

Determination of the Autism Awareness in Women Who are Future Mothers

Geleceğin Annesi Olan Kadınlarda Otizm Farkındalığının Belirlenmesi

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ABSTRACT

Autism Spectrum Disorders(ASB) is a neurodevelopmental disorder characterized by continuing deficiencies in the social interactions and communication and restricted and repetitive behaviors. There is no definitive criterion in autism, but there are some important indicators to facilitate early diagnosis. This research was carried out to determine the awareness of female students about autism, to determine the lack of knowledge of women about autism and to determine the factors affecting it. Turkey's Eastern Black Sea Region Gumushane, Trabzon, Rize, Artvin, Giresun, including the Eastern Black Sea which are thought to represent the best of the Region 5 provinces that agree to participate in research studying at university in 2604 has reached female students. The average age of the students is 20.81 ± 2.79 . It was determined that 72.5% of the students had information about autism, 28.9% of the respondents had information about internet autism from internet, 24% from written skies, 23.3% from formal education process, and 13.4% from television. In our study, it was found that 67.5% of the students stated that the mother was exposed to radiation and / or toxic agents during pregnancy, 66.3% said genetic factors, and 57.8% stated that the mother used drugs as a cause of autism. It is recommended that community-based awareness programs and other media platforms such as radio, print and social media be encouraged in order to increase mass awareness on autism. It is recommended that autism researches should be conducted in large samples by increasing the number of awareness campaigns on autism and strategic plans on autism should be made in line with the results.

Keywords: Autism, Awareness, Woman

ÖZ

Otizm Spektrum Bozuklukları (OSB), bireyin sosyal etkileşimler ve iletişimde devam eden eksiklikler, kısıtlı ve tekrarlayan davranışlar ile karakterize nöro-gelişimsel bir bozukluktur. Otizmde kesin tanı koydurucu bir ölçüt bulunmamaktadır ancak erken tanıyı kolaylaştıracak önemli bazı göstergeler bulunmaktadır. Bu araştırma kadın öğrencilerin otizm konusundaki farkındalığının saptanması, kadınların otizm ile ilgili bilgi eksikliğinin belirlenmesi ve etkileyen faktörlerin belirlenmesi amacıyla yapılmıştır. Türkiye'nin Doğu Karadeniz Bölgesi'nde Gümüşhane, Trabzon, Rize, Artvin, Giresun olmak üzere Doğu Karadeniz Bölgesini en iyi temsil edebileceği düşünülen 5 ilde üniversitede öğrenim gören araştırmaya katılmayı kabul eden 2604 kadın öğrenciye ulaşılmıştır. Araştırmanın sonuçlarına göre öğrencilerin yaş ortalaması $20,81 \pm 2,79$ 'dur. Öğrencilerin %72,5'inin otizm hakkında bilgi sahibi olduğu, cevap verenlerin %28,9'unun internette, %24'ünün yazılı kaynaklardan, %23,3'ünün örgün eğitim sürecinde, %13,4'ünün televizyondan 'otizm' hakkında bilgi sahibi olduğu belirlenmiştir. Araştırmamızda öğrencilerin %67,5'i annenin hamilelikte radyasyon ve/veya toksik ajanlara maruz kalmasını, %66,3'ü genetik faktörleri, %57,8' annenin hamilelikte ilaç kullanmasını otizm nedeni olarak belirttiği saptanmıştır. Otizm konusundaki kitlesel farkındalığın artırılması için toplum temelli bilinçlendirme programlarının ve radyo, yazılı ve sosyal medya gibi diğer medya platformlarının teşvik edilmesi önerilmektedir. Otizm konusunda farkındalık kampanyaları sayısının artırılarak otizm araştırmalarının geniş örneklemelerde yapılması ve sonuçlar doğrultusunda otizm konusunda stratejik planlamalar yapılması önerilmektedir.

