REPRODUCTIVE AND OBSTETRIC CARE FOR ADOLESCENTS AND WOMEN WITH DISABILITIES

Dr. Melanie Ornstein
Dr. Susan Ernst
Dr. Jaclyn Morrison
Learning Objectives

1. To understand the special needs of disabled adolescents and women with respect to accessing and receiving gynecological and obstetrical care
2. To understand the diversity of this population with respect to their unique physical disability and/or cognitive impairment
3. To recognize the reproductive and obstetric needs of the disabled individual and those of their caregivers
4. To discuss issues of societal misconceptions and biases regarding sexuality and reproductive health care needs in women with disabilities
5. To review the importance and challenges of sexual and reproductive healthcare in adolescents and women with disabilities
6. To discuss contraceptive considerations, reproductive planning, preconception counselling and obstetrical issues in women with disabilities
SOCIETAL MISCONCEPTIONS AND BIASES REGARDING SEXUALITY AND REPRODUCTION

Dr. Melanie Ornstein
MA, MD, FRCSC
Assistant Professor, University of Toronto
Adolescents and Women with Developmental Disabilities

- Individuals with developmental disabilities are living longer and becoming more integrated into the community.
- These changes are accompanied by a societal recognition of the importance of their rights, including those related to gynecologic and obstetric health care.
- When caring for women with developmental disabilities, special considerations for support and guidance should be given to their unique needs, abilities, and barriers.
- Often must also consider the needs and concerns of the caregivers – parents, family members, school or work supports, partners.
Developmentally Challenged

• Very varied population
  • Cognitively/intellectually challenged
  • Physically impaired
  • Multiple physical and cognitive disabilities
  • Co-morbidities
  • Poly-pharmacy
  • Mild to severe involvement
  • Independent, partially dependent, in need of full time assistance for all activities of daily living (ADL)
  • Disabled from birth vs acquired
Barriers to Reproductive Health Care

• Caregiver, provider and society attitudes
• Inaccessible facilities and equipment
• Disabled persons attitudes toward the health care system and previous medical experiences
• Limited contraceptive and menstrual suppression options with possible increased risks
• Limited experience providing gynecologic or obstetrical care to this population
• Healthcare providers insensitivity and/or lack of knowledge about disabilities
Developmentally Challenged

- Adolescence is a turbulent time of change - physically, emotionally, socially

- Developmentally disabled teens and adults:
  - Are often treated as younger
  - Assumed to be cognitively impaired
  - May have dependency for ADL
  - Possibly “medicalized”
  - Privacy issues
  - Confidentiality issues
General Considerations

• Given the diversity within the developmental disabilities population an individualized approach is necessary
• Providers must consider physical/environmental, attitudinal and emotional factors that influence the care of this population
• More time may need to be allotted for appointments
• Buildings, clinics and exam rooms should be wheelchair accessible, height adjustable examination tables
• Considerations should be given to minimize sensory stimulation within the clinic – eg. for the autistic, intellectually challenged population
• Education may need to be provided to ancillary staff
• Involvement of a multi-disciplinary team may be necessary – eg neurology, nursing, anaesthesia, social work
Caregivers of Disabled Children and Women

• Recognition of the stress of caring for an individual with disabilities
• Physical and psychological health of caregivers must be considered
• Interventions and preventative strategies to decrease caregiver stress who will then be able to respond to the unique characteristics of the disabled person
• Caregivers may include parents, partners, school or group home workers
Reproductive Health Care Evaluation

- History
  - If necessary have appropriate caregiver present, who knows the patient
  - Assess chief concerns
    - Premenstrual/menstrual concerns, menstrual suppression
    - Desire for contraception
    - Concerns re. sexual abuse, vulnerability of abuse
    - Gynecologic concerns
    - Obstetrical preconception counseling, obstetrical care
  - Assess understanding of sexual development and identity
  - Understand physical and cognitive levels
  - Co-morbidities, medications
  - Level of understanding re. development, sexuality
  - Personal hygiene issues, independence in ADL
  - Caregivers, home and school/work settings
  - Understand patients’ capacity to understand and consent to or refuse reproductive, sexual, obstetric health care
Examination Issues

