

Are the Menstrual Characteristics Similar in Adolescent and Adult Women with Cerebral Palsy?

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ABSTRACT

OBJECTIVES: This study aimed to compare the menstrual-health characteristics of adult and adolescent women with cerebral palsy.

STUDY DESIGN: This cross-sectional study included 74 women who were diagnosed with cerebral palsy. Among 74 women with cerebral palsy, women between the ages of 10-18 formed the adolescent cerebral palsy group (n= 36), and women between the ages of 19-30 formed the adult cerebral palsy group (n=38). Gross motor function levels of women with cerebral palsy were determined by gross motor function classification system expanded and revised. Menstrual-health characteristics were evaluated with a self-report questionnaire.

RESULTS: The median age in the adult cerebral palsy group (23.5 (19-29) years)) was higher than the adolescent cerebral palsy group (16.5 (11-18) years)) ($p<0.001$). The median age of menarche in the adult cerebral palsy group (14 (7-18) years) was higher than in the adolescent cerebral palsy group (13 (9-17) years)) ($p=0.017$). The presence of dysmenorrhea in the adolescent cerebral palsy group (35 women with dysmenorrhea) was more common than in the adult group (30 women with dysmenorrhea ($p=0.016$)). The menstrual suppression treatment, length of menstruation, pain onset time, pain duration, pain medicine usage during menstruation, the highest intensity of pain experienced during the menstrual period, number of drugs, use of pain relief methods, number of days absent from school or work, type and the number of menstruation products, presence and the reason of discomfort scores of questions and gross motor function classification system expanded and revised levels were similar in both groups ($p>0.05$).

CONCLUSION: Dysmenorrhea was more prevalent in adolescent women with cerebral palsy than in adults with cerebral palsy. Providing training that raises awareness and behavior-changing education for women with cerebral palsy and their caregivers can help to improve gynecological health.

Keywords: Adolescent, Adult, Cerebral palsy, Menstrual hygiene, Menstruation

Gynecol Obstet Reprod Med 2023;29(1):36-42

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Submitted for Publication: 07.03.2022 Revised for Publication: 16.03.2022

Accepted for Publication: 28.08.2022 Online Published: 13.09.2022

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Quick Response Code:	Access this article online
	Website: www.gorm.com.tr
	e-mail: info@gorm.com.tr
	DOI:10.21613/GORM.2022.1301

Introduction

Cerebral palsy (CP) is a group of persistent mobility and posture abnormalities that limit a person's activities due to problems occurring in the developing fetus or newborn brain. Motor disorders in CP are often accompanied by sensory, perceptual, cognitive, communication, and behavioral disorders, epilepsy, and secondary musculoskeletal problems (1-4). Women with CP may encounter various problems related to their gynecological functions as well as physical limitations (5,6).

Individuals with CP are known to live until adulthood and have a long lifespan. As a result, it's crucial to comprehend their menstruation experiences and demands. (6). The onset of menstruation can cause difficulties due to privacy issues and

How to cite this article: Dogan H. Turker D. Coban O. Basol Goksuluk MB. Ozengin N. Un Yildirim N. Are the Menstrual Characteristics Similar in Adolescent and Adult Women with Cerebral Palsy? *Gynecol Obstet Reprod Med.* 2023;29(1):36-42



parents need to manage the individual's self-care. Making decisions about treatment approaches, especially about reproductive health, can lead to several ethical and legal issues related to families (7). In addition, women with CP in low and middle-income societies state that they experience difficulties during menstruation due to social and cultural reasons. A lack of and/or inaccurate awareness about menstrual physiology and genital hygiene may lead to inadequate management of menstrual health such as causing genital infections (6).

Individuals with CP may have physical and mental differences during adulthood and adolescence (8). However, there is a lack of evidence regarding how women with CP at different developmental stages go through this gynecological process (9). Determining the differences in the menstrual characteristics of adult and adolescent women with CP will inform people who care for individual genital hygiene and implement physical health practices (9,10). Therefore, this study was planned to compare the menstrual characteristics of adult and adolescent women with CP.

Material and Method

This cross-sectional study was carried out with literate women aged 10-30, diagnosed with CP, had no mental problems, had menstruation at least once, classified as level I-II-III in Gross Motor Function Classification System-Expanded and Revised (GMFCS-ER), and volunteered to participate. Between August 2021 and January 2022, 74 women with CP participated in the study. Among the participants, women between the ages of 10-18 formed the adolescent CP group (n=36), and women between the ages of 19-30 formed the adult CP group (n=38).

