Confidentiality in Pediatric and Adolescent Gynecology: When We Can, When We Can’t and When We’re Challenged

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Objectives

- To learn the rights of adolescents to confidential health services and their limitations
- To learn ways to address practical issues in providing confidential health services to adolescents
- To understand how to preserve confidentiality for adolescents in the age of EMR and Meaningful Use

Faculty Disclosure Slide
Dr. Elizabeth Alderman

- I have no relevant financial relationships with the manufacturers(s) of any commercial product(s) and/or provider of commercial services discussed in this CME activity.
- I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.
Health Threats to Adolescent Girls Worldwide-WHO, 2012*

- 1.3 million adolescents died mostly from preventable or treatable causes
  - Motor vehicle accidents leading cause of death - 330 adolescents dying every day.
  - Other causes of death include:
    - Chronic illness, HIV, suicide, lower respiratory infections and interpersonal violence.
- Causes of Morbidity
  - High Risk Behaviors
    - Sexual
    - Tobacco Use
    - Alcohol Use
    - Illicit Substances
  - Mental Health Challenges

What are Essential Elements of Adolescent Health Care?*

- Enhanced Access
- Addresses adolescent concerns for privacy protection
- Adequate time for providers to care for complex needs
- Whole person orientation
- Focus on preventive services and care management
  - Care coordination
- Quality and Safety

Approach to the Adolescent Key Strategies

- Assess developmental level
- Discuss confidentiality with adolescent/parent
- Appropriately ensure confidentiality, time alone
- Risk assessment at most visits
- Systems for follow-up of confidential results
Confidentiality: When We Can

Confidentiality

Information about teen’s treatment not disclosed without his/her permission

Rationale for Confidentiality

• Avoid negative health outcomes
  > Protect the adolescent’s health
  > Public health concerns

• Research supports it
  > Adolescents avoid or stop using services*
  > Adolescents will not be honest with practitioners+
  > Adolescents will not go to medical home for services**

+Ford, Millstein. JAMA 1997)
**Cheng. JAMA 1993; Sugarman, et. al. JAMA 2000
National Organizations Support Confidentiality in Adolescent Health Care

- Expert consensus- (ACOG ‘88, AAFP ’89, AAP ’89 SAHM ’92, AMA’92)
  - Informing adolescents and parents about confidentiality protections/ limits
- Concerns for specific populations of adolescents
- Confidentiality in particular health care settings
- Support confidential access to specific health services, such as:
  - Preventive health
  - Testing & treatment for STDs & HIV
  - Contraception, pregnancy-related services, abortion, & other reproductive health services

Ethical Principles

- Respect for persons
  > Adolescent’s individual autonomy
  > Non-autonomous entitled to protection
- Beneficence
  > Minimize harm
  > Respect individual decision making
  > Do all for patient’s well-being

Case 1
Referral for Oligomenorrhea

- Susan is referred for work up of oligomenorrhea
- Without her mother present, discloses that she is sexually active and uses condoms sometimes.
- Susan does not want you to tell her mother.
- You want to screen Susan for STI and HIV, offer a pregnancy test, and counsel her about abstinence, contraception and STI prevention.
At what age can you treat the fact that Susan is sexually active as confidential?

A) If she is at least 13
B) If she is at least 14
C) May be confidential at any age
D) Not until she is 15
E) Not until she is 16

At what age can you treat the fact that Susan is sexually active as confidential-in the US?

A) If she is at least 13
B) If she is at least 14
C) May be confidential at any age
D) Not until she is 15
E) Not until she is 16

At what age can you treat the fact that Susan is sexually active as confidential-in Canada*?

A) If she is at least 13
B) If she is at least 14
C) May be confidential at any age
D) Not until she is 15
E) Not until she is 16

The Society for Obstetricians and Gynaecologists of Canada
Confidentiality

- Factors to consider
  - Age
  - Developmental level
  - Relationship with parents
- Legal requirements
  - State laws
  - Province laws
  - Federal laws

Developmental Considerations

- Determine developmental stage
- Assess autonomy
- Assess likelihood of adherence
- Support adolescents’ development as health consumer

Adolescent Cognitive Development

- **Early Adolescent (12-14 years)**
  - Retains concrete thinking and conformist morality of childhood
  - Begin to separate from parents and identify with peers
- **Middle Adolescent (15-17 years)**
  - Moral choices based on abstract values
  - Imagine future consequences of actions
  - Peer influences, risk taking behaviors, conflict with parents peak
- **Late Adolescent (18-21 years)**
  - Formal operational thinking
  - Fuller appreciation of consequences of actions
  - Development of personal values, appreciate parental values
Competence to Consent