- Explanations should be provided to the caregiver and whenever possible to the patient at a level that they can understand

- Time
  - Decrease speed of movements (if too fast may increase spasticity, or startle)
  - May need to allow more time for the woman to speak
  - More time for dressing, undressing
  - More time for explanations, education, involvement of caregivers, partners
  - May need more frequent appointments

- Safe transfers on and off exam table
  - Safety for the patient and healthcare providers

- Be aware of skin integrity and care
- May have complex medical issues influencing examination and care provision
- Avoid force
Gynecologic Exam

• Is examination necessary for the provision of care – eg menstrual suppression
• Who should be present for the exam, do you need assistance to do the exam

• Special Issues
  • Cognitive level
  • Physical handicaps – neurologic, spasticity, orthopedic, mobility
  • Accessibility issues
  • Anxiety or complacency due to multiple past medical encounters
  • Possible history of sexual abuse
Gynecologic Exam

• Assure patient feels safe, well supported, confident she will not fall
  • How much physical, emotional support does patient require
  • How much assistance do you as the healthcare provider need – use proper body mechanics and assistance to prevent injury to patient or healthcare provider
  • Need for assistants, transfer boards, lifts
  • Should caregivers, partners be involved in patient transfer, the patient exam
  • Discuss transfer plan with patient, caregivers, partners and ask for additional suggestions
  • Height adjustable exam tables, room size appropriate to accommodate wheelchair/walker/other special equipment, caregivers
  • Consider need for pillows, padding, stirrups

• **Ensure patient feels confidentiality, privacy, dignity are respected**

• Preparation, communication, involvement of and consent from the patient +/or caregiver
Accomplishing Safe Transfers

- Make sure to lock the wheel chair
- Use assistive devices
- Teach personnel safe lifting techniques
- Assistants should stay with the patient to prevent falls.

https://www.acog.org/-/media/Departments/Women-with-Disabilities/partII.ashx
Assisted Transfers with a board

- A transfer board can provide support and increase safety
- Requires exam table to be close and at the same height as the wheelchair seat height

Source: Sure Safety Transfer Board

https://www.acog.org/-/media/Departments/Women-with-Disabilities/partII.ashx
Gynecologic Exam

- Be aware of skin integrity and care
  - Watch for skin pressure points, especially over sacrum
- Be aware of impaired balance, weakness
- Note spasticity, contractures
- Note if patient appears fearful and take time to explain all procedures
- Do not use excess force, pushing, pulling
- Be prepared to stop if patient is uncomfortable, nervous, exam elicits emotional behaviour or pain
Gynecologic Exam

- Emptying bladder before an exam may be helpful
- Bimanual
  - 1 finger exam
  - Recto-abdominal exam
- Positions to maximize comfort and minimize spasticity
  - Legs together but straight up in air
  - Diamond or frog leg position
  - V position
  - May need to minimize flexion, abduction
  - Sideways fetal position – lower leg may be straightened
- Smaller more narrow speculum may be helpful – eg. Pederson
- Can insert speculum with handle facing upwards
- Q-tip PAP smear
  - Slide over finger into cervical os – decreased rate of endocervical cells
- Urine gonorrhea, chlamydia, trichomonas tests vs speculum and swabs
- HPV testing
Exam Under Sedation

• If physical exam is difficult or impossible is sedated exam needed/necessary?
• General anesthesia
• Outpatient sedation
• Anti-anxiolytic – eg. Lorazepam – use with caution
Ultrasound

• **Indications**
  • Routine annual exam??
  • Pain/dysmenorrhea
  • Abnormal uterine bleeding or AUB that does not respond appropriately to treatment
  • Suspected mass, anomaly

• **Problems**
  • Cooperation
  • Poor bladder filling
Surgical Interventions

• Requests from caregivers for hysterectomy, permanent sterilization
  • Many ethical and moral implications
  • Issues re. consent and an individual’s capacity for decision making
  • Risk of conception on individual’s health and well being
• Ascertained reason for request, fears, concerns
• Most concerns can be dealt with by education and/or medical management
• Educate that surgery does not protect against abuse, STDs, sexuality and sexual behavior
Reproductive Healthcare Throughout The Lifespan