The study design was approved by the ethics committee of Bolu Abant Izzet Baysal University (Approval number: 2021/19). Before the evaluations, the participants had read and signed a permission form that was also approved by the ethics committee. The study was carried out in accordance with the Helsinki Declaration. The protocol for the research was also submitted to <http://clinicaltrials.gov> (NCT04985045). Those who were pregnant had a history of acute genital infection and a history of gynecological surgery were not included in the study.

Socio-demographic characteristics and physical characteristics (age, body weight, height) of the participants were recorded. Body Mass Index (BMI) was calculated by dividing the women's body weight (kg) by the square of the height (m). The gross motor function levels of individuals with CP were determined by "GMFCS-ER" (5). GMFCS-ER is a five-level evidence-based tool that measures the gross motor function of children with CP. The gross motor functions that are emphasized in GMFCS-ER are sitting, walking, and wheelchair mobility. The level of motor impairment was classified according to the GMFCS-ER. GMFCS-ER ranks motor impairment with

GMFCS-ER I/II reflecting gross motor independence, and GMFCS-ER III reflecting the use of assistive walking devices (5) (Table I).

Table I: Gross motor function classification system-ER

LEVEL 1	Walks without limitations
LEVEL 2	Walks with limitations
LEVEL 3	Walks using a hand-held mobility device
LEVEL 4	Self-mobility with limitations; may use powered mobility
LEVEL 5	Transported in a manual wheelchair

A self-report questionnaire based on the relevant literature was used to assess information regarding the menstrual status of adolescent and adult women with CP. Items from valid questionnaires used in other research on menstruation disorders were utilized to construct the questionnaire (7,11-13). These items investigated the use of menstrual suppression treatment, age of menarche, presence of dysmenorrhea, length of menstruation, number of pads used on the heaviest day of menstruation, the total number of pads, pain onset time, pain duration, pain medicine during menstruation, number of drugs, use of pain relief methods, absence from school or work, number of days absent from school, whether they got treatment. In addition, the type of menstruation products (sanitary pad, piece of clothing, cotton, diapers), presence of discomfort, and the reason for discomfort (redness, itching, fungus, infection, none) were also asked.

The highest pain intensity experienced by the women during menstruation was determined using the visual analogue scale. Women were asked to determine the highest pain intensity experienced during menstruation on a straight line from 0 to 10 cm where 0 indicates no pain and 10 indicates unbearable pain (14). According to the severity of the pain, pain intensity higher than 1 indicates dysmenorrhea in these women. Pain severity was between 0 and 1 according to the visual analogue scale and was defined as those who had no symptoms (without dysmenorrhea) and those with a pain severity score between 2-10 with dysmenorrhea (15).

Statistical Analysis

Statistical analyses were performed using SPSS statistical software (version 21.0; SPSS Inc., Chicago, IL, USA). For descriptive statistics, mean and standard deviation or median and minimum-maximum values are used for numerical variables, and number and percentage values are given for categorical variables. Test (Shapiro Wilk test) and graphical (histogram, QQ plot, etc.) methods were used for normal distribution analysis. To evaluate whether there is a difference between the two groups in terms of numerical measurements, a t-test or Mann-Whitney u test was used in independent groups. Chi-square tests were used to examine whether there was a difference in terms of categorical variables. The significance level was taken as $p < 0.05$.

Results

The flow diagram of participants in the study is presented in figure 1. A comparison of demographic and menstruation characteristics of adolescent and adult CP groups is shown in table II. The median age of adolescent CP groups was 16.5 (11-18) years and adult CP groups were 23.5 (19-29) years. The median age of the adult CP group was higher than the adolescent group ($p>0.05$). The age of menarche was significantly higher in the adult CP group (14 (7-18) years) than in the adolescent group (13 (9-17) years) ($p=0.017$). Median values of BMI, use of menstrual suppression treatment, length of menstruation, number of pads used on the heaviest day of menstruation, the total number of pads, pain onset time, pain duration, pain medicine during menstruation, number of drugs, use of pain relief methods, absence from school or work, number of days absent from school, whether they got treatment scores of questions were similar ($p>0.05$). In addition, type of menstruation products (sanitary pad, piece of clothing, cotton, diapers), presence of discomfort, discomfort reasons during menstruation (redness, itching, fungus, infection, none) scores of questions, GMFCS-ER levels, and the highest mean pain severity score during menstruation scores were similar ($p>0.05$). Furthermore, dysmenorrhea was observed to be more common in the adolescent CP group (35 participants (97.3%)) than in the adult group (30 participants (%78.9)) ($p=0.016$).

