FINAL REPORT

Factors Affecting ART Uptake, Adherence and Prevention of Transmission among HIV Positive Children and Adolescents In Uganda

A Review of Literature

Prepared by

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For

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<table>
<thead>
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<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>ARVs</td>
<td>Antiretroviral drugs</td>
</tr>
<tr>
<td>CATTTS</td>
<td>Community ARV and Tuberculosis Treatment Supporter</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>DOTs</td>
<td>Directly Observed Therapy</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
</tr>
<tr>
<td>HCP</td>
<td>Health Communication Partnership</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HW</td>
<td>Health Workers</td>
</tr>
<tr>
<td>IEC</td>
<td>Information, Education and Communication</td>
</tr>
<tr>
<td>JCRC</td>
<td>Joint Clinical Research Centre</td>
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<tr>
<td>m-DOT</td>
<td>modified-directly observed therapy</td>
</tr>
<tr>
<td>MSF</td>
<td>Medicins Sans Frontiers</td>
</tr>
<tr>
<td>MTCT</td>
<td>Mother to Child Transmission</td>
</tr>
<tr>
<td>MUJHU</td>
<td>Makerere University- John Hopkins University</td>
</tr>
<tr>
<td>NGO</td>
<td>Non Governmental Organization</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>Presidential Emergency Program for AIDS Relief</td>
</tr>
<tr>
<td>PIDC</td>
<td>Paediatric Infectious Disease Clinic</td>
</tr>
<tr>
<td>PLWHAs</td>
<td>People Living with HIV/AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>TASO</td>
<td>The AIDS Support Organization</td>
</tr>
<tr>
<td>TREAT</td>
<td>Timetable for Regional Expansion of Antiretroviral Therapy</td>
</tr>
<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counseling and Testing for HIV</td>
</tr>
<tr>
<td>WFP</td>
<td>World Food Program</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Executive summary

The Joint Clinical Research Centre (JCRC) with technical assistance from the Health Communication Partnership (HCP) will embark on a campaign aimed at increasing uptake of and supporting adherence to antiretroviral therapy (ART) among children, adolescents and caretakers of children. Setting up an effective, sustainable and culturally appropriate communication campaign requires research to study the factors that affect uptake and adherence.

In response to this need, HCP contracted a consultant to conduct a literature review on factors affecting ART uptake and adherence and the prevention of transmission among HIV positive children and adolescents in Uganda and East Africa. Based on this research, recommendations were formulated for designing communication interventions by JCRC and HCP.

Findings

Uptake of ART refers to the number of people who are eligible for ART who actually start it. Although uptake of ART has markedly improved since the provision of free ART, children are lagging far behind adults. In Uganda, of 50,000 estimated eligible children, only 6000 (12%) had started by December 2006. Of these 6000, 50% receive ART from three centers in Kampala: Mulago Hospital Paediatric Infectious Disease Clinic (PIDC), Mildmay Centre, and JCRC Mengo. Most of the other children receive ART from Regional Referral Hospitals and a few District Hospitals. Some rural districts have no children on ART despite the fact that it is free for all.

Some of the barriers are at the national level. For instance, many health workers are not trained in providing ART to children and do not have the confidence to start them on ART. The Prevention of Mother-to-Child Transmission of HIV (PMTCT) program has grown to include over 300 Health Units in the country (all Districts are covered). However, there is still very poor linkage with care of these infants. HIV tests for children under 18 months are not widely available. The availability of HIV testing directly affects uptake because a person’s status has to be known before treatment can begin. Even
where testing is widely done, for instance at Mulago Hospital Paediatric wards where about 45 children test positive every month, few of children end up on ART because of problems like fear of disclosure and stigma. In the rural areas, ignorance about availability of services, poor referral systems, and transport costs are notable hindrances to uptake of free ART.

Adherence studies done in Uganda have shown that adherence to ART is better where ART is free, and better still in research settings and community-based programs. Two studies of children have shown that stigma directly affects adherence. In one of them, lack of disclosure of the child's HIV sero-status to any other person was significantly associated with non-adherence, whereas in the other, failure to inform children of their own status was associated with worse adherence.

The effectiveness of strategies to deal with ART adherence has not yet been established in sub-Saharan Africa. However, examples of interventions which have been very helpful include structured adherence counseling, treatment supporters, disclosure to the children, peer support clubs and other innovative ways.

Adolescents living with HIV are a potential source of HIV transmission. When some of them improve their quality of life while on ART, they engage in unprotected sex evidenced by the resultant pregnancies. In many centres caring for adolescents living with HIV, they are taught to either abstain from sex, or be faithful to one partner and to consistently use condoms in order to prevent transmission of HIV. Many of the adolescents are knowledgeable about the dangers of engaging in unprotected sexual activity, including the danger of re-infection. However it is mostly the younger adolescents who believe in abstinence. The older adolescent males engage in sexual activity mainly due to peer pressure and they do not use condoms because they fear to disclose their HIV sero-status to their partners. The few who use condoms are not consistent. Alcohol, blue movies and dance parties have been notorious for failing the behaviour change strategies. Adolescent girls are mainly enticed into sex by money. Many of them are orphans and have many unmet needs. They therefore do not disclose
their status so that they ensure continued financial support. Some adolescents are bitter about their sero-status and knowingly pass on the virus to others, especially those who get late disclosure of their sero-status. However, there are some adolescents who are determined not to engage in unsafe sex mainly for religious reasons, or due to good continuous social support and counselling.

**Recommendations**

The public, especially in rural areas, should be sensitized to increase awareness about the benefit of ART in children. More health workers need to be trained in pediatric ART to increase their confidence. Strong linkages between PMTCT and care of HIV-exposed infants should be built.

In order to improve adherence to ART among children and adolescents, one needs to be innovative. Interventions like disclosure of HIV sero-status to older children and adolescents before starting ART, use of a treatment supporter, reminders like adherence calendars, alarm clocks and pill boxes can be used. Information, Education and Communication (IEC) materials for children, adolescents and their caregivers should be designed and distributed to them with an element of fighting stigma which is a barrier to adherence.

Strategies to prevent transmission by HIV positive adolescents should address the economic issues faced by girls as well as their misconceptions. They should be encouraged to join adolescent clubs where they will receive correct information and be continually motivated through ongoing peer support. Condoms if requested should be made available to the adolescents. Ongoing individual and group counseling is paramount to reinforcing their personal motivation.
CHAPTER 1
Introduction

1. Background

1.1 Epidemiology of HIV among Children

Worldwide, there are about 2.3 million children infected with HIV, of whom nearly 90% live in sub-Saharan Africa. In 2006 alone, new infections in children under 15 years were estimated to be 530,000 (410,000-660,000), with 380,000 deaths. It is currently estimated that 1,600 children are infected daily by their HIV-infected mothers. The high sero-prevalence among women drives this increase in children since 90% of infection in children is through MTCT.

In Uganda, the national sero-prevalence of HIV is 6.2% and about 100,000 children under 15 years are estimated to be infected with HIV. There were 16,740 deaths of children below 15 years. The HIV transmission rate from mother to child is estimated at 30% in Uganda. Over one million women in Uganda get pregnant per year and it is estimated that about 20,000 children are infected with HIV per year through MTCT. The HIVNET 012 study documented that administration of single dose Nevirapine to mothers during labor and to children within 72 hours of birth lowered the risk of transmission by about 50%. On this basis, the Uganda PMTCT program was set up by the Ministry of Health and has now scaled up to over 300 Health Units, including all districts in the country. Infection of HIV among children is largely preventable and could be markedly reduced by the PMTCT program.

1.2 Paediatric HIV and Antiretroviral Therapy

Pediatric AIDS care is complicated by the fact that early diagnosis is rarely available in resource poor settings. The HIV tests for children under 18 months (DNA/PCR) are available in very few centers. In Kenya, by 2005 December, it was available in only 4 centers, which were mostly research settings that were accessible to very few children.
In Uganda, it is available in only 10 centers, mostly in Kampala. However, testing for children over 18 months is widely available.