- Capacity to understand alternatives & make voluntary choice
- Previous ability to cope with illness
- Emotional stability
- Previous compliance with medication/treatment

Communicating Confidential Concerns

- Set ground rules with adolescent and parent
- Facilitate collaborative decisionmaking
- Discuss information with adolescent alone
- Develop a plan with adolescent of what information will be disclosed to parent and how that will be done
- Communicate with parent

The Legal Framework for Minor Consent Laws-US and Canada

- Complex patchwork
- State and Province specific
- Federal - HIPAA privacy rule
- Constitution, statutes, court decisions
- Family law
  > Status of minor children
  > Rights/responsibilities of parents/guardians
- Reproductive rights
History of Minor Consent Laws in the US

- Earliest laws enacted in the 1950’s
- Pattern of expansion in 1960’s and 1970’s
- Few changes in the 1980’s
- Attempts to restrict/repeal beginning in the 1990’s until now

Consent Laws in 50 States & DC

- All states have minor consent laws
- Some laws based on minor’s status
- Some laws based on services minor is seeking
- A few laws allow treatment without consent
- A number of states allow for provider discretion to disclose information

Consent Laws Based on Services Provided

- STI prevention, screening, diagnosis and treatment
  - Reportable diseases
  - HIV testing laws
  - HIV/AIDS treatment?
- Drug or alcohol counseling and treatment
- Outpatient mental health services
- Diagnosis and treatment for sexual assault
Consent Laws Based On Services Provided

- Pregnancy related care
- Minors usually can consent
  - Contraception services
  - Prenatal care
- Minors often cannot consent
  - Termination of pregnancy
  - Sterilization

Consent Laws Regarding Minors in Canada*

- Age of sexual activity is 16 years
  - 14 or 15 yo can consent if:
    - Partner less than 5 years older
    - There is no issue around authority, dependency or exploitation
    - If partner is 5 years or older-criminal offense if not married
  - Marriage laws vary by province/territory

Government of Canada-Department of Justice 2-11-15

Consent Laws Regarding Minors in Canada*

- Age of sexual activity is 18 years where sexual activity “exploits” young person
- “Close in age” exception for 12 & 13 yo-may consent if partner less than 2 years older and no issue around authority, dependency, exploitation

Government of Canada-Department of Justice 2-11-15
Consent Laws Based on Status

- Emancipated minor
- Mature minor
- Minor living apart from parents
- Minor in the military
- Minor over a certain age
- Pregnant minor
- Incarcerated minor
- Foster care

Emancipated Minor

- No specific statute
- Based on case law
- Emancipation defined as renunciation of parental rights to a child
- Minor who is a parent may provide consent for their own child
- Minor emancipated if following events have occurred
  - Marriage
  - In military
  - Established a home/financially independent
  - His/her parent failed to fulfill parental support obligations and the minor seeks emancipation

Mature Minor

- Sufficient autonomy or intellect to consent for or refuse care
- Consider age and developmental maturity
- Consider gravity of illness/risks of therapy
Competency to Consent

- Capacity to understand alternatives
- Capacity to make voluntary choice
- Previous ability to cope with illness
- Emotional stability
- Previous adherence to medication/treatment

What care can you provide for Susan without her mother’s consent?

A) STD screening
B) Pregnancy test
C) Contraceptive counseling
D) All of the above
Confidentiality and STI*

- All 50 states and the District of Columbia allow minors to consent to STD services
- 11 states require that a minor be a certain age (12 or 14) to consent.
- 31 states include HIV in package of STI services to which minors may consent
- 18 states allow physicians to inform parents that a minor is seeking or receiving STI services

*www.guttmacher.org/statecenter/adolescents.html

Confidentiality for Adolescents-NY State

Adolescents May Consent To:

- STD diagnosis, & treatment
- Reportable disease prevention, diagnosis, & treatment
  > HIV/AIDS testing & treatment
- Contraceptive Services
- Prenatal & maternity care
- Termination of pregnancy
- Drug or alcohol counseling & treatment
- Outpatient mental health services
- Diagnosis & treatment for sexual assault

Sources of Information About State Minor Consent Laws

- Alan Guttmacher Institute
  > www.guttmacher.org
  > State Policies in Brief
    • Contraception
    • Prenatal Care
    • Abortion
    • Minor Parents
- Center for Adolescent Health & the Law
  > www.cahl.org
Sources of Information About Minor Consent Laws-Canada

- Government of Canada Department of Justice
- The Society for Obstetricians and Gynecologists of Canada

HIPAA Privacy Rule
Minors as Individuals

- Minors are treated as “individuals” under HIPAA Privacy Rule:
  - When the minor has the right to consent and has consented;
  - When the minor may obtain care without parental consent and the minor, a court, or someone else has consented;
  - When parents accede to confidentiality agreement between minor and health care provider.

