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Hormonal Contraceptive Prescription in Young Women With Cerebral Palsy

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A B S T R A C T

Purpose: The purpose of the study was to describe the prevalence and patterns of prescription of hormonal contraceptive medications to young women with cerebral palsy (CP) and determine if CP topography or ambulatory status was associated with the type of contraceptive prescribed.
Methods: Data were extracted by manual chart review for women with CP between the ages of 15 and 25 years who were seen at a tertiary pediatric hospital and a rehabilitation hospital between the years of 2011 and 2013. CP topography was defined as the number and pattern of limbs affected (hemiplegia, diplegia, triplegia, or quadriplegia), and ambulatory status was defined as whether a wheelchair was used for community mobility. Logistic regression analysis was used to assess associations between patient age, CP topography, ambulatory status, and contraceptive prescription.
Results: Data were collected for 483 women with CP with an average age of 19 years (standard deviation: 3 years). One hundred thirty-one patients (27%) were prescribed hormonal contraceptives. Estrogen–progestin combined oral contraceptives were most frequently prescribed (73%). Prescription of hormonal contraceptives was not associated with CP topography ($p = .95$) or ambulatory status ($p = .44$); however, older subjects were more likely to be prescribed hormonal contraceptives ($p = .01$). There was no association detected between CP topography and contraceptive composition ($p = .09$) or between ambulatory status and contraceptive composition ($p = .06$). There was also no association detected between CP topography ($p = .18$) or ambulatory status ($p = .09$) and depot medroxyprogesterone acetate prescription.
Conclusion: Ambulatory status and CP topography were not associated with the types of hormonal contraceptives prescribed in this cohort.

IMPLICATIONS AND CONTRIBUTION

The results of this study indicate that the special healthcare needs unique to women with cerebral palsy may not be taken into account when prescribing hormonal contraception. Further research needs to determine the combined effect of immobility and hormonal contraception on thromboembolism risk and bone density in this population to direct provider education and practice guidelines.

There is a growing need to understand and address women's health in the cerebral palsy (CP) population as more and more women with CP are surviving into adulthood. [1,2]. CP is a congenital physical disability characterized by problems with movement; about half of affected individuals also have some degree of intellectual disability. In women with CP, menstruation poses particular challenges and affects the quality of life of patients and their caregivers [3]. Hormonal contraceptive use can

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be an effective way to manage these challenges. However, there are unique considerations which must be taken into account when prescribing hormonal contraceptives to young women with CP. It is important to note that the term "hormonal contraceptives" should not be taken to imply that these medications are used solely for pregnancy prevention because they are often used for menstrual management by many women.

The onset of menstruation in women with CP can present challenges with hygiene, discomfort, and need for pregnancy prevention [4]. In more severely affected women who are dependent on others for care, menstrual hygiene can require an increased need for transfers and changing which is a frequent concern reported by families. These families also report worries regarding how women with behavioral issues will cope with the hygiene requirements, including pad usage [5]. Discomfort related to menstruation can also be difficult to interpret for families of women with communication impairments [6]. Pain related to menstruation can also worsen tone, potentially resulting in functional impairments. Menstruation onset also raises issues related to pregnancy prevention. Studies of adolescents with CP demonstrate that they have similar sexual interests as age-matched peers, and that sexual activity increases with the transition from late adolescence to young adulthood [7,8]. However, there is the concern that sexual activity and interest are not recognized by parents and providers, and that adolescents with CP are not receiving appropriate education [9]. Unfortunately, there are also high rates of sexual abuse reported in women with disabilities [10]. These challenges highlight the need to provide individualized, patient-focused care in women with CP to address these concerns.

