



Menstrual Management for Adolescents With Disabilities

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The onset of menses for adolescents with physical or intellectual disabilities can affect their independence and add additional concerns for families at home, in schools, and in other settings. The pediatrician is the primary health care provider to explore and assist with the pubertal transition and menstrual management. Menstrual management of both normal and abnormal cycles may be requested to minimize hygiene issues, premenstrual symptoms, dysmenorrhea, heavy or irregular bleeding, contraception, and conditions exacerbated by the menstrual cycle. Several options are available for menstrual management, depending on the outcome that is desired, ranging from cycle regulation to complete amenorrhea. The use of medications or the request for surgeries to help with the menstrual cycles in teenagers with disabilities has medical, social, legal, and ethical implications. This clinical report is designed to help guide pediatricians in assisting adolescent females with intellectual and/or physical disabilities and their families in making decisions related to successfully navigating menarche and subsequent menstrual cycles.

The physical pubertal transition is a complicated time for most adolescents and their families and may be even more challenging for teenagers with disabilities. For the purpose of this report, “family” and “families” also refers to caregivers and guardians. Teenagers may have concerns about body image, sexuality, and how menses will affect their lives. Parents often worry about the impact of pubertal development on the lives and health of their daughters with disabilities.¹ A large Canadian study showed that parents’ concerns for their adolescent daughters with intellectual disabilities include menstrual suppression, hygiene, parental burden, and menstrual symptoms.² The pediatrician and the medical home play a key role in anticipatory guidance with the family and teenager regarding emerging sexuality, physical changes of puberty and onset of menstruation, and the emotional and behavioral changes associated with puberty. Even before the onset of menses, the pediatrician could be asked to assist with anticipatory guidance and options for the menstrual cycle

abstract

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because of parental fear of menstrual periods or hormonal mood changes as well as the complex issues of sexuality, vulnerability, and fertility in the context of the disability. This clinical report briefly addresses pubertal issues in female adolescents with physical and/or intellectual disabilities and provides details on the options for menstruation management. The American Academy of Pediatrics (AAP) clinical report titled “Sexuality of Children and Adolescents With Developmental Disabilities” complements this report and includes Internet resources on this topic.³

PUBERTY IN ADOLESCENT GIRLS WITH DISABILITIES

Disabilities in children are common, with 2.8 million or 5.2% of US children and adolescents 5 through 17 years of age affected in 2010.⁴ Approximately 3% of the general population has a significant intellectual disability, and 1.2 million of those affected are teenagers with varying levels of cognitive abilities (80% have mild disability, 12% have moderate disability, and 8% have severe intellectual disabilities).⁵ This clinical report will not include specific discussions around teenagers with psychiatric illnesses.

For most adolescents with intellectual disabilities, although the pattern of pubertal maturation is similar to adolescents without disabilities, the tempo and timing of maturation may vary. Earlier sexual development may occur in girls with neurodevelopmental disabilities,⁶ whereas some girls with autism spectrum disorders may experience a slight delay in the onset of menarche.⁷ Adolescents with disabilities that compromise their nutrition or are associated with chronic inflammation may have a later onset of puberty. Premenarchal suppression is not recommended for most teenagers with intellectual

TABLE 1 General Principles for Approaching Menstruation in Adolescents With Disabilities

1. Initiate anticipatory guidance before the start of menses
2. Discuss concerns around sexual education and expression
3. Help families with guidance on safety and abuse prevention
4. Start menstrual management on the basis of issues related to interference with the teenager's activities, taking into consideration patient medical needs and mobility concerns
5. Help families understand menstrual management options and the benefits and limitations of the different methods

disabilities because expectant management allows for patients and families to determine whether they can cope, and suppressing menarche can result in premature closure of the epiphyses of the long bones, preventing the patient from reaching her full height potential.² Precocious puberty, however, should be addressed in the usual manner.

