Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study

Alice Nakiyemba, Dorothy A. Aurugai, Richard Kwasa, Thomas Oyabba.
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Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study
### Acronyms and abbreviations

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACP</td>
<td>AIDS Control Programme</td>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>ART</td>
<td>Antiretroviral therapy</td>
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<td>ARVs</td>
<td>Antiretrovirals</td>
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<td>EDM</td>
<td>Electronic drug monitoring</td>
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<tr>
<td>FGD</td>
<td>Focus group discussion</td>
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<tr>
<td>Global Fund</td>
<td>Global Fund to Fight AIDS, Tuberculosis and Malaria</td>
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<tr>
<td>HIV</td>
<td>Human Immune Deficiency Virus</td>
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<tr>
<td>JCRC</td>
<td>Joint Clinical Research Centre</td>
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<tr>
<td>JRRH</td>
<td>Jinja Regional Referral Hospital</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NTC</td>
<td>Nile Treatment Centre</td>
</tr>
<tr>
<td>PLWHIV</td>
<td>People living with HIV</td>
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<tr>
<td>pMTCT</td>
<td>Prevention of Mother-to-Child Transmission</td>
</tr>
<tr>
<td>SSI</td>
<td>Semi-structured interview</td>
</tr>
<tr>
<td>TASO</td>
<td>The AIDS Support Organisation</td>
</tr>
<tr>
<td>UAC</td>
<td>Uganda AIDS Commission</td>
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<tr>
<td>UNAIDS</td>
<td>United Nations Joint Programme on AIDS</td>
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<tr>
<td>UDVL</td>
<td>Undetectable viral load</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary counselling and testing for HIV</td>
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Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>ADHERENCE</td>
<td>Adherence to antiretroviral treatment means taking the medicines in the right quantities, at the right time and taking all the medicines as prescribed. Poor adherence rates (less than 95% adherence) can lead to treatment failure and to the emergence of drug-resistant strains of HIV.</td>
</tr>
<tr>
<td>ANTIRETROVIRALS (ARVs)</td>
<td>Medicines designed to suppress the replication of HIV and prevent the progression of AIDS.</td>
</tr>
<tr>
<td>ANTIRETROVIRAL THERAPY</td>
<td>HIV treatment involving the use of a triple combination of ARVs.</td>
</tr>
<tr>
<td>CD4 T-CELL</td>
<td>A type of immune system cell that is depleted during the progression of HIV infection. A blood test involving a CD4 cell count can be used to determine the stage of the disease and is one of the criteria that can be used for deciding when to start ART and to monitor response to therapy.</td>
</tr>
<tr>
<td>CLIENTS</td>
<td>People who use the AIDS treatment services available at the health facilities.</td>
</tr>
<tr>
<td>UNDETECTABLE VIRAL LOAD</td>
<td>When the virus is not detected in the blood after a laboratory test. Adam</td>
</tr>
<tr>
<td>VIRAL LOAD</td>
<td>Levels of virus found in the blood per 10 millilitres (mls).</td>
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AIDS is a serious public health problem in Uganda, together with malaria and tuberculosis. In the early 1990s, Uganda had the highest prevalence rate of HIV in the world. In response, the Government implemented strong preventive measures through a policy of openness, public information, communication and education, and national and international collaboration through a partnership involving both the private and public sectors. This approach succeeded in lowering the prevalence of HIV from over 30% in some sentinel sites to the current level of 7% (Ministry of Health, 2005). While these rates remain unacceptably high, Uganda offers one of the most hopeful scenarios in Africa.

Although antiretroviral (ARV) medicines do not provide a cure and are associated with other problems such as side-effects and drug resistance, they can increase the length and quality of life as well as the productivity of patients on antiretroviral therapy (ART). Antiretroviral regimens have improved survival rates and lowered the incidence of opportunistic infections in people with AIDS. Strict adherence to ART is crucial in order to maintain a low viral load and prevent the development of drug-resistant strains of the virus. However, some clients do not return for follow-up on schedule and the likely outcome for such patients is sub-optimal adherence to prescribed ARV regimens and possible treatment failure.

In Uganda, by October 2005, over 65 000 people had access to ART through accredited treatment centres (both public and private treatment centres). This exceeded the country’s target of 60 000 that was set for end-2005 (i.e. the WHO “3 by 5” target for Uganda which was designed to reach 50% of people estimated to be in need of treatment).

It is estimated that in Uganda each year about 50 000 additional AIDS patients require ART (UN Integrated Regional Information Networks, 2005). As the number of people able to benefit from ART increases, the problems associated with sub-optimal adherence to ARVs are also likely to increase.

The purpose of this study was to identify factors that facilitate or constrain adherence to ART among adults in Uganda and to suggest possible interventions at one public health facility and one private facility. It is hoped that these suggestions will also have relevance for other public and private facilities in Uganda. This pre-intervention study used a variety of methods, both quantitative and qualitative, and involved the use of focus group discussions (FGDs), ethnographic observation, key informant interviews, semi-structured interviews (SSIs), exit interviews and the use of pharmacy records. The total sample survey included 200 participants from the two study sites. The study, part of a multi-country study also carried out in Botswana and Tanzania, was conducted in
Busoga region at Jinja Regional Referral Hospital (a public facility) and at Nile Treatment Centre (a private facility) during May and June 2005. Ethical issues were considered throughout the study; approval and permission were sought from the research unit of the Ministry of Health of Uganda. All those who participated in the study did so voluntarily and gave their informed consent, and the confidentiality of the participants was assured.

The study found that some people reported problems with adherence while others had not experienced any. A number of key issues were identified. Costs, including user fees, transport and other overhead costs, had a very large impact on adherence, even for those who tried their best to be adherent. In addition, hunger was identified as a threat to the future success of ART in Uganda. The study found that many patients on ART cannot afford to feed themselves as their body metabolism improves and their appetite increases. Although stigma and discrimination are not a major problem overall in Uganda, they still exist at local levels and sometimes pose a problem for people living with HIV (PLWHIV). While social support was identified as a good motivator which can boost adherence, inadequate social support can have a negative impact on adherence.

Participants in the study were worried about dependency on medicines which they would have to take for life. Some participants also worried about treatment fatigue, including some who were found to be giving themselves 'drug holidays' when they felt like doing so. These kinds of lapses in adherence will affect viral suppression and lead to the emergence of drug-resistant strains of the virus. Meanwhile, as more patients become resistant to first-line drugs, necessitating a switch to second-line regimens, it will become impossible to scale up ART in Uganda if more expensive second-line regimens are needed for all. Another finding was that ARV users often doubted whether they were receiving the best treatment currently available, leading to inconsistent adherence to ART.

The report makes a number of recommendations on possible ways to improve adherence to ART in Uganda, including: instituting pill counting in all facilities providing ART; training more adherence counsellors to support ARV users; informing communities about the availability of ART and of the critical importance of adherence; the launch or scaling up of home-based care programmes; providing a 'food basket' during the initial six months on ART, when the increase in appetite is greatest; and encouraging spot checks for adherence.

The implementation of the recommendations of this study would focus mainly on instituting pill counting throughout the country through training health workers and ARV users about the importance of pill counting in promoting adherence. The impact of this intervention would be evaluated on the basis of how many users are able to count their pills, the keenness of health workers on the method, and efforts by health workers to keep records of pill counts.
An additional key intervention strategy emerging from this study would be educational interventions for health workers, ARV users and community members. This would include training in adherence counselling and educating ARV users and community members about the availability of ARVs and the importance of adherence. The methods used would include the use of participatory training in communities through outreach activities and the use of posters, leaflets and local FM radio programmes using mainly local languages. In each case, the approach would need to be tailored to the educational levels of the communities involved. The impact of these would be evaluated on the basis of how many people are reached, whether there is an impact on their knowledge, and whether the knowledge gained would be sustainable in the long term and lead to increased levels of adherence and general improvements in health.

The interventions suggested above have been selected because they are expected to be appropriate for the target group, are likely to have an impact on both the primary and secondary targets, are sustainable, and are likely to require resources for only a limited period of time. For example, it is easy to get access to the local media and this can be used to achieve the communication objectives in both the short and long term.

The study concludes that although Uganda has made a good start in scaling up ART, which is widely appreciated, it appears to be moving very quickly to scale up access to ARVs without addressing some of the critical issues relating to adherence. These include the need to address factors which have a negative impact on adherence such as hunger, the burden of transport and other overhead costs, and long waiting times at the facilities. Meanwhile efforts to promote adherence should include a focus on the importance of pill counting, efforts to sensitize the community to both the availability of ART and the importance of adherence, as well as the need to train adherence counsellors and have them available in all facilities.
Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study
1.1 Background
AIDS is a serious public health problem in Uganda, together with malaria and tuberculosis. Although measures by the Government and nongovernmental organizations to prevent HIV have helped lower the estimated prevalence from over 30% in the early 1990s to an estimated 7% in 2005, the current prevalence is still unacceptably high (Ministry of Health (MoH), 2005).

Emerging data suggest that among segments of Ugandan society there have been important behavioural changes. People report that they have reduced the number of sexual contacts, based on Government advice that people love carefully, love faithfully or stick to one sexual partner. However, this does not mean that Ugandans are no longer vulnerable to HIV infection.

By October 2005, over 65 000 people with AIDS in Uganda had access to ART – more than half of the people estimated to be in need of treatment. However, it is estimated that each year an additional 50 000 people will require access to ART (UN Integrated Regional Information Networks, 2005).

1.2 Research problem
In Uganda, there is growing concern about loss to follow-up and sub-optimal adherence to ART as significant barriers to care (Kityo et al., 2002). Although Uganda is described in most literature as a success story to emulate in sub-Saharan Africa (Green, 2003), there was a need to assess the quality of care and adherence among people receiving these life-extending medicines. Since the service was newly introduced, it was vital that studies be conducted to evaluate and assess levels of adherence among people on ART and factors affecting adherence in both private and public facilities. Such studies would help inform the MoH and other policy-makers in Uganda on ways of improving or maintaining adherence to ART as access to ARV medicines is scaled up nationwide.