The progress of HIV disease among children in resource-limited centers is much faster than that in the developed world due to the burden of diseases like malnutrition, diarrhoeal diseases and tuberculosis in these countries. It is estimated that a third of vertically infected children die before one year and more than 50% die by two years of age. Approximately 66% of perinatally infected children will die before their third birthday and 75% by 5 years without ART. With ART, increasing numbers of children are growing to adolescence and adulthood. This calls for early diagnosis and then comprehensive care including ART provision. These children and adolescents grow up while facing several challenges such as enduring lifelong medication regimens, disclosure issues, stigma and sexuality.

Although ART does not cure HIV infection, evidence from various countries shows that it reduces HIV/AIDS-related morbidity and mortality. It reduces incidence of opportunistic infections and other AIDS-related illnesses by delaying HIV disease progression. As a result, it improves the quality of life and life expectancy. In children and adolescents, ART has also markedly reduced death and illness. Initially there was a fear of starting ART in children because of uncertainties about tolerance. However, children given ART respond well (if not better) and tolerate drugs as well as adults.
Objectives and Methodology

1.3 Objectives of the literature review

General objective
To carry out a critical review of current literature on factors affecting ART uptake, ART adherence and prevention of transmission among HIV positive children and adolescents in Uganda and East Africa in the last 10 years.

Specific Objectives
1 To determine the factors influencing ART uptake among children and adolescents in Uganda and East Africa.
2 To estimate the levels of adherence among different scenario of people in Uganda.
3 To determine the factors influencing adherence to ART among children and adolescents in Uganda and East Africa.
4 To document experiences from successful behaviour change communication interventions on local and international scene aimed at promoting adherence among children and adolescents.
5 To determine the factors affecting prevention of HIV transmission among HIV positive adolescents in Uganda.

1.4 Methodology
The study made use of both published and unpublished data. Published data were obtained from Web search engines, Internet libraries, the Ministry of Health Library, the Albert Cook Library at the Makerere Medical School and other libraries.

Unpublished data were obtained through targeted informal interviews with key players at the Ministry of Health, JCRC, Mulago Hospital PIDC, Mildmay Centre, Nsambya Hospital Home Care Department, Reach Out Mbuya, Kamwokya Christian Caring Community, Naguru Teenage Centre and other organizations that deal with HIV positive children and adolescents. Face-to-face and telephone interviews were carried out using a Key
Informant Interview Guide (see Annex 2). Some information was obtained from an ongoing study on adolescent sexuality taking place at the PIDC.

1.5 Limitations of this literature review

This review had several limitations. First of all, there was limited time, therefore upcountry visits were not made. This is important because there could be factors that specifically affect rural communities that might have been missed. However, some telephone contacts were made to upcountry hospitals.

Most published data available in Africa were from studies of adults rather than children and adolescents.

It was very difficult to get unpublished data from other East African countries. Email communication was attempted but not much information was obtained, especially from Tanzania.
CHAPTER 2

ART uptake among children and adolescents

2.1 ART Access in Resource Poor Settings

Uptake of ART refers to the number of people who are eligible for ART who actually start it. ART access directly affects uptake. By December 2003, less than 8% of the 6 million people with HIV/AIDS who needed ART immediately had access to it in poor countries, especially sub-Saharan Africa.\(^\text{18}\) The main obstacle was the cost of the drugs. For instance, of the 200,000 people who needed ART in Uganda, only 10,000 (5%) were receiving it by the end of 2002. Most of these people were living in urban centers.\(^\text{19,20}\) In a period of only four years, access has markedly improved because the cost of drugs has come down and there are many centers providing free ARVs. Currently there are about 90,000 people receiving ART of the 200,000 who need them (45%) and there are 204 centers providing free ART from Ministry of Health (both government and non-government health centers) in Uganda.\(^\text{10}\) However, inequity still exists because ART centers are located in towns and not yet in lower health facilities in rural areas.\(^\text{21,22}\) Moreover, most people live in rural areas and cannot afford treatment even at the reduced price. Furthermore, where ART is free, transport costs are still a problem.

2.2 ART uptake in Children

Although access to ART has markedly improved in developing countries, children are lagging behind adults. For instance, out of 90,000 people on ART in Uganda, only about 6,000 (6.6%) are children.\(^\text{10}\) It is estimated that 50,000 children are eligible for starting ART but only 12% access it.\(^\text{23}\) About 50% of the children on ART in Uganda are from 3 centers in Kampala: Mulago PIDC, Mildmay Center, and JCRC Mengo. There are very few children on ART in the rural areas.

In resource limited settings, most centers started providing ART to children long after they had started providing it to adults\(^\text{6}\) except for centers with pediatricians or study centers. Health workers do not seem to have enough confidence in their understanding
of ART to start children on it. One possible explanation is that the training given to the health workers does not adequately address pediatric HIV.\textsuperscript{10} This is made worse by the fact that the HIV tests for children under 18 months are only available in very few centers. This makes access further delayed in children below 18 months.

In Kaberamaido district in Eastern Uganda, there were about 30 children under care for HIV compared to about 350 adults. When P IDC started a branch in the hospital, the number of children on ART quickly rose because of the available access to testing children under 18 months. Furthermore, many people in the community reported that they were not aware that services for children were available and that was why there were few children on ART.\textsuperscript{24}

Tables 1 and 2 show a comparison between children’s uptake of ART in rural and urban areas in Uganda among selected Health Units. Generally, there are very few children getting ART in the rural district hospitals. Kotido District has only one child on ART and some rural districts do not have any children on ART.

\textbf{Table 1: Children on ART in urban areas}

<table>
<thead>
<tr>
<th>Centre</th>
<th>Total on ART</th>
<th>Children on ART</th>
<th>% of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mildmay</td>
<td>2000</td>
<td>1,000</td>
<td>50%</td>
</tr>
<tr>
<td>Kabale Hosp</td>
<td>2800</td>
<td>450</td>
<td>16%</td>
</tr>
<tr>
<td>Mbarara Hos</td>
<td>4,600</td>
<td>450</td>
<td>9.7%</td>
</tr>
<tr>
<td>Masaka Hospital</td>
<td>3,100</td>
<td>181</td>
<td>5.8%</td>
</tr>
<tr>
<td>Nsambya</td>
<td>1280</td>
<td>150</td>
<td>11.7%</td>
</tr>
<tr>
<td>Jinja Hosp</td>
<td>1300</td>
<td>70</td>
<td>5.4%</td>
</tr>
</tbody>
</table>

\textbf{Table 2: Children on ART in rural areas.}

<table>
<thead>
<tr>
<th>Centre</th>
<th>Total on ART</th>
<th>Children on ART</th>
<th>% of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kayunga Hosp</td>
<td>275</td>
<td>25</td>
<td>9%</td>
</tr>
<tr>
<td>Nebbi Hosp</td>
<td>190</td>
<td>15</td>
<td>7.8%</td>
</tr>
<tr>
<td>Iganga</td>
<td>232</td>
<td>20</td>
<td>8.6%</td>
</tr>
<tr>
<td>Gombe Hosp</td>
<td>350</td>
<td>25</td>
<td>7.1%</td>
</tr>
<tr>
<td>Maddu HC</td>
<td>120</td>
<td>2</td>
<td>1.6%</td>
</tr>
</tbody>
</table>

