

Otizimli Bireylerde Menstrasyon Özellikleri, Ağrı ve Genital Hijyen Davranışları: Ön Çalışma

Menstruation Characteristics, Pain and Genital Hygiene Behaviours in Individuals with Autism: A Preliminary Study

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ABSTRACT

Difficulties such as somatic complaints experienced by women with Autism Spectrum Disorder (ASD) due to autism may be affected by the menstrual cycle. We aimed to investigate menstruation pain, genital hygiene behaviours and menstrual characteristics of women with ASD.

Thirty-five individuals (16 individuals with ASD and 19 healthy controls) aged 12-35 were included in this cross-sectional study. The inclusion criteria were having an ASD diagnosis and menstruation for the experimental group and having menstruation for the control group. The assessment included the classification of motor functions with Gross Motor Function Classification System, pain information with Visual Analog Scale, menstrual symptoms with Menstrual Symptom Questionnaire (MSQ) and genital hygiene behaviours with Genital Hygiene Behaviour Scale (GHBS). Chi-square tests were used to determine whether there was a difference in terms of categorical variables. The t test was used to compare two independent groups.

There was no significant difference between the groups in the total and subscale scores of the GHBS and the MSQ ($p>0.05$). As a result, it was observed that there were similarities between women with ASD and healthy women in terms of the pain, hygiene, and general characteristics of during their menstrual periods.

The ability of women with ASD to identify somatic complaints and pain during menstruation may be reduced. As a result, this may be due to individuals with ASD and their parents not being able to distinguish the physical complaints experienced during menstruation from the physical complaints experienced at other times, alternatively, because these complaints are ignored.

Keywords: Autism spectrum disorder, Dysmenorrhea, Hygiene, Women health.

ÖZ

Otizim Spektrum Bozukluğu (OSB) olan kadınların otizme bağlı olarak yaşadıkları somatik şikayetler gibi zorluklar, menstrüel döngüden etkilenebilir. OSB'li kadınların menstrüasyon ağrısı, genital hijyen davranışları ve menstrüel özelliklerini araştırmayı amaçladık.

Bu kesitsel çalışmaya yaşları 12-35 arasında değişen 35 birey (16 OSB'li birey ve 19 sağlıklı kontrol) dahil edilmiştir. Çalışmaya dahil edilme kriterleri; deney grubu için ASD tanısı almış olması ve düzenli menstrüel siklus olması, kontrol grubu için düzenli menstrüel siklus olmasıydı. Değerlendirmede motor fonksiyonlar Kaba Motor Fonksiyon Sınıflandırma Sistemi ile, ağrı Görsel Analog Skala ile, menstrüel semptomlar Menstrüel Semptom Anketi (MSQ) ile genital hijyen davranışları Genital Hijyen Davranış Ölçeği (GHBS) ile sınıflandırılmıştır. Kategorik değişkenler açısından fark olup olmadığını belirlemek için ki-kare testi, iki bağımsız grubu karşılaştırmak için t testi kullanıldı.

GHBS ve MSQ toplam ve alt ölçek puanlarında gruplar arasında anlamlı bir fark yoktur ($p>0.05$). Sonuç olarak, OSB'li kadınlar ile sağlıklı kadınlar arasında adet dönemlerindeki ağrı, hijyen ve genel özellikler açısından benzer olduğu saptandı.

OSB'li kadınların menstrüasyon dönemindeki somatik şikayetleri ve ağrıyı tanımlama becerileri azalmış olabilir. Sonuç olarak, bu durum OSB'li bireylerin ve ebeveynlerinin menstrüasyon sırasında yaşanan fiziksel şikayetleri diğer zamanlarda yaşanan fiziksel şikayetlerden ayırt edememesinden ya da alternatif olarak bu şikayetlerin göz ardı edilmesinden kaynaklanıyor olabilir.

Anahtar kelimeler: Otizm spektrum bozukluğu, Dismenore, Hijyen, Kadın sağlığı.

The ethical approval was obtained for this study from Bolu Abant İzzet Baysal University Clinical Research Ethics Committee (approval number: 2022/324, date: 20.12.2022).

