Shared Decision Making in the Care of Adolescent Patients

Ethics in Healthcare Conference
University of Iowa

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20 May 2017

Objectives

1. Analyze the ethical principles and core challenges of incorporating adolescent assent in shared clinical decision making.

2. Discuss the ethical and legal implications of caring for adolescent patients who have been deemed mature minors.

3. Identify the ethical tensions between providers, patients, and families that may arise when trying to respect the confidentiality of adolescents.

Defining Adolescence

- Time between the onset of puberty and social independence
- Transition between immature, dependent state of childhood and independent, autonomous state of adulthood
- Requires physical, social, emotional, cultural maturation
- Goal to define one's place in family and community

http://www.youstright.co.uk/whats-stressing-you-out/puberty-and-growing-up.html

Chronological Age Definition

- Depends who you ask...

Organization	Definition of Adolescence
Society for Adolescent Medicine Position Statement	10-25
American Academy of Pediatrics (2014)	11-21
US Department of Health and Human Services (2015)	10-19
Center for Disease Control and Prevention: YRBSS	9th-12th grade
US Census Bureau (2015)	12-17
World Health Organization (2004)	10-19

- Curtis AC. 2015. Defining adolescence. *J Adol and Family Health.* 7(2): article 2.

General Areas of Development

- **Physical Development**
  - Growth and sexual maturation
  - Skeletal growth spurt: girls 10-12, boys 12-14
  - Adult stature: girls 17-19, boys 20

- **Brain/Cognitive Development**
  - fMRI data shows adolescence to be a time of extensive brain maturation and changes in neural connectivity
  - Especially in reward systems (limbic), relationship systems, regulatory systems (pre-frontal cortex)
  - Reasoning capacity, affective states, impulse control
  - Plasticity through the 20s

A spectrum of development

- **Cognitive development**
  - Thinking becomes more abstract and less concrete
- **Psychosocial maturity**
  - Reduced impulsivity
  - Greater ability to understand and plan for the future
  - Increased ability to consider the perspectives of others
- **Risk benefit judgments**
- **Experience**
  - Evaluation of prior outcomes
  - Adolescents with chronic health issues may have more knowledge about their disease than adults with sudden illness

The role of the adolescent in shared decision making

Shared Decision Making

- Process where clinicians and patients work together to make care plans that balance risks and expected outcomes with patient preferences and values
- Extensive research
  - Clinical models
  - Decision making aids
- Here we focus on the adolescent patient, the parent/guardian, and the clinician

Consent, Assent, and Dissent

Consent, Assent, and Dissent

- **Consent:**
  voluntary agreement with a proposed action
- **Informed consent:**
  process by which provider explains a particular intervention and discuses the pertinent risks and benefits such that a patient may make an informed decision about whether to undergo said intervention (permission)
- **Assent:**
  agreement of someone not legally able to give consent (i.e. children and adolescents)
- **Dissent:**
  refusal to assent. "Veto Power"

American Academy of Pediatrics Committee on Bioethics

(1995, 1997, 2007, 2011)

- "Patients should participate in decision-making ***commensurate with their development***; they should provide ***assent*** to care whenever reasonable. Parents and physicians should ***not exclude*** children and adolescents from decision-making without persuasive reasons."

Assent $\neq$ Consent

- Nor is assent meant to replace consent
- Purpose is **NOT** to treat kids as if they are capable of making fully informed decisions
- Rather considers the adolescent's opinion based upon her/his level of understanding and decision-making ability

Elements of Assent

- **Inform**
  - Help pt gain developmentally appropriate awareness of the nature of his/her condition
  - Tell pt what is expected with tests/treatments
- **Understanding**
  - Assess pts understanding of the situation and the factors influencing how he/she is responding
- **Acceptance**
  - Determine pts willingness to accept proposed care
  - If pt will have to receive care despite his/her willingness, tell them
  - If dissent is not an option, assent is a questionable idea

Challenges with Assent

- **Age at which assent should be sought**
- **Resolving disputes between adolescents and their parents**
  - 16F who's parents insist she stay on Adderall
  - 15F with a BMI of 45 who requests bariatric surgery, but parents think she may not be able to adhere to the post-op diet/lifestyle modifications
  - Elective plastic surgery requested by parents, refused by adolescent
  - Fertility preservation prior to cancer treatment
- **The quantity/quality of information to disclose**
- **Methods to assess a child's understanding of disclosed information and the assent process**
  - Chemotherapy: child's focus on hair loss v survival
  - Surgery requiring an ostomy: child refuses because she does not want an ostomy
  - Instruments?