Don’t forget those 18 or older have full privacy rights for all conditions!

HIPAA Privacy Rule
Disclosure to Parents

- If state or other law requires it, provider must disclose
- If state or other law prohibits it, provider may not disclose
- If state or other law permits it, provider has discretion to disclose
- If state or other law is silent or unclear, provider has discretion to grant or withhold access.
Case 2: “I have a vaginal discharge”

- Mary is a 16 year old patient who has a vaginal discharge. You are her mom’s gynecologist. She tells you she has been dating a senior in her high school.
- She says they are in love and she’s been having sex with him.
- She does not want you to disclose this to her mom.

How should you treat Mary’s request for confidentiality?

A) Ascertain her boyfriend’s age
B) Assess for sexual or physical abuse
C) Contact law enforcement immediately
D) Honor the request and tell no one
E) Determine whether her boyfriend is using condoms
How should you treat Mary’s request for confidentiality?

A) Ascertain her boyfriend’s age  
B) **Assess for sexual or physical abuse**  
C) Contact law enforcement immediately  
D) Honor the request and tell no one  
E) Determine whether her boyfriend is using condoms

Disclosure of Confidential Information

- Explain limits of confidentiality to adolescents & parents  
- Be aware of legal requirements  
  > Child abuse reporting  
  > Reportable diseases under public health laws  
  > Harm to self or others  
- Exercise clinical and professional judgment when assessing patients for abuse and exploitation

CASE 3: “Test my daughter for drugs”

- Molly is a 15 year old patient whose mother brings her in for PCOS follow up. Her grades are dropping.  
- Mom wants you to test her urine for drugs without her knowledge.  
- When you have seen her in the past she has denied using drugs and declined drug testing.
What is your best response to Molly’s mother?

A) You will do the test but only discuss results with Molly
B) You will speak to Molly and let her know what he says about his drug use
C) Explain why urine testing this way is not the best approach
D) Do the test and tell the mom the results
E) You will speak to Molly & keep his answers confidential

What is your best response to Molly’s mother?

A) You will do the test but only discuss results with Molly
B) You will speak to Molly and let her know what she says about his drug use
C) **Explain why urine testing this way is not the best approach**
D) Do the test and tell the mom the results
E) You will speak to Molly and keep his answers confidential

Testing for Substances of Abuse in Children and Adolescents

- AAP Policy Statement-1996
- Determine competency
- Surreptitious testing of competent adolescent ethically unacceptable
- Parental consent not sufficient for involuntary screening
- Engage adolescent in decision making and inform of test, if possible
Discussion with Parent/Guardian

- Random testing poor substitute for careful questioning
- Drugs detectable in urine for varying days
- Qualitative test, does not measure frequency, amount
- Urine for test may be altered
- Physician/patient relationship

If Molly is brought to ED obtunded, under which of the following can he be screened for drugs?

A) Yes, with her mother’s permission
B) Yes, without her mother’s permission
C) No, since Molly has refused in the past
D) Yes, without anyone’s permission
E) All except C
Drug Screening without Consent

- Determine treatment or avert harm
- Determine overdose/ingestion in unconscious adolescent
- Identify conditions dangerous to health in combination with physical activity (U.S. Supreme Court)

If Molly tests positive for drugs in the ED, whom do you inform?

A) Molly
B) Law enforcement
C) Molly’s mother
D) A and C
E) Child protective services
Drug Screening and Law Enforcement

- Physicians not required to report positive drug screens to law enforcement
- Drug test results may be subject to subpoena in legal proceedings

Drug Screening in Schools

- Schools held to lesser standard under 4th Amendment than other government authorities
- U.S. Supreme Court upheld random warrantless searches for high school athletes
- Legal status of drug testing as condition of participation in other school activities uncertain

Confidentiality: When We Are Challenged
Challenges in Providing Confidential Services

• Education of Adolescents and Parents/Guardians
• Billing
• Follow-up
• Engaging Clinical Staff

Education of Adolescents & Parents/Guardians
Setting the Stage

• At age 11
  > introduce concept of confidentiality
  > seeing the adolescent alone for part of visit at next visit
• Develop written handouts for adolescents, parents/guardians
• Inform parents/guardians about confidentiality policy before visit
  > Letter home:
    • Detail when parent/guardian will be included in clinical visit and when not
    • Discuss billing issues

