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Sustaining Adherence to Antiretroviral Therapy among HIV/AIDS Patients in Uganda

Achilles Ssewaya
Sustaining Adherence to Antiretroviral Therapy among HIV/AIDS Patients in Uganda

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor

aan de Universiteit van Amsterdam

op gezag van de Rector Magnificus

prof. dr. D.C. van den Boom

ten overstaan van een door het college voor promoties

ingestelde commissie,

in het openbaar te verdedigen in de Agnietenkapel

op woensdag 14 december 2011, te 16.00 uur

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Achilles Ssewaya

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# Acronyms and Abbreviations

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ACP</td>
<td>AIDS Control Programme</td>
</tr>
<tr>
<td>AHSS</td>
<td>Assessment of Healthcare Services and Settings</td>
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<td>AMS</td>
<td>Adherence Monitoring Study</td>
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<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>BMHS</td>
<td>Behavioural Model of Health Services</td>
</tr>
<tr>
<td>CA</td>
<td>Content Analysis</td>
</tr>
<tr>
<td>CATTS</td>
<td>Community ARV-TB Treatment Supporters</td>
</tr>
<tr>
<td>CDC</td>
<td>Centre for Disease Control</td>
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<tr>
<td>CHW</td>
<td>Community Health Workers</td>
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<tr>
<td>DAI</td>
<td>Drug Access Initiative for ARVs</td>
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<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>GOU</td>
<td>Government of Uganda</td>
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<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
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<tr>
<td>HBCP</td>
<td>Home-Based Care Programme</td>
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<tr>
<td>HBM</td>
<td>Health Belief Model</td>
</tr>
<tr>
<td>HCM</td>
<td>Health Compliance Model</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>Human Immuno-deficiency Virus/Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>HSM</td>
<td>Healthcare System Model</td>
</tr>
<tr>
<td>IDUs</td>
<td>Intravenous Drug Users</td>
</tr>
<tr>
<td>IEC</td>
<td>Information, Education, and Communication</td>
</tr>
<tr>
<td>IOM</td>
<td>Institute of Medicine</td>
</tr>
<tr>
<td>JCRC</td>
<td>Joint Clinical Research Centre</td>
</tr>
<tr>
<td>KHAA</td>
<td>Kayunga Hospital ART Association</td>
</tr>
<tr>
<td>LF</td>
<td>Livelihood Framework</td>
</tr>
<tr>
<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
</tr>
<tr>
<td>MIS</td>
<td>Management Information System</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health (Uganda)</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
</tr>
<tr>
<td>MUWRP</td>
<td>Makerere University Walter Reed Project</td>
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<tr>
<td>NCST</td>
<td>National Council of Science and Technology</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>NRM</td>
<td>National Resistance Movement (Government)</td>
</tr>
<tr>
<td>NSF</td>
<td>National Strategic Framework for HIV/AIDS (Uganda)</td>
</tr>
<tr>
<td>NYSDHAI</td>
<td>New York State Department of Health AIDS Institute</td>
</tr>
<tr>
<td>OI</td>
<td>Opportunistic Infections</td>
</tr>
<tr>
<td>OVC</td>
<td>Orphans and Vulnerable Children</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living with HIV/AIDS</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother-To-Child Transmission</td>
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<tr>
<td>RCT</td>
<td>Routine Counselling and Testing</td>
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<tr>
<td>ROM</td>
<td>Reach Out Mbuya</td>
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<tr>
<td>RPF</td>
<td>Rural-based Public Facility (Kayunga Hospital)</td>
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<td>RPS</td>
<td>Resource-Poor Settings</td>
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<td>SAT</td>
<td>Social Action Theory</td>
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<td>SE</td>
<td>Drug Side Effects</td>
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<td>SLF</td>
<td>Sustainable Livelihoods Framework</td>
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<tr>
<td>TASO</td>
<td>The AIDS Support Organisation</td>
</tr>
<tr>
<td>TIA</td>
<td>Treatment Initiation Appointment</td>
</tr>
<tr>
<td>TOT</td>
<td>Trainer of Trainers</td>
</tr>
<tr>
<td>TS</td>
<td>Treatment Supporter</td>
</tr>
<tr>
<td>UAC</td>
<td>Uganda AIDS Commission</td>
</tr>
<tr>
<td>UHSBS</td>
<td>Uganda HIV/AIDS Sero-Behavioural Survey</td>
</tr>
<tr>
<td>UMF</td>
<td>Urban-based Mission Facility (Mbuya Mission Facility)</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>United Nations AIDS Programme</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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Map of Uganda and Study Sites

This map shows the districts of Uganda as they were when the Uganda HIV/AIDS Sero-Behavioural Survey 2004-05 was designed. The regions shown on the map were created for survey analysis purposes.
1

Introduction

1.1 Uganda’s HIV/AIDS Experience

For almost three decades, Uganda has been struggling to prevent and deal with the HIV/AIDS epidemic. The first case of the ‘slim disease’, as it is known in Uganda, was identified in 1982 in Rakai district, on the shores of Lake Victoria in South Western Uganda (Kaleeba et al. 1997; Aspaas et al. 1999; Okware et al. 2001). It was popularly believed that the disease was caused by witchcraft. Since then, Uganda’s epidemic has progressed through three distinct phases. The first phase was characterised by a rapid increase in HIV prevalence, peaking in 1992 with antenatal HIV prevalence ranging between 25%-30% in major urban areas. The second phase was characterised by declining prevalence and incidence during 1992-2000, particularly in urban areas. After a series of interventions over a quarter of a century, the third phase of Uganda’s HIV epidemic has been characterised by a stabilisation of HIV prevalence (UAC 2007). Results from the Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS), based on 56 districts and completed in 2006, indicated that HIV/AIDS prevalence was 6.4% among adults, with prevalence among women higher (8%) than among men (5%), (MOH 2006). In total, approximately one million people were infected nationwide. However, evidence also shows that the number of HIV positive individuals is set to increase from 1.1 million in 2006 to 1.3 million in 2012. If this trend is not reversed, the number of new cases (incidence), the number of people living with HIV and AIDS (PLWHA) needing ART (prevalence), and the number of AIDS related deaths will increase, (UAC 2007).

While experts in the developed world were reluctant to introduce ART in the South, Uganda, together with Cote D’Ivoire, Senegal, Chile, and Vietnam, was part of the first phase of Drug Access Initiatives (DAI) launched by the UNAIDS Secretariat in 1997 (Katzenstein et al. 2003). In these countries, the explicit goal of the DAI was to set up the necessary infrastructure and systems in order to increase access to HIV related drugs on a small but sustainable basis (ibid). In Uganda, DAI started in November 1997 and became operational in June 1998, implemented in partnership with UNAIDS, the Ministry of Health (MOH), and several pharmaceutical companies (Ochora Odongo 2001).
Based on Ochora’s work, available evidence suggests that Uganda developed its DAI programme carefully. First, the formulation of the institutional framework for implementation adopted an inclusionary approach. For instance, the National Advisory Board that was intended to oversee implementation incorporated the MOH and other Ministries (e.g. economic planning, gender), social scientists, physicians, and PLWHA representatives. Other actors included Medical Access Uganda Ltd, a non-profit organisation mandated to procure and distribute drugs, and a Communication Consultant to coordinate communication at all levels and the production of credible information about the programme. Second, the selection and accreditation of treatment centres involved the assessment of healthcare capacity using elaborate criteria, including clinical expertise, laboratories, psychosocial support, drug storage, and adequate management of opportunistic infections. Based on these criteria, five urban-based centres with the highest level of healthcare were initially accredited, with the composition reflecting a mix of public, missionary, and private facilities. Upcountry treatment centres were assessed during the expansion phase, and the private sector was included later. Third, the government put emphasis on capacity building, including: the training of health providers; policy development in liaison with stakeholders (NGOs, PLWHA, etc); development of monitoring tools (patient assessment forms and data processing); information, education and communication (IEC), and advocacy for the drug access initiative for ARVs (with limited publicity of new drugs); community mobilisation and treatment literacy (focusing on emerging treatment options and centres); and forging collaboration and partnership between private-private and public-private practitioners.

In spite of certain constraints (refer to Ochora Odongo 2001 for Uganda’s experience, and Katzenstein et al. 2003 for other participating countries’ experiences), the key message is that once financial, infrastructural, and institutional barriers were overcome, it was feasible to introduce HIV related treatment and achieve near-optimal adherence to ART in resource-poor settings. As a result of this successful antiretroviral pilot programme, subsequent advocacy at the international level culminated in the establishment of a multilateral Global Fund to Fight AIDS, Tuberculosis, and Malaria at the beginning of 2002 (Katzenstein et al. 2003). By October 2005, at the commencement of this study, the Ugandan government had accredited 170 healthcare

1 These Accredited Sites were: JCRC, Nsambya Hospital, The Mildmay Centre, Mulago Hospital, and Mengo Hospital.
2 Lacor Hospital (North), Mbarara Hospital (West), Jinja Hospital (near East), and Mbale (further North East).
centres (both private and public) across the country to distribute antiretroviral
treatment (ART).

Immediately after the DAI experience, the Government of Uganda formulated the
‘Antiretroviral Treatment Policy for Uganda’ (2003). Similarly, the ART Policy
was an outcome of a collaborative process spearheaded by the MOH through the
AIDS Control Programme (ACP), under the mantle of the ART Task Force and
five cross-disciplinary sub-committees and members from the private sector, civil
society, and public sector. The purpose of the Uganda Antiretroviral Treatment Policy
was/is to ‘provide [a] consistent framework for implementers for use in expanding and
providing ART services to eligible adults and children’. According to the ART Policy,
the set of services that constitute ART are: 1) counselling (at multiple times in the
chronology); 2) testing (at multiple times in the chronology); 3) clinical diagnosis
and prescriptions; 4) treatment with ARVs; 5) treatment of OIs; and 6) food
supplementation, if necessary, and community-based alternatives to institutional
care and support. In order to operationalise the community-based care, in 2004 the
Care and Support Unit in the MOH formulated the comprehensive ‘HIV Care: Home
Based Care Trainers Manual for Health Workers’. The overall goal of this manual was
to improve the capacity for medical care and psychosocial support to PLWHA in a
community setting.

It is necessary to elaborate the key policy aspects that have a bearing on this
thesis, especially on the interpretation of the empirical Chapters. First, in terms of
counselling, the ART policy emphasised focus on both HIV prevention and ART.
This was prescribed on the premise that ART services would attract more people to
Voluntary Counselling and Testing (VCT) centres. Furthermore, while VCT was
intended to serve as an entry point for enrolling for ART, it was important that the
availability of ART should not result in risky sexual behaviour. In the case of ART
counselling, it was supposed in the first instance to emphasise the benefits and
limitations of ART. Second, after determining clinical eligibility, the patient’s social
and family set-up, and the likelihood of compliance with life-long treatment, was
supposed to be determined. Third, the policy noted that community participation
is a crucial component in improving the likelihood of treatment success (MOH
2003:12). The family and community support alluded to in the ART policy was (re-)
emphasised in the subsequent National Strategic Framework (NSF) as an ‘expansion
of HIV/AIDS care and support’.

The implementation of the HIV/AIDS programme in Uganda is guided by a policy
framework. All the HIV/AIDS policies and plans are identified and implemented
under the HIV/AIDS NSF. The first HIV/AIDS NSF was formulated in 1997, updated for 2000/1-2005/6, and revised again for 2006/7-2011/12. The NSF is usually updated (every after five years) in response to the prevailing epidemic trends as a result of intervention on the ground. For instance, the Uganda HIV and AIDS National Strategic Framework Plan 2006/7-2012, which came into effect after the completion of my fieldwork, revealed that while 42% of the HIV population benefited from ART by 2005, the number in need of ART continues to grow each year; 129,000 were in need of ART in 2007, but this was projected to rise to 238,000 in 2012, far outstripping the capacity of the system to respond and the finances available. To that effect, a critical emphasis of the newly revised NSF is therefore to integrate a continuum of universal access for: 1) prevention; 2) clinical care and treatment; and 3) social support (UAC 2007). The key message is that prevention related interventions would avert infection and rising future expenditure on treatment. Specifically, the clinical care and treatment component is intended to result in an increase in the number of people receiving ART, averting early death, and reducing the orphan burden. The different Uganda's HIV/AIDS policies are continuously harmonised. The care and treatment component reiterates the key components under the ART Policy for Uganda (2003), emphasising scaling up of the three aforementioned components under the ART regime. Finally, providing much improved social support is still envisaged as one way of reducing the socio-economic impacts of the epidemic, especially among orphans and vulnerable children (OVCs), PLWHAs, and disadvantaged groups.

This situation in Uganda gives rise to four major challenges to the country’s implementation of its ART programme: 1) its capacity to economically sustain the ART programme (not discussed here); 2) the health system’s capacity in terms of planning and infrastructure (space, laboratories, logistics, Monitoring and Evaluation [M&E]) to ensure quality, efficiency, and effectiveness in the delivery of clinical and medical care; 3) the human resource capacity (technical staff and counsellors); and 4) the broadening of access and adherence to life-long ART to avoid potential resistant strains, and stimulating preventive behaviour (MOH 2003; UAC 2007). In other words, the access related constraints that previously undermined sustained implementation of universal Primary Healthcare (PHC) still threatened the implementation of ART and its integral component of quality of care. ‘Access’ requires awareness (that one’s condition needs medical intervention); availability of services (time and distance); acceptability (trust and willingness to use such services), and affordability (income and time), (Wani 1982 in Fosu.G 1989).
1.2  Adherence Discourse

The theoretical argument of this thesis emerged from comparing academic literature on adherence to antiretroviral treatment in the developed world to that on adherence in resource-poor settings (including Uganda). As Uganda’s policy direction has been described, this section contrasts empirical literature on adherence for the two settings alluded to here.

1.2.1  Compliance versus Adherence

Antiretroviral therapy, which consists of ARV drugs that must be taken at a scheduled time every day for the rest of someone’s life, is currently the main type of treatment for HIV/AIDS. For the treatment to be effective for an extended duration, the patient has to take more than one ARV drug; this combination of drugs is normally referred to as ‘triple therapy’, and the term HAART (highly active antiretroviral therapy) describes a combination of three or more anti-HIV drugs, each acting against the HIV infection itself by slowing down the replication of the virus in the body. The clinical outcome of taking ART is a decrease in viral load to undetectable levels and the rebuilding of the immune system, reflected in an increase in CD4 lymphocyte level and decreased viral load (Chesney et al. 2000; Fogarty et al. 2002; Guarinieri et al. 2002; WHO site 2002). ART reduces the rate of mortality and morbidity, prolongs life, improves quality of life, and restores a person’s productivity. It also transforms the perception of HIV/AIDS to a chronic yet manageable disease (Pontali et al. 2003). However, failure to adhere to HIV medications results in resistant viral strains, the possibility of transmission of new strains, increased morbidity and mortality, and increased cost of care (Inacio et al. 2001; Mallory et al. 2003; AIDS CARE Supplement 2004).

A key term here is the choice of the word ‘adherence’ as opposed to ‘compliance’. Although researchers agree on the importance of defining ‘adherence to product’, there is less agreement on how to define it (IOM 2008). In fact, even with ART, few studies have provided explicit definitions of adherence, and the few that do attempt to do so propose slightly different definitions (Fogarty et al. 2002). Nevertheless, there is a clear difference between compliance and adherence. Compliance describes the degree to which a patient’s behaviour in terms of taking medication, diets, and lifestyle coincides with medical or health advice (Chesney et al. 2000). As it makes the patient an object of treatment and places the burden of adherence strictly on

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3 The types of drugs from which a triple therapy is selected are: Nucleoside Reverse Transcriptase Inhibitors (NRTI); Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI); Protease Inhibitors (PI); Fusion or Entry Inhibitors; Integrase Inhibitors.
the patient, compliance is directionally biased and less empowering. In contrast, adherence, defined as the active, voluntary, and collaborative involvement of the patient and provider to produce desired preventive and therapeutic results (Meichenbaum & Turk 1987:20, in Uldall et al. 2004; see also NYSDHAI 2001), acknowledges the vital role of the patient as a partner in the goals and outcome of treatment (agency). In fact, the terms adherence and non-adherence are intended to be non-judgmental, a statement of fact rather than an expression of blame with regard to either the patient or provider. Consequently, when studying antiretroviral treatment, the notion of adherence is preferred (Lerner et al. 1998). The choice is also motivated by ethical issues, especially in the developed world, where the use of adherence is politically motivated due to the existence of a large and vocal AIDS lobby which refuses to be the ‘subject’ of treatment, and wants to play an active role instead. The term adherence is therefore used in AIDS care as much for political reasons as anything else. However, in resource-poor settings, where the majority of patients are less assertive, compliance measures are actually in force under the watchful eyes of the external donors, in order to avoid treatment failure.

1.2.2 The Adherence Debate in the Developed World

Research in the early 2000s into adherence to antiretroviral therapy, mainly in the West, revealed that there are four major interrelated factors that influence adherence. These are: 1) patient socio-demographic characteristics and mental stability; 2) therapy related factors; 3) patient clinical conditions; and 4) healthcare factors, (Bakken et al. 2000; Fogarty et al. 2002; Ickovics et al. 2002; Mallory et al. 2003; Murphy et al. 2004; Vervoort et al. 2007).

1. Patient Socio-demographic Characteristics and Mental Stability

In terms of socio-demographic factors, age, gender, ethnicity, education, literacy level, and employment status, have been – though not consistently – associated with adherence (Shuman et al. 2001; Chesney et al. 2000; Valerie et al. 2001; Fogarty et al. 2002; Ammassari et al. 2002; Weiser et al. 2003; Mallory et al. 2003; Dorz et al. 2003, Uldall et al. 2004).

Mental stability is perceived in terms of positive and negative mental attitudes. Positive mental attitudes towards medication, the disease, and having plans and hopes for the future (outcome efficacy or intrinsic reinforcement) have been associated with increased adherence (Fogarty et al. 2002; Mallory et al. 2003). Mental health problems, including emotional events, stress, depression, substance abuse (drugs and alcohol) and forgetfulness, have been associated with decreased adherence due to failure to
obtain advice, missing appointments, or missing medication time (Gordillo et al. 1999; Inacio et al. 2001; Shuman et al. 2001; Fogarty et al. 2002; Mallory et al. 2003; Ryan et al. 2003; Murphy et al. 2003, Nancy et al. 2004).

2. Therapy Related Factors
Based on Fogarty’s work and associates (2002), the therapy related factors are considered in terms of:

1. **Complexity of the therapy** - difficulty of regimen dosing, dosing scheduling, dietary instructions, the combination of multiple drugs, laboratory tests, and behavioural change.
2. **Scheduling demands** - daily routine dosing, mealtime dosing challenges.
3. **Medication accommodation** - ART interaction with other medications.
4. **Side-effects** – adverse physical, psychological, social and vocational risks/effects that are associated with medicines. The side-effects can be transient or permanent.
5. **Cognitive demand** - demands exerted by the drugs on the mind causing, for instance, forgetfulness.

Adherence to medication tended to decrease when the medications are too demanding in terms of interruption of work, daily routine, lifestyle, or coinciding with travel and meal time (Fogarty et al. 2002; Molassiotis et al. 2003; Weiser et al. 2003, Friedland et al. 2001); or when the amount of medication per day is high; or has food restrictions whereby it needs to be taken on an empty stomach, (Mallory et al. 2003; Valerie et al. 2001). However, the complexity of treatment was reduced due to the production of three-in-one pills by generic drug producers (Kovsted Jens 2005). Transient or permanent side-effects have been associated with decreased adherence (Shuman et al. 2001; Fogarty et al. 2002; Ickovics et al. 2002; Murphy et al. 2003; Friedland et al. 2001).

Antiretroviral efficacy belief is associated with adherence with scepticism about the efficacy of medicine impacting adherence (Murphy et al, 2003). Self-efficacy is associated with positive adherence. On the other hand, treatment fatigue is also known to reduce adherence level even among patients with high levels of adherence at baseline (Uldala et al. 2004).

3. Patient Clinical Conditions
The disease characteristics are assessed in the form of symptoms, immune status, and illness status. Symptomatic and disease progression has been associated with decreased adherence (Shuman et al. 2001; Spire et al. 2002; Mallory et al. 2003).
Improved immune response is measured in the form of clinical or virological responses as measured in CD4C lymphocyte counts (≥200/mm3), undetectable HIV viral load, and disappearance of depressive symptoms. In one cross-sectional study, individuals with a higher CD4 cell count tended to have better compliance than those with a lower or unknown CD4 count (Gordillo et al. 1991). Negative evaluation of the disease outcome has been associated with negative adherence (Fogarty et al. 2003), and improved health recovery with adherence. Even though, in one study, opportunistic infections increased adherence (Sigh 1996 in Ickovics et al. 2002). The most important factor here is to understand the context within which negative and positive evaluation of clinical conditions induces either positive or negative adherence to ART.

4. Healthcare Factors
The patient-provider relationship is regarded as a motivator of adherence (Dorz et al. 2003; Murphy et al. 2003). However, the nature of the patient-provider relationship was often not adequately described. Reference is simply made to the quality of patient-provider relationships (Dorz and associates 2003 study of Italian patients); or patients having a good relationship with their physician (Heckman et al. 2003 in the USA); patients satisfied with their clinician’s personal and professional style and trust (Friedland et al, 2001). However, those few studies that focused on psychologically-based variables of provider competences, trust, patient’s decision-making process, adequacy of referral, leave out the patients’ participation in adherence services at the health facility and community levels common in resource-poor settings. Nevertheless, in some literature, provider-patient interaction is regarded as a structural factor that influences access and service provision (Wekesa Year?). However, reducing healthcare services to provider-patient interaction conceals the complexity of actors and actions that promote adherence at this intermediate level.

First it should be noted, however, that these studies conducted in the developed world focused on persons naïve to ART therapy learning more about medication; disadvantaged groups with problematic access and usage of antiretroviral therapy, minority groups (for instance men who have sex with men (MSM), African-Americans, Latinos etc.); and who were exposed to mono-therapy as opposed to a combination of drugs in the form of triple therapy; and who experienced potentially stigmatising communication.

Second, most of the adherence literature in the developed world focuses on biomedical factors, but pays little attention to contextual factors (cf review work by Chesney 2000; Fogarty et al. 2002; Vervoort et al. 2007). According to Vervoort et al. (2007), most
of the studies reviewed provide some evidence on socio-economic variables (work, income, and disability), social support, and one study made reference to poverty. This explains why a patient’s poor adherence is blamed on the physician for prescribing a complex regimen, or for failing to give adequate information on the benefits and side effects of medication, or on how to fit the medication into one’s lifestyle (Osterberg et al. 2007). The major problem is that biomedical research focuses more on disease than on health, on medical care rather than on public health, on individualism rather than on collectivism (Baum 1995).

1.2.3. The Adherence Debate in Resource-Limited Settings

Between 2000 and 2004, some studies on access and adherence were conducted in the following resource-poor settings and middle income countries: South Africa, Brazil, Thailand, Rwanda, Uganda, Senegal, Cote d’Ivoire, Burkina Faso, etc. Results from these background studies revealed a slightly different set of factors affecting access and adherence to antiretroviral therapy in resource-poor settings compared with the developed world. The composition of these adherence barriers indicated a mix of biomedical factors and structural factors, with the socio-economic barriers dominating the composition of these barriers. The adherence barriers included: intolerance/side effects; forgetfulness; travel/migration; lack of ARV stock; financial costs; long distances to treatment centres; stigma; disclosure; and the socio-cultural representation of the disease (Monreal 2002; Wesier et al. 2003; Mukabutera et al. 2004; Akam 2004; Castro & Farmer 2004; Kimuli et al. 2004; Traore et al. 2004). Elsewhere, ART is associated with increased demand for food, especially at the initial stages of the treatment as the body regains strength (Population Council et al. 2004). During this period before the availability of free drugs, accessing ART involved costs, sacrifices, and making critical choices between medication expenses and domestic maintenance (food, school fees, clothes, house repair) (Weiser et al. 2003; Whyte et al. 2004; Desclaux 2005). Unfortunately, a household’s ability to cope with such access related costs was often weak, mainly because the productive and financial assets had already been depleted by HIV related income losses and expenditure incurred due to long term illness (Barnett & Blaikie 1992; Aspaas 1999; Haddad et al. 2001; Chikwendu 2004; Russell 2004; Wiegers 2006). As Jaffar et al. (2005) note, the manifestation of systemic constraints (such as healthcare resources and drugs) and structural factors (such as distance and poverty) meant that the physician-based models of care adapted from industrialised countries would not succeed in providing treatment to the majority of those in need in resource-constrained settings.
Surprisingly, despite such perceived systemic and personal constraints, early results from a few select sites in Uganda and elsewhere in resource-poor settings revealed a fairly high adherence rate to antiretroviral therapy and improved immuno response.

1.3 Objective of the Thesis

1.3.1. Theoretical Argument

The theoretical argument is based on the background evidence presented above. In summary, while background research in rich countries reveals the centrality of biomedical factors in influencing adherence to antiretroviral therapy, evidence from resource-poor settings suggests a combination of biomedical, systemic, and structural factors. For instance, Uganda’s ART Policy priority areas indicate the centrality of health system capacity, human resource development, facility- and community-based care and support, and patient adherence competencies.

However, while the available empirical evidence suggests a combination of biomedical and environmental factors in influencing adherence to ART in resource-poor settings (Uganda inclusive), at the inception of this research, there was limited evidence on the interactive nature of the two domains, and the effects they have on adherence patterns over time and space. Secondly, while the dual action of biomedical and environmental factors should have resulted in discouraging adherence rates, emerging empirical evidence suggests it is possible to achieve near-optimal adherence to ART and improved health outcomes in resource-poor settings. Such evidence suggests the role of mediating factors that reduce the interactive negative effects of biomedical and environmental factors.

To be explicit, the theoretical argument that guided this inquiry was that adherence to life-long antiretroviral treatment in Uganda’s resource-poor settings is an outcome of a reciprocal relationship between biomedical and environmental factors. In classic epidemiology, the biomedical model focuses on the epidemiologic triangle of host (patient), agent (cause), and environment (material condition in which the agent flourishes, cf. for instance the relationship between water supply and cholera) (Poundstone et al. 2004; Agar 1996). Conversely, in terms of health interventions (prevention and treatment), the biomedical model can be taken to include; the host (patient taking the medication), the agent (disease condition), the therapy factors (drug field), and the healthcare setting (environment). In adherence studies, the

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4 Such a narrow conceptualisation of healthcare setting is reflected in Ewart’s (1991) definition of ‘settings’ as physical features of one’s environment, the tasks routinely performed there,
healthcare setting is equated to the provider-patient relationship. In other words, in terms of health intervention, the biomedical factors that form the core of need, acceptability, and availability of healthcare services, are regarded to be the active variables (cause).

In this study, the theoretical argument proposed above suggests that sustained adherence to antiretroviral therapy in Uganda’s resource-poor settings is a function of the interaction between the biomedical factors and the larger social, cultural, and economic context (environment). When talking about new epidemiology, Agar (1996:398) relates it to “struggles with a shift from clearly defined material environment to symbolic context that are real for those who occupy them”. He further argues that “Context refers to several possible levels of analysis as well” (ibid. 398). Therefore, in this study, the levels, nature, and direction of reciprocity between the biomedical factors and environmental factors would need to be empirically explored and explained.

Second, by perceiving adherence to ART as an outcome it necessitated approaching adherence as both a process and as an outcome. Adherence as a process required understanding the adherence activities that preceded and culminated in taking the medication dose (event) over time and space, as well as the factors facilitating and constraining such adherence activities.

This expanded analysis of adherence factors has, in many ways, been inspired by previous work on health compliance. Hardon et al. (2004) allude to the fact that the consumption of medicines is determined by patient health and mental ability, the level of household resources, the social climate, and the quality of healthcare services at the health facility. Similarly, Poundstone et al. (2004), in advocating for application of social epidemiology in the study of HIV/AIDS recommends a model that goes beyond the “biomedical individualism” (coined by Fee and Krieger 1993) that focuses on host, agent, and environment to examine the role of social determinants. According to Poundstone and associates, a social epidemiology approach distinguishes determinants of HIV/AIDS at three levels: individual, social, and structural. The individual factors include biologic, demographic, and behavioural risk factors whereas the social-level factors include critical pathways by which community and network structures link persons to society. Structural-level factors include social and economic factors, as well as laws and policies (Poundstone et al, 2002:22). In the same way, Castro (2005) also points to the need for a biosocial approach to investigate and and the people composing one’s proximal social milieu who influence action and strategies by determining access to needed resources.
understand the complex relationship between the biomedical factors and the larger social, economic, and political context in resource-poor settings.

1.3.2. Objective and Research Questions

The major research objective was to investigate the role of biomedical and environmental factors in facilitating and/or constraining adherence to antiretroviral treatment in Uganda’s resource-poor settings, using two different ART accredited sites – an Urban-based Mission Facility (Reach Out Mbuya) and a Rural-based Public Facility (Kayunga Hospital). The ultimate goal of this research was to construct best practices for sustaining optimal adherence to ART.

This being an exploratory-explanatory study, it was guided primarily by research questions rather than by concrete research objectives. The research questions outlined below are a product of research processes, because they evolved as this research progressed through advanced stages.

**Specific Questions**

1. What are the adherence patterns and characteristics of the two comparative facilities?

2. What are the adherence activities that precede and culminate in the pill-taking event itself, and what are the respective barriers?

3. Specifically, what is the nature of the economic burden entailed in accessing and adhering to antiretroviral therapy at the patient level? What is its impact on adherence to ART? And if no observed substantial negative effect of the economic burden, what factors mitigate the economic burden in Uganda’s resource-scarce settings?

4. What factors facilitate adherence to antiretroviral therapy among patients seeking ART services in the two comparative facilities?

5. Specifically, how do education and counselling programmes in the two formal healthcare settings sustain adherence to antiretroviral therapy?

6. How does the social support process (sources, resources, reciprocity) facilitate adherence to ART?

7. What are the best practices that can be adopted to sustain adherence to ART in Uganda’s resource-poor settings?

1.4 Outline of the Thesis

After this introductory Chapter, Chapter 2 describes the methodology, providing justification for the choice of thesis design, as well as describing the sampling
procedures, the data collection process, and analysis. Chapter 3, the first empirical Chapter, analyses the five forms of adherence activities. The major argument advanced in this chapter is that, in Uganda’s resource-poor settings, the probability of taking ARVs depends on a set of adherence activities, each involving a set of barriers whose intensity varies in given seasons. Following this, Chapter 4 offers an extended discussion of the adherence barriers, and focuses on the direct and the indirect costs involved in accessing and adhering to antiretroviral therapy in the two facilities, the actual impact on adherence, and the coping strategies adopted by patients to persist with medication.

After this thorough assessment of the barriers, Chapter 5 assesses the factors facilitating adherence to antiretroviral therapy at the patient level. Chapter 6 also provides an extended discussion of the factors facilitating adherence to ART. Through a content analysis technique, this Chapter assesses the potential role of counselling and education for adherence to antiretroviral therapy. Chapter 7 goes beyond the patient-provider relationship by examining the role of social support in sustaining adherence to ART. The key message in this Chapter is that adherence involves collective action occurring at the household, community, and facility levels.

Finally, Chapter 8 discusses the research results, and proposes recommendations for sustaining ART adherence in Uganda’s resource-poor settings.
Methodology

2.1 Introduction

The nature of the theoretical arguments outlined in Chapter 1 determined the nature of the methodology\(^5\), including the research design process. The pre-field theoretical arguments and the emergent empirical findings guided the prioritisation and sequencing of the research methods. It should be noted, however, that the primary objective of this research was not to saturate theoretical categories or theoretical density (which is the purpose of a grounded theory), but to exhaust the descriptions of and explanations for adherence to antiretroviral treatment. This adherence research adopted methodological triangulation drawing from both quantitative and qualitative research methodologies. This methodology chapter is comprised of six sections. The first section here is the introduction, and the second section presents the construction of the research design in the form of a planning process. The third section justifies the sampling procedures, while the fourth and fifth describe the process of data collection. The last two sections focus on the issues of validity and reliability and the ethical considerations.

2.2 Constructing the Research Design

The research design entailed two major components: planning and execution. This section describes the first phase in the form of constructing a design or plan. This phase involved both desk work and reconnaissance to validate the plans and assumptions.

2.2.1 Literature Review and Problem Formulation

As the previous Chapter has presented the problem definition, the focus here is on how the study problem emerged. This being an exploratory-explanatory research, the literature search and review was a continuous process, with the need to find theoretical and empirical answers to the emergent research questions guiding the literature review process. In other words, literature reviewed was used not only

\(^5\) Methodology is a research strategy that translates ontological and epistemological principles into guidelines that show how research is to be conducted (Sarantakos 2005).
to provisionally generate a research problem and research questions but also to illuminate the research path. The emergent research issues on which literature was reviewed included: the economic burden of illness (health economics); sustainable livelihoods (poverty); social capital and social support (sociology); counselling (psychology); health protection models (theory); and health project documents (practice). Consequently, each empirical Chapter contains its own literature.

This formative phase was punctuated by reconnaissance in Uganda in 2005, intended to substantiate and validate the initial research hypotheses generated from the literature review. Punctuating the literature review with reconnaissance shaped the conceptualisation process and methodological choices. My discussion with HIV/AIDS service providers in five newly accredited antiretroviral facilities and policy makers revealed that Uganda had not only achieved the international target of antiretroviral drug access for 3 million people in the developing world by 2005; but also, based on unprocessed pill-count data, had succeeded in achieving 95% adherence among a large number of patients. Since both private and public facilities manifested high adherence rates it was necessary to go beyond an analysis of barriers and focus on the facilitating factors as well. Second, given the fact that the causes of high adherence rates in Uganda’s resource-poor settings remained unclear, it was necessary to begin with qualitative exploratory studies that would help make the social survey more focused. Third, in order to generate rich and/or generalisable data, it was necessary to include a mix of public and private treatment providers located in urban and rural settings respectively, whose treatment programmes had lasted for more than one year, and hosted a large number of clients. This is why, in all except one case (Mbuya Reach Out), the health facilities visited during the reconnaissance were left out of the main study.