Table 3 illustrates one example of how the number of children on ART is lagging behind that of adults. This same scenario is present in many centers in Uganda. In Kenya, it is estimated that only 10% of children who are eligible access ART.
In Nakuru Hospital, of the 799 people living with HIV, 39% were eligible to start ART but only 23.4% started. Others were lost to follow-up or died before starting.\textsuperscript{25}

\begin{table}[h]
\centering
\begin{tabular}{|c|c|c|c|}
\hline
\textbf{Date} & \textbf{Adults} & \textbf{Children} & \textbf{% of Children} \\
\hline
March 2004 & 447 & 0 & 0\% \\
June 2004 & 708 & 0 & 0\% \\
September 2004 & 1383 & 0 & 0\% \\
December 2004 & 2630 & 0 & 0\% \\
March 2005 & 3494 & 118 & 3.2\% \\
June 2005 & 6118 & 426 & 6.5\% \\
\hline
\end{tabular}
\caption{Clients on ART in Kenya}
\end{table}

Adungosi et al. 2005

There is an ongoing study in Mulago Hospital by Namusoke assessing factors that affect uptake of ART among children at the hospital. About 45 children test HIV positive every month on the general pediatric wards. They are referred to the PIDC where free ART is given to all children. Thus far, of the 50 children who are eligible for ART, only 3 have started it within a period of 4 weeks. The primary causes for the low rate of uptake are the required three adherence counseling sessions, delay in getting results of CD4 counts and other laboratory tests, and social problems including lack of transport. Some were too sick at admission and died before ART.\textsuperscript{26}

2.3 Barriers to Uptake of ART among children and adolescents

Children and adolescents are dependent on adults for uptake of ART. Barriers to uptake among adults could affect them as well. Eligible children have failed to start ART because of barriers at the national level, Health Unit Level and caregiver level.

National level
At the national level, the following barriers were identified:

1. **Lack of access to testing services.** HIV tests for children under 18 months are not widely available. This is crucial for early diagnosis and treatment because mortality is highest in the first few years of life. In order to reduce the mortality rate among young
children, there was a consensus that where this test is not available, children under 18 months should be given the antibody test and start ART if eligible, even before they get confirmation of their diagnosis.\textsuperscript{11} The test should then be repeated after 18 months and if found negative, ART would be stopped. Health workers, however, do not seem to be keen on starting ART before confirming the diagnosis.\textsuperscript{10}

2. \textbf{Few health workers are trained in pediatric HIV and ART.} Health workers gain confidence in prescribing ART when they have been trained. There are very few pediatric counselors in the country.\textsuperscript{10}

3. \textbf{There is limited sensitization and awareness} of the benefit of care and treatment for infected children. When people do not know that the services are available, they do not use them.\textsuperscript{22,24}

4. \textbf{Cost of drugs:} The cost of ART can be a barrier to uptake, considering that one or both parents are also HIV positive and may need to pay for their own ART as well.\textsuperscript{21,22} The children/adolescents may be orphans with no financial support. Fortunately, there are many centers providing free ARVs from the Ministry of Health and other donors.

\textbf{Health Unit Level}

1. \textbf{Poor linkages between PMTCT and care of HIV exposed infants.}\textsuperscript{8,10} Though PMTCT is currently in all districts of the country, there is still poor follow-up of mothers and HIV-exposed infants.

2. \textbf{Poor referral systems.} Some centers which do not provide ART to children do not refer them to locations that do offer it.

3. \textbf{Long procedures in the Health unit.} Some people are lost to follow-up or they die before starting ART because of lengthy requirements for starting treatment, such as multiple counseling sessions.\textsuperscript{26}

4. \textbf{Adolescent friendly services are limited.}\textsuperscript{22}

There are very few centers which have a separate adolescent clinic where adolescents could comfortably get tested and then get treatment including ART.

5. \textbf{Transport costs:} Eligible children or adolescents may not start ART because of lack of transport to return for refills. This is mainly in rural areas where there are still
few centers providing ART and people need to travel long distances to get the services.\textsuperscript{27,28,3}

6. **Long lines**: Some people spend a whole day whenever they take children to hospital and this may interfere with their work.

7. **Lack of supplementary food**: In a study in Rwanda, 76\% of patients expressed a fear of developing a larger appetite and therefore not having enough to eat.\textsuperscript{32} Several ART centers in Uganda reported that their clients feared starting ART because their appetite would improve and they would not have enough food. Centers in Uganda like Reach Out Mbuya Parish provide food to clients and this has contributed greatly to their success in terms of adherence and uptake of ART.\textsuperscript{33}

**Caregivers**

1. **Stigma and Discrimination**: Experienced or anticipated stigma is a major hindrance especially in centers that are devoted solely to HIV-related services. Clients have gone as far as getting ART from far-off centers where they do not expect to encounter anybody who knows them.\textsuperscript{27-31}

2. **Fear of disclosure to the child and others**: Many ART centers require a treatment supporter and that older children be informed of their own HIV positive status before starting ART as a way of encouraging adherence. Caretakers are required to disclose their child’s sero-status to the treatment supporters. For biological parents, disclosing the child’s status means disclosing their own. This has been found to hinder or delay uptake of ART mainly due to stigma. Caregivers do not like disclosing HIV sero-status to children because they think they are protecting them from stigma and worries.\textsuperscript{28,31}

3. **Lack of a treatment supporter**: Some people fail to find a suitable treatment supporter and yet many organizations require them before starting ART. They either delay uptake or give up on ART.\textsuperscript{27,28,29,30}

4. **Misconceptions about the drugs**: There are some myths that the drugs will make them infertile or make them worse. This has made some people unwilling to start ART.\textsuperscript{27-30}
5. **Lack of time/too busy:** Some caregivers admit that they cannot comply fully with the treatment regimen. For instance, some people find it difficult to administer the drugs on time because of their work schedules. Others travel frequently and have nobody to administer the drugs on time.\(^{27,30}\)

6. **Fear of ARVs:** Some people fear ARVs because the process for preparing to take them and the required counseling sessions make it seem to be complicated medication. They are scared by "too many rules.\(^{28,30}\)

7. **Fear of death.** Some clients have seen people die shortly after starting ART and give this as a reason for rejecting ART.\(^{27}\)

### 2.4 Recommendations

Since ART is so vital in improving mortality and morbidity among HIV patients, it is now free in many centers in Uganda. Efforts should address barriers to uptake of ART. The following are possible solutions.

1. **Counseling.** Most resource persons interviewed admitted that there are very few eligible people who refuse to start ART.\(^{27-31}\) Those few with misconceptions and fears should be given good counseling to help them understand and begin ART.

2. **There should be strong linkages between PMTCT and care for HIV-exposed infants.** They need to be referred for testing and further management.

3. **Increasing access to testing of children will contribute to early access to care and ART.** Serological tests are widely available but wider availability of tests for children under 18 months should be advocated for. Referral systems should be improved.

4. **ART should be rolled out in rural communities where access is hindered by lack of transport.** Outreach or satellite clinics are a possible solution.

5. **Food distribution where possible or networking with other organizations that can provide food and income-generating activities.**

6. **Sensitization of the public to increase awareness of the benefit of care and treatment for infected children.**

7. **Training more healthcare workers in pediatric HIV/AIDS**

8. **Referral systems should be improved.** Centers that do not provide ART should be able to identify eligible children and refer them to the appropriate Health Center.
CHAPTER 3
Adherence to ART

3.1 Definition of Adherence

Adherence to medication has been described as the proportion of prescribed medications that is actually taken. It is measured on a scale from 0% to 100%.\textsuperscript{34-36} Whereas compliance implies submissiveness, and suggests a more passive role for patients in their health care, adherence is associated with voluntary and collaborative behavior and conveys a sense of involvement. Adherence is the preferred term because it recognizes patient choice in therapy.