Education- Adolescents & Parents/Guardians
Goals

• Explain importance of confidentiality
• Seek parents’ support for confidential communications
• Encourage parental participation in care & support of confidentiality
• Help resolve conflicts, if any
• Transition to privacy for all of visit will take place by age 18 years old
Teens Access To Care
Tools for Educating Parents/Guardians

- Teen & Parent Welcome Letters

Challenges in Providing Confidential Services

- Education of Adolescents and Parents/Guardians
- Billing
- Follow-up
- Engaging Clinical Staff

Case 4: Sports Pre-Participation Physical

- Nancy is a 15 year old who wants to play tennis.
- She needs a physical examination
- She discloses she is sexually active with her boyfriend who is in her grade as HS
Under what circumstances can you provide Nancy confidential STI screening?

A) If you do not bill insurance
B) If Nancy pays
C) If Nancy's mother pays without an itemized bill
D) If the health insurance plan allows confidential coding
E) All of the above

Under what circumstances can you provide Nancy confidential STD screening?

A) If you do not bill insurance
B) If Nancy pays
C) If Nancy's mother pays without an itemized bill
D) If the health insurance plan allows confidential coding
E) All of the above

Confidentiality and Billing

• Cannot guarantee confidentiality in many cases
• Explanation of benefits (EOBS) may be sent by insurance company
• Need to know the “paper trail issues” in your health system
**Explanation of Benefits**
**Medicaid vs. Private Insurance**

- EOBs sent to policyholder or insured in most private plans
- Medicaid and Medicaid managed care does not routinely send EOBs for confidential services in US
- Some claim statements/EOBs are general and do not disclose service/diagnosis

**Confidentiality and Billing**
**Potential Solutions**

- Affordable Care Act covers preventive services recommended by USPSTF, AAP Bright Futures without cost sharing = no financial liability on policy holder = no EOB
  - Chlamydia screening for females
  - Reproductive counseling
- CPT Modifier 33 aids coding for ACA preventive services with no cost sharing = no EOB
- ACA may also cover contraception
- Develop system for low cost visits
- State supported reproductive health benefit

**New York State Family Planning Benefit**

- Public health insurance program needing family planning services but not able to pay
- Intended to
  - Increase access to confidential family planning services
  - Enable teens, women and men of childbearing age to prevent and/or reduce unintentional pregnancies
- Can be dually insured with parents’ commercial health plan and with NYSFPB

*http://www.health.ny.gov/health_care/medicaid/program/longterm/familyplanbenprog.htm*
New York State Family Planning Benefit
Services Covered

- Most FDA approved birth control methods, devices, and supplies (e.g., birth control pills, injectables, patches, condoms, diaphragms, IUDs)
- Emergency contraception services and follow-up care
- Male and female sterilization
- Preconception counseling and preventive screening
- Family planning options before pregnancy

NYSFPB Services Considered Family Planning Must Be Provided Within FP Visit/Directly Related to FP

- Pregnancy testing and counseling
- Comprehensive health history and physical examination (inc. breast exam & referrals to PCP) NOT Mammograms
- Screening for STD
- Screening for cervical cancer, urinary tract & female-related infections
- Screening & related diagnostic laboratory testing for medical conditions affecting choice of birth control
- HIV counselling/testing
- Counseling services related to pregnancy, informed consent, & STD/HIV risk counseling
- Bone density scan if plan to use or using Depo-Provera
- Ultrasound to assess placement of an intrauterine device

Practical Issues Related to Providing Confidential Services

- Education of Adolescents and Parents/Guardians
- Billing
- Follow-up
- Engaging Clinical Staff
Follow-up Issues

• Always get alternative phone numbers
  > Confidential number in EMR
• Possibly alternative address
• Email
  > Must consider lack of confidentiality over Internet
  > Patient portals helpful if patient 18 years or older
    • Meaningful Use 2
• Caveats when establishing confidentiality

Practical Issues Related to Providing Confidential Services

• Education of Adolescents and Parents/Guardians
• Follow-up
• Billing
  • Engaging Clinical Staff

Engaging Clinical Staff

• Educate staff:
  > Adolescent development and need for confidentiality
  > State laws
  > Office policies
  > Adolescent health guidelines
  > MAPCI-trainings, medical center policy reflecting NYS adolescent confidentiality law, annual in-service for all clinical associates includes adolescent confidentiality rights
Develop Referral Network For Confidential Care

- School Health
- College Health
- STI clinics
- Planned Parenthood
- Department of Health clinics
- Mental Health Professionals
- Hospital based Clinics
- Prenatal care services
- Abortion services
- Adoption services

