Curbside Consultation

Menstrual Concerns in an Adolescent with Disabilities

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Case scenarios are written to express typical situations that family physicians may encounter; authors remain anonymous. Send scenarios to afpjournal@aafp.org. Materials are edited to retain confidentiality.

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Case Scenario

A mother brought her 12-year-old daughter to my clinic for gynecologic concerns. The daughter has a congenitally acquired intellectual disability. Recently, the girl began to menstruate, which appeared to cause her distress. While at school, she repeatedly removed her sanitary pad. The mother asked about a procedure to stop her daughter's menstrual periods. She was unable to say which procedure she meant, only that a friend had arranged one for her daughter. We discussed long-acting contraception and recommendations to wait and see whether her daughter might become accustomed to her menses. Is it ethical to initiate a long-acting contraceptive in this adolescent to suppress menses? If the mother was requesting something more permanent than implantable or intrauterine long-acting contraception, what is the best way to proceed?

Commentary

Clinicians who care for female adolescents with cognitive and physical disabilities are often consulted on the management of menstrual bleeding for purposes of hygiene, dysmenorrhea, and treatment of premenstrual symptoms.[1-3] Contraception is also commonly discussed to mitigate pregnancy risk from consensual intercourse and situations of abuse.[1-3] During these visits, discussions regarding menstrual suppression are common. Effective interventions may improve patient quality of life and caregiver fatigue *(Table 1*[1-5]*)*. The following principles can be applied in such cases.

ASSESS CONTEXT AND NEEDS

The clinician should first determine the patient's and caregiver's concerns and their impact on the patient's quality of life and daily activities.[2-4] A patient with mild to moderate cognitive disabilities should also be interviewed alone to discuss her menstrual history, sexual interests and behaviors, and potential risk of pregnancy and sexual abuse.[2-4] She should not be assumed to be asexual.[2-5]

Menstruation can appear to be disproportionately heavy in adolescents with disabilities because of psychosocial factors and hygiene difficulties. When abnormal bleeding is suspected or risk factors are identified, clinicians should consider screening for pregnancy, sexually transmitted infections, sexual trauma, thyroid disease, and hyperandrogenism. Most cases of abnormal bleeding in this age group can be attributed to anovulatory cycles.[6] Bleeding that is refractory to treatment or causing anemia may prompt evaluation for coagulopathies.[6]

ASSESS ABILITY TO CONSENT

The psychosocial interview can also be used to assess and document the patient's decision-making capacity and ability to consent to voluntary sexual activity, which may fluctuate over time.[2,5] Patients who are unable to make informed decisions should still be given the opportunity to assent to (i.e., formally accept) treatments.[2,5] Legal guardians retain the ability to consent to therapies within the context of state and jurisdictional requirements, and courts do not challenge parental consent for provision of reversible contraception.[2,5] Patients with disabilities have a high risk of sexual and physical abuse. Accordingly, the clinician should provide developmentally appropriate education on saying "no," leaving the situation, and disclosing abuse.[2,3]

CONSIDER MENSTRUAL SUPPRESSION

Improving mild symptoms of menstruation may only require education and

reassurance.[1-5] For example, most adolescents who are successful at toileting can be taught to use hygiene products.[2,3,5] However, additional interventions are commonly needed for hygiene and contraceptive concerns. Medications to suppress menses should be delayed until menarche because of their adverse effects on growth.[1]

Menstrual suppression can be safely and reliably accomplished with extended-cycling or continuous combined hormonal contraceptives (i.e., multiple contiguous cycles followed by a hormone-free interval, or no hormone-free interval, respectively); the levonorgestrel-containing intrauterine system (Mirena); and depot

Table 1. Select Considerations for Menstrual Manipulation and Symptom Control in Adolescents with Disabilities

Treatment	*Indications*	*Advantages*
Preferred options for menstrual suppression		
Combined contraceptive patch	Menstrual hygiene, premenstrual syndrome, contraception, dysmenorrhea, menstrual suppression	Extended or continuous use; predictable duration of menses
Combined contraceptive ring	Menstrual hygiene, premenstrual syndrome, contraception, dysmenorrhea, menstrual suppression	Extended or continuous use; predictable duration of menses
Combined oral contraceptives	Menstrual hygiene, premenstrual syndrome, contraception, dysmenorrhea, menstrual suppression	Extended or continuous use; predictable and adjustable duration of menses; certain formulations may be chewed or administered per gastronomy tube
Depot medroxyprogesterone (Depo-Provera)	Menstrual hygiene, premenstrual syndrome, dysmenorrhea, contraception, menstrual suppression	Four injections per year; high rates of amenorrhea
Levonorgestrel-containing intrauterine system (Mirena)	Menstrual hygiene, contraception, dysmenorrhea, menstrual suppression	May help reduce heavy bleeding; effective for three or five years (depending on model) without need for patient action
Other options for menstrual suppression		
Hysterectomy	Contraception, menstrual hygiene, menstrual suppression	Permanent
Progestin-only pills*	Menstrual hygiene, contraception, dysmenorrhea	May be used temporarily to assess effect of progestin on behavior and mood before longer-acting progestin-only method is established
Adjunctive treatments†		
Emergency contraceptive pills	Contraception	Greatly decrease rate of pregnancy when used within three to five days of intercourse
Nonsteroidal anti-inflammatory drugs	Menstrual hygiene, dysmenorrhea (and resultant cyclical behavioral changes)	Nonhormonal; may use intermittently
Progestin implant	Contraception, dysmenorrhea	Effective for three years without need for patient action
Selective serotonin reuptake inhibitors	Cyclical behavioral changes, mood disturbance, depression, anxiety	Nonhormonal