Not all 16 year olds are created equally…

- Jane was dx w cystic fibrosis at 9mo old. Now 16yr old, her lung function has deteriorated to the point of consideration for lung transplantation. Jane has been in the ICU for mechanical ventilation multiple times. Jane is well aware of her failing lungs but does not wish to undergo lung transplantation despite the potential of the procedure to add years to her life. She feels that the rigors of surgery and subsequent ICU care/medications would mean a poor quality of life no matter how much longer she would survive.

- George is a 16M w Crohn's disease for 5 years. He has had 3 flares (abdominal pain, bloating, oral intolerance, and bloody diarrhea) that have been treated medically. He has been compliant with maintenance medication until 3mo ago when he joined the varsity basketball team. He no longer takes his medication regularly and argues with his parents about his recent weight loss and abdominal symptoms. His mother reports that he minimizes his symptoms so that he can continue to play sports. He says he just wants to be a "normal kid." He does not think think he needs any chronic medications to control his disease.

AAP Pediatrics Bioethics Resident Curriculum. 2011.

Consent, Assent, and Dissent impact clinical research as well

History of Assent in Clinical Research

- 1977 report by The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research
  - Need to recognize and respect wishes of children as they mature
  - Gain assent from research subjects >7 yr old
- 1983 Code of Federal Regulations
  - Required child's affirmative agreement to participate in research
  - Did not site specific age
- Belmont Report
  - Must determine what children understand about the assent process itself

Assent in Biomedical research

- **Biobanking**
  - Longitudinal data
  - Should children be re-approached as adults and given opportunity to withdraw their sample?
    - Often an IRB requirement
- **Genetic studies**
  - Diagnosis of long term incurable condition
  - Huntington's disease

Surpassing assent and assuming competence...Mature Minors, Emancipated Minors, and Situational Competence

Mature Minors

- Medical consent by a minor 16-17 years old who is capable of comprehending the care situation and who can make a reasoned, informed medical decision
- Iowa does not have a formal mature minors rule

Emancipated Minors

- State dependent
- Emancipated minor
  - Absent from the parental home with parental consent
  - Self-supporting (no financial income from parents)
  - Assumed a new relationship inconsistent with being part of the family of the parents
- Do not need parental consent for medical, dental, or psychiatric care

Clinical settings in which minors may consent

- Both Iowa and Federal laws have made provisions to allow minors to obtain certain services without parental consent
- Rationale: public health initiative to encourage minors to pursue care they may otherwise not if parental consent were required

Clinical settings in which minors may consent

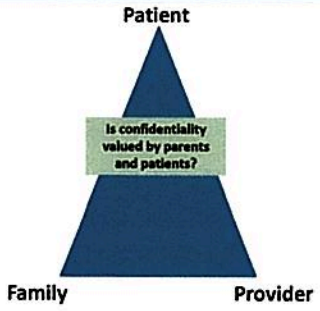
- Emergency care
- Substance abuse treatment
- STI testing and treatment
- HIV testing (+ test requires parental notification)
- Contraceptive care/counseling
- Victim medical services (mandated reporters)

But access to care doesn't assure privacy

The Trouble with Insurance

- Explanation of benefits sent to policy holders may violate confidentiality (reproductive health, mental health, substance abuse)
- Potential for long term impact since Affordable Care Act allows children to stay on parents insurance until age 26
- Options:
  - Pay for care out-of-pocket
  - Use of providers like Title X Clinics and Planned Parenthood

Confidentiality in Adolescent Healthcare



Clinical conversations about health: the impact of confidentiality in preventive adolescent care.

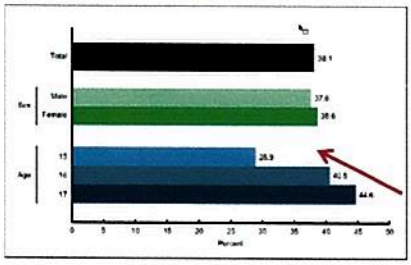
Gilbert AL et al. *J Adol Health*. 2014.