How to Handle Breaches of Confidentiality

- Most breaches are unintentional
  > May destroy patient trust
  > May impair parent’s trust
- Steps when breach has occurred
  > Acknowledge breach
  > Inform adolescent and parent separately and together
  > Avoid assigning blame
  > Obtain assistance from hospital administration (compliance), social work
  > Take steps to prevent this in the future

Challenges to Confidentiality in the 21st Century

- Electronic Medical Record
  > Regional Health Information Sharing
- Meaningful Use
  > Patient Instructions
  > Patient Portal
Adolescent Confidentiality and Electronic Medical Record*  

- Multi-stakeholder task force within health care system  
- EHR systems consistent with state laws  
- Clear labeling of sensitive information  
- Clear on-screen labeling of confidential data  
- Point of care privacy controls for clinicians  
- Linkage of adolescent prescriptions/meds orders with specific diagnosis/problem  
- Automatic non-release of sensitive elements of adolescent patients' electronic records (also related to health care exchange networks (RHIO))  


Confidentiality and Meaningful Use  

Patient Instructions  

- Patient Instructions-Need to do in 50% of visits  
  - May contain confidential information  
  - Solutions:  
    - Can give to patients 18 or older directly  
    - May need to give to adolescent, themselves  
    - MAPC/EMR-Suppression of diagnoses, lab tests, prescriptions from patient instructions

Confidentiality and Meaningful Use  

Patient Portal  

- Patient portals-50% patients must have electronic access to their health information  
  - Problem lists, allergies, medication list, lab results  
  - May contain confidential information  
- Parent may have access to all medical information for adolescents under 18 years of age  
  - Need to be able to filter out confidential labs, diagnoses, medications
**Adolescent Confidentiality and EMR**

- Develop methods of suppressing billing, visit summaries, EOB, appointment reminders, follow up surveys posted to portals or mail for adolescent sensitive services
- Limit parent access to adolescent confidential information on patient portals
- If possible, allow adolescent access to own confidential information on patient portals
- Allow parents of teens under 18 years of age/developmentally delayed access to non-confidential health info - patient portals


**Confidentiality and Meaningful Use Patient Portal-Potential Solutions**

- Encourage enrollment of patients 18 y or older
- Create a process for adolescent under 18y to have own access/parent have own access
  - Some systems not “plastic” enough to do this
  - Need to advocate in your institution when EMR first established
  - Age range controversy

**Advocacy Within a Medical Center Network Montefiore Adolescent Primary Care Initiative (MAPCI)**

- Montefiore Pediatric EMR Committee
  - Representative from MAPCI
  - MAPCI representative to Confidentiality Sub-Committee
- EMR
  - Adolescent Template
  - Labeling visit Adolescent
  - Confidential phone number in first window
- Medical Center Policies and Procedures
- Education of Medical and Non-Medical Staff
  - Site visits
  - E-Newsletter
  - Annual Review
Other Provider Resources

AAP Section of Adolescent Health Website
http://www2.aap.org/sections/adolescenthealth/


Association of Reproductive Health Professionals- Reproductive Health Model Curriculum

The American College of Obstetricians and Gynecologists Toolkit
www.acog.org/bookstore/Tool%20Kit
t for Teen Care P348C84.cfm

Emergency contraception: www.not-2-late.com

Chlamydia Coalition http://ncc.prevent.org/

NY State AAP Teen Health Care Bill of Rights

Patient Resources

American Social Health Association: www.iwannaknow.org

Center for Young Women’s Health: www.youngwomenshealth.org/

Young Men’s Health: http://youngmenshealthsite.org/

The Children Now: www.talkingwithkids.org/

MTV collaboration with Kaiser Family Foundation:
www.itsyoursexlife.com /

Other Useful Websites

www.aap.org The American Academy of Pediatrics
http://brightfutures.aap.org Bright Futures

www.aapdistrictii.org NY State American Academy of Pediatrics

www.prch.org Physicians for Reproductive Choice and Health

www.adolescenthealth.org The Society for Adolescent Health and Medicine

www.naspag.org North American Society for Pediatric and Adolescent Gynecology

http://www.aclu.org/reproductiverights The Reproductive Freedom Project of the American Civil Liberties Union
Other Useful Websites

- [www.advocatesforyouth.org](http://www.advocatesforyouth.org) Advocates for Youth
- [www.siecus.org](http://www.siecus.org) The Sexuality Information and Education Council of the United States
- [www.arhp.org](http://www.arhp.org) The Association of Reproductive Health Professionals