Adherence in adolescents - what works?

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ART Coverage Rates by Age Band

**Botswana**

**Swaziland**

**Zimbabwe**

UNAIDS 2016 Report
Cascade of Care in HIV-Infected Youth in the United States

- Infected: 78,949 (100%)
- Diagnosed: 31,979 (40%)
- Linked: 19,824 (25%)
- Retained: 8,723 (11%)
- Suppressed: 4,449 (6%)
Why are adolescents at risk?

- Adolescence is a time of important biological and developmental change as well as change to family and social contexts, which may increase HIV risk.

- Biological and developmental factors (bio-behavioral and neurobiological processes)\(^1\):
  - Heightened risk-taking behaviors
  - Difficulties controlling behavior and emotions
  - Pressure to assert individuality and to ‘fit in’

Adolescence is a time of transition

- Changes in context that may increase risk:
  - Leaving school
  - Leaving home
  - Entering first serious relationship (increase in sexual contact/frequency/partners)
  - First pregnancy
  - Alcohol/Drug use experimentation
  - Increasing independence and yet still strong need for parent/guardian support
  - Increasing socialization with peers
Importance of Context: Peers/Partners, Family & Community
Factors that influence adherence

Figure 1. Conceptual framework of the psychosocial context of adherence barriers and behavior.
Note. ART = antiretroviral therapy.
Major reasons teens cite for non-adherence:

- Pediatric vs Behavioral infection...difference and similarities
- Factors cited in studies of adolescent that influence adherence:
  - Pediatric:
    - Reactance
    - Treatment Fatigue
    - Transitions to autonomous care
    - Denial or anger about childhood illness and ART
  - Behavioral:
    - New diagnosis

Factors that influence adherence in teens

- **Unique to Adolescents**
  - Not wanting to be different from peers
  - Adherence interferes with normative adolescent behavior
  - Interference or coordination with daily activities
  - Forgetfulness!
  - Poor risk perception about non-adherence consequences
  - Travel way from home—school (boarding school), work, friends (sleepovers, parties, etc.)

- **Universal**
  - Aversion to side effects
  - Medication reminds of illness
  - Stigma
  - Food insecurity
  - Alcohol
  - Depression
  - Poor treatment self-efficacy
  - Violence at home
  - Social support
  - Complex regimens

And we can’t forget structural factors shape context

• Stigma and fear surrounding HIV is still a major barrier to testing and treatment
  – Especially true for key populations
  – Discrimination and lack of confidentiality
  – While we know stigma is associated with worse care and treatment outcomes (Katz JIAS 2013), few evidence based interventions that have shown an impact on these outcomes (Stangle et al. JIAS 2013)

• Legal and policy barriers make access to prevention and care challenging
  – Age limits for testing in many settings
  – Criminalization of sexual identity

• Lack of access
  – Distance to clinics, stock outs, hours of operation, unfriendly facilities
Barriers to care and adherence

- **Food insecurity**
  - “Across diverse populations, food insecurity is an important barrier to ART adherence, and food assistance appears to be a promising intervention strategy to improve ART adherence among persons living with HIV” (Singer AW, et al. AIDS Behav 2015 Aug)

- **Housing**
  - “Lack of stable, secure, adequate housing is a significant barrier to consistent and appropriate HIV medical care, access and adherence to antiretroviral medications, sustained viral suppression, and risk of forward transmission” (conclusion from systematic review of 152 studies: Aidala A et al. AJPH 2016 Jan)
Interventions to improve adherence in teens

- Few evidence based interventions (Shaw & Amico JAIDS 2016;72:387–399- review)
  - N=10 through 2014
  - Those that exist are small and pilots
  - Vast majority have been US based

- What we do know works:
  - One size does not fit all
    - Patient centered care key
      - What is going on? What issues need to be addressed?
  - Level 1 interventions to date have (n=3): 1) targeted non-adherent youth; 2) included some aspect of problem solving; 3) family and patient counseling to target skill building
  - Level 2 intervention (n=1): 1) targeted non-adherent youth; 2) text reminders at dose times
Promising Interventions

