Menstrual suppression in an adolescent with intellectual disability

By Casey S. Hopkins, PhD, RN, WHNP-BC

Abby is a 12-year-old girl with an autism spectrum disorder, attention-deficit/hyperactivity disorder (ADHD), and intellectual disability (ID). She presents to the pediatric and adolescent gynecology (PAG) office with her mother, Liz. Abby has not yet started having periods. Liz noticed Abby's breasts began to develop about a year and a half ago, and Abby has recently had a growth spurt in height. The pediatrician mentioned at Abby's well-child appointment last month that menarche was likely to be right around the corner. Liz expressed her concern about Abby being able to handle her periods on her own. The pediatrician referred them to the nurse practitioner at the PAG office to discuss preparation for and management of menstruation.

Abby is currently taking methylphenidate 36 mg daily for treatment of ADHD. She is communicative verbally. Liz reports Abby functions cognitively at about the level of a 7-year-old child. Abby attends school daily and enjoys her friends and teachers at school. She has an individualized education plan and is in a special education class. She lives at home with her mother, father, and older sister.

Liz expresses her concerns to the nurse practitioner (NP) regarding menstruation and how Abby will cope with it. She is concerned that Abby will not understand what is happening when menstrual bleeding occurs. She worries that Abby will experience pain with menses and may not be able to communicate effectively regarding the pain. Liz is also uncertain that Abby will be able to manage using a pad. Abby is continent of urine and stool. She is independent with toileting, but sometimes she does not thoroughly wipe after a bowel movement and needs to be reminded or assisted. Furthermore, Liz expresses that she is concerned about how all of this will increase caregiver burden for the family and Abby's teachers at school.

What should the NP know about menstruation in girls with intellectual disability?

Although there may be some variation in the timing of maturation

depending on the type of disability, for the most part, girls with ID follow the same pattern of pubertal maturation as girls without disabilities.[1] Challenges with menstruation may arise when the girl's level of understanding limits her ability to conceptually understand menstruation, develop new skills necessary to manage it, and/or communicate her feelings or needs. The impact of menstruation on the daily life of the girl and her caregivers is highly dependent on her level of disability. Generally, girls who are able to manage toilet hygiene can learn to manage their menstrual hygiene independently. Therefore, assessing continence and toileting needs is an important point of assessment. Many girls with disabilities are capable of and do manage menses very well. Anticipatory guidance for menstruation is imperative. Girls with disabilities may need longer to practice and prepare for the skills necessary to manage menstruation.[2]

How should the NP proceed with the office visit?

Although a general physical exam is warranted, a pelvic exam is almost never indicated for an adolescent who is not sexually active and would only be indicated in the case of a vulvovaginal complaint such as a vaginal discharge or if there was suspicion of sexual abuse. Depending on the adolescent and her level of understanding, the pelvic exam may be performed under anesthesia.[3] In Abby's case, there is no reason to perform a pelvic exam during her office visit. At this point, the focus of the visit should be on anticipatory guidance for Abby and her mother. The NP should engage Abby by talking to her directly about puberty and menstruation in a clear and matter-of-fact way. It is also important for the NP to use formal language for body parts and functions (eg, period, vulva, vagina) to provide clarity and to help Abby learn words to use as she continues to learn about puberty and sexuality.

The NP explains the nature of the menstrual cycle and tells Liz and Abby what to expect with menarche. In the United States, the average age of menarche is between ages 12 and 13 years. It typically occurs 1½ to 3 years after breast budding, when breasts and pubic hair are near Tanner stage 4, and after growing 3 or more inches over the course of about 6 to 8 months.[3] Irregular periods are very common within the first 2 to 3 years after menarche due to the immature hypothalamic-pituitary-ovarian axis. The NP provides a simple explanation of the menstrual cycle to Abby. The NP also encourages Liz to continue providing education at home regarding the normality of menstruation in girls going through puberty (**See "Teaching About Periods-Story" in Healthy Bodies Appendix-Girls**[A]). In an effort to normalize menses and help to prepare Abby, it is suggested that she observe her mother or sister change a pad, dispose of a used pad, and place a new pad so she can know what to expect, especially regarding the sight of menstrual blood (**See "How to Use My Pad" in Healthy Bodies-Girls**[A]). Abby should have opportunities to practice opening and placing a pad in her underwear and should also practice wearing the pad around so she can become familiar with what it feels like to wear one.