Anahtar Kelimeler: Otizm, Farkındalık, Kadın

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INTRODUCTION

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders characterized by restricted/ repetitive behaviors and recurrent deficiencies in the individual's social interactions and communication. The prevalence of autism is increasing rapidly.¹⁻³ It differs from person to person depending on factors such as severity, level of intelligence, accompanying disorders, level of reaction to education, and level of external support required.⁴

The skills of normally growing children in early childhood, such as social interaction (establishing eye contact, responding to smile, responding to the name) and initiating to develop a behavior suitable for the social environment, are not observed in children with ASD. South (2011) expressed that children with ASD are not able to establish human relations, have inappropriate social relationships, excessive use of gestures and facial expressions, and have features such as not understanding the other person's reactions in their social relationships.⁵

Although many investigations have been conducted on the epidemiology of ASD, including Asperger syndrome, childhood autism and other common developmental disorders, uncertainty regarding the causes of ASD continues.⁶ Literature reports that both genetic and environmental factors contribute to the etiology of ASD.⁷⁻⁸ Increasing evidence suggests that immune processes play a key role in its pathophysiology.⁹ However, although inflammatory changes in the central nervous system and peripheral dysfunction of the humoral and cellular immune responses have been reported many times, a single immunopathology has still not been found. The view that autism has a neurobiological etiology rather than being related to the child's upbringing or past life has gained importance.

The prevalence of autism is increasing rapidly. While 1 in every 2,500 children in the world was diagnosed with autism in 1985 in the world, today it is 1 in 68 children, and one child is diagnosed with autism every 20

minutes. Although there is no exact figure indicating the prevalence of autism in our country, it is estimated that there are approximately 1,142,586 individuals with autism when projected to the population, and 4 half million family members are affected by this situation.¹⁰ In developed countries such as the USA and the UK, the importance given to research on autism awareness is increasing day by day. It is necessary to support families not only about the etiology but also the treatment to raise awareness about autism.¹¹

Having a child is one of the most challenging tasks in a woman's life, and she needs to constantly improve on this.¹² However, having a baby diagnosed with a disability can deeply hurt the woman and cause her to perceive the event as a crisis.¹⁰⁻¹⁴ This situation may also lead to such feelings as loneliness, anger, guilt, helplessness, and denial in the woman.¹⁵⁻¹⁷

There are no definitive diagnostic criteria in autism, yet there are some major indicators that facilitate early diagnosis. Developmental monitoring/screening becomes more significant at this point. Developmental monitoring units, especially in maternal-child health services, primary pediatric units, pediatric neurology clinics, and pediatric mental health departments, are of great importance.¹⁹ Besides, autism awareness training to be provided to women is thought to be very effective for the early diagnosis and initiation of the treatment process. Although many experts have identified the reason for the increase in autism prevalence as a reflection of the increase in autism awareness, this idea has not been proven empirically yet.¹⁹ It is especially necessary to enhance the awareness of female students about autism. Therefore, the study was carried out to determine the autism awareness of future mothers. The awareness of future mothers is thought to be effective in the early detection and management of autism for both their children and community children.

MATERIAL AND METHOD

Study Design and Population

The study was conducted to determine the awareness of female students about autism, to determine their lack of knowledge about it, and to determine the influencing factors. The universe of this descriptive and cross-sectional research consisted of all of the female university students in the spring term of 2018-2019 in 5 cities, which are thought to represent the Eastern Black Sea Region in the best way. The cities were Gümüşhane (748 participants), Trabzon (238 participants), Rize (502 participants), Artvin (500 participants), and Giresun (516 participants). On the days of the study, 2604 female students who were at school and agreed to participate in the study were included in the study. Female students have an important place in early diagnosis because they are the future mother and spend more time with children. For this reason, female students with an important role in the early detection of autism were included in the sample of our study.

Data Collection Tools

A questionnaire form prepared by researchers was used to collect the data. It consists of questions that evaluate the level of autism knowledge and awareness of female students. In the evaluation process, autism diagnosis criteria were employed according to American Psychiatric Association (DSM V), and the items in the questionnaire were prepared accordingly.²⁰⁻²¹ The questionnaire consists of 3 parts. The first part includes the symptoms of autism, the second part, the causes of autism, and the third part includes questions about how to prevent autism. The form is answered as 'Yes', 'No' and 'I don't know'. Cronbach Alpha value of the questionnaire was found as .83.

Data Collection

The study was conducted by the researchers in the spring term of 2018-2019. Suitable days and hours were determined by discussing with the management of the

institutions where the study will be conducted. The participants were informed about the aim of the research in the classes at determined hours, and they were asked to participate in the study. It was also explained that participation was on voluntary basis. Questionnaire form was distributed to the participants and they were asked to fill the questionnaires after providing brief information during the study.