Menstrual management can begin if cycles are creating difficulties in the patient's life, as determined by health care providers, patients, and families. All teenagers may have irregular cycles initially, but by the third year after menarche, 60% to 80% of girls have cycles from 21 to 34 days long, consistent with those of adults.⁸ However, there are some circumstances that can cause teenagers with disabilities to have more menstrual irregularities related to medical comorbidities and medication adverse effects. Medications that affect the dopaminergic system can cause high prolactin concentrations with subsequent anovulation and amenorrhea.⁹ In adolescents with obesity and in teenagers with seizure disorders and polycystic ovary syndrome, anovulation is more common; independently, valproic acid can cause hormonal aberrations like those in polycystic ovary syndrome.¹⁰ Medications that can cause elevated prolactin concentrations include risperidone, phenothiazines, amitriptyline, cimetidine, prostaglandins, methyl dopa, benzodiazepines, haloperidol, cocaine, and metoclopramide.¹¹

Irregular bleeding in all teenagers can lead patients and families to seek medical intervention, but more so in teenagers with intellectual and physical disabilities, who may be dependent on others for their hygiene needs. The impact of menses ranges from an inability to go to school because of heavy menses and inadequate assistance in managing menses to severe pre- and perimenstrual behavioral changes in teenagers with developmental delay, prohibiting normal activities and causing additional management challenges.^{12,13}

INITIAL EVALUATION

As part of the initial evaluation, the pediatrician addresses the menstrual cycle, including regularity and heaviness of bleeding, associated dysmenorrhea, behavioral and mood changes, and the impact on the adolescent's life. Symptom calendars can be helpful in identifying noncyclical versus cyclical problems, such as catamenial seizures. Other reproductive topics may include assessment of sexual knowledge, interest in sexual activity, and the need for relationship safety education (Table 1).³

Although confidential discussions about sexuality and sexual activity are recommended for all teenagers by the AAP¹⁴ and American College of Obstetricians and Gynecologists (ACOG),⁸ teenagers with any disability are often incorrectly considered to be asexual or uninvolved in relationships, and confidential conversations with their pediatrician may not occur. Teenagers with physical disabilities

TABLE 2 Methods for Menstrual Management in Teens With Disabilities

Category	Method	Benefits	Cautions
Estrogen and progestin	COC	Extended use	Interaction with EI-AED Uncertain risk of VTE with limited mobility
	Ring	Monthly extended use	Interaction with EI-AED Uncertain risk of VTE with limited mobility Dexterity/privacy with insertion
	Patch	Weekly extended use	Interaction with EI-AED Uncertain risk of VTE with limited mobility Inadvertent removal of patch
Progesterone only	POP		Interaction with EI-AED Irregular bleeding
	DMPA	Four times per year	Bone density issues Irregular bleeding Potential weight gain
	Implant	3 y	Irregular bleeding Insertion concerns
	LNG-IUD	5 y	May need anesthesia for insertion and removal Inability to check strings Initial irregular bleeding
Surgical	Endometrial ablation		Amenorrhea rates low No long-term data
	Hysterectomy	Amenorrhea	Legal and ethical issues Permanent sterilization

COC indicates combined oral contraceptive; EI-AED, enzyme-inducing anti-epileptic drugs; LNG-IUD, levonorgestrel intrauterine device; POP, progesterone-only pills; VTE, venous thromboembolism.

are just as likely to be sexually active as their peers and have a higher incidence of sexual abuse.¹⁵ Issues of consent and confidentiality regarding reproductive health care provided by physicians to minor adolescents are complex. Most states recognize the rights of a teenager to consent for confidential services around diagnosis and treatment of issues such as sexually transmitted infections, contraception, and pregnancy care; however, when the patient is cognitively impaired, the issue of consent is more complicated and may require discussion about legal guardianship or medical power of attorney status for the families.¹⁶