Hormonal contraceptives can address the issues of hygiene, discomfort, and pregnancy prevention; however, women with CP have special health needs that should be considered on prescription. These include ambulatory status, bone mineral density (BMD), manual dexterity, and patient cooperation. Most women with CP have mobility-related impairments. Some contraceptive formulations, especially Depot Medroxyprogesterone Acetate (DMPA) injections, can lead to increased weight gain. This can negatively affect ambulation and transfers. Progestin-only formulations are associated with irregular bleeding patterns, especially in the first months of use, which can complicate hygiene by their lack of predictability. Estrogen-containing preparations, including the estrogen–progestin combined oral contraceptives (COCs), the vaginal ring, and the combined contraceptive patch, offer more predictable bleeding patterns. However, they are associated with an increased risk of venous thromboembolism (VTE) [11], which is of particular concern in a population with chronically impaired mobility, which is also a risk for VTE. Individuals with CP are also at risk for low BMD and associated osteoporosis and fragility fractures [12]. Other risk factors for decreased BMD in women with CP include decreased weight bearing, inadequate calcium and vitamin D intake, and frequent exposure to medications, particularly anticonvulsants, that negatively affect BMD [13]. DMPA injections have been showed to negatively impact acquisition of BMD in studies of healthy adolescent girls [14,15], resulting in a black box warning from the Food and Drug Administration. Manual dexterity can also be compromised in young women with CP, leading to difficulty with placement of the combined contraceptive patch and vaginal ring as well as privacy concerns for those who need help from others to place them. Finally, CP can be associated with intellectual disability and behavioral issues, which can limit patient cooperation with insertion of the levonorgestrel intrauterine device (LNG-IUD) or progestin implant. Placement may need to occur under general anesthesia, which could have increased risks in this population [16].

Despite the importance of hormonal contraceptive use to improve quality of life for women with CP and the complexities associated with prescription, there are few studies that characterize prevalence or patterns of prescription in this population and how they compare to the non-CP population. A small study of 79 women with CP in Australia revealed that 22% (18/79) used a form of hormonal contraception, with 12 women using oral contraceptives, one using DMPA, and five using the LNG-IUD [6]. In a study of 300 adolescents with disabilities at gynecologic clinic in Canada, COCs were the most common method of hormonal contraception prescribed (42.3%), followed by the patch (20%), expectant management (14.9%), DMPA (11.6%), and IUDs (7.8%) [17]. The purpose of this study was to describe the prevalence and patterns of prescription of hormonal contraceptives women with CP at two healthcare centers in New England and determine if CP topography (defined as pattern and number of limbs affected) or ambulatory status (defined by need for a wheelchair for community mobility) was associated with the type of contraceptive prescribed to guide areas of future research and provider education.

Methods

All study procedures were approved by the Institutional Review Board of each hospital. Inclusion criteria were young women (aged 15–25 years with a billing diagnosis of CP seen at a tertiary pediatric hospital and a rehabilitation hospital from 2011 to 2013). This cohort was identified by querying billing records for *International Classification of Diseases, Ninth Revision, Clinical Modification* (*ICD-9-CM*) and *International Classification of Diseases, Tenth Revision, Clinical Modification* (*ICD-10-CM*) diagnosis codes for CP (ICD-9-CM: 342.0, 342.9, 343.0, 333.71, 343.8, 343.9; ICD-10-CM: G80.0-4, G80.8-9). CP topography was categorized into hemiplegia (paralysis affecting one side of the body, right vs. left), diplegia (paralysis of both legs), triplegia (paralysis of both legs and one arm), and quadriplegia (paralysis of all four limbs). Patients were considered ambulatory if they did not need a wheelchair for community mobility. Patient data were extracted via manual chart review of problem lists, physician notes, and physical therapy progress notes to determine CP topography and mobility status. Medication lists and electronic linkage to the patient's external pharmacy prescriptions, when possible, were used to obtain documentation of contraceptive prescription and composition.

