind of a mental retardation" (23.8%; n=31), "The most basic feature is strange, repetitive behaviors" (17.7%; n=23), and "The most basic feature is speech problem" (12.3%; n=16). To the question of the age of onset of autistic symptoms, 74 mothers (57.4%) answered "between the ages of 2-5" and 44 (34.1%) answered "between the ages of 0-1". In addition, participants stated that they received information about autism from television (35.3%; n=73), internet (24.2%; n=50), neighbors-relatives (16.9%; n=35), and book-newspaper-magazine (%8.2; n=17) (Table 2).

Table 2. General Knowledge About Childhood Autism and General Experience of Autism

Variable	n	%
Having heard the word autism		
Yes	125	91.9
No	10	7.4
I am not sure	1	0.7
The most appropriate definition of autism		
Kind of a mental retardation	31	23.8
The basic feature is speech problem	16	12.3
The basic feature is strange, repetitive behavior.	23	17.7
The basic feature is social interaction problems	43	33.1
A kind of distraction	4	3.1
Kind of a mental illness	2	1.5
A kind of epilepsy	1	0.8
A kind of balance disorder	5	3.8
Other	5	3.8
Age of onset of autistic symptoms		
0-1 years	44	34.1
2-5 years	74	57.4
6-12 years	8	6.2
13-18 years	0	0.0
Above 18 years	3	2.3
Autism prevalence		
1/10,000	27	22.5
15-20/10,000	34	28.3
5-6/1000	27	22.5
1-10/100	32	26.7
Sources of information about autism (select all that apply)		
TV	73	35.3
Internet	50	24.2
Neighbor-Relatives	35	16.9
Book-Newspaper-Magazine	17	8.2
Doctor/Health Personnel	11	5.3
Education-Course	5	2.4
Conference	3	1.4
Other	13	6.3
Having met a person with autism		
I am not sure	11	8.5
No	34	26.4
Yes	84	65.1
Presence of an individual with autism in the social circle		
I am not sure	10	7.6
No	98	74.2
Yes	24	18.2
Presence of an individual with autism in the family		
I am not sure	14	10.3
No	116	85.3
Yes	6	4.4

Autism Awareness of Mothers Scale (AAMS) of Preschool Children

The factor structure of the Autism Awareness of Mothers Scale (AAMS) of preschool children is presented in Table 3. The KMO value was 0.911 and p value of Barlett's test of sphericity was found as <0.001. As a result of principal components analysis (orthogonal varimax rotation), 23 items in the scale were loaded in two factors. The Eigenvalue of factor 1 was 7.480 and 15 items loaded on this factor explained 32.52% of the total

variance. Items loaded on this factor were related to the behavioral patterns seen in children with autism (Table 3).

Table 3. Factor Structure of Autism Awareness of Mothers Scale (AAMS; n = 136)

Item by Factor		Factor*		Item-Total
		1	2	Correlations
Factor 1: Behavioral Patterns				
14.	They can constantly play with something in their hands (by turning or shaking).	**.762**	.266	.730
19.	They can overreact to changes in their daily life.	**.745**	.179	.663
21.	They do not like to be touched/stopped during a tantrum.	**.742**	.256	.708
18.	They can be uncomfortable in noisy environments and can close their ears to many sounds (vacuum cleaner sound. fluorescent lamp sound. etc.).	**.730**	.167	.637
10.	They may shout suddenly and make sudden movements.	**.729**	.253	.695
20.	They may overreact to child crying, ambulance noise and various hums and start a tantrum.	**.713**	.283	.706
9.	Children with autism may flap their hands from time to time like a bird flapping its wings.	**.665**	.054	.520
11.	They can be extremely active and always act in their own way.	**.665**	.343	.697
13.	Eyes of children with autism may stare blankly into empty space and/or staring blankly without concentration to a specific object.	**.633**	.407	.713
8.	They can say some phrases/words over and over in unrelated environments as if they were speaking to themselves.	**.624**	.426	.719
15.	They may stare for a long time at spinning objects such as wheels or propellers or at fast-moving images such as running water or flashing light.	**.618**	.463	.738
23.	They cannot imitate what you are doing (for example, waving, clapping to say bye-bye to you, or making funny noises when you make it).	**.555**	.186	.517
12.	A child with autism may sit quietly swinging his body back and forth for a long time.	**.546**	.442	.665
22.	During a tantrum, if they are calmly taken to a quiet room their tantrum will pass in a short time.	**.520**	.333	.579
7.	Like a parrot, they can answer the questions by repeating what you said.	**.517**	.386	.610
Factor 2: Communication and Interaction with the Environment				
4.	They do not look at you/turn to you when you call them by name.	.100	**.823**	.543
3.	They do not point with their finger to ask for something.	-.012	**.801**	.446
2.	When you point your finger at something across the room the child with autism has trouble looking at it.	.322	**.724**	.666
5.	Sometimes they can seem like they do not hear the other person at all.	.434	**.623**	.689
16.	They may be indifferent to their environment and to what is going on around them. They are not aware of dangerous situations (fire, earthquake, etc.).	.494	**.588**	.714
17.	They may be indifferent to the games their peers play.	.477	**.584**	.698
6.	A baby with autism may not show interest in social games such as 'peekaboo'.	.387	**.544**	.605
1.	They have difficulty in speaking and expressing themselves as compared to their age group.	.316	**.502**	.519