Adherence and ART

Adherence is the most important determinant of success of ART. Proper adherence determines the biological, clinical and public health outcomes of treatment. Good adherence to ART regimens is closely associated with the degree of viral suppression.\textsuperscript{37-40} Poor adherence can lead to incomplete viral suppression, emergence of resistant viral strains, and treatment failure. Sub-optimal adherence to ARVs is the most common cause of virologic failure of ART regimens. In addition, non-adherence to one regimen can result in viral mutations that confer virus resistance to many ARVs in the same class. Drug resistance might necessitate changing to another, probably more expensive second-line drug regimen; yet, only a few treatment options are available in developing countries. Furthermore, children have fewer treatment options than adults due to the lack of suitable formulations.

In the case of ART, an adherence level of 95% or more is required in order to obtain a successful treatment outcome (see figure 1).\textsuperscript{37}
Adherence levels

Studies conducted in Africa have largely been of adults and they have generally shown a higher level of adherence than in the developed world. In Senegal, using self-report and pharmacy records, on average, patients said they had taken 91% of each monthly dose (n= 158). In Malawi, defining adherence as taking 80% of prescribed therapy among 464 adults, prevalence was 93%. A study done in Botswana among 176 randomly selected patient records using 7-day recall questionnaires and pill counts, found overall monthly average adherence was 83%. In Nigeria, adherence was reported as “good” in 74% of patients among 226 adults. A few studies conducted in Africa showed low levels of adherence. In all, poor adherence was attributed to the high costs of drugs and stock-outs. For instance in Botswana, the prevalence of adherence was 54% (n=112).

3.2 Adherence levels in Uganda

Adherence among paying adults

In Uganda, the first study on ART adherence levels was done in 2002 by Byakika et al. They found non-adherence levels to be 28.8%, 30.5%, 31.8%, 32.1% and 37.8% (n=302) one day, two, three, four and seven days before the interviews, respectively, at the 5% benchmark. At the 20% benchmark, it was 28.8%, 29.8%, 30.2%, 28.3% and 25.7% (n=304), respectively. The prevalence of non-adherence in this population per day was 28.8%. The study was conducted in three centers in Kampala (JCRC, Nsambya Hospital, and Mildmay Centre) and included only adults, most of
whom were paying for their treatment. This study found that the biggest barrier to adherence was the cost of the drugs. At that time, ARVs were still very expensive and the study population was composed primarily of paying clients.

The next study in Uganda was carried out by Oyugi et al in 2003 in JCRC. This study found a higher level of adherence. Using multiple measures, mean adherence was found to be 91% to 94% (n=34) in JCRC, Kampala.44 The sample size was much smaller than the earlier study. It included only adults on Triomune. While they were also paying patients, Triomune was a much cheaper generic drug and this could explain the higher level of adherence. The first study was cross-sectional whereas this was a prospective cohort where they were followed for 12 weeks. The frequent encounters with the researchers could have influenced their adherence levels.

In the Mother-to-Child Transmission (MTCT) Cohort Adherence Study in Mulago Hospital in 2004, very high mean adherence levels (ranging from 97.5 to 99.8%) using different measures were attributed, among other reasons, to the medication packaging (blister packs).45

**Adherence in JCRC TREAT**

Adherence levels for the month of January 2006 were obtained using records review from ten sites in Table 4. In these 10 sites, 92.5% of the clients who had adherence records had ≥95% adherence to ART. These were all adult records.

**Table 4. Adherence levels in selected TREAT sites**

<table>
<thead>
<tr>
<th>TREAT site</th>
<th>Total patients</th>
<th>Patients with adherence records</th>
<th>Adherent (≥95%) n, (%)</th>
<th>Non-adherent (&lt;95%) n, (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mbale</td>
<td>481</td>
<td>481</td>
<td>447, (92.9%)</td>
<td>34, (7%)</td>
</tr>
<tr>
<td>Fortportal</td>
<td>590</td>
<td>560</td>
<td>537, (95.9%)</td>
<td>23, (4.1%)</td>
</tr>
<tr>
<td>Kakira</td>
<td>208</td>
<td>181</td>
<td>173, (95.5%)</td>
<td>8, (4.4%)</td>
</tr>
<tr>
<td>Bombo</td>
<td>61</td>
<td>61</td>
<td>61, (100%)</td>
<td>0, (0%)</td>
</tr>
<tr>
<td>Gulu</td>
<td>161</td>
<td>161</td>
<td>155, (96.3%)</td>
<td>6, (3.8%)</td>
</tr>
<tr>
<td>Kasese</td>
<td>55</td>
<td>44</td>
<td>36, (81.8%)</td>
<td>8, (22.2%)</td>
</tr>
<tr>
<td>Ishaka</td>
<td>232</td>
<td>218</td>
<td>179, (82.1%)</td>
<td>39, (21.8%)</td>
</tr>
</tbody>
</table>
Limitations of the records review are summarized below.

- The ART card from which these records were obtained did not specify what measures were used to assess adherence. Hence, the methods used are not uniform; some used self-report, others pill counts. The days in question for self-report are not known.
- Both pill counts and self-report tend to over-estimate adherence.
- The centres with the most patients do not have adherence records. The findings would have most likely been different if these centres had been included.
- The findings may not be representative of the over 30,000 on ART in TREAT at that time. The sample size is too small.

A qualitative study by Crane et al. among adults paying for low-cost ART in Kampala revealed that missed doses were more attributable to failure to access medication than failure to adhere to regimens.\(^\text{46}\)

**Adherence to free ART**

When drugs are free, adherence levels are much higher. Uganda Cares, an organization providing free ARVs in Masaka, reports 98% adherence. This was by self-report alone from operational research among adults.\(^\text{47}\) Clients are asked about their adherence levels at every visit. The study group consisted of highly motivated clients, most of whom were in the first two years of ART when treatment fatigue has usually not set in.

**Adherence in community-based programs**

In another study done by Alamo-Talisuna in the Reach Out Mbuya Parish HIV/AIDS program, mean adherence among 405 clients using records review was 99.4%.\(^\text{33}\) This program registers very good adherence levels for the following reasons:
• They are not in a hurry to start ART. There is ample time spent in education in preparation for ART.

• Each client must have a treatment supporter before starting ART.

• Each client is assigned a trained Community ARV, TB Treatment Supporter (CATT) who knows where the client lives and who not only supports but regularly measures adherence in the client’s home. CATTs are given allowances so they are motivated to carry out their responsibilities.

• Adherence counseling and pill counts are done at every clinic visit.

• The program is a holistic care model which affects aspects of the body, mind, family and community.

• Clients sign an agreement before starting ART and renew it every three months.

• Food as well as soft loans are provided to clients.

This program covers a limited geographical area and is well funded. It is a very good program but may not apply to hospital-based programs with a wide catchment area.

In a recent study done by Centers for Disease Control and Prevention (CDC) in a rural home-based AIDS care program, Weidle et al assessed adherence to antiretroviral therapy among a cohort of HIV-infected people.\(^\text{48}\) The programme provides ART and other AIDS care, prevention, and support services in rural Uganda. Adherence interventions included group education, personal adherence plans developed with trained counsellors, a medicine companion, and weekly home delivery of ART by trained lay field officers. Of the 987 clients, pill count adherence of less than 95% was found for 0.7-2.6% of participants in any given quarter. Home-based programs usually have very good adherence levels. The weekly home delivery of ART and other interventions are responsible for the very good adherence levels.

**Adherence to ART in the private versus public facilities**

In Nakiyemba’s qualitative study in Jinja in 2005, adherence levels were not described; however, in comparison to the private health facility, the public facility had many factors which were barriers to adherence such as crowding, long waiting hours,
some demoralized staff, and no adherence counselors. From this study, private facilities are more likely to have better adherence than the public ones.

### 3.3 Adherence levels in children in Uganda

Just as access to ART among children lags behind adults, pediatric adherence to daily drug regimens has not been widely assessed in Africa where the majority of HIV-infected children live. Few studies have been done in Uganda.