- National online survey of adolescents 13-17 yr old and parents of adolescents 13-17 yr old
- Examines relationship between adolescent and parent beliefs regarding confidential consultation and the number of topics discussed during visit
- 89% of parents believed adolescents should be able to speak with providers alone
- 61% of parents preferred to be in the room for entire visit
- 50% of adolescents believed parental presence impacted conversation
- More topics discussed when visit was partially confidential as compared to not confidential

Do concerns about confidentiality affect care requested and care delivered to adolescents?

Confidentiality concerns and sexual and reproductive health care among adolescents and young adults aged 15-25

Copen CE et al. *NCHS Data Brief*. 2016. 266



38% of adolescents aged 15-17 spent any time alone during a visit with a health care provider

Confidentiality concerns and sexual and reproductive health care among adolescents and young adults aged 15-25

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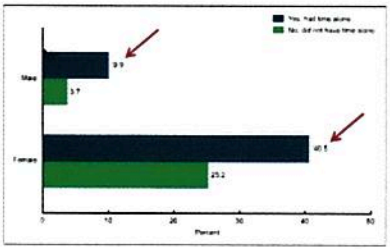

Higher percentages of adolescents who spent time alone with a health care provider received sexual or reproductive health services.

Confidentiality concerns and sexual and reproductive health care among adolescents and young adults aged 15-25

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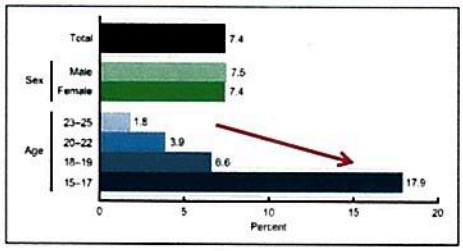

7% of pts 15-25 would not seek sexual or reproductive health care because of concerns that their parents may find out.

Forgone health care among U.S. adolescents: Associations between risk characteristics and confidentiality concern

Lehrer JA et al. *J Adol Health*. 2007. 40:218-226.

- Review of home interviews from the National Longitudinal Study of Adolescent Health (18,924 subjects, 2438 had foregone health care)
- Increased odds of citing confidentiality as a concern for avoiding health care in pts with prior STI, past-year EtOH use, birth control nonuse at last sex, high and moderate depressive symptoms, suicidal ideation or attempt, unsatisfactory parental communication.
- The adolescents who forego health care due to concerns over confidentiality are particularly vulnerable and in need of health care

When must confidentiality be broken

Mandated reporters of child abuse

- **Child is any person under 18 yrs old**
- **9 categories of abuse in Iowa**
  - Physical abuse
  - Mental abuse
  - Sexual abuse
  - Denial of critical care
  - Child prostitution
  - Presence of illegal drugs
  - Manufacturing or possession of a dangerous substance
  - Bestiality in the presence of a minor
  - Allows access by a registered sex offender
  - Allows access to obscene material

Duty to Protect/Warn

- Threat to self
- Threat to others
- Explicit threat of harm/death to a clearly identified person(s) such that pt has the intent and ability to carry out the threat

Gray Areas?

- Substance use
- Smoking
- Mental health issues
- Sexual activity
- Bullying
- Problems at school
- How might a breech in confidentiality impact trust?

Recommendations

- Disclosure to the patient about what you may not keep confidential
- Disclosure to the parent/guardian about confidentiality
- Encourage disclosure to parent/guardian when appropriate

Confidentiality Matters

- Adolescents value confidentiality
- They may avoid seeking care if confidential care is not offered
- Those most in need of care may be the most likely to avoid it due to concerns about confidentiality
- Encourage disclosure but acknowledge limitations

Summary

- Adolescence is a dynamic process
- Ability to participate in shared decision making may change over time and requires frequent reassessment of the individual
- Decision making authority is granted in some arenas
- Appropriate confidentiality is imperative
- Engaging the adolescent in appropriately confidential discussions with developmentally appropriate opportunities for decision making may allow better delivery of healthcare

Thank you