Lifelong Gynecology Needs and Hormonal Interactions with Other Common Medical Conditions for Women with IDD

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Conflicts of Interest

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- I am solely responsible for this presenter's contents, findings, and conclusions, which do not necessarily represent the views of IDILRR, NICHD, or Neilsen Foundation.

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Magee Center for Women with Disabilities celebrates 25 years, and the legacy of founder Sandra Welner

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UPMC Magee-Womens Hospital Center for Women with Disabilities

- Opened in 2001
- Providing gynecologic care for people with intellectual and developmental and mobility disability
  - Annual exams
  - Gyn problem visits
  - Surgical consultations
- 70% with intellectual and developmental disabilities
  - 70% with coexisting intellectual and developmental & mobility disabilities
  - 30% with intellectual and developmental disabilities
  - Most of these patients live in community group homes
- 30% with mobility disabilities alone

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Goals for today's talk

- Discuss lifelong gynecology needs for women with intellectual and developmental disabilities

- Discuss conditions with hormone interactions and hormone treatment options

Lifelong gynecologic care

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Many possible gynecology needs across the lifespan

- Menstrual management
- Premenstrual syndrome and premenstrual dysphoric disorder
- Cervical and breast cancer prevention
- Sexual education / health / contraception
- Endometrial and ovarian cancer awareness
- Pelvic pain and related conditions
- Sexual abuse prevention / recognition
- Vaginal infections
- Perimenopause and menopause
- Postmenopausal bleeding
- Pelvic organ prolapse

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Menstrual Management

- Menstrual management is the most common gyn question among girls and young women with IDD and their family
- Education and preparatory discussion with healthcare provider helps lessen anxiety
- No hormonal treatment should be started before the first natural period

Menstrual Management

- Any discussion of hormone suppression should be a shared discussion with person with IDD, family, caregivers, and patients
  - There should be no pressure or expectation to suppress periods
  - If someone can learn to toilet independently, she can also often manage menstruation hygiene independently
  - If menstruation adversely affects the quality of life of the person and caregivers, it is reasonable to consider suppression
- Other causes for possible discomfort with periods, pelvic pain, abnormal uterine bleeding should be considered

Menstrual Management

- If menstrual management is desired, we generally try to make periods more regular and lighter or more infrequent to absent.
- There are many options available to suppress periods, but most options use hormones
- Non-hormonal medication options include ibuprofen or tranexamic acid—these may decrease subjective volume of bleeding, but not frequency
- Improving underlying thyroid dysfunction may also improve menstrual patterns and volume

Menstrual Management

- Hormonal medications include pills, patches, injections, upper arm implants, and intrauterine devices
- Hormones include estrogen and progestins OR progestin-only options
  - Difference in effectiveness
  - Difference in risk of blood clots
  - Hormone options may worsen other issues such as hormone associated behavior changes
- Permanent, surgical options such as endometrial ablation or hysterectomy are possible, but have higher risks of complications than medical options

Premenstrual syndrome and premenstrual dysphoric disorder

- PMS and PMDD are the mild and severe form of hormone cycle related physical, behavioral, or psychological changes that cause distress or interfere with daily function
- Symptoms include mood swings, sadness, anger, irritability, depression, difficulty concentrating, changes in appetite, diminished interest in usual activities, decreased energy, sleep changes
- Other causes for these symptoms should be ruled out such as mood / anxiety disorders, thyroid disorder, migraines, or irritable bowel syndrome
- Treatment usually seeks to decrease or eliminate hormonal cycling the triggers these behaviors

Cervical Cancer Screening

- Cervical cancer screening and vaccinations should be performed at ASCCP-recommended intervals
- Unfortunately, women who have never been sexually active are at risk because of unknown sexual abuse / assault
- Consider use of HPV only testing for patients that have limited capacity to tolerate exams
- Exams under anesthesia are an option, but may not be necessary if provider team is experienced, skilled, and efficient