- Childhood/Adolescence
  - Transition through puberty
- Reproductive Age
  - Premenstrual/menstrual concerns
  - Contraception
  - Pap tests, STD screening, HPV vaccine
  - Sexuality and capacity for intimate relationships throughout the lifespan
  - Obstetrical care
- Ageing and menopause
  - Mammograms
  - Osteoporosis
  - Bladder problems
  - Hormone replacement therapy
- Disabled adolescents and women are entitled to the same medical care as their able bodied peers
- Issues of healthcare providers attitudes and accessibility must be examined
References


• ACOG pelvic exam - https://www.acog.org/-/media/Departments/Women-with-Disabilities/partII.ashx


Sexual Education for Adolescents with Disabilities

Susan Ernst, MD
Chief of Gynecology Services
University Health Services
University of Michigan
Sexual Education for adolescents with Disabilities

• Teens and women with disabilities are vulnerable
  • To abuse and exploitation
  • Social isolation
  • To restrictions of their Reproductive Rights

• As Reproductive Health providers:
  • Great opportunity to help teens and families with the adolescent transition
  • Focus on Sexual education and Abuse prevention
Mastectomy is a little more inflammatory than removal of breast buds--so I changed to the latter
Paula J. Hillard, 4/3/2016
Sexual Education for adolescents with Disabilities

Puberty - Anatomic and physiologic changes
Sexual development - knowledge, beliefs, attitudes and values
Gender Identity – gender role - socialization
Social aspirations – relationships, marriage, children
Healthy relationships – contraception, STI protection, STI screening, pap screening, HPV vaccination

Breuner, CC, Mattson, G. Pediatrics 2016; 138 (2) e20161348
There is a new clinical report from the AAP Committee on Adolescence giving guidance on Sexuality Education
Ernst, Susan, 2/11/2018
Sexuality in adolescents with and without physical disabilities

Girls Experiences at age 16 by Physical Disabilities Status

<table>
<thead>
<tr>
<th>Physical Disability Status</th>
<th>Ever Had Sex</th>
<th>Been Forced</th>
</tr>
</thead>
<tbody>
<tr>
<td>No disability</td>
<td>33.7%</td>
<td>6.0%</td>
</tr>
<tr>
<td>Minimal disability</td>
<td>51.8%</td>
<td>10.9%</td>
</tr>
<tr>
<td>Mild disability</td>
<td>36.3%</td>
<td>12.9%</td>
</tr>
<tr>
<td>Severe disability</td>
<td>42.1%</td>
<td>11.1%</td>
</tr>
</tbody>
</table>

Disability severity index is set on a functional, self and parent defined scale at the time of the survey
Source: Cheng and Udry, 2002
Society often holds misbeliefs about youth with disability - either they’re seen as asexual and infantile or hypersexual if they exhibit inappropriate sexual behaviors. There are data which show us that adolescents with disabilities are indeed sexually active but have higher rates of forced sexual experiences.

Ernst, Susan, 2/11/2018
Case Presentation

- Farrah is an 18 year old with mild cognitive impairment
- Her mother brings her in for contraception
- Farrah goes to high school and is integrated in some regular education classes
- Mother states Farrah isn’t sexually active as far as she knows but Farrah often meets men over the internet
- Mom needs help teaching Farrah about safety
Mastectomy is a little more inflammatory than removal of breast buds--so I changed to the latter

Paula J. Hillard, 4/3/2016
Sexual Education for adolescents with Disabilities

- Assess knowledge and safety
- Assess ability to consent
- Give age and development level appropriate education
Mastectomy is a little more inflammatory than removal of breast buds--so I changed to the latter

Paula J. Hillard, 4/3/2016
Sexual Education for adolescents with Disabilities

Most important things for the Provider to do:

- Bring up the topic
  - Confidential interview
- Acknowledge the family’s concerns and values
- Help families educate their daughters
- AAP has specific recommendations
  - Encourage dialog with families
  - Ask about sexuality and behaviors
  - Monitor for abuse