OVERVIEW OF MENSTRUAL MANAGEMENT

The decision for menstrual suppression is based on a discussion with the patient and parents or guardians, clinical considerations (eg, anemia), and social context (eg, hygiene, risk of abuse/pregnancy). It is important to discuss that any

menstrual suppression does not change the risk of abuse or sexually transmitted infections. The patient's cognitive disabilities may complicate the decision about menstrual intervention. Similar to the use of suppressive hormonal treatment in the nondisabled population, the decision to suppress menses in teenagers with physical disabilities is based on whether the patient believes this will help her better manage her life. In contrast, when families of adolescents with severe intellectual disabilities ask for menstrual suppression, the issues are more complicated if there is no clear medical indication, such as heavy bleeding or dysmenorrhea. When the stated reasons for suppression are an inability of caregivers to deal with menses or fear of abuse or pregnancy, further investigation into the patient's circumstances and safety is warranted. If the issue is mainly to get assistance at school, then health care providers can help families to address the student's needs with the school.

There are several important issues that need to be considered in menstrual management. No matter what method is used, it is difficult to make patients completely and reliably amenorrheic. For any teenager, having unscheduled bleeding may be worse than having scheduled controlled withdrawal bleeds but may be especially difficult for teenagers who rely on others for hygiene assistance. For teenagers in wheelchairs, even minimal weight gain can be the difference between the ability to transfer themselves or having to rely on someone else, thereby limiting independence. It is important to set outcome goals (eg, no periods, scheduled bleeding 3 times a year, no interference with activities) with the adolescent and her family and periodically reassess whether the goals have been reached or whether changes are indicated. In a large cohort of teenagers with developmental disabilities, it took an average of 1.5 hormonal methods before satisfaction was reached (range, 1–4). The most commonly selected initial method of suppression was the extended or continuous oral contraceptive pill (42.3%), followed by the patch (20%), expectant management (14.9%), depot medroxyprogesterone acetate (DMPA [11.6%]), and the levonorgestrel intrauterine device (LNG-IUD [2.8%]). There was a significant decrease in the selection of DMPA as the initial choice for menstrual suppression noted over time.² Gonadotropin-releasing hormone agonists are not generally recommended for long-term menstrual suppression because of adverse effects such as decreased bone density, except in cases of precocious puberty.²

The following overview focuses on how the use of hormonal methods for menstrual suppression may specifically affect teenagers with intellectual and/or physical

disabilities (Table 2). As recommended by ACOG and AAP,¹⁷ a pelvic examination is not necessary before 21 years of age or to start hormonal medications.¹⁸ Extensive reviews of contraception methods have been published and will not be addressed in this report.¹⁹

Estrogen-Containing Methods

Combined Oral Contraceptives

Combined oral contraceptives (COCs) are often used in a continuous or extended-cycle fashion to limit the amount of bleeding. Because complete amenorrhea is difficult²⁰ to obtain and reported in only 62% of individuals, scheduled withdrawal bleeds every 3 to 4 months may be more helpful to patients with disabilities than unpredictable breakthrough bleeding.^{21,22} For those teenagers with difficulty swallowing, there are chewable COCs that can also be put into food or crushed and given through a gastrostomy tube.²³ A Cochrane review examining efficacy and safety of continuous or extended-cycle versus monthly cycle use of combined oral contraceptives concludes that extended-cycle pills have similar contraceptive efficacy and safety profiles to monthly cycle pills. Some studies suggest that menstrual symptoms of headaches, genital irritation, tiredness, bloating, and menstrual pain may be less in extended-cycle regimens.²⁴

Combined Contraceptive Patch

The combined contraceptive patch may be useful in patients who have difficulty swallowing pills. It can be used in an off-label continuous weekly fashion with similar breakthrough bleeding patterns as the continuous oral contraceptive pill.²⁵ Because some patients with developmental disabilities may attempt to pull off the patch,

placement high on the back or buttocks is helpful.