**—Higher dosages with less frequent hormone-free interval (compared with standard contraception regimen) may be needed to suppress menses.*

†—For contraception, condoms or other barrier methods should be offered in addition to nonbarrier methods to protect against sexually transmitted infections.

Information from references 1 through 5.

medroxyprogesterone (Depo-Provera).[1,2,7] A large cohort study showed that caregiver satisfaction was achieved after trials of up to four methods (mean = 1.5).[1] A comprehensive review of contraception has been published in *American Family Physician*.[8]

Estrogen-Containing Methods. Combined hormonal contraceptives are safe for adolescents with disabilities; however, clinicians should be aware of conditions that may preclude their use.[7-9] More research is needed to elucidate any additional risk of thromboembolic disease in immobile adolescents using combined hormonal contraceptives. Patients may benefit from exercise of the extremities, avoidance of

Disadvantages	*Comments*
Breakthrough bleeding; may be less effective at contraception in persons weighing > 198 lb (90 kg); patient may prematurely remove patch	Additional risk of thromboembolic events in patients who are immobile is unknown; estrogen exposure may be higher than with use of other estrogen-containing methods; effectiveness may decrease with use of specific antiepileptic drugs (e.g., topiramate [Topamax])
Breakthrough bleeding; assistance often needed for placement (privacy issues)	Additional risk of thromboembolic events in patients who are immobile is unknown; effectiveness may decrease with use of specific antiepileptic drugs (e.g., topiramate)
Breakthrough bleeding; may require surveillance for daily use	Additional risk of thromboembolic events in patients who are immobile is unknown; daily regimen may be advantageous in situations where other daily medications are regularly given; effectiveness may decrease with use of specific antiepileptic drugs (e.g., topiramate)
May decrease bone mineral density, especially in patients who are immobile; weight gain in adolescents who are overweight or obese; irregular bleeding (tends to improve over time)	Weight gain may affect independence and mobility (e.g., patient transfers)
Irregular bleeding (tends to improve over time); potential need for sedation; patients may be unable to voice pain or discomfort associated with procedure or complications	Five-year model likely preferred because the three-year model has limited data on menstrual control and requires more frequent replacements
Surgical complications	Legal and ethical considerations of sterilization apply; generally not a first-line treatment
Irregular bleeding; may require surveillance for daily use	Daily regimen may be advantageous in situations where other daily medications are regularly given; effectiveness may decrease with use of specific antiepileptic drugs (e.g., topiramate)
Not typically intended for ongoing contraceptive needs	May be considered as a primary contraceptive method in persons who have infrequent and consensual intercourse, and who can remember to take pill at time of intercourse
Not likely to result in complete menstrual suppression; gastrointestinal adverse effects	—
Likelihood of irregular bleeding limits its usefulness for menstrual suppression	Insertion and removal may be challenging for some patients; effectiveness may decrease with use of specific antiepileptic drugs (e.g., topiramate)
May worsen mood	U.S. Food and Drug Administration's boxed warning on risk of suicidality applies

third-generation progestins, and evaluation for thrombophilia (or inherited thrombophilia) if indicated by personal or family history.[2,4] Breakthrough bleeding experienced by patients using extended or continuous combined hormonal contraceptives may be addressed with scheduled hormone-free intervals.[7,8] The combined contraceptive patch provides a relatively high dose of estrogen and may be inadvertently removed, whereas the vaginal ring may introduce privacy concerns.[2,3,5]

Progestin-Only Methods. Progestin-only methods are safe for postmenarchal adolescents.[9] Although the frequency and amount of uterine bleeding may be unpredictable initially, depot medroxyprogesterone and the levonorgestrel-containing intrauterine system reliably decrease bleeding over time.[2,3,5,7] Approximately 15% of subdermal implant users request early removal because of irregular bleeding,[10] thereby limiting its use in these circumstances. Placement and removal of the levonorgestrel-containing intrauterine system may require sedation, and some patients may not communicate pain associated with complications.[2,9] Depot medroxyprogesterone has historically been used as a first-line method to suppress menses; however, this trend may have reversed because of concerns about reversible bone mineral density loss (albeit unclear fracture risk) and weight gain in users who are overweight and obese that could potentially hinder their mobility and independence.[1-3,11] *Table 1* discusses indications for and advantages and disadvantages of progestin-only pills.[1-5]