1.3 Research objective
The main objective of the study was to identify factors that facilitate or constrain adherence to ART among adults in Uganda.
1.3.1 Specific objectives

(a) Determine patients’ knowledge, attitudes and perceptions on the use of ARVs.

(b) Establish patients’ information sources and the communication channels most acceptable to them.

(c) Determine beliefs and practices that affect adherence to ARVs.

(d) Establish the type of services delivered to patients receiving ARVs in selected sites in Uganda.

(e) Establish the kinds of social support given to patients taking ARVs.

(f) Gather information from ARV users, support groups and health workers on improving ARV adherence, which can be useful for planning an intervention.
Chapter 2: Background to the study

2.1 History of AIDS in Uganda

In the early 1990s, Uganda had the highest prevalence of HIV in the world. In response, the Government implemented strong preventive measures through a policy of openness, public information, communication and education, and national and international collaboration through a partnership involving the private and public sectors (Uganda AIDS Commission (UAC), 2001). This approach succeeded in reducing HIV prevalence from over 30% in some sentinel sites to the current level of 7% (MoH, 2005). Although HIV prevalence remains unacceptably high, Uganda offers one of the most hopeful scenarios in Africa and is seen as a model to emulate (Green, 2003).

In 1986, Uganda established the AIDS Control Programme (ACP) in the MoH. The UAC was established in 1992 to coordinate multisectoral approaches to HIV, of which one of the major initiatives was the introduction of interventions for the prevention of mother-to-child transmission (pMTCT) of HIV through the UNAIDS-brokered Accelerating Access Initiative. This initiative is a partnership involving UN agencies and a number of pharmaceutical manufacturers who have offered to supply products at reduced prices in resource-poor countries. Other Government strategies for prevention include an emphasis on the “ABC” strategy (Abstinence, Be faithful, Condom use) (UAC, 2001).

2.2 History of ARVs in Uganda

Since 1996 Uganda has pioneered the use of ART in sub-Saharan Africa. The ARVs were initially imported and distributed to those patients who could afford to buy them. Joint initiatives between international organizations such as UNAIDS and private organizations such as the Joint Clinical Research Centre (JCRC) helped to reduce the cost of ARVs, making them accessible to many more people. The importation of cheaper generic drugs into the country by private institutions such as the JCRC has caused pharmaceutical companies to significantly reduce the price of some patented ARVs (Mugyenyi, 2001).

As AIDS became the second highest cause of death in Uganda after malaria, the JCRC was established in 1991, with support from the Government, as the country’s first AIDS treatment research centre. However, since ART was very expensive only a few government officials and other high-income people could access the medicines. Even

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1 HIV sentinel sites are those where blood samples from clients of antenatal and sexually transmitted infection (STI) clinics are collected, using unlinked anonymous methods. The blood samples are collected on a quarterly basis for testing at the Uganda Virus Institute. Results from these sites are generalized to establish HIV prevalence in Uganda.
after securing permission to import generic ARVs, prices were still prohibitively high for the general population.

ARV medications became more widely available in Uganda in 2004 when the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and the US President’s Emergency Plan for AIDS Relief (PEPFAR) came in to support the provision of ART for people with AIDS. These two agencies provided unprecedented multilateral support and enabled the scaling up of access to ART (Gill et al., 2005).

In June 2004, the Government of Uganda implemented an ARV programme in one national referral hospital (Mulago), in all 11 regional referral hospitals and 11 district hospitals, providing ARVs to 2700 patients. At the time of this study, the Uganda Government, under the National Strategic Framework for Expansion of HIV/AIDS Care and Support – 2001/2-2006/7, was providing ARVs through 140 accredited sites. Most of these are district hospitals and health centre IVs (rural health units offering primary health care, usually staffed by one doctor, one clinical officer, three nurses and three midwives). By September 2005, 14 300 patients were accessing ARVs through these Government facilities (National Strategic Framework for Expansion of HIV/AIDS Care and Support – 2001/2-2006/7).

In addition to the Government facilities, some nongovernmental (private not-for-profit) organizations also provide ART. The foremost of these are: The AIDS Support Organisation (TASO) with 6600 patients; JCRC which provides ARVs to 18 000 people through its various sites across the country; and Mildmay International Centre with 2500 clients on ART. Others include Uganda Cares, Medical Access and the Uganda Business Coalition for HIV/AIDS.
Chapter 3: Literature review

The literature on ART reviewed in this chapter relates mainly to non-African countries, where most studies have been conducted so far. There is a great need for African studies of experience with ART in order to help fill this gap. However, where evidence is available from some sub-Saharan African countries, this is also included.

3.1 Importance of adherence to ART

Since 1996, an overwhelming amount of evidence from clinical trials has been published validating the use of ART for the treatment of AIDS. The biological and clinical goals of treatment have been defined as the suppression of viral replication, restoration of the immune response, a halt in the progression of disease, increased survival rates, reduced morbidity and a better quality of life. In countries where access to this level of care is available, AIDS-related mortality and morbidity have significantly declined (Pallela et al., 1998).

Maximum and sustainable suppression of HIV viral replication to below the level of detection is necessary to achieve these biological and clinical goals. To achieve success requires near-perfect adherence to combination ARV regimens. Adherence to an ARV treatment regimen involves taking all pills in the correctly prescribed doses, at the right time, and in the right way (Carter, 2005). It involves the following elements:

♦ Taking all the medicines which make up the ARV combination in the correct quantities.

♦ Taking the pills at the right times. Taking the medication at the wrong time can cause a rise in viral load and this may lead to the development of drug resistance.

♦ Ensuring that the medication is taken with or without food, according to the instructions. Some medicines need to be taken with food to ensure that the body absorbs them properly while others need to be taken on an empty stomach, a certain amount of time before or after eating. It can also be important that the patient eats the right kind of food; for example, the amount of fat eaten can make a difference to how well some drugs are absorbed.

♦ Checking for interactions with any other medication or drugs. This includes medicines that have been prescribed for the patient, or bought at a pharmacy, supermarket or health store, including complementary or alternative therapies. Some recreational and illegal drugs can have potentially dangerous interactions with ARVs.
Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study

The best response to ART is seen when adherence is 100%. Levels of adherence below 95% have been associated with poor suppression of HIV viral load and a lower increase in CD4 count (Carter, 2005).

♦ If a patient is taking once-daily treatment, 95% adherence means missing no more than one dose a month.
♦ If a patient is taking treatment twice a day, 95% adherence means missing no more than three doses a month.
♦ If a patient is taking treatment three times a day, 95% adherence means missing no more than four doses a month.

However, many people with AIDS do not manage to achieve such high levels of adherence. Failure to suppress viral replication completely inevitably leads to the selection of drug-resistant strains, limiting the effectiveness of therapy. Sub-optimal adherence to ART is the strongest predictor of failure to achieve viral suppression below the level of detection and most often underlies treatment failure. Evidence suggests that greater than 95% adherence may be necessary to adequately suppress viral replication, produce a durable response and halt disease progression (Paterson et al., 1999). This means that missing more than one dose of a regimen per week may be enough to cause treatment failure. In addition to leading to disease progression this may result in the development and transmission of drug-resistant viruses which cannot be treated with first-line (lower cost) medicines. This will require treatment with second- and/or third-line medicines, which are more expensive, associated with many side-effects and are complex to manage.

The challenge of adherence in the face of potential viral resistance, treatment failure, disease progression and the spread of drug-resistant virus to sexual partners is of great concern. Patients on long-term ART with undetectable levels of HIV still harbour replication-competent virus (Furtado et al., 1999). For this reason, with current medications, ART is a life-long process. While conscientious treatment adherence is difficult under any circumstances, the unforgiving nature of HIV replication, the complexity of the ART regimens, and the associated short- and long-term toxicity of the medicines all pose particularly difficult challenges for patients.

It should be recognized that adherence to ART is a critical issue, and it is clear from the literature that the factors that influence a patient’s ability to adhere are multiple and complex. A multitude of variables such as income, education and marital status have all been shown to affect adherence to ART, to differing degrees. In addition, some studies of ART in developing countries show that resistance is already circulating among patients starting their first "official" course of therapy (i.e. when somebody has acknowledged their HIV status, is willing to speak about it freely, and is seeking treatment from an accredited site for proper monitoring and follow-up) (Mugyenyi, 2002). Before ART was scaled up, fear of stigma led many people to seek ARVs clandestinely on the black market. As a result, people sometimes took medicines on the
basis of instructions from the person selling them on the black market and the use of ART was poorly monitored.

3.2 Measurement of adherence

Researchers who have tried to measure adherence have realized that there is no gold standard by which it can be quantified (Farmer, 1999). The many methods employed by the different studies include: pill counting, electronic drug monitoring (EDM), pharmacy refill records, biochemical markers and other self-reporting techniques such as visual analogue and recall methods. The relative accuracy of adherence measures ranks from physician assessment and self-assessment being the least accurate, to pill counting being intermediate, and EDM being the most accurate (Gill et al., 2005).

Electronic drug monitoring more accurately predicts undetectable viral load (UDVL) than self-report or pill count. Its main advantages are that it provides data on the timing of doses taken and permits monitoring over long periods. Since adherence can be known precisely, the link between adherence levels and UDVL can be established with a high degree of confidence. Arnsten et al (2001) noted that patients whose EDM data indicated high adherence (above 90%) were far more likely to achieve UDVL than patients self-reporting the same level of adherence. Other studies have reported similar results on the relationship between UDVL and EDM-rated adherence: Paterson et al (2000) observed UDVL in 80% of those with above 95% adherence, while in a trial conducted by Kirkland et al (2002) mean adherence was 94% with 85% of the patients achieving UDVL. However, no single measure is appropriate for all settings or outcomes. It has been found that the use of more than one measure of adherence allows the strengths of one method to compensate for the weakness of the other and to more accurately capture the information needed to determine adherence levels (Vitolins et al., 2000).