Statistical Analyses

The data were analyzed using SPSS 23.0 package program. To evaluate the data, arithmetic mean, number and percentage calculations were made.

Aspect of Research Ethics

This study was approved by the local University Scientific Research and Publication Ethics Committee (2018/3), and it was carried out after obtaining the necessary institution permissions. Before the data collection, participants were informed about the purpose of the study, and their verbal consent was obtained, and data collection forms were applied under direct observation in line with the principle of volunteering. The confidentiality and anonymity of findings were preserved (According to the Helsinki Declaration).

Limitations of the Study

The limitation of the study was that it was conducted with female university students from five universities in the spring semester of the 2018-2019 academic year. The research was conducted with women of a certain educational level. The reliability of data is limited with the information provided by the participants.

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RESULTS AND DISCUSSION

The results revealed that the average age of the participants participating in the research was 20.81 ± 2.79 . 72.5% of the participants had information about autism, 28.9% got information from the internet, 24% from written sources, 23.3% during formal education, and 13.4% from television. 72.7% of the students stated that they had not read a book about autism, 61.5% thought that autism could not be determined before a baby was born, 64.5% indicated that autism was a preventable disease, and 86.4% did not know any autistic person (Table 1).

When participants were asked to describe autism, 53.5%, 23.8%, 19.7%, 3% defined it as impairment in social-communicative skills, mental retardation, an auditory disability, and a physical disability respectively. 64.5% of the students said that autism is a preventable disease, 50.1% thought that autism is not a curable disease, and 47% stated that autism can be treated with psychotherapy (Table 1).

67.5%, 66.3%, and 57.8% of the participants indicated the radiation and/or toxic agents the mother is exposed to during pregnancy, genetic factors, and the drugs the mothers use during pregnancy as a cause of autism, respectively (Table 2).

The participants listed the symptoms of autism as follows: 'excessive movement or immobility' (71.3%), 'not allowing or disliking physical contact' (67.5%), 'being indifferent to the environment' (63%), 'being socially and emotionally isolated from the outside world' (60.6%), and 'speech disorders' (63.8%) (Table 3).

The participants participating in the study did not define the following features as a sign of autism; 'preferring non-living things mostly rather than people' (62.1%), 'expressing their needs by using the hand of the adult, not his/her own hand' (56.4%), 'repeating what is said' (69%), 'speaking with inappropriate emphasis and stereotyped sentences' (49%), 'having mechanical and routine sound tones' (65%), 'having order and object obsessions'

(60.3%)', 'reacting to changes in their routines' (61%), and 'being insensitive to hot, cold and pain' (66.9%) (Table 3).

Table 1. Participants' Knowledge and Awareness of Autism

	n	%
Knowing about autism		
Yes	1889	72.5
No	715	27.5
Sources of information about autism		
Television		
Formal education	350	13.4
Internet	607	23.3
Written sources	878	33.7
Internet-formal education	143	5.5
written sources	626	24.0
Reading about autism		
Yes	710	27.3
No	1894	72.7
Knowing an autistic person		
Yes	355	13.6
No	2249	86.4
Students' definitions of autism		
Physical disability	79	3.0
Auditory disability	514	19.7
Mental disability	619	23.8
Impairment in social-communicative skills	1392	53.5
Can autism be determined before the baby is born?		
Yes	1003	38.5
No	1591	61.5
Is autism curable?		
Yes	1300	49.9
No	1304	50.1
How is autism treated?		
Medication	643	24.6
Psychotherapy	1225	47.0
Family-oriented therapy	359	13.8
Other (eg. non-pharmacological methods)	377	14.6
Can autism be prevented?		
Yes	1678	64.5
No	926	35.5

Table 2. Causes of Autism According to Participants

		N	%
Genetic factors	Yes	1727	66.3
	No	877	33.7
Drugs used by the mother during pregnancy	Yes	1505	57.8
	No	1099	42.2
Maternal pregnancy at an older age	Yes	1215	46.7
	No	1389	53.3
Chronic illness of the mother or father	Yes	931	35.8
	No	1673	64.2
Exposure of the mother to radiation and/or toxic agents during pregnancy	Yes	1757	67.5
	No	847	32.5
Mother's smoking, using alcohol or drugs	Yes	1195	45.9
	No	1409	54.1
Socioeconomic level	Yes	560	21.5
	No	2044	78.5
Wrong parental attitudes	Yes	681	26.2
	No	1923	73.8
Maternal malnutrition during pregnancy	Yes	339	35.8
	No	1671	4.2

