Reproductive Issues in CSHCN

2013 National Conference & Exhibition
Session #: H2031
Title: H2031- Section on Adolescent Health Program

Hatim A. Omar, M.D.
Professor, Pediatrics and Ob\Gyn.
Director, Adolescent Medicine
Department of Pediatrics
University of Kentucky
Lexington, KY
Email: haomar2@uky.edu
Faculty Disclosure Information

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WHO definition

Chronic conditions are health problems that require ongoing management over a period of years or decades.
Disability

• **Definition of disability**

• **Impairment**
  – Defined as the loss or abnormality of psychological, physiological or anatomical structure or function

• **Disability**
  – Is any restriction or lack of ability to perform an activity in a normal manner

• **Handicap**
  – Is the disadvantage experienced by the individual as a result of impairments and disabilities that limits performance of a normal role, taking account of age, sex and cultural background
Influencing factors

- Duration
- Physical or mental
- Visible or not
- Limiting or not
- Congenital or acquired
- Episodic or persistent
- Life-threatening or not
Chronic conditions: Prevalence

- France (1994): 8.3% (girls) 9.0% (boys)
- Switzerland (2002): 9.5% (girls) 10.4% (boys)
- Canada (1994): 11.0% (girls) 7.0% (boys)
- Catalonia (2001): 11.2% (girls) 7.7% (boys)
Children with disabilities in Scandinavia, United States and Israel

<table>
<thead>
<tr>
<th></th>
<th>Denmark</th>
<th>Finland</th>
<th>Iceland</th>
<th>Norway</th>
<th>Sweden</th>
<th>Total</th>
<th>United States</th>
<th>Israel</th>
</tr>
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<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Girls</td>
<td>6.7</td>
<td>8.3</td>
<td>7.1</td>
<td>6.7</td>
<td>8.0</td>
<td>7.4</td>
<td>4.4</td>
<td>5.4</td>
</tr>
<tr>
<td>Boys</td>
<td>6.7</td>
<td>11.5</td>
<td>7.7</td>
<td>8.2</td>
<td>6.9</td>
<td>8.2</td>
<td>7.2</td>
<td>9.8</td>
</tr>
<tr>
<td><strong>Age (*)</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-6 yrs</td>
<td>5.8</td>
<td>9.3</td>
<td>7.8</td>
<td>5.8</td>
<td>5.1</td>
<td>6.8</td>
<td>5.2</td>
<td>5.2</td>
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<tr>
<td>7-12</td>
<td>7.5</td>
<td>10.1</td>
<td>6.0</td>
<td>7.5</td>
<td>7.8</td>
<td>7.9</td>
<td>6.3</td>
<td>10.7</td>
</tr>
<tr>
<td>13-18</td>
<td>6.5</td>
<td>9.9</td>
<td>8.2</td>
<td>8.9</td>
<td>8.8</td>
<td>8.5</td>
<td>9.3</td>
<td>7.0</td>
</tr>
<tr>
<td>Total</td>
<td>6.6</td>
<td>9.8</td>
<td>7.3</td>
<td>7.4</td>
<td>7.2</td>
<td>7.7</td>
<td>5.8</td>
<td>7.7</td>
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<tr>
<td><strong>Sample</strong></td>
<td>2,219</td>
<td>2,705</td>
<td>1,761</td>
<td>1,856</td>
<td>1,934</td>
<td>10,475</td>
<td>66.135</td>
<td>13.453</td>
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</table>
Adolescent Sexuality

• Same sexual desires and fantasies that all youth have

• Leads to increased risks for:
  – Sexual behavior
  – Sexual assault
  – Sexually transmitted diseases
  – Pregnancy
Adolescent Sexuality

• Complicated by often limited sexuality education provided to these youth

• Need education about inappropriate sexual touching and abuse

• Address GYN needs of adolescent females
What are we talking about?