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Geliş Tarihi / Received: 31.12.2024

Kabul Tarihi/Accepted: 01.04.2025

INTRODUCTION

Autism spectrum disorders (ASD) are a group of neurodevelopmental disorders characterized by problems in communication and repetitive behaviours that may contribute to menstruation problems¹⁻⁵. Although the etiopathogenesis is unclear, ASD is thought to be a polygenetic disorder with genetic and environmental factors⁶. The prevalence of ASD has been reported to be 65/10,000 children and is more common in boys⁷. In autism prevalence studies, the male to female ratio has been reported as 4 to 5:1⁸. ASD is predominantly seen in males, and sex steroids such as testosterone are thought to be one of the biological factors, which has led to gender bias in diagnosis^{9,10}. In the literature, studies on autism mostly included males on the spectrum. The number of studies on women with autism is quite low¹¹. Because ASD is more common in males, there is a lack of focus in the literature on issues such as menstruation and menopause, which play an important role in the lives of women with autism^{9,10}.

High androgen levels in the prenatal period also known as the androgen theory, may be a precursor for ASD¹². This theory also reports that women with ASD may be more prone to problems such as menstrual difficulties and acne^{13,14}. Limited studies in the literature suggest that women with ASD are more likely to experience menstrual difficulties such as premenstrual syndrome, irregular menstrual

cycles (amenorrhea), unusually painful periods and increased menstrual bleeding^{3,15,16}. In addition to difficulties with menstruation, women with autism also experience difficulties in maintaining genital hygiene behaviors compared to healthy individuals¹⁷.

Genital hygiene consists of a series of hygiene behaviors for menstruating women, such as using sanitary pads, bathing regularly, and cleaning the perineal area with soap and water to prevent diseases and protect reproductive health¹⁸. Women with ASD are often dependent on others to perform these and other basic functions¹⁷. Due to the nature of ASD, these personal hygiene skills need to be clearly explained and taught to individuals with autism to prevent health issues arising¹⁹. When they need help from others for genital hygiene, their risk of sexual harassment increases²⁰. In addition, failure to fulfill genital hygiene behaviours can cause biological problems such as urinary tract infections²¹.

There are very few studies on menstruation characteristics in individuals with autism, and to our knowledge, none investigating genital hygiene in women with autism. Therefore, the purpose of this study was to investigate menstruation characteristics, pain and genital hygiene behaviours in individuals with autism.

MATERIAL AND METHOD

Study Design

This study was designed as a cross-sectional study, consisting of adolescent and young women with autism and healthy women.

Ethical Aspects of the Research

Ethical approval for this study was taken from the Bolu Abant İzzet Baysal University Clinical Research Ethics Committee (approval number: 2022/324, date: 20.12.2022). The research was conducted in Private Düzce Gökkuşığı Special Education

and Rehabilitation Center and Private Kdz. Ereğli Gökkuşığı Special Education and Rehabilitation Center, where the research was conducted. Permission was obtained from these centers to conduct the study. All individuals and their parents gave written informed consent in accordance with the principles of the Declaration of Helsinki.

Participants

A total of 35 individuals, 16 with ASD and 19 healthy individuals between the ages of 12-35 years, were included in the study. In 2023, individuals with ASD who attended Private

Düzce Gökkuşuğu Special Education and Rehabilitation Center and Private Kdz. Ereğli Gökkuşuğu Special Education and Rehabilitation Center and their parents participated. Parents with healthy daughters who had menstruation were reached through the social media accounts of the researchers. The control group (healthy individuals) consisted of 19 individuals, since 19 individuals who met the inclusion criteria from healthy individuals and their parents who agreed to participate in the study applied. For the autism group, 16 individuals and their parents who were registered in the centers where the study was conducted and who met the inclusion criteria were included. According to the power analysis, 15 participants were needed for each group to provide 80% power to detect the difference at 0.05 significance level. The inclusion criteria were as follows: (1) having started menstruation (2) being diagnosed with ASD or being a typically developing individual between the ages of 12-35 (3) being level I or level II according to the Gross Motor Function Classification System. Exclusion criteria were being in menopause and lack of involvement in a technology-based and caregiver-supported education model that improves genital and menstrual hygiene behaviours.

