Youth Adherence to ART in Sub-Saharan Africa: The Suubi+Adherence Study

Dr. Apollo Kivumbi, MBChB.
Suubi+Adherence Study Coordinator, ICHAD

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**Brief Statistics**

- People living with HIV Worldwide: 35.3 Million
- Children living with HIV worldwide (<15 yrs): 3.3 Million
- People living with HIV SSA: 25.0 Million
- Children living with HIV SSA (<15 yrs): 2.9 Million
- People living with HIV in Uganda: 1.5 Million
- Children living with HIV in Uganda (15 yrs): 190,000

*(UNAIDS 2012)*

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Adherence Defined

- Adherence is defined as the extent to which a person’s behavior in terms of taking medications, following a diet and executing lifestyle changes, follows agreed recommendations from health care provider.

- For desired treatment outcomes using ART, Adherence has to be beyond 95% (Garcia et al 2003; Nilsson et al 2006; Sarna et al 2005).

- Studies show ART adherence at 66% in Uganda (Byakika et al 2005).
Reasons for non-adherence among youth in Uganda

Patient factors
- Stigma
- Non-disclosure - the overall rate of disclosure is low
- Lack of social support
- Guilt
- Ignorance

Patient-Provider relationship
- Confidentiality
- Lack of emotional and psychological support (counseling)
- Inadequate monitoring
Reasons for non-adherence continued

**Adverse regimen characteristics.**
- Pill Burden
- Food restrictions
- Side effects

**Health care system**
- Location of health centers
- Motivational activities (Clubs for positives)
- Sensitization (Information and education materials)
- High patient: health worker ratio
Why economic strengthening for youth infected with HIV?

- To have protection via social and financial safety nets and avoid engaging in high-risk behaviors.

- To avoid prematurely engaging in exploitative labor or leaving school to care for dependents.

- To access education and improve future human development prospects.

- To access medical treatment, food supplements, and care.

(USAID, Psp-one project, 2009)
Current Status

- A number of projects in Uganda currently aim at economic strengthening for HIV infected adults e.g. SILC program for Villa Maria Hospital and SEEP project for Uganda Cares.

- These projects seek to retain clientele in care through economic empowerment.

- However, none of these projects are directly aimed at Youth infected with HIV.

- Suubi+Adherence project seeks to bridge this gap.
The Suubi+Adherence Study (N=736)

Overall Purpose:
- Increase or support adherence to antiretroviral therapy (ART) for low income HIV+ adolescents
- Promote income-generating activities/microenterprise for low income HIV+ adolescents and their families.

Inclusion Criteria:
- HIV+ adolescents between 10-16 years
- On ART and fully disclosed to.
- Registered at one of 40 selected clinics for follow-up care and drug refills
- Living within families (not institutions)
Monitoring Adherence

Self reports

- Limitation: Biased - tendency to overestimate adherence.

Pill count

- Done by Health providers on refill visits and research assistants on abrupt home visits.

Use of biomarkers

- Assess CD4+ counts and Viral load since the goal of treatment is to suppress viral load and improve on the CD4+ count.

Medical Event Monitoring System (MEMS)

- Use an electronic device to monitor intake of pills.

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Implementation of the project

Suubi+Adherence
ART Adherence monitoring
Geo-Mapping

Control
Literature about ART adherence
Standard care

Intervention
Child development accounts
Mentorship sessions
Income Generating Activity trainings
The road so far...

- Recruitment

<table>
<thead>
<tr>
<th>Turned up</th>
<th>Recruited</th>
<th>Not recruited</th>
</tr>
</thead>
<tbody>
<tr>
<td>857</td>
<td>610</td>
<td>247</td>
</tr>
<tr>
<td>Males</td>
<td>Females</td>
<td>Males</td>
</tr>
<tr>
<td>396</td>
<td>461</td>
<td>267</td>
</tr>
<tr>
<td></td>
<td></td>
<td>343</td>
</tr>
<tr>
<td></td>
<td></td>
<td>128</td>
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<tr>
<td></td>
<td></td>
<td>119</td>
</tr>
</tbody>
</table>

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Reasons for Exclusion

- [42] on only Septrin
- [43] Under age
- [15] Above age
- [22] No guardians
- [31] Others
- [94] Undisclosed to

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## Sample Characteristics

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td><strong>School Enrollment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enrolled in school</td>
<td>86.4%</td>
<td>86.3%</td>
<td>86.3%</td>
</tr>
<tr>
<td>Not enrolled in school</td>
<td>12.5%</td>
<td>12.5%</td>
<td>12.5%</td>
</tr>
<tr>
<td>Never enrolled</td>
<td>1.1%</td>
<td>1.2%</td>
<td>1.2%</td>
</tr>
<tr>
<td><strong>Orphanhood Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Double orphan</td>
<td>29.5%</td>
<td>26.2%</td>
<td>27.7%</td>
</tr>
<tr>
<td>Non-orphan</td>
<td>33.0%</td>
<td>35.3%</td>
<td>34.3%</td>
</tr>
<tr>
<td>Single orphan</td>
<td>37.5%</td>
<td>38.5%</td>
<td>38.1%</td>
</tr>
</tbody>
</table>
## Viral Load data

<table>
<thead>
<tr>
<th>Classification</th>
<th># of participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undetectable</td>
<td>239</td>
<td>39.8</td>
</tr>
<tr>
<td>Detectable</td>
<td>362</td>
<td>60.2</td>
</tr>
</tbody>
</table>
In their own words...

“I had to leave school since my fellow students were laughing at me because I had HIV with this skin condition.”

-A study participant with [plano warts](https://www.nhs.uk/conditions/warts/types/plano/)

“I cannot let my daughter know that she is positive because of me. She is my life and I cannot lose her.”

-A mother who hadn’t disclosed to a 14 yr old girl

“When I first started taking ARVs, I learned I had to take them with food else I’d become nauseous. They also made my appetite too high. I felt hungry all the time. I tried to eat more than usual, but the hunger I felt during that time was too much. I just didn’t have enough food to satisfy my hunger, so I stopped taking my ARVs.”

—HIV+ teenager in Rakai District
Acknowledgements

- Principal Investigator: Fred M. Ssewamala, PhD.
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- Reach the Youth-Uganda
- Columbia University School of Social Work
- National Institute of Child Health & Human Development (NICHD)-our funders
- All study participants: children and caregivers
References


5. Uganda Health sero-status and behavioral Survey, 2005

6. UNAIDS Global epidemiological report 2012

7. USAID ,Psp-one project 2009

8. WHO, Essential Medicines and Health Products Information Portal

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