2.2.2 Selecting the Research Framework

For any formal research, the researcher’s own underlying assumptions that locate the research problem within a body of knowledge should be explicitly stated using a research framework (Eisenhart 1991). A research framework provides a structure for conceptualising the phenomenon, designing the research study, interpreting data resulting from the study, and drawing conclusions. A research framework is the basic structure of the ideas (abstraction and relationship) that serve as the basis for a phenomenon that is to be investigated (Lester 2005).

6 The five treatment sites selected were: Jinja Hospital (Mid-Eastern), Tororo Hospital (Eastern Region), Masaka Hospital and Kitovu Mobile Clinic (Central South-Western), and Mbuya Reach Out (Central Region). For pragmatic reasons, only Mbuya was selected from the original sampling list, and a new site was incorporated, Kayunga.
There are three research frameworks from which to select, and these are a theoretical framework, a conceptual framework, and/or a practical framework (Einsenhart 1991, in Lester 2003). A theoretical framework guides research activities by its reliance on a formal theory that already exists. The existing theories are used to explain observed events, predict the outcome of events and relationships, or systematically summarise existing knowledge. A conceptual framework is itself an argument based on selected concepts that are perceived by the researcher as relevant and appropriate to use for a given research problem. A conceptual framework is built upon a wide array of previous research, various theories, and the practitioner’s knowledge. It is therefore a skeletal structure of justification, rather than of explanation (Lester 2005). On the other hand, a practical framework guides research by using ‘what works’ in the experience of doing something by those directly involved. This framework is not guided by a formal theory but the accumulated practical knowledge of the practitioners and administrators.

This research did not rely on a theoretical or a practical framework but on a conceptual framework to guide the research process. A review of theory-based literature revealed that individual health models and the structural models had strong points and limitations. For instance, while psychologically-based models concentrated on the biomedical factors, they left out the structural factors. On the other hand, while anthropological and sociological models focused on the structural and institutional factors, they tended to be weak in explaining the biomedical factors. At this point, I will briefly highlight the strong and weak points of the main health models from psychology, anthropology, and sociology.

The Health Belief Model (HBM) by Rosenstock (1950, 1991) can be classified as an expectancy model of healthcare decision making because of its role in predicting preventive health behaviours or compliance (Walker et al. 1982; Greenfield et al. 1987; Kirn 1991). It focuses on self-efficacy and states that health behaviours depend mainly on two major factors: the desire to avoid illness (or to get well), and the belief that a particular action will relieve illness (Malcolm et al. 2003). Based on Sanzero (2008), if this theory were to be applied, the likelihood of adherence to Highly Active Antiretroviral Therapy (HAART) would be:

- **Perceived susceptibility**: the individual’s belief that a person is susceptible to HIV disease progression
- **Perceived severity**: the individual’s belief that HIV disease progression has serious consequences
- **Perceived benefits**: the individual’s belief that adherence to ART would reduce susceptibility to HIV disease progression or disease severity
**Perceived barriers:** the individual’s belief that the materials, physical and psychological costs of adhering to ART outweigh the benefits

**Cues to action:** the individual’s exposure to factors that prompt adherence to ART

**Self-efficacy:** the individual’s confidence in his/her ability to successfully adhere to ART

In other words, the HBM is an individual-based cost-benefit analysis and, for change to occur, benefits must outweigh the costs (UNAIDS 1999). The major weakness with this health model is that it focuses on individuals’ personal beliefs, knowledge, and attitudes but lacks the research capacity to investigate the health system’s capacity and social response to the epidemic. To use Agar’s (1996:397) observation, it is not that material explanation is irrelevant but neither is it adequate. Host lives in a symbolic environment as well as material one.

Next, the psychologically-based *Health Compliance Model* (HCM) focuses on the **operant conditions** that interact with basic behavioural repertoires. These are physician variables, physician-patient variables, compliance promotion variables, quantity and frequency of prompts, and social-medical environment variables (Heiby & Carlson 1986; Heiby et al. 2005). This is also a social-cognitive theory that focuses on provider and patient characteristics and behaviour, reinforcement strategies, and the operant environment. There are other psychologically-based models not discussed here, including the *Theory of Reasoned Action* (advanced by Fisbein and Ajzen in the 1960s), *Information-Motivation-Behavioural Skills Model* (Fisher et al. 2006), all of which suffer from the major weakness of focusing on the host (rational human beings) and thus explaining important phenomena such as individual learning, memory, choice, and performance (also after Ewart 1991), but failing to explain the social processes (e.g. systemic and social support systems) that are crucial for adhering to ART.

Finally, there are the sociological and anthropological theories. Despite the UNAIDS (1999) article being primarily interested in the relevance of the health models for HIV prevention, it provides an adequate overview of the theoretical orientation of various sociological theories. It notes that any sociological theory ‘asserts that society is broken up into smaller sub-cultures and it is the members of one’s immediate surroundings, the peer group that someone identifies with, that has the most significant influence on individuals’ behaviour’ (UNAIDS 1999:8). Of particular interest here is the anthropologically-based *Healthcare System Model* (HSM) by Kleinman (1978), which is useful in identifying the role of support systems and sub-cultures (popular, folk, and professional), but it leaves out the biomedical factors and the social-contextual
Methodology

barriers, including the economic burden. The sociological Behavioural Model of Health Service (BMHS) by Anderson (1968, 1995) is more inclusive, capturing predisposing factors (all patient characteristics), enabling factors (availability of services, financial resources, health insurance, social networks), and need (perception of severity, duration of illness, number of days missed from work). However, since its primary goal is to explain equitable access to healthcare, not adherence to a life-long regimen for chronic illnesses, it tends to emphasise the availability of healthcare services but not adherence factors, including the role of a regimen and the healthcare setting.

Given the fact that the existing psychologically- and sociologically-based health models lacked the working capacity (conceptual categories, dimensions, and meanings) to accommodate the theoretical argument, this research used a skeletal structure of justification (conceptual framework), rather than a skeletal structure of explanation (theory) (see Appendix Table A.1). This is because the conceptual framework would allow the incorporation of differing points of views. But even then, the conceptual framework was dropped after the preliminary phase of data collection because it also proved to be conceptually restrictive, especially in analysing the relationship of the key emerging concepts and the context. This was particularly evident in the preliminary survey results that revealed that adherence to ART was consistently high, regardless of patient socio-demographic characteristics, healthcare settings and capacity, and the level of affordability of access and adherence costs.

2.2.3. Conceptualisation and Operationalisation of Adherence

Conceptualisation and operationalisation involves refining and specifying abstract concepts (conceptualisation) and developing specific research procedures (operationalisation) that will result in empirical observation of things that represent those concepts (empirical referents) in the real world (Rubin et al. 2001; Sarantakos 2005:139). To put it simply, operationalisation deals with translating a concept or construct into functioning and operating reality7. Most of the literature implies that conceptualisation and operationalisation apply primarily to quantitative research, with some qualitative researchers arguing that the best form of operationalisation is no operationalisation at all (Sarantakos 2005:140); ‘because interpretive research implicitly assumes that every person conducting a research study will have [a] unique interpretation of the results’ (Labianca et al. 2000:24, in Sha et al. 2006). This explains why the way in which concepts are developed and employed in qualitative research is rather different from that implied in quantitative research strategy. Quantitative research tends to put emphasis on definitive concepts (with fixed dimensions and

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7 Web centre for Social Research Methods.
indicators) while qualitative research identifies *sensitising concepts* (providing a general sense of reference and guidance to what is being studied) (Bryman 2004:270, quoting Blumer 1954). In order to strike a balance between the two traditions, the important dimensions and indicators of ‘adherence’ as a core concept (or outcome variable) were defined prior to commencement of the study, and allowing the dimensions and meanings of the explanatory variables (independent variables) to emerge as the research progressed.

In practical terms, the definition of adherence which I present in the introductory Chapter is too general, as it is concerned with adherence to health products and plans and lacks specific parameters for measuring adherence to antiretroviral regimens. The operational definition* for this research, therefore, was adopted from Osterberg *et al.* (2007), who stated that *adherence is the extent to which patients take medication as prescribed by the healthcare providers.* In this respect, adherence rates are used to measure the extent of adherence, calculated as the ratio of pills taken to pills prescribed, multiplied by 100. It should be noted; however, that the theoretical orientation for this research suggests that adherence to medication is an outcome of a complex process. The use of a single number to define adherence would, consequently, mask adherence activities that precede, culminate in, and follow the pill-taking event itself, and the attendant barriers. For that reason, five adherence activities were identified and used. These were: 1) adherence to initiation appointments; 2) adherence to medication refill; 3) adherence to meal/snack-taking; 4) adherence to medication time; and 5) adherence to the medication dose itself.

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**Text Box 2.1: Adherence Activities**

- **Adherence to Initiation Appointments** – Refers to adherence to the initial treatment activities intended to prepare a client for life-long treatment;
- **Adherence to Refill Appointment** – Returning for a new prescription on the appointment date;
- **Adherence to Meal/ Snack-Taking Advice** – Taking a meal or snack to avoid adverse metabolic effects associated with antiretroviral medication;
- **Adherence to Medication Time** – Taking the prescribed dose within one hour of the scheduled time;
- **Adherence to Medication Dose** – Taking the prescribed number of pills at each medication time.

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8 The ‘operational definition’ refers to the translation: the operations, or indicators, used to determine the quantity or quality of the category observed about a particular variable (Rubin *et al.* 2001).
The second operational assumption was that each of the adherence activities is associated with unique adherence barriers that act independently or interactively to affect the final outcome – adherence to medication dose.

2.2.4. Selection of Methods for Measuring Adherence to ARVs

So far, adherence to medication dose is the standard measure of adherence, and adherence to ART has been measured by two methods: objective and subjective (Farmer 1999; Osterberg et al. 2007). The subjective or indirect methods include self-reporting and self-administered questionnaires, electrical monitoring devices, pharmacy refill records, pill-count, keeping medication diaries, and assessing adherence through care-givers. The objective methods include drug assay of blood or urine, examination of the CD4 count, and direct observation of the patient taking/receiving medication. The strengths and weaknesses associated with direct and indirect methods are well documented in other work (see Farmer 1999; IOM 2008:124).

This research also reveals the weaknesses associated with using a single measure of adherence. The questionnaire included two consecutive questions: ‘According to the respondent has s/he ever skipped taking an ARV dose on any given day?’ and ‘According to pill-count records, has the patient ever skipped taking an ARV dose?’ The results indicated inconsistencies between self-reporting and pill-count information. Of the 142 patients whose clinical records indicated that they had missed pills during the past treatment time period, 41 cases (26%) denied ever missing pills through self-reporting. As a result, this research opted for pill-count data rather than self-reporting. The urban-based Mission Facility had a strong home care programme, permitting validation of the pill-count data through un-announced pill-count visits by the community volunteers known as Community AIDS and TB Treatment Supporters, or CATTS.

In order to minimise inaccuracies associated with using a single subjective measurement of adherence to ART, health indicators (CD4 cell count, weight, and functional status) were also extracted from clinical records in order to establish treatment response. Despite all these control measures, Chapter 3 shows that urban patients in particular still masked the actual adherence barriers, using the term ‘I forgot’ in order to avert punitive measures imposed as a result of non-adherence by health workers. At the time of this research, the normal refill interval was one to two months, but grossly non-adherent patients were asked to return after 2 weeks for close monitoring, which involves extra transport costs on the part of the non-adherent patient.
2.2.5. Selection of the Study Sites

Two study sites were selected to implement this research: Reach Out Mbuya, here referred to as the Urban-based Mission Facility (UMF), and Kayunga Public Hospital, referred to as the Rural-based Public Facility (RPF). Both treatment sites were running a main treatment centre and treatment outposts. For the RPF, fieldwork was carried out in the main hospital, while for the UMF fieldwork was carried out at Kinawataka, a treatment outpost located near the main facility, offering the same healthcare services.

The two sites shared certain common characteristics. In both facilities, ART treatment had been running for more than two years. Both the urban and rural sites were geographically situated in impoverished conditions and served a multi-ethnic group. In terms of healthcare arrangements, both facilities were under the overall supervision of the MOH, and both dispensed single and multiple pill regimens, with rapidly expanding enrolment for HIV/AIDS services coinciding with a shrinking number of professional staff. However, as the following table shows, there were also differences between the two facilities.
Table 2.1: Differences between the Two Study Sites by September 2006

<table>
<thead>
<tr>
<th>Mbuya Reach Out (UMF)</th>
<th>Kayunga Hospital (RPF)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban site located in the suburbs of Kampala city. Clientele come from the nearby suburb (Kinawataka), presumably not travelling long distances or incurring access costs.</td>
<td>Rural site located 46 km from Kampala city. Clientele come from a wide catchment area, experiencing long distances and travel costs.</td>
</tr>
<tr>
<td>The core values of faith, charity, and volunteering guided service delivery.</td>
<td>The principles of equity and utilitarianism guided service delivery.</td>
</tr>
<tr>
<td>Implements a holistic healthcare service (medical, psychosocial, socio-economic, community network of care) for patients and OVCs, with huge external funding (see Appendix Table A.7).</td>
<td>Provides a minimal healthcare package (medical and psychosocial support) to rural patients, and is under-funded by the government.</td>
</tr>
<tr>
<td>Accredited as an ART outlet in March 2004, with a large clientele of 1,833 patients, 27% male and 73% female (June 2005).</td>
<td>Accredited as an ART facility in January 2005, with 250 patients by January 2007 (based on this survey, 37% male and 67% female).</td>
</tr>
<tr>
<td>Small number of doctors (4), with a large (52) base of a community network of care, with a structure of home care-givers.</td>
<td>A small number of professionals manage the HIV/AIDS clinic, with 1 doctor, 4 nurses, and few (6) health volunteers, but with a strong base of professional staff (Table A.6).</td>
</tr>
<tr>
<td>As an NGO, the HIV facility lacked health infrastructure, and depended on external laboratory facilities (at the Mildmay Centre) to carry out all laboratory tests, and referrals for potential inpatients.</td>
<td>Possessed a laboratory facility, with CD4 machine donated by the Walter Reed Project in 2008, and 8 outpatient departments.</td>
</tr>
<tr>
<td>Served a multi-ethnic clientele speaking different languages, with some being mobile due to work and rural kinship ties.</td>
<td>Multi-ethnic clientele but united by common language (Ganda), and rural permanent residence.</td>
</tr>
</tbody>
</table>

The inclusion criteria assumed that differences in healthcare services, resources endowment, and social environment were likely to have a substantial impact on adherence to ART.

2.2.6. Selection of the Unit of Analysis

Micro-based research can be implemented on three levels: individual, household, and community. Normally, the selection of the household as a unit of analysis is based on the premise that household members share resources and decision making processes (Seeley 1995). With adherence studies, taking the household as a unit of analysis proved unfeasible and conceptually limiting. It would be erroneous to assume that PLWHA benefited from intra-household resource allocation. In fact, results from this survey revealed that a high proportion of patients (44.3%, 116) were excluded from intra-household financial resources due to a combination of reasons, resulting from non-disclosure of their serostatus, lack of income earning opportunities in the home, or simply being a single-occupancy household. The second problem was
directly linked to logistical constraints. HIV patients, or ART clients for that matter, are not a horizontal but a vertical community. A horizontal community is a group of people within a geographically defined area, while a vertical community is a group of people living in different locations but with a common interest that they defend, e.g. the homosexual community, religious and ethnic-based groups (see James 1994, in Kofi 1999). Since HIV patients do not occupy a definable space in relation to other areas, selecting the household as the unit of analysis would pose logistical constraints to locating ART clients over a vast area without a proper address.

As a result, individual patients seeking services at the facility were taken as the unit of analysis, though household characteristics were still attributed to the individual patient. Theoretically, the patient served as the primary unit of analysis and observation (sampling unit), sampling element (subject), as well as the population (aggregate of study elements) within a broad ‘healthcare setting’ embracing the household, community, and facility. To that effect, the questionnaire included the household characteristics and social support system; while the qualitative interview guide included issues of healthcare capacity and treatment support systems (see Appendix Supplementary Material SM.1; SM.2; SM.3; SM.4). This extended unit of analysis would also allow the investigation of the major hypothesis that adherence to ART is the outcome of a complex process involving biomedical and environmental factors.

2.3 Sampling Procedure

Once the preliminary research design was completed, the next step was to decide how to systematically and objectively select a representative sample for the research purpose. On the basis of the theoretical argument, this research adopted methodological triangulation, hence the adoption of a combination of quantitative and qualitative sampling procedures.

2.3.1. Quantitative Sampling Procedure

A pseudo-random sampling technique was used to select the patients for the survey. I will describe what I mean by a ‘pseudo-random sampling technique’. The sampling frame was obtained during the exploratory phase, when research assistants extracted

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9 Sampling is the process of identifying, from a large population, a smaller group which not only shares the former’s characteristics but is more manageable for study (Shensul & Lecompte 1999).

10 A sampling frame is a comprehensive list of all members or units within a population from which samples are chosen (Shensul & Lecompte 1999).
pill-count data, and the clinical data from the patients’ files at the health facility. At the pre-selection stage, a minimum inclusion criterion of ≥ 6 months of being on antiretroviral treatment was considered. Arguably, this biased the study sample because only those patients in their persistence phase were selected. However, the rationale for such a selection criterion was to obtain information-rich patients, as well as deriving adherence trends. Inherently, this involved an infusion of qualitative and quantitative sampling procedures. Based on the review of clinical records, the initial sampling frame included 300 patients.

However, pre-selection of patients for interview in routine healthcare settings was rendered useless because different patients come for monthly pharmacy refills on different dates, spanning over a two month period. Strict adherence to the 300-person sampling frame would slow down fieldwork and eventually increase fieldwork costs. As a result, the original sampling plan was discarded, and we resorted to interviewing patients who had come for pharmacy refill or medical consultation, provided they satisfied the 6 months’ persistence inclusion criterion. But also this meant re-extracting pill-count and clinical data for those patients who were readily available at pharmacy refill.

This is what is referred to as pseudo-random sampling, as opposed to the pure lottery method, or the convenience (or accidental) sampling procedure. A convenience (or accidental) sampling procedure, or ‘man-in-the-street’, involves selecting any group of people readily accessible to the researcher that might reasonably be assumed to possess characteristics relevant to the study. In this case, while the application of randomness was unsystematic, it was guided by a selection criterion of 6 or more months treatment duration (right subjects), seeking pharmacy refill on scheduled appointments (right time), from the ART accredited site (right place).

Finally, 262 patients were interviewed during the survey, with 142 in the Mission Facility and 120 in the Public Facility. Although there is no gold standard for ‘when a sample stops being too small and becomes large enough’ (Amin 2005), the sample size of 262 respondents was regarded to be large enough to permit generalisation of results. Furthermore, the repeated and intensive qualitative studies permitted collection of additional qualitative data (see 2.3.2 below). However, the ever increasing enrolment for HIV and ART services still makes it impractical to precisely determine a statistically acceptable sample size.

The table that follows presents the characteristics of the respondents that were included in the survey.
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Urban Mission Facility</th>
<th>Rural Public Facility</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age</td>
<td>38 (142)</td>
<td>38 (120)</td>
<td>n=262</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62% (88)</td>
<td>63% (76)</td>
<td>63% (164)</td>
</tr>
<tr>
<td>Male</td>
<td>38% (54)</td>
<td>37% (44)</td>
<td>37% (98)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never Married</td>
<td>6% (8)</td>
<td>2% (2)</td>
<td>4% (10)</td>
</tr>
<tr>
<td>Married</td>
<td>48% (68)</td>
<td>36% (43)</td>
<td>42% (111)</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>13% (19)</td>
<td>19% (31)</td>
<td>19% (50)</td>
</tr>
<tr>
<td>Widow/Widower</td>
<td>33% (47)</td>
<td>37% (44)</td>
<td>35% (91)</td>
</tr>
<tr>
<td>Place of Residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>2% (3)</td>
<td>62% (74)</td>
<td>29% (77)</td>
</tr>
<tr>
<td>Urban</td>
<td>98% (139)</td>
<td>38% (46)</td>
<td>71% (185)</td>
</tr>
<tr>
<td>Members of Household Having Access to Regular Sources of Income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>76% (105)</td>
<td>75% (88)</td>
<td>75% (193)</td>
</tr>
<tr>
<td>No</td>
<td>24% (33)</td>
<td>25% (30)</td>
<td>25% (63)</td>
</tr>
<tr>
<td>(Missing Cases = 6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of Months on ART According to Clinical Records</td>
<td></td>
<td></td>
<td>n=259</td>
</tr>
<tr>
<td>12 Months</td>
<td>9% (24)</td>
<td>16% (42)</td>
<td>25% (66)</td>
</tr>
<tr>
<td>24 Months</td>
<td>24% (62)</td>
<td>28% (72)</td>
<td>52% (134)</td>
</tr>
<tr>
<td>38 Months</td>
<td>22% (56)</td>
<td>1% (3)</td>
<td>23% (59)</td>
</tr>
<tr>
<td>(Missing Cases = 6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of Regimen</td>
<td></td>
<td></td>
<td>n=262</td>
</tr>
<tr>
<td>Triomune-40 (simplified)</td>
<td>47% (68)</td>
<td>71% (85)</td>
<td>58% (153)</td>
</tr>
<tr>
<td>Multiple pills (PEPFAR)</td>
<td>52% (74)</td>
<td>29% (35)</td>
<td>42% (109)</td>
</tr>
</tbody>
</table>

Education attainment was evaluated at the household level rather than at the patient level. The statistical output reflected similar patterns of education attainment between the rural and urban households – 14% (199) never attended formal education, 56% (805) attended primary school, 25% (361) attended secondary school, 2% (25) obtained advanced level, 2% (24) certificate, 2% (21) obtained a diploma, 1% (13) obtained a degree. The household education characteristics reflect the patients’ level of education as other survey questions suggest that the respondents were the household head (cf. respondents marital status and age). For detailed analysis of patient profile see section 5.3.6).
2.3.2. Qualitative Sampling Procedure

A *purposive sampling technique* was used to select the study participants. This technique, also known as judgmental sampling, selects the sampling element based on the researchers’ knowledge of the population and its elements, and purpose of the study (Rubin & Babbie 2001:254). The inclusion criteria of the sampling element normally include diverse background, information-rich and contrasting cases (Hardon et al. 2001, 2004). In this case, the basic selection criterion was the participants’ ability to provide credible and/or contrasting information. Inclusion of information-rich participants was guided by background information available from patients’ medical files, the health staff, and the health volunteers who practically knew the patients on treatment.

In order to validate emergent data and hypotheses and understand the social context, the purposive sampling technique was applied sequentially during the explorative studies and the post-survey explanatory studies. In total, 37 qualitative studies were conducted, staggered over a period of three years. Table 2.3 below provides the breakdown of interviews held in the UMF and RPF.

**Table 2.3:** Qualitative Sampling Elements

<table>
<thead>
<tr>
<th>Type of Studies</th>
<th>Mission Facility</th>
<th>Public Facility</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Qualitative Exploratory Studies</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Staff Key Informants</td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Individual Patient Interviews</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Healthcare Volunteers</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Observation of ART Counselling Sessions</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Healthcare Volunteers FGD</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total Number of Participants</strong></td>
<td>20</td>
<td>18</td>
<td>38</td>
</tr>
</tbody>
</table>

Table 2.4 below singles out the FGDs and presents the composition of each FGD by gender. Like in the case of the survey, females formed the largest proportion.
Table 2.4: Number of Participants in Each FGD

<table>
<thead>
<tr>
<th>Type of FGD</th>
<th>Gender Composition</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Healthcare Volunteer FGD</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Survey Follow-up (Mission Facility)</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Survey Follow-up (Public Facility)</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Social Support Beneficiaries (Mission Facility)</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Social Support Beneficiaries (Public Facility)</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Social Support Providers (Mission Facility)</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Social Support Providers (Public Facility)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Healthcare Volunteers (Mission Facility)</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Healthcare Volunteers (Public Facility)</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Total Number of Participants</td>
<td>33</td>
<td>50</td>
</tr>
</tbody>
</table>

2.4 Data Collection

A methodological triangulation\(^{11}\) was used to implement this research study. An iterative process involving qualitative and quantitative methods was used to answer the central question and the emergent research questions and hypotheses. The quantitative method was mainly a survey intended to generate descriptive statistics. Since ‘qualitative methods are a set of data collection and analysis techniques that can be used to provide description, build theory, and to test theory’ (Van Maanen 1979, in Sha et al. 2006:1824), the major goal for implementing qualitative data was the ability to study, describe and interpret the medication patterns, processes and experiences.

Obviously, quantitative and qualitative research traditions consist of distinct methods for data collection and analysis. The following section will distinguish the data collection procedures between the two different traditions that were used. Three major studies were implemented: qualitative exploratory studies, a survey, and qualitative explanatory studies, each of which is described next.

2.4.1. Qualitative Exploratory Studies

The qualitative exploratory studies marked the beginning of the actual fieldwork. They are so described because, even after comprehensive review of the literature, there was still a need to clarify and verify the a priori hypotheses, discover new variables and questions, and establish a rapport with gatekeepers (patients, providers, and volunteers) in both sites. Instead of a hurried survey, three sub-studies were

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\(^{11}\) Triangulation is the practice of using more than one methodology, method, sample, times, and/or researcher within the context of the same study (Sarantakos 2005).
implemented: 1) assessment of the healthcare services and settings (AHSS); 2) extraction of adherence and clinical data from patients’ files; and 3) gathering patients’ life stories.

1) Assessment of Healthcare Services and Settings
AHSS provided a means of understanding the physical settings, actors, resources, and social processes, and the impact they have on adherence to ART. The first activity targeted the health staff. A semi-structured interview guided the discussion with the health staff, focusing on seven themes (see Supplementary Material S.M. 3).

After the AHSS, the counselling trajectory was observed in both UMF and RPF. At the time of research, counselling involved five stages: 1) client enrolment (VCT/RCT\textsuperscript{12}); 2) ART education (clients and care-givers); 3) prescription counselling; 4) adherence counselling; and 5) client follow-up (facility or home visits). Since ART education is directly linked to adherence, I attended the ongoing ART counselling sessions twice between September 2006 and January 2008. This ‘time-point observation technique’ permitted verification of consistency in the counselling methods and content, and its implication for modelling adherence behaviour. A content analysis was used to analyse the information text collected from the ART counselling session (see section 2.5.2 below).

2) Review of Patient Files
In Uganda, all patient’s clinical and adherence data is recorded on the HIV CARE/ART CARD provided by the Ministry of Health. The rationale for undertaking this tedious exercise was that the existing database on patient assessment and drug refill forms was more likely to yield authentic data than self-reporting during interviews. This is because clinical and adherence data is technical in nature (at least within the Ugandan context) and patients would find it difficult to recall such data. The issues captured included the following:

- Client name (later tagged to the questionnaire as number and abbreviation);
- Date of ART initiation enrolment;
- Type of regimen and, if applicable, instances of switching regimen and reason for doing so;
- Whether client was ever suspended from ART treatment and reasons for such;

\textsuperscript{12} Routine Counselling and Testing (RCT) is provider-initiated for effective clinical management of the patient.
Sustaining Adherence to Antiretroviral Therapy among HIV/AIDS Patients in Uganda

- Symptomatic illness at time of enrolment for HIV treatment;
- Adherence to treatment initiation appointments (CD4 test, picking CD4, 1st, 2nd, and 3rd counselling appointment, ART initiation), recorded as date expected and actual date reporting;
- Date being initiated on Cotrimoxazole and ARVs;
- Episodes of skipping pharmacy refill appointment and reasons recorded;
- Incidence of taking extra doses, or returning fewer pills in the pill bottle than expected, and reasons recorded;
- Episodes of non-adherence to ARVs, documented as date of recording, number of pills missed over prescribed, and reasons recorded;
- Quality of life indicators (WHO staging, CD4+ T cell count, functional status, weight) and dates of recording such indicators;
- Dates and types of opportunistic infections and side effects ever recorded;
- Number of people who are HIV positive in the household.

Significantly, extraction of the actual date (‘dd/mm/yy’) when the information was taken from the patient by the provider made it possible to derive a retrospective trend analysis for pill-count adherence, health indicators, and (re)occurrence of side effects and opportunistic infections. This clinical record data was integrated into the survey questionnaire before the actual interview, and verified them with the patient at the time of individual interview. The abbreviation that was used to mark that technical data on the questionnaire for subsequent verification was ‘CR’ (for clinical records). Integrating the clinical record-based data into the questionnaire well in advance of the survey meant that the survey dealt not with two separate datasets but one; it also permitted verification of such data with the patient, and with the adherence counsellors in the event of a patient’s denials.

3) Individual Patient Interviews

As stated, prior to the survey, 10 (5 at each site) Individual Patient Interviews were implemented, with informants selected on the basis of gender and the duration of treatment (2 years). The Individual Patient Interviews were intended to obtain a life history on personal (subjective) and social (objective) lives (see Supplementary Material S.M.2). A descriptive questioning technique was used, with patients asked to describe the key events in their life journey, for instance: growing up, moving to places, becoming engaged in a relationship, encountering and coping with HIV as a stigmatised illness, seeking medical attention, coping with treatment demands and obligations, people in their lives and illness, and the future.
Emergent data from the life stories illuminated core variables that should be taken seriously in subsequent research phases. The key issues that merited inquiry were: adherence as a process and outcome; adherence pre-conditioning factors, especially the shift from herbal to Western medication; the indirect costs of accessing and adhering to ART; the instrumentality of social support in the health seeking process; the role of information and education; and facilitating and constraining factors.

In addition, one FGD, consisting of 11 healthcare volunteers known as CATTS, who are PLWHA themselves, was implemented in the Mission Facility in order to identify consensus and different opinions about the perception of illness and treatment experiences.

2.4.2. The Survey

Once the explorative qualitative studies were complete and the questionnaire revised, the survey was implemented. Text Box 2.2 presents the key research questions included on the questionnaire (also see the Supplementary Material S.M. 4).

**Text Box 2.2: Key Questions Included in the Questionnaire**

- What are the patient’s characteristics and household characteristics?
- What is the level of household resource endowment (physical, natural, financial assets)?
- Specifically, what are the household income sources and expenditures on consumption items, including health?
- What is the social support stock (providers, relationships, assistance, and frequency)?
- What is the level of adherence to various adherence activities (treatment initiation appointment, pharmacy refill, food intake, dosing time, and medication dose) and what are the respective adherence barriers?
- What changes, over time, are there in the quality of life indicators (weight, CD4, function, WHO staging)?
- What is the effect on disease condition and side effects of commitment to ART?
- What individual and programmatic factors influence adherence?
- What are the costs involved in accessing and utilising ART services? What is the impact of economic burden on adherence, and what coping strategies are there?
- What is the level of satisfaction with healthcare services, including counselling?
2.4.3. Qualitative Explanatory Studies

The qualitative explanatory studies were implemented after the survey, and were staggered over a period of one year through the thesis writing process. They were intended to generate qualitative insights into the quantitative data, find answers to emergent hypotheses and questions, and seek unique explanations for unexpected results. Without pre-empting the empirical Chapters, it can be said that, in general terms, socio-demographic characteristics, locational factors, facility resource endowment, biomedical and adherence barriers, and so on, did not have a substantial negative effect on adherence to ART. Rather than using further computer-aided statistical analyses, it was better to seek explanations through qualitative studies.

A renewed search for answers resulted in phased and repeated implementation of qualitative explanatory studies. For instance, the first post-survey qualitative studies intended to discover how patients accommodated or navigated the economic burden in the two resource-scarce settings. Subsequently, FGDs were conducted in order to obtain consensus and differences in opinion about the perceived patterns and trends in adherence levels and barriers between the two accredited sites. Discoveries that weather conditions had a potential effect on adherence trends led to collecting rainfall performance data from the Makerere University Weather Station and comparing it with seasonal fluctuations in adherence to ART. Furthermore, since the survey findings pointed to the role of information in adherence to ART, the counselling information previously collected during the exploratory qualitative studies and set aside as secondary material was retrieved, and content analysis performed to assess the potential link between counselling and education with adherence to ART. Finally, because patients and health facilities survived amidst resource-scarcity, it became necessary to assess the instrumentality of social support systems. All these qualitative studies allowed a clear picture to emerge of how biomedical factors interact with environmental factors to create adherence to ART.
2.5 Data Analysis

2.5.1 Quantitative Data Analysis

After the survey, some of the open-ended questions whose responses could not be predicted in advance were coded. Once the coding process was complete, the questionnaire was entered onto the computer using EPI-INFO version 6 and the output data exported to SPSS version 12.0 for statistical analysis. During analysis, two types of adherence measuring were statistically derived, namely: adherence level and adherence status. The first is the traditional way of measuring adherence to medication dose, recorded as the number of tablets taken correctly, as a proportion of those prescribed. This is what is commonly presented as ‘mean’ and ‘median’ adherence in most of the background adherence studies. This form of measuring adherence is an important marker for the clinical evaluation of individual patients, as well as for counselling purposes. In my opinion, adherence level is a more precise way of measuring adherence itself because it gives the exact figure in the form of a mean (or median). However, the major limitation with establishing adherence through adherence level is that it does not reveal the proportion of patients within a given sample who achieve the 95% adherence, which is the optimal adherence required to suppress the HIV virus. Adherence status was, therefore, calculated as the percentage of patients who took at least 95% of their pills correctly. This is essential for programmatic or public health evaluation (Laing & Hodgkin 2006:28). However, as
there is no gold standard for measuring optimal adherence, four adherence thresholds were derived: optimal adherence (100%), near-optimal adherence (95-99%), sub-optimal adherence (80-94%), and non-adherence (<80%), indicating the proportion of patients under each threshold. The overall mean adherence was based on the 3-years’ pill-count data preceding the survey.

The analysis also focused on two kinds of adherence: global adherence and adherence trends. The global adherence reflected the overall adherence for all years combined. On the other hand, based on the date recordings as extracted from the patients’ files, the adherence trend was broken down into mean monthly and mean quarterly adherence for each year (from October 2004 to July 2007), as well as a pooled seasonal calendar adherence (January to December). The seasonal calendars adherence was intended to establish seasonal fluctuations in adherence, and the potential causes.

