

Menstrual Suppression in Adolescent Females with Intellectual Disability

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Received: 29/1/2020; revised 25/2/2020; Accepted: 3/3/2020

[citation: Johnson, Macey. & Omar, Hatim. (2020). Menstrual Suppression in Adolescent Females with Intellectual Disability. DHH, 7(1):https://journalofhealth.co.nz/?page_id=2060].

Introduction

When caring for adolescent females who have an intellectual disability (ID), a variety of factors must be considered that may not be implicated in other patients. One of these is the complex reproductive and sexual function needs of these patients. More specifically, menstruation brings challenges with these patients due to a variety of factors that will be discussed throughout this article. The caregivers of these patients may seek medical advice for ways to manage menstruation and alleviate symptoms for the patient.

If these patients experience mild symptoms of menstruation, education and reassurance can be an effective way to treat these symptoms. Many of these girls are able to manage proper hygiene without help from caregivers once this education and reassurance occurs [18]. For those adolescent girls with more severe symptoms or those who are unable to manage menses on their own, menstrual suppression can be effective. Menstrual suppression has been an option for those adolescent girls with ID whose caregivers feel that menstruation brings physical and psychological challenges to the adolescents as well as themselves, and that the adolescents would experience a benefit or increased quality of life if it is suppressed.

Caregivers seek counsel regarding menstrual suppression for several reasons. One of these is that many adolescent females with intellectual disabilities experience distress when they menstruate, often alarmed because of a lack of sexual health education and subsequent understanding of the purpose and normality of menstruation [5, 6]. Additionally, reproductive hygiene can be a challenge for these patients, and menstruation exacerbates this. Patients who have physical limitations may be unable to practice adequate menstruation hygiene, and caregivers often find it very challenging to help patients with this need [4]. These patients also experience the same menstrual side effects and morbidities that other adolescents face, such as dysmenorrhea, hemorrhagic diatheses, behavior changes, and uterine bleeding [1, 12]. In some cases, patients with intellectual disabilities face these side effects or disorders at higher rates than the overall population [13, 14, 15]. Another common concern from caregivers is the vulnerability that patients with intellectual disabilities have for sexual abuse [1]. This population is more at risk for sexual abuse than those who do not have intellectual disabilities [8]. For this need, contraception is particularly important. However, menstrual suppression will not affect the possibility of contracting a sexually transmitted infection (STI), which must be iterated to caregivers. Ethical concerns of menstrual suppression should also be assessed, specifically when caregivers are responsible for decision-making.

A growing body of research exists that investigates the methods of menstrual suppression in this population, the efficacy of these methods, and the implications and facets of menstrual suppression that physicians should consider when treating with patients. This article aims to highlight recent findings in menstrual suppression in patients with intellectual disabilities, as well as identify areas where more research is needed.

Considerations and Implications of Menstrual Suppression in Adolescents with Intellectual Disability

Intellectual Disability

Adolescent females with ID face significant challenges posed by menstruation and proper management and hygiene. These challenges differ in severity, and specific intellectual disabilities pose their own distinct challenges, from behavior changes during menstruation to increased prevalence of endocrine disorders affecting menstruation. Menstrual suppression is a common treatment that caregivers will seek for adolescents with ID. Intellectual disability categories that have been identified as associated with menstrual suppression are chromosomal/syndromic genetic disorders (such as Trisomy 21), Cerebral Palsy, Autism Spectrum Disorder (ASD), unspecified intellectual disability [3], neurological disorders, and developmental disorders [10].

Emotional Effects

Menstruation has long been characterized as a symbol of change. With this change, emotions and behavior are often affected. Specifically in adolescents with ID, behavioral changes can often occur post-menarche. Many caregivers report behavioral changes that occur after a girl begins to menstruate [3], which cause distress to both the girl and her caregiver. These behaviors include irritability, restlessness, self-inflicted injury, crying, and trouble sleeping [4]. Behavior change is one of the most common reasons a caregiver seeks information about menstrual suppression [3].

