Adolescent Autonomy and Decision-Making: Implications for Prescribing PrEP

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Overview

- Health care providers thoughts on PrEP
- Adolescent autonomy
- Adolescent decision-making
- Practical suggestions
How We May Feel About Prescribing PrEP to Adolescents

Feel Scared

Feel Overwhelmed
How We Should Feel

Feel a little nervous . . . and excited for the opportunity
Why Do We Feel Scared and Overwhelmed?

- **Parents**
  - Do they have a role?
  - Will the parents get an explanation of benefits (EOB)?
    - Does that create a risk of unintentional loss of confidentiality?

- **Neighbors**
  - Will the adolescent have to go to the pharmacy?
    - Will that create a risk of unintentional loss of confidentiality?

- **Adolescents**
  - How much time will the appointment take?
  - Will they adhere and take it daily?
  - Will they come back in 3 months?
What Are We Doing?
15 clinicians from Adolescent Medicine Trials Network for HIV/AIDS Interventions between October 2012 – April 2013

- Found the guidance from CDC confusing
- Some thought the interval for return visits needed to be shorter
  - In fact, NYS guidance: “The first prescription of PrEP (Truvada 1 tablet PO daily) should only be for 30 days to allow for a follow-up visit to assess adherence, tolerance, and commitment.”
- Mental health or substance abuse issues were viewed as both being a reason for and a reason against PrEP
- Lack of adherence to PrEP or missed monitoring visits was a reason to discontinue
  - Doesn’t mean it is a reason not to try

Adolescent Autonomy
General Guidelines about Autonomy

- Includes the right to give another person decision-making responsibilities
- Should not be based on what we think is the “right decision”
- Treating adolescents as having diminished autonomy assumes that parents/parent surrogates act in the best interest of their adolescent and that parents have the cognitive maturity to make good decisions
Do **ALL** Adolescents Have Diminished Autonomy?

- Adolescent’s ability to make autonomous decisions depends on:
  - Age and cognitive ability of the adolescent
  - Topic area (or experience with topic area)
  - Situation they are in
  - Cultural and family context
  - Interaction of the above
Certain minors can consent to any type of health care:
- Emancipated minors: minors on their own and financially independent of their parents
- Married minors
- Minors who have children
- Mature minors: determination of maturity is made by the health care provider, and should be documented in the medical record.

All minors can consent on their own to:
- **Reproductive health care** (pregnancy tests and options counseling, abortion services, contraceptive care and counseling, including emergency contraception (EC)).
- **Testing and treatment for STIs**
- **Testing for HIV**
Adolescent Decision-Making
Adolescent Decision-Making

- 16-19 may be a critical period for development of mature judgment
- After 19 years, socially responsible decision-making may stabilize
- Linear decline in impulsivity between ages 15 and 30
  - Reward-seeking followed a curvilinear pattern, increasing between preadolescence (10yrs) and mid-adolescence (15yrs), and declining (or remaining stable) thereafter
  - Thus, intersection of rewarding seeking with less impulse control may lead to higher vulnerability to risk-taking

Risk-Compensation Theory

- Concerns have been expressed about risk compensation for a variety of HIV prevention/control strategies including PrEP
- Also called Risk Homeostasis Theory & disinhibition
- Inherent set-point that determines willingness to take risks
- Interventions that reduce risk will result in persons increasing their risk-taking behavior to maintain their homeostatic set-point, nullifying the effects of the interventions
- Implies an inherent personality trait common to all individuals; not unique to ADOLESCENTS
Evidence for Risk-Compensation

- Empirical evidence is mixed
- Review of condom promotion programs accompanied by mathematical modeling:
  - Some risk compensation may occur
  - Generally does not neutralize the beneficial effects of increased condom use stimulated by the programs
- Risk-compensation clearly not universal & inevitable and likely dependent on:
  - The prevention method and target of the strategy (e.g., vaccine vs. PrEP and HIV vs. one or multiple pathogens)
  - Individual characteristics (e.g., impulsive decision-making)
  - The larger social context (e.g., romantic relationship, family)

Pinkerton SD, Risk Analysis, 2001
Adolescents and Risk-Compensation

- No evidence that HPV vaccine has led to risk compensation in terms of behavior or sense of protection from other infections in adolescents
- Unlikely that adolescents as a group are going to be different than adults as a group

Practical Suggestions
Supporting the Adolescent: Clinical Staff

Should be chosen for and trained to work with adolescents otherwise:
- May have negative attitudes about adolescents
- Uncomfortable and judgmental about the topics
- React as a parent or as a peer
- Lack boundaries with own experiences
Supporting the Adolescent: The Decision

- Do they view PrEP as appropriate for them?
  - Sexual orientation – does it match their behavior?
  - Do they view themselves at risk for HIV?
  - Do they admit to using injection drugs?
  - Does their partner have HIV infection?

- Do they believe that PrEP works and is the best option for them?

- Do they believe they can remember to take it every day and return for follow-up appointment.

- How might teens be different . . . . . .
Supporting the Adolescent: Differences in the Decision-Making

- May be more deferential – may have trouble eliciting concerns.
- May engage in magical thinking about their own vulnerability
- May feel less in control of their sexual decision-making
- If they live with their parents:
  - How can their parents help? What do their parents already know?
- If they are living on their own, what are their support systems?
Supporting the Adolescent: Adherence

- Difficult to take a daily pill if a “secret”
  - Where do you keep it?
- Important to have it tied to a routine
  - Teeth brushing, phone alarm
- Non-coitally dependent:
  - Advantage - Don’t need to think about it in heat of the moment
  - Disadvantage – Have to continue using during gaps in sexual activity
Supporting the Adolescent: Three Month Return Appointments

- Address the “other reasons” for not returning
  - Getting another HIV test
  - Blood draws
  - Scheduling issues: transportation, babysitting, costs

- Ask how do they want to be reminded, particularly if confidentiality is an issue
Conclusions

- The major difference between adolescents under 18 years and those over 18 is legal status
  - Probably under-estimate minors’ capacity and over-estimate that of young adults
- Regardless of whether they are minors
  - Where they live and their degree of independence is relevant
- For PrEP or any other prevention option,
  - Adolescent and LGBTQ friendly space, staff, and reminders
- Additional time needed should be built into clinic scheduling to do the necessary counseling