Vaginal Ring

The monthly placement of a vaginal ring is another delivery form of combined hormones. The ring has enough hormones for 35 days, and leaving it in for 28 days at a time can provide continuous hormones in an off-label use.²² However, the physical and privacy concerns of having another person place the ring intravaginally for teenagers without adequate dexterity or with intellectual disabilities have severely limited its use in this population. Bleeding profile for the ring when used continuously shows a rate of 8% for amenorrhea and 19% for spotting.²⁶

Special Considerations: Venous Thrombotic Events and Estrogen-Containing Methods

The use of estrogen-containing hormones increases the risk of venous thrombotic events (VTEs). The risk of VTEs is higher for formulations with increasing doses of estrogen (compare 20 to 35 µg ethinyl estradiol) and likely higher with newer generations of progestins and for women using the combined contraceptive patch and the vaginal ring, although there are conflicting studies.^{27–29}

The data on estrogen-containing hormones and VTEs have led to concerns about the risk of VTE for patients in wheelchairs; however, there are no data to provide guidance on this type of immobility in teenagers. Immobility is not a contraindication in the medical eligibility criteria for contraception per Centers for Disease Control and Prevention (CDC) recommendation.³⁰ Although the use of estrogen-containing contraceptives is not contraindicated in teenagers with mobility issues, a thorough family history can decrease the likelihood of an inherited thrombophilia. Health care providers can consider using

the lowest-dose estrogen COCs that contain a first- or second-generation progestin, such as norethindrone and levonorgestrel for teenagers with limited mobility, because these progestins have been shown to be likely associated with lower rates of VTE.^{19,27,28}

Progestin-Only Methods

Oral Progestins

Oral progestins can be used cyclically for teenagers with anovulation to induce menses or continuously to cause amenorrhea. Because the lowest dose daily progestin, known as the “minipill,” only has a 20% rate of amenorrhea³¹ and has to be taken at the same time every day, higher daily doses of oral progestins such as medroxyprogesterone (10–40 mg) or norethindrone (5–15 mg) have been attempted to achieve amenorrhea (as well as pain control in patients with endometriosis). Amenorrhea rates are not consistently reported. Although not well studied in teenagers, mood changes related to all progestins have been described.³²

Depot Medroxyprogesterone Acetate

DMPA, the intramuscular and now subcutaneous injection, has been used for years as both a contraceptive and for menstrual suppression. The rate of amenorrhea is 50% to 60% at 1 year and 80% at 5 years.³³

There are 2 specific areas of concern for use of DMPA in teenagers with disabilities.

1. Weight gain: the weight gain (average 13 pounds in 4 years, according to package insert) associated with the use of this medication is troubling for all teenagers, but for teenagers with mobility issues, even a small amount of weight gain may complicate transfers and could impede independence. There appears to be more weight gain in obese teenagers and in teenagers whose weight increases >5%

over baseline weight in the first 3 months of use.³⁴

2. Bone health: there have been significant concerns around the effects of DMPA on bone mineral density (BMD), which led to a “black box warning” from the US Food and Drug Administration (FDA) to limit its use to 2 years. It is specifically of concern to teenagers, because girls accrue approximately 30% to 40% of their bone mass during adolescence. The rate of BMD loss decreases with longer duration of the DMPA use. The World Health Organization,³⁵ ACOG,³⁶ and Society for Adolescent Health and Medicine³⁷ have advised that health care providers interpret the 2-year duration limit individually and discuss with the patient and families whether DMPA is the best option for them in the context of relative risks and benefits.³⁵ In teenagers with disabilities and limited mobility, BMD may already be lower, but it is not clear whether this is actually associated with increased fracture risk.³⁸ The bone-density loss appears reversible after stopping the DMPA; however, for teenagers with limited mobility, no data are available.³⁹

In summary, the use of DMPA in teenagers in wheelchairs can be considered for menstrual suppression after careful counseling and assessment of any contraindications to estrogen and considering whether the potential risk of decreased BMD is outweighed by the need for the suppression. The AAP and ACOG do not support the use of bone-density screening if long-term use of DMPA seems prudent, including in adolescents with limited mobility, unless fractures have occurred.^{36,39} Calcium and vitamin D intake may be optimized per current guidelines.^{40,41}

Levonorgestrel Intrauterine Device

LNG-IUDs have been used extensively in adult women and, although not approved by the FDA for adolescents

younger than 18 years, more recently have been advocated for use in teenagers for birth control by national organizations because of their excellent contraceptive effect.⁴² The original LNG-IUD dispenses 20 µg of levonorgestrel daily with a 50% dose reduction at 5 years. It is well tolerated with a 5-year duration and amenorrhea rates of approximately 50% at 1 year.⁴³ It has been used in women with disabilities and medical conditions that exclude estrogen use.