3.3 Factors affecting adherence to ART

3.3.1 Demographic and socioeconomic factors

Although the literature consistently demonstrates that demographic characteristics are not strong predictors of adherence, some correlates of adherence are described below together with socioeconomic factors.

3.3.2 Age

Age may influence adherence. Studies have found that, with the exception of the most elderly, adherence increases with age. In two studies associated with ART adherence, sub-optimal adherence showed a positive correlation with being younger (Jones et al., 1999).
### 3.3.3 Level of education

A lower level of general education and poorer literacy may impact negatively on some patients’ ability to adhere, while a higher level of education has a positive impact (Catz et al., 1999).

### 3.3.4 Financial constraints

Studies conducted in Africa reveal that the cost of medication is one of the most significant barriers to treatment adherence. In Botswana, Weiser et al. (2003) report adherence difficulties related to the financial demands of therapy and an inability to afford medicines for varying periods. They note that 70% of patients claimed that the cost of ARVs posed a problem for them, and 44% of patients believed that the cost impeded their ability to adhere to treatment. Similarly, over one-half of health care providers (56%) believed that financial problems often or always impeded adherence to ART. The extent to which financial difficulties played a key role in sub-optimal adherence is also reported in study findings in Uganda for patients receiving non-subsidized therapy (Byakika-Tusiime et al., 2003). Medications and clinic visits cost money and may stretch an already meagre budget. In resource-poor countries many people live below the poverty line and there is often no medical insurance or disability pension for people living with HIV (PLWHIV) (Katabira, 2002).

### 3.3.5 Social support

Living alone and a lack of support have been associated with an increase in sub-optimal adherence (Williams and Friedland, 1997), and social isolation is predictive of sub-optimal adherence. Not living alone, having a partner, social or family support, peer interaction, and better physical interactions and relationships are characteristics of patients who achieve optimal adherence (Motashari et al., 1998).

### 3.4 Impact of the drug regimen on adherence

Almost all of those who are currently on ART are on a regimen of three or more ARVs (Grierson et al., 2000). The likelihood of a patient's adherence to a given regimen declines with polypharmacy, the frequency of dosing, the frequency and severity of side-effects, and the complexity of the regimen (Williams and Friedland, 1997). Drug hypersensitivity is common in patients with HIV and regimen-associated toxicity is a common predictor of, and reason for sub-optimal adherence, which has been identified across many studies. Side-effects associated with each individual ARV medicine have been well documented and, while not universal for every patient, can be predicted. Although these side-effects usually subside after the first few weeks of therapy, for some people they persist. The anticipation and fear of side-effects also have an impact on adherence. Poor adherence has also been associated with patients’ desire to avoid embarrassing side-effects (like sweating) in certain situations such as on a date or at a job interview (Burgos et al., 1998).
Chapter 3: Literature review

For people on ART, a typical combination of medicines consists of three ARVs, plus other medication to prevent opportunistic infections. This can result in a high pill burden, taking medicine three times a day, dietary and dosing idiosyncrasies, large capsules or tablets, and specific storage instructions. The complexity of this regimen may have a significant impact on a patient’s ability to adhere. Additional medications taken for symptomatic relief (such as analgesics, cough remedies and other common treatments) in patients with advanced disease further add to the pill burden and toxicity. In Uganda, first-line treatment involves the use of the following combinations: lamivudine, stavudine, and nevirapine or efavirenz; and zidovudine, lamivudine, and nevirapine or efavirenz. Second-line medicines used are didanosine; lopinavir or ritonivir; and stavudine or zidovudine.

The generic fixed-dose combination Triomune, which is provided by the Global Fund/MoH consists of three ARVs (lamivudine, stavudine and nevirapine) in a single pill. However, PEPFAR provides these same ARVs as three separate pills. As a result, patients taking the separate pills have to take three times as many pills as those on Triomune, with significant implications for adherence. A study in Senegal reveals that a high pill burden is associated with poor adherence among patients who have to take a large number of ARV pills (Dansburg et al., 2003).

3.4.1 Effects of ARV regimen on eating patterns

Dietary restrictions add to the complexity of ART and often require adjustments in lifestyle. Patients can find their meal schedule compromised by ARVs that need to be taken on an empty stomach. This can be particularly difficult if workmates, family or friends are unaware of the patient’s HIV status (Grierson et al., 2000). Complicated regimens with rigid dosing intervals may also interrupt sleep. The physical aspects of a particular medication (for example, taste, size or formulation) may also affect a patient’s ability to adhere.

3.5 Treatment characteristics affecting adherence

3.5.1 Physical state and disease stage

Prior opportunistic infections, symptom severity and low CD4 counts are all predictors of adherence. One patient described the progression of disease as “creating a sense of urgency for treatment.” Another said: “As I first entered the study, I had a T-cell count below 10. I was at the hospital 20 some times...... The grim reaper was standing above me.” (Erlon and Mellors, 1999).

Seeing an improvement in the immunological and virological indices used to monitor ART (CD4 cell counts and HIV viral load) may be a powerful incentive to maintain adherence (Kaplin et al., 1999). However, caution should be exercised in emphasizing a patient’s improved laboratory indices without assurance that adherence is almost faultless. The value of these indices may improve in the short term, despite sporadic adherence and this may reinforce a patient’s level of sub-optimal adherence.
Lack of symptoms (despite laboratory evidence of the need for ART) may have an adverse effect on adherence (Jones, et al., 1999). Most patients with untreated HIV infection have a median AIDS-free time of 11 years, and ART is often begun when patients have laboratory evidence of disease progression but are essentially asymptomatic and feeling well. In Uganda, the policy is to initiate treatment in patients with documented HIV infection and:

- WHO Stage IV disease, irrespective of CD4 cell count; or
- Advanced WHO Stage III disease, including persistent or recurrent oral thrush and invasive bacterial infections, irrespective of CD4 cell count or total lymphocyte count; or
- With a CD4 cell count of 200/mm³ or less for patients in WHO Stage I, II or III; or
- Tuberculosis with a CD4 cell count of 200-350/mm³.

### 3.5.2 Depression and severe anxiety

Depression and severe anxiety are both predictors of sub-optimal adherence (Hirschorn L et al., 1998). At some time in the course of their illness, most people with HIV, experience a psychiatric disorder (Buhrich and Judd, 1997). Depression and/or anxiety are reported in up to 70% of AIDS patients with symptomatic disease. Adherent patients demonstrate significantly less depression or other psychiatric disturbance (Catz et al., 1999).

As the disease progresses, HIV may have an impact on the central nervous system and affect memory. AIDS-related dementia (AIDS Dementia Complex) is a common finding in patients with advanced disease and is characterized by abnormalities in cognitive and motor functions. Although studies describing adherence and AIDS Dementia Complex were not found, cognitive deficits have a negative impact on adherence to ART (Meisler et al., 1993). Even when cognition is unimpaired, it is difficult to remember when to take medications.

### 3.5.3 Beliefs and knowledge

A patient's beliefs about their illness and the effectiveness of medication are predictive of adherence. A good level of understanding about HIV by the patient, a belief that ART is effective and prolongs life, and recognition that poor adherence may result in viral resistance and treatment failure (Wenger et al., 1999) all impact favourably upon a patient’s ability to adhere. Conversely, a lack of interest in becoming knowledgeable about HIV and a belief that ART may in fact cause harm adversely affect adherence.
3.6 The clinic setting and service provision

The effect that the clinic setting has on adherence should not be underestimated. Clinic characteristics that impact on adherence include: proximity to the patient’s home or place of work, the expense of getting there, lengthy delays between appointments, clinic opening and closing times, long waiting times, lack of services such as child care, privacy, confidentiality, and unsympathetic or inconsiderate staff (Nemecheck and Tritle, 1998).

3.6.1 Difficulties with re-supply of medicines

Obtaining a prescription during a clinic visit is reported as an obstacle to adherence. In some developing countries, just over 50% of ARV users are given a prescription which lasts for three months, 40% receive a prescription for one month and 12% for two months (Burgos et al., 1998). In addition, some dispensing pharmacies will only dispense one month’s medication at a time (often on a single designated clinic day) and not all pharmacies are able to dispense ARVs. As a result of such difficulties in prescription procedures, some patients attend their local pharmacy for most prescription medicine and another separate pharmacy for their ARVs. This is a barrier to optimum adherence in that problems in obtaining or taking medicines have to wait until the designated clinic day, by which time patients may already be defaulting on their dose (Grierson et al., 2000).

3.7 Simplifying treatment regimes to improve adherence

Simple regimens and regimens that ‘fit into’ a patient’s lifestyle enhance adherence. Patients talk of “incorporating the regimen into their lives and of it becoming a way of life” (Erlon and Mellors, 1999). As a regimen increases in complexity, its inconvenience makes it difficult to incorporate into daily living. Much recent research is aimed at simplifying ART to twice daily or even once daily dosing (Grierson et al., 2000).

3.8 Conceptual framework

The conceptual framework (Figure 1) was developed during the proposal development process. It identifies service factors, patient factors and socioeconomic and cultural factors leading directly and indirectly to sub-optimal adherence to ARVs. This study aimed to investigate all of the identified factors to assess which were the most important in the Ugandan context and which were amenable to intervention.
Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study

Figure 1: Factors leading to sub-optimal adherence to ARVs

<table>
<thead>
<tr>
<th>SERVICE FACTORS</th>
<th>PATIENT FACTORS</th>
<th>SOCIOECONOMIC AND CULTURAL FACTORS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor support services</td>
<td>Lack of knowledge &amp; information</td>
<td>Perception of the causes and transmission of HIV</td>
</tr>
<tr>
<td>Long waiting time</td>
<td>Side-effects/ADRs</td>
<td>Age, sex, literacy level of patient</td>
</tr>
<tr>
<td>Inadequately trained health workers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment guidelines not available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor medicines supply system</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insufficient infrastructure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor quality of services provided</td>
<td>Beliefs and patients’ preference for traditional medicines and alternative therapy</td>
<td></td>
</tr>
<tr>
<td>Poor staff motivation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate counselling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate follow-up of patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low accessibility of services</td>
<td>Long distance to the health facility</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Poor social support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stigma</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of employer support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mobility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Occupation</td>
</tr>
</tbody>
</table>
Chapter 4: Methodology

4.1 Study design

The study investigated factors that facilitate or constrain adherence to ART for people on treatment at one public facility and one private facility in Uganda. The study used both quantitative and qualitative methods. These two approaches complemented each other. This research is part of a multi-country study carried out in Uganda, Tanzania and Botswana.