- Family Interventions
  - Interventions to improve parent/child communication (CBT) - learn from other chronic illness interventions- diabetes and pain management for teens
  - Miscarried helping- mismatched desired & received support

- Cognitive Behavioral Therapy (CBT)
  - Life Steps- adult CBT, motivational interviewing and problem solving (Safren & Otto 1999)- 5 session, individual sessions
    - Define problem impacting adherence
    - Generate alternate solutions
    - Make decisions about alternatives
    - Collaboratively decide on plan to implement solutions
    - 11 steps over 5, 1 hour sessions- adapting Life Steps
    - Address adherence barriers- models on managing mood, social life, privacy and disclosure and independent HIV care
    - Multicomponent interventions such as patient education, self-monitoring, medication reminders are most effective in improving adherence
Promising Interventions

- Vuka- South Africa Family Intervention for HIV infected young adolescents – 10 session interventions, adolescents 10-13 and caregiver
  1. AIDS-related loss and bereavement;
  2. HIV transmission and treatment knowledge;
  3. Disclosure of HIV status to others;
  4. Youth identity, acceptance and coping with HIV;
  5. Adherence to medical treatment;
  6. Stigma and discrimination;
  7. Caregiver-child communication, particularly on sensitive topics such as puberty and HIV;
  8. Puberty;
  9. Identifying and developing strategies to keep children safe in high-risk situations where sexual behavior and drug use are possible;
  10. Social support. (Bhana A, AIDS Care. 2014 January; 26(1) –self reported adherence qualitative)
Strategies to improve adherence: common sense?

- Establish trust and identify mutually acceptable goals for care.
- Identify depression, low self-esteem, substance abuse, or other mental health issues in the child/adolescent and/or caregiver that may decrease adherence. Evaluate and initiate treatment of mental health issues before starting ARV drugs, if possible.
- Identify family, friends, health team members, and others who can support adherence.
- Work with the patient and family to make specific plans for taking medications as prescribed and supporting adherence. Assist them to arrange for administration in day care, school, and other settings, when needed. Consider home delivery of medications.
- Establish readiness to take medication through practice sessions or other means.

- Choose the simplest regimen possible, reducing dosing frequency and number of pills.
- When choosing a regimen, consider the daily and weekly routines and variations in patient and family activities.
- Choose the most palatable medicine possible (pharmacists may be able to add syrups or flavoring agents to increase palatability).
- Choose drugs with the fewest AEs; provide anticipatory guidance for management of AEs.

- Provide ongoing support, encouragement, and understanding of the difficulties associated with maintaining adherence to daily medication regimens.
- Encourage use of pill boxes, reminders, alarms, and timers.
- Provide follow-up clinic visits, telephone calls, and text messages to support and assess adherence.
- Provide access to support groups, peer groups, or one-on-one counseling for caregivers and patients, especially for those with known depression or drug use issues that are known to decrease adherence.

Conceptual framing - social-structural barriers and methods for change

PROBLEM: Low uptake HIV testing & care

REASON: Social and structural barriers

Gender norms
Stigma
Fear of disclosure
Poor treatment literacy
Clinic distance/ lines
Gender norms
Lack of family support

INTERVENTION: Disrupt community social processes putting these barriers into place

Mobilize for change
ACTIVATING TREATMENT AS PREVENTION
THROUGH COMMUNITY MOBILIZATION
IN SOUTH AFRICA

Lippman, Pettifor 2016
CONCEPTUAL FRAMEWORK

Figure 1: Conceptual framework of the intervention, community mobilization components, and outcomes.

Lippman, Pettifor 2016
Way Forward

• Need more evidence based interventions shown to address barriers to care for adolescents living with HIV and improve adherence.
• Need to remember that adolescents are not mini adults and have unique needs.
• Need to think about adolescents’ lives holistically—not just focus on HIV but other key developmental milestones.
• We know things that can work in LMICs- are we implementing them?