- Pubertal development, variations and related problems.
- Menstrual hygiene in disabled adolescents
- Potential sexual abuse and prevention strategies
- Pregnancy prevention and sexuality education
- Common reproductive/gynecologic problems in disabled teens and how to recognize them.
Physical Disability

Definition

• Any long-or short-term reductions in a person’s activity that results from acute or chronic conditions.
Physical Disability
Statistics

• 43 million disabled persons in USA
• One third of these are women
• One third of total is adolescents
• Two thirds of disabled women are not receiving routine gynecologic care
• Most disabled men have no reproductive counseling
Pubertal development

• Due to the condition or the treatment, their pubertal timing may be different than for peers
# Age at menarche

<table>
<thead>
<tr>
<th>Condition</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cystic Fibrosis</td>
<td>14.5 years</td>
</tr>
<tr>
<td>Sickle cell Disease</td>
<td>14.5 / 15.4 years</td>
</tr>
<tr>
<td>Childhood malignancies</td>
<td>12.2 years</td>
</tr>
<tr>
<td>Chronic renal disease</td>
<td>15.9 years</td>
</tr>
<tr>
<td>Diabetes</td>
<td>12.8 / 13.0 years</td>
</tr>
</tbody>
</table>
# Positive body image: girls

<table>
<thead>
<tr>
<th>Location</th>
<th>Chronic C.</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>BC, Canada (1994)</td>
<td>36%</td>
<td>50%</td>
</tr>
<tr>
<td>MN, USA (1994)</td>
<td>48%</td>
<td>60%</td>
</tr>
<tr>
<td>Barcelona (1994)</td>
<td>49%</td>
<td>61%</td>
</tr>
</tbody>
</table>
An abnormal body image may lead to:

- Lowering of self-esteem
- Segregation from peers
- Lower participation at school and other activities
- Higher anxiety over their sexual functioning and sexual relationships
- Depression and/or anger
Physical Disability
Consequences

- TBI, CNS progressive d-rs
- Musculoskeletal impairment
- Mobility Problems
- Chronic malnutrition
- Poor dental hygiene
- Aspiration, GER, atelectasis
- Severe pain, muscle atrophy
Physical Disability
Consequences

• Spinal Cord Injuries:
  - Neurogenic bladder & bowel
  - Sensory & motor loss below
  - Impaired resp. function & Autonomic dysreflexia in high cord injuries
Physical Disability
Gynecologic Exam

• May trigger bowel or bladder incontinence
• Disabled women may not be able to assume traditional exam position
• Exam may precipitate autonomic dysreflexia (~85% of patients with spinal cord injuries)
• Exam position
Physical Disability
Autonomic Dysreflexia

• Caused by loss of hypothalamic control over sympathetic spinal reflexes
• Stimuli from bladder, bowel, uterus, skin below the lesion or from the genital area can trigger that. Constipation also can cause it.
• Symptoms include: Hypertension, bradycardia, cardiac arrhythmia, sweating, flushing, tingling, nasal congestion and occasionally respiratory distress.
Physical Disability
Attitudinal Barriers to reproductive care

• Misconceptions: “disabled are sexless beings”
• This misconception is shared by society in general, parents, teachers and unfortunately some health care providers
• This leads to inadequate knowledge and training of educators and health care professionals in the area of adolescent sexuality in disabled teenagers and lack of adequate reproductive care for these patients
Reasons why health care providers do not give consideration to the sexual issues of chronically ill adolescents:

(Angerson & Wolf, 1986)

A) sex is viewed as an area not vital to recovery and the maintenance of good health.

B) not comfortable and/or not competent confronting sexual issues.

C) they frequently assum that the causes of sexual disfunctioning are disease-based.
Physical Disability
Affected sexual function

- Sexual response
  - Decreased vaginal lubrication & accommodation, orgasmic problems, dyspareunia

- Fertility
  - usually intact, altered signs & symptoms of pregnancy

- Motor function
  - Inability to carry out sex act
Physical Disability
Affected sexual function

- Urine, bowel, gas control
- Sexual interest
- Sexual identity
- Partnership

- Especially during sex
- may be reduced or absent
- Self perception & performance anxiety
- Inadequate social skills
Physical Disability

Important points in patient’s history

• Age: adverse influence of aging
• Partnership status: persons desire for sexual fulfillment
• Occupation & education: indicates ability to handle information
• Mood levels: reflects mental status, depression
Physical Disability

Important points in patient’s history

• Medications: effect on sexual function
• Nature of disability: Congenital (? Sheltered life), Acquired after puberty (prior experience in relationships & sexual activity)
• Progressive medical condition: adverse effect on sexual function
Mental Disability
Common Causes