In a bivariate analysis, Pearson’s Chi-Square tests were carried out to measure the relationship between key independent variables and sub-optimal adherence (<95), with results indicating no statistically significant relationship. Such results do not necessarily imply that there are no predictors of adherence in the two settings. As my statistician noted, an association that is not statistically significant does not necessarily imply that it is not socially significant. Complicated statistical modelling has its limitations. As indicates Huwe (2005:4):

Traditional statistical techniques (such as p-values or confidence intervals) can aid interpretation amongst the statistically literate, but are confusing to many and are open to significant pitfalls. Apparent differences across indicators may not in fact represent real underlying differences but may be the result of random variation. Conversely, real and important differences may go undetected when all measures fall within statistical limits (false reassurance). Assessing changes over time in indicators can also be difficult.

In this study, combining both quantitative and qualitative data helped in constructing the facilitating factors as the predictors of adherence (refer to Chapter 5).

In order to establish treatment response as a function of adherence to antiretroviral therapy, data on health indicators were analysed. These included CD4 count, weight,
functional status, and WHO staging. The two facilities collected CD4+ T cell tests for individual patients once every six months. At the time of the survey, patients had undergone CD4 tests between 1 and 5 times. A paired Samples T-Test was used to assess the mean change in CD4 count over consecutive visits. The data for other health indicators other than CD4 count was also calculated in terms of the mean, on a monthly and/or quarterly basis, and compared with the ART adherence trends.

### 2.5.2. Qualitative Data Analysis

Given that qualitative data aided in providing plausible explanations for the emerging hypotheses and questions during the research process, the actual data analysis was not done after but between fieldwork phases. Analysing and reanalysing data, and writing while collecting the data, made it possible to collect more data to answer emergent questions and hypotheses before the data collection was over.

Analytical induction was used to analyse the qualitative data. In simple terms, analytical induction aims to produce complete and universal statements about social phenomena (Sarantakos 2005). This means moving from the specific to the general, that is, constructing abstract concepts from study specific data (ibid: 351). Here, analytical induction involved relating the data to the emerging hypotheses, confirming the hypotheses, or generating new hypotheses until saturation was achieved. The Chapter ‘Working with Data’ in Taylor et al. (1984) guided the analysis of qualitative data, which involved (re)reading field notes and qualitative data line-by-line and making notations in the margins. The key questions that guided this process were:

- What does this piece of evidence tell me?
- What is the participants’ major concern?
- What themes, concepts, and propositions emerge here?
- What meaning is assigned to the concepts by the participants?
- Within what setting and by which people is this being said or done?

In some cases, the patterns were less apparent or subtle, necessitating discovery of the deeper meaning of what was being said and done. This was the case while analysing the interaction of adherence barriers and facilitating factors.

A second set of qualitative data that was analysed was the counselling material. A content analysis (CA) was used to analyse the content of ART counselling material. A complete CA looked for the manifest and the latent content of counselling material14. With manifest content, descriptive content analysis was used to identify

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14 The *manifest content* refers to the visible, surface text, and the actual part of the text manifested on the document – the words, sentences, paragraphs and so on. The *latent content* is the underlying
the frequency of the appearance of a given message. In looking for latent content, *meaning-contextual analysis* was used to deconstruct and reconstruct the purpose of communication strategy, meanings encoded in the message, the context in which meanings are constructed, and the impact such messages may have had on health compliance. The second level contextual analysis involved a thorough (re)reading of the text to identify underlying meaning that may cause emotional and cognitive impact, as well as recalling the counsellors’ communication behaviour and motives, and the social context within which such counselling messages were created (see Chapter 6, section 6.4.3).

In the pursuit of accuracy, I shared the counselling material with the two counsellors who had previously conducted the counselling sessions. In addition, in order to have the reader participate in the interpretation of the counselling material, in Chapter 6 the counselling text is reproduced in its original form with the meaning labels that I personally developed during open coding (see Chapter 6, section 6.3).

2.6 A Note on Validity and Reliability

Validity refers to whether the instrument measures what it intends to, and reliability refers to whether the instrument is free of random error (Pequegnat *et al.* 2000, in IOM 2008). With validity, the major issue is whether the findings are in agreement with theoretical or conceptual values, while reliability is about whether the method produces the same results whenever it is repeated, and is not sensitive to the researcher, the research condition, or the respondents (Sarantakos 2005:83-92). The process of describing the methodology has highlighted the rigour with which this study was conducted, especially in terms of study design, the care taken to measure adherence itself, and the explanatory variables (*internal validity*). As already indicated in this Chapter, the research instruments included all key relevant variables for measuring the core argument (*content validity*), and the open-ended research design allowed additional explanatory concepts/variables to emerge.

In terms of *external validity*, the *primary* aim of this research was not to generate results that are generalisable or transferable to other resource-poor settings, but to provide a *reasonably* complete explanation of adherence to ART and the desired best practices. This is because Uganda’s HIV treatment programme, in terms of history, policy direction, and implementation process, would differ from other resource-poor settings. Even with intra-country experience, the results would not be comparable because this study included pioneer ART sites and an early majority of patients with meaning conveyed through the document. Here, the researcher identifies the hidden meaning (Sarantakos 2005:301).
a wealth of coping experiences, strong social support systems, in routine healthcare settings. It is possible that adherence results and barriers would have been different if this study had been conducted in hard-to-reach areas, in a conflict situation, or somewhere without regular antiretroviral supplies.

In terms of reliability for this research, firstly the accuracy of the measuring instruments and procedure lay not in pre-determination of the methodology path but in the flexibility of the research design. Secondly, in order to overcome inaccuracies associated with adherence methods, a combination of self-report and pill-count (subjective methods) and health indicators (objective methods) were used in order to reduce the errors associated with measuring adherence methods using a single tool. Third, the survey was conducted by six social scientist enumerators (3 male and 3 female), adequately trained in the techniques of administering the questionnaire and facilitating a field relationship. Fourth, the questionnaire was pre-tested in order to assess the relevance of the questions and the completed pilot questionnaire was passed on to the statistician for a trial analysis. Fifth, as exit interviews were conducted on pharmacy refill visits, the questionnaires were immediately edited for accuracy by the principal researcher before the respondent left for a one-month refill recess.

Since, with interpretive research, the traditional notions of validity and reliability do not apply in the same fashion as in the positivist tradition, alternative criteria have to be employed to judge the rigour of qualitative research. The alternative criteria for evaluating qualitative research are trustworthiness and authenticity15 (Bryman 2004:273). In this case, the reliability of qualitative methods can be judged by the inclusion of multiple individuals and groups, therefore generating multiple accounts (credibility); inclusion of two comparative study sites and implementing fieldwork for an extended duration (transferability); and sharing the research process and outcomes with peers (dependability).

2.7 Ethical Considerations

This research was cleared by the Uganda National Council of Science and Technology (NCST), the supreme body vested with power and authority to review and grant permission to conduct research that requires such permission. The NCST verifies whether the proposed research complies with ethical standards before permission is granted. At the level of implementation, permission was sought from the Project Director of the Mission Facility and the Medical Superintendent of the Public Facility.

15 Trustworthiness is made up of four criteria, each of which has an equivalent criterion in quantitative research – credibility, transferability, dependability, confirmability. Authenticity refers to the wider impact of the research, for instance action research (Byman 2004:273).
Although the clinical records were reviewed without patients’ direct permission, permission was granted by the provider, who equally reserved the right to use the patient data provided such usage posed no harm to the provider or the patient. The questionnaire itself had an informed consent statement which was read out before the commencement of the interview. In terms of anonymity, the name of the respondent did not appear on the research instrument. Instead, the questionnaire bore respondents’ initials and number, with the actual names kept separate from the questionnaire. Finally, for confidentiality, direct quotes presented in this thesis do not bear respondents’ names, nor has the raw data been made public.

2.8 Discussion

The fundamental conclusion is that even with adherence to medication, quantitative and qualitative methodologies are not mutually exclusive. The methodology section presented above provides systematic guidance to how the two methodologies can be infused in a single adherence study, and the benefits associated with such methodological triangulation.

The major issue, however, is not whether it is possible to have combined methodologies, but the reasons for desiring and adopting methodological triangulation. Here, the intrinsic purpose of implementing a combined methodology was to explicate and thus to prove or disprove the theoretical argument. However, the implementation strategy was not determined by the researchers’ underlying belief about the methodology but by the emergent data. As a result, the two methodologies were approached with caution, thus adopting an ‘open and flexible’ strategy in the quest for valid and reliable results within overall ethical concerns. In other words, the emergent results and attendant assumptions determined what data would be sought and from whom, using which appropriate research methods and techniques. In summary, in this case, the quest for plausible and accurate explanations (outcome) determined the methodological fit and path, but not the research object (adherence), theoretical perspectives (health models), or the researcher’s belief in a given methodology (subjective conviction).
3

Adherence to Antiretroviral Treatment in Uganda: Patterns and Barriers

3.1 Introduction

One of the research questions posed at the beginning of this study was to assess the adherence activities that precede and culminate in the pill-taking event itself, and the respective barriers. The decision to investigate the adherence barriers based on the key activities stemmed from earlier work that indicated that an aggregate measure using a single number of pills concealed the important activities that precede and culminate in the medication action. By 2004 (at the inception of this study), the only work that suggested an expanded measurement of adherence was that of Ryan et al. (2003), who made a distinction between global and episodic adherence.

Global adherence was regarded as an aggregate measure, referring to an overall probability of pill-taking, presented as a percentage of prescribed doses actually taken. Episodic adherence, on the other hand, was intended to assess whether an individual took a particular dose of medication in a timely manner. Ryan and associates argued that episodic adherence highlights the dynamics of the activities and emotional experiences that occur immediately before or during the scheduled pill-taking time, and that adherence is not an event but an outcome of a succession of events. Later, in 2008 the Institute of Medicine (IOM)\textsuperscript{16} also revealed that the use of a single number to define adherence may mask crucial insights to adherence problems, product acceptability, and potential areas of intervention.

Based on the composition of adherence barriers in the background studies implemented in the developed world and resource-poor settings on the one hand, and the preliminary findings from the exploratory qualitative studies on the other, it became necessary to investigate adherence to ART as both a process and as an episodic event using five adherence activities. These five adherence activities were: 1) adherence to initiation appointments; 2) adherence to refill appointments; 3) adherence to meal/snack-taking; 4) adherence to medication time; and 5) adherence to the medication dose itself. The assumption is that these adherence activities by

\textsuperscript{16} USA Academy
themselves or via their associated barriers directly or indirectly influence adherence to medication dose itself.

The first part of this Chapter takes stock of the first four adherence activities that precede and culminate in the medication dose and attendant barriers. The last section examines adherence to medication and the barriers to taking the required medication dose. Finally, the last section synthesises the adherence barriers for all the adherence activities.

### 3.2 An Overview of Non-Adherence Levels

As already indicated in the methodology Chapter, this study identifies five sets of adherence activities, each with specific adherence barriers. The five adherence activities are: 1) adherence to initiation appointments; 2) adherence to medication refill; 3) adherence to meal/snack-taking; 4) adherence to medication time; and 5) adherence to medication dose. However, before discussing for each of these adherence activities in details, it will be necessary to present an overall picture of non-adherence for all of the adherence activities.

#### Table 3.1: Non-adherence to Particular Adherence Activities over the 3-Year Period

<table>
<thead>
<tr>
<th>Type of Adherence Activity</th>
<th>Percentage (Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-adherence to any of the 6 initiation appointments</td>
<td>2%-9% (-)³</td>
</tr>
<tr>
<td>Non-adherence to pharmacy refill</td>
<td>40% (103)</td>
</tr>
<tr>
<td>Non-adherence to meal/snack advice</td>
<td>66% (172)</td>
</tr>
<tr>
<td>Non-adherence to dosing time</td>
<td>53% (139)</td>
</tr>
<tr>
<td>Non-adherence to medication dose</td>
<td>46% (142)</td>
</tr>
</tbody>
</table>

Overall, Table 3.1 above shows that between 2% and 66% of patients failed to adhere to a particular adherence activity over a time-period of three years preceding the survey. Overall, the level of non-adherence was low, especially given the fact such adherence was based on the dataset for the three years preceding the study. The following section will describe each of the five adherence activities and their respective barriers.

### 3.3 Adherence Activities

#### 3.3.1. Adherence to Induction Activities

‘Adherence to induction activities’ refers to the probability of complying with initial counselling activities intended to prepare the ART client for life-long treatment. Adherence to induction appointments is crucial because it helps the patient to gain knowledge of the disease condition, the goals of the therapy and its limitations,
potential side effects, therapeutic behavioural change, as well as orienting their Treatment Supporters in care and support practices. To the provider, this phase provides vital information on patient characteristics, potential adherence barriers, and on possible corrective measures for (re-)enforcing adherence to ART.

Adherence to induction activities was measured by establishing the level of adherence to appointments for VCT, CD4 cell count tests, collecting CD4 test results, induction counselling sessions (1st-3rd session), and the ART initiation appointment. Adherence data for each of these six appointments was extracted from the clinical records and recorded as ‘date expected’ and ‘date reported’, as were the reasons for having missed the appointment, where applicable. Those patients who reported for their appointment on the expected date were considered adherent to that particular activity. It should be noted, in the table below, the fluctuation in the number of cases between consecutive visits is mainly due to individual patients’ (in) eligibility for subsequent health appointments. For instance, if an individual’s CD4 cell count was above or extremely below the required threshold, it often resulted in delayed or early introduction of antiretroviral treatment, thus deferring or skipping some VCT activities respectively. In the table below, the VCT row cells are blank because both VCT and routine counselling and testing (RCT) are sought without prior appointment.

Table 3.2: Proportion of People who Returned on the Exact Date of Appointment

<table>
<thead>
<tr>
<th>Types of Initiation Activity</th>
<th>Total Number of Respondents</th>
<th>Actual Number of being Adherent</th>
<th>Percentage Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date for Seeking VCT/Diagnosis</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Date Returned for CD4 Test</td>
<td>247</td>
<td>232</td>
<td>94%</td>
</tr>
<tr>
<td>Date Picked up CD4+ Test Results</td>
<td>244</td>
<td>222</td>
<td>91%</td>
</tr>
<tr>
<td>Date Returned for 1st Counselling</td>
<td>243</td>
<td>225</td>
<td>93%</td>
</tr>
<tr>
<td>Date Returned for 2nd Counselling</td>
<td>106</td>
<td>103</td>
<td>97%</td>
</tr>
<tr>
<td>Date Returned for 3rd Counselling</td>
<td>68</td>
<td>64</td>
<td>94%</td>
</tr>
<tr>
<td>Date Initiated on ARVs</td>
<td>108</td>
<td>106</td>
<td>98%</td>
</tr>
</tbody>
</table>

Results in the table above indicate a high adherence to initiation appointments as ≥ 91% returned for each of the initiation appointments in a timely manner. For those who were non-adherent to the initiation appointment the qualitative reasons given were: fear of knowing CD4 count results; not being fully prepared to start ART; CD4 cell count still being above the threshold (200 cell count); having a busy schedule; delayed return from the village; being seriously sick; because a Treatment Supporter
was not available to accompany the patient to the health facility; and because the appointment occurred on a public holiday. It was outside the scope of this Chapter to discuss the facilitating factors (see Chapter 5).

3.3.2. Adherence to Pharmacy Refill Appointments

Here, adherence to refill appointments is intended to refer to the act of turning up for a prescription on the exact date of the appointment. Results from the quantitative study indicated that a large proportion of ART clients (40%, 103) had skipped one or more antiretroviral refill appointments over the three years preceding the survey. The comparison of adherence to refill appointments between the two sites indicates a statistically significant proportion (47%, 67) of urban clients was more likely to be non-compliant to refill appointments than their rural counterparts (30%, 36) ($x^2= 8.049, df = 1, p = .005$). The major reason for this being travel to the village. In a bivariate analysis, a statistically significant proportion (75% 76) of patients who missed pharmacy refill were more likely to miss medication doses ($x^2= 13.435, df=1, p=.000$) at some point, in both cases the data source consisted of clinical records.

A separate question that captured the number of times individuals patients ever skipped pharmacy refill appointments, indicated that having missed a pharmacy refill does not necessarily imply that the patient completely ran out of pills17. The table below presents the two scenarios of skipped refill appointments and the possibility of experiencing stock-outs.

Table 3.3: Incidences of Missing Pharmacy Refill and Possibility of Running out of Doses

<table>
<thead>
<tr>
<th>Level of Non-Adherence</th>
<th>Type of ARV Site</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mission n=111</td>
<td>Public n=37</td>
</tr>
<tr>
<td>Missed Pharmacy Refill but had Continuity Dose</td>
<td>60% (67)</td>
<td>32% (12)</td>
</tr>
<tr>
<td>Missed Pharmacy Refill and Ran Out of Pills</td>
<td>40% (44)</td>
<td>68% (25)</td>
</tr>
</tbody>
</table>

N.B.: These are multiple responses over three years.

The above table shows that out of the 148 total incidences of missed pharmacy refills in the two sites, less than half (47%, 69) of such incidences resulted in individual drug stock-outs, with a resultant possibility of the patient being non-adherent to medication doses. The possibility of running out of both the continuity dose was higher in the rural setting (68%, 25) than in the urban settings (40%, 44). Missed pharmacy refills

17 Recall the survey captured the data for the date expected and the actual date of reporting for the appointment, and the reasons given by the patient if there was a mismatch
Adherence to Antiretroviral Treatment in Uganda: Patterns and Barriers

Do not necessarily result in individual stock-outs because the dispensing procedure in both Public and the Mission Facility allowed ‘continuity doses’ for either 2 or 7 days respectively over and above the scheduled prescription time period. Such evidence suggests the greater the number of continuity doses the lower the possibility of completely running out of stock.

Delayed return for pharmacy refills in the rural settings was attributed to transport problems and prolonged sickness (refer to figures for reasons such as ‘transportation difficulties’ and being ‘seriously sick’ in Table 3.4 below)

Table 3.4: Reasons for Missing Pharmacy Refill Appointment

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Mission (n=53)</th>
<th>Public (n=31)</th>
<th>Total (n=84)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel (to the Village)</td>
<td>49% (26)</td>
<td>16% (5)</td>
<td>37% (31)</td>
</tr>
<tr>
<td>Transportation Difficulties</td>
<td>4% (2)</td>
<td>42% (13)</td>
<td>18% (15)</td>
</tr>
<tr>
<td>Employment Obligations</td>
<td>25% (13)</td>
<td>3% (1)</td>
<td>17% (14)</td>
</tr>
<tr>
<td>Still Had Some Pills Left</td>
<td>2% (1)</td>
<td>29% (9)</td>
<td>12% (10)</td>
</tr>
<tr>
<td>Child Was Sick</td>
<td>11% (6)</td>
<td>7% (2)</td>
<td>10% (8)</td>
</tr>
<tr>
<td>Attending Burial in the Village</td>
<td>13% (7)</td>
<td>3% (1)</td>
<td>10% (8)</td>
</tr>
<tr>
<td>Mistaken Dates</td>
<td>9% (5)</td>
<td>7% (2)</td>
<td>8% (7)</td>
</tr>
<tr>
<td>Was Feeling Better</td>
<td>4% (2)</td>
<td>3% (1)</td>
<td>4% (3)</td>
</tr>
<tr>
<td>ARVs Delivered by Treatment Supporter</td>
<td>4% (2)</td>
<td>0% (0)</td>
<td>2% (2)</td>
</tr>
<tr>
<td>No Reason</td>
<td>25% (13)</td>
<td>0% (0)</td>
<td>15% (13)</td>
</tr>
<tr>
<td>Other</td>
<td>2% (1)</td>
<td>10% (3)</td>
<td>5% (4)</td>
</tr>
</tbody>
</table>

N.B.: Multiple responses allowed.

In terms of the composition of barriers, patients in both urban and rural settings experienced almost the same type of barriers to adhering to refill appointments. The eight most important reasons were: 1) travel to the village; 2) transport difficulties; 3) employment obligations; 4) sickness; 5) child sickness; 6) attending a burial; 7) mistaken dates; 8) feeling better. A close scrutiny of the percentages and respective number of cases shows a high probability of missing a pharmacy refill in the urban settings due to travel to the village and employment obligations; while in the rural settings the main cause of missing a pharmacy refill was mainly due to failure to raise money for transport and sickness.

3.3.3 Adherence to Meal/Snack Intake

Adherence to Meal/Snack-Taking Advice refers to taking a meal or snack to avoid adverse metabolic effects associated with antiretroviral medication. Significantly, there
was no specification for dietary intake for the type of antiretroviral regimen\textsuperscript{18} that was being dispensed in the Mission Facility and the Public Facility. Nevertheless, findings from qualitative exploratory studies revealed that even with non-dietary prescription ARVs, patients tended to complain of adverse metabolic effects after taking ARVs on an empty stomach, and some went to the extent of vomiting the pills, or postponing taking the medication due to lack of food at home.

Eeh! If this medicine is not accompanied with food it can cause trouble. It causes drowsiness, it makes the heart race, vision becomes a problem, one develops tears in the eyes, joints become weak, and one starts shaking. This medicine demands a lot of water and food. But because we sometimes find it difficult to find food, we simply take the medicines on an empty stomach and live with the consequences as they occur. (Focus Group Discussion, RPF)

As a result, the survey was interested in the extent to which dosing on an empty stomach was a problem. Self-report results revealed that a large proportion (66\%, 172) of patients had at one time taken ARVs on an empty stomach. There was no statistically significant difference in empty stomach dosing between the urban-based patients (53\%, 74) and rural-based patients (54\%, 65) ($x^2 = .023(b)$, $df = 1$, $p = .879$).

The occurrence of empty stomach dosing was attributed to several causes, as table 3.5 indicates. The major cause of empty stomach dosing at both study sites was failure to have ready food available and food shortage at medication time. Adherence barrier like food shortage in a home was more common in an urban than in a rural setting.

### Table 3.5: Reasons for Taking ARVs on an Empty Stomach

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Type of Facility</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mission ($n=142$)</td>
<td>Public ($n=119$)</td>
</tr>
<tr>
<td>Food was not Ready</td>
<td>85% (121)</td>
<td>97% (116)</td>
</tr>
<tr>
<td>Food Shortage in a Home</td>
<td>56% (80)</td>
<td>50% (60)</td>
</tr>
<tr>
<td>Medication Time Occurs Earlier</td>
<td>4% (6)</td>
<td>4% (5)</td>
</tr>
<tr>
<td>Too Busy at Place of Work</td>
<td>5% (7)</td>
<td>3% (4)</td>
</tr>
<tr>
<td>Travelling on that Day</td>
<td>3% (4)</td>
<td>3% (3)</td>
</tr>
<tr>
<td>No Appetite for Food</td>
<td>4% (6)</td>
<td>8% (1)</td>
</tr>
<tr>
<td>Other</td>
<td>.7% (1)</td>
<td>2% (2)</td>
</tr>
</tbody>
</table>

N.B.: Multiple responses allowed.

\textsuperscript{18} Regimens that require taking a meal or snack before dosing are Lopinanavir + Ritonavir (LPV/r), Kaletra, Ritonavir (RTV), Norvir, Saquinavir SGC (SQV-S), Fortovase, Saquinavir HCG (SQV-H), Invirase, Nelfinavir (NFV), or Viracept.
The reasons given under ‘Other’ included: 1) failure to accommodate medication whereby taking medicine after food led to bodily reactions such as palpitations, vomiting etc; 2) fasting, 3) being in prison; 3) social commitments.

### 3.3.4 Adherence to Dosing Time

Adherence to dosing time is closely linked to ‘scheduling accommodation’, which is defined by Fogarty et al. (2002), in a Western sense, as a person’s ability to fit medication into a daily schedule as facilitated by timers, proper adherence instructions, reminders, and such like. In this study ‘adherence to medication time’ was regarded as taking the prescribed dose within one hour of the scheduled time. Half (53%, 139) of all the patients at both sites admitted having forgotten taking pills on time over the last 3 years preceding the survey. There was no statistically significant difference in missing dosing times between the urban-based patients (53%, 74) and the rural-based patients (54%, 65) ($x^2 = 0.743$, df = 1, p = .786).

The next question intended to estimate the amount of time that elapsed between the scheduled time for pill-taking and the actual time the pill was taken. Of the 139 patients who had skipped the dosing time over the 3-year treatment period preceding the survey at least once, half (55%, 78) were in a position to recall the number of episodes and number of hours that elapsed after the dosing time. Of those patients, they had recorded 82 missed dosing time episodes. The table below presents patient’s estimation of the number of dosing hours they ever defaulted.

**Table 3.5b: Number of Hours defaulted (both sites combined)**

<table>
<thead>
<tr>
<th>No. of Hours Skipped</th>
<th>Percent (n=78)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>73% (57)</td>
</tr>
<tr>
<td>2</td>
<td>18% (14)</td>
</tr>
<tr>
<td>3</td>
<td>6% (5)</td>
</tr>
<tr>
<td>4</td>
<td>1% (1)</td>
</tr>
<tr>
<td>7</td>
<td>1% (1)</td>
</tr>
<tr>
<td>8</td>
<td>3% (2)</td>
</tr>
<tr>
<td>10</td>
<td>1% (1)</td>
</tr>
<tr>
<td>24</td>
<td>1% (1)</td>
</tr>
</tbody>
</table>

Patients’ estimation of the time defaulted indicated that majority (73%, 57) had skipped by only one hour. However, if the data were to be disaggregated on a six-hourly basis, 6% (5) of episodes of missed dosing times might have resulted in missing half a day’s ARV dose. Table 3.6 presents the barriers to adherence to dosing time.
Table 3.6: Reasons for Missing Dosing Time

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Mission (n=72)</th>
<th>Public (n=64)</th>
<th>Total (n=136)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lacked Reminder</td>
<td>33% (24)</td>
<td>33% (21)</td>
<td>33% (45)</td>
</tr>
<tr>
<td>Travel/Safari</td>
<td>21% (15)</td>
<td>17% (11)</td>
<td>19% (26)</td>
</tr>
<tr>
<td>Too Busy at Workplace/Farming</td>
<td>21% (15)</td>
<td>16% (10)</td>
<td>18% (25)</td>
</tr>
<tr>
<td>Domestic Work</td>
<td>7% (5)</td>
<td>13% (8)</td>
<td>10% (13)</td>
</tr>
<tr>
<td>Food was not Ready</td>
<td>8% (6)</td>
<td>8% (5)</td>
<td>8% (11)</td>
</tr>
<tr>
<td>Social Obligations</td>
<td>7% (5)</td>
<td>3% (2)</td>
<td>5% (7)</td>
</tr>
<tr>
<td>Burial</td>
<td>3% (2)</td>
<td>6% (4)</td>
<td>4% (6)</td>
</tr>
<tr>
<td>Entertaining Visitors</td>
<td>1% (1)</td>
<td>5% (3)</td>
<td>2% (4)</td>
</tr>
<tr>
<td>Lacked Food on that Day</td>
<td>1% (1)</td>
<td>3% (2)</td>
<td>2% (3)</td>
</tr>
<tr>
<td>Returned Late from Work</td>
<td>4% (3)</td>
<td>0% (0)</td>
<td>2% (3)</td>
</tr>
<tr>
<td>Other (Too Sick)</td>
<td>3% (2)</td>
<td>2% (1)</td>
<td>2% (3)</td>
</tr>
</tbody>
</table>

N.B.: Multiple responses allowed

Table 3.6 above shows that patients in the two sites tended to share common barriers to adherence to dosing time. The major factors contributing to missing the dosing time were lack of a reminder, travelling, being too busy, and domestic work; other reasons included oversleeping, imprisonment, and being seriously sick. In some cases, excessive desire to adhere with other forms of treatment activities led to missing the dosing schedule.

I normally take my medicines at 8:00am; but sometimes I delay. The day I am supposed to collect my medicine I have to get up early in order to be at the hospital before the queue gets long. When I return home, I have to make sure that I prepare something to eat before I take the medication. I end up taking the medicine late.

(Male Respondent, Kayunga Public Hospital)

3.3.5 Failure to Return Unused Extra Pills

Review of patients’ clinical records revealed the unusual phenomenon of failure to return extra unused pills (continuity doses) at scheduled pharmacy refill visits. According to data extracted from the pill-count data, a small proportion (29%, 74) of all patients at both sites failed to return extra unused pills present in the medication bottles. In a bivariate analysis, a statistically significant proportion (49%, 68) of urban-based patients were less likely to return extra unused pills than (5%, 6) the rural-based patients ($x^2= 60.248, df=1, p=.000$). Several reasons were given for failure to return with unused pills.
Table 3.7: Reasons for Failure to Return Extra Unused Pills

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Type of Facility</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mission (n=61)</td>
<td>Public (n=5)</td>
</tr>
<tr>
<td>Vomited and Ended up Taking More than Once</td>
<td>43% (26)</td>
<td>80% (4)</td>
</tr>
<tr>
<td>Forgot and Ended up Taking More than Once</td>
<td>33% (20)</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Only Misplaced/ left behind the Pills</td>
<td>20% (12)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Can’t Recall what Happened to the Missing Pills</td>
<td>8% (5)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Took Strong Dose to Get Better Quickly</td>
<td>7% (4)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Under-Counting at Pharmacy</td>
<td>5% (3)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Refunded Borrowed Pills</td>
<td>3% (2)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>No Reason Given</td>
<td>18% (11)</td>
<td>0% (0)</td>
</tr>
</tbody>
</table>

N.B.: Multiple responses allowed

Failure to return extra unused pills was variously attributed to: 1) failure to accommodate medicine reflected in taking extra-dose after vomiting; 2) lack of concentration reflected in unintended overdosing and misplacing the pills; 3) taking an overdose in order to achieve quick recovery; refunding pills previously borrowed from fellow patients, 4) putting the blame on the pharmacy for under-counting the pills.

3.3.6 Adherence to Medication Dose

3.3.6.1 Global Adherence

This is the common measure of adherence which can be operationally defined as taking the appropriate number of pills as prescribed by the health worker. Table 3.7 below shows the incidence of missed pills among patients for the entire treatment period of 3 years that preceded the survey. As already noted, the data were extracted from patients’ files and integrated into the survey questionnaire.

Table 3.8: Proportion of Patients who Ever Missed Pills over the Three Years

<table>
<thead>
<tr>
<th>Ever Missed Pills</th>
<th>ARV Site</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mission</td>
<td>Public</td>
</tr>
<tr>
<td>Yes</td>
<td>78% (110)</td>
<td>27% (32)</td>
</tr>
<tr>
<td>No</td>
<td>23% (32)</td>
<td>73.3% (88)</td>
</tr>
</tbody>
</table>

In a bivariate analysis, a statistically significant proportion (78%, 110) of urban-based patients was more likely to miss medication dose than (27%, 32) the rural-based patients ($x^2 = 67.608$ (b) $df = 1, p = .000$). However, such higher levels of adherence did not necessarily affect the overall 95% adherence in the Mission Facility. In the others, the recorded difference in non-adherence between the two facilities represents missed pill episodes but not the actual number of missed pills.
As already indicated in the methodology Chapter, two types of adherence measures were used, that is: adherence level (calculated as mean adherence) and adherence status (calculated as the proportion of patients in a sample taking 95% of their prescribed pills). I have also indicated that for adherence status, this is classified as the proportion of patients achieving optimal adherence (100%), near-optimal adherence (95-99%), sub-optimal adherence (80-94%), and non-adherence (<80%). Table 3.8 below shows the adherence status for the sampled patients (262) for the entire treatment period of 3 years preceding the survey.

### Table 3.9: Adherence Status for the Mission and Public Facility (n=262)

<table>
<thead>
<tr>
<th>Adherence rates</th>
<th>ARV Site</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mission Facility</td>
<td>Public Facility</td>
</tr>
<tr>
<td>Non-adherence (&lt;80%)</td>
<td>1.4% (2)</td>
<td>5.0% (6)</td>
</tr>
<tr>
<td>Sub-Optimal (80-94%)</td>
<td>9.9% (14)</td>
<td>3.3% (4)</td>
</tr>
<tr>
<td>Near-Optimal (95-99%)</td>
<td>66.2% (94)</td>
<td>17.5% (21)</td>
</tr>
<tr>
<td>Optimal (100%)</td>
<td>22.5% (32)</td>
<td>74.2% (89)</td>
</tr>
<tr>
<td>Total</td>
<td>100% (142)</td>
<td>100% (120)</td>
</tr>
</tbody>
</table>

Table 3.9 above shows that, of the 262 patients sampled, 90% (236) achieved the 95% near-optimal adherence level over the 3 years that preceded the survey – that is, both optimal and near-optimal adherences combined. This implies that only 10% (26) failed to achieve 95% adherence. Surprisingly, while Table 3.8 shows that a statistically significant proportion of urban-based patients was more likely to miss medication dose than the rural-based patients, there was no substantial difference in the ≥95% adherence between the two groups of patients. This is because 89% (126) of patients in UMF, which provides holistic healthcare services, and 92% (110) of patients in RPF, providing minimum healthcare, took ≥95% of their prescribed pills over the three years preceding the survey. In fact, in terms of the actual optimal adherence (100%), the rural-based patients outperformed the urban-based patients, with 74% (89) compared to only 23% (32) respectively taking 100% of their prescribed pills. Chapter 5 will examine the facilitating factors; for this Chapter, Table 3.10 below presents the barriers to medication dose.
Adherence to Antiretroviral Treatment in Uganda: Patterns and Barriers

Table 3.10: Reasons for Missing Antiretroviral Medication (n=144)

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Type of Facility</th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mission n=97</td>
<td>Public n=46</td>
<td></td>
<td>n=144</td>
</tr>
<tr>
<td>Forgot</td>
<td>90% (87)</td>
<td>26% (12)</td>
<td></td>
<td>69% (99)</td>
</tr>
<tr>
<td>Travel</td>
<td>13% (13)</td>
<td>14% (7)</td>
<td></td>
<td>14% (20)</td>
</tr>
<tr>
<td>Sickness</td>
<td>16% (15)</td>
<td>9% (4)</td>
<td></td>
<td>13% (19)</td>
</tr>
<tr>
<td>Ran out of Pills</td>
<td>13% (13)</td>
<td>13% (6)</td>
<td></td>
<td>13% (19)</td>
</tr>
<tr>
<td>I Was Too Busy</td>
<td>8% (8)</td>
<td>13% (6)</td>
<td></td>
<td>8% (14)</td>
</tr>
<tr>
<td>Attending Burial</td>
<td>5% (5)</td>
<td>13% (6)</td>
<td></td>
<td>8% (11)</td>
</tr>
<tr>
<td>Lacked Accompanying Food</td>
<td>5% (5)</td>
<td>2% (1)</td>
<td></td>
<td>4% (6)</td>
</tr>
<tr>
<td>Feeling Better</td>
<td>2% (2)</td>
<td>4% (2)</td>
<td></td>
<td>3% (4)</td>
</tr>
<tr>
<td>Attending a Social Event</td>
<td>2% (2)</td>
<td>2% (1)</td>
<td></td>
<td>2% (3)</td>
</tr>
<tr>
<td>Lost the Pills</td>
<td>2% (2)</td>
<td>2% (1)</td>
<td></td>
<td>2% (3)</td>
</tr>
<tr>
<td>Side Effects</td>
<td>0% (0)</td>
<td>6% (3)</td>
<td></td>
<td>2% (3)</td>
</tr>
<tr>
<td>Transport Problems to Pick up Pills</td>
<td>1% (1)</td>
<td>4% (2)</td>
<td></td>
<td>2% (3)</td>
</tr>
<tr>
<td>Misplaced Pills</td>
<td>2% (2)</td>
<td>0% (0)</td>
<td></td>
<td>1% (2)</td>
</tr>
<tr>
<td>Vomited</td>
<td>1% (1)</td>
<td>0% (0)</td>
<td></td>
<td>0.7% (1)</td>
</tr>
<tr>
<td>Was Sharing Medicine</td>
<td>1% (1)</td>
<td>0% (0)</td>
<td></td>
<td>0.7% (1)</td>
</tr>
<tr>
<td>Can’t Tell</td>
<td>12% (12)</td>
<td>0% (0)</td>
<td></td>
<td>0.7% (12)</td>
</tr>
</tbody>
</table>

N.B.: Multiple responses allowed

Forgetfulness was the leading cause of being non-adherent to antiretroviral medication, followed by travel to the village, sickness, individual stock-outs, being too busy, attending a burial, and lack of food at medication time. It should be noted that the biomedical factors seem to be at the periphery, with few incidences of missed doses attributed to feeling better (3%, 4), side effects (2%, 3), lost tablets (2%, 3), or vomiting (0.7%, 1). It is worth noting that while forgetfulness affected adherence in both rural and urban settings, this problem was higher in the urban than in the rural setting.

