Wednesday, 10:00 – 11:30, D1

**Sexual and Reproductive Health for Adolescents with Disabilities**

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**Objective:**

Identify effective methods for the practical application of concepts related to improving the delivery of services for persons with developmental disabilities at the level of the state.

Identify advances in clinical assessment and management of selected healthcare issues related to persons with developmental disabilities.

**Notes:**
Sexual and Reproductive Health for Adolescents with Disabilities

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I have no financial disclosures.

Agenda

Topics to be Covered

- Puberty and Adolescent Milestones
- Gynecological Care of Individuals with Disabilities
- Sexuality in Individuals with Disabilities
- Sexual Abuse Potential
- Reproductive and Sexuality Education

Puberty and Adolescent Milestones

Normal Puberty

- Normal menses starts approximately 2-2.5 years following the initial presence of breast buds
- Approximately 90% of Tanner 4 girls have started their menses
- Indicates intact, responsive hypothalamic-pituitary-gonadal axis
- Mean age of menarche in the US is 12.5 years (ranging from 9-16 years)
- Average duration of cycle 28 days (+/- 7 days)
- Average duration of menses 4 days (+/- 2-3 days)
- Median blood loss is 30mL/cycle
Puberty in those with Disabilities

- Puberty can be altered in those with disabilities and chronic illnesses.
- Can be altered by disorder itself, or medications used to manage the disorder.
- Medications can also alter sexual function.
- Neurodevelopmental Disabilities: Cerebral Palsy – begins earlier and ends later.
  - Median age of menarche is over 1 year later.
  - Increased risk of idiopathic precocious puberty.
  - Incidence approaches 20% in those with spina bifida.

Adolescent Milestones

- Attaining an adult body capable of reproducing.
- Having and maintaining intimate relationships.
- Managing a range of complex emotions.
- Independently thinking and problem solving.

Adolescent Milestone Barriers

- Functional limitations (physical limitations).
- Participation in fewer social activities.
- Involved in fewer intimate relationships.
- Lack of information on topics such as parenthood, birth control, STDs.

Gynecological Care

- Communication difficulties.
- Perceived pain or behavioral concerns.
- Cognitive limitations.
- Anatomic complications.
- Impaired sitting position.
- Lack of knowledge in regards to gynecological care.
- Caregiver refusal to provide gynecological care.

Factors Complicating Gynecological Care

- Complete gynecological history.
- Obtained from adolescent, parent, caregiver.
- Menstrual history.
- Concerns or abnormalities.
- Physical examination.
- Recognize that speculum exams are often NOT indicated in the adolescent population.
- Laboratory Testing as needed.
Pelvic Exams

- Speculum exam may not be necessary for all patients coming in with a gynecological concern
- Pap testing is indicated:
  - 21 years and older
  - HIV positive
  - Immunocompromised

Pelvic Exams

- Speculum exams are necessary:
  - Menstrual irregularities (pending history)
  - Amenorrhea not because of pregnancy, and prolonged or heavy vaginal bleeding
  - Abdominal and pelvic pain (pending history)
  - Persistent, symptomatic vaginal discharges that may be caused by a forgotten tampon, condom fragments, or other objects

Pelvic Exams

- Will need to gain trust before performing exam
- Will need to describe exam in a way the patient will understand
- May need to adjust positioning for exam
- One-finger bimanual exam
- Rectoabdominal examination
- Examination under sedation may be needed

Proper Hygiene

- May need assistance with menstrual hygiene
- May request menstrual suppression
- Request by parent/caregiver or by adolescent

Menstrual Suppression

- Long Acting Reversible Contraceptives
  - IUD (Intrauterine device)
  - Implant
  - Depo-medroxy-progesterone acetate shot
  - OCPs (Birth Control Pills)
  - Sterilization – controversial and fraught with legal-ethical considerations

IUDs
**Intrauterine Devices (IUD)**
- Very effective with minimal user effort
- Releases either copper or progestin
- Safe in teens and nulliparous women
- May need to be inserted under sedation
- Mechanism of action:
  - Changes in cervical mucus
  - Chronic inflammatory changes and thinning of endometrium
  - Direct ovicidal effects
- Copper IUD can stay in place 10 years, progestin IUD for 5 years
- New progestin IUD does not increase risk of PID or ectopic pregnancy (unlike older Dalkon Shield)
- Contraindications: Abnormal uterine anatomy, an active pelvic infection, suspected pregnancy, copper allergy, unexplained abnormal uterine bleeding