Measurement

Demographic characteristics (age, height, weight, body mass index, educational status) were recorded. Medical history of participants were recorded. The assessments were as follows: Level of motor functions with the Gross Motor Function Classification System (GMFCS), pain information and pain intensity experienced during menstruation with the Visual Analog Scale, menstrual symptoms with the Menstruation Symptom Questionnaire (MSQ), genital hygiene behaviours with the Genital Hygiene Behaviour Scale (GHBS). All assessment methods were performed face-to-face with the participants and their parents in a calm, quiet and child-safe room.

Menstruation Status

Information on menstrual status consisted of questions prepared according to similar

studies in the literature. These addressed issues including the following: treatment to delay menstruation, frequency of painful menstruation, regularity of menstruation, frequency of menstruation, duration of menstruation, total number of pads used during the menstrual period, and the product used during menstruation (sanitary napkin, diaper).

Gross Motor Function Classification System

Gross motor function levels of the individuals were evaluated with the GMFCS. The GMFCS is a 5-level system enhanced by Palisano et al.²² used to classify the severity of motor impairment. Level I indicates minimal motor impairment, and Level V, maximum motor impairment. The validity and reliability of the system was conducted by El et al. The reliability coefficient was 0.98 for children under 2 years of age, 0.97 for children aged 2-4 years, 0.94 for children aged 4-6 years, 0.98 for children aged 6-12 years, and 0.97 for children aged 12-18 years. Test-retest reliability was 0.94²³.

Pain

The highest pain intensity experienced during menstruation was measured using a visual analogue scale. Participants were asked to mark the highest intensity of pain experienced during menstruation on a straight line corresponding to 0-10 cm (0 indicates no pain, 10 indicates excruciating pain). For the clarity of the assessment, facial expressions were added below the line (0 smiling face, 10 crying sad face). They were asked which part of the body is painful during menstruation and asked to mark this area on the visualized human body.

Menstruation Symptoms

MSQ was used for evaluation of the participants' menstruation-related symptoms. The MSQ, which has proven reliability and validity, and has been used in studies worldwide, was developed by Chesney and Tasto²⁴ to assess menstrual pain and symptoms. It is a five-point Likert-type scale consisting of 24 items and is widely used worldwide. Participants are asked to assign a

number between 1 (never) and 5 (always) to the menstruation-related symptoms experienced. The scale has three sub-divisions: "Negative Effects/Somatic Complaints", "Menstrual Pain" and "Coping Methods". The score achieved from the subscales is calculated by averaging the total scores of the items in the subscales. The overall score is the average score of all items in the scale. A higher overall score means that menstruation symptoms are more severe. Cronbach's alpha value is 0.92 for the whole MSQ. The Cronbach's alpha coefficients of the sub-dimensions were calculated as 0.90 for the "Negative Effects/Somatic Complaints" sub-dimension, 0.81 for the "Menstrual Pain" sub-dimension and 0.74 for the "Coping Methods" sub-dimension. Test-retest reliability is 0.89²⁵.

Genital Hygiene Behaviour

Genital hygiene behaviours of the participants were evaluated using GHBS, whose validity and reliability have been proven. The GHBS scale consists of 23 items and 3 sub-divisions: general hygiene, menstrual hygiene, and abnormal finding awareness. In the genital hygiene sub-dimension, the questionnaire asks whether she bathes at least once a week, whether her underwear is usually white and made of cotton fabric, whether or not she shares her underwear with others, whether she irons her underwear, whether she changes her underwear every 3-4 days, whether she washes her hands before and after using the toilet, whether she always cleans herself from front and back after using the toilet, whether she dries herself with toilet paper after each visit to the toilet to avoid dampness, and whether she frequently cuts genital hair to prevent it from growing too long. In the menstrual hygiene sub-dimension, the questionnaire asks whether she uses ready-made pads and diapers during menstruation, whether she washes her hands before and after changing pads, whether she changes her pad every 3-4 hours even if not soiled during menstruation, whether she takes regular