3.3.6.2. Trends in Non-Adherence

While the global adherence presented above (in Table 3.9) provides the overall picture of adherence to ART, it may conceal adherence trends and their attendant barriers. Therefore, this section concentrates on time-course non-adherence, for those 142 patients who ever recorded missed pills over the three years that preceded the survey. However, due to limitations of space, only the seasonal non-adherence for the calendar year (January to December) will be presented here. The longitudinal adherence data will be presented in Chapter five. Further, because the measure of adherence using adherence level (mean percentage pills taken correctly) is more revealing of the central tendency than adherence status (proportion of patients who take 95% of prescribed
doses), this section will analyse non-adherence in the form adherence levels. Table 3.11 below presents seasonal non-adherence for the calendar year, with pill-count data pooled on monthly basis. Both the mean and median are presented here because the two have different levels of accuracy. The episodes of missed pills simply refer to the number of times (incidences, or counts) the 142 patients missed their pills in a given month over the entire treatment time period.

**Table 3.11: Mean Proportion and Episodes of Missed Pills for Each Month**

<table>
<thead>
<tr>
<th>ARV Site</th>
<th>Months</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>J</td>
<td>F</td>
</tr>
<tr>
<td><strong>Urban Mission Facility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean % Missed Pills</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Median % Missed Pills</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Episodes of Missed Pills</td>
<td>48</td>
<td>45</td>
</tr>
<tr>
<td><strong>Rural Public Facility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean % Missed Pills</td>
<td>7</td>
<td>50</td>
</tr>
<tr>
<td>Median % Missed Pills</td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Episodes of Missed Pills</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total (both sites)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean % Missed Pills</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Median % Missed Pills</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Episodes of Missed Pills</td>
<td>51</td>
<td>47</td>
</tr>
</tbody>
</table>

A close look at Table 3.11 above reveals a slightly different pattern in non-adherence to medication dose between the urban and the rural settings. While the urban-based patients seeking antiretroviral services in the Mission Facility recorded high episodes of missed pills (29-57) throughout the year, they tended to skip few antiretroviral doses, which is reflected in a lower mean percentage of missed pills (4%-7%) recorded throughout the year. On the other hand, while the rural-based patients recorded few episodes of missed pills (1-5), they tended to skip large antiretroviral doses, which is reflected in a high mean percentage of missed pills (1% - 50%) recorded in certain months of the year. A second observation is the coincidence of sub-optimal adherence on a quarterly basis between two different facilities, namely; January-February, May, August, and October-November (refer to the bold figures, especially the mean and episodes of missed pills).

When data for adherence barriers (same question for Table 3.10 above) were plotted on a line graph, the outcome indicated coincidence of multiple adherence barriers during February, June, and November, with those months roughly coinciding with non-adherence and adherence barriers roughly coincide because this adherence analysis is based on pill-count data collected by health workers on the next pharmacy refill visit.

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19 Non-adherence and adherence barriers roughly coincide because this adherence analysis is based on pill-count data collected by health workers on the next pharmacy refill visit.
Adherence to Antiretroviral Treatment in Uganda: Patterns and Barriers

those in which decrease in adherence to medication dose was recorded. The main adherence barriers are: forgetfulness, sickness, travel, individual stock-outs, and being busy.

Figure 3.1: Reasons for Occurrence of Missed Pills in Calendar Months.

[Graph showing reasons for missed pills in calendar months]

Seasonal Calendar Tools used in Participatory Poverty Assessments have always indicated the effect of weather conditions on the levels of poverty. While the amount of rainfall for Central region of Uganda varied dramatically between 2004 and 2005, the output on the bar-graph (Fig 3.2 below) reveals that the intensity of rainfall during the beginning, mid, and end-of-year corresponds to the same period in which non-adherence and multiple adherence barriers were recorded. In each of those months, the rainfall lasted for between 9-16 days, suggesting that a combination of the amount and duration of rainfall has an impact on adherence to medication dose and adherence barriers (for source, see Appendix Table A.2).

Figure 3.2: Seasonal Rainfall (mm) for Central Uganda.

[Bar graph showing seasonal rainfall in Central Uganda]
The subsequent Qualitative Explanatory Studies conducted at both sites provides insights into the cause-effect relationship.

Poverty is severe during February because all the money is spent during the end-of-year holidays. Hardly any money is left to buy food. Between September and November, poverty is ‘biting’, the children are back to school and all the money has been spent on school fees... Still, some of us send our children to the village for holidays and collect them for the next school term. It is better to have children spend their holidays in the village than have them spoilt in the urban setting. It is even cheaper that way ... School holidays affect business (performance); customers tend to be tight with their money purse, saving money for the subsequent school term. ... This is also when landlords become aggressive when demanding rent. Those months are associated with deaths and journeys for burials. However, it is foolish to make lame excuses to the doctor, like ‘I failed to take the tablets because I was travelling’ or ‘I did not have money on me’. Every pill and every reason presented to the doctors counts. Once such silly mistakes pile up (as a patient), you are in for trouble. (Focus Group Discussion, UMF)

Those are busy months for planting and one can easily forget (the medication). It is also true we tell lies to the doctors. Missing a pill is prohibited, and the higher the incidence of missed pills, the higher the threats of suspending treatment. Treatment can only be reinstated after refresher counselling. For us, we rarely travel – how can one afford money for travel when raising money for transport to pick up medicine is a nightmare! (Focus Group Discussion, RPF)

The rainfall season has a disruptive effect because it is associated with a high prevalence of waterborne diseases (malaria, cholera, flu); intensification of farm work and dwindling stocks of food reserves in a home in rural settings also triggers high food prices in the urban setting; temporal disruption of business in the informal sector; all of these leading to income poverty in both the rural and urban setting. Coinciding social obligations, economic activities, sickness and losses trigger travel to the village (mainly for the urban folk), forgetfulness, and missed pharmacy refills. Depending on the nature of work, some upcountry travels can suddenly lift patients from their normal therapeutic environment, leading to concealment of medication behaviour due to stigma, ultimately resulting in missed doses. A soldier vividly explained what happens when he goes on safari.

I am a soldier who is supposed to provide security to my boss round the clock. Sometimes we abruptly travel upcountry (sometimes leaving my tablets behind – my emphasis). It becomes rather strange to pull out these tablets and start swallowing them in front of my boss and this intimidating crowd. People may start wondering that, ‘Eehh, why is this soldier is swallowing all those tablets?’ On occasions, I get
carried away (by the day’s events) and end up forgetting (to take the medication).

(Focus Group Discussion, UMF)

3.4 Supplementary Data

To facilitate subsequent discussion (here and in the concluding chapter) of the adherence barriers, Table 3.12 synthesises all adherence barriers (from Table 3.1-3.10) against the adherence activities that have been identified above.

Table 3.12: Appearances of Adherence Barrier under a given Adherence Activity

<table>
<thead>
<tr>
<th>Categorical Barriers</th>
<th>Specific Barrier</th>
<th>Outcome</th>
<th>Urban</th>
<th>Rural</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biomedical Factors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Health Condition</td>
<td>Sickness</td>
<td>- Induction Appointment</td>
<td>6</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Pharmacy Refill</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Dosing Time</td>
<td>15</td>
<td>4</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Vomited</td>
<td>- Medication Dose</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Had No Appetite</td>
<td>- Meal/Snack Intake</td>
<td>6</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Child was Sick</td>
<td>- Pharmacy Refill</td>
<td>7</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Improved Health condition</td>
<td>- Pharmacy Refill</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Medication Dose</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Sub-Total</td>
<td></td>
<td></td>
<td>41</td>
<td>15</td>
<td>56</td>
</tr>
<tr>
<td>2. Regimen Factors</td>
<td>Side-effects</td>
<td>- Medication Dose</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>3. Failure in Concentration</td>
<td>Forgot</td>
<td>- Medication Dose</td>
<td>87</td>
<td>12</td>
<td>99</td>
</tr>
<tr>
<td></td>
<td>Lost the Pills</td>
<td>- Medication Dose</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Misplaced the Pills</td>
<td>- Medication Dose</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Mistaken Dates</td>
<td>- Pharmacy Refill</td>
<td>5</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Sub-Total</td>
<td></td>
<td></td>
<td>96</td>
<td>15</td>
<td>111</td>
</tr>
<tr>
<td>Livelihood Strategies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Reproductive Work</td>
<td>Busy with Domestic Work</td>
<td>- Dosing Time</td>
<td>5</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Picking up Child from School</td>
<td>- Pharmacy Refill</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Sub-Total</td>
<td></td>
<td></td>
<td>6</td>
<td>11</td>
<td>17</td>
</tr>
<tr>
<td>2. Production</td>
<td>Too Busy with Work (On Farm/off Farm)</td>
<td>- Induction Appointment</td>
<td>13</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Pharmacy Refill</td>
<td>7</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Meal/Smack Intake</td>
<td>8</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Returned Home late that Day</td>
<td>- Dosing Time</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Sub-Total</td>
<td></td>
<td></td>
<td>31</td>
<td>10</td>
<td>42</td>
</tr>
<tr>
<td>2. Social Factors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 3. Social Engagement and Participation

<table>
<thead>
<tr>
<th>Activity</th>
<th>Induction Appointment</th>
<th>Pharmacy Refill</th>
<th>Medication Dose</th>
<th>Meal/ Snack Intake</th>
<th>Dosing Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travelled for (Social Event)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entertaining Visitors</td>
<td>- Dosing Time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Attending Burial</td>
<td>- Pharmacy Refill</td>
<td>7</td>
<td>1</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Dosing Time</td>
<td>2</td>
<td>4</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Medication Dose</td>
<td>5</td>
<td>1</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Sub-Total</td>
<td></td>
<td>75</td>
<td>31</td>
<td>106</td>
<td></td>
</tr>
</tbody>
</table>

#### Access & Adherence Barriers

1. Poverty

<table>
<thead>
<tr>
<th>Activity</th>
<th>Induction Appointment</th>
<th>Pharmacy Refill</th>
<th>Medication Dose</th>
<th>Meal/ Snack Intake</th>
<th>Dosing Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travelled for (Social Event) - Transport Problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food Shortage in a Home or Lack of Accompanying Food on that Day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sub-Total</td>
<td>91</td>
<td>78</td>
<td>169</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Practical Problems

<table>
<thead>
<tr>
<th>Activity</th>
<th>Induction Appointment</th>
<th>Pharmacy Refill</th>
<th>Medication Dose</th>
<th>Meal/ Snack Intake</th>
<th>Dosing Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food was not Ready</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ran out of Pills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment Supporter not Available or Lacked a Reminder</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment Supporter Delivered ARVs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had Some Pills in Stock</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sharing Medicine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sub-Total</td>
<td>168</td>
<td>157</td>
<td>325</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Concealed Reasons

<table>
<thead>
<tr>
<th>Activity</th>
<th>Induction Appointment</th>
<th>Pharmacy Refill</th>
<th>Medication Dose</th>
<th>Meal/ Snack Intake</th>
<th>Dosing Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Reason or Cannot Tell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The Triple Role Framework, which is also used in Gender Studies, can be used to classify the livelihood activity related barriers (cf. March 1999)\textsuperscript{20}. “A livelihood comprises the capabilities, assets (including both material and social resources) and activities required for a means of living” (DFID 1999). The assets that make up a livelihood are: human capital (education and health), financial capital (liquidity), physical capital (means of production), social capital (social networks) and natural capital (land and vegetation).

\textsuperscript{20} Reproduction activities involve maintenance and caring for family members. Production activities involve production of goods and services for consumption and trade in the sector of employment and self-employment. Socio-political activities are linked to the collective organisation of social events and services (ceremonies and celebrations, participation in groups and organisations, local political activities, and maintenance of social networks).
Table 3.13 below is a summary of Table 3.12, it shows effect of a given barrier on one or more adherence activities.

**Table 3.13:** Effects of Adherence Barriers on Adherence Activities

<table>
<thead>
<tr>
<th>Multiple Effects on Treatment Activities</th>
<th>Direct Effect on Medication Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Biomedical Barriers</strong></td>
<td></td>
</tr>
<tr>
<td>Sickness, and improved health condition affected adherence to pharmacy refill, dosing time, and medication dose.</td>
<td>Sickness, improved health condition, side-effects, difficulty in concentration (forgetting, lost pills, and misplaced pills) directly resulted in non-adherence to medication dose.</td>
</tr>
<tr>
<td><strong>Livelihood Activities</strong></td>
<td></td>
</tr>
<tr>
<td>Being too busy, travelling, attending burial, affected adherence to each of the five adherence activities (adherence to treatment initiation appointments, pharmacy refill, meal/snack, dosing time, and medication dose).</td>
<td>Being too busy, travel, attending burials have a direct effect on non-adherence to medication dose.</td>
</tr>
<tr>
<td><strong>Poverty and Practical Barriers</strong></td>
<td></td>
</tr>
<tr>
<td>Inability to raise transport money affected adherence to pharmacy refill and medication dose. Lack of food in a home affected adherence to meal/snack intake, dosing time, and medication dose. Absence of the Treatment Supporter affected adherence to induction appointment and dosing schedule.</td>
<td>Inability to raise transport money directly resulted in non-adherence to medication dose.</td>
</tr>
</tbody>
</table>

Source: Table 3.12 Chapter 3

### 3.5 Discussion

The purpose of this Chapter has been to prove or disprove the argument that (non-)adherence to antiretroviral therapy is an outcome of a set of adherence activities and adherence barriers. The interactive set of adherence activities are adherence to: 1) treatment initiation appointments, 2) refill appointments, 3) meal/snack-taking, 4) dosing time and, ultimately, adherence to medication dose. The evidence presented above suggests that (non-)adherence to the medication dose is influenced by a set of adherence activities. Whereas adherence to treatment initiation appointments was already high (above 90%) in the group of patients that were studied, a close look at the content of the Voluntary Counselling and Testing activities (section 3.3.1) suggests that patients who skip the VCT activities were more likely to miss out on vital information necessary to overcome potential adherence barriers during the persistence phase. One of the other compelling findings is that a statistically significant number of patients who ever missed pharmacy refills also ever missed medication doses ($x^2 = 13.435, df=1, p=.000 – see section 3.2.2$). While patients’ recall
of episodes and hours skipped may have been inaccurate, the estimation of the time that elapsed between the dosing time and the actual time the pill was taken suggests that 6% (5) may have ended up skipping half a day’s medication dose. (Table 3.5b). There is also a close relationship between adherence to pharmacy refill and adherence to medication dose. In the 148 cases that missed pharmacy refills in both sites, 47% (69) ran out of continuity doses. Yet non-adherence to medication dose was also attributed to lack of accompanying food in a home, to inability to attend pharmacy refill, and to being too busy with travel (thus skipping the dosing time) (Table 3.10). There was no significant difference in non-adherence to the adherence activities, except for non-adherence to pharmacy refill appointments and returning the unused pills in the pill-bottle (Sections 3.32 and 3.3.5).

Overall, the research findings for the adherence barriers, including the economic burden, are consistent with the existing background studies on South Africa (Nachega 2006); Botswana (Wesier et al. 2003), Brazil (Monreal 2002), Rwanda (Mukabutera et al. 2004), Uganda (Kimuli et al. 2004, Byakika-Tusiime et al. 2009), Haiti (Castro & Farmer 2004), Burkina Faso (Traore 2004) and others. In these studies, the common barriers reported were: lack of financial resources, stigma, disclosure, socio-cultural representations of the disease, travel or migration, financial costs, forgetfulness, drug stock-outs, drug intolerance and/or side effects, long distances to treatment centres, and (lack of) food. However, these studies lack the analytical framework to aid the interpretation of such barriers.

Based on the Table 3.12 above, adherence barriers can be summarised in three categories namely:

1. **Biomedical barriers**

In this study, the only biomedical barriers that were recorded are linked to improved health condition, sickness (patient or child sickness, vomiting, lack of appetite), and antiretroviral side-effects such as difficulties with concentration (forgetfulness, lost/misplaced pills, and mistaken dates).

2. **Livelihood Activities**

Livelihood activities take the form of *reproductive work* (busy with domestic work, picking up child from school), *productive work* (too busy, returning home late that day); and *social engagement and participation* (travelled for social event, entertaining visitors, attending burial). Travel related barriers have been categorised as part of social engagements because in a resource-poor setting, most of the time, travelling is intended to attend social events and to pay visits to relatives.
3. Access and Adherence Related Costs

Access related barriers are closely linked to the costs that are yet to be discussed in Chapter 4. These costs include direct costs (medical and non-medical costs); indirect costs (loss of time, loss of income, physical access constraints); costs incurred by treatment supporters (loss of income, loss of time, physical access constraints); and practical problems (when sharing medicine).

Table 3.13 indicates that a given adherence barrier can have absolute effect on the medication dose and/or multiple effects on several adherence activities, including medication dose itself.
4
Rising From the Dead to Carry the Cross: The Economic Burden of Accessing and Adhering to ART in Uganda’s Resource-Poor Settings

4.1 Introduction
This Chapter provides an extended discussion of adherence barriers, specifically of the economic burden of accessing and adhering to antiretroviral therapy. The motivation for carrying out a detailed assessment of the economic burden of accessing and utilising ART was twofold. As already indicated in Chapter 1, results from background studies published before the implementation of this research in 2005 revealed that overall, patients’ economic situation interfered with their abilities to take up and adhere to HIV medicines in Botswana (Weiser et al. 2003), Senegal (Laurent et al. 2002), Cote d’Ivoire (Laniece et al. 2003), and Uganda (Byakiika-Tusiime et al. 2005, Whyte et al. 2004). The key message in these background studies was that accessing HAART involved costs and sacrifices, and patients had to make critical choices between medication expenses and domestic maintenance (food, school fees, clothes, house repairs). HIV/AIDS related morbidity and mortality might previously have eroded the household’s ability to cope with such treatment costs21.

As ARVs became increasingly available free of charge in resource-poor settings, it appeared as if patients were relieved of the access and utilisation costs. However, preliminary evidence from my qualitative exploratory studies and survey itself reveal that, even after the provision of free antiretroviral drugs, patients still suffer a wide range of costs. Evidence presented in Chapter 3 reveals that a small number of patients, mainly in the rural setting, skipped pharmacy refills due to transport problems, while others failed to swallow their ARVs due to food shortage related problems. These problems are referred to as access related problems, as well as the adherence barriers.

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However, what was even more perplexing is that despite such apparent costs, of the 262 patients who were sampled, 90% (236) achieved the 95% near-optimal adherence for the three years preceding the study. This implies that only 10% (26) failed to achieve 95% adherence. What is even more remarkable is that there was no substantial difference in adherence to ART between the rural patients who experienced transport difficulties and those in the urban settings who lived within a closer proximity of the health facility and benefited from comprehensive healthcare services. This contrasts with the assumption that rural patients coming from households exposed to vulnerability\(^2\) (shock, trends, seasonality) whose assets (capability) to cope and adapt to shocks is low (non-resilience), are more likely to interrupt or drop treatment due to access related costs even when the biomedical factors are fairly favourable.

This Chapter sets out to find answers to four questions:

1. What is the vulnerability context within which ART was introduced in Uganda’s resource-poor settings?
2. What costs do patients incur when accessing and adhering to ART?
3. What is the impact of the economic burden on adherence to ART?
4. What strategies do patients take to continue taking ART medication in spite of such costs?

### 4.2 Conceptualisation of the Economic Burden of Illness

Before considering the actual empirical evidence, two key concepts need to be defined; these are economic burden and coping strategies.

#### 4.2.1. Economic Burden

The notion of economic burden has its roots in the discipline of Health Economics. While the concept of economic burden is relatively new in the study of antiretroviral therapy, in the past it has been researched when studying short-lived illnesses (e.g. malaria) in poor households (see Russell 1996, 2004, 2005). The economic burden of illness entails both direct and indirect costs. Direct costs refer to household expenditure linked to seeking treatment, including non-medical expenses such as transport and special foods. The indirect costs refer to the loss of household productive time for patients and caregivers, and the decrease in wage and profit due to the inability to

\(^2\) Vulnerability relates to insecurity, sensitivity of well-being in the face of a changing environment, and the households’ resilience and ability to respond to risks and negative changes (economic, environmental, socio or political, including shocks, trends and seasonal cycles) and opportunities (Rakodi Carole 1999).
work (Russell 2004). Though for a different purpose, work by Kabir et al. (2000) shows illness to have an effect on livelihood security among urban poor.

The cost-burden is measured in terms of healthcare expenditure as a proportion of household income, also known as the Health Expenditure-Income ratio. According to the same author (Russell 2004), there are three arbitrary levels for measuring the (in)ability to pay for health services in developing countries. A typical household spends 2-5% of its income on healthcare which is regarded as affordable. A household spending of above 5% of its mean income on health services is regarded as unaffordable, while a healthcare payment of above 10% of the mean household income is regarded as catastrophic because it is likely to cause cuts in consumption of minimum needs, trigger the sale of productive assets or high levels of debt, and can lead to impoverishment (Russell 1996, 2004, 2005). According to Russell (2004), the direct and indirect costs of illness are influenced by the type and severity of illness and the health service characteristics that influence access and choice.

4.2.2. Coping Strategies

In spite of appearances, a given level of cost-burden does not necessarily result in the termination of health seeking practices. Poverty studies show that individual households have capabilities in the form of resources and strategies to endure shocks or avert ‘damaging fluctuations’ (also see website chronicpoverty.org). A coping strategy is a short-term strategy adopted within the prevailing value system to avert a negative effect on the actor (in Sauerbon et al. 1996). Use of the phrase ‘averting a negative effect’ implies that a given coping strategy entails a reversible management strategy (Haddad et al. 2001). However, any measure that is too costly, resulting in long-term deprivation, distress sales, and destitution, may not be ‘coping’ because it is irreversible. A coping strategy should not lead to household destitution and disintegration. Evaluation of coping strategies usually entails examining the type, level, sequence, and success of the coping strategy (Sauerbon et al. 1996). Coping strategies for responding to the economic cost of illness can be grouped into two categories: those adopted to cope with financial costs, and those for coping with time costs.

Whether a given household can absorb an economic burden depends on its initial asset endowment (financial, physical, human and social resources) and its exposure to shocks, trends, and seasonal shifts. Seasonal shifts can take the form of gradual changes in prices, production, health, employment opportunities, and food availability. Trends can be in the form of policy, economy, drug supply etc. Shocks can take the form of rapid and destructive events, for instance severe illness, death of the provider/spouse, crop failure, storms, and civil conflict (DIFID 2004). Studies in poverty
indicate that when marginality and susceptibility (vulnerability) is high, resilience and adaptability (coping) is normally low. This is because being vulnerable to risks, shocks, and stresses creates financial and asset instability, undermining the ability to cope and recover from shocks and risks. Hence, the following section examines the household economy of the ART patients in the two sites.

4.3 Overview of the Household Economy

Before assessing the economic burden associated with accessing and adhering to antiretroviral therapy, it is necessary to establish the household endowment context.

4.3.1. Household Income

The survey included questions about household income, expenditure, and shocks. Specifically, the survey recorded income data as a basis for assessing the affordability of access and adherence of ART services. The problems associated with using income-based approaches to assess household wealth are well known. Nevertheless, during the survey patients were asked to mention the various income activities in which household members participate, in order to estimate the income earned and the frequency of income from such sources (see Survey Questionnaire Question 2.7b in the Supplementary Material SM.4). The frequency of income was recorded as daily, weekly, monthly, and 6 monthly, and such was converted into 30 days in order to have a standardised frame of reference.

Of the 262 respondents, three-quarters (75%, 193) of the patients belonged to households whose members had regular sources of income. There was no statistically significant difference in access to income between urban-based patients (76%, 105) and rural-based patients (75%, 88) ($\chi^2 = 0.78$, $df = 1$, $p = .780$). Examination of the composition of sources of income revealed that ART patients belonged to household participating in a wide range of income earning activities, mainly informal sources of livelihood. The graph below presents the percentage of households participating in given production activities. It is based on total number of cases $n=187$, urban $n=101$, and rural $n=86$.

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23 The problems take the form of a distorted mean due to certain income outliers in the dataset, seasonal variations in income, omission of certain income sources and strategies by the respondents themselves, and the inability to capture intra-household income distribution and disparity.
While a large proportion of rural households concentrated on agriculture, the majority of households in the urban settings depended on salaried jobs. Overall, majority of urban and rural residents depended on informal sector for the sources of livelihood in the form of: agriculture (rural), self-employment (both groups), seeking assistance (both groups), and wages (mainly urban). In terms of subtle differences, a greater number of rural household tended to seek external assistance compared to their urban counterparts.

For brevity, the mean income data is omitted here. The overall estimated income was Ushs 299,414 or US$ 187 per month (US$ 1 = Ushs 1600 in 2004). In other words, an average household was surviving on US$ 6 a day. Income data disaggregated by site show a small income disparity between the two settings, of Ushs 317,995 (US$ 199) and Ushs 277,592 (US$ 174) in the urban and rural setting respectively. For urban residents, the highest mean income is earned from salaried jobs (Ushs 204,214 US$ 128), whereas for rural residents the highest mean income come from (not agriculture but) self-employment (Ushs 232,177 US$ 145). Whereas both groups benefited from social support, the monthly mean income from such was small, estimated at Ushs 96, 146 US$ 60, higher in the urban settings (Ushs 154,141 US$ 96) than in the impoverished rural setting (Ushs 49,026 US$ 16).

### 4.3.2 Household Expenditure

The second question queried the household items on which money was spent. The survey results revealed that the household income is spent on 17 expenditures that
can be further categorised as follows: 1) *daily consumption goods* (food, beverages, and tobacco); 2) *non-durable household goods frequently bought* (non-durable personal items, household personal items, transport and communication, health expenditure, hired services); 3) *semi-durable goods and services* (clothing, education, furniture, and household appliances); 4) *non-consumption expenditure* (tax, remittances, and contributions); and 5) *household and enterprise assets* (Household assets, land, enterprise assets). Figure 4.2 reveals households expenditure pattern.

**Figure 4.2: Proportion of Household Spending on an Item.**

As the figure shows, a large proportion of households engaged in consumption-based spending as opposed to investing in durable or productive items/expenses. In a descending order, a large proportion of household income is spend on mainly 1) food; 2) non-durable household goods frequently bought (domestic items for instance soap, paraffin); 3) health, 4) education; 5) personal non-durable personal items (personal effects, hair, and entertainment); 5) semi-durable items (clothes).

The mean monthly expenditure was small at an estimated Ushs 20,087 (US$ 13).

### 4.3.3. Household Asset Ownership

The survey included 23 personal or household assets in order to measure household asset endowment and ability to absorb recurrent expenditure. The asset profile can be divided between 1) quality of life related assets and 2) productive assets. Unlike

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24 The **quality of life assets** included 1) information and communication utilities (radio, TV, landline telephone, mobile telephone, newspapers, clock, watch); 2) transport facilities (bicycle, motor cycle, and vehicle; 3) domestic utilities (fridge, reliable water supply, electricity,
productive assets, quality of life assets cannot be readily converted into financial assets. At worst, most personal quality of life related assets involve recurrent maintenance costs (e.g. credits for a mobile phone). For details of Household Asset Ownership see Appendix Table A.8. The key message is that large proportion of households had limited access to physical or productive assets that can be readily converted into liquidity.

4.3.4. Exposure to Shocks

A large proportion (63%, 165) of patients in both rural and urban areas (p=.972) came from households that had previously suffered from shocks and misfortunes. The commonest shock reported was crop failure. According to qualitative evidence, poor performance in the agricultural sector was attributed to a slowdown in agriculture due to bad and/or unpredictable weather conditions, and the effect of pests and disease (coffee-wilt disease and banana weevil). The occurrence of such agro-based shocks might explain why, in terms of income, agriculture came third after self-employment, salary, and was followed by external assistance.

Other misfortunes took the form of floods, drought, storm, fire, and death of a spouse or friend. Death of spouse was attributed to HIV related illnesses (see Chapter 7), with attendant effects of health expenditure, loss of property to in-laws, and orphan burden. Amidst all those hardships, the coping strategies that were reported were: becoming strong, seeking medical care, seeking social support, taking no action, and seeking solace from God. The nature of the coping strategies shows that the patients came from profoundly poor households.

4.4 Direct and Indirect Cost of Accessing and Adhering to ART Treatment

After assessing the household economy to which ART patients belonged, it is necessary to consider the structure of costs incurred by patients in accessing and adhering to ART.

4.4.1 Structure of the Direct Cost Involved in Accessing HIV Treatment Services

A set of questions were included in the survey to establish; 1) the direct costs (medical and non-medical) incurred by patients whenever they visited the health facility (for and descent house. On the other hand, productive assets included; sewing machine, draught, rickshaw, wheel cart, kiosk/shop, commercial water tap, land, plot of land (≤0.25 acres), and rental houses.
any service): 2) the item on which such costs are incurred, and, 3) the sources of funding. Of the 262 patients (in both settings), a large proportion (71%, 187) stated that they incurred access related costs whenever they came to the health facility to seek HIV/AIDS related services.

Table 4.1 below presents the structure of direct costs incurred by patients. The first main column on the left shows the cost items that were mentioned, then under both the urban and the rural facilities, the left hand column contains the number of cases who mentioned the expenditure item, and the right hand column presents the mean costs (in Ushs) incurred per visit.

**Table 4.1:** Structure of the Direct Costs in the Mission and Public Facility

<table>
<thead>
<tr>
<th>Item</th>
<th>Costs and Proportion of Costs by Site</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urban Mission Facility</td>
<td>Rural Public Facility</td>
</tr>
<tr>
<td></td>
<td>Number</td>
<td>Ushs</td>
</tr>
<tr>
<td>Transport</td>
<td>39</td>
<td>5,005</td>
</tr>
<tr>
<td>Snack</td>
<td>77</td>
<td>640</td>
</tr>
<tr>
<td>Bicycle Security Charges</td>
<td>2</td>
<td>750</td>
</tr>
<tr>
<td>Total</td>
<td>118</td>
<td>2084.75</td>
</tr>
</tbody>
</table>

N.B.: Multiple responses allowed

All the direct costs were mainly non-medical in nature. The highest cost incurred were in the form of transport (Ushs 4270 US$ 3), followed by snacks (Ushs 885 USD .5), and lastly bicycle security charges (Ushs 567 US$ .4). As expected, the incidence of a cost burden was higher in the rural setting than in the urban setting, with a greater number (194 vs. 1180) of patients incurring higher (Ushs 2697.42 vs. Ushs 2084.75) costs. Surprisingly, a small number (39) of patients in the urban setting, who presumably lived within easy reach of services, also incurred transport costs. This is because the quality of services offered by the UMF tended to attract patients from other parts of the country, as this female patient indicated.

I was seriously sick. I got breast cancer and I lost my breast. After enrolling for ARVs, I developed meningitis. All the treatment expenses were footed by Mbuya Reach Out (the Mission Facility). I started (treatment) with Reach Out and I don’t want to change, I would rather receive my ARVs from here rather than getting them from Mbarara Hospital (her home area located 250km from Mbuya). Here I can get Trioumune which might not be available in Mbarara. I have a brother who regularly meets the travel costs so that I get my ARVs from here. (Female respondent, UMF)
Besides access related costs, patients also incurred adherence costs in the form of daily expenses associated with adhering to antiretroviral therapy. It was rather difficult to document such adherence costs because most of them are largely invisible and tend to vary from one patient to another. For example, while the survey included one question intended to establish personal dietary costs, it proved rather difficult to draw a meaningful interpretation of such data because the number of times preferred food is bought varied considerably over time and between patients. Nevertheless, qualitative evidence suggests a high food consumption burden during the first 6 months of taking up antiretroviral treatment, with such dietary costs stabilising during the ‘persistence’ phase.