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Paula J. Hillard, 4/3/2016
Consent for adolescents with Disabilities

No standard definition of consent but the following understanding should be assessed:

• That sex is an activity that both participants want and engage in voluntarily.
• That no one can force or threaten you to have sex.
• That you can refuse to engage in sexual activity with someone even if you have agreed to engage in it before with the same person, and that it is enough to just say "no" without having to provide justification for the refusal.
• That sex is usually engaged in private
• That it is not proper to have sex for money or gifts
• That it is not proper to have sex with children, immediate blood relations

FooterAdapted from: Griffiths (Ed) Ethical Dilemmas: Sexuality and Developmental Disability, 2002
Mastectomy is a little more inflammatory than removal of breast buds—so I changed to the latter

Paula J. Hillard, 4/3/2016
Sexual Education for adolescents with Disabilities

- Use Props and pictures

- Resources

![Image of healthcare workers and patient with baby doll]
Mastectomy is a little more inflammatory than removal of breast buds--so I changed to the latter

Paula J. Hillard, 4/3/2016
Content for Sexual Education

• Simple but accurate terms for anatomy
• Physical boundaries
• Negotiating sexual situations
• Understanding and avoidance of sexual abuse and exploitation
• Same-sex and opposite-sex attraction
• Healthy sexual interactions (intercourse and noncoital alternatives)
• Assertiveness training (saying “No”)
• Safer sexual practices
• Pregnancy prevention
Prevention of Sexual Abuse

- Reality: People with disabilities are at increased risk for sexual assault/abuse
- Don’t deny risks, relationships, or rights
- Parents need to be alert and focus on prevention
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Paula J. Hillard, 4/3/2016
Risk of Sexual Abuse

17 studies including 18,374 children with disabilities. Age birth to 21. Meta-analysis sponsored by WHO

- Pooled prevalence of violence 27% (ranges from 5-68%)

- Sexual violence pooled prevalence of 14% including 1,455 incidents in 14,675 children

- In children with mental or intellectual disability - 27% experiencing physical violence and 15% sexual violence

- Study showed that children with disabilities are 3-4 times more likely to be victims of violence than peers without disabilities

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Risk of Sexual Abuse

- 39%-68% of female and 16% to 30% of male developmentally disabled individuals will be sexually abused before they reach adulthood.

- Primarily male perpetrators but both male and female victims

- The largest group of perpetrators against individuals with DD are caregivers – 48%

- 65% of cases involve masturbation/touching, 31% involve actual or attempted penetration

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Paula J. Hillard, 4/3/2016
Sexual Maltreatment of student with disabilities in American Schools

<table>
<thead>
<tr>
<th>Type of Maltreatment</th>
<th>Percent of students reporting YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Touched, pinched or rubbed</td>
<td>62.3</td>
</tr>
<tr>
<td>Pulled off or down clothing</td>
<td>41</td>
</tr>
<tr>
<td>Exposed private parts</td>
<td>40.4</td>
</tr>
<tr>
<td>Forced kissing</td>
<td>30.1</td>
</tr>
<tr>
<td>Sexual messages/notes</td>
<td>22.4</td>
</tr>
<tr>
<td>Sexual pictures/photos</td>
<td>16.6</td>
</tr>
<tr>
<td>Forced intercourse</td>
<td>14.2</td>
</tr>
</tbody>
</table>

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Paula J. Hillard, 4/3/2016
Prevention of Sexual Abuse

...children armed with information about personal safety are 6-7 times more likely to develop protective behavior . . .

• Teach personal space and privacy by 3 years of age.