showers during menstruation, whether she changes her underwear even if not soiled during menstruation, and whether she changes her pad only when full. Awareness of abnormal findings asks whether she goes to the doctor when she has itching or burning in her sexual area, when she has vaginal discharge with a foul smell and unusual color, and whether she attends to the symptoms of diseases in her sexual area. The scale uses a five-point Likert-type scale and possible scores range between 23 and 115. The level of deal with the items is scored as "completely agree (5), agree (4), undecided (3), disagree (2), completely disagree (1)". The total score in the scale is calculated by summing the scores of all items, and higher scores indicate better genital hygiene. It was developed by Karahan (Karahan, 2017). While the Cronbach's alpha value for the whole scale was 0.80, the alpha value of the general hygiene subdivision was 0.70, the menstrual hygiene subdivision was 0.74 and the abnormal finding awareness subdivision was 0.81 (Karahan, 2017).

Statistical Analysis

Sample size calculation was done by G*Power software²⁷. Comparisons between groups with t tests (one tail) for independent samples, medium effect size ($d=0.95$), 15 participants for each group were needed to provide 80% power to detect difference at 0.05 significance level²⁸. Qualitative data related to descriptive data were given as number (n) and quantitative data were given as arithmetic mean (Mean) and standard deviation (SD) values. The normal distribution of the data in the evaluations was evaluated by Kolmogorov Smirnov test, skewness and kurtosis values and histogram and it was determined that the data showed normal distribution. Chi-square tests were used to determine whether there was a difference in terms of categorical variables. The t test was used to compare two independent groups. The significance level was accepted as $p<0.05$.

RESULTS AND DISCUSSION

Study participants were a total of 35 individuals, including 16 individuals with autism spectrum disorder and 19 individuals with typical development. Demographic characteristics of the participants are shown in Table 1. The mean age of the ASD group was

significantly higher than the control group ($p=0.001$). The mean height of the control group was significantly higher than the ASD group ($p=0.001$).

Pain and menstruation status of the participants are shown in Table 2.

Table 1. Clinical Characteristics of the Participants

Variables	Groups	N	Mean (SD)	p
Age(year)	ASD	16	18.50(6.03)	< 0.001*
	Control	19	14.10(1.44)	
Height(cm)	ASD	16	157.18(11.2)	< 0.001*
	Control	19	162.26(4.34)	
Weight(kg)	ASD	16	53.81(15.46)	0.632
	Control	19	59(15.88)	
BMI(kg/m ²)	ASD	16	21.40(3.72)	0.081
	Control	19	22.33(5.60)	
Age at first menstruation (year)	ASD	16	12.50(2.06)	0.077
	Control	19	11.89(1.28)	
		ASD (n=16)	Control (n=19)	p
Education	Literate	1	0	0.121
	Primary School	3	0	
	Middle School	3	7	
	High School	9	12	
GMFCS	Level 1	13	19	0.143
	Level 2	2	0	
	Level 3	1	0	

* $p<0.05$

ASD: Autism Spectrum Disorder; SD: Standart Deviation; BMI: Body mass index GMFCS: Gross Motor Function Classification System

Table 2. Participants' Pain and Menstruation Status

		ASD (n=16)	Control (n=19)	p
Use of Menstrual Delayers	Yes	1	1	0.900
	No	15	18	
Painful Menstruation Frequency	Every menstrual period	4	7	0.287
	One during menstruation	0	2	
	Sometimes	8	7	
	I don't know frequency	3	1	
Regular Menstruation Status	Yes	13	11	0.173
	No	2	2	
	Usually	1	6	
Menstrual Cycle	Less than 21 days	4	2	0.066
	21-35 days	12	12	
	More than 35 days	0	5	
Bleeding Duration	2-7 days	13	16	0.817
	More than 7 days	3	3	
Number of Pads Used	2-5	1	1	0.503
	5-10	1	4	
	10-15	7	10	
	15-20	6	4	
Product Used During Menstruation	Hygienic Pad	13	17	0.489
	Diapers	3	2	
Menstrual Pain Severity	Mean (SD)	Mean (SD)	Mean (SD)	0.136
	2.4	3.78	3.78	
	(1.99)	(3.11)	(3.11)	