Abby and her mother are reassured and instructed to keep a bleeding calendar when menses begins. The NP also explains that scheduled nonsteroidal anti-inflammatory drugs (NSAIDs) dosed appropriately may reduce menstrual flow by 30% to 40% and may help with dysmenorrhea.[3] They are advised to follow up with the NP if they decide they would like to explore options for menstrual suppression following Abby's initial experience with menses.

What is menstrual suppression?

The goal of menstrual suppression is to lessen the total number of menstrual flow days and to reduce the amount of flow.[3] Initiation of methods to suppress menstruation before menarche is not recommended.[3] Allowing menarche to occur confirms normal hormonal and anatomic function and does not limit the child's height potential.[3] Nurse practitioners should set realistic expectations and explain to girls and their caregivers that even with the use of hormonal methods for menstrual suppression, it is unlikely that complete amenorrhea will be achieved. Thus, some bleeding is to be expected.[1]

In a recent systematic review of the literature concerning menstrual suppression in girls with disabilities, the authors found that healthcare providers are most commonly using combined oral contraceptive pills (28-day, extended-cycle, or continuous dosing) to suppress menses.[4] Depot-medroxyprogesterone acetate (DMPA) and levonorgestrel-releasing intrauterine system (LNG-IUS) (most often placed under sedation or anesthesia) are also used. Both of these methods may initially cause irregular bleeding, but amenorrhea is usually achieved after several months. Other options such as the progestin-only birth control pill, transvaginal ring, and transdermal patch are used less commonly for menstrual suppression in girls with ID. Unscheduled bleeding is common with progestin-only birth

Nurse practitioners should partner with girls with ID and their caregivers to support open communication and optimal gynecologic health. Clear communication, goal setting, realistic expectations, and consistent follow-up are key to promoting positive experiences with menstruation and menstrual suppression for girls with ID and their caregivers.

control pills especially if not taken at the same time each day. Girls with ID may have difficulty inserting a transvaginal ring or cooperating for a caregiver to do the insertion. They may decide to remove the transdermal patch or not be attentive to inadvertent separation from the skin.[3,4]

The etonogestrel subdermal implant is not recommended as a first-line therapy for menstrual suppression due to the high incidence of irregular, prolonged bleeding and the degree of patient cooperation needed to place the implant.[3]

Hormonal contraceptives are not approved by the US Food and Drug Administration solely for menstrual suppression. However, both the American College of Obstetricians and Gynecologists and North American Society for Pediatric and Adolescent Gynecology provide guidelines for use for this purpose after careful patient evaluation and consideration of advantages and disadvantages based on individual needs.[1,3] Healthcare providers should assess for contraindications or risks to use of any hormonal contraceptives using the US Medical Eligibility Criteria for Contraceptive Use.[5] Caution is recommended with regard to the use of any of the estrogen-containing contraceptive methods if the patient also has physical disabilities that significantly limit mobility because of a possible increase in risk for venous thromboembolism.[3]

Some caregivers of girls with ID will ask about surgical options for menstrual management considering the benefit of pregnancy prevention and menstrual control. Surgical sterilization of a woman with disabilities is an ethically complex issue, and a major surgery that is not without health risks (especially in an individual with disabilities who may have other comorbidities) and has considerable costs.[1] Endometrial ablation is not recommended for adolescents with disabilities and should not be offered.[3] A hysterectomy for menstrual control should be considered only when all other reasonable alternatives have been attempted and failed.[3] Laws regarding hysterectomy, sterilization, and consent in minors vary from state to state and must be considered before proceeding with surgery.[3]

The follow-up visit

Abby and Liz return to the PAG office 8 months after their first visit. Abby started her period a month after her 13th birthday. She has had four periods so far. Liz reports the first period lasted about 8 days. Seven weeks went by before Abby had her second period, which lasted 7 days. The two periods following her second period were regular, occurring 28 days apart and lasting 5 to 7 days. Abby's mother describes the menstrual flow as moderately heavy. Abby needs to change a pad about every 3 to 4 hours. She has to be reminded to change her pad and has placed the pad upside down a few times, which has caused discomfort and problems with blood staining onto her pants. Liz has managed this by accompanying Abby to the bathroom to ensure the pad is placed appropriately.

In addition to difficulty with menstrual hygiene, Abby is experiencing changes in her mood and behavior during the week leading up to her period and while she is on her period. During this time of the month, she has frequent outbursts of anger resulting in tantrums involving screaming and throwing things. She is able to calm down within an hour by watching a movie, coloring, or sitting quietly and taking deep breaths. Regarding pain with menses, Abby did complain that her "stomach hurt" during her last period. Liz reports giving Abby 400 mg of ibuprofen, which seemed to alleviate the pain. Abby is quiet throughout the office visit. She responds appropriately with yes and no answers to questions from the NP and looks to her mother to explain

details of her experience with menstruation. Liz asks the NP what they can do to make Abby's periods easier.

