Menstrual Manipulation for Adolescents With Disabilities

ABSTRACT: Defining the reasons for intervention and the precise goal of treatment are the most critical issues regarding use of interventions to alter menstrual flow in adolescents with disabilities. Reasons for intervention may relate to abnormal uterine bleeding, hygiene, mood issues, fear of pregnancy, and acute onset of other medical conditions. Goals of treatment may include a decrease in the amount of bleeding, periodic amenorrhea, or treatment of symptoms, such as mood issues or dysmenorrhea. First-line treatment options should be safe, minimally invasive, and nonpermanent. Endometrial ablation has not been studied in adolescents, has not been studied long-term, is considered irreversible and, therefore, is not recommended in teenagers.

For an adolescent with either physical or developmental disabilities, menstruation can provide significant challenges for the patient and her caregivers. The hygiene component of often irregular early bleeding episodes and the behavioral concerns that accompany menstrual periods especially in developmentally delayed teenagers may cause significant problems. In addition, concerns regarding sexuality and vulnerability to abuse and pregnancy contribute to the worries of many parents. Requests for amenorrhea or menstrual manipulation will be presented to obstetrician–gynecologists, who then need to offer information and counseling in this area. This committee opinion focuses on the concerns, assessment, and methods used for menstrual manipulation in adolescents with disabilities.

Communication and Special Considerations for History Taking

Optimal gynecologic health care of adolescents with disabilities is comprehensive; maintains confidentiality, if possible; does not treat the patient as infantile, affirms the patient’s dignity; maximizes the patient’s interests; and avoids harm. When possible, the patient should have the opportunity to be interviewed in private (1). Communication should be directed to the teenager and not to a family member or personal assistant. Having knowledge of the teenager’s mode of communication and provider patience in the process are critical.

Knowledge of puberty, menstruation, sexual activity, safety, and the ability to consent to any sexual act should be assessed. Adolescents with disabilities often are thought to be asexual, but they are as likely as other teenagers without disabilities to be sexually active, and are at greater risk for forced sexual encounters (2). When knowledge deficits are present, developmentally appropriate education on hygiene, contraception, sexually transmitted infections, 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 or both appropriately.

When the obstetrician–gynecologist receives a request for amenorrhea or menstrual manipulation, it is important to assess the reason(s) for the request, especially if the request does not directly come from the patient. If the patient herself requests to have her menstrual periods eliminated, her reasons can be discussed directly with her. If her caregiver requests this for the teenager, especially if the teenager has a significant developmental delay, the issues become more complex. Before determining the next steps,
the health care provider needs to ascertain whether the request is based on convenience for the family or caregivers, vulnerability for abuse and pregnancy, or menses that truly affect the patient’s quality of life. If the adolescent with disabilities cannot participate in her usual activities during her menses, this may be due to inadequate help with her hygiene needs, behavioral issues during menses, or dysmenorrhea.

**Menstrual Concerns**

Although all teenagers may have irregular cycles during the first 2–5 years after menarche (3), adolescents with disabilities may have additional reasons to experience menstrual irregularities, including thyroid disease in teenagers with trisomy 21, high prolactin levels due to mood stabilizing medication, and polycystic ovary syndrome in teenagers with seizure disorders (10–20%) (4, 5).

**Examination**

With the new guidelines regarding cervical cytology screening (6), a pelvic examination is rarely needed in a teenager who is not sexually active and is only recommended for specific indications, including abnormal bleeding, vaginal discharge, suspicion of a vaginal foreign object, or abuse evaluations, which may require an examination under anesthesia. Sexually transmitted infection screening can be done by urine and blood testing. The evaluation for abnormal bleeding is the same for adolescents with disabilities as for other adolescents.

**Treatment Options**

If after an evaluation, the teenager, her family and health care provider have decided that menstrual intervention is warranted, the least invasive, reversible, and least harmful intervention should be used. It is important to assess if predictable but potentially longer bleeding is easier to manage than sporadic, irregular bleeding and counsel that total amenorrhea is difficult to obtain. The following options are available.

**Nonsteroidal Antiinflammatory Drugs**

Antiprostaglandin drugs in adequate dosages decrease ovulatory bleeding by approximately 30–40% with less reduction in anovulatory cycles. Although this will not stop menses, it may help with pain and bleeding (7).

**Estrogen-Containing Methods**

**Combined Oral Contraceptives**

Combined oral contraceptives (OCs) used cyclically result in less menstrual blood loss in patients. Combined OCs can be used continuously or for an extended period to attempt to reduce the total days of menstrual flow. This, however, increases the incidence of unscheduled bleeding, especially early in use, but amenorrhea rates may increase to 50%. There are only sparse data on how to manage the unscheduled bleeding; however, one study suggests that use of norethindrone acetate resulted in more amenorrhea than levonorgestrel (8). There is a chewable combined OC available to use with G-tubes or patients who are unable to swallow pills.

**Contraceptive Patch**

Pharmacologic data indicate that estrogen exposure is higher with use of the contraceptive patch than with oral contraceptives or the vaginal ring. It is unclear how this may affect the risk of deep vein thrombosis (DVT) (9, 10). Caution, therefore, is recommended for use of the patch in nonmobile women (see following discussion of DVT). In teenagers with developmental disabilities, unscheduled removal of the patch may occur. Placement of the patch on the buttocks or shoulder, where the individual cannot reach it, may remedy this problem.

**Contraceptive Ring**

Contraceptive rings often are difficult for adolescents with mobility issues or functional hand limitations to insert. There are clear intimacy issues with using caregivers to assist with inserting a ring, although some women may feel comfortable with partner help. The ring can be used for 3 weeks, with an interval free week, but rings used for 4 weeks continuously lead to lighter bleeding and more days of amenorrhea (11).