* Principal Components Analysis (orthogonal varimax rotation) was used.

Note. Bartlett Test of Sphericity value was $\chi 2 = 1875.74$, $p < 0.001$ and the Kaiser-Meyer-Olkin value was 0.911. The Cronbach's alpha coefficient of the scale was 0.947 (0.933 for Factor 1, 0.876 for Factor 2). The total variance explained was 54.17% (Factor 1: 32.52%. Factor 2: 21.64%). The Eigenvalues for the factors are 7.480 and 4.978, respectively. The mean inter-item correlation value was 0.436.

The Eigenvalue of Factor 2 was 4.978 and 8 items loaded on this factor explained 21.64% of the total variance. Items loaded on this factor were related to communication and interaction with the environment of children with autism. The item-total correlations of the scale ranged from 0.446 to 0.738 and only item 3 was below 0.5. The mean inter-item correlation value was found to be 0.436 (Table 3).

The Cronbach's alpha coefficient of the scale was found to be 0.947. This value is 0.933 for Factor 1 and 0.876 for Factor 2. Correlation coefficients were 0.870 (df=134, p<0.01) between AAMS and Factor 1 (*Behavioral Patterns subscale*), 0.955 (df=134, p<0.01) between AAMS and Factor 2 (*Communication and Interaction subscale*), and 0.701 (df=134, p<0.01) between Factor 1 (*Behavioral Patterns subscale*) and Factor 2 (*Communication and Interaction subscale*).

Table 4. Autism Awareness of Mothers Scale (AAMS) Scores by Sociodemographic Characteristics, General Knowledge About Childhood Autism and General Experience of Autism

Variable	AAMS		*p*
	Median	IQR	
Age (years)			
21-30	63.0	54.0-75.0	
31-40	61.0	53.0-73.0	0.720*
≥41	60.5	52.5-81.0	
Number of children			
1-2	63.0	56.0-76.0	0.112†
≥3	61.0	51.0-69.0	
Educational level			
Primary education or below	59.0	51.0-64.0	**<0.001**†
High school or higher	66.0	58.0-81.0	
Occupation			
Healthcare worker/teacher/educator	81.0	73.0-91.0	
Housewife	59.5	52.0-66.0	**<0.001***
Other	65.5	58.0-77.0	
Having heard of the word autism			
Yes	63.0	57.0-76.0	**<0.001**†
No/I do not remember	46.0	46.0-59.0	
The most appropriate definition for autism			
Social interaction problem	65.0	59.0-74.0	0.121†
Other	61.0	52.0-75.0	
Age of onset of autism symptoms			
0-1 years	63.5	54.5-72.0	
2-5 years	62.0	54.0-77.0	0.284*
≥6 years	59.0	46.0-74.0	
Presence of an individual with autism in the family			
Yes	82.5	68.0-86.0	**0.032**†
No/I do not know	62.0	54.0-74.0	
Presence of an individual with autism in the social circle			
Yes	69.5	61.0-83.0	**0.014**†
No/I do not know	61.0	52.5-73.0	
Having seen a person with autism			
Yes	64.0	57.0-79.5	**0.008**†
No/I do not know	59.0	49.0-71.0	