In a cross-sectional study of 170 children aged 2 to 18 years in Mulago Hospital by Nabukeera et al, adherence to HAART was defined as taking ≥95% of prescribed medication. Adherence was assessed using three measures: three-day self-report from the caregivers, clinic-based pill counts at enrollment, and home-based unannounced pill counts two to three weeks later. Results were different for each measure as shown in Figure 2. The majority of children had good adherence levels even when measured by unannounced pill counts. Possible explanations for the higher adherence in this study could be (1) about 82.4% of the children had been on HAART for one year or less and were probably not yet fatigued with the medication regimen; (2) 91% of the children were taking medication with a simple twice daily dosing schedule (Triomune and Duovir N); (3) only 21% reported the presence of side effects; and (4) the majority of the children were receiving free therapy (only two children in the study were paying for their ARVs). Furthermore, 81% of the children and 75% of caregivers reported that ART did not interfere with daily life.
A recent study, using records review, by Semmere in Nsambya Hospital Home Care found that 71% of 150 children under 18 years had no missed doses by self-report and pill counts. The children in the study were receiving free ART.

A study done in Makerere University and Johns Hopkins University (MU-JHU) Research collaboration by Musoke et al found 90% mean adherence. Adherence levels are checked at every visit using pill counts and self-report. This is a study setting where drugs are free and patients are provided with transport refunds. In addition, home visits were conducted where necessary. However, they found that adherence to syrups is worse than tablets. Adherence is reported to be better in a study setting than a clinical care setting as has been reported elsewhere in the world.

Using in-depth interviews of 42 HIV-infected children taking ART and/or cotrimoxazole prophylaxis, and 42 primary caregivers, at a comprehensive HIV/AIDS clinic in Uganda, Bikaako et al found that complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good adherence. Structural factors including poverty and stigma were barriers to adherence even for children who had had complete disclosure and a supportive relationship with a parent.

All in all, different programs have different adherence levels depending on the adherence strategies they use, the number of people on ART, the duration people have been on ART (fatigue sets in after some years) and the adherence measures.
used. Free ART especially in study settings and community programs is associated with better adherence.

3.4 Factors affecting adherence to ART among children and adolescents

Factors relating to the child and to the caregivers, and to the relationship between the two, are important in contrast to the somewhat simpler dynamics in adults. Young children entirely depend on adults for drug administration, while older ones need a parent or caregiver to supervise them. The following factors have been found to affect adherence:

Child Factors
Nabukeera’s study found two child factors which were significantly associated with adherence.\(^{50}\) The children whose caregivers had not disclosed the child’s serostatus to any other person had worse adherence. Another study by Reddington also showed that children whose HIV status was not disclosed had lower adherence levels.\(^{55}\) Stigma usually underlies this failure to open up to anyone about the child’s HIV status. Similarly, Bikaako’s study revealed that complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good adherence.\(^{53}\) She also found that stigma and poverty are a hindrance to adherence to ART by children.

Gibb’s study revealed that symptomatic HIV disease was associated with better adherence.\(^{56}\) Catz and colleagues also found that healthy HIV-infected outpatients had lower rates of adherence to medical appointments than the symptomatic ones.\(^{57}\) Nabukeera also found that those who had been hospitalized two or more times had better adherence.\(^{50}\) This implies that those who are healthy be less vigilant about taking their medication.

Gibb’s study revealed that age >10 years was associated with better adherence.\(^{56}\) However, other studies showed that adolescents had worse adherence.\(^{58,59,60,61}\) In
adolescents and young adults, Martinez found that housing stability and duration on HAART treatment were significantly related to non-adherence in the United States. However, he did not find significant association with social support, number of clinic visits, number of pills per day, age, health status and knowledge of medication schedule.

Children in boarding schools who do not disclose their status to a teacher or school nurse had worse adherence rates that those who did according to Nabukeera’s study, though this was not statistically significant. Children who have siblings or caregivers on ART are expected to have better adherence because it is easy to remember as a group, but the research reviewed has not substantiated this assumption. No study reviewed showed that orphans were at risk of non-adherence.

**Caregiver Factors**

In Reddington’s study, the relationship between the child and primary caregiver did not affect adherence levels. In this study, however, the perceptions of caretakers that adherence was too difficult and concerns about privacy were significantly associated with non-adherence. The caregiver being a grandmother was associated with less than 70% adherence to ART, using unannounced pill counts at home. Using self-report, the primary caregiver being an aunt was associated with better adherence. In Gibb’s study, neither the fact that the caregiver was also on HAART nor the caregiver’s perceptions of the difficulty significantly affected adherence. Level of education and socio-economic status did not affect adherence in a study by Nabukeera.

**Drug Factors**

The cost of drugs contributes greatly to non-adherence. Adults who used alternative therapies like herbs, Eastern medicine and spiritual approaches reported higher rates of non-adherence to ART. The time spent on administering drugs is said to affect adherence. There was better adherence for children where the responsibility of
administering drugs was shared with the other parent or other relatives, babysitters or school staff. The number of medications did not significantly affect adherence.\textsuperscript{50,55,63} The regimen of ARVs used also affects adherence. This was due to difficulties in taking specific medications such as bad taste, patient refusal, scheduling problems and number of medications. Other studies have also revealed that inconvenient dosing, frequency, dietary restrictions, pill burden and side effects affect adherence.\textsuperscript{63,64}

\textbf{Health unit Factors}

Adherence levels are higher in clinical trial settings than in clinical settings.\textsuperscript{52}

\textbf{Reasons for non adherence}

In Nabukeera's study in Mulago Hospital, the most common reason reported for missing doses was forgetting n=46 (32%). Altogether, forgetting by the caregiver and older children who are involved in drug administration, caregivers being away from home 21(14%) and change in daily routine 12 (8%) accounted for 54% of the reported reasons for missing doses.\textsuperscript{50} Several studies have shown that forgetting is the most common reason reported for non-adherence. Other reasons reported by adolescents in a study by Kangavve include lack of support and problems associated with transport.\textsuperscript{28}
Table 3: Summary of Factors affecting adherence to ART in children and adolescents