**Estrogen Use and Risk of Deep Vein Thrombosis**

Immobility is not listed as a contraindication to estrogen-containing contraceptives by the World Health Organization and the American College of Obstetricians and Gynecologists (12). However, there are minimal data on the risk of DVT in women who take contraceptives with or without exogenous estrogen and who use wheelchairs. Clinicians, therefore, will want to assess patients for hypercoagulability by obtaining a careful family history (13) and encourage exercise of extremities in patients who are physically able. Because there is a possible concern about clotting risk with patches and combined OCs with third-generation progestins (14), they may not be the first choice for women who are immobile.

**Progestin-Only Methods**

**Oral Medications**

Cyclic progestins reduce blood loss in women with anovulation, but do not work in this capacity for women who are ovulatory (15). While taking the progestin only "minipill," patients will have ovulatory cycles approximately 40% of the time, short irregular cycles 40% of time, or lack of cycles from amenorrhea to irregular bleeding 20% of the time (16). Oral progestins in higher doses than the progestin-only birth control pills can be used daily to achieve amenorrhea. Occasional depressed mood has been noted by clinicians, although, there is not substantial data to support this.

**Implants**

Progestin contraceptive subdermal implants have an incidence of unscheduled bleeding of up to 40% in the first
months after insertion (17) and need significant patient cooperation or sedation for insertion.

**Intramuscular Depot Medroxyprogesterone Acetate**

Use of depot medroxyprogesterone acetate (DMPA) results in relatively high rates of amenorrhea by the fourth dose (approximately as high as 90% per 90-day cycle in some studies) and has traditionally been used extensively to suppress menses (18). There are two main areas of concern for adolescents with disabilities.

1. **Bone density:** Although a decrease in bone density has been described with DMPA use in teenagers, there is evidence showing recovery of bone after DMPA is discontinued (19). However, in teenagers where the suppression may need to be long term or when the risk for very low bone density may be increased because of immobility or being under weight or both, DMPA use may be less advisable. Supplementation with calcium and vitamin D should be considered. Several studies of adolescents and women demonstrate that low-dose estrogen supplementation limits bone mineral density loss in DMPA users; however, estrogen supplementation during DMPA use is not currently recommended (19).

2. **Weight gain:** Weight gain is variable but appears to be particularly problematic for overweight patients (20). 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 affect their independence and should be closely monitored.

**Progesterone-Releasing Intrauterine Contraception**

The levonorgestrel intrauterine device (IUD) is utilized outside of its contraceptive labeling as a method of menstrual suppression (21). Irregular bleeding is common initially, but amenorrhea rates increase over time and overall blood loss is significantly decreased. One meta-analysis of levonorgestrel IUD use in the general population indicates a 70–80% reduction of blood loss (22). Ovulation is variable so amelioration of ovulatory symptomatology will vary. Current data on the levonorgestrel IUD is not specific to adolescents with disabilities. In adolescents with disabilities, IUD insertion may need to be done under anesthesia because of a higher likelihood of nulligravid status (23), unpredictable cooperation, a narrow vagina, a small uterus, and significant contractures.

**Special Consideration: Antiepileptic Drugs and Hormone Use**

Even though estrogen is a proconvulsant, combined OCs have not been associated with an increase in seizures. Irregular bleeding is common and contraceptive effectiveness may be affected by enzyme inducing antiepileptic drugs (24). Progestins increase seizure threshold and can play an important role for women with epilepsy (25). Estrogen or progesterone content may need to be increased or DMPA may be used in 10-week intervals to decrease irregular bleeding (26).

**Surgical Methods**

**Endometrial Ablation**

Endometrial ablation aims to treat heavy bleeding by selectively destroying the endometrial lining while leaving the uterus intact. It is generally recommended with concomitant contraception or sterilization, only if reproduction is no longer desired. The use of endometrial ablation in adolescents with disabilities is not recommended because of the following issues:

- There is no real long-term outcome data (for example, 20–40 years) or data on adolescents.
- Guardians and patients who request endometrial ablation in adolescents with disabilities do so in the hope to obtain amenorrhea, which occurs in approximately 13–47% of adults at 12 months (27).
- Women younger than 45 years experience a significantly higher failure rate of the procedure than older women (28).
- Although ablation is not considered sterilization by many, the destruction of the endometrium will render the patient subfertile, if not infertile. In the event that pregnancy ensues after an ablation, complications are likely (29).
- Consent requirements for sterilization in adolescents with disabilities who cannot give their own consent, either because of age or developmental delay, should apply to this procedure as well (1). Although there are laws in some states protecting minors from sterilization procedures, it is unclear if these laws apply to ablation.

**Hysterectomy**

Occasionally, a family may request a hysterectomy for definitive amenorrhea in adolescents with disabilities. Issues with hysterectomy in this situation include that this method is always irreversible and has the highest potential for morbidity and mortality. In situations when guardians request hysterectomy, it is critical to define what benefits they desire. Hysterectomy is seen by some as ideal for pregnancy prevention, and menstrual control may be a secondary goal. It is critical for guardians to understand that a hysterectomy will not protect the child from the hazards of sexual abuse or sexually transmitted infections. Only very rarely should a hysterectomy be considered for adolescents with disabilities, just as for teenagers without disabilities, such as when they are done for extreme situations like cancer. Abnormal bleeding is almost always managed medically for a teenager without disabilities. The same should be true for adolescents with disabilities. Laws regarding minor sterilization, hysterectomy, and consent issues vary from state to state.
Guidelines are available from the American College of Obstetricians and Gynecologists regarding consent (1).

References