Hormonal contraceptive prescription was subdivided into the categories of estrogen-containing preparations, which included COC's, the vaginal ring, and the patch, and progestin-only preparations, which included progestin-only pills (POPs), DMPA injections, the contraceptive implant, and the LNG-IUD. COCs were further classified as extended cycle if they were formulated in an 84/7 schedule or included directions to be used continuously as extended cycle. Frequency of screening for *Chlamydia trachomatis* was used to assess for testing of sexually transmitted infections. Annual screening of sexually active women aged younger than 25 years is recommended by the United States Preventive Services Task Force [18] and is used as a performance measure in the Health Effectiveness Data and Information Set for

the National Committee for Quality Assurance, both for private insurance companies and Medicaid [19]. Only patients from the pediatric hospital were queried as chlamydia screening data were not available from the rehabilitation hospital cohort. Patients not meeting criteria for the diagnosis of CP or those for whom CP topography or ambulatory status could not be adequately defined were excluded from the database.

Statistical methods

Patient characteristics were summarized for all patients by frequency and percent or mean and standard deviation, as appropriate. The prevalence of contraceptive prescription in the CP population was estimated along with a 95% confidence interval. Comparisons in patient age, CP topography, and ambulatory status were analyzed using Student's *t*-test and chi-square test, as appropriate. Associations between patient age, CP topography, and ambulatory status and the odds of contraceptive prescription were analyzed using logistic regression. Odds ratios along with 95% confidence intervals were estimated for significant effects. All tests were two-sided, and *p*-values less than .05 were considered significant.

Results

Cohort characteristics

Five hundred eleven female patients with CP between the ages of 15 and 25 years were identified. Of these 28 were removed, as CP topography could not be confirmed. The remaining 483 patients were analyzed at an average age of 18.8 years (±3.0 years). Half of the cohort was quadriplegic (50%, 240/483) whereas 27% (129/483) was hemiplegic, and the remaining 23% (113/483) were diplegic, and one subject (.2%) triplegic. Fifty percent (242/483) of the cohort was ambulatory (Table 1).

Table 1
Patient and contraceptive characteristics (N = 483)

Characteristic	Frequency (%)
Age (y; mean ± SD)	18.8 ± 3.01
Topography	
Hemiplegia	129 (27)
Diplegia	113 (23)
Triplegia	1 (.2)
Quadriplegia	240 (50)
Ambulation	
Ambulatory	242 (50)
Non-ambulatory	240 (50)
Hormonal contraceptive	131 (27)
Composition (N = 119)[a]	
Estrogen-containing	87 (73)
Combined oral contraceptives	86 (72)
28-d cycle	75 (87)
Extended cycle	11 (13)
Patch	1 (1)
Progestin-only	32 (27)
Progestin only pill	22 (69)
DMPA injection	9 (28)
Progestin implant	1 (3)
Composition unknown (N = 12)[a]	
Oral contraceptives	11 (92)
Unknown contraceptive	1 (8)

DMPA = depot medroxyprogesterone acetate; SD = standard deviation.
[a] Hormone composition was unknown in 12 subjects.

All contraceptives

One hundred thirty-one (27%) patients were prescribed some form of hormonal contraceptive. Of these, 66% were prescribed COCs, 18% were prescribed POPs, 7% were prescribed DMPA, and .1% were prescribed either LNG-IUD, vaginal ring, or the patch (Table 1). There were no differences detected across subjects who were prescribed hormonal contraceptives and those who were not with respect to topography ($p = .95$) or ambulation status ($p = .44$); however, subjects who were prescribed contraceptives were 8 months older on average ($p = .01$). Moreover, for each additional year of age, the odds of hormonal contraceptive prescription increased by 8% (OR = 1.08; 95% CI = 1.01–1.15; $p = .01$).

Estrogen-containing preparations

Of the 119 patients for whom data were available regarding hormonal contraceptive composition, 73% (87/119) were prescribed COCs, and 1% (1/119) was prescribed a combined estrogen-progestin patch (Table 1). Of those prescribed COCs, 13% (11/86) were prescribed extended-cycle COCs.