SD: Standart Deviation

The comparison of the total and subscale scores of the Genital Hygiene Behaviour Scale and Menstruation Symptom Questionnaire of the groups is shown in

Table 3 and no significant difference was found between the groups

Table 3. Comparison of the total and subscale scores of the Genital Hygiene Behavior Scale and Menstruation Symptom Questionnaire of the groups

	Groups	N	Mean (SD)	p
MSQ	ASD	16	30.75(11.38)	0.064
Somatic Complaints	Control	19	31.68(7.90)	
MSQ	ASD	16	12.56(6.01)	0.284
Pain Symptoms	Control	19	16.05(7.18)	
MSQ	ASD	16	5.37(3.96)	0.526
Methods of Coping	Control	19	6.36(3.30)	
MSQ	ASD	16	48.68(19.55)	0.312
Total	Control	19	54.10(15.84)	
GHBS	ASD	16	50.56(5.50)	0.581
Hygiene Habits	Control	19	48.89(6.52)	
GHBS	ASD	16	33.68(5.48)	0.692
Menstrual Hygiene	Control	19	32.21(6.25)	
GHBS	ASD	16	11.37(2.36)	0.337
Awareness of Abnormal Findings	Control	19	11.66(2.80)	
GHBS	ASD	16	96.25(10.84)	0.930
Total	Control	19	94.88(10.67)	

MSQ: Menstruation Symptom Questionnaire; GHBS: Genital Hygiene Behaviors Scale

In this study, we investigated menstruation characteristics, pain and genital hygiene behaviours in individuals with autism, and it was determined that individuals with autism and healthy controls had similar genital hygiene and menstrual health behaviours. To the best of our knowledge, this is the first study to investigate both genital hygiene and menstruation characteristics of individuals on the autism spectrum.

In terms of the clinical characteristics of participants, it was found that the age of individuals with ASD was statistically significantly greater. But here was no significant difference between the two groups in terms of genital hygiene behaviours. Normally, hygiene behaviours are expected to improve with increasing age. Studies on menstruation and girls with intellectual disabilities are very limited in the literature. Inadequate hygiene during menstruation is an important cause of urogenital tract infections. Therefore, it is important for young girls to practice necessary health behaviors during menstrual cycles starting from menarche²⁹. The hygiene behaviours of individuals with ASD in this study were similar to healthy controls, possibly because women with ASD bring additional demands and concerns for themselves, their caregivers and their families

during menstruation. Wortalik and Kubina reported that many individuals with ASD and other developmental disabilities are often dependent on others to provide genital and menstrual hygiene, as well as to meet their basic needs¹⁷. Yanık et al. reported that adolescent girls with ASD were mostly unable to fulfill their self-care and hygiene needs and that mothers did not prepare their daughters for puberty. It has also been reported that the most stressful situation for mothers during adolescence is usually the difficulties their daughters experience in using sanitary pads, cleaning armpit and genital hair and bathing³⁰. Adequate and appropriate genital and menstrual hygiene is very important for women. Poor intimate hygiene can have negative health effects, such as bacterial infections, urinary tract infections, cancer, swollen lymph nodes and body odor. Poor genital and personal hygiene can also affect an individual's social life, employment opportunities, sex life and school attendance^{31,32}. In two different studies conducted with adolescents on the autism spectrum and adolescents with moderate/severe intellectual disabilities, it was reported that peer education using a technology-based and caregiver-supported education model improved genital and menstrual hygiene behaviours^{33,34}. In our study, the similarities in genital hygiene

between healthy controls and individuals with ASD, may be due to the their caregivers response.