When I started taking ARVs, my appetite went out of control. During the first two months, I used to eat several times a day, (taking food like) plantains (matooke), posho, and Irish potatoes. I used to take eggs from my business stock. Eventually, I had to give up the egg business because the losses became increasingly high. Instead, I had to resort to buying eggs from my neighbours twice a week. I also take a lot of mukene, because it is highly recommended by doctors because of its nutrition contents; it is also cheap and readily available on the local market. Within the first two months, I had gained weight, from 42 Kg to 46 Kg. (Female respondent, RPF)

Evidence from subsequent qualitative explanatory studies reveals that direct costs tend to be regressive, imposing a greater burden on certain categories of patients. Accounts from three blind patients, for example, revealed that while they were excluded from labour opportunities, they still had to find their transport money and for their guides as well.

4.4.2 Impact of the Economic Burden of Adherence to ART

The first major point to note here is that adherence to ART was high in the studied sample. As already stated in Chapter 3, of the 262 patients, 90% (236) achieved 95% adherence over the three years preceding the study. Second, there was no significant difference in adherence between the two sites, with 89% of patients in UMF and 92% in RPF achieving the 95% adherence. In other words, irrespective of cost implications, adherence was still high. This is also the key message from Table 4.2 below that looks at the levels of affordability of adherence to ART.

While the overall sample included 262 patients, the sample size for which the effect of the economic burden of adherence to ART could be derived was smaller. Out of the 193 patients whose income could be established (as a denominator for calculating the direct costs), 145 reported incurring costs, and of those only 65 had

25 Mukene is a small protein-rich fish scientifically known as *Rastrineobola argentea*. 

67
ever missed taking their ARVs. The first column of the table presents the adherence threshold. The second three columns present the affordability levels of healthcare related expenditure derived by looking at healthcare expenditure as a proportion of household income. As previously stated, healthcare expenditure that is below 5% of the mean household is considered to be *affordable*, healthcare expenditure that is between 5-9% is *unaffordable*, and above 10% of mean household income is regarded as *catastrophic*. The purpose of the table below is to establish whether the three affordability levels are closely associated with the three adherence levels.

<table>
<thead>
<tr>
<th>Adherence Level</th>
<th>Affordability Levels</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Affordable &lt; 5%</td>
<td>Unaffordable 5-9%</td>
</tr>
<tr>
<td>Non-Adherence &lt; 80%</td>
<td>5% (3)</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Sub-Optimal 80-94%</td>
<td>18% (10)</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Near-Optimal &gt; 95%</td>
<td>77% (44)</td>
<td>60% (3)</td>
</tr>
<tr>
<td>Total</td>
<td>100% (57)</td>
<td>100% (5)</td>
</tr>
</tbody>
</table>

These results suggest that the level of economic burden does indeed have an influence on adherence to ART. Reading the row of near-optimal adherence (>95%) and the non-adherence row (< 80%) from left to right, the evidence shows that the higher the level of affordability, the greater the possibility of achieving the required 95% adherence, and vice-versa. In this case, 77% (44) of patients whose household income to access and adherence ratio was less than 5% achieved the near-optimal adherence of > 95%. However, the overall interpretation is that the economic burden poses an insignificant effect on adherence to antiretroviral therapy, with only 17 patients falling under the >95% adherence threshold (see non-adherence and sub-optimal totals, i.e. 6+11=17). The immediate explanation is that the cost for accessing and utilising antiretroviral services was affordable, with only 8 out of 65 cases (12%) falling under the thresholds of unaffordable or catastrophic economic burden combined (cf. columns 3 and 4).

### 4.5 Indirect Cost Burden

As stated above, *indirect cost of illness* refers to the loss of household productive time for patients and care-givers, and wage and profit decrease due to the inability to work (Russell 2004). This section assesses the problems experienced by HIV patients and their care-givers in accessing and adhering to ART.
4.5.1. Time Loss
Survey results showed that, on average, patients spend 5.3 hours at the health facility, up to a maximum of 9 hours. Findings from my follow-up visits conducted in 2010 revealed that the number of hours waited for services were increasing due to an expanded enrolment for HIV-treatment services and a high health worker to patient ratio, especially in the Public Facility. Using an arbitrary measure of what is a ‘lengthy waiting period’, any 3 hour wait can be regarded as an ‘excessive time loss’ because it is equivalent to 25% of a day’s productive time. Unlike other kinds of health services, HIV/AIDS healthcare services require patients to undergo routine clinical examinations for vital indicators (blood pressure, weight, functional status, WHO staging), pharmacy refill procedures, and sometimes, consultations for opportunistic infections and regimen side effects. Occasionally, opportunistic infections and drug side-effects occur that require the patient to seek consultations sooner than the scheduled pharmacy refill appointments.

4.5.2. Income Loss
Evidence from this study indicates that in the process of seeking ART services some patients at both sites lose income, with less than a half (42%, 95) losing an average income of Ushs 7,866 or US$ 5 per pharmacy refill/consultation visits. While this foregone income makes up only 3% of the household mean monthly income (Ushs 299,414 or US$ 187), it is still high given the fact that it is a hard earned income from agriculture and informal sector sources. Furthermore, more than a half (56%, 146) of patients were exempted from intra-household contributions towards health expenses. The other section of patients whose productive work was not affected were mainly engaged in flexible service-based activities (where customers have to wait), or were unemployed; and as some simply put it, ‘my life comes first’.

4.5.3. Physical Access
While the traditional definitions of indirect cost-burden tend to restrict the conceptualisation of the indirect economic burden of accessing health services to the two indicators of time loss and income loss, findings from this study indicate that patients seeking ART services suffer also from accessibility constraints. In transport planning, the term physical access\(^{26}\) embraces travel time, distance, modes of transport, and transport bottlenecks. Measuring the travel time lost in accessing health services also proved difficult, because of variations in the modes of transport used by patients,

\(^{26}\) In transport planning, physical access encompasses ‘mobility’ of people and ‘locations’ of different services/facilities (Nejadfard, no date).
distance travelled, and the disjointed routes (see Appendix Tables A.3a and A.3b). The physical access burden affected mainly rural-based patients, who usually travelled long distances to the few existing ART outlets (in 2006), resulting in loss of money, energy, and time. Patients in rural or hard-to-reach settings endure long distances, bumpy and dusty roads, scorching sun and drenching rain, and wade fords on the way to and from ART accredited sites.

I live on one of the islands on Lake Victoria. I have to cross the lake in order to reach the hospital. I cover a distance of approximately 300km over the lake and then travel a distance of 80km by 'Matatu' (Swahili for Taxi). I left my home the day before yesterday (Monday) at 4:00am and reached the Kiyindi landing site at midday, finally arriving at my mother’s home at 7:00pm in the evening. Today (Wednesday), on my way to the hospital, I left my mother’s home at 8:00am and I arrived here (at the hospital) at 9:00am. I will spend the night at my mother’s and return home on Friday, because by now (10:12am) the vehicles heading for the Kiyindi landing sites have already left and the boat from the island comes only on certain days of the week, that is, on Monday, Wednesday, and Friday. (ART Female client, Kayunga Public Hospital, May 2007)

As already stated, after such long distances, patients have to find something to eat before taking the ARVs. Partly due to the long distances walked and/or drug side effects, patients taking ARVs complain of fevers and joint pains.

4.5.4. Incidence of Indirect Burden on Care-Givers

Since HIV/AIDS is a labour intensive condition, the process of providing care and support extends the burden of care from the health facility to the family and community levels. The family-based Treatment Supporter suffers the access and adherence burden as much as the patients themselves, particularly during the treatment initiation phase. During the treatment initiation phase, Treatment Supporters (TSs) are required to attend 1-2 ART counselling sessions in order to acquaint themselves with the protocol of care and support (refer to section 3.3.1). Once in a while, the Treatment Supporter collects medicines on behalf of patient, especially when the patient is too sick to attend the pharmacy refill. Whenever a patient registers sub-optimal adherence, his/her Treatment Supporters are also summoned to explain the cause and to attend adherence reinforcement counselling together with the non-adherent patient. All these trips involve sacrifices in terms of time, income, energy, and patience. In later stages of this study, I wanted to triangulate the accounts of patients and their Treatment Supporters, and I requested that health staff invite a select number of patients and their respective Treatment Supporters to
come for interviews. During the discussion, one of the Treatment Supporters vividly explained the hardships he experienced in raising money for transport on that day.

Yesterday my mother came to my home and informed me that I am required to attend the clinic tomorrow. I had to raise Ushs 6000 (US$ 4) for transport for both of us by any means possible. I had to find a friend who would lend me money. I have to bear that burden alone because my mother is sick and my elder sister is disabled. On top of that, I have to take care of my wife and three children. I desperately earn what I can from casual work – timber extraction, chopping wood, and fetching water. On top of that, I have to raise money to buy the food she (my mother) wants. What I have discovered is that taking this medicine without having sufficient nice food like milk and nutritious sauce results in loss of weight by the patient. Sometimes she behaves like a pregnant woman, having appetite for special meals... (Another participant interjects) ... Mine behaves like child; she keeps reminding me that today I should return home with the item she is yearning for. (Male Treatment Supporter, Kayunga Hospital)

4.6 Factors that Mitigate the ART Access and Adherence Costs

The survey included several questions to evaluate a set of coping strategies adopted to reduce the impact of ART access and adherence costs. The key message from the analysis of the results is that only 40% (across all coping strategies) engaged in regressive coping strategies in order to meet the cost of food and transport costs. In fact, a large proportion of patients avoided adverse coping strategies, such as foregoing minimum basic necessities, forced sale of productive assets, postponing personal plans, or borrowing, by relying on free healthcare services, seeking external support, and on advance personal savings.

4.6.1 Healthcare Services

First, the availability of free medical and nursing care services in the form of ARVs, preventive therapies, treatment for drug side effects, laboratory services, and reproductive health services substantially reduce the overall cost of accessing and adhering to ART, and make the costs affordable. Second, antiretroviral efficacy restores the patients’ health condition and their ability to mobilise financial resources for meeting subsequent recurrent health related expenses. As one respondent noted:

Obviously, if this medicine pulled you back from the edge of the grave, how can one fail to raise transport money (to collect ARVs)? Even in extreme condition[s] of poverty, one can look around for casual work, (Survey Follow-up FGD, RPF).
Third, effective management of pharmacy refills reduces access related cost. This effective management can take the form of appropriate scheduling of pharmacy refill appointments; dispensing continuity doses over and above the scheduled appointment dates, allowing long lasting doses over end-of-year festive seasons, providing concessionary doses to patients seeking treatment for drug side-effects and opportunistic treatment earlier than the scheduled dates, and allowing the treatment buddy to collect drugs in emergency situations. It also includes allowing, newly enrolled patients who are given a beginner dose of 1-2 weeks to graduate to monthly doses, and then to 2-3 months’ doses after having been on treatment for a year or more. At the same time pharmacy refills are used as a correctional tool whereby grossly non-adherence patients are either suspended from treatment or re-introduced to adherence counselling, and given a beginner’s dose.

Thirdly, induction and adherence counselling strongly emphasise the need for attending pharmacy refills, thereby reinforcing the need for forced saving.

Fourth, beyond the role of free medical and psychosocial support, a significantly higher proportion of patients seeking services from the urban-based Mission Facility benefited from comprehensive socio-economic support in the form of micro-credit, income activities, support to OVCs, and food assistance (up until 2008), as indicated on Table 4.3.

<table>
<thead>
<tr>
<th>Type of Assistance</th>
<th>Urban Mission Facility</th>
<th>Rural Public Facility</th>
<th>Total</th>
<th>Chi-Square value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food</td>
<td>91% (128)</td>
<td>7% (9)</td>
<td>53% (137)</td>
<td>P=.000</td>
</tr>
<tr>
<td>Micro-Credit</td>
<td>40% (56)</td>
<td>0.0% (0)</td>
<td>23% (56)</td>
<td>P=.000</td>
</tr>
<tr>
<td>OVC Support</td>
<td>13% (18)</td>
<td>0.9% (1)</td>
<td>7% (19)</td>
<td>P=.000</td>
</tr>
<tr>
<td>Income Generation</td>
<td>1% (2)</td>
<td>0.8% (1)</td>
<td>12% (3)</td>
<td>P=.664</td>
</tr>
</tbody>
</table>

N.B. Each item was analysed separately but is presented here in the same table.

The effect of socio-economic aid on sustained use of health services is, however, questionable. For instance, qualitative evidence on the utilisation of micro-credit indicated that the money was not necessarily invested in productive activities by patients but served to offset their immediate financial demands and social obligations, as these three cases from a Focus Group Discussion at UMF revealed.

I received Ushs 100,000 and I used the money to clear my husband’s medical bills. I managed to pay back Ushs 25,000.
I got a loan of Ushs 50,000. I fell sick and used the money to meet health expenditure. I am almost failing to repay the loan because I am weak, I have headaches, palpitations, anaemia, I am dehydrated and suffering from the side effects of drugs.

I got a loan of Ushs 50,000. Seven times I invested it in my micro-business (dry fish, onion, and greens). I also have a sister who is completing her studies at Makerere University this year – the loan helped me a lot.

4.6.2 Role of Social Support

As already stated in section 4.3.1, external assistance featured as one of the major sources of household income, ranking third and fourth in the Mission and Public facilities respectively. This social support is located at the household and community levels. Regarding household-based support, 44% (116) of the ART clients at both facilities combined benefited from intra-household contributions towards their healthcare expenditure. In addition, a large proportion (97%, 248) of ART patients received care/assistance/support from their confidants, with no statistically significant difference between the Mission (UMF 97%, 136) and Public (RPF 97% 112) facilities ($\chi^2 = .002[b], df=1, p=.966$).

However, rarely do patients benefit from financial assistance during normal health conditions. For the same question regarding receipt of care/assistance/support, if we were to rank the forms of support, financial assistance came third after advice and emotional support. Furthermore, the question on the ‘frequency of financial assistance’ revealed that only 39% (68) at both facilities combined, received financial assistance on a regular basis. Evidence presented in this Chapter shows that external assistance yielded a small income estimated at US$ 60 per month. In addition, intra-household contribution to household expenditure was small. Results from the survey indicated that 56% (146) of the ART patients were exempted from household contributions towards the healthcare expenditure, the major reasons being unemployment; living alone; and non-disclosure of one’s HIV status to the other household members. The following quotation shows the inadequacy of financial assistance received.

My brothers help me to meet the cost of tuition, while my brother in-laws help me occasionally. However, sometimes the assistance does not come through because those relatives have to meet their own personal financial obligations. My children end up doing casual work in order to make ends meet. For instance, today I had Ushs 1000 but when I reached here I learnt that I had to pay my membership subscription (for Adherence Support Organisation based at the facility). That means that today I will have to walk back home. (Female Key Informant, RPF)
4.6.3 Personal Financing Strategies

The question assessing the structure of direct costs also captured the source of funding for financing the expenditure item mentioned by the patient (Table 4.1 and Survey questionnaire 4.5). Table 4.4 shows the outcome.

Table 4.4: Sources of Funds for Financings Non-medical Costs

<table>
<thead>
<tr>
<th>Site</th>
<th>Sources of funding</th>
<th>Transport</th>
<th>Food</th>
<th>Bicycle Security Charges</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban Mission Facility</td>
<td>Personal Saving</td>
<td>90% (34)</td>
<td>91% (67)</td>
<td>100% (2)</td>
<td>90% (103)</td>
</tr>
<tr>
<td></td>
<td>Household Saving</td>
<td>8% (3)</td>
<td>1% (1)</td>
<td>0% (0)</td>
<td>4% (4)</td>
</tr>
<tr>
<td></td>
<td>Kin Support</td>
<td>3% (1)</td>
<td>8% (6)</td>
<td>0% (0)</td>
<td>6% (7)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>100% (38)</td>
<td>100% (74)</td>
<td>100% (2)</td>
<td>100% (114)</td>
</tr>
<tr>
<td>Rural Public Facility</td>
<td>Personal Saving</td>
<td>63% (66)</td>
<td>64% (52)</td>
<td>100% (1)</td>
<td>64% (119)</td>
</tr>
<tr>
<td></td>
<td>Household Saving</td>
<td>11% (11)</td>
<td>11% (9)</td>
<td>0% (0)</td>
<td>11% (20)</td>
</tr>
<tr>
<td></td>
<td>Kin Support</td>
<td>23% (24)</td>
<td>22% (18)</td>
<td>0% (0)</td>
<td>23% (42)</td>
</tr>
<tr>
<td></td>
<td>Social Support</td>
<td>2% (2)</td>
<td>1% (1)</td>
<td>0% (0)</td>
<td>2% (3)</td>
</tr>
<tr>
<td></td>
<td>Borrowing</td>
<td>2% (2)</td>
<td>1% (1)</td>
<td>0% (0)</td>
<td>2% (3)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>100% (105)</td>
<td>100% (81)</td>
<td>100% (1)</td>
<td>100% (187)</td>
</tr>
</tbody>
</table>

N.B: Multiple responses allowed, of the 145 patients who incur access and adherence costs spend on more than one item.

As the table 4.3 above indicates, the 145 patients who were previously mentioned depend on five sources to finance the non-medical costs, namely: 1) personal savings, 2) household savings, 3) kin support, 4) social support, and 5) borrowing, dependence on social support and borrowing exclusively applying to the rural patients.

In both facilities the majority (90%, 103) of urban-based patients and a fairly big number (64%,119) of rural-based patients largely depend on personal savings to meet access and adherence costs. However, also the rural-based patients who fail to achieve internal resource mobilisation resort to kin support (23%, 42), social support and borrowing (2%, 3 each) to meet the cost of transport, food, and bicycle security charges. Nevertheless, overall, these results reveal that the most dependable form of financing of the access and adherence burden at all times are personal savings. In a qualitative interview, a patient alluded to this: “I cannot be a burden to others all the time; the most important resource is my brain.”

There are several coping strategies that are adopted to either avert access and adherence related costs or to maximise personal savings. First, to avoid spending on snacks, some will take breakfast before leaving home, while others may carry a snack with them. Second, to avoid the cost of transport; some decide to relocate to the nearest ART
outlets, while others with basic means of transport ride their bicycle to the clinic. Third, other patients rely on the comprehensive care and support provided in the Mission Facility. Fourth, those who have saved in advance engage in multiple coping strategies that include: casual labouring; engagement in fast income accumulating enterprises (hair plaiting, charcoal burning); breeding fast-maturing and prolific small livestock and poultry; begging or seeking small loans; and sometimes foregoing luxurious spending or business profits.

I save on a regular basis in order to raise money to collect medicines at the end of the month. I rarely forego basic necessities; instead I tend to forfeit business profits. I run a small kiosk selling soda, sugarcane, and bananas. I used to stock five crates of soda but I had to take a tough decision to reduce the number of crates of soda to four so that I save the money to pay for the monthly transport costs … I realised that it was a rational decision because, in my business soda has the largest share of capital. I cannot reduce the banana stock because it serves as a source of food for the household. (Female ART Client, Kayunga Hospital)

With the perpetual pharmacy refills, however, some patients were increasingly running out of options.

I used to have two goats and a plot of land. I sold the plot of land for one million shillings. I spent a large proportion of that income on collecting medicine. Very soon I will run out of options. Unless my son provides assistance, I will have no alternative but to succumb to death. I have only one cow left, and it gives me milk; I can only dispose of it when I reach a dead end. I have tried to avoid luxurious food and use ddoodo (a backyard vegetable) for sauce. I used to be seriously sick but I am feeling better now. (Male Respondent, Kayunga Public Hospital)

Another said:

We would prefer to take one pill a month. We have reached a point of almost not turning up to collect the drugs, let alone taking the drugs on a daily basis and the public opinion. We are only forcing ourselves to come for regular drug refill. (Key Informant, Focus Group Discussion, RPF)

4.7 Discussion

This Chapter has examined the impact of the economic burden of accessing and adhering to antiretroviral therapy in the two different facilities. The motivation for assessing the impact of economic burden on adherence was twofold. First, evidence from antiretroviral studies conducted in sub-Saharan Africa between 2003 and 2004 indicated that patients who incurred access related costs in some cases had lower adherence to ART. Second, preliminary evidence from this longitudinal study
revealed that even after the availability of free antiretroviral drugs in Uganda, patients still experienced access and adherence costs, even if such direct and indirect costs did not have an impact on the 95% adherence to ART.

The findings presented here confirm the fact that the majority of patients are exposed to poverty and a vulnerability context that is characterised by low household income obtained from mainly informal sector activities, small household asset base, periodic exposure to shocks and shifts, multiple consumption-based expenditure obligations, and exposure to access and adherence costs. With the availability of free health services (diagnosis, counselling, preventive therapies) the direct costs are largely non-medical costs including food/snacks, transport, and costs for bicycle safety. The indirect costs manifest in the form of time loss, income loss, and a difficult and long journey to the facility.

Travel costs and long journeys reflect constrained access to accredited ART in the early days of scaling up antiretroviral services; while time loss due to lengthy waiting hours can be attributed to a high patient to staff ratio. Differential access to such resources and services might explain why a large number of rural-based patients incurred a large amount of non-medical cost compared to a small number of patients in the urban setting that incurred a small amount of non-medical costs (Table 4.1).

Nevertheless, the non-medical and indirect costs did not substantially alter near-optimal adherence as only 10% (26) failed to achieve the near-optimal (95%) adherence over the three years preceding the study (Table 4.2). In addition, only a small proportion of patients in the rural setting would miss pharmacy refills due to the inability to raise transport money to collect medicines on time (cf. section 3.3.2). Similar evidence from Zambia indicates that travel related factors did not predict adherence (Carlucci et al. 2008).

The insignificant effect of direct cost and indirect costs on adherence can be attributed to a combination of factors. Evidence has shown diverse coping strategies between the urban and rural settings. The nature of these coping strategies reflects the patients' socio-economic characteristics, the healthcare services, and the prevailing socio-economic environment. Rural patients subject to the poverty and vulnerability context but having limited access to comprehensive HIV/AIDS care services tend to draw from multiple sources of social support namely: personal savings, household savings, kin support, and borrowing (Table 4.4). On the other hand, the urban patients having access to comprehensive care and support in the Mission Facility mitigated the economic burden by benefiting from the socio-economic aid (food,
credit, orphan support), but due to limited social capital stock in an urban setting, maximise personal savings (Table 4.3 and 4.4).

There are limited options for coping with indirect costs (time loss, production loss, long journey) besides enduring such hardships. This endurance stems from the ‘normalisation of suffering’, a phrase coined by Carlucci et al. (2008) when explaining why long travel distances may not necessarily adversely affect adherence to ART in Zambia. Normalisation of suffering is regarded as the acquired experience and knowledge of dealing with hardships in a predominantly agricultural population that is normally used to travelling long distances for selling products, obtaining water, and accessing healthcare.

However, perseverance with multiple access and adherence costs comes about because of perceived beneficial effects of antiretroviral therapy. The antiretroviral efficacy restores the ‘functioning’, thus making it possible even for poor patients to navigate, mitigate, and overcome the economic burden. The healthcares services in terms of the availability of free medical and nursing care services and appropriate scheduling of pharmacy refill appointments makes the access and adherence costs more predictable and manageable.
5
Factors Facilitating Adherence to Antiretroviral Therapy at the Patient Level

5.1 Introduction
The first two empirical Chapters have explained the barriers to adherence to antiretroviral therapy. The key message is that differences in location, the range of healthcare services provided at a health facility, provider characteristics, and adherence barriers do not have a significant negative effect on adherence rates to ART. This implies that there are key factors that facilitate adherence to antiretroviral therapy in the two facilities. However, prior to the implementation of this research in 2006 (and even today), most of the adherence studies tended to concentrate on predictors or determinants of adherence to ART hardly making any distinction between adherence barriers and facilitating factors at the individual and the facility levels. This Chapter therefore explores the factors facilitating adherence to ART at the patient level in the two different health facilities. Section 5.2 begins by analysing the adherence patterns and characteristics for the urban-based Mission Facility and rural-based Public Facility. As a way of establishing the immunological response due to adherence to ART, section 5.2 also presents the health outcome indicators for patients taking antiretroviral therapy. Using that background evidence, the subsequent section (5.3) assesses the factors facilitating adherence to antiretroviral therapy between the two ART sites. Finally, section 5.4 presents the discussion and conclusions.

5.2 Adherence Patterns and Trends
The following section starts by presenting the overall global adherence measured as: non-adherence (<80%), sub-optimal (80-94%), near-optimal (95-99%), and optimal (100%). However, given the fact that cross-sectional adherence data may conceal the adherence trends that are likely to occur during the treatment persistence phase, this Chapter will also present the longitudinal adherence. There are two possible ways of presenting time-course adherence data. The first is to present the complete time-course adherence data for each month for the entire three-year treatment period.
The second approach would be to present compressed time-course adherence data pooled on a quarterly or monthly basis. As it is unnecessary to present lengthy time-course adherence data for the entire three-year treatment period, especially when the printout analysis already shows consistently high levels, the second approach will be followed.

Furthermore, the introductory Chapter alluded to the fact that adherence can be measured in two ways, that is, adherence level and adherence status. As already indicated; each of those adherence measures is associated with its strengths and its limitations (See Section 2.5.1). Putting that debate aside, while Chapter three presented the time-course (non)adherence level with the intent of illustrating the small mean percentage of missed pills, this Chapter will focus on the time-course adherence status in order to reveal the performance of optimal adherence in the entire study sample.

### 5.2.1. Adherence Characteristics

Adherence characteristics are already discussed in Chapter 3. Table 3.8 is reproduced here as a starting point for the analysis of adherence to ART in the two facilities.

<table>
<thead>
<tr>
<th>Adherence Rates</th>
<th>% ART Clients</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mission Facility</td>
<td>Public Facility</td>
</tr>
<tr>
<td>Non-Adherence (&lt;80%)</td>
<td>1.4% (2)</td>
<td>5.0% (6)</td>
</tr>
<tr>
<td>Sub-Optimal (80-94%)</td>
<td>9.9% (14)</td>
<td>3.3% (4)</td>
</tr>
<tr>
<td>Near-Optimal (95-99%)</td>
<td>66.2% (94)</td>
<td>17.5% (21)</td>
</tr>
<tr>
<td>Optimal (100%)</td>
<td>22.5% (32)</td>
<td>74.2% (89)</td>
</tr>
<tr>
<td>Total</td>
<td>100% (142)</td>
<td>100% (120)</td>
</tr>
</tbody>
</table>

As already stated, adherence was high for the sampled patients; of the 262 patients sampled, 90% (236) achieved the 95% cumulated near-optimal adherence rate in the three years preceding the study. In a bivariate analysis, there was no statistically significant difference in adherence to ART between the two different health facilities, as 89% and 92% of patients at the Mission Facility which provides holistic healthcare services and in the Public Facility providing basic healthcare services achieved the required 95% adherence respectively, ($\chi^2=109, df=1, p=.741$)

Tables 5.2 and 5.3 present the compressed time-course adherence status pooled on a quarterly or a monthly basis respectively. All adherence data represents the three years\(^{27}\) preceding the survey combined. It should be noted, for Table 5.2 while the

---

\(^{27}\) Reference is made to 3 years as opposed to 4 years (2004-2007) because there are no complete adherence rates for 2004 and 2007 due to the fact that site accreditation did not necessarily take
Factors Facilitating Adherence to Antiretroviral Therapy at the Patient Level

The sample size that was studied was 262, only 68 had started ART during the fourth quarter of 2004. Secondly, on both tables, to avoid overcrowding of the table, the cases which fell below 95% adherence have been excluded, except for their number of cases.

Table 5.2: Proportion of Patients Achieving >95% Adherence on a Quarterly Basis

<table>
<thead>
<tr>
<th>Facility</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4th</td>
<td>1st</td>
<td>2nd</td>
<td>3rd</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 95% Adherence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mission</td>
<td>%</td>
<td>98%</td>
<td>99%</td>
<td>97%</td>
</tr>
<tr>
<td>No.</td>
<td></td>
<td>63</td>
<td>76</td>
<td>94</td>
</tr>
<tr>
<td>Public</td>
<td>%</td>
<td>100%</td>
<td>88%</td>
<td>100%</td>
</tr>
<tr>
<td>No.</td>
<td></td>
<td>4</td>
<td>7</td>
<td>28</td>
</tr>
<tr>
<td>Total</td>
<td>%</td>
<td>99%</td>
<td>98%</td>
<td>98%</td>
</tr>
<tr>
<td>No.</td>
<td></td>
<td>67</td>
<td>83</td>
<td>122</td>
</tr>
</tbody>
</table>

< 95% Adherence Number of Cases

<table>
<thead>
<tr>
<th>Facility</th>
<th>J</th>
<th>F</th>
<th>M</th>
<th>A</th>
<th>M</th>
<th>J</th>
<th>J</th>
<th>A</th>
<th>S</th>
<th>O</th>
<th>N</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥ 95% Adherence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mission</td>
<td>%</td>
<td>100%</td>
<td>99%</td>
<td>99%</td>
<td>99%</td>
<td>98%</td>
<td>98%</td>
<td>100%</td>
<td>94%</td>
<td>99%</td>
<td>99%</td>
<td>99%</td>
</tr>
<tr>
<td>No.</td>
<td></td>
<td>142</td>
<td>140</td>
<td>141</td>
<td>140</td>
<td>139</td>
<td>139</td>
<td>142</td>
<td>133</td>
<td>140</td>
<td>140</td>
<td>141</td>
</tr>
<tr>
<td>Public</td>
<td>%</td>
<td>100%</td>
<td>99%</td>
<td>100%</td>
<td>100%</td>
<td>99%</td>
<td>100%</td>
<td>100%</td>
<td>99%</td>
<td>100%</td>
<td>98%</td>
<td>99%</td>
</tr>
<tr>
<td>No.</td>
<td></td>
<td>120</td>
<td>119</td>
<td>120</td>
<td>120</td>
<td>120</td>
<td>120</td>
<td>120</td>
<td>119</td>
<td>120</td>
<td>118</td>
<td>119</td>
</tr>
<tr>
<td>Total</td>
<td>%</td>
<td>100%</td>
<td>99%</td>
<td>99.6%</td>
<td>99%</td>
<td>99%</td>
<td>99%</td>
<td>99%</td>
<td>100%</td>
<td>96%</td>
<td>99%</td>
<td>99%</td>
</tr>
<tr>
<td>No.</td>
<td></td>
<td>262</td>
<td>259</td>
<td>261</td>
<td>260</td>
<td>259</td>
<td>259</td>
<td>259</td>
<td>262</td>
<td>252</td>
<td>260</td>
<td>258</td>
</tr>
</tbody>
</table>

< 95% Adherence Number of Cases

<table>
<thead>
<tr>
<th>Facility</th>
<th>J</th>
<th>F</th>
<th>M</th>
<th>A</th>
<th>M</th>
<th>J</th>
<th>J</th>
<th>A</th>
<th>S</th>
<th>O</th>
<th>N</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mission</td>
<td>No.</td>
<td></td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Public</td>
<td>No.</td>
<td></td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>No.</td>
<td></td>
<td>262</td>
<td>262</td>
<td>262</td>
<td>262</td>
<td>262</td>
<td>262</td>
<td>262</td>
<td>262</td>
<td>262</td>
<td>262</td>
</tr>
</tbody>
</table>

Table 5.2 above shows consistently high adherence rates throughout the three years treatment period, with 95-100% of patients at the Mission Facility and 88-100% at the Public Facility achieving ≥95% in each quarter. The other indicator of high place in January, and furthermore this study was not carried out during December.
adherence is the small number of cases (1-6) across both sites who failed to achieve the 95% adherence (see last rows).

A closer look at the performance between the two ART sites reveals that the rural-based Public Facility offering basic healthcare services, registered optimal adherence (i.e. 100%) 8 times, compared to the Mission Facility which only registered optimal adherence 4 times over the three years preceding the survey. This confirms the earlier observation that comprehensive healthcare services may not necessarily have a direct effect on adherence to ART.

Table 5.3 above also presents time-course adherence in the form of pooled monthly adherence for the three years preceding the survey combined. Even in terms of monthly adherence, adherence remains high, ranging between 94% and 100% at the Mission Facility and between 98% and 100% at the Public Facility. The overall conclusion is that both cross-sectional and longitudinal analyses show a consistently high adherence.

5.3 Health Outcome Indicators

Pill-count data is subject to a degree of inaccuracy due to concealment of adherence behaviour and/or failure to accurately recall the number of pills taken. It is therefore necessary to compare such adherence results with changes in health outcome indicators for individual patients. With the exception of a few cases, a consistent rate of 95% adherence is supposed to result in a positive clinical and immunological response within 6 months of starting antiretroviral therapy. Given the costs associated with viral load testing, both health facilities tend to depend on WHO staging parameters. Although WHO staging of a client is not reversible (i.e. it is determined once, at the beginning of a patient’s treatment trajectory, and even after an improved health condition due to antiretroviral therapy it remains the same). Nonetheless, the actual parameters used in WHO staging that is, the CD4 lymphocyte counts and other health outcome indicators (functional status, weight, and presence of OIs) can be used to monitor suppression of viral load replication. Improvement in these parameters after initiation of therapy can only be attributed to treatment effectiveness.

5.3.1 Changes in Mean Score CD4+ Cell Count

In principle, the CD4+ T cell test for individual patients should have been carried out at six months intervals in the two facilities. By the time of implementing this study, patients had undergone CD4 tests between one and five times.
A paired Samples T-Test was used to assess the mean change in CD4 count over consecutive visits. The two tables below indicate changes in CD4 count. Table 5.4 shows the mean score of the CD4+ cell count at a six month time-point preceding the survey. Whereas Table 5.4 only shows the mean score of the CD4+ cell count for the entire sample, Table 5.5 shows the actual mean change in CD4+ cell count and the respective level of significance (p value and SD).

It should be noted that a decrease in number of patients over time (in both Tables) represents inconclusive data for newly enrolled patients as this is not a cohort study that follows the same group of patients who enrolled for services at the same time. Second, the number of patients in Table 5.5 is smaller than anticipated because the calculation is based on only those patients who had comparable CD4 cell count data for the two consecutive visits. Figures in Table 5.4 and 5.5 indicate a steady increase in CD4+ cell count over the five consecutive tests, suggesting a positive immunological response attributable to antiretroviral efficacy.