Data were collected at three different levels: individual, community and facility levels. The research team, comprising the principal investigator, three research associates and one data collector, collected data through interviews and observations, with the use of tape recorders. Data were collected during May and June 2005.

4.2 Study population

The study was conducted at two facilities providing ART in the Busoga region of Uganda. The study population consisted of patients aged 18 years or above who were receiving treatment at the study sites, and health workers and community members at the selected sites.

4.3 Inclusion and exclusion criteria

The study sites in Busoga region, a sub-region of Eastern Uganda were selected according to the following criteria:

1. The area has both a public and private facility supplying ARVS.
2. The sites were relatively research naïve.

Two facilities were chosen for the purpose of this research. One of these, the Jinja Regional Referral Hospital (JRRH), is accredited to offer ART through the Global Fund. At the time of this study, the services available at this facility included ART, voluntary counselling and testing (VCT) for HIV and treatment for opportunistic infections. The hospital collaborates with TASO, to which they refer their patients for continuing support.

The other facility, the Nile Treatment Centre (NTC), is a nongovernmental agency in Jinja. Since January 2004, NTC has been providing AIDS care and treatment for opportunistic infections for about 600 inpatients. In addition, NTC has outpatient facilities for AIDS treatment and VCT. However, it has no support programme for PLWHIV.
All patients attending the two facilities who were at least 18 years of age, on ART, and willing to participate in the study were included. Systematic sampling was used to select the final sample, based on the selection of every third patient visiting the clinic on the day of the fieldwork. Where a patient was not interested in being included in the study, the next patient was considered instead (except when selecting participants for the focus group discussions (FGDs) according to sex, when the next female or male patient was chosen, as appropriate).

### 4.4 Sample size and selection

A registry file from each facility’s reception was used as a sampling frame from which ARV users were selected for the study, using systematic sampling. This was done to avoid bias in the sample. A total of 200 people participated in the study. Of these, 130 were ARV users interviewed through the use of one of the following tools: FGD guide, adherence tool, semi-structured interview (SSI) guide, exit interview guide, key informant interview guide and observation guide. Fifty of the study participants were community members interviewed using the FGD guide and key informant interview guide. The remaining 20 participants were staff members interviewed using the FGD guide, SSIs and the pharmacy records tool.

The study included 10 FGDs, (five with ARV users, four with community groups who were categorized by sex, and one with health workers) which helped clarify issues raised by participants. Twenty exit interviews were undertaken with ARV users to establish the quality of care, procedures and conduct while at the facility. Another 20 ART users completed adherence measurement interviews to assess levels of adherence. Two pharmacy stock records were completed.

<table>
<thead>
<tr>
<th>Tool</th>
<th>Public Facility Jinja Regional Referral Hospital</th>
<th>NGO Facility Nile Treatment Centre</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>FGD* – staff</td>
<td>1x8</td>
<td>-</td>
<td>8</td>
</tr>
<tr>
<td>FGD - ARV users</td>
<td>3x10</td>
<td>2x10</td>
<td>50</td>
</tr>
<tr>
<td>FGD - community</td>
<td>2x10</td>
<td>2x10</td>
<td>40</td>
</tr>
<tr>
<td>SSI** - staff</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>SSI - ARV users</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Key informants</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Exit interviews</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Adherence tool</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Pharmacy records</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Observations</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>109</td>
<td>91</td>
<td>200</td>
</tr>
</tbody>
</table>

* Focus group discussion, ** Semi-structured interview
4.5 Data collector selection and training

After completing the study materials and having obtained permission from the MoH research unit and both of the facilities involved, the research team selected and trained data collectors. The selection criteria for data collectors involved having a multi-disciplinary team including one social scientist and one health worker with adequate experience in conducting health-related research. The research team was gender balanced, comprising two female and two male members. The data collectors were trained in the various methodologies of data collection and also on critical ethical issues. As part of the training, the data collectors participated in pre-testing the instruments with the guidance of the principal investigator.

4.6 Pilot testing

The research team conducted a pre-test of the instruments with two FGDs (one per facility) involving four AIDS patients (two per facility) and two service providers (one from each facility). The pre-test served to rectify and revise instruments as well as the research procedures in general. Changes made included omitting the pill count method since it is not used at the facilities.

4.7 Data collection

While many of the planned data collection methods were used, some modifications had to be made in response to a broadening focus and the need to adapt to the local culture. However, the main emphasis remained on using a mix of qualitative and quantitative methodologies to collect the information. This strategy was chosen because triangulation of methods would yield different types of information, and such a mixture would not only enable a cross-validation of data, but also minimize bias. Some tools provided both quantitative and qualitative data.

4.7.1 Quantitative data

Quantitative data were collected using a coding manual which had been developed earlier and answers were recorded using the manual. Information on demographics, timing of drug administration, and some default interruptions leading to non-adherence were entered in the manual. Additional quantitative data were collected using SSIs, observation (consultations), exit interviews, and pharmacy records. Information collected on demographics included age, religious background, educational level, knowledge, attitude, perception and experience in the use of ARVs.

4.7.2 Qualitative data

The bulk of the data for the study were based on qualitative methodologies because the key problem studied, sub-optimal adherence to ART, could best be captured in this way. The following qualitative methods were used: FGDs, observations, in-depth interviews, SSIs and exit interviews. FGDs were administered to the following study populations: four groups in the community categorized by sex, five groups of ARV users, and three groups of health workers who were not categorized according to type
since it was assumed that all health workers face similar challenges as they interact with PLWHIV and those on ART. Key informant interviews were conducted with local council and opinion leaders, cultural leaders, religious leaders, traditional healers and PLWHIV support groups. Semi-structured interviews were conducted with ARV users, service providers from both facilities, and ethnographic observations were conducted in both facilities with notes compiled on themes related to adherence. Other techniques used included: exit interviews with ARV users, checking pharmacy records with staff, and the use of the adherence tool with ARV users.

Focus group discussions

Focus group discussions, organized by age and sex, were conducted both with community members and with people on ART and enrolled at the selected sites. The aim was to identify difficulties that were being encountered by people on ART. The moderator had an FGD guide, used to keep the research focused on the main themes of the study. Ten FGDs were conducted (four with the community, five with ARV users and one with health workers). The location was considered when selecting participants for the FGDs (i.e. urban, peri-urban and rural setting). The FGDs were used to: determine community knowledge, beliefs, attitudes and behaviour in relation to the use of ARVs; investigate social support given to PLWHIV; and to get suggestions on ways of improving adherence to ARVs. Four of the 10 FGDs focused on getting the views of community leaders and other opinion leaders on the use of ARVs as well as the community’s perception of and solutions to the problem. At each facility the counsellor helped select participants for the discussion.

In-depth interviews

These involved the use of semi-structured, open-ended interview guides with flexible probing, ideal for investigating personal experiences of ART from the subjective perspective of each respondent. The exit interviews were helpful in assessing the quality of care. They served as a back-up to the FGD findings. Twenty key informant interviews were conducted, 10 at each facility. The aim was to establish: beliefs about HIV and ARVs; community participation in HIV-related activities; support systems in place for people on ARVs; and the problem of sub-optimal adherence.

Observation (consultation)

Ten observations, five at each facility, were conducted with a doctor, pharmacist, nurse, counsellor/social worker and receptionist. The aim was to explore aspects such as interactions between clients and service providers in health facilities, the availability of ARV stocks, stigma, and the length of time spent at the facility, privacy, and organizational procedures. Observational notes were taken and later used in data analysis. The notes were used to help fill in any gaps in the data obtained during FGDs or in-depth interviews, and to triangulate data.
4.8 Data analysis

Data checking and cleaning were done by the entire research team under the direction of the principal investigator. At the end of every field day, data were checked for completeness and consistency, and FGDs were transcribed. All relevant sources of data were considered to allow for triangulation. After transcribing and cleaning, data were converted to rich text format and entered into Nudist Nvivo, a package used for analysis of textual data. A code book was developed which was used for coding the text, after which searches related to adherence were run. Quantitative data were entered using the MS Access 2000 database, and descriptive and bivariate analyses were completed using SPSS version 11.01.

4.9 Evaluation of methods

The mix of methodologies was very useful in both urban and rural settings, and in the public and private facilities. It allowed for both flexibility and cross-validation of data. The FGDs were particularly informative. The study yielded a large amount of additional qualitative data. Wherever possible, this information has been used. The in-depth interviews, which were carried out in both rural and urban settings, yielded not only information on factors facilitating or constraining adherence but also more general information on trends in the use of ARVs in Uganda. Although originally the research team believed that, for ethical reasons, treatment observations may not be possible, the researchers were allowed by staff and patients to observe while consultations were going on.

4.10 Ethical considerations

Approval and permission for the study were requested from the MoH health research unit. Due care was taken to ensure that all those who agreed to participate in the study did so voluntarily, and gave their written informed consent. To this end, the researchers explained the aims and objectives of the study to all those involved and they were given an opportunity to ask for any clarification. Participants were informed that any information collected was to be kept confidential and that no names would appear on research documents, only identity (ID) numbers.
Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study
Chapter 5: Description of the study sites

5.1 Jinja Regional Referral Hospital

Jinja Regional Referral Hospital (JRRH) is located in the industrial town of Jinja, 80 km east of the capital city, Kampala, in the eastern region of Uganda. Established in the 1920s, it now serves as both a primary contact hospital and as a regional referral hospital for seven districts (Bugiri, Iganga, Jinja, Kaliro, Kamuli, Kayunga and Mayuge) with an overall population of 3.5 million people. The hospital has 500 beds and a staff of 360 instead of the 480 approved by the MoH.

