Menstrual Manipulation for Adolescents With Physical and Developmental Disabilities

**ABSTRACT:** For an adolescent with physical disabilities, intellectual disabilities, or both, and for her caregivers, menstruation can present significant challenges. If, after an evaluation, the adolescent, her family, and the obstetrician–gynecologist have decided that menstrual intervention is warranted, advantages and disadvantages of hormonal methods should be reviewed and individualized to each patient’s specific needs. Complete amenorrhea may be difficult to achieve, and realistic expectations should be addressed with the patient and her caregivers. The goal in menstrual manipulation should be optimal suppression, which means a reduction in the amount and total days of menstrual flow. Menstrual suppression before menarche and endometrial ablation are not recommended as treatments. Optimal gynecologic health care for adolescents with disabilities is comprehensive; maintains confidentiality; is an act of dignity and respect toward the patient; maximizes the patient’s autonomy; avoids harm; and assesses and addresses the patient’s knowledge of puberty, menstruation, sexuality, safety, and consent.

**Recommendations**

The American College of Obstetricians and Gynecologists offers the following conclusions and recommendations:

- **Optimal gynecologic health care for adolescents with disabilities is comprehensive; maintains confidentiality; is an act of dignity and respect toward the patient; maximizes the patient’s autonomy; avoids harm; and assesses and addresses the patient’s knowledge of puberty, menstruation, sexuality, safety, and consent.**
- **Adolescents with disabilities may have other causes for menstrual irregularities, including thyroid disease in adolescents with trisomy 21, high prolactin levels due to mood-stabilizing medication, and polycystic ovary syndrome in adolescents with seizure disorders.**
- **In adolescents with disabilities, sexually transmitted infections (STIs) may be undiagnosed, underdiagnosed, or mistaken for urinary tract infections because the obstetrician–gynecologist may assume that the patient is not sexually active or the patient may not have the ability to feel or report symptoms.**
- **If, after an evaluation, the adolescent, her family, and the obstetrician–gynecologist have decided that menstrual intervention is warranted, advantages and disadvantages of hormonal methods should be reviewed and individualized to each patient’s specific needs.**
- **Complete amenorrhea may be difficult to achieve, and realistic expectations should be addressed with the patient and her caregivers. The goal in menstrual manipulation should be optimal suppression, which means a reduction in the amount and total days of menstrual flow.**
- **Antiprostaglandin drugs, in adequate dosages based on the patient’s weight, decrease ovulatory menstrual bleeding by approximately 30–40%.**
- **Combined oral contraceptives can be used continuously or for an extended period to attain optimal suppression.**
- **Oral progestins in high doses, including progesterin-only birth control pills, can be used daily to attempt menstrual suppression, but efficacy in achieving amenorrhea is dependent on dose and adherence to...**
taking the hormone as close to the same time each day as possible.

- Use of depot medroxyprogesterone acetate (DMPA) results in relatively high rates of amenorrhea by the fourth dose (approximately 90% per 90-day cycle) and has a long history of clinical use to suppress menses.

- The levonorgestrel intrauterine device (IUD) should be considered for any adolescent patient. Irregular bleeding is common initially, but amenorrhea rates increase over time and overall blood loss is decreased significantly.

- Hysterectomy for the purpose of cessation of normal menses may be considered only after other reasonable alternatives have been attempted.

- Menstrual suppression before menarche and endometrial ablation are not recommended as treatments.

Background

For an adolescent with physical disabilities, intellectual disabilities, or both, and for her caregivers, menstruation can present significant challenges. Irregular bleeding episodes, which commonly occur in adolescents during the first 2–5 years after menarche, and the behavioral concerns that accompany menstrual periods, especially in developmentally delayed adolescents, may cause significant problems. In addition, concerns regarding sexuality and vulnerability to abuse and pregnancy contribute to the worries of many caregivers. Obstetrician–gynecologists should anticipate requests for menstrual suppression, possibly before menarche, and be able to offer information, counseling, and guidance to caregivers. This Committee Opinion focuses on the concerns, assessment, and methods used for menstrual manipulation in adolescents with physical and developmental disabilities.