**Table 5.4:** Mean Score CD4+ cell count at each Clinical Test

<table>
<thead>
<tr>
<th>Clinical Test</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>262</td>
<td>233</td>
<td>116</td>
<td>43</td>
<td>8</td>
</tr>
<tr>
<td>Mean</td>
<td>145</td>
<td>276</td>
<td>318</td>
<td>404</td>
<td>374</td>
</tr>
<tr>
<td>SD</td>
<td>107.3</td>
<td>152.6</td>
<td>163.9</td>
<td>246.2</td>
<td>157.0</td>
</tr>
</tbody>
</table>

In terms of mean score of CD4+ cell count, at Test 1 the mean score CD4+ cell count was 145 cells/ml of blood (SD 107.3) which improved to 374 CD+ cell count at Test 5 (SD 157.0). The SD figures indicate that the dispersion from the mean increases with subsequent visits, which may suggest increasing CD4 count, with different patients recording different positive response rates.

**Table 5.5:** Mean Change in CD4+ Cell Count between Two Consecutive Visits

<table>
<thead>
<tr>
<th>Clinical Test Intervals</th>
<th>Test 2-1</th>
<th>Test 3-2</th>
<th>Test 4-3</th>
<th>Tests 5-4</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>233</td>
<td>116</td>
<td>43</td>
<td>8</td>
</tr>
<tr>
<td>Mean</td>
<td>123</td>
<td>62</td>
<td>87</td>
<td>43</td>
</tr>
<tr>
<td>SD</td>
<td>159</td>
<td>149.5</td>
<td>171.7</td>
<td>87.7</td>
</tr>
<tr>
<td>P</td>
<td>.000</td>
<td>.000</td>
<td>.002</td>
<td>.204</td>
</tr>
</tbody>
</table>

In terms of mean change in CD4+ cell count, the results were statistically significant for all visits (Visits 2, 3, 4, with all Ps ≤ .002). Insignificant increase in CD4+ cell count between the 4th and 5th tests can be attributed to the small number of patients attending the fifth test.
5.3.2 Changes in Weight

The second parameter for assessing treatment response was changes in weight. The data for weight was readily available on patients’ clinical records, because the health workers record such data at every pharmacy refill. Figure 5.1 presents changes in weight from the baseline month of treatment until the 21st month of being on ART treatment.

Figure 5.1: Mean Change in Weight (Median)

The bar graph above shows a steady increase in mean weight, with an increase of 1 to 7 kilograms between the 1st and 18th months of starting antiretroviral therapy. A close look at the absolute figures shows that patients tended to gain one extra kilogram at a three month interval, especially for rural patients. The Mission Facility and Public Facility manifest different pattern in weight increase. The patients in the urban-based Mission Facility tended to register a gradual weight increase of 1 kilogram at the end of each three months’ treatment interval (month 4, 7, 9, 12, 18), while patients in the rural-based Public Facility registered a significant mean weight score of more than two kilograms almost at the end of each two months’ treatment interval (2, 4, 7, 12). A significant weight gain in the rural settings is attributed to the clinical benefits associated with almost perfect adherence among patients who previously suffered from their prolonged HIV/AIDS condition as well as reliable access to food from their gardens. Patients also spoke of an increase in appetite and weight gain during the first three months of antiretroviral treatment, an indicator of improved health outcome. A positive mean change in weight during the seventh month coincides roughly with an increase in CD4 count during the sixth month of being on ART.
5.3.3 Functional Status

The third parameter for assessing the health outcome was the ‘functional status’, which is normally categorised as bedridden, ambulatory, or work. Clinical assessment of functional status is based on patient self-reporting.

**Table 5.6:** Changes in Functional Status (Both Facilities Combined)

<table>
<thead>
<tr>
<th>Functional Status</th>
<th>Quarterly Changes (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1st</td>
<td>2nd</td>
</tr>
<tr>
<td>Work</td>
<td>80%</td>
<td>89%</td>
</tr>
<tr>
<td></td>
<td>530</td>
<td>593</td>
</tr>
<tr>
<td>Ambulatory</td>
<td>19%</td>
<td>11%</td>
</tr>
<tr>
<td></td>
<td>122</td>
<td>71</td>
</tr>
<tr>
<td>Bedridden</td>
<td>1%</td>
<td>.4%</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>661</td>
<td>667</td>
</tr>
</tbody>
</table>

The results in the table above indicate a significant improvement in health condition during the third quarter, with patients moving from an ambulatory or bed-ridden functional status to a work functional status. The proportion of patients with a work functional status increases from 80% (530) to 92% (546) between the 1st and 3rd quarter, while the proportion of patients under ambulatory and bedridden functional status consistently decreases throughout the entire treatment period - an indicator of durable improvement in health condition. The pattern of functional statuses is consistent with an increase in CD4 cell count and weight at 6 month time-point and later. In the functional status of ‘work’, a decrease in the proportion of patients during the sixth quarter is not an effect of lost-to-follow-up but due to inconclusive data for the last quarters because of variability in treatment initiation dates.

The fourth and last parameter measured was the WHO clinical staging, normally used to predict the prognosis of HIV infection. This consists of four stages for HIV infection and disease in adults, with clinical stages 1 and 2 indicating an acceptable health condition, and stages 3 and 4 indicating deteriorating health conditions. Stage 4 is predictive of death because of severe HIV related opportunistic infections. The assessment of WHO clinical staging is omitted here because it may not be useful in evaluating improved health condition, as the original clinical stage is not reversed even when patients’ clinical and immunological conditions improve (see Appendix Figure A.1). The overall conclusion is that the health indicators (CD4 count, weight, and functional conditions) show improved health outcomes attributable to the high adherence rates already presented above.
5.3 Factors Facilitating Adherence to Antiretroviral Therapy

5.3.1 Constructing the Factors Facilitating Adherence to ART

As already indicated, bivariate analyses were carried out using Pearson’s Chi-Square tests to assess the relationship between key independent variables and a 95% adherence. The results indicated a statistically insignificant relationship between the two variables (for details see Appendix Technical Notes A.9 after Table A.8). The major explanation for such inconsequential statistical results can be attributed to the fact that pill-count adherence was already high. As indicated in Huwe (2005:4), ‘real and important differences may go undetected when all measures fall within statistical limits (false reassurance)’. On the other hand, the qualitative data generated from some of open-ended questions on the questionnaire and subsequent explanatory qualitative studies revealed that there are factors that facilitate adherence to ART.

The survey included a set of questions in order to assess patients’ commitment to antiretroviral therapy, as well establishing the reasons for commitment levels. As already indicated in section 2.4.1, data for side-effects and opportunistic infections were extracted from the clinical records in advance of the survey, included in the questionnaire, and verified with the respondent at the time of the individual interview.

The following questions asked whether the patients “get discouraged in taking ARVs because of (previously recorded) drug side-effects, and opportunistic infections.” Results for the side-effects indicated that a large proportion of patients (87%, 226) suffered from drug side-effects. Side-effects were recorded as severe, moderate, or mild, as presented in the Table below.
Table 5.7: Severity of Drug Side-effects (both Sites combined) (n=225)

<table>
<thead>
<tr>
<th>Side Effects</th>
<th>% Cases Reporting Side-effects</th>
<th>Severity of Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Severe</td>
</tr>
<tr>
<td>Rash</td>
<td>40% (89)</td>
<td>25%</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>36% (80)</td>
<td>42%</td>
</tr>
<tr>
<td>Headache</td>
<td>35% (79)</td>
<td>39%</td>
</tr>
<tr>
<td>Abdominal Pain</td>
<td>31% (70)</td>
<td>37%</td>
</tr>
<tr>
<td>Nausea</td>
<td>23% (52)</td>
<td>52%</td>
</tr>
<tr>
<td>Burning/Numbness/Tingling</td>
<td>16% (36)</td>
<td>28%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>8% (18)</td>
<td>28%</td>
</tr>
<tr>
<td>Anaemia</td>
<td>1% (3)</td>
<td>33%</td>
</tr>
<tr>
<td>Jaundice</td>
<td>1% (2)</td>
<td>0.9%</td>
</tr>
<tr>
<td>Fat Redistribution</td>
<td>2% (5)</td>
<td>80%</td>
</tr>
<tr>
<td>Anxiety/Depression/Confusion</td>
<td>13% (30)</td>
<td>37%</td>
</tr>
<tr>
<td>Other (Specify)</td>
<td>33% (74)</td>
<td>27%</td>
</tr>
</tbody>
</table>

(Source: Clinical Records)

Based on the results above, there are some important points to note. First, in terms of prevalence of side-effects the two health facilities had recorded a wide range of drug side-effects over the three years that preceded the survey. These side-effects were: rash, diarrhoea, headache, abdominal pain, nausea, burning/numbness/tingling, fatigue, anaemia, jaundice, fat redistribution, and anxiety/depression/confusion.

In response to the question whether they “get discouraged in taking ARVs because of those (previously recorded) side effects,” 90% (231) of the respondents indicated never. Of those who said they never get discouraged by drug side-effects, the reasons given were that: “ARVs reduce the impact of side-effects, side-effects are less severe or occasional, side-effects are properly treated, was previously counselled, my priority is to prolong my life.”

Another set of questions that were interested in the effect of Opportunistic Infections (OIs) on commitment to life-long antiretroviral therapy revealed that patients suffered from a wide range of opportunistic infections. The OIs extracted from the patients’ files were: cough (70%, 182), fever (60%, 156), thrush (oral/vaginal; 35%, 91), ulcers (mouth/genital; 15%, 38), weight loss (11%, 28), herpes zoster (5%, 14), difficult breathing (4%, 10), pneumonia (3%, 9), immune reconstitution inflammatory syndrome (IRIS; 2%, 6), dementia/enceph (0.8%, 2), and others (52%, 137). When asked if they are discouraged from taking ARVs because of (previously recorded) opportunistic infections (OIs), the majority (91%, 233) answers that they are never discouraged by OIs. The reasons given were similar to those of not being discouraged.
by side-effects namely: ARVs are strong drugs that keep OIs at bay, OIs are not severe, OIs are occasional; was counselled, OI treated by the Health Worker, priority is to prolong my life, ARVs restored health condition.

Another question asked the patients “How committed are you to taking ARVs for life,” and followed by asking the reasons for the given level of commitment. In terms of the reported level of commitment, across the two ART sites, 93% (241) were ‘highly’ committed to treatment for life. The reasons provided were: a strong desire to prolong life, desire to provide care, support, and planning for children, improvement of health conditions by ARVs, satisfactory counselling, simply complying to doctor’s advice, to serve as an example (role model) for ARVs effectiveness.

Included were two other questions on in the various reasons for being adherent to ART (see Appendix Table A.4), and the reasons for being optimally adherent to treatment initiation appointments (section 3.3.1) The reasons for optimal adherence to treatment induction activities coincide with those for optimal adherence to ART (see Appendix Table A.4).

Based on all that background evidence on patients commitment to ART the overall outcome is that there are five factors facilitating adherence to ART at the patient level. These facilitating factors are: 1) previous clinical conditions; 2) personal life goals; 3) therapeutic skills; 4) effectiveness of treatment; and 5) patient background characteristics.

5.3.2 Previous Clinical Conditions

HIV/AIDS is a chronic but also a fatal illness, especially if the symptoms are not treated appropriately. In this case, patients with HIV/AIDS during the early phase of the epidemic suffered multiple infections of an extended duration. As part of disease diagnosis and staging, and monitoring of treatment effects and failures, both health facilities record the HIV/AIDS related history for patients who are initiated on ART. A review of clinical records that preceded the survey recorded the type of illnesses that bothered the patient before taking up antiretroviral treatment, and the duration and the severity of that condition. This primary data was verified with the patients during the survey. The 217 patients whose clinical data was available reported multiple (419) opportunistic infections upon commencement of ART. These included fever (73%, 159), wounds (34%, 73), cough/flu (31%, 67), diarrhoea (24%, 53), TB (20%, 43), headache (16%, 35), skin rash (10%, 22), abdominal pain (8%, 17), thrush (vaginal) (6%, 12), and herpes zoster (56%, 10). For all the above conditions combined, 65% were bedridden as a result, 93% were ambulatory, and 75%
were active (*multiple responses allowed*). A combination of bedridden and ambulatory conditions suggests that a majority of patients were experiencing impaired immune systems upon commencement of antiretroviral treatment. For each of these health conditions, ≥60% of patients suffered from such illnesses for more than 12 months. Evidence from a separate question indicates a possible link between the progression of HIV/AIDS and patients’ motivation for seeking VCT. Survey results revealed that 68% (176) of patients in both health facilities were compelled to seek VCT due to recurrent illnesses.

A second source of evidence to support the view that previous health condition determines adherence are the reasons that were volunteered by patients for being adherent to Treatment Induction Appointments. Section 3.3.1 indicates that ≥ 91% adhered to each of the initiation appointments (cf. table 3.2). For those who volunteered reasons, the Table below presents the reasons for adherence to each of the induction appointments.

**Table 5.8:** Reasons for Being 100% Adherent to the Initiation Appointments (both Sites Combined)

<table>
<thead>
<tr>
<th>Appointment</th>
<th>CD4 Test (n=80)</th>
<th>First Counselling (n=75)</th>
<th>Second Counselling (n=81)</th>
<th>Third Counselling (n=34)</th>
<th>Started on ARVs (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eager to know the CD4 results</td>
<td>14% (11)</td>
<td>5% (4)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Eager to receive ART information</td>
<td>3% (2)</td>
<td>3% (2)</td>
<td>13% (10)</td>
<td>6% (2)</td>
<td></td>
</tr>
<tr>
<td>Needed treatment urgently</td>
<td>44% (34)</td>
<td>41% (30)</td>
<td>46% (37)</td>
<td>50% (17)</td>
<td>56% (9)</td>
</tr>
<tr>
<td>Counselling improved my confidence</td>
<td>3% (2)</td>
<td>3% (2)</td>
<td>4% (3)</td>
<td>3% (1)</td>
<td>6% (1)</td>
</tr>
<tr>
<td>I was psychologically ready</td>
<td>4% (3)</td>
<td>8% (6)</td>
<td>4% (3)</td>
<td>0</td>
<td>6% (1)</td>
</tr>
<tr>
<td>Was complying to health advice</td>
<td>33% (26)</td>
<td>39% (29)</td>
<td>33% (27)</td>
<td>38% (13)</td>
<td>31% (5)</td>
</tr>
<tr>
<td>Other</td>
<td>3% (2)</td>
<td>4% (3)</td>
<td>1% (1)</td>
<td>3% (1)</td>
<td>0</td>
</tr>
</tbody>
</table>

The most important reason for timely return to collect CD4 test results, to attend induction counselling (1st-3rd session), and to be initiated to ART was “needed treatment urgently,” implying that patients were eager for ARVs. The urgent need to be introduced to ART is directly linked to deteriorated health conditions. The other reasons are linked to effectiveness of counselling reflected in the nature of reasons given namely; “compliance to health advice,” or “was psychologically ready” and “counselling improved my confidence.”
Patients’ qualitative accounts also provided confirmatory evidence that deteriorated health conditions must have influenced subsequent adherence.

I suffered from cough and syphilis. I got medication for syphilis, about 20 injections. I used to have rashes all over my body and the itching was unbearable. I used to use a knife to scratch my body. I had chest problems; whenever I coughed it felt like a thunderbolt had exploded, everybody around me would flee in disarray. On the day I came for the tests (VCT) here, I woke up at 7:00am and arrived at 9:00am (travelling a distance of 1 km). The doctors cut a piece of flesh from my body (biopsy) and also took a blood sample … Results indicated that I had only 3 soldiers (CD4 cells). In 2004 I started taking ARVs. Now I am as fresh as a flower (big applause from FGD participants). I am in better health to take care of the two orphans left behind by my deceased brother. (Female Key Informant, UMF)

Patients from the rural-based Public Facility presented similar accounts:

I used to feel severe chest pain whenever I tried to ride a bicycle carrying a big load. I also frequently suffered from malaria, later I developed herpes zoster. That (zoster) finally confirmed my fear and suspicion that I am infected. Later, my brother came for me and took me for treatment at the Joint Clinical Research Centre. The tests indicated that I was HIV positive. I started getting ARVs from Mengo (Kampala city Mission Hospital). At that time, the monthly dose costed Ushs 250,000 (US$ 139). Eventually, the cost became unbearable and I suspended treatment for six months. Then, like a baby, I started sweating profusely at night. I later returned to Kamwokya Hope Clinic (Kampala), the doctors diagnosed me with pneumonia, and I received treatment. In 2004, with (financial) assistance from my brother, I resumed taking the (antiretroviral) medicine, still from Mengo Hospital. Later, I switched from Mengo to the Makerere University Walter Reed Project here. By that time, I had only 38 soldiers (CD4 cells). Luckily, my wife, who was tested five times, was negative. (Male Key Informant, RPF)

While the link between prolonged illness and adherence to ART may be unclear, in those two cases, the explicit message (or meaning) is that of prolonged and recurrent illnesses, unceasing pain, stigmatisation of the HIV/AIDS symptoms, frantic health seeking behaviour, volunteer care-giving, prohibitive health costs, criss-crossing treatment centres, antiretroviral efficacy, and restored hope. Results from one of the survey questions indicated that prior to ART treatment, a high proportion 87% (229) of patients in both sites incurred costs and the highest health expenditure ever incurred was of Ushs 208,103 (US$130).

The degree of physical and social suffering also influenced subsequent adherence behaviour, as this patient said:
The more they laugh at us, the more committed and determined we become to take the drugs. … The more I see an emaciated person, the more I fear deteriorating to such a state. (Focus Group Discussion, UMF)

Previous loss of partner and/or relatives also acted as a reminder of the likely consequences of not taking up and adhering to health advice.

One of the effects of prolonged illness was disclosure of one’s HIV status. Results also show that the majority (97%, 250) of patients had previously disclosed their HIV status, disclosing to on average 9 people. The qualitative reasons show that prolonged illness and desire to maximise social support accounts for high disclosure rates of one’s serostatus to friends, family members, and fellow patients. The reasons were: 1) these people help me; 2) these people stood by me when I was seriously sick and I had to tell them the truth; 3) I had to tell the Treatment Supporter; 4) I do not care because the whole world is infected; 5) HIV is an old phenomenon; 6) I have to spread the gospel so that other people do not get the virus.

5.3.3 Personal Life Goals

As previously mentioned, one of the reasons for being committed to ART was the desire to provide care and support for children. Similarly, the qualitative evidence presented above makes reference to the need to take care of orphans, be they biological children or step-children. All this suggests that an improved health condition is not an end in itself but a means to achieving higher personal goals in life. The question could be asked as to why taking care of children/orphans was such a major concern to most patients. One of the survey questions revealed that half (51%, 130) of the respondents (both sites combined) came from households with orphans. The follow-up question wanted to know the number of orphans in a household and the survival status of their parents, who may not necessarily be the ones taking antiretroviral medication. Table 5.9 shows the average number of orphans in the household and the survival status of their biological parents.

Table 5.9: Number of Orphans per Household and Survival Status of Biological Parents (Both Sites)

<table>
<thead>
<tr>
<th>Number</th>
<th>Both Parents are Dead</th>
<th>Only Mother is Alive</th>
<th>Only Father is Alive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Orphan</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Minimum No. of Orphans</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Maximum No. of Orphans</td>
<td>7</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>Number of Orphans (sum) in the sample</td>
<td>52</td>
<td>303</td>
<td>69</td>
</tr>
<tr>
<td>Number of Respondents (n)</td>
<td>21</td>
<td>97</td>
<td>28</td>
</tr>
</tbody>
</table>
Of the 424 total number of orphans (total second last row), 303 (72%) were paternal orphans (lost the father), and 69 (16%) were maternal orphans (lost the mother), 52 (12%) were double orphans (both parents died), possibly due to HIV/AIDS related causes. Implying that in most cases the main guardians were the surviving widows, who might be the very female ART patients who formed the majority of ART patients (cf Table 2.2 Gender). Further, Explanatory Qualitative Studies provided insights into the relationship between orphan care and adherence to ART.

It is heartbreaking to look at these children, you really pity them. You wonder how they will survive on their own without me as a biological parent. Even if my close relatives were to be rich, they cannot provide the care my children deserve. Relatives and friends pamper our children during our lifetime. When we die, such relatives are more interested in grabbing property than providing care and support to the little ones. Tell me, in such an unfriendly social environment, how can I give up the medication to die and leave my children in the hands of such wicked people? (Follow-up Focus Group Discussion- female participant, RPF)

However, if only half (51%, 130) of patients lived in households with orphans, then taking care of orphans can only be one among other motivations for taking antiretroviral medicines religiously. The qualitative evidence suggests a broader notion of providing care and protection to dependants.

We take medication because we want to get well. Some patients do not have children but still take their medicines properly. Some patients are supposed to provide care and support to their parents, others support dependents (Follow-up Focus Group Discussion- female participant, RPF).

Another participant clarifies:

Most of our parents and relatives have died, who else can come to our rescue if we happen to fall sick? It does not make any sense to invite illness, you shift from being benefactors to being a dependent. (Focus Group Discussion, UMF)

While the message in the two quotations does not displace the ‘parental goal’, it introduces another notion in the goal structure: starting with the need for self-preservation (personal goal) and its associated self-sufficiency; providing care and support to orphans (parental goal); and providing care to a wider network of relatives (higher altruistic goal).

Evidence presented in this Chapter (and Chapter 7), indicates that diverse goals drive adherence, for instance: to avoid the sick role and the associated dependence

28 Definition - Sick role is the socially acceptable role of a sick person (Helman 2001:85; also Jones 1991:94).
and exclusion from work (self-sufficiency), being a living testimony that HIV/AIDS treatment is effective (pharmacologist), deflection of stigmatisation and social exclusion associated with physical wasting (social conformism). Large amounts of qualitative evidence attest to such purposeful behaviour, as can be gleaned from phrases such as: “The more they laugh at us, the more committed and determined we become to take the drugs.”

5.3.4 Therapeutic Skills
The process of falling ill, coping with illness, and engaging in health seeking behaviour facilitated the accumulation of treatment knowledge and skills among the infected and the affected. In the context of Uganda, acquisition of these therapeutic skills started as early as 1982 when the first AIDS case was recorded in South-Western Uganda, with the condition stigmatised as silimu or physical wasting. Self-help groups emerged spontaneously to find a solution to a strange disease without a cure.

My health condition gradually deteriorated (respondent becomes depressed for a moment). At that time, I had friends who were experiencing similar conditions. During 2001 we got together and started gathering and boiling local herbs (Eddagala Egganda). The herbs worked fairly well, I regained some strength. Our group comprised of 33 members, almost all of them from the same village, Kanjuki. After testing (HIV) positive, we formalised our association and named it the Kanjuki Post-Test Club. Only four members tested as HIV negative. In 2004, we started seeking medical services from Kayunga Hospital. At that time only Septrin (Cotrimoxazole) was readily available in the hospital. Today, we ‘talk to’ (counsel) our fellow patients who come for services here, as well as those still in villages, about the disease and treatment prospects.

(Leader and founder of Kayunga Healthcare and ART Association)

For these early patients, the therapeutic skills were acquired through three overlapping stages, namely: herbal medication, cotrimoxazole prophylaxis (septrin), and the commencement of ART. Possibly due to a combination of stigma and the advice of health workers, only a small proportion (30%, 78) of ART clients admitted having used herbal medicine prior to the ART phase. The average duration of herbal use was 2.5 and 5.5 years among urban patients and rural patients, respectively. On the other hand, survey results revealed that, on average, urban patients and rural patients took cotrimoxazole prophylaxis for 5 months and 2 months respectively. A lengthy application of herbal medicine and short-lived exclusive application of cotrimoxazole prophylaxis among rural patients suggests more deteriorated health conditions that warranted early introduction of ARVs.
The intermediate stage of using preventive therapies like cotrimoxazole prophylaxis influences the ability to adhere to life-long drug regimens in several ways. Because cotrimoxazole is a broad spectrum prophylaxis against bacterial and parasitic infection, it reduces the incidence and severity of opportunistic infections, thus improving patients’ confidence in conventional (bio-) medicines for HIV/AIDS (see quotation that follows). The majority (83%, 216) of patients indicated that the period of being on cotrimoxazole prophylaxis influenced their adherence behaviour. They felt they became “used to routine medication” and “developed confidence in HIV treatment.” It is also during this phase that patients developed personalised adherence strategies to cope with pharmacy refill transport costs. On the supply side, dispensing and monitoring the use of cotrimoxazole prophylaxis creates an opportunity for the health workers to identify potential non-adherent patients and adherence barriers, and to intensify education well in advance of the commencement of ART. For some patients, the administration of cotrimoxazole prophylaxis coincided with treatment for meningitis, TB, or pneumonia, which prepared the patient for complex regimens.

The second source of therapeutic competence is counselling and education provided at both health facilities. Continuous counselling and education sessions have been one of the main channels for sharing therapeutic skills, in the form of technical and practical advice. The counselling trajectory consists of six interactive phases, namely: 1) client enrolment; 2) ART education (clients and care-givers); 3) prescription counselling; 4) adherence counselling; and 6) client follow-up (monitoring and home visits) (for a detailed discussion of counselling see Chapter 6). As patients said, “counselling opened our eyes to the idea that we have to take pills till death.”

5.3.5 Effectiveness of HIV/AIDS Treatment

The assessment of quality of life indicators (5.2.2) has already revealed that ARVs are associated with immunological and clinical improvement characterised by positive changes in CD4 count, weight, and functional status. Supplementary evidence from the survey also indicates that the patients were happy about their improved physical condition. Answers to the question ‘How do you evaluate your health conditions after being on HIV/AIDS treatment for some time’ indicated that 13% (33) across both health facilities regarded their condition as ‘excellent’, while half (50%, 132) regarded it as ‘very good’, and 37% (97) considered it as ‘good’. No patient fell into the category of feeling ‘bad’, ‘worse’, or ‘worst’. If the figures for ‘excellent’ and ‘very good’ were combined, then 63% (165) of patients were satisfied with their rejuvenated health condition. In describing the reasons for not being discouraged by the side-effects
and opportunistic infections, some patients felt that ARVs reduce the impact of side-effects (even if they caused them in the first instance) and the occurrence of opportunistic infection. Qualitative evidence suggests that antiretroviral therapy had gained supremacy over other medicines previously tried.

We started with ‘buddomola’ (small jerry cans of herbal medicine), that had given us company through hard times. We appreciate the role herbal medicines played in our lives at that time. When Septrin (cotrimoxazole) came, we embraced it and we felt a great relief in our bodies. It ended the bulk of illnesses – rashes, sores, and fevers. Even when you came into contact with flu, with Septrin, the body can resist it. However, our friend Septrin causes that burning sensation in the heart (chest), needing a lot of water to quench it. Then there is this new drug (ARVs). That one is a ‘silencer’. Even if that drug does not completely free the body from infection, it is a potent drug. (Focus Group Discussion, RPF)

Attribution of human-like qualities to the medicines previously tried not only shows the intimacy patients have with their medicines, but also their adherence behaviour. Using the metaphor of a ‘silencer’ to describe ARVs creates the impression that ARVs are powerful suppressants that should be taken continuously. As one patient noted, ‘I normally tell people that the virus is just hibernating but still alive’. The other indicator that ARVs are effective is the subjective evaluation of bodily appearances and function by the patients themselves.

The medicine is effective. It has restored our bodies. The health complications which we had have been reversed. We are a lot better now … When we look at ourselves, we regain hope … We look totally different from the past. We are healthier than normal people. Don’t you see how we glow! (Focus Group Discussion, UMF)

I sought medical attention in Reach Out (Health Facility), after three weeks of medication, I suddenly regained my appetite. I kept on waiting for the fevers to return, to my surprise it did not; the blisters also disappeared. (Focus Group Discussion, RPF)

As a result, whenever patients come to the clinic, they are enthusiastic about gaining weight. Those who record weight increase treasure any kilogram gained, and those who lose some kilograms become downcast and inquisitive about the cause. Since antiretroviral therapy ‘worked for them’ (a phrase commonly used by patients themselves), the patients are extremely grateful to the donors and health providers. When I solicited for questions and clarifications at the close of one of the FGDs at the RPF, this interaction between 3 patients ensued:

We do not know who they are, where they live, neither will we have the opportunity of meeting them one day. We cannot travel (abroad). Take this message to those
people – we are extremely grateful for the medicine they sent to us. Also extend our sincere appreciation to the doctors for being kind hearted and caring.

Another patient interjects:

For me, this is a question: is there a possibility of taking just one tablet a month?

Another seemingly embarrassed patient replies:

Come on, absolutely impossible, that is family planning!

The quotation indicates that patients treasure ARVs as gifts because they work for them. The same quotation anticipates imminent pill fatigue and expresses the desire for a cure.

An individual’s health condition has an impact on the adherence among other patients.

We have not had many discontinuities. Clients are inspired by the ‘role models’, mainly those patients who were once severely sick but have since recovered after taking ARVs. (Nurse, ART Clinic, RPF).

Beyond the antiretroviral efficacy, HIV patients indicated that drug side-effects and opportunistic infection did not have a negative effect on adherence because patient received timely and effective treatment, and were adequately counselled about such potential barriers. In the Public Facility with a wide-range of diagnostic services, patients undergo test for syphilis, and if the results are positive the patient is referred to the Clinical Officer and treated for syphilis. In addition, patients take liver function test, and if the tests indicate liver malfunction the patient is referred to a doctor. As indicated above, where necessary patients are treated for meningitis, TB, or pneumonia, as well as being maintained on cotrimoxazole prophylaxis during antiretroviral treatment (See the HIV/AIDS Treatment Pathways in the Appendix Supplementary Material SM.1).

In implementing such comprehensive medical care the Health staff also tries to reduce potential drug side-effects.

Some HIV patients have TB. In order to reduce the combined side-effects of Refampicin (TB drugs) and Nevirapine in Trioumune, we recommend PEPFAR. In place of Nevirapine the clients gets Efavirenz in order to avoid liver toxicity. Even among the children we do not have a Trioumune syrup so we prescribe PEPFAR drugs. (Key Informant, RT Nurse, RPF).
5.3.6 Patient Background Characteristics

Whereas the statistical tests (Pearson’s Chi-Square test) that were carried out to measure the relationship between several independent variables and the adherence 95% yielded statistically insignificant results, a critical assessment of patients’ background might provide supporting evidence of the individual level facilitating factors (refer to Table 2.2).

Of the 262 ART clients selected, the majority (63%, 164) were female respondents. This is to be expected since women form the majority of HIV/AIDS patients seeking treatment services in Uganda’s routine settings, where healthcare service are free of charge. However, it is also significant to note that most of the orphans were paternal orphans with a surviving mother.

The mean age of the respondents was 38 years. Mid-life age is normally associated with stakes in life, and with half complete life goals; with one of the unaccomplished goals being to see children through to their advanced life stages.

Less than a half (42%, 111) of the respondents were married, with the rest being single in the form of widows/widowers (35%, 91), separated (19%, 50), or single (4%, 10). In any case, marital life is associated with social responsibility, while being in a state of widowhood means being a sole benefactor.

In addition, the HIV/AIDS burden in a household was high. To the question “how many people in your household are HIV positive”, 256 respondents indicated that they lived with 1.43 (mean) HIV-infected persons, with a total of 367 (sum) household members reported to be HIV positive. Obviously, fear of susceptibility to disease progression and the serious consequences they may have on the household induce strict adherence behaviour.

Based on household education characteristics, 70% (1004) household members were semi-literates (without and with primary education), surviving on US$ 6 per month. Once exposed to credible health information about a life-threatening problem, underprivileged people are more likely to be compliant to health advice than the highly educated people who are more aware of the drug side-effects, or harbouring felt stigma, or having freedom to chose from the available healthcare services.

Lastly, the majority had been on ART for more than 12 months, and almost equal numbers on the simple and complex regimens. These were already expert patients.
5.4 Conclusion

The purpose of this Chapter has been to provide a detailed account of the factors facilitating adherence to antiretroviral therapy among patients seeking HIV treatment services in two different ART facilities in Uganda’s resource-poor settings. This is because despite the multiplicity of adherence barriers in form of biomedical and structural factors, 90% of the patients took 95% of their prescribed doses over the three years preceding the study. Such a high adherence status is confirmed by the health outcome indicators (CD4+ cell count, weight, and functional status).

The adherence levels and treatment outcomes in this study are comparable to the adherence studies conducted in sub-Saharan Africa before and after this study, with these studies showing significant self-report adherence and better treatment outcomes. See, for instance, a study on the early Drug Access Initiative (DAI) in Uganda, with 221 patients in 850 (88%) reported having taken antiretroviral drugs ‘about as prescribed’ with results showing an undetectable viral load (<400 copies/mL) among adults (Weidle 2002). Another evidence is the study that shows favourable levels of adherence in 12 sub-Saharan countries, with 77% achieving a given threshold of adherence monitoring ranging between 100% to >80% (Mills et al. 2006). Another one shows that of 424 HIV patients in rural Zambia, 83.7% achieving 95% adherence, (Carlucci et al. 2008). Although there are also countries in which adherence is significantly lower, see for instance lower adherence levels in Benin Teaching Hospital (Erah and Arute 2008).

Whereas there is paucity of information of facilitating factors in most of background adherence research, results from adherence studies conducted in Uganda, Tanzania, and Botswana are consistent with those reported in this study. For instance, the desire to stay alive in order to care for and support one’s children’s health and other family members was reported to be one of the motivators of adherence among the HIV-infected parents and their children attending Mother-To-Child Transmission Plus Programme in Kampala (Byakika-Tumusiime et al. 2009). An adherence study based on a small sample of 6 healthcare providers and 36 patients at a healthcare centre in Arusha (Tanzania) in 2006 found five factors facilitating adherence to ART (Watt et al. 2009). These factors are: 1) respondents experienced substantial improvement in their heath conditions after starting ART; 2) the need to meet family responsibilities motivated patients to stay healthy; 3) patients engaged in personalised adherence strategies, especially linking pill taking time to daily activities or events; 4) receiving material and emotional support; and 5) having trust in the advice of the healthcare provider who regularly emphasised adherence. Evidence in other
background adherence studies conducted in the developed world also indicates that the common motivation for adherence is the desire to stay alive in order to provide care and support to one’s own children and other family members (Watt et al. 2009); or having plans and hopes for the future (Fogarty et al. 2002, Mallory et al. 2003) – also referred to as outcome efficacy or intrinsic reinforcement.