• Limit the individuals who provide genital, perianal and bathing care to those who they trust to reduce risks

• Teach appropriate names of body parts

Finkel, MA. Child Abuse Research Education Services (CARES) Institute The Pediatrician 2012
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Paula J. Hillard, 4/3/2016
Prevention of Sexual Abuse

- Discourage co-bathing with siblings and adults.
- Introduce the concept of “OK and NOT OK” touching
- Teach that it is NEVER ok to have a “secret”
- Teach PRIVACY and reinforce the concept often
- The only people who touch private parts are parents, caregivers and doctors

Finkel, MA. Child Abuse Research Education Services (CARES) Institute The Pediatrician 2012
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Paula J. Hillard, 4/3/2016
Prevention of Sexual Abuse

**NO – GO – TELL:** Teach the child or adolescent to be their own first line of defense

This program of prevention has been widely used, originally created for children with developmental disabilities.
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Paula J. Hillard, 4/3/2016
Patient Presentation

• Upon further questioning boys had touched Farrah inappropriately at school

• Her “friends” tried to convince her it would be cool to get pregnant

• Men on the internet had asked her to send pictures of her breasts and she willingly did it

• She gave another man her address – he said that he wanted to marry her and he would come visit
Back to Case Presentation - Farrah

Basic anatomy education
Sex education and boundaries
Teach NO-GO-TELL
Social media safety education

Review Safe Sex and STI testing
Offer Contraception
Mastectomy is a little more inflammatory than removal of breast buds--so I changed to the latter

Paula J. Hillard, 4/3/2016
Reproductive Health Plan

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>How important is it to avoid pregnancy now?</td>
<td></td>
</tr>
<tr>
<td>What would you do if you became pregnant now?</td>
<td></td>
</tr>
<tr>
<td>What is your desired family size?</td>
<td></td>
</tr>
<tr>
<td>What is your intended timing for pregnancy?</td>
<td></td>
</tr>
<tr>
<td>Are there health issues that need addressing before becoming pregnant?</td>
<td></td>
</tr>
</tbody>
</table>
Comparing effectiveness of Contraceptive Options

**More effective**
Less than 1 pregnancy per 100 women in one year
- Implant
- Vasectomy
- Female Sterilization
- IUD

**6-12 pregnancies per 100 women in one year**
- Injectable
- Pills
- Patch
- Ring
- Diaphragm

**Less effective**
18 or more pregnancies per 100 women in one year
- Male Condoms
- Female Condoms
- Sponge
- Withdrawal
- Spermicides
- Fertility Awareness-Based Methods
Essential Components of Contraceptive Counseling
Gynecologic Care

- Follow standard guidelines for:
  - HPV Vaccination
  - STI screening – studies show decreased rates of screening and higher rates of STI in persons with disabilities (Cheng Dev Phys Disabil 2005)
  - Cervical cancer screening – multiple studies show lower rates of pap testing than in general population (Horner-Johnson Womens Health Issues 2015; Brown J Intellect Disabil Res 2016)

- Consider menstrual suppression for premenstrual symptoms such as mood or behavioral changes, heavy menstrual bleeding, difficulty with menstrual hygiene
HPV Vaccination – 10 year history

Oct 2009 Bivalent HPV 16, 18

June 2006 Quadrivalent HPV 6,11,16,18 (AU, US)

Dec 2014 Nanavalent HPV 6, 11, 16, 18 + 31,33,45, 52, 58

2006 CDC recommended HPV vaccine for girls target age 11-12 and catch up up through age 26

2009 CDC recommended HPV vaccine for boys age 11-21 or up through 26 for MSM

2016 CDC found non-inferior immunogenicity with 2 doses of HPV vaccine 6-12 mo apart for age 9-14 years, 15 and older requires 3 doses (0, 2, 6mo)

*Clinical Infectious Diseases, Volume 63, Issue 4, 15 August 2016, Pages 519–527*
Encourage Vaccination – Cancer Prevention!
<table>
<thead>
<tr>
<th>STI</th>
<th>USPSTF</th>
<th>CDC</th>
<th>AAFP</th>
<th>ACOG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chlamydia</td>
<td>Screen women younger than 25 years and others at increased risk</td>
<td>Screen women 25 years and younger and others at increased risk</td>
<td>Screen women 25 years and younger and others at increased risk</td>
<td>Screen women 25 years and younger and others at increased risk</td>
</tr>
<tr>
<td>Gonorrhea</td>
<td>Screen women younger than 25 years and others at increased risk</td>
<td>Screen women at increased risk</td>
<td>Screen women younger than 25 years and others at increased risk</td>
<td>Screen adolescents and others at increased risk</td>
</tr>
<tr>
<td>Syphilis</td>
<td>Screen women at increased risk</td>
<td>Screen women exposed to syphilis</td>
<td>Screen women at increased risk</td>
<td>Screen women at increased risk</td>
</tr>
<tr>
<td>HIV</td>
<td>Screen women at increased risk</td>
<td>Screen all</td>
<td>Screen women at increased risk</td>
<td>Screen women at increased risk</td>
</tr>
</tbody>
</table>