Breast Cancer Screening

- Women with disabilities may not be able to use standard mammography equipment
- Breast cancer screening should be performed at recommended intervals
- May have to use ultrasound as alternative screening method
- Clinical breast exam is more important for women that are not able to perform regular exams

Sexual health education and contraception

- Complex topic that varies widely based on individual, situation, and background
- Education of typical and problem sexual behavior
  - Typical sexual behaviors: curiosity, masturbation, interest in peer genitals, sitting or standing to close
  - Problem sexual behaviors: results in distress or pain, is associated with aggression or coercion, resistant to redirection
    - Examples include public masturbation, nonconsensual groping
- Try to allow healthy human development and life, including sexuality, while limiting harm and exploitation
- Inclusion of the person with ID in decisions affecting her
- Respecting decision-making capacity and respect for autonomy
- Issues related to legal guardianship, coercion and abuse, contraception/pregnancy/sexually transmitted infections

Hysterectomy / Sterilization

- The process to undergo hysterectomy (for menstrual suppression / sterilization / pelvic pain) is challenging for patients, family, and providers
- There is a long history of the coercive sterilization for women with IDD, and that history makes it
- Women with physical or sensory disabilities have twice the odds of sterilization as women without those disabilities (29% vs 15%) in National Survey of Family Growth
- Women with cognitive disabilities more likely to receive sterilization and hysterectomy than those without cognitive disabilities
- There are multiple ethics statements on this issue from ACOG (though the Committee Opinion has been withdrawn) and ACP
- Best considered with help of patient, family, and sometimes ethics consultation

Sexual Abuse Prevention

- Adolescent girls with disabilities are more likely to report forced sexual contact 11% (vs 6% in girls not reporting a disability)
- Risk of abuse is still high among women with severe disabilities
- Education of patient , their family, and caregivers is important
- STIs can have similar symptoms for some women such as UTIs, which are common with many people with disabilities

Sexually Transmitted Infections

- All women should be considered for STI screening
- Urine-based STI testing for gonorrhea, chlamydia, and trichomonas is appropriate for women who have difficulty with pelvic exams

Vaginal infection / discharge

- Vaginal yeast infection involves Candida overgrowth, while bacterial vaginosis reflects disruption of normal flora
- Symptoms include itching, discharge, odor, irritation, and discomfort with urination or intercourse
- Yeast infections cause thick white discharge and itching; BV causes thin gray discharge with fishy odor
- Management includes antifungal therapy for yeast and antibiotics like metronidazole or clindamycin for BV

Pelvic Pain Conditions

- Pelvic pain may be related to menstruation (i.e., dysmenorrhea), but is often caused by other conditions
- Gyn causes include fibroids, endometriosis, adenomyosis, ovarian cysts
- Urologic causes include UTIs, kidney/bladder stones, interstitial cystitis
- Musculoskeletal causes include pelvic floor spasms, abdominal wall pain, hip joint pain, pelvic girdle disorders, hernias
- Gastrointestinal causes include irritable bowel syndrome, constipation, diverticulitis, inflammatory bowel disease, appendicitis

Abnormal Uterine or Postmenopausal bleeding

- Defined as heavy or very frequent periods before bleeding or any bleeding after menopause
- Can be caused by abnormal hormone cycles, polyps, fibroids, medications, endometrial precancer or cancer
- Evaluation for abnormal uterine bleeding and postmenopausal bleeding is often challenging due to inability to have office pelvic exam or transvaginal ultrasound
- Exams under anesthesia allow diagnosis and treatment
- Long-term treatment may include hormone medication, IUDs, endometrial ablation or hysterectomy.