This adherence study distinguishes individual level factors from structural factors. Hence, the effect on social support and healthcare services on adherence to ART is addressed in Chapter 6 and 7.
6

Inside the Counselling Room: The Role of Information, Education and Communication in Adherence to Antiretroviral Therapy

6.1 Introduction

In the preceding Chapters, counselling\textsuperscript{29} has been a recurrent theme. In Chapter 3, health advice was mentioned as one of the reasons for being adherent to induction appointments. In Chapter 4, perseverance despite the economic burden was attributed partly to effective counselling. Chapter 5 has demonstrated the role of therapeutic skills in adherence to ART, with success attributed to counselling and education. Furthermore, in assessing cross-sectional and longitudinal adherence, we have seen that there was no statistically significant difference between the urban-based Mission Facility providing comprehensive HIV/AIDS related services and the rural-based Public Facility providing basic services. From a supply point of view, such results suggest that adherence to ART is not determined by comprehensive HIV care and support services, but by a minimum healthcare package, namely: medical components and the information itself.

As already indicated, existing studies tend to emphasise the patient-provider relationship, without indicating the nature of such relationships. Psychologically-based studies show that the education or health literacy communication through the provider-patient interaction is one of the significant and independent predictors of adherence. The key message to be taken from this literature is that in order to increase adherence it is important to: provide information about HIV, HIV treatment, its efficacy and need for adherence using clear, explicit language appropriate for

\textsuperscript{29} Smith (1951) states that counselling is a process in which the counsellor assists the counselee to make an interpretation of facts relating to a choice, plan, or adjustments which he needs to make (in Narayana 1992). Kaleeba et al. (1997), regarding HIV/AIDS work in Uganda, gave a similar definition, with counselling referred to as a dialogue between a counsellor and client during which issues are discussed, options are examined, and possible plans for coping are made.
the patient (Friedland et al. 2001). In an attempt to supply complete and credible information international health bodies, (sometimes in conjunction with) ministries of health and civil society organisation developed HIV/AIDS counselling guidelines (e.g. see WHO/HIV/2004).

The existing literature on resource-poor settings tends to emphasise preventive counselling as distinct from adherence counselling. Preventive counselling mainly occurs in the setting of voluntary counselling and testing, or routine counselling and testing (RCT). Evidence from Uganda shows that preventive counselling promotes seeking early testing and treatment for HIV/AIDS; reduces stigma, which has led to the revelation of serostatus to relatives and the acceptance of people living with HIV and AIDS (PLWHA) at the household and community level; increases knowledge of transmission and preventive behaviour; enables planning for the future; and improves quality of life (Kaleeba et al. 1997). Beyond preventive counselling, recent work has focused on ‘treatment literacy’, mainly its potential effect on improving access to drugs, protective behaviour, healthy living, and the lowering of stigma (see www.healthlink.org.uk). However, against all that background theoretical and practical work, there is still a paucity of empirical evidence on the potential effects of such counselling and education and training on adherence to ART itself, especially in resource-poor settings.

This Chapter sets out to substantiate the argument that counselling and education commit and sustain adherence to antiretroviral therapy in the two ART sites. This Chapter is divided into five sections. This introduction is the first. The second section, 6.2, describes the healthcare setting in which counselling is provided and received. Thereafter, section 6.3 presents the actual counselling content, as presented by the two counsellors at the Mission Facility and Public Facility. Section 6.4 evaluates the content of the counselling and its potential impact on adherence to ART. Lastly, section 6.5 presents concluding remarks.

### 6.2 The Healthcare Settings

This being an observation study, it is necessary to provide a brief description of the healthcare settings in terms of the study phenomenon, the observation object, the physical setting, and the time of observation.

**Study Phenomenon and Observation Object**

The study phenomenon is adherence to medication. The observation object is the ART counselling sessions in the two health facilities, studied as part of the overall
counselling trajectory. As already indicated, the counselling trajectory comprised of five interactive counselling phases: 1) client enrolment; 2) ART education (clients and care-givers); 3) prescription counselling; 4) adherence counselling; and 5) client follow-up counselling. While each of the five counselling activities is important and was observed, this Chapter concentrates on ART education because it is the most comprehensive education and counselling session that prepares patients for life-long treatment, while the subsequent counselling sessions simply reinforce the earlier induction counselling. The prescription counselling itself is a pill-count *cum* pharmacy refill pep talk; while adherence counselling is intended to rectify perceived adherence barriers, and client follow-up counselling implemented at the facility and/or home settings is targeted to specific patients needing additional adherence support monitoring and feedback, including the announced pill count visits.

**Physical Setting, Infrastructure, and Human Resource Capacity**

Physical setting is used here to refer to the healthcare environment in which the provider-patient interaction takes place. In a typical observation, there are several important criteria to look for when evaluating the necessary and sufficient conditions for the delivery of health services\(^\text{30}\). This section concentrates on the infrastructure at the two facilities. By 2006, Mbuya Reach Out, the Mission Facility located in the Kampala peri-urban area, was running four treatment centres conveniently located within its neighbourhood. For easy management, induction counselling was centralised at Mbuya Church Headquarters. At the time I attended the counselling sessions, group sessions were being held in a semi-open venue adjacent to the main Catholic Church. The day I attended the ART counselling, drizzle and strong winds occasionally disrupted the seating formation, with the participants surging towards the facilitator’s platform in order to escape the rain. Environmental noise in the form of passing vehicles, high pressure water taps, and toilet doors often interfered with the counselling session. As a result, the counsellor had to shout at the top of his voice.

The conditions of the physical setting at Kayunga Hospital were almost the same as at the Mbuya Mission Facility. The Kayunga Hospital is a District Referral Hospital\(^\text{31}\)

\(^{30}\) These can be in the form of time, room or space for meeting, availability of utilities, ease in negotiating access, privacy/confidentiality, waiting time, and procedure for leave taking (Hackney et al. 1988:97).

\(^{31}\) According to the Uganda National Health Sector Strategic Plan (2005) National Health System is organised as follows:

i) **Ministry of Health and other National Level Institutions**

ii) **National Referral Hospitals** (27,000,000)

iii) **Regional Referral Hospitals** (2,000,000 population)
located 46 km from Kampala city, located ¼ km from the busy local town. The HIV Clinic was semi-autonomous separately hosted in the Eastern wing of the hospital, with one full-time doctor and several nurses and volunteers. Such a location offered privacy and confidentiality. In the Public Facility, during 2006, group counselling was held in the interior reception lounge of the hospital where diffuse noise from human activity within the hospital often interfered with the counselling session. By then, the accommodation problem also affected individual counselling sessions and consultations at the Public Facility. Despite the fact individual counselling sessions were being carried out behind closed doors, when I attended the individual VCT sessions, we had to switch from one office to another in order to create room for clinical examinations.

With external funding, the physical infrastructure in both health facilities has since drastically improved. The Mission Facility completed an executive office block in September 2006; while the Public Hospital, with funding from the Makerere University Walter Reed Project, also upgraded and expanded its HIV clinic in 2008. However, in terms of aesthetics, both facilities lacked an elaborate ‘fancy’ reception; for instance, one with TV entertainment, IEC materials, magazines, infant games, drinking water cylinders, hanging pictures, upholstery, and sign boards.

iv) **District Health Services** (District level, 500,000 population)

v) **Health Sub-District**

- Referral Facility General Hospital (District level - 500,000 pop) or Health Centre IV (County level - 100,000 pop)
- Health Centre III (Sub-country level - 20,000 population)
- Health Centre II (Parish Level – 5,000 population)
- Health Centre I (Village Health Team - 1,000 population)
While the Mission Facility enjoyed access to a substantial amount of funding, being a private organisation, it lacked a CD4 machine and laboratory. Instead, it depended on another health facility (Mildmay) located along the Entebbe airport road. Furthermore, without an inpatient facility, the Mission Facility depended on a referral system to manage complicated cases. On the other hand, although the Public Facility was under-funded, it had a laboratory equipped with a CD4 machine and laboratory technician, and a fairly large number of health workers managing the inpatient and outpatient departments, who also serviced the HIV/AIDS department (see Table A.6 and Table A7 in the Appendix).

Even so, the HIV clinics in both settings were experiencing a severe shortage of doctors amidst rapidly expanding enrolment for HIV services (see Chapter 7). By 2008, the only doctor serving the ART Clinic in a Public facility had left to pursue post-graduate training. The two facilities therefore depended on patient-based volunteers to handle counselling and the community network of care (though this was more prominent in the Mission Facility).

**Management Information System (MIS)**

MIS can be considered to be part and parcel of the diagnostic technology. As a generic concept, a management information system refers to interrelated components working together to collect, store, retrieve and disseminate information to support decision making, coordination, control, analysis and visualisation in an organisation (Laudon and Laudon 2009). The important components of MIS are: data, hardware, software, communication network, and procedures. In 2006, the health management information system was weak in both facilities as they lacked a separate Monitoring and Evaluation (M&E) unit, a computer, and appropriate channels for sharing information. Later (2007?), the Mission Facility established an M&E unit; the Public Facility had not yet done so.
Time
The time of arrival at the clinic varied, with rural patients starting to arrive as early as 8:00am, while in the urban Mission Facility patients normally arrived after 9:00am. Rural patients were typically earlier because they were aware of long waiting hours and the long distance to return home. It was a requirement that Treatment Supporters attend the ART counselling at least once. Based on observations, while the majority of patients in the rural settings came with their Treatment Supporters for the induction counselling, many patients in the urban settings did not. Women formed the majority of clients, and most were middle aged (30 years and above). Privation and anxiety was reflected in clothing and bodily appearance. Newly enrolled clients exhibited a mutual awareness of each other’s presence but rarely directly attended to each other. However, as the number of physical contacts in the healthcare settings increases along a continuum of visits, the intensity of social interaction likewise increases. Talking and sharing revolves around episodic illness, drug side effects, comforting, and compliments about physical appearance. In other words, as treatment progresses, ‘un-focused interaction’ is replaced by ‘focused interaction’.

Duration of Observation
As mentioned in the methodology Chapter, I attended ART education sessions twice in both facilities in order to establish consistency in the content and the amount of information given over time. Results indicated a variation in communication style but not in the content of information given in the two health facilities. I devoted the rest of the remaining time to quantitative and explanatory qualitative studies. The material for other verification sessions has been excluded from this Chapter in order to avoid cumulative bias by including additional concepts and scores from different counselling sessions that were conducted by different facilitators for different types of patients.

Facilitation Method
A problem solving approach was used whereby the counsellors mainly used a self-questioning and self-answering facilitation technique intended to prompt answers and to simplify complicated information. Sometimes counsellors posed questions to the patients to obtain a feeling for the patients’ knowledge. No reference materials were supplied, and visual aids were used in the Mission Facility only. However, even here these visual aids were in the form of diagrams drawn on materials cut out of polythene sacks.

32 Focused Interaction relates to mutual awareness of ones existence and active interaction (cf. Giddens 1989).
Entry Arrangements

While I sought formal permission from the gatekeepers (Administration and HIV/AIDS clinic) to conduct my research, including attending counselling sessions, the other participants were not aware of my identity as a researcher. On ART counselling days, I reported early and waited for the facilitator like any other patient. Even during the interpersonal VCT closed sessions that normally precede ART counselling, I was introduced as a Trainee Counsellor (in the Public Facility) and simply as ‘one of us’ (in the Mission Facility). However, as research progressed through advanced stages, the amount of research activities, frequency of contact, depth of inquiry, and supervision of research assistants naturally disclosed my identity.

Collecting and Analysing the Data

The Methodology Chapter has already described the steps taken to collect and analyse the data obtained. During a counselling session I used unstructured observation without a checklist to collect the data. For fear of disclosing my identity when
collecting data, I avoided a tape recorder and recorded my observations manually. I respected the boundaries between observer and observed by not asking questions during the counselling session.

In terms of data analysis, I performed a simple content analysis, stopping at descriptive analysis that would involve breaking down the data, identifying the empirical indicators, and collapsing similar empirical indicators into concepts. My analysis stopped at open coding, which involves identifying first-order concepts and their substantive codes (Sarantakos 2005:349). However, in the presentation of findings, the original counselling material has been maintained and reproduced in its original form with the open codes here below in order to allow the reader to participate in the interpretation of the counselling material and, perhaps, arrive at alternative interpretations.

For easy understanding of the subsequent counselling material, it would be better for the reader to familiarise him/herself with the coding frame (concepts and their respective codes used). Hence I provide Table 6.1 before the counselling material itself. On the coding frame below, each empirical indicator has a score, representing not statistical significance, but ‘frequency of appearances’, or the ‘emphasis and space’ given to a given piece of information by the counsellor. Counsellors, especially in the Public Facility, tended to use a communication technique of paraphrasing or emphasising key messages. In order to avoid double counting of repeated messages, a Message Repetition Technique code was adopted abbreviated as MRT.

**Table 6.1: Information Appearances between the Two Sites**

<table>
<thead>
<tr>
<th>Code</th>
<th>Concepts and Indicators</th>
<th>Mission Facility</th>
<th>Public Facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>AS</td>
<td>Adherence Standards/Requirements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AC</td>
<td>Adherence – Commitment</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>ACS</td>
<td>Adherence – Coping Strategies</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>AD</td>
<td>Adherence – Medication Dose</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>AG</td>
<td>Adherence – Goal</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>ALT</td>
<td>Adherence – to Life-Long Therapy</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>AMA</td>
<td>Adherence – Seek Medical Advice</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>AS</td>
<td>Adherence – Schedule/Time</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td><strong>Sub-Total</strong></td>
<td><strong>16</strong></td>
<td><strong>20</strong></td>
</tr>
<tr>
<td>BA</td>
<td>Barriers to Adherence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BA</td>
<td>Barrier – Alcohol</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>BI</td>
<td>Barrier – Opportunistic Infections</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>BP</td>
<td>Barrier – Poverty</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>BM</td>
<td>Barrier – Misconception/Misled</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>BRA</td>
<td>Barrier – Access (Costs)</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>
The section below reproduces the original oral counselling materials that I recorded verbatim during ART counselling at both the Mission Facility and Public Facility, and coded afterwards using the coding frame presented immediately above.

## 6.3 ART Counselling Content

### 6.3.1 Counselling Material for the Mission Facility

A female co-counsellor started pinning up the pictorial visual aid at 9:35am and thereafter a male counsellor, (previously an Expert Client) walked into the open
venue and introduced himself together with the co-counsellor. The co-counsellor did not participate in talking except switching the visual aid. The counsellor opened the presentation.

_Counsellor:_ First I would like to thank you for coming to this session. Let me also remind you that each of you will have to undergo an interview before being initiated on ARVs. I should begin by emphasising the importance of coming with the Treatment Partner. If you have not come with your Treatment Supporter today, I will allow you attend for today, but make sure you come with [your] Treatment Supporter next time [TP]. If you have a question [during the session], please feel free to ask. Before I talk about ARVs, we should start by talking about HIV/AIDS itself [KHA]. True, I am here to teach you about the new medicine, but first all you should know the reasons for taking the medicine.

_Counsellor:_ Why are you here today?

Clients: We are sick and craving to extend our lives [AG].

_Counsellor:_ What health problem brings you here today?

Clients: HIV/AIDS [KHA].

_Counsellor:_ What is the difference between HIV and AIDS? [KHA]

Clients: HIV is the weevil (Kawuka), while AIDS is a condition of multiple symptoms [KHA].

_Counsellor:_ With AIDS, the symptoms are obvious, but you should avoid pointing a finger unless tests have been done.

_How_ is the virus transmitted from one person to another?

Clients: Through sexual intercourse, especially if someone had unprotected sex; piercing or using sharp objects; blood transfusion [KHA].

_Counsellor:_ (Interjecting) This used to be the case in the past but today all blood is screened.

Clients: (Continuing) Breast-feeding and umbilical cord cutting [KHA].

[Disruptions] Meanwhile, the raindrops splash into the venue and we push our plastic chairs towards the counsellor and the session continues.

_Counsellor:_ So, in order to avoid mother-to-child transmission, one has to take preventive medicines as well treating the baby within 72 hours of birth [KCT].
**Counsellor:** Does anyone have a question? [MRT]. No question from the audience.

**Counsellor:** (Using a self-questioning technique) - What is positive living? You should also know the (preventive) measures. Avoid sex, feed well, and take your medicines [CSB, CD, AD]. You should avoid the habit of taking red meat thinking that you are taking a balanced diet [CD]. Take food that is readily available [CCE]. Avoid sexual behaviour that can lead to re-infection [CSB].

**Counsellor:** (As he introduces a new topic, he continues talking as he rolls down the visual aid that shows the biology of the virus) - We are here in order to know the amount of blood soldiers we have in our body, and to seek medicine [MRT].. Mr White Blood Cell or the soldier is armed with a gun [KBM]. When the number of soldiers in your body goes down, the body becomes exposed to any kind of infection, for instance flu, and that infection becomes persistent. The ARVs restore the number of body soldiers [EA]. The WBC, or CD4 cell for that matter, or the ‘body soldiers’ which defend our bodies against the enemy, are restored [MRT]. When the number of ‘body soldiers’ substantially decrease the enemy wins the battle [KBM]. The medicines you will take will restore the CD4 cells [EA].

**Counsellor:** (He introduces a new topic through self-questioning and self-answering) - What are ARVs? ARVs are powerful medications that fight the virus and can improve your health [EA]. ARVs stop the virus from making more copies of itself [MRT]. They help the body army to fight the invading enemy thus prolonging our lives [MRT].

**Counsellor:** (Self-questioning and self-answering) - Do the ARVs cure HIV/AIDS? [Interruptions] Once again rain disrupts the session.

**Counsellor:** (Continues) - You should know this, ARV is not a cure for HIV, it only puts an enemy to sleep [AL]. If you take the ARVs you can still infect others, especially if you have unprotected sex [MRT, KHA]. The new person (re-infection) awakens the virus [MRT].

**Counsellor:** (Displaying another visual aid showing the ARVs and the human-like sleeping virus.) The moment you stop taking ARVs, the virus will wake up [AL, KBM]. If it wakes up it is will be more ferocious than ever before [KVR, MRT].
Counsellor: (Using a self-questioning technique) - How should we take ARVs? ARVs should be taken as the doctor tells you. If you miss a dose or share your ARVs, the medicine will not work [AD]. You cannot economise ARVs by taking a half a dose – that is wrong. Always take a full dose [MRT].

Counsellor: (Using a self-questioning and self-answering technique) - How long should I take the ARVs? ARVs do not cure HIV/AIDS [AL]. They must be taken for life [ALT]. ARVs do not work when taken for only 2 weeks or 1 month [ALT]. Do not start ARVs unless you have enough money (for transport) to continue (with medication) [BRA].

Counsellor: (Using a self-questioning technique)- How do ARVs work? (Displaying another visual aid showing the cell structure) The virus leaves its coat at the entrance and escapes through the first gate (cell membrane) up to the second gate [KBM]. It further slips into the second gate reaching the inner training ground (nucleus). It takes control of the ‘soldiers’ [KBM]. The virus disorients the command chain and it asks the soldiers to produce many copies of the virus. It eventually ruptures the shell, releasing numerous enemies. It is at this stage that your body becomes weak and weaker. Because your body soldiers have been either killed or disoriented, the body becomes exposed to all sorts of attacks [KBM, KTI]. Therefore, it takes three stones to cook a pot [EK, EA]. It takes three medicines to fight the HIV [AD, MRT]. If you try to cook a pot on two stones, it will certainly topple with all its contents and you will end up starving that day [AD, KVR]. One of the drug components intercepts the enemy at the quarter guard [EK, EA]. The second medication neutralises the virus that must have slipped through the quarter guard [EK, EA]. The third drug neutralises the enemy who is already deep inside the cell, thus stopping its reproductive activities [EK, EA]. If you took your medications properly and consistently, it will certainly restore the ability of your body to fight the invading enemy, and eventually become productive [EK, EA, AG]. If you stopped taking ARVs for a while, it is as if locking up a dog in a kennel and starving it for three days [KVR]. If it breaks loose it will bite any object that stands in its way [KVR]. It is the same with starving the virus of medications [MRT].

Counsellor: (Using a self-questioning technique) - Can ARVs cure all the sicknesses? ARVs do not cure all complications associated with HIV [AL]. You can...

33 This message falls short of making clear that the fixed dose combination contains the three drug components.
still suffer from TB, diarrhoea, malaria, or other different infections [AL, KTI]. Disease like TB can be best treated with other types of medications [CATI]. You must treat those infections separately as well as continue to taking ARVs [AD].

Counsellor: (Using a self-questioning technique) - Do all people who are HIV positive need ARVs? No, it is only after a large number of body soldiers have been destroyed by HIV that a person will need ARVs [KBM]. If ARVs are introduced before the body is ready for them, the medicine will hurt your body. You should wait for the doctor’s advice [AMA].

Counsellor: (Switching to discussing preventive measures.) Avoid contracting malaria [CATI, BI]. Cook or boil your food properly in order to avoid diarrheal [disease] [CATI, CH]. If you wash your mango using a lesu[34] and you take that mango on the assumption that the mighty ARVs will protect you from any infection, then that is committing a serious mistake [AL]. Take ‘initiatives’ to maintain your hygiene [MRT].

Counsellor: (Using a self-questioning technique) - Are ARVs really too strong? They (ARVs) cause side effects and, at the same time, are difficult to take [BSE]. Fortunately, when your body is extremely down, ARVs will help you gain more years [EA]. If you happen to develop side effects do not sit back or stop taking ARVs. You should tell the CATTS (Community AIDS and TB Treatment Supporter) as well as reporting to the clinic immediately [AMA].

Counsellor: (Using a self-questioning technique) - Is it ok if I can have one Nile Special (strong beer brand)? ARVs and alcohol do not go together [CAH, BA]. If alcohol is a problem, I implore you to discuss such a problem with us so that we can help you [AMA]. It hurts if you take alcohol [CAH]. Lastly, take a lot of water so that ARVs circulate well in your body [CD]. Drink, but not alcohol [MRT]. Feed well on the available food. Mukene (small protein fish) is good for your body [CD, CCE]. Do not fry food [CD]. You do not need a sack of money to feed well [MRT, CCE]. Avoid reckless (sexual) behaviour [CSB]. But also kneel down and thank God that has given you this opportunity of accessing the drugs for life [CF].

Counsellor: Does anyone have a question?

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[34] Cotton fabric used by African women for multiple purpose – skirt, hip wrapper, head gear
Client: What happens if I vomit up the drugs?

Counsellor: If you only vomited up the pill, take another one but explain to the doctor that you vomited. But before you take another pill make sure you check whether you have actually vomited it [AD].

Client: If, some time after the dosing time, I happen to remember, can I still take my medication? [AS]

Counsellor: If you remember that you missed your medication after 1-1.5 hours, take your medication, but if you remember when it is just 1-0.5 (hours) to the next dose time, you have to wait and take your dose at the right dosing time. But also tell the doctor what happened [AMA, [AD]].

[Observer’s comments] The ART education session stopped here and the people dispersed. The counsellor informed the clients that he and the CATTS were available to answer questions. I asked the clients to comment on the training they had just had. The majority stated that they had some knowledge about HIV/AIDS but the information concerning ARVs was particularly useful. They pointed out that the message was clear, though some desired another session.

6.3.2 Counselling Material for the Public Facility

On 3 November 2006, I attended an ART education session at Kayunga Public Hospital. The session was handled by a senior nurse, still here referred to as a counsellor. The group of clients comprised of three categories: those attending ART education for the first, second, or third time. The size of the group was 17 patients – 13 females and 4 males. The counselling took place in an open outpatient waiting lounge.

Counsellor: (Using a self-questioning technique) - What are we studying today? We are here to know how we are going to take the drugs (ARVs), the time, dose, and diet. First, you should know that ARVs is not a cure, but you take it to ‘bring down’ the infection, and to boost the number of ‘body soldiers’ [AL, EA]. Second, you should be ready and prepared to take it for the rest of your life – it is not a matter of trying [ALT]. This medication is hyper-sensitive, you should not ‘marry’ it with the ‘small jerry cans’ (meaning herbal supplements) [CHM]. Thirdly, our medication restores the severely deteriorated health conditions [EA]. I call upon you to understand it, accepting it, and complying with the rules [KCT, KBM].
**Counsellor:** (Using a self-questioning technique) - How will the medication be taken (i.e. treatment schedule)? Treatment for malaria is a short-term treatment, and the medication process is not a routine. This one (ARVs) is a fixed-dose and fixed-time regimen [AS, AD]. It is up to you to decide your dosing time [AS]. Though, the rule of thumb is taking it during the morning and evening hours [AS].

Now we get into [a] problem here! Only one household member may have a watch [BP, TP]. What will you do in case that person is far away from home? Aha! You may decide in favour of depending on the school bell. What will happen when the school closes for holiday? [ACS]

**Clients:** We will depend on the wall clock, cock crow, or a radio [ACS].

**Counsellor:** But what happens when the wall clock runs out of battery? [BP] You see! If the available cues for action are failing you, the ultimate solution is to trust your intuition, fit the medication time into your mind [CSE].

**Counsellor:** (Introducing a new topic) - There also those other illnesses that may interrupt your treatment [BI]. Without hesitation report such symptoms to us (health staff) [AMA]. However, every time you appear for consultations, come with your pill bottle which will be given to you [AD]. Know this: whenever you lie to the doctor, you lie to yourself, and above all, you lie to your health [AMA, CSE].

[Interruption] The counsellor’s mobile phone rang, and she stepped out to attend to incoming call, returning after a while.

**Counsellor:** (Returning to the venue and continuing) - You should not forget this. Of all things in life, what is your wealth? Life [MRT]. Can you forget your life? Can you please tell me: who is your favourite friend in your life? [MRT]

**Clients:** Father, mother, my child (etc.)

**Counsellor:** That is alright. If that person died, immediately after grieving, reach out for the most favourite living friend – the medicine [AS]. Take your medicine [MRT, AC]. Let the medicine be your closest companion. Let it be your identity card. Do you remember those old bad days (political instability) when soldiers used to stop us at the roadblock and ask for our IDs? That necessity still applies to these medicines, everywhere you go take them with you [MRT]. Make use of reminders, for instance, placing your pills next to your toothbrush [MRT, ACS]. If you started taking
these ARVs you will have to take it for life till death does you part with your ARVs [ALT, AC].

Counsellor: (Introducing a new topic) - Be aware of the relationship between these drugs and hygiene [CH]. Use only boiled cold water to take your medicine. Have a personal container for your drinking water [MRT]. After playing football, children will simply dip their dirty cups and hands into the water pot. At worst, occasionally the household might run out of safe drinking water [MRT, CH]. Avoid the risks associated with taking cold food, you will expose yourself to diarrhoea – have a separate container [CH]. During daytime, cockroaches tend [to] seek refuge in the jerry cans and toilets, and return to your uncovered food and pee at night. Therefore, (proper) storage for food is as important as the type of food you are taking [MRT]. In order to avoid more infection, take warm food [CH]. You should know that your body is vulnerable, every part of your body is weak [KHS, CATI]. By now you must have realised that your eyebrow and hair tend to peel off [MRT]. Take care of your body. You should also know that ARVs do not cure malaria [AL]. Seek appropriate treatment for malaria [AMA].

Counsellor: (Introducing a new topic) - Besides ARVs, there is an equally important medication that you should take on a regular basis – that is, food [CD]. It is common knowledge to you, if a child feeds properly it looks healthy and grows faster [MRT]. Go for the kind of food that will boost your body [CD]. I am not talking about expensive and luxurious food [CCE]. You should not be a liability to the care-givers due to an insatiable appetite for sumptuous meals to accompany your medication [MRT]. When I speak of a balanced diet, I don’t mean any type food, for instance, banana, Irish potatoes – but sauce [CD, BM]. By sauce, I mean nutritious sauce like beans, groundnuts, soy, mukene (high protein fish), fish, meat, chicken, eggs. I realise you are frowning suggesting that such is a luxury and expensive [CCE]. Whatever I have mentioned you have in your homes – you produce it locally [MRT]. You should not try to mislead your friends that the new medicine (ARVs) is damn expensive to take [CCE, BM]. A single egg is not expensive, but the benefits are enormous [MRT]. Put some money aside for ‘another pill’. If milk is available in your home feel free to take it [MRT]. However, avoid this business of obtaining half litre milk and diluting it with a 20 litre jerry can of water, and ending up taking milk colour rather than milk itself
Whenever you have an opportunity to take milk, take only a concentrated cup of milk. Seasonal fruits are equally essential and readily available – I mean pawpaw, sweet plantains, mangoes, what else? Do not say that such fruits are reserved for children. However, you don’t have to indulge in eating the whole pineapple – a slice of pawpaw will do. Do not try sugarcane because your jaws are too weak to chew sugarcane. Greens (vegetables) are also essential for your health. You do not have to wait for cooking oil to enjoy your vegetables. Take food before taking your ARVs. Failure to take ARVs with food will upset your stomach, your head will spin, and at worst, you can throw up the pills. ‘Squeeze’ a passion fruit, add a little sugar, and take it before or after the medication. You will need a (vacuum) flask.

Counsellor: (Introducing a new topic) - In order to take our medication properly, you have to have a ‘Treatment Supporter’. Not someone who lives far away from your home, because that one is likely to disappear soon after being recruited. Neither is it wise to pick a fellow patient from the main (hospital) gate and present him/her to us as your Treatment Supporter. You may assume that a fellow patient know your health condition and needs better. Forget it. That patient supporter is equally pre-occupied with his health condition. Do not pick a person who is too busy to attend to you – a person who is always in a rush to find his/her customers/clients. You need a person who is always available, who can remind you, alternate meals for you. Such a person can be a family member, head of household, or your child. My advice is – on a day-to-day basis, a child is handy.

Counsellor: (Introducing a new topic) - Another issue I have to talk about today is self-control and discipline. ARVs are likely to improve your physical and emotional condition. Your body will get better and the ‘desire’ will come. Some people justify their (sexual) actions by saying, ‘After all, I did contract this virus from a tree’. To some, they rationalise that ‘Do I have to grow as old as a mahogany for timber extraction?’ ‘Let me service everybody that comes my way’. Remember this, you service as much as you are being serviced (with a virus). My advice is one – if you fail to control your desires then use a condom.

35 The two messages refer to people who deliberately infect other people and brag about the idea of longevity.
[CPS]. I usually hear this street talk that ‘I used a condom last night.’ The question is: ‘do you know how to use it properly?’ [CPS] But if [you] use a condom properly, it can protect you from Candida, syphilis, and gonorrhoea [CATI]. However, a condom has limitations. If you are a married woman, a condom will not always protect you from pregnancy. Becoming pregnant will make matters worse [CRH]. When you contract HIV, the number of body soldiers drastically reduces [KBM]. When you become pregnant, you overburden your body because you are feeding two persons. So, as a woman, the condom will not always protect you from pregnancy, you need another method of family planning [CRH].

Men, sometimes you are amazing. If a man realises that he is unwell, he will force himself (to have sex) for the sake of proving a point that he is still capable (of fulfilling marital obligations). As a man, you should know this: one round (of sex) is like taking a marathon of 7 kilometre on a hot day, 3 rounds makes it 21 kilometres [CSB]. Look! You drain your body, you become weak and weaker, and what are you after anyway? Stop such reckless behaviour [MRT].

[Interruption] At this point there was an interruption, as a client asked a question about the need to take an HIV test as a couple. Afterwards, the talk continued.

Counsellor: (Introducing a new topic) - A person who does not drink is always sober. On the other hand, after taking a number of bottles, you will become ‘wiser’ [CAH,BA]. As drunk as you are, you (as a woman) will stumble and slumber at the roadside. I pity you – don’t think men will spare you, they will prey on you [CAH]. Let me be frank with you, a drunken virus becomes wild [KVR]. The other bad habit is (taking) cigarette [CSH]. Smoking exposes you to contracting TB [MRT].

Counsellor: (Introducing a new topic) - I end up by advising you, simply ignore what people say. Avoid stigma [CAF]. Have that talk with yourself – ‘Today it is me, tomorrow it is someone else’ [MRT]. You should know this – every person around you is sick, it is a matter of time. The epidemic is here to stay. I know when you go to bed, you tend to lie awake all night long, imagining your death, your burial, your children [CAF]. Please, talk to your God [CF]. However, we should not turn to God in a crazy way [BM]. Pastors will lay hands on you and then ask you to take (HIV) test. Because you have been taking medication for some time, the test

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36 The message here is that married people rarely use condoms consistently.
results will show negative. You start chanting 'Alleluia!', praising Jesus for the miraculous healing [BM]. Stopping medication is a big mistake [ALT, BM]. I doubt very much whether Jesus will accept your decision to stop medication. Let Jesus be your witness as you take your medicine [ALT, AC].

Client: What if I forgot to take my pills and remember another day?

Counsellor: The first rule, never forget to take your medication. However, in event of missing a pill, return the missed pill when you visit the clinic [MRT].

[Observer's comments] This session lasted for two hours. From my observation, before the beginning of the session little interaction existed among the patients, but at the end of the session the patients opened up and started interacting. The general opinion of the participants was that the information restored hope and was useful in helping them to understand how the medicines work and what is involved in adhering to the medicine.

6.4 Evaluation of the Counselling Content

Undertaking a comprehensive content analysis requires identifying what is being said, how it is being said, why is it being said, and its potential effect. Therefore, there are two ways of approaching such a question: one, by focusing on the manifest content, and two, by focusing on the latent content. As mentioned in the methodology Chapter, the manifest content concerns the visible and surface text, while the latent content deals with the underlying meaning conveyed through the document or material. In other words, while the manifest focuses on the what, the latent approaches the delicate questions of how and why, while evaluating the effect is subjective in nature.

The manifest content is usually analysed by counting the frequency of the appearance of the messages, and the latent content by constructing and deconstructing the meaning, the underlying justification, as well as the context within which such meanings were being conveyed. That said, the purpose of this Chapter is not to carry out a content analysis for its own sake but to evaluate the potential impact of counselling and education material on adherence to ART.