• GENETIC: chromosomal, metabolic, hereditary degenerative, hormonal, primary CNS defects, malformation syndromes, sporadic syndromes
• ACQUIRED(prenatal): infection, toxins, irradiation, maternal metabolic problems
Mental Disability
Common Causes

• ACQUIRED (perinatal): prematurity, trauma, asphyxia, infection, hypoglycemia, kernicterus
• ACQUIRED (postnatal): brain injury, poisoning, cerebrovascular accidents, postimmunization encephalopathy, infection, early severe malnutrition, hormonal deficiency, psychosocial deprivation, abuse, neglect
Mental Disability

- Affects approximately 3% of population
- At least 60% of these patients do not have adequate reproductive care
- Parents often unable to find health care providers willing and able to provide reproductive care
- Societal attitudes regarding mentally disabled patients
- Difficulty in performing gynecologic exam
Epidemiology of teens with disabilities

- 3% general populations has significant intellectual deficit
- 1.2 million are teens
  - 80% mild: (IQ 50-75) – trainable, live with family
    - Often lack sex education, feel aware of differences
  - 12% moderate (IQ 30-50) – trainable, live in a home, with family
    - Protected from sexual exploitation
  - 8% severe – need a lot of care
    - Protected from abuse

Pratt HD et al. Prim care 2007
Mental Disability

Sexual activity

• 30% F, 60% M masturbate
• 60% F, 70% M engage in kissing non-relative of opposite sex
• 50% F and M- hugging & kissing for a long time
• 20% F, 50% M going further than hugging and kissing
Care of teens with developmental delay—survey of gynecologists

- Routine care for teen with moderate to severe cognitive or physical disability
  - 20.1% were significantly apprehensive
  - 8.9% were completely unprepared

- Overall 14-42% had some level of discomfort when presented with specific scenarios

- Reasons: time, reimbursement, education, access

Shah P, J Pediatr Adolesc Gynecol 2005
Mental Disability

- Menstruation/menstrual problems
- Contraception/options
- Sterilization/legal issues
- Sexual abuse
- Pregnancy
- Sexually transmitted diseases
Mental Disability
Gynecologic EXAM

• History: sources
• Pre-exam counseling
• Speculum or no speculum
• Pap smear
• Sedation
• Ultrasound
Presenting Gynecologic Issues

**Menstrual suppression:**
- Difficulty with menstrual hygiene
- Perimenstrual behavioral problems
- Heavy or Painful menses
- Contraception

**Sterilization or Hysterectomy request:**

**Other:**
- Ovarian cysts
- Vaginitis
- Vulvar skin disorders
- Breast masses

Quint et Al 2012
### Factors Complicating Gynecologic Care in Females with Developmental Disabilities

<table>
<thead>
<tr>
<th>Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased communication difficulties in those with DD</td>
</tr>
<tr>
<td>Cognitive limits that may be found in some with DD</td>
</tr>
<tr>
<td>Increased neurological problems in some with DD (as seizures)</td>
</tr>
<tr>
<td>Multiple joint complications in some DD patients (i.e., deformities, contractures, spasticity, autonomic dysreflexia)</td>
</tr>
<tr>
<td>Increased presence of other orthopedic disorders (as kyphoscoliosis)</td>
</tr>
<tr>
<td>Impaired sitting position in some with DD, such as decubitus ulcers</td>
</tr>
<tr>
<td>Increased nutritional issues in some with DD, such as feeding tubes or gastroesophageal reflux</td>
</tr>
</tbody>
</table>

**Others:**
- Lack of knowledge on part of parents or clinicians regarding such care
- Parents’ or clinicians’ refusal to provide such care
Pubertal Maturation

• For most adolescents with disabilities the process and pattern of pubertal maturation varies little from peers. It’s the tempo and timing of maturation that frequently varies.