The participants stated that they did not know if autism can be prevented if the pregnant mother uses cigarettes, alcohol, and drugs (% 45.3), has malnutrition while pregnant (%51.2), and gets pregnant at older ages (%42.5). Besides, 43.6%, %38.2 of them expressed that autism can not be prevented if the mother has a chronic disease, and even if the family has a good socioeconomic status (Table 4). The study is the first and only study examining the level of awareness and knowledge about autism in female university students in Turkey. In this study revealed that 72.5% of the participants knew about autism. A study conducted with university students in Zambia (2019) reported that 24.7% of them knew about autism. In African countries such as Nigeria and Zambia, which are among the undeveloped countries, the levels of autism awareness were found to be quite low in studies conducted in both clinical settings and educational.²³⁻²⁷ Studies conducted in underdeveloped countries, such as Pakistan, found the level of autism knowledge low.²⁸⁻²⁹ Another study conducted in a university

community in the USA showed that 72% of the 1000 students and staff sampled were aware of autism.³⁰ A study of autism in Northern Ireland, among young participants aged 11 and 16 showed that autism awareness was 50% and 80%, respectively.³¹ Other studies Northern Ireland and the UK, autism awareness levels for the general population in were above 80%.³² France was reported to have the highest adult autism awareness (100%).³³ All these studies prove the thesis that there is a direct proportion between the countries' levels of development and the level of awareness of autism.

In this study also displayed that 28.9% of participants got information about "autism" from the internet, 24% from written resources, 23.3% during formal education, and 13.4% from television. In a study conducted by Chansa & Kabali et al. (2019) in Zambia, the majority of the participants (41%) learnt autism from television, 22% from the printed media, 5.7% from radio, 4.8% from friends and the Internet.³⁴ These findings show that not only income inequality but also digital inequality is one of the factors related to autism awareness.

The vast majority of the participants (53.5%) defined autism as impairment in social-communicative skills, 23.8% defined it as mental retardation, and 19.7% and 3% defined it as auditory and physical disability respectively. Similar to our study, in 2014 Töret et al. found that a significant number of parents (38%) described autism as a disorder in social-communicative behavior, a certain number of parents (28%) could not describe autism, some parents defined autism as emotional behavior disorder (20%) and language speech disorder (16%), or introversion, intense loneliness, and socialization problem (12%).³⁵

In this study, when the participants were asked to express the symptoms of autism, the majority (71.3%) defined the situation of 'excessive movement or immobility' as a symptom of autism. The others listed the symptoms as 'not allowing or disliking physical contact' (67.5%), 'being indifferent

to the environment' (63%), 'being socially and emotionally isolated from the outside world' (60.6%), and 'speech disorders' (63.8%) (Table 3). Töret et al. asked parents about the symptoms of autism observed in their children in 2014, and in response, 51.0 stated that they had language-speech and communication disorders, 44.0% stated stereotypical behaviors, and 28% expressed social interaction problems.³⁵

Table 3. Participants' Views on Symptoms of Autism

		N	%
Their eye contact is limited or absent.	Yes	1543	59.3
	No	1061	40.7
They are indifferent to environment.	Yes	1645	63.2
	No	959	36.7
They do not respond when calling out their names.	Yes	1411	54.2
	No	1193	45.8
They have excessive movement or immobility.	Yes	1857	71.3
	No	647	28.5
They do not allow or dislike physical contact (kissing, hugging).	Yes	1759	67.5
	No	845	32.5
They mostly prefer non-living things rather than people.	Yes	988	37.9
	No	1616	62.1
They isolate themselves socially and emotionally from the outside world.	Yes	1579	60.6
	No	1025	39.4
They express their needs by using the hand of the adult, not their own hand.	Yes	1135	43.6
	No	1469	56.4
Many of them have speech disorders.	Yes	1661	63.8
	No	943	36.2
They have echolalia, that is, they repeat what is said like a parrot.	Yes	807	31.0
	No	1797	69.0
They speak with inappropriate emphasis and stereotyped sentences.	Yes	1057	40.6
	No	1547	49.4
They have mechanical and routine sound tones.	Yes	911	35.0
	No	1693	65.0
Inappropriate laughter and giggles are observed.	Yes	1085	41.7
	No	1519	58.3
They are obsessive about order and objects.	Yes	1034	39.7
	No	1570	60.3
They react to changes in their routines.	Yes	1016	39.0
	No	1588	61.0
They have repetitive behavior.	Yes	1178	45.2
	No	1426	54.8
They make meaningless hand-arm and leg movements.	Yes	1529	58.7
	No	1075	41.3

