Menstrual Management and Sexuality in Young Women with Developmental Disabilities

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Definition

“Human sexuality encompasses the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. It deals with the anatomy, physiology, and biochemistry of the sexual response system; with roles, identity, and personality; with individual thoughts, feelings behaviors, and relationships. It addresses ethical, spiritual, ad moral concerns, and group and cultural variations.” (SIECUS, Haffner)
Sexuality Education

- SIECUS: Sexuality Information and Education Council of the United States
- www.SIECUS.org
Consultation questions

- 12 yo girl with developmental delay, recent menarche, desires menstrual control
- 15 yo girl with developmental delay and seizure disorder, worse around menses
- Teen desires contraception
Pubertal maturation

- Process usually similar to peers, tempo may be variable:
  - Delayed puberty
    - Prader Willi
    - Down syndrome
  - Early puberty
    - CP (menarche later)
    - Hydrocephalus
    - Myelomeningocele
    - Source: Blum 2006
Contraception
Assessment

- Obtain the history
- Specific concerns – hygiene, contraception, menstrual control
- Vulnerability to sexual abuse
Case

- 15 yo patient with mild developmental delay, verbal
- In regular school with special classrooms, no sex ed
- Mom: “I just tell her that boys should never touch her”
Sex Education

- Bring up the topic
- Acknowledge the family’s concerns and values
- Help family educate their daughter
- Provide resources
Sex Education

- Assess knowledge and experience
- Assess safety – high risk for sexual abuse
- Physical and behavioral signs of abuse
AAP recommendations – Sexuality of children/adolescents with DD

- Discuss issues of puberty and sexuality starting early and continuing through adolescence
- Encourage parents in understanding their child’s needs in puberty and sexuality education and being the primary educator for their child
- Recognize that children with disabilities are at increased risk for sexual abuse and monitor for indications of it

Depo-Provera

- 21 carbon progestin like natural progesterone
- Dosage: Medroxyprogesterone 150 mg IM every 12 weeks or 104 mg subQ
- May give as often as every 8 weeks to help control irregular bleeding
- 73% of high-risk teens discontinue by 1 year
- Side effects: – Irregular bleeding – Weight gain – Transient bone mineral density loss

Menstrual Control in Young Women with Devel Delay

- Discuss available options
- Most start with pills or Depo-Provera
- Mirena IUD safe and effective, no lower age limit
- Permanent options
Contraceptive Options

- Extended cycling
- Low-dose pills – how low?
- Depo-Provera
- Contraindications
- Chronic illness
Contraindications to Estrogen

- History of DVT, stroke, active liver disease, migraine with aura
- Uncontrolled hypertension
- Pregnancy
- Other considerations: obesity, immobility, surgery, fractures
Extended Use Pills

- May increase **efficacy** and adherence
  - Up to 25% of women have follicle ready to ovulate by day 7 of placebo week!
  - If the start of the new pack is delayed, they are at high risk!
“Low-dose” OCPs: How low is too low?

- Recent studies indicate that 20 mcg estrogen pills may be too low for strong bone development in teens

- May use lowest dose pills with caution, balance risks and benefits

- More studies needed
Other combination options

- Nuvaring – intravaginal ring, monthly, may use continuously
- Ortho-Evra Patch – weekly patch x 3 weeks on, one week off
- Slightly increased risk for DVT
Case

- Teen with seizure disorder, worse with menses
- Consider progesterone-only as progesterone raises seizure threshold
- Assess possible medication interactions
Progesterone-only options

- Cycle with Provera
- Progesterone-only-pill, the “minipill” (brand Micronor)
- Depo-provera (medroxyprogesterone) q12 week injection
- Mirena IUD, Nexplanon

- Control bleeding, Protect the uterus
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LARC: Mirena IUS and Nexplanon

- LARC = Long-Acting Reversible Contraception
- No lower age limit
- Safe and Effective
Implants and intrauterine devices (IUDs) should be offered as first-line contraceptive options for sexually active adolescents, according to new guidelines issued today by The American College of Obstetricians and Gynecologists (The College). Both the implant and the IUD are the most effective reversible contraceptives for preventing unintended pregnancy and abortion in teens and adult women.
Levonorgestrel IUS (Mirena)

- Lasts 5 -7 years
- 99.9% contraceptive efficacy
- 40% of patients amenorrheic at 2 years
- Very low systemic levels of levonorgestrel
- 90% reduction in blood loss with menses
- Safe in adolescents and nulliparous women
- Same rates of PID as population without IUS
- Protects endometrium against effects of unopposed estrogen
Implanon / Nexplanon (etonorgestrel implant)

- Lasts three years
- 99.9% efficacy
- Progesterone-only
- 20% amenorrhea rate
- Does not require pelvic exam
- Irregular bleeding common

March, 2012: Nexplanon – improved insertion
Contraception in chronic illness

- WHO Medical eligibility criteria for contraceptive use, 4th ed, 2010
  - medical eligibility criteria for use of all contraception methods
  - safety of use of different methods for women and men with specific characteristics or known medical conditions
  - based on systematic reviews
Permanent Sterilization

- Need a court order in WA state
- Must show that medical management has failed
- Medical management usually effective
- Endometrial ablation not indicated in adolescents and is not contraception
HPV Vaccine

- Females 9-26 y for prevention of cervical cancer, genital warts, precancerous lesions of cervix, vagina, vulva: RECOMMENDED
- Available data suggest no therapeutic effect if already infected
- Vaccine consists of synthesized L1 capsid proteins that self-assemble into virus-like particles

www.cdc.gov/std/hpv
Pelvic Exam

- Pelvic exam not necessary for menstrual control, prescribing birth control
- Recent Pap guidelines – first Pap smear at age 21 years
Case

- 12 yo F with heavy periods, poor school performance
- Exam – vaginal discharge
- Concern for STD?
Case

- Positive wet mount for Trichomonas, positive for Chlamydia
- History of abuse, CPS report made
- HIV & RPR negative/non-reactive
STD Screening

- Concerns for sexual abuse
- Symptoms: vaginal discharge, dysuria, genital lesions
- Have a high index of suspicion!
Conclusions

- Sexual abuse is a common problem for persons with disabilities
- Sex education and self-protection are important and may decrease risk
- There are a number of options for menstrual control
- Team up with families
References

Intrauterine Device and Adolescents: ACOG Committee Opinion number 392, December 2007


www.youngwomenshealth.org - Website from Boston Children’s Program: excellent resource for patient information

www.cdc.gov

www.who.int/reproductivehealth/publications/family_planning