**Nexplanon (Etonogestrel contraceptive implant)**
- A single rod progesterin inserted subdermally in the arm
- Hormone is slowly released over at least three years
- Among the most effective contraceptives available, surpassing sterilization
- Side effects: Irregular bleeding, headache, weight gain, acne, breast tenderness, mood changes
- Contraindications: Same as hormonal contraceptives
- No data on the use in adolescents with disabilities

**Oral Contraceptive Pills**
- Most OCPs contain both a synthetic estrogen and a synthetic progestin
- How they work:
  - Estrogen-induced inhibition of the mid-cycle surge of LH, preventing ovulation
  - Thickening cervical mucus (barrier for sperm)
  - Thinning the endometrial lining of the uterus
  - Impairment of tubal mobility and peristalsis
- Injectable, progestin-only contraceptive given every 12 weeks (good compliance in adolescents)
- Mechanism: Suppresses LH secretion which inhibits follicular maturation and ovulation
- Inhibits endometrial proliferation, making it less receptive to implantation
- High rate of amenorrhea long-term
- Side effects: Menstrual irregularities (improve with time), weight gain, headache, mood changes—depression, bone mineral density loss
- Patients should have a calcium rich diet, with weight-bearing exercise
**Side Effects**

- **Estrogen related effects**
  - Headaches
  - Breast tenderness
  - Nausea
  - Weight gain (although not as much as in past)
  - Hypertension
  - Bleeding and spotting

- **Progestin related effects**
  - Fatigue
  - Depression
  - Menstrual changes

**Special Considerations**

- Increased risk of thromboembolic event especially in those who are wheelchair bound and have limited mobility
- Needs to be taken at the same time every day
- Will still have withdrawal bleeding
- There is a chewable OCP available for use in G-tubes
- In progestin-only pills, there is a concern for bone mineral loss especially in those with limited movement/weight bearing exercise ability

**Contraindications**

- **Category 1 (no restrictions)**
  - Benign breast disease
  - Benign ovarian tumors
  - Epilepsy* (but check their medications)
  - Family history of breast cancer
  - Headaches (mild)
  - Postpartum at or over 21 days
  - Viral hepatitis carrier

- **Category 2 (use with caution)**
  - Cervical cancer
  - Diabetes mellitus (uncomplicated)
  - Migraine with no focal neurologic involvement
  - Sickle cell disease
  - Obesity
  - Smoker

- **Category 3 (usually no OCP given)**
  - Gallbladder disease
  - Lactating (6 weeks to 6 months)
  - Less than 21 days postpartum
  - Medications that interfere with OCP efficacy
  - Undiagnosed abnormal vaginal-uterine bleeding
  - Hyperlipidemia (uncontrolled, LDL>160 mg/dl)

- **Category 4 (contraindicated)**
  - Complicated structural heart disease
  - Cardiovascular event, Coronary Heart Disease
  - Deep vein thrombosis or pulmonary embolism
  - Diabetes mellitus (with retinopathy, neuropathy, nephropathy)
  - Headaches (and migraines) with focal neurologic symptoms (aura)
  - Hypertension severe (systolic>160 and/or diastolic >100)
  - Lactation, under 6 weeks postpartum
  - Liver disease (Due to drug metabolism)
  - Breast Cancer
  - Surgery (involving prolonged immobilization)
Extended Cycle OCPs

- Include 3 months of “active” pills followed by 7 days of placebo pills
- Essentially, one period every 3 months
- Higher risk of breakthrough bleeding
  - This decreases over time
- Seasonale, Seasonique
- Same effectiveness as other OCPs

Transdermal Patch

- Ortho Evra
- 20 mcg of ethinyl estradiol and 150 mcg of norelgestromin daily
- The patch is changed once a week for three weeks, followed by one week that is patch-free
- Can be applied on buttocks, upper outer arm, lower abdomen and upper torso (excluding the breasts)
- Therapeutic effects are achieved at lower peak doses
- Although data is limited, may have an increased risk of VTE compared to OCPs
- Possibility of detachment and skin irritation

Intravaginal ring

- NuvaRing
- Delivers 15 mcg ethinyl estradiol and 120 mcg of etonogestrel daily
- Inserted intravaginally for three weeks and then removed for one week
- It can be removed for 3 hours during intercourse
- Can cause vaginitis, leukorrhea
- Adolescent has to be comfortable inserting this
- May be difficult for adolescents with mobility issues

Sexuality

- Merriam-Webster
- The quality or state of being sexual
- The condition of having sex
- Sexual activity
- Expression of sexual receptivity or interest especially when excessive

Sexuality

- A complex phenomenon that involves intricate interactions between:
  - Individual’s biological genital sex
  - Core identity
  - Gender Role Behavior
  - Physical maturation and body image
- Core and profound component of humanity
- Linked to basic human needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive
Myths