In addition to the usual medical care programmes, the hospital is involved in regional training programmes for the Integrated Management of Childhood Illnesses (IMCI), pMTCT, VCT, and ART.

The hospital’s HIV clinic runs all HIV-related programmes including ART. The hospital has three programmes for ART access:

- Free MoH programme
- Free Treat Orphans programme (JCRC-coordinated)
- Cash and Carry programme for paying patients (JCRC-coordinated).

All participants in the study at this facility were chosen from the free MoH programme. This was because the other free programme, the Treat Orphans programme, caters only for children. The patients on the free programmes collect their refills on the weekly clinic day, while the patients in the Cash and Carry programme can come on any working day to collect their refills. The Cash and Carry programme is available for anyone who does not want the inconvenience of queuing for treatment and is able to pay for the medicines.

A total of 300 patients are currently enrolled on ART through these programmes (230 on the free MoH programme, 65 on the free Treat Orphans programme and five on the Cash and Carry programme). The hospital uses the MoH treatment policy and criteria and thus offers the recommended treatment regimens for ART.

The clinic attends to all HIV-related cases one day a week. During other days of the week, patients with HIV-related problems are identified and advised to attend the weekly HIV clinic.

On a typical weekly HIV clinic day, two rooms are converted to one reception and one consultation room (on other days the same rooms are used for other routine hospital activities). Two doctors and seven nurses are assigned to attend to the HIV patients,
including those on ART. Some of the nurses act as both receptionists and counsellors. About 80 patients attend the weekly clinic, of whom about 50 are already on ART. The clinic opens at 0830 hours and patients start arriving as early as 0700 hours. The patients report to reception, where their names and numbers are taken and their file retrieved from the filing cabinet. The patient’s file is taken to the counsellor, who calls in the patient from the shadu waiting area. After the counselling session, the patient has to queue again if they need to see the doctor. Otherwise the counsellor/nurse writes a refill prescription for the patient, who then takes the prescription to the pharmacy and sits outside waiting to be called in.

5.2 Nile Treatment Centre

The Nile Treatment Centre (NTC) which opened in January 2004 is a nongovernmental agency located on the Jinja to Kampala highway, 5 kilometres from Jinja. The location makes it less accessible than the public facility and allows for greater privacy. NTC is funded by PEPFAR and is under the aegis of the Uganda Business Coalition against HIV/AIDS, which has two other centres in Kampala.

NTC has 12 staff members: three doctors, two counsellors, two phlebotomists, one dispenser, one pharmacist, two nurses, and one medical assistant who offer services to PLWHIV. It is open five days a week and the staff work a half-day on Saturdays. The Centre receives 30 patients a day on average and the doctor patient ratio is 1:15, with two doctors on duty at any one time. Like JRRH, NTC follows the National Antiretroviral Treatment and Care Guidelines and offers similar regimens.

NTC opens at 0830 hours. On arrival patients are welcomed into comfortable seats and welcomed by a receptionist who then asks for the patient’s confidential number. The receptionist keys this number into the computer and checks whether the patient has come for their appointment on the correct day. She then refers the patient to the health workers they are scheduled to meet that day.

For all new patients, the importance of near-perfect adherence is emphasized by the adherence counsellor on the first visit. This counselling is carried out in groups or individually on request. Patients are then sent to the doctor, who assesses the patient’s condition and requests blood or other tests, including a repeat HIV test. Prior to testing, the phlebotomist checks that the client is aware of the critical importance of adherence. A similar check is carried out by the pharmacist before releasing medicines to any patient.

5.3 Study limitations

The study focused on patients who are accessing ART through only two facilities, one private and the other public. Furthermore, the quantitative data on adherence were limited and have not been presented in this report.
Chapter 5: Description of the study sites

Patients’ waiting area at Jinja Hospital.

The pharmacy window and waiting area, Nile Treatment Centre.

One of the three consulting rooms for doctors at the Nile Treatment Centre.
6.1 Demographic characteristics of ARV users

The study was conducted at Jinja Regional Referral Hospital (JRRH) and Nile Treatment Centre (NTC) both in Busoga region. A total of 200 respondents (109 from JRRH and 91 from NTC) participated in the study. Demographics were calculated for all the ARV users who participated in the study from adherence, exit and semi-structured interviews. Twenty six (37%) of the ARV users were male and 44 (63%) were female. Fifty-six per cent of the participants had been on ART for two years or less and the rest (44%) had been on ARVs for more than two years (Table 2).

Table 2: Length of time participants have been taking ARVs, by site

<table>
<thead>
<tr>
<th>Duration taking ARVs (months)</th>
<th>JRRH</th>
<th>NTC</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
<td>Number</td>
</tr>
<tr>
<td>&lt; 3 months</td>
<td>0</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>3 - 6</td>
<td>4</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>7 - 12</td>
<td>13</td>
<td>37</td>
<td>5</td>
</tr>
<tr>
<td>13 - 18</td>
<td>3</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>19 - 24</td>
<td>3</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>25 - 30</td>
<td>2</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>31 - 36</td>
<td>2</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>37 - 42</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>43+</td>
<td>8</td>
<td>23</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
<td>36</td>
</tr>
</tbody>
</table>

Of the 71 respondents interviewed, 40 (56%) had finished secondary education, 17 (24%) had completed primary education and 14 (20%) had completed tertiary education. The lowest educational level was seven years’ schooling (Table 3).

Table 3: Educational status of study participants

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Number who completed</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary</td>
<td>17</td>
<td>24</td>
</tr>
<tr>
<td>Secondary</td>
<td>40</td>
<td>56</td>
</tr>
<tr>
<td>Tertiary</td>
<td>14</td>
<td>20</td>
</tr>
<tr>
<td>Total</td>
<td>71</td>
<td>100</td>
</tr>
</tbody>
</table>

While ARVs were provided free of charge at the public facility (JRRH), most patients (97%) at the private facility (NTC) reported a monthly expenditure of Ushs 5000 (US$ 3.00) in the form of user fees. Overall, 82% (58) of the patients at the two facilities incurred additional costs associated with obtaining or taking ARVs. Only 18% (13) did not incur such additional costs (Table 4). There were no significant differences in the additional costs between the two facilities.
Table 4: Costs incurred by ARV users per month

<table>
<thead>
<tr>
<th>ARV costs in Uganda shillings*</th>
<th>JRRH N=35</th>
<th>NTC N=36</th>
<th>Total N=71</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Percent</td>
<td>Percent</td>
<td>Percent</td>
</tr>
<tr>
<td>&lt;5000</td>
<td>97</td>
<td>0</td>
<td>48</td>
</tr>
<tr>
<td>&gt;5000 &lt;10000</td>
<td>3</td>
<td>97</td>
<td>51</td>
</tr>
<tr>
<td>10000+</td>
<td>0</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other Costs</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>17</td>
<td>19</td>
</tr>
<tr>
<td>yes</td>
<td>83</td>
<td>81</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

* US$ 1.00 = approx. 1700 Uganda shillings (Ushs)

The average distance travelled to the health facility was 20 km, with the minimum distance being 1 km and the maximum distance travelled 184 km. Distances were considered because they had implications for costs, which in the long run may affect adherence (Table 5).

Table 5: Distance travelled to the health facility by ARV users on each visit

<table>
<thead>
<tr>
<th>Distance (km)</th>
<th>JRRH</th>
<th>NTC</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>Percent</td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td>1 - 10</td>
<td>24</td>
<td>69</td>
<td>18</td>
</tr>
<tr>
<td>11 - 20</td>
<td>3</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>21 - 30</td>
<td>2</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>31 - 40</td>
<td>4</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>41 - 50</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>51+</td>
<td>1</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
<td>36</td>
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</table>

A considerable number of patients on treatment had to travel at least 10 km to the clinic which may also be a significant factor in relation to adherence. This implies that some of them had to travel by taxi or hire a bicycle, entailing extra cost for the client, while those who came from far away had no alternative but to shoulder the additional transport costs.

6.2 Factors influencing adherence to ART

6.2.1 Costs

Although all the respondents were receiving medicines free of charge, additional costs incurred through travel to the facilities and user charges at the private facility have implications for adherence, as indicated in the following quotes:

“Sir, I came from very far. Over fifty kilometres from here. Before I come to the hospital I have to plan the money for journey fare to the clinic. In fact my extra drugs got finished yesterday.” (Male ARV user, JRRH)
"I have many people in the village. They are dying because they don’t have money to transport themselves to the hospital. You need to have this money monthly. Like me, from the village where I come from, getting up to this place costs Ushs 15 000 (US$8.50). To and fro is Ushs 30 000 (US$17), which is a lot of money…Right now only Lira Referral Hospital gives ARVs, and that is 130 km from our place (Kyoga). Very far!” (ART user)

“Some people have failed to report to the clinic on time because they failed to get transport to reach the clinic. Some people come from the islands, and they will tell you that they did not get money to cross the waters and they will tell you that is why they did not come on time. And when you are told that, you cannot do much but to hope that when the next visit comes, he can afford to come on time.” (Health worker)

The issue of cost was even worse at the private facility, where there is a user fee of Ushs 5000 (US$ 3.00) payable at each monthly visit in addition to transport costs. It is possible that these costs could contribute to sub-optimal adherence in the near future.

Another respondent receiving treatment at NTC complained about the user fee charged at the private facility, explaining how it had affected his budget. When asked whether he and his family had to give up anything to be able to pay for ART, he said:

“Yes it is a sacrifice. I am considering going to a government hospital which is completely free.” (Male, semi-structured interview, NTC)

Group discussions with men on ART also highlighted some cost-related factors that have made taking ARVs difficult and may in the long run affect adherence.