<table>
<thead>
<tr>
<th><strong>CHILD FACTORS</strong></th>
<th><strong>Barrier</strong></th>
<th><strong>Promoter</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure status of child</td>
<td>Non Disclosure</td>
<td>Disclosure</td>
</tr>
<tr>
<td>Schooling issues</td>
<td>Boarding schools</td>
<td>Day schools</td>
</tr>
<tr>
<td>Disclosure to Another person</td>
<td>Not disclosed to anyone</td>
<td>Disclosed to at least one person</td>
</tr>
<tr>
<td>Age</td>
<td>Adolescents</td>
<td>children</td>
</tr>
<tr>
<td>Supervision of child</td>
<td>Lack of supervision</td>
<td>Good supervision</td>
</tr>
<tr>
<td>Social support</td>
<td>None</td>
<td>Good</td>
</tr>
<tr>
<td>Symptomatic HIV disease</td>
<td>Not symptomatic</td>
<td>Symptomatic</td>
</tr>
<tr>
<td>HIV+ siblings</td>
<td>Absent</td>
<td>Present</td>
</tr>
<tr>
<td>Hospitalizations before ART</td>
<td>None</td>
<td>2 or more</td>
</tr>
<tr>
<td>Interference with daily life</td>
<td>Present</td>
<td>Absent</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>CAREGIVER FACTORS</strong></th>
<th><strong>Barrier</strong></th>
<th><strong>Promoter</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver economic status</td>
<td>poor</td>
<td>not poor</td>
</tr>
<tr>
<td>Relationship with the child</td>
<td>grandmothers</td>
<td>aunts</td>
</tr>
<tr>
<td>Caregiver also on ART</td>
<td>may have no effect</td>
<td>Better adherence</td>
</tr>
<tr>
<td>Interference with daily life</td>
<td>barrier when present</td>
<td>No interference promotes</td>
</tr>
<tr>
<td>Knowledge, attitudes and perceptions</td>
<td>negative perceptions</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>DRUG FACTORS</strong></th>
<th><strong>Barrier</strong></th>
<th><strong>Promoter</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug regimen</td>
<td>complex</td>
<td>simple</td>
</tr>
<tr>
<td>Cost of drugs</td>
<td>expensive</td>
<td>free</td>
</tr>
<tr>
<td>Duration on HAART</td>
<td>over 2 years</td>
<td>first year</td>
</tr>
<tr>
<td>Drug formulation</td>
<td>unpalatable</td>
<td>palatable</td>
</tr>
<tr>
<td>Pill burden</td>
<td>big</td>
<td>small</td>
</tr>
<tr>
<td>Time spent on drug administration</td>
<td>longer than 10 minutes</td>
<td>shorter</td>
</tr>
<tr>
<td>Side effects</td>
<td>Present and distressing</td>
<td>absent</td>
</tr>
<tr>
<td>Alternative Therapy use</td>
<td>used</td>
<td>Not used</td>
</tr>
<tr>
<td>Shared responsibility of drug administration</td>
<td>Shared</td>
<td>Not shared</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Health Unit Factors</strong></th>
<th><strong>Barrier</strong></th>
<th><strong>Promoter</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship between patient and Unit staff</td>
<td>bad</td>
<td>good</td>
</tr>
<tr>
<td>Waiting time</td>
<td>long</td>
<td>short</td>
</tr>
<tr>
<td>Distance</td>
<td>far</td>
<td>near</td>
</tr>
<tr>
<td>Shortage of drug supplies</td>
<td>Stock-outs</td>
<td>No stock-outs</td>
</tr>
</tbody>
</table>
### 3.5 Interventions to improve adherence in resource poor settings

The effectiveness of strategies to deal with adherence to ART has not yet been established in sub-Saharan Africa. However, numerous adherence strategies have been adopted by various ART programs in resource poor settings. Strategies to maximize adherence in this setting should emphasize ready access to affordable and simple ART regimens, as well as HIV education programs to help increase awareness and decrease disease stigmatization.

Since no single intervention is adequate, most programs use different combinations of interventions. It is mostly achieved through Information Education and Communication (IEC) and psychosocial support. In the case of children, IEC is mostly directed to the caretaker. Most of these programs involve increasing use of People Living with HIV/AIDS (PLWHAs) in care.

Crane et al. suggested that missed doses may be more due to a failure to access medication rather than a failure to adhere to medications, and that structural rather than behavioral interventions may be most useful to ensure optimal treatment response.\(^{46}\)

**Successful International Interventions**

In a program in Cuba, privately organized meetings, conferences, outpatient gatherings and workshops are regularly organized. Regular counseling and support is provided by PLWHA. Patients who have poor adherence get regular visits from nurses at home or at the AIDS Sanatoria to assess and support adherence.\(^{65}\)

In a program in India, the final decision to start ART is left to the patients and close family. This is thought to give them greater commitment. This program also provides several sessions of individual and group counselling to patients and their close family...
members. Directly Observed Therapy (DOTs) providers are close family members. In addition, alternative therapies are discouraged.  

A case study of Khayelishta programme in South Africa is a good example of a patient-based strategy. The program uses simplified and standardized drug regimens that minimize the pill burden and risks of side effects. It has also implemented a solid patient-centered education approach that ensures a good understanding of the treatment by the patient and has fostered a strong support system.  

Moreover, individual support is further strengthened by use of "Treatment Assistants." Lay counselors are always available at the clinic to help with individualized adherence plans. In addition, home visits are carried out by the counselors as needed for those with serious adherence problems. The program also holds bi-monthly support groups to promote peer support. Counselors regularly carry out workshops at the support groups. Furthermore, material support is provided by issuing pillboxes, drug identification charts, daily schedules, diaries and education support.

In a centre for comprehensive HIV/AIDS treatment and care in Malawi, patient empowerment is achieved through daily group discussions, individualized counselling, leaflets which reinforce key messages, use of a suggestion box and "guardian supported treatment."  

In a randomized controlled clinical trial in Mombasa, women randomized to use the alarmed device were significantly more likely to have good adherence to their one-month supply of multivitamins than those with non-alarmed control. (82% Vs 36, P < 0.001). The acceptability of the device was high and 99% of participants said that they would choose to use it again.
Community interventions

Although community strategies are demanding in terms of time and resources, they are, in part, the “way forward” for sustainability of adherence programs. Community interventions have been reported to reduce stigma which is a barrier to adherence.

A case study of “Partners in Health ARV programs” in Haiti has demonstrated very high levels of adherence of over 90%, and has reduced patient visits (and length of stays) to the hospital as a result of using DOT Highly Active Antiretroviral Therapy (HAART). Community health care workers visit patients on ART at home daily. They observe the patient swallowing one of the two daily doses and also provide support and respond to family concerns. In addition, there are regular meetings between these community outreach workers with people new to ART. Family support is also provided in terms of schooling, housing, money and nutrition. 70

In Khayelitsha, South Africa, Medicens Sans Frontiers (MSF) has pioneered community-based programs that have demonstrated better than 90% adherence rates, with more than 90% of patients with optimal viral suppression at six months and a more than 70% reduction in opportunistic infections. 67

Bohlabela, Limpopo Province is one of the poorest rural districts in South Africa. Roll-out of ART started in 2004 with limited skilled personnel. There was high community HIV/AIDS awareness but limited use of health care services due to lack of transport and poor services. Consequently, there was low uptake of VCT, PMTCT and HIV care. A cadre of 132 volunteers was trained and general and treatment support groups were established in all clinics. Through this program, the use of volunteers and support groups is shown to be an acceptable and cost-effective form of support for people with HIV/AIDS and those on ART in a resource poor setting. 71

While home-based follow-up is beneficial, it is still resisted by some communities because of stigma. A study was done in Mombasa prior to developing a modified-directly observed therapy (m-DOT) intervention to promote adherence. 72 Most PLHA preferred health facility-based follow-ups (29/38) to home-based follow-ups by health
workers (HW), mainly because of perceptions of greater confidentiality (12/29), better care and monitoring (9/29) and a sense of independence (6/29). Barriers to a health-facility based m-DOT strategy included distance from health centres, severe ill health, transportation costs, and time off from work. HWs identified practical strategies to overcome some of these barriers such as satellite-observation sites, early opening hours for employed PLHA and using community HWs to follow up severely ill PLHA.

Successful interventions in Uganda

In Uganda, the Ministry of Health guidelines, which should be used by all institutions, recommend that ART should not be started at the first clinic visit. A period of preparation and education is suggested to maximize adherence. It is further recommended that each patient complete a personal adherence plan, which includes arranging to have a treatment supporter who also receives educational counselling on ART. Currently adherence counselling is part of routine ART care in all programs.\textsuperscript{19,73}

At home in Uganda, Mbuya Reach Out, as part of their holistic model of care, goes a step further by making patients sign an ART Agreement before starting treatment. This agreement is renewed every three months. Together with individualized dosing schedules and community involvement, it has contributed to very high adherence levels.\textsuperscript{33}

Patients clubs have been started in many ART centres in Uganda including The AIDS Support Organization (TASO), JCRC Mengo, PIDC in Mulago Hospital and Mildmay Centre, among others. They meet regularly and their activities are intended to increase client education which ultimately improves adherence.\textsuperscript{27-30}

In a study by Nabukeera et al. (2005) of Ugandan children receiving free ART, 29% of caretakers reported that adherence was easier when the children were actively involved in reminding them. Other measures they suggested to improve adherence were shared responsibility of drug administration, alarm clocks, special pill boxes and disclosure to the child of his/her serostatus.\textsuperscript{50}
Institutions also make and utilize tools for adherence assessment and monitoring. These are incorporated into routine patient care. In Uganda, JCRC, PIDC, Mildmay Centre and all PEPFAR-funded ART centres have adherence assessment integrated into routine patient care.