Discussion

In this study, menstruation-related characteristics of women with CP in different age groups were compared. All menstrual-specific characteristics were similar in both groups, except for the presence of dysmenorrhea. To our knowledge, this is the first study evaluating menstruation in individuals with CP using self-reported methods.

In Turkish society, menstruation can be described as 'to get dirty or 'to become sick. Topics of menarche or menstruation may be difficult to discuss freely and comfortably in the family (16). In a meta-analysis published in 2019, it was reported that there is limited evidence about the menstrual status and hygiene needs of individuals with mental or physical disabilities, and disability rights and sociality can be neglected by ignoring this part of life (17). Studies on menstrual health in the CP population were mostly focused on the thoughts and experiences of caregivers (17-20). Therefore, studies investigating the menstruation characteristics of women with CP who have good GMFCS-ER levels and can communicate are very limited. The reason for the limited evidence regarding menstrual health in disabilities group may be due to a lack of understanding of gynecological issues in women with CP.

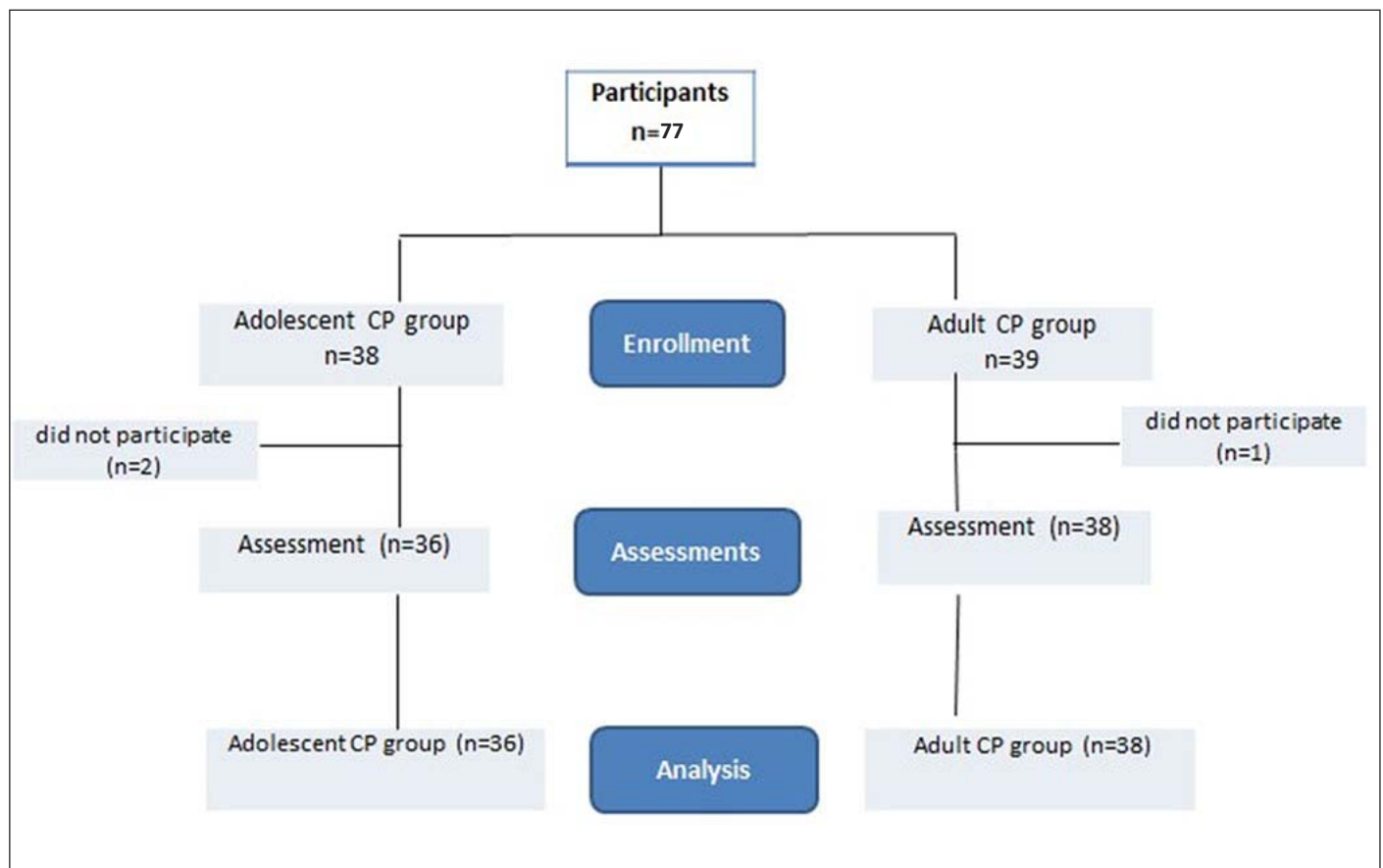


Figure 1: Flow Chart

Table II. Demographic and menstruation characteristics of the groups

Features	Groups		
	Adolescent (n=36)	Adult (n=38)	<i>p</i>
Age (years)	16.5 (11-18)	23.5 (19-29)	<0.001*
BMI (kg/m ²)	20.2 (14.8-32.9)	20.1 (13.7-35.7)	0.052
Menstrual Suppression	Yes	5 (13.9)	0.103
	No	31 (86.1)	
Age of Menarche (years)	13 (9-17)	14 (7-18)	0.017*
Length of menstruation	< 2 days	1 (2.8)	0.576
	2-7 days	31 (86.1)	
	> 7 days	4 (11.1)	
Number of pads used on the heaviest day of menstruation	1-3 days	9 (25.7)	0.102
	4-6 days	25 (25.0)	
	7-10 days	1 (2.9)	
Total number of pads	15 (5-49)	15 (7-42)	0.412