Progestin-only preparations

Twenty-seven percent (32/119) of the patients were prescribed progestin-only preparations. Of these, 72% (23/32) were prescribed POPs, 28% (9/32) were prescribed DMPA, and 3% (1/32) were prescribed a progestin implant (Table 1).

Ambulatory status and topography

There was no association detected between CP topography and contraceptive composition ($p = .09$) or between ambulatory status and contraceptive composition ($p = .06$; Table 2). There was also no association detected between topography ($p = .18$) or ambulatory status ($p = .09$) and DMPA prescription.

Sexually transmitted infection screening

Of the 442 patients from the children's hospital, 8% (n = 34) were screened for *Chlamydia trachomatis*.

Site characteristics

Most subjects (91%) were analyzed from the children's hospital, and the remainder from the rehabilitation hospital. In a side-by-side comparison, there were minimal differences in the subject samples across sites. The rehabilitation hospital had a slightly higher average age and a higher proportion of quadriplegia, although these differences were not found to be significant. There was a higher proportion of nonambulatory subjects at site 2 ($p = .02$). There was no difference detected in the hormonal contraceptive prescribing across sites. There was no effect on any hypothesis test or effect estimate when using site as a covariate.

Discussion

This is the largest study to date to describe the prescription patterns of hormonal contraceptives for young women with CP. It demonstrates that women with CP were prescribed

Table 2
Comparisons by estrogen-containing contraceptive (N = 147)

Characteristic	Estrogen-containing hormonal contraception (n = 105)	Progestin-only hormonal contraception (n = 42)	*p*
	Frequency (%)	Frequency (%)	
Age (y; mean ± SD)	21.5 ± 6.26	21.8 ± 5.68	.36
Topography			
Hemiplegia	27 (26)	12 (29)	.50
Diplegia	32 (31)	5 (12)	
Quadriplegia	46 (44)	25 (60)	
Ambulation			
Ambulatory	54 (51)	15 (36)	.25
Nonambulatory	51 (49)	27 (64)	

SD = standard deviation.

contraceptives at a rate of 27%, were most frequently prescribed 28-day cycle COCs, and that the composition of the hormonal menstrual management was not associated with degree of disability or ambulatory status. The results of this study suggest that practitioners may not be considering the special healthcare needs of women with CP when prescribing hormonal contraceptives. This has implications for the function and quality of life of these women and offers areas of further research to inform practice improvement and guidelines.

Hygiene and the care burden associated with menstruation is a great concern for women with CP and their families [3]. This study's finding that 28-day COCs were most frequently prescribed to women with CP is consistent with the literature [6,17]. However, prescription of extended-cycle COCs, in which hormones are prescribed for 84 days followed by 7 days of placebo, is an opportunity for practice improvement as they reduce the frequency of menstruation but have equal efficacy [18].

The risk that the use of estrogen poses to overall VTE risk in this population is unclear but potentially worrisome. Estrogen-containing pills increase the risk of VTE, and risk factors are additive [11]. The CP population is theoretically at an increased risk for VTE, given their limited mobility, and many patients with hemiplegic CP have presumably already experienced an embolic event (such as in utero stroke, which results in the characteristic distribution of paralysis). However, few reports of VTE in the CP population exist in the literature. This could be because muscle spasticity found in many patients with CP prevents venous stasis and reduces VTE formation. However, in the multiple sclerosis (MS) population, where muscle spasticity is also frequently present, women with prolonged immobility are not recommended to use COCs because of the inferred VTE risk [20]. Although CP is unique from MS in that it is a congenital and not an acquired diagnosis and the risk for clot formation may differ between these two populations, further research needs to be done to determine if the same guidelines for the MS population should be applied to the CP population.