Communication and Special Considerations for History Taking

Optimal gynecologic health care for adolescents with disabilities is comprehensive; maintains confidentiality; is an act of dignity and respect toward the patient; maximizes the patient’s autonomy; avoids harm; and assesses and addresses the patient’s knowledge of puberty, menstruation, sexuality, safety, and consent. When possible, the patient should have the opportunity to be interviewed in private. Communication should be directed to the adolescent and not to a family member or personal assistant. It is critical for the health care provider to have patience during the process and knowledge of the adolescent’s mode of communication.

Adolescents with disabilities often are thought of as asexual. Although some adolescents with disabilities may be behind their peers in knowledge of puberty, menstruation, sexual activity, and safety, this does not necessarily mean that they are not sexually active, do not have sexual thoughts, or do not express themselves sexually through masturbation. When knowledge deficits are present, developmentally appropriate education on hygiene, contraception, STIs, and abuse prevention measures should be provided. Most adolescents who are able to use the toilet without assistance can learn to use pads or tampons appropriately.

When the obstetrician–gynecologist receives a request for menstrual suppression, it is important to assess the reasons for the request. If the request does not come directly from the patient, the obstetrician–gynecologist should determine if menses is affecting the patient’s quality of life or if it is a matter of preference of the patient or convenience of the caregiver. Complete amenorrhea may be difficult to achieve, and realistic expectations should be addressed with the patient and her caregivers. The goal in menstrual manipulation should be optimal suppression, which means a reduction in the amount and total days of menstrual flow. It should be emphasized that although many methods may help prevent unintended pregnancies, none will prevent potential sexual abuse.

Causes of Menstrual Irregularities

Although adolescents may have irregular cycles during the first 2–5 years after menarche, adolescents with disabilities may have other causes for menstrual irregularities, including thyroid disease in adolescents with trisomy 21, high prolactin levels due to mood-stabilizing medication, and polycystic ovary syndrome in adolescents with seizure disorders (10–20%) (4, 5). The obstetrician–gynecologist should evaluate for underlying causes before initiating a suppressive treatment. The evaluation for abnormal bleeding is the same for adolescents with disabilities as it is for other adolescents.

Examination

Current cervical cytology guidelines state that women younger than 21 years should not be screened for cervical cancer regardless of the age of sexual initiation or the presence of other behavior-related risk factors (6). A pelvic examination rarely is needed in an adolescent who is not sexually active and is recommended only in specific situations, including abnormal bleeding, vaginal discharge, suspicion of a foreign object in the vagina, or abuse evaluations, any of which may require examination under anesthesia. Screening for gonorrhea, chlamydial infection, and Trichomonas infection typically can be done using urine-based testing or vaginal swab specimens for nucleic acid amplification. Screening for other STIs (eg, herpes, human immunodeficiency virus [HIV], hepatitis, syphilis) can be done by blood testing. In adolescents with disabilities, STIs may be undiagnosed, underdiagnosed, or mistaken for urinary tract infections because the obstetrician–gynecologist may assume that the patient is not sexually active or the patient may not
have the ability to feel or report symptoms. A positive test result for an STI may warrant evaluation for sexual abuse (7). See Committee Opinion No. 592, Sexual Assault, for more information on sexual assault.

**Treatment Options**

If, after an evaluation, the adolescent, her family, and the obstetrician–gynecologist have decided that menstrual intervention is warranted, advantages and disadvantages of hormonal methods should be reviewed and individualized to each patient’s specific needs. It is important to assess whether predictable but potentially longer bleeding is easier to manage than sporadic, irregular bleeding. In addition to counseling patients and caregivers that total amenorrhea is difficult to obtain, the obstetrician–gynecologist should review the risks and benefits specific to the individual patient before presenting potential options for menstrual manipulation. Because most methods of menstrual manipulation involve hormonal contraceptives, the obstetrician–gynecologist should review the Centers for Disease Control and Prevention’s *U.S. Medical Eligibility Criteria for Contraceptive Use* for comprehensive, evidence-based guidance. Although this resource is intended for contraceptive needs, it contains important safety information on contraceptive methods. See Table 1 for a list of options for menstrual manipulation in adolescents with disabilities.

**Nonsteroidal Antiinflammatory Drugs**

Antiprostaglandin drugs, in adequate dosages based on the patient’s weight, decrease ovulatory menstrual bleeding by approximately 30–40%. Although this treatment will not stop menses, it may help with pain and bleeding (8).