They prefer to play the same games all the time.	Yes	1042	40.0
	No	1562	60.0
They may be extremely sensitive to sound, pain, smell, light and touch.	Yes	1145	44.0
	No	1459	56.0
They may be insensitive to cold, heat and pain.	Yes	863	33.1
	No	1741	66.9
They may be insensitive to danger.	Yes	1371	52.6
	No	1233	47.3
They can harm themselves, people and objects around.	Yes	1028	39.5
	No	1576	40.5
They cannot tolerate waiting or postponing their wishes.	Yes	1140	43.8
	No	1464	56.3

In line with these findings, it can be said that participants perceive autism as a disorder or insufficiency, unlike a syndrome or a disease in general. The study showed that 67.5%, 66.3%, and 57.8% of the participants defined the causes of autism as the radiation and/or toxic agents the mother is exposed to during pregnancy, genetic factors, and the drugs the mother uses during pregnancy, respectively.

Table 4. Participants' Views on How to Prevent Autism.

		N	%
Autism can be prevented if the mother does not use alcohol and drugs during pregnancy.	Yes	893	34.3
	No	531	20.4
	Don't know	1424	45.3
Autism can be prevented if the mother has no malnutrition.	Yes	555	21.3
	No	717	27.6
	Don't know	1332	51.2
Autism can be prevented if the mother has no chronic illness.	Yes	489	18.8
	No	1135	43.6
	Don't know	980	37.6
Autism can be prevented if the family's socioeconomic level is good.	Yes	754	29.0
	No	997	38.2
	Don't know	853	32.8
Autism can be prevented if the mother is not pregnant at an older age.	Yes	824	31.6
	No	674	25.9
	Don't know	1106	42.5

Regarding the views of parents with autistic children about the cause of autism, relevant literature report especially genetic

factors,³⁶⁻³⁷ prepartum and sequential causes that arise during childbirth,³⁸⁻³⁹ brain trauma, vaccines, and postpartum causes such as poor postpartum care.⁴⁰ The participants responded the question of how to prevent autism as follows: they did not know whether autism can be prevented if the mother smokes, uses alcohol and drugs (45.3%) has

malnutrition (51.2%) while pregnant, if the mother gets pregnant at older ages (42.5%), even if the family has a good socioeconomic status (38.2%), and if the mother has a chronic disease (%43.6). In line with these results, it was shown that the majority of the individuals associated autism with the mother's malnutrition.

CONCLUSION AND RECOMMENDATION

The study is of great importance since the literature on autism reports almost no similar studies and a statistical database in the primary sense in Turkey. Although most of the participants stated that they have knowledge about autism, it was determined that the information about what autism was, why, and treatment was not satisfactory. While women are aware of some of the symptoms related to autism, some of them do not know. Some of the information about the causes of autism was found to be incorrect. In line with these findings, it can be said that participants' awareness of autism is not sufficient.

Autism is a lifelong developmental disabilities that impairs the formation of social and communication skills, but if it is diagnosed early, great improvements in the prognosis can be observed. In this respect, it is very important for female students, who are the future mothers, to gain awareness

about autism. Lack of information about autism in the community affects not only autism awareness levels, but also care practices, quality of life, and individuals' independence. Because autism is not fully understood or ignored, there are delays in treatment, and thus the lives of individuals are affected badly.

In line with the results, it is recommended to encourage community-based awareness programs and other media platforms such as radio, printed/social media to raise mass awareness of autism. It is also suggested that autism researches are carried out in large samples by increasing the number of awareness campaigns, and strategic plans are made in the direction of autism. In addition, nurses will contribute to the diagnosis and treatment of autism by organizing trainings for women who have an important role in early diagnosis of autism.

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