The plan for Abby

Attentive to Liz's concerns regarding Abby's mood changes, dysmenorrhea, and challenges with managing menstrual flow, the NP discusses viable options to meet their needs. Due to the significant challenges with mood changes during the menstrual cycle, Liz states that she would be interested in a hormonal method. The options discussed are hormonal contraceptive methods including oral contraceptive pills, the transdermal patch, the transvaginal ring, DMPA, and LNG-IUS. After discussing each method with the NP and weighing the risks and benefits of each, Liz and Abby decided they would like to start continuous oral contraceptive pills to suppress menstruation and manage the associated mood changes and dysmenorrhea.

The NP selects a monophasic combined oral contraceptive pill containing 30 µg of ethinyl estradiol (EE). Oral contraceptive pills containing doses of EE lower than 30 µg are less likely to provide adequate stabilization of the endometrium, therefore resulting in more frequent breakthrough bleeding.[6] She provides instructions on taking the pill at the same time daily, preferably after a meal to prevent nausea. For continuous dosing, active pills should be taken continuously. The inactive (or placebo) pills should be discarded. The NP explains that it is common to have irregular bleeding, especially within the first 2 months on a new oral contraceptive pill. Once menstruation is suppressed on the pill, if bleeding ever becomes heavy or persistent for more than a few days, she is instructed to take 4 days off the pill to allow for a withdrawal bleed and then restart the active pills. Lastly, the NP reviews other common side effects associated with combined oral contraceptive pills such as temporary mood changes and breast tenderness and adverse effects including warning signs of venous thromboembolism. Liz and Abby are happy to have a plan for menstrual management moving forward. Before leaving the office, they schedule an appointment to follow up with the NP in 3 months.

Reflections for practice

When discussing menstrual suppression, it is imperative to consider the expressed wishes of the girl with ID and those of her caregivers, any existing comorbidities, risk of deep vein thrombosis, compromised bone mineral density, and any other risks and benefits related to the medical modality being used.[4] In addition to providing information on menstrual suppression, the NP should also discuss sexual activity and related risks. It should not be assumed that the adolescent girl with disabilities is not sexually active. Furthermore, it is important that girls and their caregivers understand the use of a contraceptive method or even a hysterectomy for menstrual suppression will not protect from sexual abuse or sexually transmitted infections. Nurse practitioners should partner with girls with ID and their caregivers to support open communication and optimal gynecologic health. Clear communication, goal setting, realistic expectations, and consistent follow-up are key to promoting positive experiences with menstruation and menstrual suppression for girls with ID and their caregivers. ■

Casey S. Hopkins is Assistant Professor of Nursing at Clemson University in Clemson, South Carolina, a women's health nurse practitioner in the Division of Pediatric and Adolescent Gynecology, Department of Obstetrics and Gynecology, at Prisma Health-Upstate in Greenville, South Carolina, and Clinical Assistant Professor at the University of South Carolina School of Medicine-Greenville. The author has no actual or potential conflicts of interest in relation to the contents of this article.

References

1. Quint EH, O'Brien RF; Committee on Adolescence; North American Society for Pediatric and Adolescent Gynecology. Menstrual management for adolescents with disabilities. *Pediatrics*. 2016;138(1):e1-e9.
2. Tracy J, Grover S, Macgibbon S. Menstrual issues for women with intellectual disability. *Aust Prescr*. 2016;39(2):54-57.
3. American College of Obstetricians and Gynecologists' Committee on Adolescent Health Care. Committee opinion no. 668. Menstrual manipulation for adolescents with physical and developmental disabilities. *Obstet Gynecol*. 2016;128(2):e20-e25.
4. Hopkins CS, Fasolino T. Menstrual suppression in girls with disabilities. *J Am Assoc Nurse Pract*. 2020. Online ahead of print.
5. Curtis KM, Tepper NK, Jatlaoui TC, et al. U.S. Medical Eligibility Criteria for Contraceptive Use, 2016. *MMWR Recomm Rep*. 2016;65(3):1-103.
6. American College of Obstetricians and Gynecologists. Committee opinion no. 785. Screening and management of bleeding disorders in adolescents with heavy menstrual bleeding. *Obstet Gynecol*. 2019;134(3):e71-e83.

Web resource

A. vkc.vumc.org/healthybodies/files/HealthyBodies-Girls-web.pdf