Menarche can often be a traumatic experience for adolescent girls with ID. Often, these girls have not received adequate sexual health education, often due to misconceptions surrounding individuals with ID and sexuality [6], so menses can be surprising and disturbing. Along with proper sexual health education, menstrual suppression is a way to prevent unnecessary distress that these adolescents would face each month.

Menstruation Hygiene

A common challenge for parents and guardians of adolescent girls with ID is the management of hygiene during menstruation. Over half of adolescent females with intellectual disabilities are not able to carry out management of menses on their own, with a portion completely relying on a parent or caregiver to do so [1]. With these adolescents going to school and participating in other extracurricular activities, this can be a burden on both the girls and their caretakers. With these adolescents attaining menses at an average age of 11-12 [1,3] and a majority of girls having menses that last from 3 to 7 days [1], management can be a very involved process for many caregivers, and one that can lead to these adolescents becoming distressed. Hygiene concerns and challenges is a potential motivator to seek menstrual suppression. Many adolescents refuse to wear pads, often taking them off throughout the day [4], and caregivers are required to wash sheets daily and clothes multiple times throughout each day the adolescent menstruates [4]. Additionally, some adolescents with ID have difficulties with distinguishing appropriate boundaries between public and private socially accepted behaviors. This can lead to inappropriate management and discard of used menstrual products in public [5]. Menstrual suppression takes away or decreases the burden placed on many caregivers to manage menstruation hygiene and prevent improper management.

Sexuality and Sexual Education in Adolescents with ID

Adolescents with ID face significant barriers to being exposed to adequate sexual education. Most notably, these adolescents are perceived to be asexual by the public [7], although adolescents with ID experience sexual feelings and desires at comparable rates to typically developing (TD) adolescents [5]. This misconception leads to a lack of education both at home and school that includes appropriate information regarding sexual activity, healthcare

needs, and contraception [5]. This lack of education contributes to distress and difficulty managing menstruation in adolescents with ID. Because of the current lack of education that these individuals receive, healthcare providers are an essential source for support and education regarding these individuals' sexual health. Pediatricians and Adolescent and Pediatric OB/GYNs are best suited to educate these patients and their caregivers [5]. This education should include basic knowledge such as anatomy and privately versus publicly appropriate behaviors, as well as information about sexual intercourse and preventing pregnancy and STIs [6]. Despite many caregivers wanting to wait until adolescents are older before exposing them to sexual education information, it is shown that it benefits these adolescents to deliver early sexual education [9]. Many of these adolescents are fertile and have a higher risk of pregnancy as well as a lower rate of education of risks and preventative screening, showing the need for education to prevent pregnancy and STIs [11]. Educating these individuals is an important component of sexual health that should not be underestimated as a management tool for menstruation-associated issues.

Sexual Abuse

Females with ID have an increased vulnerability to sexual abuse compared to their TD peers, with reports that they are 2 to 3 times more likely to be sexually abused [8]. One proposed factor that influences this is the dependence these adolescents have on others for needs such as bathing and dressing, influencing them to have difficulties differentiating appropriate and inappropriate touching [6]. Education can allow these individuals to distinguish between what is appropriate and what is not.

One reported reason for seeking medical counsel regarding menstrual suppression is the worry of sexual abuse vulnerability [1]. While menstrual suppression can result in pregnancy prevention, it must be emphasized to caregivers that it does not prevent sexual abuse or sexually transmitted infections, and that the adolescent girls are still at risk for sexual abuse and the physical and mental trauma that follows. Sexual education and vigilance are effective ways to decrease the risk of sexual abuse that these adolescents face.