**high-risk sexual behavior - multiple current partners, a new partner, using condoms inconsistently, having sex while under the influence of alcohol or drugs, having sex in exchange for money or drugs**
<table>
<thead>
<tr>
<th>STI</th>
<th>USPSTF</th>
<th>CDC</th>
<th>AAFP</th>
<th>ACOG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis B</td>
<td>Do not screen general population</td>
<td>Provide prevaccination screening for women at increased risk</td>
<td>Do not screen general population</td>
<td>No specific recommendation</td>
</tr>
<tr>
<td>Hepatitis C</td>
<td>Do not screen general population; insufficient evidence to recommend for or against screening women at increased risk</td>
<td>Screen women at increased risk</td>
<td>Do not screen general population; insufficient evidence to recommend for or against screening women at increased risk</td>
<td>Screen women at increased risk</td>
</tr>
<tr>
<td>HSV</td>
<td>Do not screen</td>
<td>Do not screen general population</td>
<td>Do not screen</td>
<td>Screen if sexual partner has HSV</td>
</tr>
</tbody>
</table>
Screening for Cervical Cancer

• ASCCP 2012 guidelines recommend screening begin at age 21 repeat pap every 3 years between 21 and 30 years

• May consider primary HPV screening in women 25 and older and repeat every 3 years.

• Women age 30 and older can be screened using cotesting with cytology and HPV repeated every 5 years (preferred) or cytology alone repeated every 3 years

• New USPSTF guidelines in review – women 30 and older can be screened by cytology every 3 years or HPV every 5 years as primary screen

• Stop screening age 65 in women who have had adequate negative screening and no h/o CIN2+ in last 20 years ( 3 negative paps or 2 negative HPV in last 10 years)

• Journal of Lower Genital Tract Disease, Volume 17, Number 5, 2013, S1YS27
# Medical Options for Menstrual Suppression

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Advantages</th>
<th>Disability Concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSAIDS</td>
<td>Decreases flow</td>
<td>Gastric distress</td>
</tr>
<tr>
<td></td>
<td>Non-hormonal</td>
<td></td>
</tr>
<tr>
<td>Combined oral contraceptive</td>
<td>Decreases flow</td>
<td>Immobility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Daily reminders</td>
</tr>
<tr>
<td>Contraceptive Patch</td>
<td>Weekly</td>
<td>Immobility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patients with IDD may pull it off</td>
</tr>
<tr>
<td>Contraceptive Ring</td>
<td>Monthly</td>
<td>May be difficult to place</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patients with IDD may remove</td>
</tr>
<tr>
<td>Progesterone only pill</td>
<td>Decreases flow</td>
<td>Daily reminders</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Irregular bleeding</td>
</tr>
<tr>
<td>DMPA</td>
<td>4 times yearly</td>
<td>Risk of low bone density with prolonged use</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Weight gain interferes with transfers</td>
</tr>
<tr>
<td>Progesterone containing IUD</td>
<td>5-7 years</td>
<td>Insertion issues-anesthesia?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Initial irregular bleeding</td>
</tr>
<tr>
<td>Implants</td>
<td>3 years</td>
<td>Irregular bleeding, insertion issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Amenorrhea 21%</td>
</tr>
</tbody>
</table>

Source: ACOG Committee Opinion 2009
Preconception and Obstetrical Issues in Women with Physical & Developmental Disabilities