**Estrogen-Containing Methods**

Combined oral contraceptives can be used continuously or for an extended period to attain optimal suppression. Although this method may increase the incidence of unscheduled bleeding, especially early in use, amenorrhea rates eventually may increase to 50%. Chewable combined oral contraceptives are available for patients who are unable to swallow pills. Crushed pills also may be an option.

Pharmacologic data indicate that estrogen exposure is higher with use of the contraceptive patch than with

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**Table 1. Overview of Menstrual Management Methods for Adolescents With Special Needs**

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Specific Benefits</th>
<th>Disability Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSAIDs</td>
<td>Decreases flow and pain</td>
<td>GI issues</td>
</tr>
<tr>
<td>Combined oral contraceptives</td>
<td>Can use extended or continuous regimen</td>
<td>If immobile: possible risk of VTE</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Daily reminders</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interfere with certain EI-AED</td>
</tr>
<tr>
<td>Contraceptive patch</td>
<td>Weekly application</td>
<td>If immobile: possible risk of VTE</td>
</tr>
<tr>
<td></td>
<td>Can use extended or continuous regimen</td>
<td>Patient can remove from skin</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interfere with certain EI-AED</td>
</tr>
<tr>
<td>Contraceptive ring</td>
<td>Monthly</td>
<td>If immobile: possible risk of VTE</td>
</tr>
<tr>
<td></td>
<td>Can use extended or continuous regimen</td>
<td>Placement by others (privacy)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interfere with certain EI-AED</td>
</tr>
<tr>
<td>Oral progestin</td>
<td>Decreased flow</td>
<td>BTB</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Daily reminders</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interfere with certain EI-AED</td>
</tr>
<tr>
<td>Depot medroxyprogesterone acetate</td>
<td>Every 3 months</td>
<td>Weight gain in obese adolescents</td>
</tr>
<tr>
<td>Progestrone implant</td>
<td>Every 3 years</td>
<td>BTB</td>
</tr>
<tr>
<td></td>
<td>Decreased dysmenorrhea</td>
<td>Insertion may be challenging</td>
</tr>
<tr>
<td>LNG-IUD</td>
<td>Every 3–5 years</td>
<td>Challenging insertion, may need anesthesia</td>
</tr>
<tr>
<td>Surgical methods: hysterectomy</td>
<td>Complete amenorrhea</td>
<td>Legal and ethical implications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Major surgery</td>
</tr>
</tbody>
</table>

Abbreviations: BTB, breakthrough bleeding; EI-AED, enzyme-inducing antiepileptic drugs; GI, gastrointestinal; LNG-IUD, levonorgestrel intrauterine device; NSAIDs, nonsteroidal antiinflammatory drugs; VTE, venous thromboembolism.

oral contraceptives or the vaginal ring. It is unclear how increased estrogen exposure affects the risk of deep vein thrombosis (9). Caution, therefore, is recommended for use of the patch in women with limited mobility.

Contraceptive rings often are difficult for adolescents with mobility issues or functional hand limitations to insert. There are clear intimacy issues with caregivers assisting with insertion of a ring, although some women may feel comfortable with partner help. The ring can be used for 3 weeks, followed by a hormone-free week, but rings used for 4 weeks continuously lead to lighter bleeding and more days of amenorrhea (10).

The issue of immobility and estrogen-containing contraceptives is unclear and remains controversial. The risk of thrombosis with use of combined hormonal contraceptives by women who are immobile or who have limited mobility has not been studied. However, because some data suggest an increased risk of thrombosis with the use of third-generation combined hormonal contraceptives, these methods may not be the first choice for women who are immobile or who have limited mobility (11).

Progestin-Only Methods

Oral Medications

Cyclic progestins reduce blood loss in women with anovulation who are not nulliparous (12). Oral progestins in high doses, including progestin-only birth control pills, can be used daily to attempt menstrual suppression, but efficacy in achieving amenorrhea is dependent on dose and adherence to taking the hormone as close to the same time each day as possible (13). Heavy bleeding often can be resolved by using an oral progestin taper (14).

Intramuscular Depot Medroxyprogesterone Acetate

Use of DMPA results in relatively high rates of amenorrhea by the fourth dose (approximately 90% per 90-day cycle) and has a long history of clinical use to suppress menses (15). There are two main areas of concern for DMPA use in adolescents with disabilities:

1. Fracture risk—Although a decrease in bone density has been described with DMPA use in adolescents, there is evidence of adequate bone density recovery after DMPA is discontinued. The potential health risks associated with the effects of DMPA on bone density must be balanced against excessive menstruation and the likelihood of unintended pregnancy. Routine bone density scanning is not recommended in adolescents (16).