Several recent studies have addressed LNG-IUD use in teenagers with intellectual disabilities. Satisfactory outcomes by families were reported in 1 study,⁴⁴ and a 50% amenorrhea rate in 7 of 14 teenagers in another.⁴⁵ From a larger Canadian cohort, among 26 adolescents with disabilities (mean age, 15.4 years) who chose LNG-IUD insertion, 3 patients had LNG-IUD expulsions (11.2%), and another 2 had the LNG-IUD removed because of spotting and low positioning. Amenorrhea was noted at 1 year in all 21 patients who continued using the LNG-IUD.² As described for most patients in these series, the LNG-IUD can be inserted or removed under sedation or anesthesia, or if having another surgical procedure, could be inserted at the same time. The expulsion rate of the LNG-IUD is slightly higher in nulliparous women (approximately 3%–4%)⁴⁶ and is reported at 8% in teenagers with disabilities combining all published studies.⁴⁷ Whether ultrasonography before insertion of the LNG-IUD in this population is helpful to predict successful insertion is under discussion. A uterine length of 6 to 10 cm is recommended for 1 LNG-IUD; a newer, slightly smaller 3-year version does not have that recommendation. Although preinsertion ultrasonographic measurements were recommended in 1 report,⁴⁵ another study on 26 LNG-IUD insertions in adolescents with developmental disabilities showed

that of 5 patients who had cavity length of less than 6 cm measured by ultrasonography, 4 had a successful insertion of the LNG-IUD.⁴⁷

A sudden increase in vaginal bleeding may indicate LNG-IUD expulsion, and families are educated to look for this potential sign. If the families notice the increase in bleeding and the LNG-IUD string cannot be checked in the office because of patient intolerance of the examination, ultrasonography for device location can be performed. A newer, slightly smaller, and lower-dose device, 13.5-mg LNG-IUD (Skyla, Bayer HealthCare Pharmaceuticals, Wayne, NJ) has recently become available in the United States, is approved by the FDA for patients younger than 18 years, and is effective for 3 years. Although the decreased size may be helpful to address placement and expulsion in nulliparous women, the initial bleeding profile reported on the product insert gives significantly lower amenorrhea rates (12% after 3 years)⁴⁸ than the 5-year LNG-IUD, which may be an important factor to consider.

Progestin Implant

Use of the etonogestrel single-rod implant for menstrual suppression in teenagers with disabilities is limited because of the continued concern regarding the unpredictable bleeding patterns that are associated with the implant. Amenorrhea is approximately 13% after 1 year, with many days of spotting each month.⁴⁹ Insertion and removal requires patient cooperation, which may be an issue for some teenagers with intellectual disabilities.

Special Considerations

Seizures and Hormonal Contraception

For patients with epilepsy taking anticonvulsant medications, interactions with hormones are described. Many anticonvulsants and some other neuropsychiatric medications induce the hepatic

cytochrome P450 system and, thus, interfere with contraceptive efficacy and cycle control reliability. As a result, COCs can cause irregular bleeding, and higher doses of COCs may be indicated to achieve amenorrhea. The CDC medical eligibility criteria categorize the estrogen-containing methods and the progesterone-only pill as category 3 for contraception (ie, risks outweigh the benefits) for enzyme-inducing anticonvulsant agents. In general, hormonal contraceptives do not affect the efficacy of anticonvulsant medications, with the 1 exception of lamotrigine, which can have decreased efficacy when combined with a COC. The lamotrigine dose may need to be adjusted, and discussion with the prescribing physician is recommended when starting a COC (CDC medical eligibility criteria, category 3).⁵⁰ LNG-IUDs, injectables, and implants are recommended for patients on anticonvulsant medication. For the progesterone injectables (medroxyprogesterone acetate), some experts recommend dosing on an every-10-week schedule if irregular bleeding continues.⁵¹ Finally, cyclical or catamenial epilepsy and other cyclic menstrual symptoms may be a clinically significant problem for some patients, and suppression of hormone fluctuations can be helpful.⁵²