IDENTIFY CATAMENIAL SEIZURES

Seizures associated with menses are common in patients with disabilities, and combined hormonal contraceptive use in this circumstance is typically safe.[2,9] Some antiepileptics, such as topiramate (Topamax), may decrease the effectiveness of combined hormonal contraceptives, progestin-only pills, and contraceptive implants; therefore, depot medroxyprogesterone or a levonorgestrel-containing intrauterine system may be most helpful for pregnancy prevention.[9] Patients taking lamotrigine (Lamictal) may experience decreased serum levels during combined hormonal contraceptive use, potentially limiting its effectiveness in preventing seizures.[9]

ADDRESS MOOD AND BEHAVIOR

Premenstrual symptoms, distress over the sight of blood, and dysmenorrhea can affect the patient's mood and behavior, and contribute to caregiver burnout. Education and reassurance are first-line treatments. Nonsteroidal anti-inflammatory drugs may mitigate transient dysmenorrhea and bleeding, which may reduce behavioral symptoms.[2,3,5] Menstrual suppression or provision of a selective serotonin reuptake inhibitor may be a reasonable approach to improving mood and behavior, albeit supported by limited evidence.[2,3]

ADDRESS REQUESTS FOR STERILIZATION

In some cases, caregivers inquire about irreversible surgical management. State requirements regarding sterilization of minors and individuals with disabilities vary greatly and may be found in statutes or case law.[5] Endometrial ablation may lead to amenorrhea and infertility; however, the failure rate is greater in younger patients, and less than one-half experience amenorrhea.[2,3] The American College of Obstetricians and Gynecologists does not support endometrial ablation for menstrual suppression.[2-4]

Hysterectomy is considered a last resort and is primarily reserved for medically necessary cases because of associated morbidity and mortality rates, and the availability of less invasive options. Additionally, there are concerns that hysterectomy may be prompted by a coerced decision or forced effort to violate a patient's reproductive rights; that it does not lower the risk of sexual abuse or harassment; and that it does not affect the patient's sexual behavior.[1-5] When other treatments have been unsuccessful and sterilization is sought in good faith (e.g., not for convenience), an ethics committee or legal consultation may be helpful before proceeding.[5]

RECOMMENDATIONS

The patient in this case may be resistant to taking oral medications and unreliable in using the contraceptive patch. She would

likely be a good candidate for levonorgestrel-containing intrauterine system placement under anesthesia. The appointment could be coordinated with another visit requiring procedural sedation to avoid repeated anesthesia (e.g., a dental visit). Primary care clinicians can successfully manage menstrual suppression for adolescents, often producing significant and positive changes in the lives of these individuals and their caregivers.

The opinions and assertions contained herein are the private views of the authors and are not to be construed as official or as reflecting the views of the U.S. military at large, the U.S. Air Force, the U.S. Army, or their respective medical departments.

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REFERENCES

1. Kirkham YA, Allen L, Kives S, Caccia N, Spitzer RF, Ornstein MP. Trends in menstrual concerns and suppression in adolescents with developmental disabilities. *J Adolesc Health*. 2013;53(3):407-412.
2. Quint EH. Menstrual and reproductive issues in adolescents with physical and developmental disabilities. *Obstet Gynecol*. 2014;124(2 pt 1):367-375.
3. American College of Obstetricians and Gynecologists. Reproductive health care for adolescents with disabilities (supplement to guidelines for adolescent health care, 2nd edition). 2012. http://www.acog.org/Resources_And_Publications/Guidelines_for_Adolescent_Health_Care/Reproductive_Health_Care_for_Adolescents_With_Disabilities (login required). Accessed March 30, 2015.
4. American College of Obstetricians and Gynecologists Committee on Adolescent Health Care. ACOG committee opinion no. 448: Menstrual manipulation for adolescents with disabilities. *Obstet Gynecol*. 2009;114(6):1428-1431.
5. Paransky OI, Zurawin RK. Management of menstrual problems and contraception in adolescents with mental retardation: a medical, legal, and ethical review with new suggested guidelines. *J Pediatr Adolesc Gynecol*. 2003;16(4):223-235.
6. Committee on Practice Bulletins—Gynecology. Practice bulletin no. 136: Management of abnormal uterine bleeding associated with ovulatory dysfunction. *Obstet Gynecol*. 2013;122(1):176-185.
7. Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC). U.S. selected practice recommendations for contraceptive use, 2013: adapted from the World Health Organization selected practice recommendations for contraceptive use, 2nd edition. *MMWR Recomm Rep*. 2013;62(RR-05):1-60.
8. Klein DA, Arnold JJ, Reese ES. Provision of contraception: key recommendations from the CDC. *Am Fam Physician*. 2015;91(9):625-633.
9. Centers for Disease Control and Prevention (CDC). U.S. medical eligibility criteria for contraceptive use, 2010. *MMWR Recomm Rep*. 2010;59(RR-4):1-86.
10. Darney P, Patel A, Rosen K, Shapiro LS, Kaunitz AM. Safety and efficacy of a single-rod etonogestrel implant (Implanon): results from 11 international clinical trials. *Fertil Steril*. 2009;91(5):1646-1653.
11. Lopez LM, Edelman A, Chen M, Otterness C, Trussell J, Helmerhorst FM. Progestin-only contraceptives: effects on weight. *Cochrane Database Syst Rev*. 2013;(7):CD008815. ■