• Delayed puberty
  – Prader Willi
  – Downs Syndrome

• Early Puberty
  – CP (menarche is later)
  – Hydrocephalus
  – Myelomeningocele
Developmentally Disabled Adolescent and Puberty

• Adolescence = Turbulence
• For parents: one more thing to worry about
• Teens seen as asexual beings, the more disabled, the less likely parents and school will address sexuality
• Living situation at home
  – Privacy issues
  – Separation issues
• Teaching and discussing
  – Sexuality often revolves around a crisis
Developmentally Disabled Adolescents and Puberty

• May be complicated by predisposing factors
  – Seizure disorders
  – Medications
  – Eating issues/weight issues
  – Thyroid abnormalities
  – Lack of verbalization
  – Inability to maintain hygiene
  – Behavioral issues
Menstrual Concerns

• Periods can be affected by disability
  – Thyroid disorder in teens with DS
  – PCOS more common in teens with seizures (10-20%) and in women on Valproic acid
  – Antipsychotic medications may lead to hyperprolactinemia
Menstrual Suppression

• **GOAL** – safe, minimally invasive, non-permanent.
• Best options
  – Antiprostaglandin drugs – NSAIDs
  – Continuous oral contraceptives
  – Continuous oral progestins
  – DMPA
  – Progestin subdermal Implant
  – Levonorgestrel IUD
• Usually not appropriate
  – Endometrial ablation
  – Hysterectomy
Menstrual Suppression

• Hysterectomy- Sterilization
  – ACOG (2007):
    • The presence of a mental disability does not, in itself, justify either sterilization or its denial.
    • The initial premise should be that non voluntary sterilization is not ethically acceptable because of the violation of privacy, bodily integrity and reproductive rights
    • Hysterectomy solely for the purpose of sterilization is inappropriate

• Hysterectomy should be only done for medical indications
Education

• Puberty – normal sequence, timing
• Puberty – challenges for girls with developmental disabilities
• Menstrual Hygiene
• Menstrual Suppression
• Sexual Health
• Contraception
• Sexual Assault Prevention
Education – Menstrual Hygiene

• Identify names of body parts – public and private
• Simple explanation of where blood comes out and other associated menstrual symptoms
• Periods are normal, healthy
• Keep it simple – use pictures, models, videos- Be consistent and use positive reinforcements
• Teach menstrual hygiene habits simply
• Washing hands
• Changing pads
• Keeping genital area clean
• Changing clothes/underwear
• Daily bathing/showering
UN 2006 recommendations – Sexuality of persons with DD

• Train reproductive and sexual health providers on accommodations for persons with DD
• Make sexual and reproductive health information and services appropriately accessible to persons with disabilities and their families
• Train persons with disabilities to become peer educators on sexual and reproductive health for other persons with disabilities
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 indication of it.

AAP recommendations – Sexuality of children/adolescents with DD

• Advocate for sexuality education at home, community and school settings
• Remain vigilant in assessing for abuse
• Assess family’s strengths and needs for resources to meet the needs of children and families.

Sexual Education

HOME IS THE BEST PLACE TO LEARN

• Privacy
• Safety
• Mutual respect, self-esteem
• Assertiveness and communication skills
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

• “The participants in the study identified that current sex education materials available to them were too broad and overwhelming. Safety issues were a concern of the parents, professionals, and healthcare professionals.”

Risk of Sexual Abuse

- 39%-69% 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

Risk of Sexual Abuse

- Children with disabilities often receive praise for being friendly and cooperative
- Children with disabilities often need others’ assistance with the most private activities
- Children with disabilities may be dependent on adults for all activities of daily living
- Children with disabilities often receive little or no sex education
- Children with disabilities may be isolated from peers
- Difficult for children with disabilities to distinguish appropriate vs. inappropriate touch
- REALITY: People with disabilities are at increased risk for sexual abuse

Prevention of Sexual Abuse

• Review of studies reveal small number of participants, all women except one study included adolescents
• Participants were primarily mildly/moderately cognitively impaired and had verbal skills
• General teaching materials included Behavioral Skills training program (private/public, appropriate touch/behaviors), in situ training and no, go, tell
• Sessions were typically weekly for 8-10 weeks with pre and post testing
• Assessment included verbal-report, role-playing, in situ assessments and skill generalization
• Skills are learned, maintained and generalized to an extent

Educational Goals for Prevention of Abuse and for Building Self Esteem

• Age and relationship appropriate social behavior
• Understanding sexual development and identity
• Relationships
• Boundaries
• Assertion and safety
Mental Disability

HISTORY

• 1927: Buck vs. Bell; theory of ‘eugenics’
• 1942: Skinner vs. Oklahoma (1965: Griswold v. Connecticut); Procreation-Fundamental right
• 1974: Relf vs. Weinberger; no federal funding for sterilization of an incompetent person
THANK YOU