Perimenopause and Menopause

- Perimenopause is transitional period before menopause with fluctuating ovarian function and irregular cycles
- Menopause is defined as twelve months without menstruation due to permanent ovarian estrogen deficiency
- Symptoms include hot flashes, night sweats, sleep disturbance, mood changes, and vaginal dryness. These symptoms may be difficult to assess depending on the communication and health literacy of the person.
- Management includes lifestyle measures, nonhormonal therapies, and individualized hormone therapy based on symptoms and risk

Pelvic organ prolapse

- Pelvic organ prolapse is descent of pelvic organs into vaginal canal due to weakened support
- Symptoms include vaginal bulge, pelvic pressure, urinary dysfunction, and bowel emptying difficulties
- First-line management includes pelvic floor exercises, pessary devices, and behavioral modifications
- Surgical repair considered for severe symptoms, including reconstructive or obliterative procedures

Ovarian Cancer Awareness

- Ovarian cancer is rare (lifetime risk 1 in 90 women) and often presents with vague symptoms, leading to delayed diagnosis and poorer outcomes
- Common symptoms include bloating, pelvic or abdominal pain, early satiety, and urinary urgency
- Awareness emphasizes symptom persistence, family history, and genetic risk factors like BRCA mutations
- Early evaluation and prompt referral improve survival, as no effective population screening exists

Urinary Incontinence

- Urinary incontinence is involuntary urine leakage due to impaired bladder control or support
- Symptoms include stress leakage with exertion, urgency, frequency, nocturia, and incomplete emptying sensation
- First-line management includes lifestyle changes, pelvic floor muscle training, bladder retraining, and fluid modification
- Pharmacologic therapy or surgery considered for refractory cases depending on incontinence type and severity

Vulvar skin issues

- Vulvar dermatologic conditions include lichen sclerosus, lichen planus, dermatitis, psoriasis, precancer, and infections
- Symptoms include itching, irritation, pain, skin discoloration, and fissures
- Diagnosis is clinical, supported by exam findings, biopsy when malignancy or unclear diagnosis suspected
- Management includes topical corticosteroids, skin protection, trigger avoidance, and treating underlying infections or inflammation

Discuss conditions with hormone interactions and hormone treatment options

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Hormone interactions

- Hormones play a role beyond periods
- They are related to
  - Mood and behavior issues (premenstrual syndrome and premenstrual dysphoric disorder)
  - Some types seizure disorders
  - Some types of migraines
  - Endometriosis / adenomyosis
  - Ovarian cysts / PCOS (now called PMOS)
  - Acne / excess hair growth

Periods versus Hormone interactions

- Patient, family, and caregivers must consider how to manage periods and any related conditions (seizures, behavioral changes (PMDD), pelvic pain)
- Some treatments that help improve periods will not improve other hormone-related conditions
  - **Cyclic** hormone regimens
  - **Progestin IUDs**
  - Hysterectomy **without removal of ovaries**
- Treatments that will improve periods and hormone-related conditions
  - **Continuous** hormone regimens (combined estrogen and progestin OR progestin only)
  - **Hormone suppression** (“medical menopause”) with GnRH agonist
  - **Removal of ovaries**

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Progressive options for bothersome periods with other hormone-related conditions

- Always work with neurology or psychiatry or GI or Gyn specialists to optimize hormone-related condition (e.g., neurology for seizures or psychiatry for mood or behavior changes)
- I commonly work through these options with patients, family, and caregivers for these situations:
  - **Level 1:** Continuous combined estrogen and progestin pills (or patch)
  - **Level 2:** Continuous progestin only pills
  - **Level 3:** 3-month progestin injection (sometimes progestin implant)
  - **Level 4:** 1-month hormone suppression trial
  - **Level 5:** 3-month hormone suppression trial
  - **Level 6:** Counseling about risks of early menopause, removal of ovaries

Resources

- There are excellent advocacy groups for type of disability, and they all have sections (with pamphlets and videos) on healthcare interactions
- To name a few: The Arc!, American Academy of Pediatrics, United Cerebral Palsy, National Down Syndrome Society

Summary

- There are many lifelong gynecology needs for women with intellectual and developmental disabilities
- While some women may not be able to report gynecologic symptoms with great nuance or clarity, they are at the same or higher risk of developing many gyn conditions and should be evaluated for these conditions when appropriate
- Managing hormones may be a powerful adjunctive treatment for conditions disruptive behaviors, seizures, and migraines, when these conditions have a relationship with hormonal cycles

Thank you!

Questions?

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