Low BMD is a common health concern reported in the CP population. By age 10 years, greater than 95% of nonambulatory children with CP demonstrated evidence of osteoporosis [21], and the annual fracture rate is 5% [22] twice that of typically developing children [23]. The use of DMPA injections in women with CP, regardless of ambulatory status, is a concern. DMPA injections may have a negative effect on BMD [14,15] and can theoretically increase the risk for fractures in this population with long-term use, particularly for women who are nonambulatory. Fractures have negative consequences on function and quality of life as they lead to pain, further reduce mobility and independence, and increase caregiver burden [24]. The impact of DMPA on BMD and fracture risk in women with CP is an area for further investigation.

Weight gain associated with progestin-only formulations can also have negative impacts on function. In ambulatory individuals with CP, even small changes in body mass can result in decreased walking speed and increased energy consumption [25]. In nonambulatory women, weight gain can cause transfers to be more difficult for caregivers.

It is interesting to note that the prevalence of hormonal contraceptive prescription in this cohort is actually higher than in a Center for Disease Control survey of contraceptive use in women ages 15–44 years where prevalence was reported at 17% [26]. A possible explanation is that this study captured the indications of dysmenorrhea and hygiene in addition to pregnancy prevention. It may also further reflect the increased burden that menstruation places on women with CP. Interestingly, although prescription of hormonal contraceptives was higher to women with CP, the rate of chlamydia screening was lower. In a nationwide HEDIS study, the estimated rate of chlamydia testing was 43.1% [19]. In our study, it was only 8%, although this likely underestimates the rate of chlamydia screening as data were collected from a tertiary hospital and patients screened at their primary care provider or gynecologist might not have been captured. However, this rate is still significantly lower than the national average. Studies of adolescents with CP demonstrate rates of sexual activity between 20% and 37% [7,8]. The low rate of chlamydia screening in light of this suggests that providers may not be recognizing that in addition to management of hygiene and dysmenorrhea, some women with CP are also using hormonal contraceptives for pregnancy prevention. Adults with CP frequently report that maintaining sexual relationships is important to their quality of life [27], and it is important for providers to facilitate this by providing adequate education and preventive care.

The low rate of IUD use found in this study is a potential area for practice improvement as it is more effective than other methods for pregnancy prevention, lasts much longer, and can bring about amenorrhea in many patients. This study's data may not accurately reflect the true rate of IUD use due to underreporting on the medication list by healthcare providers such as rehabilitation specialists, and the fact that outside pharmacy records could not document use.

Although this study provides an important contribution to the literature regarding hormonal contraceptive prescription patterns in women with CP, it is not without limitations. It would have been helpful to have more information available about the women in the study, whether they had intellectual disability, and the reasons why they or their caregivers were choosing to use hormonal contraceptives—that is, for menstrual management or pregnancy prevention, but this information was not readily available in records of rehabilitation visits. This study relied on a retrospective chart review and medication lists, which might not accurately reflect true rates of contraceptive use, as some patients may not have disclosed use of contraceptives prescribed by other physicians (such as gynecologists or primary care physicians outside these tertiary care facilities). To limit these inaccuracies, medication lists were confirmed with the patient's pharmacy. This study also only collected data from two tertiary care providers. It is possible that women seen at these centers

would be more likely to be using hormonal contraceptives, given greater interaction with the healthcare system. Regional differences in prescription rates could also not be accounted for in this study as both institutions were in the same geographic area. The rates of chlamydia screening were likely underestimated as data were collected from a tertiary care hospital and patients screened at their primary care providers or gynecologists might not have been captured. The rate of chlamydia screening represents a gross proxy for sexual activity or concern for sexual abuse in this population as screening is only indicated for those who have had sexual contact, but due to methodological limitations, we believe this is likely significantly underestimated.

This study points out areas of further research and practice improvement in the prescription of hormonal contraceptives to women with CP. When prescribing hormonal contraceptives, it is important for providers to understand the special health needs of this population and of the individual patient to improve the quality of life and function of these women. More research is needed about the implications of hormonal contraceptive choice on VTE risk and bone density for women with physical disabilities.

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