Menstruation characteristics of individuals with neurodevelopmental disabilities differ in the literature. In a study by Türker et al. comparing adolescents with cerebral palsy and healthy controls, it was reported that the former group had fewer menstrual symptoms and different coping strategies for existing symptoms (such as taking fewer painkillers, not seeing the doctor) ³⁵. In Zacharin et al. study, the menstrual characteristics of adolescents with cerebral palsy and healthy adolescents were similar in terms of pad use, bleeding duration, number of pads used and first menstrual period ³⁶. However, a study conducted by Burke et al. examining menstrual characteristics in adolescents with Down syndrome, cerebral palsy and autism spectrum, reported more frequent menorrhagia, dysmenorrhea, irregular bleeding and hygiene problems. It was also emphasized that psychological changes during menstrual period were more prominent in girls with autism. Kyrkou et al. reported that women with ASD are much more sensitive to body changes, with more than 75% complaining of irritability and mood changes. In addition, they experience more severe menstrual pain than women in the general population ³. In our study, menstrual

somatic complaints, pain characteristics and coping methods of individuals with ASD were statistically similar to healthy controls but were rated clinically lower. Women with ASD may have a reduced ability to identify and score somatic complaints and pain during menstruation. In addition, neither individuals with ASD nor their parents may be able to distinguish between somatic complaints (such as irritability, anger, and depressive symptoms) experienced during menstruation and other times. Individuals with ASD expressed lower pain intensity, and this may have caused them to avoid seeking methods of coping with the difficulties experienced during menstruation, and dramatic changes in their daily emotional states may cause both themselves and their parents to overlook the menstrual somatic complaints ³⁷. The most preferred product for individuals with autism during menstruation is menstrual underwear. This preference is due to its ability to better adapt to the sensory reactivity present in people with autism. Pad manufacturing companies can develop products to better support the comfort, confidence and sensory needs of menstruating people with autism ³⁸. Also, it has been reported that autistic women have characteristics closer to their healthy peers than autistic men. Due to being female, autistic and healthy peers have similar characteristics ³⁶.

CONCLUSION AND RECOMMENDATIONS

Menstrual experiences, menstrual pain and genital hygiene behaviours of individuals with ASD were found to be similar to healthy individuals. With this study, we believe that the awareness of both individuals with ASD and their parents in terms of genital hygiene and menstrual health is inadequate, and therefore, revealing a different result from the literature. Adolescents should acquire effective self-care skills through education. It is very important for healthcare professionals to provide girls with intellectual disabilities with cleanliness habits for menstrual periods and to increase their acceptability in the society. However, the number of studies focusing on this issue is limited ²⁹. More research is needed to understand the impact of

menstrual health and hygiene education programs for adolescents and young women with intellectual and developmental disabilities on self-efficacy and menstrual health-related skill development ³⁹.

Limitation of the study

There are many limitations in this study. Menstrual and genital hygiene behaviors were assessed based on parent reports due to the limited communication skills of individuals with autism. However, the educational status, knowledge, attitudes, and behaviors of parents regarding genital hygiene and menstrual health were not evaluated. Since parents play a key role in managing hygiene routines, especially for individuals with limited

independence, their level of awareness and approach to these topics may directly influence the accuracy of the data. Future studies should consider including parental factors and, when possible, use additional methods such as direct observation or structured interviews to obtain more comprehensive and objective data. Depending on the region where the study was conducted, it may be thought that mothers could not inform their daughters about menstruation due to cultural characteristics and religious beliefs. This is because menstruation is a frightening, worrying or embarrassing event in some societies. There are similar attitudes towards menstruation in the Turkish society where this study was conducted. Descriptions such as 'getting sick' or 'getting dirty' are used for menstruation among women⁴⁰. Also, since the incidence of autistic women is quite low, it seems that finding the sample will take time. This study is a preliminary study, and the results will be presented again with a larger sample.

Conflict of Interest

The authors have no conflict of interest.

Authors' contributions

All authors have read and approved the published version of the article.

S.A.T; Idea/concept, design, consultancy, data collection, data processing, analysis and/or interpretation, literature review, writing of the article, critical review. **S.Y.Y;** design, consultancy, data Processing, analysis and/or interpretation, literature review, writing of the article, critical review. **Z.M;** design, consultancy, data collection, data processing, analysis and/or interpretation, literature review, writing of the article, critical review. **E.M;** design, consultancy, data collection, data processing, analysis and/or interpretation, literature review, writing of the article, critical review. **S.Y;** design, consultancy, data collection, data processing, analysis and/or interpretation, literature review, writing of the article, critical review

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