Menstrual Irregularities and Symptoms

Adolescents with ID face all of the menstrual irregularities that TD adolescent girls face, and some may face specific menstrual irregularities at higher rates than TD adolescent girls. This is another common reason that caregivers seek information regarding menstrual suppression [1]. Menstrual irregularities that adolescents with ID have include a variety of issues. One of the most common issues faced is dysmenorrhea, affecting over half of these adolescents [1]. Other symptoms include abdominal cramps and discomfort, nausea and vomiting, diarrhea, headache, and backache [1]. An additional challenge many caregivers report facing is that it is often difficult to tell when the adolescents are experiencing many of these symptoms and that they often rely on mood and behavior changes to recognize discomfort [4]. More severe irregularities or symptoms that can occur with menstruation in these adolescents include cyclic exacerbation of seizures or migraines in patients with neurological disorders, severe dysmenorrhea due to endometriosis, abnormal uterine bleeding, hemorrhagic diatheses, hormone withdrawal symptoms, and premenstrual dysmorphic disorders [12]. Some of these irregularities and symptoms occur more often in adolescents who have ID than in TD adolescents. These irregularities include dysmenorrhea or amenorrhea that can occur more frequently in those who take antipsychotic medications that affect the dopaminergic system [14]; those who have thyroid disease associated with trisomy 21 [13]; and polycystic ovary syndrome (PCOS) in individuals who have seizure disorders [15]. Menstrual suppression is an effective treatment for all of these associated irregularities and symptoms.

Menstrual Suppression Methods

There are a variety of menstrual suppression methods available, each with specific benefits and drawbacks that should be discussed by physicians and caregivers in order to find the best patient-centered option. These methods include combined oral contraceptives (COC); transdermal combined hormones in the form of a weekly contraceptive patch; vaginal ring; progestin-only contraceptive pill (POP); Depot medroxyprogesterone acetate (DMPA), a 12-week subcutaneous or intramuscular injection; subdermal implant; and the Levonorgestrel Intrauterine Device (LNG-IUD) [5]. Surgical interventions including endometrial ablation, tubal ligation, and hysterectomy are permanent and result in infertility, and they are not endorsed or recommended for menstrual suppression or contraception in adolescents [5]. COCs allow for decreased bleeding with possible amenorrhea if taken continuously without placebo pills but pose the challenge of requiring oral administration within the same time period each day [11]. The weekly patch also allows for decreased bleeding with possible amenorrhea with continuous use, but it is easily removed by patients and causes health risks including interactions with antiepileptic medications taken by adolescents with neurological disorders, venous thromboembolism (VTE), lower efficacy in obese adolescents, and increased risk of gallbladder disease. [11, 12]. The vaginal ring has the same advantages and risks as the weekly patch, except for it lasting a month, but being difficult to insert or remove and often requiring a caregiver [11]. POPs cause decreased bleeding but take higher doses to achieve amenorrhea. Other benefits include increasing seizure threshold and being better tolerated by adolescent females with contraindications to estrogen. The drawbacks of POPs are the unpredictability of bleeding, possibility of depression, and necessity to be administered within the same time period every day [11, 12]. Most patients who achieve menstrual suppression with the first method tried used DMPA [10]. DMPA is injected every 10-12 weeks by a provider, preventing the caregiver from administering the medication. Drawbacks include a risk of breakthrough bleeding and weight gain, as well as the discomfort of injections [12]. LNG-IUD was the second most likely method to achieve amenorrhea [10]. Benefits of the LNG-IUD include insertion every 5 years and minimal side effects. Risks include a difficult and painful insertion that may require sedation, initial breakthrough bleeding, minimum uterine length requirement of 5-6 cm, and risk of perforation, expulsion, or infection [11, 12]. Subdermal implants have been studied less than other methods, but do not seem to be proven as an efficacious method of menstrual suppression. These studies lead to the conclusion that DMPA or LNG-IUD are most likely to lead to menstrual suppression. Providers and caregivers must discuss the specific needs of each patient leading to a decision of which method is the best fit.

