Common HAART Adherence Barriers for Adolescents

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HIV/AIDS in Uganda

- Young people ages 10-24 constitute 33% of Uganda's population but nearly half of its HIV/AIDS cases. (1)
- The United Nations estimates that between 400,000 and 1.6 million children in Uganda have been orphaned due to the AIDS crisis. (2)
- An estimated 900,000 Ugandans are living with HIV-AIDS. (1)
- About half receive antiretroviral treatment. Many are undiagnosed; 100,00 others are in need of treatment which is cost-prohibitive or unavailable. (1)

(1) UN AIDS. Uganda country profile, HIV data. Available at: http://www.unaids.org/en/Regions_Countries/Countries/Uganda.asp2006

(2) Alan Guttmacher Institute. Adolescents in uganda: Sexual and reproductive health research brief. Available at: http://www.guttmacher.org/pubs/rib/2005/03/30/rib2-05.pdf

HAART Treatment Adherence

- 95% of doses must be taken correctly and on time for full effect
- HAART brings dramatic improvement to the immune function, growth, physical development, and life expectancy for HIV positive children and adolescents

Measuring Adherence

In Uganda (adults)

- 3-day patient recall and 30-day VAS closely corresponded with electronic pill monitoring, pill counts, and viral load in 12 week study. (1)
- All measures indicate 92-97% adherence in adult clinic
- Major barrier is cost

In children and adolescents

- Assessment of caregiver rather than patient adherence in studies including young children
- In the US, teens report low rates of adherence
- Major barriers are changes in routine and medication side effects (2)

(1) Oyugi, J., Bangsberg, D., et.al. Multiple Validated Measures of Adherence Indicate High Levels of Adherence to Generic HIV Antiretroviral Therapy in a Resource-Limited Setting J Acquir Immune Defic Syndr 2004;36:1100-1102

(2) Murphy, D., Barriers to HAART Among HIV-Infected Adolescents Arch Pediatr Adolesc Med 2003; 157:2490255

Research Objectives

1) To identify and analyze barriers to full adherence (defined as successfully completing ≥95% of prescribed doses)

2) To describe the relationship between the patient's reported barriers and their reported adherence

Focused on gaining understanding self-reported barriers.

Funding received from the Pfizer International Health Initiative through the University of Virginia Center for Global Health

IRB Approval gained from University of Virginia IRB for the Social and Behavioral Sciences, Makerere University Medical School, Mulago Hospital, Provisional approval from the Uganda national research review board

Study Population

- Pediatric Infectious Disease Clinic, Mulago Hospital, Kampala UG
- Aged 10-21
- Perinatally HIV infected
- Receiving ARV therapy in twice-daily regimen for at least 15 days prior to study participation
- Disclosed to

Adolescent Clinic

- ALL services are free
- Patients receive HAART medication at no cost
- Funding from President's Emergency Fund for AIDS Relief (PEPFAR) and Pediatric AIDS Canada, private sources
- Counseling for adherence and social issues provided for all patients

Challenges and Limitations

- Adolescents come to clinic on their own, were instructed to return with parent/guardian for consent
- Patients are accustomed to telling doctors the ‘right’ answer, especially about adherence
- Physical space in the clinic was very limited, participating required the patient to return to clinic on a day that they would not otherwise be there

Method:
Components and structure

- Patients individually interviewed using a structured questionnaire, with opportunity for open response
- Interviews conducted in English or Luganda

-Questionnaire modeled after ACTG international adherence

*-Barrier questions asked **before** adherence assessment*

-Yes/no questions about common barriers, including physical side effects and social stigma

-Adherence measurements: previous 3-day, previous weekend, and previous 30-day recall, VAS of average monthly adherence

Data analyzed using SPSS 11 for Macintosh

Results: Demographics

43 Females (62%)
28 Males (38%)

Average age: 15.21(15.5 F; 14.2 M)

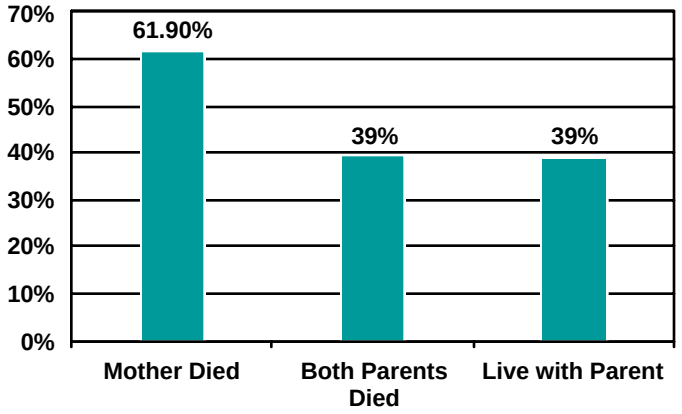
74% on HAART for six months or longer

27% Live in a household where another person takes ARVs (usually a parent, sometimes sibling)

Family Characteristics

68% Attend School

54% Attend Social Support Group



Findings: Adherence

- Overall mean adherence on Visual Analog Scale: 97.97% (95% CI 96.97-98.96)
- 49% reported missing one day or more; 13 patients (18%) reported missing a dose in the last 30 days
- VAS and 3-day recall of missed doses did not always correlate
- VAS, 3-day recall also unrelated to reports of barriers

Common Barriers

Yes/No Questions

-Simply forgot (39%)

-Staying away from home (30%)

-Slept through dose time (22.5%)

-Busy with other things (18%)

-Did not have adequate food (18%)

-Physical side effects (10%)

Open Responses

"I want to live, so I take them"- male, 15

- 90% reported that someone helps them remember their drugs, usually a family member
- 74% believe that they could do better with taking their medication as directed
- 72% reported that something such as an alarm clock, watch, or radio helped them remember

Adherence and Food

- Even when the patient responded 'no' in the structured section of the survey, the most common open response related to skipping doses or taking them late due to lack of food. Nearly 1/3 of all participants indicated it as an issue.
  - "At times I get so hungry I feel like not swallowing it" –female, 18
  - "Dad goes on safaris, so without food I have to swallow drugs on empty stomach. It gives me abdominal pain." – male, 13
  - "Mainly I lack food and someone responsible to provide for me" – female, <18

Conclusions

- Ugandan adolescents report high levels of adhere with twice-daily HAART regimens
- Social support important to adherence
- Significant barriers remain to perfect adherence
- Access to food stands out as a concrete barrier

Future Directions

- Increasing focus on food security as an essential component of HIV therapy
- Studies to evaluate lack of food as a barrier to **treatment** success in children and adolescents
- Further studies to investigate what support is effective for older adolescents as they transition into adulthood
- Questions?