Menstrual Manipulation for Adolescents with Disabilities

Allison Rodrigues
PGY-4 Pediatrics
October 1, 2013
Case

- 11 yo female with moderate intellectual disability
  - Parents concerned regarding onset of puberty
  - Fear of blood and sensory issues of blood
  - Would like to discuss options for managing menses
Case

- How do you approach the family and the patients’ concerns?

- What information can you provide for managing her menses?
Objectives

- **Medical Expert**
  - Review common issues related to menstruation in girls with disabilities
  - Review options for menstrual manipulation with risks and benefits

- **Health Advocate**
  - Gain an appreciation and understanding of the menstrual concerns of families of girls with disabilities
History

- 1928 - Sexual Sterilization Act of Alberta
  - Allowed for sterilization of mentally disabled people to prevent the transmission of undesirable traits to their offspring

- British Columbia had similar legislation
1928
CHAPTER 37.
The Sexual Sterilization Act.

(Assented to March 21, 1928.)

HIS MAJESTY, by and with the advice and consent of the Legislative Assembly of the Province of Alberta, enacts as follows:

1. This Act may be cited as "The Sexual Sterilization Act.

5. If upon such examination, the board is unanimously of opinion that the patient might safely be discharged if the danger of procreation with its attendant risk of multiplication of the evil by transmission of the disability to progeny were eliminated, the board may direct in writing such surgical operation for sexual sterilization of the inmate as may be specified in the written direction and shall appoint some competent surgeon to perform the operation.

4. When it is proposed to discharge any inmate of a mental hospital, the Medical Superintendent or other officer in charge thereof may cause such inmate to be examined by or in the presence of the board of examiners.

5. If upon such examination, the board is unanimously of opinion that the patient might safely be discharged if the danger of procreation with its attendant risk of multiplication of the evil by transmission of the disability to progeny were eliminated, the board may direct in writing such surgical operation for sexual sterilization of the inmate as may be specified in the written direction and shall appoint some competent surgeon to perform the operation.
History

- Target populations
  - Developmental disability
  - Physical disabilities
  - Marginalized groups

- 2832 sterilization procedures were performed in Alberta

- In 1972 – Sexual Sterilization Act of Alberta was repealed
- In 1973 – BC’s Sexual Sterilization Act was repealed
History

- In 1986 – Supreme Court of Canada established limitations related to therapeutic sterilization of mentally incapable patients

- Sterilization should never be authorized for mentally incompetent persons for non-therapeutic purposes

- Prohibits the ability of a parent or SDM to authorize the sterilization of a mentally incapable person for non-therapeutic reasons

CMPA. The legal limits of sterilizing the mentally incapable, What physicians need to know. April 2010.
Introduction

- Pubertal development and menses are a significant change in the life of all adolescents.

- Adolescents with disabilities may have more difficulties with puberty and menses.

- Major concerns related to:
  - Menstrual irregularity
  - Hygiene
  - Behavioural issues
  - Sexuality, pregnancy and abuse

Caregiver and Patient Concerns

Approach

- Optimal gynecologic health care of adolescents with disabilities is:
  - Comprehensive
  - Confidential, if possible
  - Affirms patient’s dignity
  - Maximizes the patient’s interests
  - Avoids harm

Approach

- Direct communication with the adolescent
  - Understand their mode of communication
- Assess their knowledge
  - Puberty
  - Menstruation
  - Sexual activity
  - Safety
  - Ability to consent to sexual activity
- Provide developmentally appropriate education

Menarche

- Epidemiology of menstrual cycles in women with developmental disabilities is lacking

- Menarche can be early, normal or delayed in girls with developmental disabilities
Menstrual Irregularity

- All adolescents have irregular menses in the first 2-5 years after menarche.
- Adolescents with disabilities may have additional reasons for menstrual irregularity:
  - Anticonvulsant use
  - Anti-psychotic use
  - Thyroid disease
  - FTT

Hygiene

- Physical challenges
- Communication challenges
- Sensory challenges
- Caregiver challenges
Behaviour

- Cyclic behavioural changes
  - Temper tantrums
  - Crying spells
  - Self-injurious behaviour
  - Catamenial Epilepsy
    - Pattern of seizure clustering related to menstrual cycle