Ethical Considerations

When providers make any decisions regarding patients with ID, they must consider the ethical implications of treating a patient who may be unable to give full consent. Providers must assess the ability of each individual patient to understand and consent to treatment [17]. An important consideration is whether a caregiver's inquiry regarding menstrual suppression is to benefit the daughter or the caregiver; this affects whether or not certain risks should be taken when choosing to attempt menstrual suppression [17]. If a caregiver's concern is entirely based on what will benefit the patient, then it is appropriate to assess the use of menstrual suppression techniques, even if they have risks. However, if their concerns are mainly focused around the convenience of the caregiver, it would be more appropriate to consider non-medical interventions such as setting alarms on a patient's phone to help her remember to change her menstruation product [17]. As previously mentioned, surgical interventions such as tubal ligation and endometrial ablation are not appropriate methods of

menstrual suppression, and are only indicated if the patient has a medical necessity for them [17].

Summary

Adolescent females with ID face specific challenges due to menstruation that are endured by both patient and caregiver. Menstrual suppression along with proper patient education is a strategy that can be utilized in order to minimize discomfort and distress experienced by these patients and their caregivers. Potential benefits that these patients and caregivers can experience from menstrual suppression include the following:

1. Preventing negative emotional and behavioral changes that are associated with menstruation, such as irritability, restlessness, crying, trouble sleeping, and self-mutilation
2. Better management of personal hygiene, preventing or lessening the need for menstrual hygiene products that need to be regularly changed, as well as the need to frequently wash clothes and sheets
3. Preventing pregnancy
4. Treatment of menstrual irregularities and symptoms, such as abdominal pain and discomfort, nausea and vomiting, headaches, cyclic exacerbation of seizures, severe dysmenorrhea due to endometriosis, abnormal uterine bleeding, hemorrhagic diatheses, and premenstrual dysmorphic disorders.

While there are many possible benefits of menstrual suppression, there are also risks.

Possible risks include:

1. Thromboembolism from hormonal birth control
2. Risks undergoing general anesthesia if used for IUD placement
3. Weight gain
4. Interactions with anti-epileptic medications
5. Behavioral and mood changes

There are a variety of menstrual suppression methods available, including combined oral contraceptives (COC), transdermal contraceptive patch, vaginal ring, progestin-only contraceptive pill (POP), Depot medroxyprogesterone acetate (DMPA), and Levonorgestrel Intrauterine Device (LNG-IUD). DMPA followed by LNG-IUD have been found to be the most effective and well-tolerated menstrual suppression treatments. Surgical techniques including tubal ligation, endometrial ablation, and hysterectomy are not recommended due to being permanent and high-risk, as well as ethical concerns. Combined with proper sexual education, menstrual suppression is an effective method to managing a variety of problems adolescent females with ID face due to menses.

Conclusion

Menstrual suppression for adolescent females with ID can treat many challenges that present with management of menstruation for these patients and their caregivers. As more methods of contraception are developed and made available to the public, it is important that their potential benefits and risks are assessed for menstrual suppression in this patient population. Additionally, when physicians prescribe any menstrual suppression or contraceptive treatment, it is imperative that both the patient and caregiver receive appropriate education regarding menstruation and sexuality, taking into consideration that many of these patients do not receive the same sexual education that their TD peers do [5]. Despite stigma surrounding these patients, they experience sexual attraction and are often sexually active [5], underlining the need for proper sexual education. Additionally, they are vulnerable to sexual abusers, especially when they have not received appropriate sexual education [8]. Future studies focus

on the efficacy of proper sexual education for these patients, as well as its role combined with menstrual suppression in managing the care of these patients.