Different institutions adopt their own unique models. For instance, the Mildmay Centre in Uganda is a specialized outpatient care and training centre. The medical team, counselors and chaplains provide physical, social, spiritual and psychological care. The institution has a daycare program for children who are too sick, called "Jajja's home." The children are transported daily from their homes to the centre. They are provided good nutrition, treatment, and psychosocial support. They are taken home in the evening. They also have an adolescent club and a client support group that meet regularly at the Centre. Disclosure to children is also encouraged to promote adherence.  

Institutions can package drugs in such a way as to promote adherence. Pill boxes with days of the week with indicators for morning and evening doses have been widely used in Uganda. In the MTCT-plus cohort Adherence Study in Mulago Hospital, very high mean adherence levels ranging between 97.5% and 99.8% using different measures were attributed to drug packaging (the blister packs), among other reasons.

The PIDC Clinic in Mulago has the largest number of children on ART and is a centre of excellence in paediatric HIV Care. Several interventions support adherence.  

- Before starting ART, the program encourages disclosure to children aged 8 years and above who are deemed old enough to understand.
- All caregivers are encouraged to get a treatment supporter who also receives counseling.
- All caregivers get three adherence counselling sessions before ART.
- The doctors do not prescribe ART unless the counselors have signed off.
In addition, Home Health Workers assess selected patients at home for readiness to start ART. They also follow up with those who are suspected of having adherence problems.

- Pill boxes are used which have sections for the morning and evening doses for each day of the week.
- Adherence is assessed at each visit and those found to be non-adherent are referred for more adherence counseling.
- Peer support is available from the adolescent club.

Similar approaches in Uganda are provided by TASO, Mbuya Reach-Out, Kamwokya Christian Caring Community and Nsambya Home Care. Although these organizations do not use DOT-HAART, home visits are incorporated into the ART program. These organizations utilize community volunteers who are motivated by their will to serve and small allowances. A majority of volunteers are PLHA.

**Community Partnerships**

Partnerships with other organizations can make home-based care possible. Arua Regional Referral Hospital has over 2,500 people on ART. Their main strategy for providing more comprehensive services is networking with other partners. These partners include MSF France, AIDS Information Centre (AIC), TASO and World Food Program (WFP), which provides food for patients. The Ministry of Health provides policy and infrastructural development. Arua local government provides supervision and World Health Organization (WHO) provides human resource. Availability of food has contributed to the high adherence levels.

Home visits are conducted for high-risk groups such as the bed ridden, children and those with adherence problems. Good community and family links established through the National Community of Women Living with HIV/AIDS (NACWOLA), Prevention of Mother to Child Transmission of HIV (PMTCT) support groups and others have helped to increase awareness in the community.
UGANDA CARES is an initiative of the Ministry of Health and AHF-Global Immunity designed to provide ARVs along with comprehensive clinical care for HIV positive people in rural districts of Uganda. The program is based on a framework of care, support and follow-up provided by the treatment centers, families and CBOs. Patients receive ongoing counseling plus education on treatment and medication adherence from the CBOs and Masaka Healthcare Center providers. Over 98% of patients maintained full adherence to ARV regimen by self-report and pill counts after 2 years of treatment.74

Many organizations use more than one strategy for better efficiency of ART programs.

### 3.6 Recommendations

Some of the interventions that are being used by other organizations could be adopted. These include:

**Counseling:**

- Disclosure of HIV sero-status to older children and adolescents before starting ART.
- Adherence agreement signed and renewed every 3 months.
- Each client should have treatment supporters.
- All caregivers get structured adherence counseling sessions before ART. There should not be long periods of time between adherence counseling sessions.
- The doctors should not prescribe ART unless the counselors have confirmed that he/she is satisfied with the caregiver's knowledge.
- Adherence should be assessed at each visit and those found to be non-adherent should be referred for more adherence counseling.
- Peer support from adolescent clubs. Clubs have helped clients disclose their sero-status and have also contributed to reducing stigma.
- Involving children actively in drug administration since this has been reported to help.
- Adolescents themselves are a valuable resource. Training adolescents as peer educators would be very helpful.
- Group counseling in waiting areas. This could be provided by the caregivers.
**IEC Materials**

- IEC Materials appropriate for children, adolescents and their caregivers should be designed and distributed to take home. Material to display on the walls of Health Units should also be designed.
- IEC Materials for providers displayed to remind them to always talk about adherence.
- Integrate fighting stigma and negative spiritual beliefs into all IEC interventions.
- Videos in waiting areas to continually reinforce the importance of adherence.

**Reminders**

- Alarm clocks can be used to indicate when to take medicine.
- Pill boxes can be used as reminders.
- ART cards or calendars should be designed and distributed.
CHAPTER 4
PREVENTION AMONG HIV POSITIVE ADOLESCENTS

The progression of HIV is slow in about 5% of vertically infected children who end up reaching adolescents without needing ART.\(^{11}\) A growing number of children with vertical transmission of HIV are reaching adolescence and adulthood with the help of ART.

Adolescence is the period between 10 and 19 years. During this stage, rapid changes in the physical, emotional cognitive and social characteristics take place. The physical and sexual maturity of adolescents does not necessarily match their emotional and cognitive maturity, and, therefore, undesirable effects of sex such as pregnancies and sexually transmitted diseases (STDs) are frequently encountered.\(^{11}\) Adolescence is a time of experimentation including engaging in risky sexual behaviors.

HIV-infected adolescents include long-term survivors of mother-to-child transmission, those infected through sexual abuse occurring in childhood and those who contracted the disease during adolescence through sexual relationships. This is a heterogeneous group including those who are in school, out of school, heads of household, orphans and adolescents under the care of adult guardians. Some know their HIV sero-status while others don’t. Some of them are in long term relationships.\(^{11}\)

Uganda policy guidelines do not address issues such as the sexuality of adolescents with HIV, psychosocial support, and disclosure procedures.\(^ {19}\)

4.1 Sexual behavior among people living with HIV
In a cross-sectional study of 1092 TASO Jinja clients, 58% of people living with HIV opted for abstinence. Of these, 51% decided to abstain permanently, 49% had temporary reasons for abstaining such as poor health, no current partner and no interest in sex. It was also found that 33% of HIV positive men and women were practicing pregnancy risk behaviors (no condoms or family planning).\(^ {75}\)
Table 4: Sexual behavior among people on ART (N = 992)

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>6 months</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Men</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexually active</td>
<td>47%</td>
<td>53%</td>
<td>0.2</td>
</tr>
<tr>
<td>Unprotected sex</td>
<td>21%</td>
<td>11%</td>
<td>0.004</td>
</tr>
<tr>
<td>Increased sexual desire</td>
<td>2%</td>
<td>38%</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexually active</td>
<td>21%</td>
<td>24%</td>
<td>0.18</td>
</tr>
<tr>
<td>Unprotected sex</td>
<td>9%</td>
<td>6%</td>
<td>0.01</td>
</tr>
<tr>
<td>Increased sexual desire</td>
<td>1%</td>
<td>14%</td>
<td>&lt; 0.0001</td>
</tr>
</tbody>
</table>

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This study shows that before ART, many are willing to abstain. While on ART, there was a statistically significant increase of both men and women who reported an increase in sexual desire. While lower than at baseline, 11% reported engaging in unprotected sex. No similar study has been done of adolescents but we can deduce that the same would happen to them while on ART.