Jaclyn Morrison MD, FACOG
Assistant Professor, University of Rochester
Medical Director, Strong Memorial Hospital Birth Center
Women with Disabilities Can and Do Get Pregnant

- Misconceptions and stigma around pregnancy and family planning
- Differences between physical disabilities and intellectual/developmental disabilities
- Women with multiple disabilities are no longer significantly less likely to have been pregnant
- Increased rates of unplanned pregnancy
- The number of pregnancies in this population is expected to increase

- Women with disabilities are marginalized by misinformation, bias, and assumptions without supporting medical evidence
- Lack of clear guidance from providers whether these women can safely have children
Pregnancy Among Women with IDD

- Historical shift from institutionalization to community-based integrated living has changed the social relationships and reproductive experiences of women with IDD
- Legal protections against involuntary sterilization
- Assumptions that women with IDD are unable to raise children
- Lower rates of preventative care prior to pregnancy
- Little knowledge about sexual health and pregnancy, especially childbirth experiences
- Risk of reproductive rights abuses and custodial issues
Role of Preconception Counseling

- Focus on reproductive choice and planned pregnancies
- Optimize management of potential medical co-morbidities prior to conception
- Address reproductive genetic counseling needs
- Limit fetal exposure to teratogenic medications
- Identify potential needs and challenges during the peripartum period
- Locate appropriate providers and healthcare services for patients prior to conception
Preconception Risk Factors

- Twice as likely to use tobacco
- Only two-thirds of women with disabilities reported engaging in exercise in the month prior to conception
- More likely to report poorer health on all health status indicators
- Four-fold higher prevalence in reporting frequent mental distress
- Increased prevalence of health co-morbidities:
  - Diabetes (80%)
  - Obesity (40%)
  - Asthma (90%)
Challenges and Differences in Obstetrical Care and Birth Outcomes
Prenatal Care

- Prenatal care should allow for as much independence and autonomy as possible
- Need for a higher degree of care coordination

- Significant disparities in healthcare utilization, health behaviors, and health status before and during pregnancy
- More likely to delay prenatal care until after the 1st trimester and have inadequate prenatal care
- Less likely to present for postpartum visits
- Disability status is not included in the PRAMS survey (which is meant to identify groups of women and infants at high risk for health problems)
Prenatal care barriers and challenges are multi-factorial in this population.

There is a wide spectrum of issues and considerations based on type and severity of disability.
Prenatal Care Barriers/Challenges

- **Socioeconomic barriers**
  - Lower education levels
  - Less likely to be married
  - Lower household income

- Higher rates of public insurance
- Higher rates of intimate partner violence
Prenatal Care Barriers/Challenges

- **Accessibility barriers**
  - Physical office accessibility and transportation
  - Need for additional equipment
  - Need for additional visit time and care coordination
  - Lack of provider training and education
  - Lack of appropriate level antenatal education
Prenatal Care Barriers/Challenges

- **Healthcare challenges**
  - Physical disabilities and functional changes during pregnancy
    - Increased frequency of seizure activity
    - Increased frequency/severity of muscle spasms
    - Mobility issues and limitations related to weight/physiologic changes in pregnancy
    - Decreased activity levels and exercise
  - Teratogenic medications
  - Increased rates of antepartum medical complications
  - Higher rates of maternal infections (predominately urinary source)
Case Example

Jennifer is a 28 yo G2P1001 at 12 weeks gestation with pregnancy complicated by spastic cerebral palsy and seizure disorder who presents for routine prenatal care. What disability-specific issues should you address at her visit?

Medication safety?
Mobility changes?
Mode of delivery?
Teratogenic Medication Considerations

- **Anticonvulsant medications**
  - Valproic acid
  - Carbamezepine
  - Phenytoin
  - Phenobarbital
  - Acceptable medications: Lamotrigine (Lamictal), Keppra

- **Psychiatric medications**
  - Lithium
  - Risperidone
  - Acceptable medications: SSRIs, NSRIs