Pain onset time	A week before menstruation	7 (25.0)	0.328
	1-3 days before menstruation	20 (71.4)	
	First day of menstruation	1 (3.6)	
Pain duration	< 48 hours	14 (50.0)	0.598
	48-72 hours	11 (39.3)	
	> 72 hours	3 (10.7)	
Pain medicine during menstruation	Yes	11 (32.4)	0.804
	No	23 (67.6)	
Number of drugs	1 (1-2)	1 (1-2)	0.910
Pain relief methods status	Yes	21 (60.0)	0.320
	No	14 (40.0)	
Absence from school or work	Yes	14 (46.7)	0.855
	No	16 (53.3)	
Number of days absent from school (days)	1 (1-3)	2 (1-3)	0.309
Have you received any treatment related to menstruation?	Yes	2 (5.7)	0.226
	No	33 (94.3)	
Type of menstruation products	Pad	32 (88.9)	0.209
	Diaper	4 (11.1)	
State of discomfort	Yes	25 (69.4)	0.419
	No	11 (30.6)	
Discomfort reason during menstruation	Redness	2 (18.2)	1.000
	Itching	10 (90.9)	
GMFCS-ER	1	19 (52.8)	0.818
	2	9 (25.0)	
	3	8 (22.2)	
The highest intensity of pain experienced during the menstrual period	5 (0-10)	5 (0-8)	0.245
Status of Dysmenorrhea	No	1 (2.7)	0.016*
	Yes	35 (97.3)	

CP: Cerebral Palsy, BMI: Body-mass-index, GMFCS: Gross Motor Function Classification System-Expanded Revised. Median (minimum-maximum) and number (percentage) values are given for descriptive statistics. **p*<0.05 is statistically significant.

Physical limitations during menstruation which decrease the quality of life of women with CPs may cause additional concerns for families both in terms of home and school life and other contexts. Women may be unable to attend school due to

hygiene issues and menstrual symptoms (premenstrual symptoms, dysmenorrhea, heavy or irregular bleeding) (20). Approximately 47.6% of all women with CP who participated in our study were absent from school or work, and absenteeism

was similar in adolescent and adult CP. The similarity of absenteeism between groups. During menstruation may show that the neglect of people on this issue continues in older ages.