“I can no longer pay school fees for my children because I am burdened by extra costs of maintaining my health.” (Male ARV user, FGD)

Another man said:

“The compromising nature of the treatment is very difficult to adhere to. You have to sacrifice others for the sake of yourself.” (Male ARV user, FGD)

Travel costs were also identified by health workers as one reason why they could not follow up on some of their patients who failed to turn up to refill their drugs on time. The health workers were worried that travel costs for patients would affect adherence in the near future. One said:

“People coming from very far will always have an extra cost especially where barriers are included. For instance, some patients have to cross waters to come to the centre. You cannot keep blaming them for defaulting. It is really hard.” (Doctor, NTC)

Lack of money for travel seemed even worse for patients at the public facility which provides services for ARV users who are very poor. Some of the patients had already
Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study

started missing follow-up, mainly due to lack of transport to come to the centre. One health worker stated:

“It is really good the Government brought this medicine but many people who attend this clinic are poor. Sometimes they fail to come back to refill the drugs because they failed to raise just 1000 shillings (about 60 US cents) so they lose follow-up like that and eventually die.” (Nurse, JRRH)

6.2.2 Hunger

ARV medicines tend to increase the user’s appetite. Patients who were interviewed at both facilities reported having an insufficient supply of food to match their rising appetite as they began to feel better. Lack of food was seen to frustrate patients’ determination to take and adhere to ART since they had nothing to eat as their appetite improved. A doctor at the private facility told a story of one patient who declined ARVs, saying:

“Some patients have expressed lack of food as a reason for not wanting to swallow the life-saving drugs. In fact we have one woman who has declined her life-saving drugs because she does not have enough food to feed herself.” (Doctor, NTC)

Another said:

“I missed on Sunday because I could not find what to eat and yet I had to eat first before taking the tablets.” (Female ARV user, SSI)

This finding is echoed by a report in Uganda’s Daily Monitor newspaper (see below) about patients on ART at another organization, Uganda Cares, who were threatening to stop ART because they lacked food.

<table>
<thead>
<tr>
<th>Daily Monitor</th>
<th>October 19, 2005</th>
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<tbody>
<tr>
<td><strong>100 hungry people stop ARV Treatment</strong></td>
<td></td>
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<tr>
<td>This drug enhances one’s appetite and many AIDS patients on ARVs don’t have the capacity to get enough food to match their appetite. They have therefore decided to do away with the drugs. Unless the Government and the World Food Programme come in and help, a number of patients on ARV treatment in the district will soon die. (LC5 Chairman Rakai District, Mr Vincent Semakula)</td>
<td></td>
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</table>

Another ARV user said:

“I want to eat all the time and fear the hunger will eat into my stomach since I have ulcers already. Sometimes I have to wake up in the night to eat food. This is a difficult situation for me.” (Male ARV user, JRRH)
These findings apply to a majority of the clients in the study facilities, most of whom either do not have a regular income or whose income is low. This is one of the key factors that should be taken into account when designing future interventions.

Some patients at the public health facility are currently getting food support (soya flour, cooking oil, rice, sugar, maize flour) as a food basket provided by TASO-Jinja for registered members. This has acted as a motivator for those reluctant to join.

“When people hear our testimony and they see the way we look like they may get encouraged to join. They even start asking about how you improved.” (Male, community FGD)

6.2.3 Stigma and disclosure

In Uganda, HIV-related stigma and discrimination have been reduced through the Government’s committed efforts to demystify HIV and AIDS and through strong political support from the President. While this approach has been successful in reducing the level of stigma and discrimination at the national level, these problems persist at the local level (i.e. between individuals, in families and in communities). PLWHIV said that while it is not easy to disclose their status to community members they do not know well, it is very easy to do so among other PLWHIV. Focus group discussions with PLWHIV generated many comments about stigma, discrimination and disclosure:

“Disclosing status is not easy, especially to those who don’t know you. They talk about you in small groups and when you join them they pretend they don’t mind. Yet they have been discussing you. We are OK disclosing to fellow PLWHIV, who understand our problem.” (PLWHIV, female FGD)

People with AIDS may receive negative reactions from their community once they are known as ARV users. They feel they are being looked upon as useless. Though this definitely hurts them, it does not always affect their behaviour, as is clearly expressed by a female ARV user:

“It is my husband who died first. So, I also thought I was next. But when I started ARVs I got better and better. But some time in between I lost two of my relatives. When I lost my two brothers in between, what, however, weakened me was that when people heard the bad news they came out thinking it was me. Actually, on the day of the burial of my relatives, people kept pointing fingers at me wishing that I should have died instead of my relatives. People were saying I was of no use any more, while people who were of use are being buried. I felt so bad. I could not sleep that night but I could not stop taking my drugs. These did not or do not affect me to tell them the truth about my status and ART.” (Female, FGD)

Another ARV user reported having received similar negative comments from community members. Sometimes community members do not seem to understand why AIDS patients need to be treated instead of letting them die:
“People wonder why they bring me drugs instead of leaving me to die. So, as a result, people in my village look at me as nothing and I also do not value them.” (Female, ARV user)

As people with AIDS do not feel accepted and understood by community members, this may lead to them taking their ARVs secretly:

“I cannot take my drugs when people are seeing. I always go and hide and take them. Otherwise, people start whispering about you all the time.” (ARV user, female FGD)

For other ARV users, negative reactions from community members make them withdraw entirely from any contact with the community, and rely entirely on the support of family members, as one ARV user confided to us:

“At first I got so scared to tell people because of the stigma but ever since I started on ARVs they have began to wonder what has happened. In fact I hear some say why they don’t inject her and put her to rest otherwise she is going to finish everybody. Because of these I remained alone. So I remained with only a few of my family members who I cooperate with. The counsellor advised us to tell our family members about it. In fact these helped me so much when I told them I became free about my status and up to now I have a lot of courage and strength with the ARVs.” (ARV user, SSI)

While several ARV users complained about being stigmatized by community members, others experienced similar reactions from their own spouses. A number of ARV users reported that they were abandoned by their spouses because of their HIV status:

“My wife abandoned me the moment I disclosed my status to her. She left me with the children. And to make it worse, my own family said I deserved harsh treatment because I infected my wife with the deadly virus.” (Male, semi-structured interview)

The above reactions to people with AIDS are both discriminative and stigmatizing, both of which can lead to non-disclosure, and hence to non-adherence.

6.2.4 Social support

Participants in the FGDs stressed the importance of their children in providing treatment support:

“My children after seeing the state I was in and after getting ARVs, I called them and told them about my state. They got encouraged and as a result they buy me passion fruits and sugar because they know the drugs I am taking are so strong. I even wrote my file number in TASO on the wall and told them that just in case I am badly off they can go to TASO and get me help. My children know very well that my drug needs to drink enough and to eat on time. One thing that motivated me to tell them is because I
thought I could be so weak to collect my refill of the drugs (ARVs). They even know the name of my counsellor.” (ARV user, mother of five).

ARV users report that their children support them in different ways. As illustrated in the example above, children may help them to have food and meals at regular times. In addition, the children know where to go and whom to contact in case their mother feels too ill to collect her refill herself. Another participant said that he was so pleased he had told his children he is an ARV user, as his children remind him to take his drugs on time.

“I would fall sick so often. So my children kept asking me what I was suffering from. They kept advising me to go and find out and promised me all the help whatever the illness could be. So when I went there I was put on ARVs and told them immediately when I went back home. They have been very supportive in my adherence ever since. Because I told my children that I take the drug on time they endeavour to rush to any one who has a watch or radio and ask the time for me to take my drug. Telling them has helped me so much because of the comfortable relationship that exists between me and my children and neighbours.” (ARV user, FGD)

However, not all children are equally supportive, as shown in the following complaint:

“It is only my young children who give help. They cook for me and bring me whatever I send them. But my elder children abandoned me yet I told them about my status.” (Female ARV user, SSI)

Children are not the only source of support. ARV users also feel greatly supported by people from the TASO clinic. Meeting other ARV users who are equally or even worse affected than they are encouraged them to start and continue ART.

“One thing that strengthened me was the people I met at the TASO clinic. There were people who were so badly off. So I asked myself: if such people still have the hope of getting better then what about me. I saw those with bad rashes, others almost losing their eyes.” (Male, group discussion)

ARV users are very much aware of the important role they can play as role models in encouraging people to open up, disclose their HIV status and seek treatment.

“We - the people living with HIV - we get back and tell them about the medicine. And when people look at some of us and see how we were and how we look now, they get the guts and come to ask us what has helped to make us look better. They pretend to have a patient and ask us to help their patients as well.” (Female, FGD)

TASO committees, which visit communities to help sensitize people to the availability of ART, are considered to play a very important role in the education of the public.

“When my husband died, he had not been tested. However, when we shifted to this place most people who saw him knew what the cause was. My neighbours – after the
death of my husband - came out and encouraged and advised me to go and test early. So, when the different [TASO] people came to me, some were HIV-positive themselves, they told me about ART treatment in Jinja. They have continued to support me throughout. These TASO committees who come visiting homes have helped to teach and sensitize people about ART.” (Female, semi-structured interview)

Other people learn to overcome stigmatization and are encouraged to start using ARVs through hearing the testimonies of people who are already on ART:

“Drama groups like ours called ‘White’ helps people to come out from stigma.”

and

“(We have) our own networks like the Jinja Net for People Living with AIDS. Whenever we gather people are forced to ask why (we attend) the meeting and as a result we tell them about the medicine.” (Female ARV user)

Some clients also acknowledged support from relatives and friends, while emphasizing that most of the support would normally come from the immediate family.