- **Muscle relaxants**
  - Baclofen
Patient – Provider Experience

- Women with disabilities report increased negative experiences with healthcare providers
  - Ineffective pregnancy management
  - Possess negative and inaccurate stereotypes about their sexuality
  - Disapprove of pregnancy
  - Questions ability to parent
- Lack of information about the interaction of their disabilities and pregnancy
- Failed to ask the patient what her needs were, what assistance (if any) they wanted, and how best assistance could be given
- Need knowledgeable providers who are “sensitive to their needs and respectful of their desire to become parents”
- Negative attitudes and behaviors among healthcare providers are often cited as harder to overcome than physical barriers to care
Birth Outcomes

- Overall limited data available
- Pregnancy outcomes are overall favorable with few differences between women with and without disabilities
- No significant differences in live birth, miscarriage, or abortion rates

Higher rates of:
- Preterm birth
- Low birth weight infants
- Fetal demise (*IDD group)
- Infant NICU admission
- Longer hospital stays

<table>
<thead>
<tr>
<th></th>
<th>PTB</th>
<th>LBW</th>
<th>FDIU</th>
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<tr>
<td><strong>With IDD</strong></td>
<td>2.08</td>
<td>2.41</td>
<td>3.52</td>
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</tbody>
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Pregnancy-Related Issues
Antepartum Issues

- The majority of antenatal and obstetrical issues can be managed effectively and are not prohibitive
- Important role for birthing and parenting classes
- Slight increase in labor induction and cesarean delivery rates
- Same obstetrical indications for labor and delivery management
- Similar rates of:
  - Gestational diabetes
  - Gestational hypertension
  - Preeclampsia *(may be slightly increased in women with IDD)*
  - VTE
Case Example

Annie is a 30 yo G1P0 who presents for routine prenatal care at 36 weeks gestation. At age 22, she was involved in a MVA that resulted in a spinal cord injury at T6. She would like to discuss delivery planning and what to expect during the labor and delivery process. How do you counsel her?

Recognition of labor?
Mode of delivery?
Analgesia?
Other considerations?
Antepartum Issues

- Symptom recognition
  - Sensory deficits
  - Intellectual disability
- Transportation issues
- Assistive technology and physical space accommodations
- Analgesia considerations
  - Use of epidural anesthesia is recommended for women at risk of autonomic dysreflexia (spinal cord injury T6 or higher)
  - Consider anesthesia consultation prior to L&D admission
Additional Considerations Specific to IDD

- Heterogeneous group with varying types and severity of physical and intellectual/developmental disabilities – need for individualized care plan
- High mental health co-morbidity rate
- Health literacy issues
  - Basic language
  - Avoid text-based education
  - Longer and more frequent prenatal visits
- Early referral to support services and early involvement of pediatric team
Postpartum Issues

• Less social support following delivery
  • May require home nursing and PT services
  • Social work involvement early in pregnancy
  • Early involvement of pediatric team
  • Links to community services

• Potential need for increased length of stay

• Issues with medication compliance and breastfeeding

• Lower breastfeeding rates

• Higher rates of postpartum depression

• Need for adaptive infant equipment
Case Example

Kate is a 24 yo G1P0 who presents to your office with a new diagnosis of pregnancy. Her history is significant for mild intellectual/developmental disability. She presents today with her mother and boyfriend (who also has a mild intellectual disability). Her mother has concerns about Kate being pregnant and raising a child. What counseling/resources do you provide?

Discuss risks of medical co-morbidities?
Education?
Patient and parental resources?
References

References


QUESTIONS
Helpful Clinical Resources

CDC STI Screening Guidelines (*APP)
www.cdc.gov/std/tg2015/screening-recommendations.htm

CDC US Medical Eligibility Criteria for Contraceptive Use (*APP)
www.cdc.gov/reproductivehealth/contraception/mmwr/mec/summary.html

ACOG Interactive Site for Clinicians Serving Women with Disabilities
www.acog.org/About-ACOG/ACOG-Departments/Women-with-Disabilities

Through the Looking Glass & The Arc (Perinatal/Parenting resources)
www.lookingglass.org / www.thearc.org

CROWD (Center for Research on Women with Disabilities)
www.bcm.edu/research/centers/research-on-women-with-disabilities

National Council on Disability
www.ncd.gov