In a study examining menstruation problems in women with CP, it was stated that these women often experience symptoms of vaginal infection (7). In our study, it was found that women experience problems such as itching and redness. This demonstrates that women with CP lack genital hygiene awareness and require training and help (21). In addition, women frequently used pads in terms of managing menstrual hygiene, and there was no difference in product type preference between the groups. This may show that women with CP prefer ergonomic methods in which they can move physically more comfortably during menstruation, starting from adolescence age. However, it was found that eight people were using diapers. This might imply that some women with CP are concerned about other gynecological issues (i.e. incontinence) and wished to take measures.

There are studies showed that women with menarche age 13 and younger have a higher incidence of dysmenorrhea (22). Consistent with this study, our study showed that the mean age of menarche was lower and the presence of dysmenorrhea was more common in adolescents with CP. The age of the first menarche may also be an important parameter for the presence of dysmenorrhea in women with CP.

Multiple pain etiologies have been shown to be the source of pain in the population of CP (23). In our study, the duration, onset, and severity of pain experienced during menstruation were similar in both groups. The similarity of the pain may indicate that the lack of awareness about pain control may continue in different developmental periods. Although the severity of pain during menstruation (mean value 5 in both groups) was at moderate levels in women with CP, the rate of consulting a doctor and the use of painkillers were quite low. This may indicate that the problems experienced are generally ignored and that new strategies should be planned for effective pain control. More than 70% of young women with CP are thought to suffer from dysmenorrhea. It's unclear whether women with CP can express their menstrual-related feelings. (6). Although the mean of the highest pain intensity experienced by both groups in the last 3 months was similar, the incidence of dysmenorrhea in adolescent CP was higher. The higher incidence of dysmenorrhea in the adolescent group may be due to the fact that primary dysmenorrhea (PD) is more common in adolescent girls. This supports studies stating that the incidence of PD in adolescent women varies between 60% and 90%, and PD decreases with age (24). In addition, several studies have shown a significant association between the age of early menarche and dysmenorrhea. In its etiology, it has been hypothesized that longer exposure to uterine prostaglandins in girls with early menarche may result in an increased prevalence of dysmenorrhea (25,26).

Our study had some limitations. First, adults were considered in a single category in the study. However, a recent classification revealed that adults can also be classified as young adults and adults. Second, the findings of this study were based only on individual interviews in a cross-sectional sample of participants. Asking these questions to caregivers requires more time and budget, and these methods are not as practical as inquiry or scale approaches in multi-factor studies. In addition, long-term study protocols can reduce the adaptability of individuals and therefore the strength of the study. In addition, we did not evaluate the intelligence and perception levels of women with CP. We recommend that these issues be carefully examined in future studies.

Among the strengths of this study is the use of a detailed questionnaire based on the other studies to explore a very specific topic with people who may never have talked to another person about menstruation. Another strength was the inclusion of the physically disabled person, not the caregiver. In general, the social perception was that disabled people could not express their experiences regarding menstrual health, and it should be known only to the extent that the caregivers could tell. This study can help women with CP to understand and deal with the changes that can occur during adolescence and adulthood. This study shows that women with CP have similar experiences with menstruation in different age groups.

In conclusion, this study motivates to challenge the discourse of silence on menstruation for disabled people in Türkiye and to consider the needs of women with CP. Most importantly, this study aimed to increase knowledge and awareness of the reproductive health needs of young women with CP who cannot easily express their own experiences and concerns. It seems extremely necessary to provide these women with comprehensive education and appropriate guidance to gain knowledge and skills in coping with pain. In addition, future studies are needed to explore low-cost and culturally acceptable strategies to reduce menstrual pain in women with CP. Furthermore, women with CP in different age groups can be evaluated and compared on the topic of menstruation with more objective measurement tools.

Declarations

Ethics approval and consent to participate: All participants signed informed written consent before being enrolled in the study. The study design was approved by the ethics committee of Bolu Abant İzzet Baysal University (Ethics approval reference number: 2021/191 date 13.07.2021). All procedures were performed according to the Declaration of Helsinki. The protocol for the research was also submitted to <http://clinicaltrials.gov> (NCT04985045).

Availability of data and materials: The data supporting this study is available through the corresponding author upon reasonable request.

Competing interests: The authors declare that they have no competing interests.

Funding: None.

Authors' contributions: Conception and design: HD, DT, OC, NO; data collection: HD, DT, OC; analysis and result interpretation of data: HD; drafting of the manuscript: HD; critical revision of the manuscript for important intellectual content: NUY, NO; statistical analysis: MGB, HD. All authors read and approved the final manuscript.

Acknowledgments: None

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