2. Weight gain—Weight gain is variable but appears to be particularly challenging for overweight patients (17). For adolescents with disabilities who may be dependent on their own strength or the help of caregivers for transfers in and out of chairs and beds, a relatively small weight gain may negatively affect their independence and should be closely monitored.

Progestosterone-Releasing Intrauterine Device

The levonorgestrel IUD should be considered for any adolescent patient. Irregular bleeding is common initially, but amenorrhea rates increase over time and overall blood loss is decreased significantly (18). Although the 52-mg levonorgestrel IUD is slightly larger in comparison with the 13.5-mg levonorgestrel IUD, there are benefits: a patient using the 52-mg levonorgestrel IUD has a higher likelihood of attaining amenorrhea, and the device is approved for use for up to 5 years rather than 3 years. Meanwhile, insertion under sedation is just as likely to be needed with both devices. In adolescents with disabilities, considerations for IUD insertion under anesthesia include nulligravid status, unpredictable cooperation, a narrow vagina, and significant contractures. Increased bleeding and pain may indicate the need for evaluation for expulsion.

Special Consideration: Antiepileptic Drugs and Hormone Use

Although estrogen is a proconvulsant, combined oral contraceptives have not been associated with an increased number of seizures. Irregular bleeding is common and contraceptive effectiveness may be affected negatively by enzyme-inducing antiepileptic drugs (19). Thus, estrogen or progestosterone content may need to be increased or DMPA may be used in 10-week intervals to decrease irregular bleeding (20). Progestins, however, increase seizure threshold and can play an important positive role for women with epilepsy (21). Obstetrician–gynecologists should consult the Centers for Disease Control and Prevention’s U.S. Medical Eligibility Criteria for Contraceptive Use.

Not Recommended as First-Line Treatment Methods

Implants

Progestin contraceptive subdermal implants have a high incidence of unscheduled and prolonged bleeding (up to 40% in the first months after insertion) (22) and require significant patient cooperation or sedation for insertion and removal. Despite the irregular bleeding profile, there are important benefits, including a large decrease in dysmenorrhea and the extreme reliability of this contraceptive method. A small percentage of patients achieve amenorrhea (approximately 20%), but this is unpredictable, and greater than 10% of patients choose to have the device removed because of bothersome bleeding (23, 24).

Surgical Therapy

Occasionally, families may request a hysterectomy for definitive amenorrhea in adolescents with disabilities. Hysterectomy is seen by some as ideal for pregnancy prevention, and menstrual control may be a secondary goal. It is critical for patients and guardians to understand that hysterectomy is irreversible, has a risk of morbidity and
mortality, and will not protect the child from the hazards of sexual abuse or sexually transmitted infections. The risks and cost of the procedure are disproportionate to the benefit, given the available alternatives. In disabled women with limited functional capability, indications for major surgical procedures remain the same as in other patients. In all cases, indications for surgery must meet standard criteria, and the benefits of the procedure must exceed known procedural risks. On occasion, such women’s caregivers have sought hysterectomy for menstrual control. Hysterectomy for the purpose of cessation of normal menses may be considered only after other reasonable alternatives have been attempted. Laws regarding sterilization, hysterectomy, and consent issues with regard to minors vary from state to state (25). If hysterectomy is being considered, surgeons should check their state laws before proceeding with surgery. Guidance regarding consent is available from the American College of Obstetricians and Gynecologists (1).

Not Recommended as Treatment Methods
Menstrual suppression before menarche and endometrial ablation are not recommended as treatments. See the following sections for additional information.

Premenarchal Suppression
Premenarchal suppression of menses is not recommended. By allowing menarche to occur naturally, a patient genital tract is confirmed, full stature is obtained, and the maturation process is completed. Then, with initial expectant management, patients and their families can determine their ability to cope with menses (26).

Endometrial Ablation
Endometrial ablation aims to treat heavy bleeding by selectively destroying the endometrial lining while leaving the uterus intact. It should not be performed in any adolescent because the failure to achieve amenorrhea in general is high in younger patients, and it is not considered a sterilization procedure (27).

References