“Yes, friends and extended family members may help but you are better off when your immediate family gets involved in your sickness. For me my brother brought me here and he has supported me throughout.” (Male ARV user)

**6.2.5 Drug regimen**

ARV users take at least a three-drug combination and they have to take these ARVs at different times, sometimes alongside other medicines for the treatment of opportunistic infections. Some participants complained about the demanding drug regimens and about the size of the individual pills they had to take (especially those on efavirenz). This often becomes a problem over time, especially when too many different medicines have to be taken at once. A 50-year-old male graduate underlined how the size and number of medicines can frustrate adherence even when people know that the treatment is essential to save their life:

“Strocrin (efavirenz) tablets are strenuous when you take them. It is as if they have stuck to the throat; they are big and sometimes this causes people to postpone or dodge taking it intentionally.” (Male ARV user)

Because health workers are aware of the potential side-effects of ARVs and understand that adherence is not always easy, they persist in emphasizing the importance of adherence:

“Sincerely, adherence is not a joke. Sometimes when people fail we feel it. But you have to keep pumping them about the importance of adherence. It can be worse when you have to combine ART with treatment for opportunistic infections.” (Doctor, NTC)
The number of medicines to be taken was felt to be even more problematic when these had to be combined with prophylaxis for opportunistic infections, such as tuberculosis, cryptococcal meningitis or malaria.

**6.2.6 Side-effects**

Some respondents experienced adverse effects that discouraged them from taking the medicines. In particular, people complained about nausea, skin rash and dizziness. Participants also reported having “weird” dreams that made them frightened to take the medicines.

“You fear to take the drug because of the weird dreams. You can see dead bodies and you are walking with them. You are in races struggling and many other struggles. It frustrates and soon you get fed up.” (ARV user, female FGD)

The physical and social impact of side-effects is also a concern for ARV users and can have an adverse effect on adherence. As one man said:

“Feeling a lot of heat in the body, especially after taking the drug, and excess sweating makes one embarrassed in public. So, you feel like postponing the drug to a later time when you are not relating with people.” (Male ARV user, JRRH)

Side-effects often appear with the initiation of ART but disappear over time. Those who were being treated at the private facility were better informed about side-effects as a result of ongoing adherence counselling. When asked whether they inform their clients about side-effects one health worker said:

“We tell them about the side-effects so that they know what is bound to happen but it so happens that women get more worried when you tell them about side-effects especially rash. The men don’t express fear but I think they also worry.” (Adherence counsellor, NTC)

ARV users expressed mixed feelings about the drugs: while people appreciated the fact that the medicines are effective, at the same time they feared the medicines. When asked whether they were happy about ART, one participant said:

“I only fear the side-effects of the life-saving drug. I fear it will kill us instead of the HIV.” (Female ARV user, FGD)

During FGDs some women expressed similar beliefs about ARVs. It was assumed that ART was designed to kill people, because most of people who had taken them had died, as shown by the quotes below:

“By the time I began the drug I heard of it killing people. So, when I began I knew I was taking this drug and it was going to kill me. And sincerely the time I began I collapsed three times. I could take the drug but without faith. I knew I was taking this drug and it was going to kill me so it was after some time that I got used. The third time I really
As a result of these fears, some people reported delaying taking their medications, even when they had the opportunity to do so:

“I also want to add that I only just joined TASO this year [2005] because I was always hearing that their main objective was, to finish these people [PLWHIV] off because they are getting sick and they are not getting better. So I never wanted to go to TASO. At first they were saying, why don’t you go to TASO? I said no way. I had that belief until 2005 and yet I had heard something about ARVs in 1994.”(Female, FGD)

6.2.7 Dependency and treatment fatigue

Participants knew that they would have to remain on ARVs for life. Some feared that the time would come when they would get tired of taking the medicines and would fail to achieve optimal adherence:

“I don’t think it is realistic to take drugs or treat a disease until you die. Treatment should be for a limited time and the disease is treated and you don’t have it any more. So, now we have nothing to do. It is like a failure.” (ARV user, female FGD)

Although most of the respondents had been on ARVs for less than two years, they had already started to complain about treatment fatigue. A female ARV user, a graduate in her late thirties, felt it was not worth living with AIDS when the medicine to cure her illness has still not been found. She felt it was a failure and useless to take the ARVs unless they could cure her. Therefore, on several occasions she decided to take a “drug holiday”, without consulting her doctor. This kind of personal decision without a physician’s expert advice has serious implications for adherence, and should be addressed when designing interventions or providing adherence counselling.

ARV users also questioned whether they were actually receiving the best treatment currently available:

“We hear rumours that there are some drugs which came out and cure. But they are still in America. So I just request the Government if it can at least bring those drugs so that we are helped and get cured.” (ARV user, female FGD)

6.2.8 Patients’ information sources and communication channels

TASO was the first AIDS support organization to be established in Uganda and it is not surprising to hear participants say that TASO was the first to offer ART. In fact, TASO initially provided support for PLWHIV through offering VCT and providing a fortnightly food basket to boost their nutritional needs. TASO was also the major source of information on HIV and AIDS in Uganda.
“The food support we get from TASO motivates people to ask how we come to get it and as a result we tell them about the medicine. We get soya, cooking oil, etc.” (Female ARV user, FGD)

In collaboration with JRRH, TASO set up a research programme on HIV and AIDS. Subsequently, information was decentralized to TASO centres throughout the country and the emphasis was placed on VCT, and on the prevention and treatment of opportunistic infections. Community seminars were held to inform people that ART was available and was going to be provided free of charge in Uganda.

As discussed in 6.2.4 above, people also learn about ART through testimony from people who are already on ART:

“We the people living with AIDS, we get back and tell them about the medicine.” (Male ARV user, FGD)

In Uganda the main source of information for the general public is the radio. Radio stations, especially local FM stations, broadcast programmes about HIV and AIDS.

6.2.9 Sustainability

In view of the fact that medicines have to be taken for life, participants were anxious to know what would happen if the free medicines were phased out. They wondered whether the Government would take on the responsibility for providing the drugs. This anxiety about the continuing availability of medicines could have an adverse affect on their future adherence.

“We are grateful to the Government for bringing medicine to the people, but we hear it is only for five years. Whenever I take these drugs, I am wondering whether in the next five years I will still have them free. Actually, I get disturbed by that.” (ARV user, male FGD)

6.2.10 Structural/health facility issues

Throughout the study, structural issues relating to access and service provision were observed. Both ARV users and health workers commented on the level of infrastructure established for service provision, especially at the public facility. The public facility was facing difficulties in that the scaling up of ART had occurred without any increase in personnel to cater for the increasing number of patients. For example, while the doctor-patient ratio was 1:15 a day at the private facility it was only 1:25 a day at the public facility. Health workers were visibly overworked and they struggled to attend to the large number of patients on a clinic day. As one health worker explained:

“You overwork like this without even a break because there are too many people all coming one day and yet you are very few.” (Health worker FGD, JRRH)
The public facility had no adherence counsellors and did not have adequate designated rooms/offices for counselling or for patients to discuss personal issues with the health workers. At times, the health workers have to try and locate a suitable room before they can start a counselling session or private discussion with a patient. In contrast, the private facility was very well organized, with comfortable seating, shorter waiting times than at the public facility, and everybody was attended to. There were two adherence counsellors, all patients were required to have adherence counselling, and spot checks on adherence were also carried out at various sections of the facility.

At the private facility, all recommended tests for AIDS management were done within the centre. In contrast, the public facility had to send out some of their samples for CD4 and viral load testing. This implied that people who were very sick had to wait at least two weeks before they could be put on therapy. This lack of up-to-date equipment was another limiting factor at the public facility.

6.2.11 Quality of care issues

Forty-eight ARV users seen during exit and semi-structured interviews were asked to comment on the quality of the services provided in the clinic in terms of: trusting the health workers; privacy during counselling; respect from the health workers; whether the health workers listened to the ARV users; and the general environment.

Out of 26 users in the public facility, 16 said the services offered were “good”, eight rated them as “fair”, and two felt they were “poor”. In contrast, all 20 participants interviewed at the private facility said the services provided were “very good”. With the exception of two users at the public facility, patients at both facilities felt the service providers listened to them. They said they trusted the health workers, and that they were allowed privacy in both facilities.

On the issue of waiting times, patients at the public facility waited five hours on average compared to only one hour at the private facility. Long waiting periods were acknowledged to be a demotivating factor for already sick patients, some of them very weak.

It was also observed that services at the private facility were quite fast and each patient had adequate time to discuss issues with the health care providers. However, patients at the public facility had to queue for a long time at the once-weekly HIV clinic and the time spent with the health worker was very limited. This may be the reason why some of the study participants reported inadequate counselling at the public facility. There were no long waits at the private facility, which had a very welcoming atmosphere and was open six days a week.
Chapter 7: Discussion, conclusions and recommendations

7.1 Discussion

Two hundred participants including key informants (such as religious leaders and traditional herbalists), health workers and ARV users were enrolled in this study and interviewed using one of the instruments designed to collect data. This research lays the groundwork for future quantitative studies as well as informing future interventions aimed at improving adherence.

This study was largely qualitative rather than quantitative. By directly quoting statements from the study participants, we present qualitative information that would otherwise be missed by the quantitative data. The qualitative data provide in-depth insight into people’s experiences with ARVs.

It is important to note that 56% of the ARV users who took part in the study had only been on ART for a year or less (Table 2). As a result, the issues which patients currently face in these settings may not be the same as those faced by people who have been on therapy for a longer time. It is likely that the results of follow-up studies would deviate from the current findings as people face treatment fatigue.

Both facilities involved in the study had first-line ART according to the Uganda national guidelines. Medicines to prevent opportunistic infections were available in the public facility but not at the private facility. The public facility used generic medicines while the private facility used patented medicines.