*Kruskal-Wallis test
†Mann-Whitney U test
Note. AAMS = Autism Awareness of Mothers Scale; IQR = Interquartile range

The distribution of AAMS scores according to sociodemographic characteristics, general knowledge about autism, and general experience of autism are presented in Table

4. It was found that the AAMS scores were higher for those who have an educational level of high school or higher, who have heard the word of autism, who had an individual with autism in the family, who had an individual with autism in the social circle, and who have met an individual with autism ($p<0.001$, $p<0.001$, $p=0.032$, $p=0.014$, $p=0.008$; respectively). In addition, awareness levels of healthcare workers/educators were found to be higher than those working in other occupational groups and housewives ($p<0.001$).

Discussion

In our study conducted with mothers who applied to a family health center in İstanbul and had children in the 3-5 age group (preschoolers), the awareness levels of the participants about autism were evaluated. Although a significant part of the mothers participating in our study had heard the word 'autism' before and had met an individual with autism, few participants stated that there was an individual with autism in their families or in their social circle. The participants stated the most appropriate definition for autism as social interaction problem which is similar to the literature (Karabekiroğlu et al., 2009). However, the frequency of those describing autism as 'a kind of mental retardation' is higher than in previous studies (Arslan, 2023; Karabekiroğlu et al., 2009).

Principal component analysis was used for the factor analysis to investigate the validity of the scale. According to the analysis, this model consisted of two factors and explained a total of 54.17% of the variance. Even though this value is partially below 60.0%, it was considered an acceptable level for the studies in social areas (Hair, 2010). All items of the scale were loaded on a single factor by more than 0.50. The fact that there was no item loaded above 0.50 on both factors strengthens the construct validity of the scale (Hair, 2010). Factor 1 was named ‘Behavioral Patterns’ because of the loading of items measuring the awareness levels of participants for typical behaviors that can be seen in a child with autism. The Cronbach's alpha coefficient of the Behavioral Patterns subscale was 0.933. In addition to the fact that the expressions in this subscale are included in many studies in the literature as the signs and symptoms of autism, it is also compatible with the expressions under the heading of 'restricted, repetitive behaviors and interests' among the ASD diagnostic criteria in Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) (American Psychiatric Association [APA], 2013; Lord et al., 2020; Regier et al., 2013). Factor 2 was named as 'Communication and Interaction' considering the characteristics of the items loaded on the factor. The Cronbach's alpha coefficient of the Communication and Interaction subscale was found to be 0.876. Social nonresponsiveness, impairment in verbal and nonverbal communication, and problems in developing and maintaining social relationships in individuals with autism are among the characteristic features of autism (APA, 2013; Maenner et al., 2020).

In our study, the mean inter-item correlation value was found to be 0.436. Ideally, the mean inter-item correlation value for a set of items should be between 0.15 and 0.50 (Clark & Watson, 2019). The value of 0.436 found in our study is within acceptable limits. In addition, the Cronbach's alpha value for AAMS was found to be 0.947, which indicates that the level of internal consistency is strong (Clark & Watson, 2019; Taber, 2018). The item-total correlation values of the items in the scale ranged from 0.446 to 0.738. The lowest item-total correlation value, calculated as 0.446, is above the accepted lower limit value of 0.4 (Nurosis, 1994). In addition, it was determined that the correlation coefficients between the AAMS and the subscales were all at high levels (Mukaka, 2012).

Limitations

There are some limitations in our study. First, the population of the research consisted of mothers who applied to only one family health center. Therefore, analyzes comparing individual characteristics and awareness of participating mothers did not represent similar mothers to other family health centers in Istanbul. In addition, since our study is about a social issue, it is possible that the social compatibility bias may have affected the answers of the participants to show themselves as well-informed about autism and as if having higher levels of self-awareness.

Conclusion

In conclusion, our results show that AAMS is a valid and reliable measurement tool. Our scale has the feature of assessing the autism awareness levels of mothers who have children at preschool age by reducing to two main dimensions (*Behavioral Patterns* and *Communication and Interaction*). This study can guide about the points to be considered in awareness training programs for mothers in terms of autism awareness. With the increase of autism awareness in mothers, it will be ensured that they show a positive attitude to children with autism both in social environments and in their children's schools. Moreover, increasing positive attitudes will reduce the perceived stigma of parents with children having autism and encourage seeking interventions at an early stage.

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