- Dysmenorrhea is common in teenagers
  - If unable to communicate discomfort or pain → behavioural changes

Menstrual Manipulation

- Understand the reasons for request
  - From patient
  - From caregivers
    - Convenience
    - Vulnerability for abuse and pregnancy
    - Affect quality of life
Menstrual Manipulation

- Decision to treat should be based on:
  - Assessment of the menstrual cycle
  - Tolerance of the patient for her period and menstrual products
  - Impact of cycles on daily activities

- Goals for treatment
- Periodic evaluations
Non-Hormonal Options
NSAIDs

- **Goals:**
  - Decrease dysmenorrhea
  - Can decrease menstrual flow up to 30-40%

- **Challenges**
  - Does not provide contraception
Estrogen-Containing Options
Combined Oral Contraceptive Pills

- Once daily pill containing combination of estrogen and progesterone
  - Cyclically – break every month for withdrawal bleed
  - Extended or Continuously – break every 3-4 months or no break

- Goals:
  - Regulate cycle with predictable bleeding
  - Decrease menstrual flow
Combined Oral Contraceptive Pills

Benefits:
- Extended cycling – can produce amenorrhea
- Decreased dysmenorrhea
- Decreased risk of endometrial and ovarian cancer

Challenges
- Monitoring for consistent daily pill taking
- Interaction with anticonvulsants
  - Breakthrough bleeding
  - Need for increased estrogen dose
- Increased risk of thromboembolism
- Increased risk of breast and cervical cancer
Transdermal Contraceptive Patch

- Patch changed every week for 3 weeks, followed by a patch-free week

- Benefits:
  - Difficultly swallowing pills
  - Same as OCP
  - Avoids first-pass metabolism → less interaction with other medications
Transdermal Contraceptive Patch

- Challenges
  - Sensory issues – patch can be bothersome, may try to remove it
  - Overall higher estrogen concentration - ? Risk for DVT
Contraceptive Rings

- Ring inserted for 3 weeks, then removed for ring-free week
- Not commonly used in patients with disabilities
- Difficult for adolescents with mobility issues
- Assistance often needed for inserting and removal of ring
Progestin - Only Options
Oral Progestin Pills

- Once daily oral progestin only pills
- Cyclic (10 days / month) – if anovulatory

Benefits:
- If use higher doses can produce amenorrhea
- Does not increase VTE risk

Challenges
- If cyclic use – complicated regimen
Depot Medroxyprogesterone Acetate (DMPA)

- IM progestin injection of every 12 weeks

Benefits:
- High rates of amenorrhea
- Avoids oral route or regular administration issues
- Decreased dysmenorrhea
Depot Medroxyprogesterone Acetate (DMPA)

- Challenges
  - Decreased BMD
    - Increased concerns with immobility, low weight
    - Reversible after stopping DMPA
    - Supplement with Calcium and Vitamin D
  - Weight gain
    - Concern for patients with mobility issues
  - Irregular bleeding initially

Intrauterine Device (IUD)

- Progesterone-releasing IUD lasts 3 to 5 years

- Benefits:
  - Decreased menstrual flow eventually
  - Decrease ovulatory symptoms

- Challenges:
  - Irregular bleeding initially
  - Likely need GA for insertion

Implantable Progestin

- Progesterone rod implanted sub-dermally
- Currently not available in Canada
Surgical Options
Endometrial Ablation

- Typically used for dysfunctional uterine bleeding only
- Not studied in adolescents with normal menses

Benefits:
- Decreased menstrual flow
- Amenorrhea can occur

Challenges:
- Impaired fertility
- Required cervical dilatation in likely nulliparous cervix

Other Surgical Procedures

- Tubal Ligation
  - For contraception only
  - No changes to menses

- Hysterectomy
  - Cessation of menses and contraception

- Should not be options – unless for therapeutic reason after failed medical management and ethics review!
Summary

- Menstrual concerns are common for both caregivers and adolescents with disabilities
- Need to understand the underlying reasons for menstrual manipulation
- Involve the adolescent as much as possible
- Treatments should be goal-directed
- Consider non-hormonal and hormonal options
  - Risks and benefits must be reviewed thoroughly
- Surgical options only for therapeutic reasons