**HIV positive adolescents are involved in sexual activities**

HIV positive adolescents who are healthy usually start engaging in intimate sexual relationships. Several health centres that provide services to adolescents living with HIV have reported that a number of pregnancies have occurred. Recently, a study assessing sexual risk reduction needs amongst adolescents living with HIV carried out in PIDC Mulago Hospital, many adolescents admitted engaging in sexual activity. Some of them even admitted having several sexual partners on self-administered questionnaires. The Uganda HIV/AIDS Sero-Behavioural Survey 2004/05 revealed that 64% of females and 45% of males have engaged in sex before the age of 18. It also found that 14% of males and females reported having sex before the age of 15. Since HIV positive adolescents are at risk of re-infection, getting STDs, pregnancies and infecting others, there is a need to design interventions to promote safer sexual behavior. Those who attempt to use condoms are not usually consistent. For instance, in Minnesota USA, among 36 youths living with HIV with mean age 21 years, 83%
reported inconsistent condom use.\textsuperscript{78} In focus group discussions at PIDC, many adolescents reported inconsistent condom use.\textsuperscript{76}

4.2 Factors influencing prevention of transmission of HIV among adolescents living with HIV.

Adolescents living with HIV are a potential source of HIV transmission. In many centres caring for adolescents living with HIV, they are taught the ABCs: “Abstinence from sex, ð Be faithful to one partner and ð Condom use.” Those who are attending Catholic-based organizations are mainly told to abstain and that condoms are not an option for them. Many of the adolescents are knowledgeable about the dangers of engaging in unprotected sexual activity, including the danger of re-infection. Some of them are very committed to prevention and some even profess that HIV will stop with them. However, others do not comply.

Below are some of the reasons that influence adolescents’ choices concerning sexual behaviour and HIV prevention.

Why some HIV+ Adolescents practice prevention behaviors.\textsuperscript{27-39,76,79}

1. Age: Younger adolescents below 16 years tend to believe in abstinence.
2. Counseling: Those who have had good counseling are likely to adhere to prevention.
3. Family support/ background: Those who have good family support are more likely practice prevention behaviors.
4. Religion. Those who are committed to their religions choose to abstain until marriage.
5. Fear of consequences like pregnancy, re-infection and STDS.
6. Some fear being removed from ART if found out by the medical team taking care of them. Some think that if they involve themselves they would be found out and penalized by stopping ART.
7. **Availability of condoms** in their Health Units. Some Units like Naguru Teenage Centre and PIDC have condoms available when adolescents ask for them.

8. Some believe that sex is strenuous exercise and since they are sick, they would become weak faster.

9. **Compassionate**: Some do not want other people to go through the same pain as they have out of compassion.

**Why some adolescents living with HIV do not practice prevention behaviors**

**Social reasons**

1. **Peer pressure**: One of the most powerful reasons, boys are made to feel that they have to prove their manhood by having sex.

2. **Fear of disclosing**. Their status to their partners because of stigma. They end up not using protection and thus passing on the virus.

3. **Desire to have children**. Older adolescents want to have children and think that having an HIV negative partner will lower the risk of having an infected baby. Some prefer an HIV negative partner because there is no risk of re-infection.

4. **Misconceptions** about sexual and reproductive health, such as the belief that only blood, not semen, carries the virus. They do not feel they are passing on the virus if there is no blood involved.

5. **Alcohol consumption** reduces inhibitions.

6. Adolescents watch movies like blue movies and they lose control of themselves.

7. **Ignorance**. Some adolescents do not know their own sero-status.

**Psychological**

1. Some think everyone has the virus but don’t know it. Therefore, they do not believe they are infecting anyone.

2. **They have lost hope of living long** and the future is uncertain. They ask “Abstain until when?” Some do not see the point in abstaining because people are usually told to abstain so that they do not get HIV. They already have HIV anyway and do not see the need to abstain.
3. **Some take HIV lightly.** An adolescent in Nsambya Hospital asked if they could donate their blood for transfusion. When asked what she thought about it, she said they should also donate blood because the person who gets it can start on ART.

**Economic**

1. **Financial benefits:** Many adolescents are orphans and have many unmet needs. Some indulge in sex to get money for school and other basic needs.
2. **Some have no access to condoms.** Some have no access to condoms even if they wanted to use them. Some centres teach only abstinence and offer no alternatives.

**Physiological/ Emotional**

1. **Adolescence itself.** Some adolescents know their HIV status and that they could transmit the virus. They do not think deeply about the consequences and tend to be selfish. They also like experimenting at that age.
2. **Increased sexual desires** as a result of being on ART.
3. **Anger and bitterness** about the disease especially with late disclosure. Some go on a rampage to spread HIV to as many people as possible.

**Recommended interventions to prevent transmission of HIV by adolescents living with HIV**

1) **Separate adolescent clinics**

HIV positive adolescents may not feel comfortable attending a children’s clinic. At the same time, they do not fit in with adults. An adolescent clinic is designed to meet the specific needs of adolescents. Mulago PIDC, Mild May and other centres have this type of clinic. Adolescent-friendly services should be provided to them.

2) **Adolescent clubs**

HIV positive adolescents may transmit the virus to their sexual partners. During club meetings, they learn about transmission risks and receive ongoing...
peer support. These adolescents need to be continually motivated to protect themselves and others from the unwanted consequences of sexual activity.

3) Counselling
   - Individual and Group counselling
     Counselling is centered around the ABCs. A sexual behavior plan should be developed with a counselor who can help reinforce the motivation to avoid transmitting the virus.
   - Peer counselling
     An organization running an HIV positive adolescent program in California, which is peer-based and peer run, found that when young people are brought together to help one another and to mentor their peers, living with HIV becomes more manageable.

4) Condoms should be made available if requested.

5) Encourage openness about sex. Adolescents only talk to their peers about sex and end up getting inaccurate information. Parents and caregivers need to be made aware of this.

6) Publish IEC materials and disseminate them as reminders.

7) Address the economic problems among adolescents where possible. This could be done by networking with concerned organizations.
Annex 1
People Interviewed

**Ministry of Health**
Dr Elizabeth Namaggala - coordinator ART program. AIDS Control Program

**Mulago Hospital, Department of Paediatrics**
Dr Philippa Musoke
Dr Eleanor Namusoke Post Graduate student (doing a study on Uptake of ART in children in Mulago Hospital)

**Mulago Hospital, PIDC**
Esther Kangave, Counsellor
Sr Mary, Nursing Officer

**Nsambya Hospital Home Care Department**
Dr Sandra Nabachwa, Medical Officer
Francis Ssozi, Counselor

**Mildmay Centre**
Margaret Awori, Nursing Officer
Dr. Kasirye Ivy, Paediatrician

**MU-JHU**
Dr Monica Etima, Paediatrician
Linda Barlow, Paediatrician

**Nagguru Teenage Centre**
Diana Baryayembwa, Nurse/counsellor. Assistant Coordinator of HIV/AIDS programs in Naguru Health Centre

**Reach Out Mbuya Parish HIV/AIDS Initiative**
Dr. Namisi Charles, Paediatrician

**MJAP**
Dr. David Okiror
Head of Clinical services, Mbarara

**PIDC Soroti**
Dr Elyanu Peter
Paediatrician

Annex 2
**Key Informant Interview Guide**

**Uptake**
What makes eligible children/adolescents and their caretakers accept to start on ART in your unit? What are the barriers to starting ART among those who are eligible to start?

**Adherence**
What promotes adherence to ART among children/adolescents in your unit? What barriers of adherence to ART do you experience? What are the adherence levels among children and adolescents in your unit? What interventions are you using to improve adherence?

**Prevention of HIV transmission**
In your experience, what makes HIV positive adolescents decide to transmit the virus to others? What makes them decide not to transmit to others?
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77. Uganda HIV/AIDS Sero- behavioural Survey 2004-05


79. Diana Baryayembwa, Nurse/counsellor. Assistant Coordinator of HIV/AIDS programs in Naguru Health Centre