- Persons with disabilities are or should be asexual
- They are child-like and in need of protection
- They suppress their sexual needs
- They are inappropriately sexual or have uncontrollable urges

The Truth

- Adolescents with disabilities are, like all adolescents, sexual human beings
- Attention to their complex medical needs may overshadow time that could otherwise be spent focusing on their developing sexuality
- Societal and psychosocial barriers may be more of a hindrance to sexual development than the limitations from the disability itself
- Adolescents with physical disabilities are as sexually experienced as their peers without disabilities

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Individuals with disabilities:

- Express desires and hopes for marriage, children and normal adult sex lives
- Need education on sexuality
- Need help managing their sexual health

Sexual Abuse

- Sexual consent is a complex and legal issue for cognitively impaired individuals
- Children with disabilities are sexually abused 2.2 times more than those without disabilities
- 68%-83% of women with developmental disabilities will be sexually assaulted in their lifetimes
- Less than half will seek legal or treatment services
- Incest represents approximately 40% of reported sexual assault

Why are they more vulnerable?

- Dependence on others for intimate care
- Increased number of caregivers and settings
- Inappropriate social skills
- Poor judgment
- Inability to seek help or report abuse
- Lack of strategies to defend themselves from abuse
Signs of Abuse
- Alterations in bowel and bladder patterns
- Changes in appetite or sleep
- Change in mood and behaviors
- Decrease in community participation

Consequences of Abuse
- Chronic Drug Abuse
- Depression and other mental health disorders
- Juvenile delinquency/youth violence
- Psychosomatic disturbances (ex. Headaches, Abdominal Pain, etc)
- Pregnancy
- School failure and drop-out
- STDs
- Sleep Dysfunction

Reproductive and Sexuality Education

Lack of Education
- For protection, parents may limit unsupervised social interactions
- May limit any knowledge of sex
- Fears that discussions about sex will lead to sexual activity
- Educational materials available may not be developmentally appropriate
- Actually, when sexual questions are freely discussed, the likelihood of abuse is reduced

Sexuality Education
- Sexuality should be discussed routinely and openly
- Conversations should be initiated early and should be age appropriate and developmentally appropriate
- Introduce issues of physical, cognitive and psychosexual development
- Explore expectations of both the parents and the child

Sexuality Education
- Keep it simple and direct
- Try multiple teaching techniques
- Use “teachable moments”
- Encourage independent thinking and action, decision-making skills and boundary setting
- Expose the child to a variety of social situations and experiences
- Teach them the power of saying no
**Sexuality Education**

- Must incorporate the family’s values on different issues
- Personal Modesty
- Adult Sexuality
- Best accomplished when parents are the principle teachers
- Should offer education appropriate for the cognitive and functional abilities of the child

**Topics to be covered**

- Sexual Development
- Sexual Orientation
- Sexually Transmitted Diseases
- Contraception (including abstinence)
- Health implications of pregnancy
- Masturbation

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**Sexuality Education**

- Practitioners should cultivate a sense of independence when appropriate
- Discuss issues and concerns in private with the child or adolescent
- Inform the parents/caregivers of the topics discussed
- Be aware of the confidentiality
- Make sure to discuss topics in a way that the patient will understand
  - Anatomically correct dolls
  - Role Playing
  - Frequent Review and reinforcement of information
  - Provide developmentally appropriate educational materials

**Barriers to Education**

- Discomfort on the part of everyone involved
  - Parents, children, caregivers
  - Cultural, religious or personal beliefs
  - Acute medical and developmental concerns may overshadow reproductive health discussions
  - Lack of access to age-appropriate peers
  - Lack of access to privacy
  - Parents may infantilize their children
  - Parents may overlook opportunities for their children to achieve greater maturity and independence

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**The Role of the Practitioner**

- Create an environment in which it is safe to ask questions
- Discuss physical developmental changes of puberty
- Ensure privacy for each child/adolescent
- Assist parents in understanding how their child’s disability can effect behavior and socialization

**The Role of the Practitioner**

- Help find ways to optimize independence
- Be aware of special medical needs and how it can effect reproductive and sexual care
- Look out for signs of abuse
- Encourage sexuality education, starting in the home
- Provide appropriate resources
Resources

- University of Michigan Resource List
  - http://www.med.umich.edu/yourchild/topics/disabsex.html
- Healthy Relationships, Sexuality and Disability
  - Prepared by MDPH and MDDS
- SafePlace (Safety Awareness Program)
  - http://safeplace.org/about/programs-and-services/disability-services-asap/

References

- Patel DR, Greydanus DE, Collins A, Porti HP. Developmental Disabilities Across the Lifespan: Disease-Related, Vol 56 No 4 June 2012; 293-294