Herbal Supplements

Because the use of complementary medicine is widespread and increasing in the population, pediatricians can advise families that the use of these compounds can interfere with the hormonal medications.⁵³ For example, St John's wort is known to decrease the bioavailability of oral contraceptives, which might interfere with contraceptive efficacy and may lead to spotting.^{54,55} Other herbals have been implicated in increasing bleeding risk as well as in hepatotoxicity.⁵⁶

Nonhormonal Methods

Nonsteroidal antiinflammatory drugs can be used to help with dysmenorrhea as well as with heavy bleeding. Studies show a small decrease in flow when nonsteroidal antiinflammatory drugs are used around the clock during the menses.⁵⁷

A new oral antifibrinolytic medication, tranexamic acid, was approved by the FDA for heavy menses in 2009. It can be taken for up to 5 days of menses and results in 40% lighter bleeding.⁵⁸

Surgical Requests and Options

Parents may ask the pediatrician about surgical interventions, especially endometrial ablation or hysterectomy, for their daughter with severe intellectual disabilities, in the hope that it will help with menstrual bleeding, behavior changes, or perceived or expressed dysmenorrhea or because of concerns about the risk of pregnancy. Surgical interventions in these cases have clear ethical and legal implications because most of patients with intellectual disabilities cannot give their own consent.

Endometrial Ablation

Endometrial ablation destroys most or all of the endometrium and was designed for women who have completed childbearing to alleviate heavy cycles. The rates of amenorrhea range from 13% to 83%, and complications include pain, cramping, and continued bleeding as well as the need for additional procedures. Ablation leads to only relative infertility, and birth control is still recommended, because pregnancy after an ablation may have complications. Because of this relative infertility, there are legal implications for use in teenagers with disabilities (see Hysterectomy). There are no studies on use of ablation in adolescents including long-term consequences and

outcomes, and therefore, endometrial ablation is not recommended for this age group.¹²

Hysterectomy

Families sometimes request hysterectomy for menstrual management in their daughter with severe intellectual disability. When hysterectomy is requested, it is critical to delineate why the family desires this intervention. It may be considered the ideal way to achieve birth control and amenorrhea. This is a complex and controversial issue and can cause conflict between health care providers and families. A hysterectomy (removal of the uterus and cervix) does not prevent behavioral hormonal concerns. Hysterectomy in the adolescent years for medical indications is extremely rare for teenagers, with or without disabilities. Laws regarding sterilization in minors with intellectual disabilities, hysterectomy, and consent issues vary from state to state. There is a network of legal experts on disability with offices in every state (<http://www.ndrn.org/about/paacap-network.html>). In most jurisdictions, sterilization of women with known cognitive impairments has specific legal oversight mandated.

Referral to a gynecologist with experience in this area may be considered as well as an ethics consultation and legal representation for the patient as part of the review process. The ACOG has guidelines regarding permanent sterilization.⁵⁹

CONCLUSIONS

The pediatrician plays a pivotal role during the sometimes difficult pubertal transition for patients with physical and intellectual disabilities, when concerns about

menstruation, sexuality, and fertility come to the forefront. Pediatricians should assist with anticipatory guidance for patients and families by normalizing menses as an expected part of life, helping with the management of menses, and referring to experts as needed for more complicated concerns.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
 ACOG: American College of Obstetricians and Gynecologists
 BMD: bone mineral density
 CDC: Centers for Disease Control and Prevention
 COC: combined oral contraceptive
 DMPA: depot medroxyprogesterone acetate
 FDA: US Food and Drug Administration
 LNG-IUD: levonorgestrel intrauterine device
 VTE: venous thrombotic event

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