References

- [1] A. I. Nurkhairulnisa, K. T. Chew, A. A. Ainudin, et al., "Management of Menstrual Disorder in Adolescent Girls with Intellectual Disabilities: A Blessing or a Curse?," *Obstetrics and Gynecology International*, vol. 2018, pp. 1-5, 2018.
- [2] M. Zacharin, I. Savasi, and S. Grover, "The impact of menstruation in adolescents with disabilities related to cerebral palsy," *Archives of Disease in Childhood*, vol. 95, no. 7, pp. 526–530, 2010.
- [3] I. Chuah, A. McRae, K. Matthews, A. Maquire, and K. Steinback, "Menstrual management in developmentally delayed adolescent females," *Australian and New Zealand Journal of Obstetrics and Gynaecology*, vol. 57, no. 3, 2017.
- [4] Y. Chou and Z. Lu, "Caring for a daughter with intellectual disabilities in managing menstruation: A mother's perspective," *Journal of Intellectual & Developmental Disability*, vol. 37, no. 1, pp. 1-10, 2012.
- [5] C. Hall and E. Quint, "Sexuality and Disability in Adolescents," *Pediatric Clinics of North America*, vol. 64, no. 2, pp. 435-449, 2017.
- [6] E. Quint, "Adolescents with Special Needs: Clinical Challenges in Reproductive Health Care," *Journal of Pediatric and Adolescent Gynecology*, vol. 29, no. 1, pp. 2-6, 2016.
- [7] S. Esmail, K. Darry, A. Walter, and H. Knupp, "Attitudes and perceptions towards disability and sexuality," *Disabil Rehabil*, vol. 32, no. 14, pp.1148-1155, 2010.
- [8] S.J. Caldas and M.L. Bensy, "The sexual maltreatment of students with disabilities in American school settings," *Risk Factors and Outcomes for Victims of Child Sexual Abuse*, vol. 23, no. 4, pp. 345-366, 2014.
- [9] J.D. Pownall, A. Jaholda, and R.P. Hastings, "Sexuality and sex education of adolescents with intellectual disability: mothers' attitudes, experiences, and support needs," *Intellect Dev Disabil*, vol. 50, no. 2, pp. 140-154, 2012.
- [10] R. Leeks, C. Bartley, B. O'Brien, T. Bagchi, and R.M.N. Kimble. "Menstrual Suppression in Pediatric and Adolescent Patients with Disabilities Ranging from Developmental to Acquired Conditions: A Population Study in an Australian Quaternary Pediatric and Adolescent Gynecology Service from January 2005 to December 2015," *Journal of Pediatric and Adolescent Gynecology*, vol. 32, no. 5, pp. 535-540, 2019.
- [11] D. Abells, Y.A. Kirkham, and M.P. Ornstein, "Review of gynecologic and reproductive care for women with developmental disabilities," *Current Opinion in Obstetrics and Gynecology*, vol. 28, no. 5, pp. 350-359, 2016.
- [12] Y.A. Kirkham, M.P. Ornstein, A. Aggarwal, and S. McQuillan, "Menstrual Suppression in Special Circumstances," *Journal of Obstetrics and Gynaecology Canada*, vol. 36, no. 10, pp. 915-924, 2014.
- [13] V.P. Prasher, "Down syndrome and thyroid disorders: a review," *Down Syndrome Research and Practice*, vol. 6, pp. 25-42, 1999.
- [14] S.I. Bargiota, K.S. Bonotis, I.E. Messinis, and N.V. Angelopoulos, "The Effects of Antipsychotics on Prolactin Levels and Women's Menstruation," *Schizophrenia Research and Treatment*, vol. 23, pp. 1-10, 2013.
- [15] A.G. Herzog and S.C. Schacter, "Valproate and the polycystic ovarian syndrome: final thoughts," *Epilepsia*, vol. 42, pp. 311-315, 2001.
- [16] L. Allen and M. Ornstein, "Chapter 28: Developmental disability," *Practical pediatric and adolescent gynecology*, vol. 1, pp. 158-162, 2013.

- [17] K. Acharya and J.D. Lantos, "Considering Decision Making and Sexuality in Menstrual Suppression of Teens and Young Adults with Intellectual Disabilities," *AMA Journal of Ethics*, vol. 18, no. 4, pp. 365-372, 2016.
- [18] Y.A. Kirkham, L. Allen, S. Kives, et al., "Trends in Menstrual Concerns and Suppression in Adolescents with Developmental Disabilities," *Journal of Adolescent Health*, vol. 53, no. 3, 2013.