Scaling up ART in developing countries is not an easy task since there is a lack of uniformity in the way different organizations carry out this function. While many studies have indicated that Uganda’s overall achievement in its approach to HIV is a success story which could be emulated, there are many aspects of adherence which need further investigation. Although the Uganda National Treatment Guidelines (November 2003) are comprehensive, the issue of adherence is addressed on only one page. Uganda has increased access to free ART, especially in the MoH centres. However, some institutions, particularly the private facilities, still charge a user fee, while other larger institutions such as JCRC, which have championed the use of ART in the country, have paying patients as well as patients who are treated free of charge. Both Government and private ART facilities in Uganda lack organized procedures for carrying out pill counts. Meanwhile, many health workers argue that carrying out pill counts is an additional burden on their already heavy workload.
Costs

Costs such as user fees, transport and other overhead costs were reported to be a concern that may influence adherence. ARV clients frequently complained about the cost of transport and other treatment-related costs incurred as a result of being on ARVs. Some patients failed to report on time to get their refills because they were still trying to get together the money needed to pay for transport to the clinic. This is a serious problem that is likely to affect adherence, even for those who try to be adherent. It is also not cost-effective if people fail to achieve optimal adherence and rapidly develop resistance to the first-line drugs.

Hunger

Some nongovernmental organizations such as TASO provide food support (soya flour, cooking oil, rice, sugar, maize flour) to their ARV clients to help them meet the increased demand for food as their body metabolism improves. However, such food support schemes are not available in any of the private health facilities providing ART, and are rarely available at the public sector treatment centres. As a result, many ARV clients in need of food support are not receiving it. This threatens the future success of ART in Uganda. Hungry people are inclined to stop taking ARVs because they cannot afford to feed themselves as their body metabolism improves and the demand for food increases. ART programmes will continue to face serious challenges unless the Government addresses the problem of low-income subsistence farmers who do not have a reliable and regular supply of food. Food supplementation for low-income patients, as occurs in Botswana, should be considered in Uganda.

Stigma and discrimination

Patients who are stigmatized may avoid taking their medicines in the presence of other people. If this situation continues (for example, when patients have to attend large traditional funerals which usually last for several days), it is likely to have an impact on adherence. Although HIV-related discrimination and stigma have been (and are still) vigorously addressed in Uganda, many of the ARV clients interviewed at both facilities said stigma and discrimination were still a problem, especially at the micro-level. Some had experienced stigma even within their immediate families. At least two clients (a man and a woman) described being abandoned or divorced by their spouse because of their HIV status. In their accounts of receiving negative criticism and discrimination within their own communities, some patients reported taking their doses in private for fear that they would be discriminated against. However, ARV users felt they were free to disclose their status to fellow ARV users without any fear.

Social support and children

While social support was seen as motivating adherence, lack of such support can have a negative impact. Some ARV users acknowledged the support they received from their immediate families. In particular, some stressed the importance of support from their children to ensure they took their medicines at the right time. However, not all children are equally supportive. Some were reported to have abandoned their parents without any support. Many ARV users felt extremely well supported by TASO and
Chapter 7: Discussion, conclusions and recommendations

suggested that people who were afraid to take ARVs should be encouraged by hearing testimonies from other people who were on treatment.

**Drug regimen and side-effects**

For ART to achieve viral suppression, combined treatment with at least three ARVs is needed. Some patients experienced side-effects; others none at all. For those experiencing side-effects, the impact seemed so pronounced that they said it might affect their ability to adhere to the medicines, which have to be taken for life. Some participants said that the side-effects (e.g. dizziness or scratching due to a rash) were sometimes a nuisance when they were in public, especially when in an office. The study also revealed that some side-effects were feared due to the belief that ART was designed to kill people. As a result, some people were afraid to take the ARVs in case they died and others delayed starting ART even when they had the opportunity.

**Dependency and treatment fatigue**

From the literature it is clear that sub-optimal adherence is a widespread problem. Internationally, estimated rates of sub-optimal adherence to ART range from 10%-92% with an average of 50%, while reports of optimal adherence (usually defined as taking 80% or more of the prescribed regimen) range from 25%-85% (Bachiller, Arrando, Liceago, Iribarren and Olloquiegui, 1998). However, in patients on ART, 80%-90% adherence has been associated with failure to achieve complete viral suppression in 50% of patients (Paterson et al., 1999).

It was therefore not surprising to find participants who were worried about the long-term consequences of depending on medicines for the rest of their lives (treatment fatigue), and some who were found to be giving themselves a “drug holiday”. However, it will be impossible to scale up access to ART in Uganda if many patients become resistant to first-line ARVs and more expensive second-line medicines are needed instead. Another finding was that ARV users often doubted both whether they were receiving the best treatment currently available and whether the free treatment would remain available over time.

**Quality of care**

Despite the fact that this study was carried out at two facilities in the same region, there were remarkable differences between the two facilities in terms of organization, doctor-patient ratios, length of waiting times, and the kind of services that were available. The private facility was well organized and had strict treatment protocols. For instance, patients were given spot checks on adherence when they returned for follow-up. Patients were asked to say something they remembered about adherence issues and if a patient declined to participate the medicines would be withheld. The doctor-patient ratio of 1:15 a day at the private facility was much better than at the public facility, where it was 1:25 a day.

The public facility was usually crowded and slow in its procedures. Large numbers of people had to be attended to within the space of a few hours in the morning because the clinic closed at 1300 hours. The limited opening hours were a problem since many people travelled long distances to the clinic but might end up missing their
appointment, either because they arrived late after the clinic had closed or because not all the patients could be seen on one day. In the group discussions, some patients said they thought that the quality of counselling at the public facility was not as good as that provided by TASO. This is an important observation since counselling is an integral part of AIDS management. The nurses at the public facility had a dual role as counsellors and nurses. This double burden on the nurses, who are usually overworked and so cannot give quality counselling to their patients, could be the reason why some of the patients reported them as being rude.

The once-weekly clinic day is a limiting factor in offering quality care to ARV users. It is also possible that some people had to spend the night in nearby towns in order to arrive at the clinic early, thereby incurring additional costs.

### 7.2 Conclusions

The strength of this study lies in the qualitative data, in which we present views about adherence by reporting statements from the study participants themselves. This qualitative data supports the quantitative findings reported in other studies, such as the Tanzania and Botswana studies.

We anticipate that as ART is rolled out in Uganda, optimal adherence will be difficult to achieve. The costs involved in terms of transport, waiting times and other overhead costs are already impeding adherence and some patients are dropping out of treatment as a result.

Hunger is usually a major concern among those who have just started therapy. One organization reported that 100 patients were threatening to stop taking their ARVs because of increased food needs which they could not meet. This is a serious threat to adherence. Unless programmes are designed to provide food assistance in the first months of ART, optimal adherence is going to be difficult to achieve.

In this study, it was reported that the level of infrastructure for service provision and the quality of care provided were better at the private ART-providing facility than at the public facility. Structural problems at the public facility included overcrowding at the ART clinic, lack of training for health workers and the inability of the few that are trained to cope with the growing number of people on ART. Unless these kind of structural issues are addressed by the Government as ART is rolled out in Uganda, it will be difficult to ensure adherence. Other challenges that will also have to be addressed include the lack of social support, stigma and discrimination, and treatment fatigue.

Uganda has made a good start in scaling up ART and this is widely appreciated. However, Uganda appears to be moving very quickly to scale up access to ARVs without addressing critical issues such as the problem of additional costs, hunger and excessive time spent at the facilities, as well as the need for pill counting, training of adherence counsellors, community sensitization and home-based care services.
Efforts to minimize constraints and improve adherence levels will require the efforts of the community, health workers and patients as well as Government commitment to resolve key structural problems.

7.3 Recommendations

The following recommendations are made on the basis of the pre-intervention study. However, we recognize that these have not been subject to intervention testing or evaluation. We therefore propose that such studies should be undertaken as a matter of urgency.

♦ **Institute pill counting across the country:** Only a very small number of ART facilities in Uganda have adopted the use of pill counting, which is a major shortcoming. Pill counting will help track the use of ARVs as well as help in calculating adherence rates throughout the country. However, this will require an increase in financial and human resources for both Government and private facilities providing ARVs, in order to institute and operate a pill counting system.

♦ **Train more adherence counsellors:** In order to support ARV users, more staff should be trained specifically in counselling. This would help ensure that nurses do not have to double up as counsellors and enable adherence counselling to be scaled up countrywide. This would help in delivering quality adherence counselling and may also contribute to efforts to reduce the long waiting times.

♦ **Sensitize the community** on the availability of treatment and the importance of adherence. This would help to educate and inform caregivers who work as treatment buddies. Community sensitization could also help in reducing discrimination, thereby encouraging more people to disclose their HIV status as stigma is reduced.

♦ **Increase provision of home-based care:** As the disease progresses, some people may not be able to go to the clinic to get a medicines refill. Such people should be attended to in the home for both refills and counselling services, which the entire family can benefit from. Therefore, facilities providing ART should initiate or scale up (as appropriate) home-based care programmes.

♦ **Provide food baskets:** Food baskets should be provided at the start of ART to counter the excessive hunger experienced by ARV users.

While we have not yet developed intervention studies to evaluate these recommendations, we would welcome the opportunity to do so. We set out below some thoughts on possible intervention and evaluation studies.

The implementation of these recommendations would mainly focus on instituting pill counting through training health workers and ARV users about the importance of pill counting in relation to adherence. This would be done by counting the number of dosage units that the patient has not taken by the scheduled appointment or clinic visit.
The impact of this intervention would be evaluated on the basis of how accurately pill counts are undertaken, the use of pill count data to guide adherence counselling and the keenness of health workers to use the method.

Health workers in all facilities that provide ART would be trained in adherence counselling through formal training seminars. In addition to evaluating changes in the level of knowledge of health workers, adherence measurements through pill counts would be used to assess the impact of this training.

Meanwhile, ARV users and other community members would be sensitized about the availability of ARVs and the importance of adherence. The methods involved would include the use of participatory training in communities through outreach programmes and local FM radio programmes using mainly local languages, posters and leaflets tailored to the educational levels of the communities involved. Accessibility to the local media is easy and could achieve communication objectives in both the short and long term. The impact of these approaches would be evaluated on the basis of how many people are reached, and if there is an impact on the level of their knowledge. It would also be evaluated in the long term on the basis of whether the knowledge gained was sustainable and led to increased levels of adherence.
References