6.4.1 Quality of Information and It Potential Effect on Adherence to ART

Quality of information is associated with individual impact. However, information completeness may be subjective. The best way to measure information completeness
would be to compare the information content and the adherence barriers already identified in Chapters 3 and 4. The only limitation with this analytical approach is that the counselling and educational material that is presented above targeted newly recruited patients while the adherence barriers (in Chapters 3 and 4) were extracted from clinical records for continuing patients. Nonetheless, the reliability and validity of this analytical approach is based on four important principles. First, the composition of counsellors in the two facilities remained the same over time (before 2006). Second, counselling and education was guided by the MOH, ensuring the similarity of counselling and education materials between the two different health facilities over time (see table 6.1). Third, the adherence barriers presented in this study are consistent with the adherence barriers reported in studies conducted in resource-poor settings elsewhere (cf. section 1.2.3). Fourth, the proposed approach is only intended to establish the potential effect of information on adherence to ART.

Table 6.2 matches the adherence barriers and the information and knowledge given, and is built from the findings of Chapter 3 (adherence barriers) and this Chapter (Table 6.1) combined. The first two columns (1 and 2) show the adherence barriers, while last columns (3 and 4) show the information and knowledge disseminated and their respective codes for the two Health Facilities combined.
**Table 6.2: Relationship between Counselling Information and Adherence Barriers**

<table>
<thead>
<tr>
<th>Adherence Barrier</th>
<th>Specific Barrier and its Effect on Adherence Activities</th>
<th>Code</th>
<th>Information and Knowledge Disseminated</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individual Factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Condition</td>
<td>Sickness as a barrier to induction appointment, pharmacy refill, dosing time, medication dose</td>
<td>• CATI • CD • CH • CSB • AMA • AD • BI • CSH • BM</td>
<td>• Avoid/contracting OI or treat OI separately • Take dietary food • Follow safe hygiene practices • Avoid reckless sexual behaviour • Follow Doctor’s Advice • Adherence to triple therapy • Report the symptoms of OI without hesitation • Avoid smoking habits • Avoid being misled about the cause and cure</td>
</tr>
<tr>
<td>Improved health condition as a barrier to pharmacy refill and medication dose</td>
<td>• ALT • AL • KBM • EK • AMA • AD • EA</td>
<td>• ART is a life long treatment • ARVs are not a cure but restore immunity • Puts the virus to sleep • Knowledge about the HIV/AIDS • Follow Medical Advice • Knowledge of triple therapy • Antiretroviral Efficacy</td>
<td></td>
</tr>
<tr>
<td>Regimen Side-Effects</td>
<td>Side-effects affects as a barrier to medication dose</td>
<td>• BSE • AD • AMA</td>
<td>• ARVs are strong drugs and cause SEs • Adherence Goal • Follow the medical advice</td>
</tr>
<tr>
<td>Failure in Concentration</td>
<td>Mistaken time/dates as a barrier to pharmacy refill</td>
<td>• AMA • AS</td>
<td>• Follow the medical advice • Have a watch, and depend on your cues for action/intuition</td>
</tr>
<tr>
<td>Forgetting, losing pills, misplacing pills as barriers to dosing schedule, medication doses</td>
<td>• CAH • ACS • CAH</td>
<td>• Maintain mental stability by avoiding alcohol • Let the ARVS be your companion • Avoid Alcohol</td>
<td></td>
</tr>
</tbody>
</table>

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*Note: The code system used in the table is not specified in the image.*
<table>
<thead>
<tr>
<th>Livelihood Activities</th>
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<tbody>
<tr>
<td><strong>Reproductive Work</strong></td>
<td></td>
</tr>
<tr>
<td>Busy with domestic work as a barrier to dosing time and medication dose</td>
<td>ACS</td>
</tr>
<tr>
<td>Picking child from school as a barrier to pharmacy refill</td>
<td>ACS</td>
</tr>
<tr>
<td><strong>Economic Production</strong></td>
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<tr>
<td>Too busy with work (farm/off-farm) as a barrier to induction appointment, pharmacy refill, meal/snack, dosing time medication dose</td>
<td>ACS</td>
</tr>
<tr>
<td><strong>Social Engagements</strong></td>
<td></td>
</tr>
<tr>
<td>Travelled for (social events) as a barrier to induction appointment, pharmacy refill, meal/snack, dosing time medication dose</td>
<td>ACS</td>
</tr>
<tr>
<td>Entertaining Visitors as a barrier to dosing time</td>
<td>ACS</td>
</tr>
<tr>
<td>Attending burial as a barrier to pharmacy refill, dosing time medication dose</td>
<td>ACS</td>
</tr>
<tr>
<td><strong>Poverty</strong></td>
<td></td>
</tr>
<tr>
<td>Transport problem as a barrier to pharmacy refill, meal/snack intake, medication dose</td>
<td>BRA</td>
</tr>
<tr>
<td><strong>Food Shortage</strong></td>
<td></td>
</tr>
</tbody>
</table>
| Food Shortage in a home/ lack of accompanying food on that day as a barrier to meal/snack intake, dosing time medication dose | CCE | Feed well on the readily available food  
Avoid luxurious food |
| **Practical Problems**   |  |
| Food was not ready as a barrier to meal/snack intake, dosing time medication dose | AS | Adherence to Dosing Schedule |
| Sharing Medicine is a barrier to medication dose | AD | If you share your ARVs, the medicine will not work |

Table 6.2 above indicates that the information and knowledge provided in the two facilities targeted the common adherence barriers, as well as providing practical solutions for overcoming and/or reducing such adherence barriers. Therefore, counselling provides knowledge and advice for overcoming barriers such as associated health condition, regimen side-effects, engagement in livelihood activities, access constraints, food shortage, and others.
The accuracy of information given is reflected in it being factual, reducing uncertainty, and providing a basis for action. It is consistent because patients benefit from the same accurate information during each provider-patient encounter throughout the HIV/AIDS treatment cycle. The relevance can be measured as the extent to which the information given provides practical solution to barriers based on patients’ realities, experiences, and perspectives. For instance, rather than suggesting the use of expensive exotic food, the advice was to use locally available food; in the absence of modern time-keeping devices the advice was to depend on internal cues for action; in the event of unreliable sources of income it was advised to avoid starting antiretroviral treatment until financial readiness is achieved. The latter message is not intended to discourage patients from taking up antiretroviral treatment but to encourage them to be creative in mobilising funds.

A combination of quantitative and qualitative evidence indicates that the clients were happy with the quantity and quality of information provided by the counsellors. First, the survey included a question: ‘Were you satisfied with the information you received on ART counselling?’ Of the 260 who responded to the question, half (51.1% 134) were ‘extremely satisfied’, 48% (124) were ‘satisfied’, and only 1% (3) stated that they were ‘somewhat satisfied’ (0.4% 1 were missing cases). A combination of ‘extremely satisfied’ and ‘satisfied’ suggests that 98% (258) were satisfied with the amount of information received. Evidence from qualitative explanatory studies also suggests that the amount of information and quality of care was satisfactory.

The doctors (meaning health workers) bombarded us with a lot of information before we started treatment, and we continue to be educated (whenever we come here) about the medicine and lifestyle. Learning never stops, otherwise a professor would not revise his/her notes regularly. Our doctors are like parents, extremely compassionate. You enter the hospital gate with a worried face and leave with a smile on [your] face. (Kayunga Explanatory Qualitative Focus Group Discussion)

6.4.2 Potential Effect of Communication Method on Absorption of Information (Latent Analysis)

This section draws a distinction between adequacy of information and comprehension of information. Even if the information provided may be rich, the absorption of such information by the audience may be low due to poor communication methods and environment. Communication refers to a selective process of producing or conveying meaning in a social context (Sarantakos 2005:39; Lewis James 2004:415). Poor communication not only obscures the meaning but also undermines the internalisation of a piece of information.
1. Communication Methods

During observations of the actual counselling sessions, counsellors demonstrated communication skills, knowledge, respect, confidence, and a sense of humour. As the texts above indicate, counsellors at both facilities tended to break information up into pieces in order to help patients absorb it (*message chunking*); as well giving audience the opportunity to spontaneously ask questions (*two-way interaction*).

There were, however, differences between the two counsellors in their presentation style. At the Mission Facility, the counsellor used the *probing approach* in order to avoid confusing patients with information of a technical nature. Here, the counsellor also simplified technical information by using visual aids to depict complex disease conditions (biology of the virus), the pharmacological effects of ARVs (ART activities and efficacy), and potential resistance (limitations). On the other hand, at the Public Facility, the female nurse deliberately avoided technical issues and dwelt more on adherence to medication, health protection, and promotion measures – the kind of information the rural folk needed. This may also explain why she did not use visual aids but a persuasive freestyle talk punctuated with humorous phrases and analogies. This freestyle approach explains why the counselling text for the rural setting had a higher frequency of Message Repetition Technique (MRT) codes.

In order to simplify the biomedical technical vocabulary and jargon, both counsellors customise technical terms by using metaphors. Metaphors are comparisons that show how two things that are not alike in most ways are similar in one important way. ‘Metaphors are a way to describe something. Authors use them to make their writing more interesting or entertaining’37. Metaphors help grasp ‘reality’ in an intellectual sense, to see the world in a certain way and, consequently, to communicate about the intellectual experience (Sjaak and Whyte 1989:353). In the two counselling texts above, metaphors were used as creative solutions to communicate technical concepts, because they stimulated the imagination, explained the meanings of the desired health action, as well as making the action attractive and/or imperative.

For instance, when describing disease pathogenesis (even during VCT sessions), metaphors make it possible to draw a distinction between HIV and AIDS – ‘HIV is the ‘weevil’ that brings *slim*, and AIDS is the stew of infections’ . Equating a virus to a weevil vividly describes its destructive nature, since a weevil destroys the seed from inside (cell), and hatches to proliferate. Importantly, the weevil metaphor makes HIV testing a necessity, because weevils can only be detected by sampling and cracking

37 English Basics Volume 3, Number 26, March 29, 1999 www.rhlschool.com
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(screening) the seed. Military metaphors that depict the fierce battle that rages in one’s body and the eventual collapse of the system in the face of external aggression are an equally powerful tool for conveying information. If it is true that the enemy infiltrates past three defence lines, disorients the command chain, and causes friendly fire, then it must be a strong and smart enemy. ARVs become a liberating or salvation army. Aside from painting a picture of antiretroviral efficacy, metaphors are used to demonstrate the limitations of ARVs and the need for life-long adherence. If ARVs simply ‘put an enemy to sleep’ (as it was put in the Mission Facility) or are taken to ‘bring down the infection’ (Public Facility), then ARVs are as good as sedatives; and the effectiveness of sedatives lies in continuous medication. To convey the necessity of a triple therapy, the counsellor switches from a military metaphor to the fable of a pot that cooks on three stones. Clearly, since it takes three stones to cook with a pot, and two stones result in the pot tumbling and spilling its contents, nobody wants to starve due to a silly mistake. Metaphors convey the dangers of being non-adherent. Few can face a dog that breaks loose from a kennel after being starved for a couple of days. In rural settings, fewer metaphors were used because the counselling content concentrated not so much on the technical biomedical factors, but on health protection and promotion.

2. Counselling Strategy

The second observation is the counselling methods that are used. A typical counselling intervention is supposed to define the presenting problem (problem identification), desired outcome (goal), the type of counselling intervention to be used (process), the theoretical orientation (guiding theory), under the overall structure of the counsellor-counselee relationship (relationship). However, the counselling process at the two facilities appears to fall short of this idealised type. Clearly, the counselling is based on the assumption that treatment barriers and the nature and amount of information patients need are known. In the Mission Facility, the counsellor begins by telling the audience, ‘I am here to teach about the new medicine.’ He goes on to ask, ‘Why are you here today?’ Patients responded, ‘We are sick and craving to live longer.’ Similarly, in the Public Facility, the counsellor poses an opening question and answers it herself: ‘How we are going to take the medicine?’ This is quite different from formal counselling procedure whereby the actual counselling session is preceded by the identification of the problem and/or barriers. Furthermore, the Mission Facility counsellor alerts the participants that ‘You will have to undergo an interview before being accepted for medication’ (the standard practice), showing the asymmetrical, authoritarian, and directive approach taken to counselling, quite contrary to the desired dyadic dialogue that charts out the intervention alternative. In doing so, the
healthcare setting becomes a classroom, the counsellor a teacher, the client a student, the information lecture notes, and a choice an obligation.

Here, ART education is conducted in a group formation because of the ever increasing enrolment for HIV treatment services against the backdrop of human resource and financial constraints. In orthodox counselling, individual and/or group counselling is acceptable depending on the presenting problem and strategy adopted. Group counselling tends to create a conducive environment for mutual facilitation, feelings of belonging, collective action, and the de-stigmatisation of HIV treatment. However, group counselling lifts counselling out the dyadic relationship (Narayana Rao 1992) and is sometimes seen as lacking sensitivity to individual problems.

3. Enforcement Strategies

Beyond counselling session, there are ‘back-stage’ manoeuvres to enforce adherence to ART. Results for one of the survey questions intended to assess the level of treatment discontinuation indicated that the threats of treatment suspension are real. Of the 262 patients, a slight 2.3% (6) had ever discontinued antiretroviral treatment, with 1% (2) and 3% (4) from the Mission and Public Facilities respectively ($\chi^2 = 1.077(b), df = 1, p = .299$). The reasons for being discontinued from treatment were: non-adherence to antiretroviral therapy (3), overstaying in the village (1), taking TB drugs (1), or being seriously sick (1).

Pharmacy refills are also used to correct perceived adherence barriers. Patients are allowed longer-refill intervals only after demonstrating high levels of adherence and negligible side-effects. Patients with unpredictable adherence pattern are maintained on weekly pharmacy refills. Shorter pharmacy refill returns have a cost implication in terms of travel costs and waiting time. Non-adherent patients are re-introduced to adherence counselling together with their treatment buddies.

6.5 Conclusion

The motivation for focusing on counselling and education in this Chapter is to demonstrate the potential effect of counselling and education on adherence to antiretroviral treatment in both the Mission and Public Facilities. Assessment of the potential impact of counselling and education has been done by comparing the counselling and education material with the adherence barriers. While there are no standard criteria upon which adequacy of information in a prevailing situation can be judged, the analysis and interpretation of the information and knowledge material above suggests a likelihood of adherence to ART if patients are exposed to information that tackles the adherence barriers. In this case, the information given
addresses the most common adherence barriers in form of biomedical barriers and structural barriers, as well as providing practical solutions. The information given is also factual and credible (quality). As Erger et al. (2000) have argued, information in the medical treatment setting is best when it reduces uncertainty, provides a basis for action, and/or strengthens the patient-provider relationship.

It is also necessary to point out the policy context within which mentioned information is provided. Counselling in Uganda is guided by the HIV Policy drafted by the Ministry of Health under the watchful eye of international health agencies (alluded to in Chapter One). Uganda’s ART Policy, which predates the National Strategic Plan, categorically emphasises that HIV patients are supposed to benefit from preventive and treatment information. This is because VCT (and Routine Counselling and Testing) is supposed to serve as a means for referral and enrolment for ART, while enrolment for ART should not lead to risky behaviour (MOH 2003). This explains why a single counselling session tackles both preventive and treatment issues. Beyond policy statements, as indicated in the introductory Chapter, operational manuals like the Home Based Care Trainers’ Guide for Health Workers (2004) exist, which define the counselling trajectory and issues to be covered. The existence of such policy guidelines explains the co-occurrence of education topics in the two healthcare settings, and may possibly explain the similar adherence patterns.

The evidence presented above, suggests that information can only be understood if the communication strategy is appropriate. The communication strategy should satisfy important elements namely:

1. Disseminating both technical concepts (theory) and practical strategies (action);
2. Tailoring information to client’s information needs and absorption capacity;
3. Making information accessible throughout treatment duration;
4. Targeting information to both patients and treatment support networks.

In other words, both the content of the treatment information and the communication strategy potentially influence adherence behaviour. Nevertheless, information alone does not influence adherence to ART independent of other individual and social support factors.
The Role of Social Support in Sustaining Adherence to Antiretroviral Medication

7.1 Introduction
This last empirical Chapter is one of the products of the qualitative explanatory studies intended to establish the factors facilitating adherence to antiretroviral therapy at the community level. The primary aim of this Chapter is to demonstrate the instrumentality of social support, as a structural factor, in sustaining adherence to antiretroviral therapy among patients seeking HIV treatment services at both the Mission and Public Facilities. It should be recalled that in Chapter 4 social support featured as one of the factors mitigating the economic burden involved in accessing and adhering to ART. Secondly, despite the fact the Mission Facility endeavoured to provide comprehensive care and support, only a small proportion of benefited from micro-credit, OVC support, and Income Generating Activities (see table 4.3, 4.4 & 7.3 here below), and supplies were irregular with food assistance terminated in 2008. Second, the management of HIV related symptoms pre-dates the ART programme itself (Chapter 5).

Evidence from Uganda, India, and Malawi shows that community support and/or home-based care interventions were associated with better ART outcomes in resource-poor settings (cf. Weidle et al. 2006 for Uganda; Kumarasamy et al. 2005 for India; and Zachariah 2005 for Malawi). Even in the developed world, social support is associated with positive treatment outcome (Burgoyne 2005). The utilisation and productivity of social support depends on an individual’s entrepreneurial abilities. According to Singh et al. (1999), patients with high levels of skills regarding obtaining instrumental support have high adherence to ART (in Fisher 2006).

However, such studies do not show the context within which social support emerges, is exchanged, and the implications for adherence to ART. A systematic treatment of the concept of social support must distinguish among: 1) the preconditions for seeking and giving social support; 2) the providers of social support
(those agreeing to volunteer support); 3) the resources exchanging hands; and 4) the potential benefits accrued from social support. Based on this model, this Chapter expands the notion of the patient-provider relationship. Since social support has not been discussed so far, the second section below presents the conceptualisation of social support. The third section examines the preconditions for seeking and providing social support. The fourth section assesses the nature of support networks available to patients, as well as to the health facilities themselves. The fifth section examines the context within which social support is given and, finally, the conclusion is provided. By discussing the social support available to the health facilities, the key message is that in resource-poor settings, both the patients and providers need social support, albeit in different forms.

7.2 Conceptualisation of Social Support

Social support is regarded as a multidimensional concept with many definitions and meanings (cf. Funch et al. 1986; Hupcey 1998). Among these, O’Reilly’s (1998:863) definition of social support derived from review of other authors’ work is comprehensive, partly because it was synthesised from a review of 33 articles:

Social support is regarded to be an interactive process, in which particular actions or behaviour can have a positive effect on an individual’s social, psychological, or physical well-being.

This definition suggests that social support is both tangible and intangible, involves reciprocity, and yields a wide range of benefits to the recipient. A similar definition is given by Hafen et al. 1996 who defined social support as “the degree to which a person’s basic needs are met through interaction with other people” (in Kritsotakis 2003:46). 263). O’Reilly shows that differences in definition exist regarding what actions, interactions, and effects should be considered as related to social support. Based on other authors, there are two broad types of social support: socio-emotional aid (i.e. affection, intimacy, care, affirmation/approval, self-esteem, respect, empathy, belonging, appraisal), and instrumental or practical aid (tangible aid, money, services, advice, and information), Funch et al. (1986). This implies that social support can be broadly categorised as cognitive and affective, and instrumental behaviour.

The concept of social support is sometimes confused with social capital.38 This confusion arises because both social capital and social support share the common ‘elements’ of social networks and social engagement, and a sense of belonging and

38 For a detailed discussion of social capital issues refer to Coleman (1988, 1990); Portes (1998); Bourdieu (1986); Almedom (2005); Baum (2003); DFID (2005); Seeman & Berkman (1988) in White (2003); Campbell et al. (2001); McLanaham (1981); Stansfeld (1992).
reciprocity. Like social capital, social support operates within an individual’s social networks, which consist of a set of persons who are relied upon for support and who may in turn rely upon the individual. However, social capital debates tend to focus on social structure and community resources (social networks or connectedness) while social support is the supportive behaviour (or functional element) of a given social relationship (Östergren et al. 1991). Therefore, social capital is the structure while social support is the content. Bourdieu, was one of the first authors to analyze systematically the properties of social capital, defining it as “the sum of resources, actual and virtual, that accrue to an individual or a group which are linked to possession of durable network of more or less institutionalised relationships of mutual acquaintance and recognition” (Bourdieu, 1986:248). Similarly, Kritsotakis et al. (2004:46) allude to the same fact by indicating that while social support refers to relations a person develops in his/her social environment, social capital breaks away from this individualistic approach to address more effectively the influence of society on the individual. Therefore, even though social capital and social support have the same theoretical characteristics, they describe two different phenomena.

7.3 Precondition for Seeking Social Support among HIV/AIDS Patients

The need for social support among the patients that were studied can only be understood by assessing the objective conditions for seeking and providing social support. This section will examine those needs, and the problems experienced by the patients and health providers that necessitated seeking external assistance.

7.3.1. Patients’ Needs

The needs experienced by HIV patients in the two facilities tended to vary within the cycle of HIV/AIDS management. Based on patients’ accounts, the HIV/AIDS management cycle can be broken down into three overlapping stages: falling sick, treatment initiation phase, and treatment maintenance phase (also referred to as the persistent phase). The health conditions suffered during the first cycle of HIV management have been presented previously (in Chapter 5, section 5.3.2). I will provide extra information here to that effect.

Based on the qualitative accounts, the stage of falling sick was characterised by a ‘cocktail of illnesses’, a ‘prolonged period of pain and suffering’, ‘helplessness’, and ‘humiliation’, and it was such impaired health conditions that necessitated and attracted social support.
I had high blood pressure and developed a stroke. As a result, my mouth became twisted on one side. Friends and relatives attributed such a condition to witchcraft. I was too weak to talk. The caregivers delivered me to the traditional healer. (Female Focus Group Discussion Participant, UMF)

Aside from severe health conditions, impoverishment during this first phase attracted empathy and social support behaviour.

I moved from one clinic to another. At that time, payment of Graduated Tax was still in force. When I presented my money to the Tax Collector, he became sympathetic. He said to me, ‘Mzee (Swahili for old person), I am exempting you from tax, use that money to buy some medicine’. People used to frighten me by saying that the doctor will administer medicine that will kill you. A good friend of mine accompanied me to the hospital. George, who is my son and also serves as my treatment supporter, used to accompany me to the hospital by then. (Male Focus Group Discussion Participant, RPF)

Owing to the deepening economic hardships experienced at this time, some patients became increasingly unable to afford basic necessities and engaged in adverse coping strategies: ‘My daughter dropped out of school, and became pregnant’ (Female Key Informant, UMF). For some, meeting the cost of accessing health services became difficult: ‘I managed to reach the clinic but failed to return home, I was helped by a stranger who gave me 5000 Shillings’ (Female Key Informant, RPF).

This phase attracted both assistance and trouble. Some widows suffered harassment from in-laws during the post-mourning period: ‘In 1994 my in-laws grabbed my property and I ended up putting up in a house as small as a pit-latrine’ (Female Key Informant, UMF). At that same time, the burden of care for their own children and orphans became unbearable, and some patients tried entrusting them to relatives.

My husband had died previously. I had no food, and no money. By then I was too scared to go to Hospital. I also had orphans and three biological children to take care of. I sent them to my brother, but he kept them for only six months and sent them back to me. After some time, my eldest son came and brought me to hospital. (Female Focus Group Discussion Participant, RPF).

The second stage, treatment initiation, was characterised by seeking Voluntary Counselling and Testing (VCT) or Routine Counselling and Testing (RCT), the assessment of clinical conditions, the introduction of multivitamins and cotrimoxazole prophylaxis, the treatment of OIs, and subsequently being initiated on ARVs. Based on patients’ accounts, the first three months were very demanding and required all forms of assistance (money, advice, information, affection, belongingness, affirmation, and approval) in order to manage the costs associated with the mandatory induction
visits and to overcome the anxiety associated with taking up life-long treatment. The subsequent three months after initiation on ARVs were associated with improved appetite, hence heightened dietary costs and social support seeking behaviour.

Finally, during the treatment maintenance phase, patients’ health conditions generally improved dramatically, and the major problem experienced was in meeting the travel costs for regular pharmacy refills, food, and other basic household necessities. This phase also coincides with the resumption of household maintenance responsibilities. In Chapter 5 we saw that the first six months after initiation on ART is associated with clinical and immunological improvement, and such functioning makes it possible to resume or look for livelihood opportunities, especially in the informal sector: “As soon as we recover, we have to start looking for small casual jobs, just to keep us afloat” (Male Key Informant, UMF). However, in some cases, resumption of work becomes difficult due to the previous loss of social networks and contacts, lack of seed money, limited employable skills, and general physical weakness: “A person may have the energy and will to work, but capital to resume work might fail him/her” (Male Key Informant, UMF).

7.3.2. Health Facility Needs

In Uganda’s resource-limited settings, health facilities providing HIV treatment need social support as much as the patients themselves. By May 2009, Mbuya Reach Out (the urban-based Mission Facility, UMF) had 4 doctors and 12 nurses to handle 1644 patients in the four treatment centres. Similarly, at that same time, the HIV Clinic in Kayunga Public Hospital (the rural-based Public Facility, RPF) had 1 medical doctor and 5 nurses serving a total of 800 patients actively on ART. In both facilities, the level of staffing was small compared to the workload, in terms of psychosocial support provision, clinical care and treatment, and general care and support. The number of patients diagnosed with HIV/AIDS and who are eligible for ART has increased since 2005 (Refer to Appendix Figure A.2 and A.3 for 2005/2006 and 2006/2007).

The situation was no better at the national level. Uganda’s National HIV and AIDS Strategic Plan (2008) revealed that while 42% of the population in need was benefiting from ART by 2005, the number in need continued to grow each year, to 129,000 in 2007, and it is projected to rise to 238,000 in 2012 – far outstripping the capacity of the system and the finances available to respond to the demand. This study reveals that health workers’ workload was increasingly becoming unbearable, especially in the Public Facility where the recruitment of auxiliary staff had remained small.
On a typical day of ART clinic, we experience a large volume of work. The most difficult part is processing data for the Ministry of Health (MOH). The MOH requires us to extract the information from the patients’ records to a standardised format. That means that we have to stay behind to make tallies after the patients have left. The advice we received from the MOH is to be committed and to love this kind of work. (Nurse, ART Clinic, RPF)

Given the fact that we (staff) are few, we do not have a fixed time for reporting and leaving the workplace. Instead, the amount of work on a given day determines the number of working hours. (Administrative Assistant, ART Clinic, RPF)

In summary, both the patients and the providers were in need of external sources of social support.

### 7.4 Overview of Availability of Social Support from Social Networks

The survey included a set of questions to determine the availability of friends and/or relatives, and the dynamics of social support in the form of type, sources, frequency, and satisfaction. In terms of availability of confidants (friends who love unconditionally), results indicated that of the 262 respondents across both health facilities, 99% (257) ‘had close friends and/or relatives they felt at ease with and with whom they talked about personal life, including health problems’. There was no statistically significant difference in terms of availability of confidants between the two sites, with 99% (140) in the UMF and 99% (117) in the RPF having access to confidants ($\chi^2 = .016$, $df=1$, $p=.899$). However, another question interested in patient’s membership of an organisation revealed that few (29%, 74) patients belonged to any formal association, with a bigger (41%, 48) number of urban-based patients being more likely to belong to an association than (18%, 26) rural-based patients ($\chi^2 = .15.567$, $df=1$, $p=.000$).

Of those patients in the two sites who had confidants, a large proportion (97%, 248) usually received care, assistance, and support from the confidant. There was no statistically significant difference in levels of access to assistance between the UMF (97%, 136) and the RPF (97%, 112) ($\chi^2 = .002$, $df=1$, $p=.966$). This implies that patients in the rural and urban settings benefited equally from social support resources, which is consistent with results in chapter four, see figure 4.1).

In terms of forms of assistance received from friends and relatives, in descending order, the commonest form of social support was advice 84% (208), followed by emotional support 77% (190), financial support 71% (176), practical support 68%
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(168), food 64% (158); spiritual support 43% (107), a social network 41% (102), compliments 39% (96), and material support 36% (88) [both sites combined]. The 262 ART patients benefited from more than one form of support, reflected in a total of responses that exceed 262 cases.

The sources of social support were spouses, sons, daughters, sisters, brothers, parents, and friends. Yet, the analysis of each of the nine ‘forms of social support’ by ‘source’ shows that the main source of social support was sister/brother – with the highest number (≥52%) of respondents obtaining financial, material, practical support, advice, spiritual support, emotional, compliments, social network, and food from their sister or brother.

In order to assess the frequency of social support, a rating scale was used whereby the respondent was supposed to show whether the mentioned social support was ‘always’ (regular), ‘occasional’, or ‘rare’. For the sake of brevity and clarity, by looking at the highest score for each form of social support, socio-emotional aid was ranked as ‘regular’ while the flow of ‘financial support’ and ‘material support’ was considered ‘occasional’. Results from qualitative studies indicate that social support from wider networks typically became available during the falling sick phase and early part of the treatment initiation phase, and receded once a patient’s health condition stabilised during the treatment maintenance phase.

When I started ART treatment, I informed my brothers. One contributed some money, another one tray of eggs, another bought soft drinks, and another 3 kilograms of sugar, as well as asking the fish vendor to supply fish on Saturdays. They tried their level best. If it wasn’t for that support, I would have dropped out of (HIV) treatment at the very beginning. When I recovered, I started taking care of myself. I reared chickens in order to have a reliable source of eggs. I also grew vegetables. I also convinced my children to buy me a cow, which produces 3 litres of milk. I consume practically all that milk myself. Over a period of 3 months, I had regained weight. I started getting compliments from people about my bodily appearance. The more the compliments, the more I was encouraged to continue taking my medicine. (Male Key Informant, RPF)

In assessing the level of satisfaction with social support, the respondents were simply asked if they were “happy with that kind of assistance?” For each of the nine form of social support between 97-100% of respondents indicated that they were happy. Beyond these statistical figures, the following section examines the forms of treatment support available to the patient as well as the health facilities themselves.
7.4.1. Treatment Supporter

The first source of social support is Treatment Supporters (TSs), also known as Treatment Buddies, or home care-givers. TSs are people, more often than not family members, who participate continuously in the daily management of HIV patients, with a genuine motive to restore, maintain, and promote patients’ health conditions. Understanding the background characteristics of the TSs is necessary because this can have a potential effect on their helping behaviour. As already mentioned in the methodology Chapter, the FGD targeted fifteen TSs, 8 from the Mission Facility and 7 from the Public Facility. While it might be unrealistic to deduce meaningful conclusions from such a sample size, it is still possible to provide information about the characteristics of some of the people who become Treatment Supporters in these settings.

In terms of gender, of the 15 TSs, 9 were female and 6 were male. This may be expected because in traditional African societies women occupy an important position as home care-givers. In terms of social relations, the TSs were: sisters (5), sons (4), wives (2), father (1), mother (1), daughter (1), and brother (1). Table A.5 in the Appendix shows the provider-recipient relationships based on the FGD attendance list. The commonest form of helping relationship was sister-to-sister (5 across both sites), followed by son-to-mother (3). Friends did not feature as Treatment Supporters, possibly because associational ties do not necessarily guarantee ‘daily’ supportive behaviour. Friends appear as Good Samaritans in times of severe need and disappear as soon as health conditions normalise. Daughter-to-father did not feature at all. Daughter-to-father treatment support relations may be difficult to come by because of daughters’ marital engagements and, in the central region of Uganda, it is culturally inappropriate for a daughter to nurse a bed-ridden father, unless in extreme necessity. Similarly, no husband-wife helping relationship was recorded in this particular Focus Group Discussion. Evidence from Individual Patient Interviews indicated that HIV or discordant status is often associated with conflict. Husbands’ failures to meet their breadwinner responsibilities due to sickness and limited economic opportunities sometimes had a stifling effect on the husband-wife relationship.

My wife serves as my Treatment Support but the situation is not good at home. Sometimes she demands basics necessities. Whenever I explain my position, that I am too weak to work, she storms off, saying, “Look, it is none of our business, it was of your free will that you caught the virus.” Marriage, poverty, and medication do not go together well. (Male, (Social Support Recipient FGD, RPF)
In terms of duration of social support, for all the 15 cases, treatment support relationships had lasted between 9 months and 6 years, with almost a half (7) of TSs having served for more than 4 years. This implies that, in some case, the antiretroviral programmes must have built on existing treatment support relationships, presumably the family-based family system, given the fact that the two study sites had only been accredited for just under 4 years preceding this study.

Finally, the treatment support mechanism was based on a weak economic foundation, because TSs were employed in subsistence farming, the informal economy, and some were unemployed, studying, or below the working age (below 11 years of age).

**Intentions for Providing Treatment Support**

The intentions or motivations for providing social support have implications for the quality and, possibly, the duration of support. Ideally, the support provider’s intentions should correspond with the recipient’s needs and the context within which such support is demanded. The consensus was that social support emerged naturally out of the desire to save the life of an ailing relative. This is also the key message in section 7.3.1 in this Chapter. It is at the onset of severe illness that friends and relatives stepped in to reverse the situation, as the following TS indicates:

She (the patient) was living with the husband at the time she fell sick. Despite the fact that the husband never went for a (HIV) test, he was aware of his status. After birth, her baby died from multiple illnesses – vomiting, fever, and cough. The husband abandoned her with her two children in a rented house. I picked her up and took over that responsibility. She was ill, with swollen lymph nodes in her armpits. Because I had gone through the same experience (of AIDS), I advised her to take a test (at Mbuya Reach Out). She resisted. I asked the CATTS (CHW Mission facility) to lend a hand counselling her. On the day she was supposed to take a test, she dressed and, all of a sudden, changed her mind. It was only after some weeks that that resistance waned and she presented herself for test. After being on (cotrimoxazole and multivitamin) for one year, her CD4 went down to 120… She and I underwent education (counselling). After passing the (pre-treatment) interview, she was started on medicine. The doctors asked me whether I could manage. I replied that with the help of the CATTS I would manage. Now she has greatly improved. She takes the medicine on time. Only in a few instances does she seek advice from me. With the exception some simple illnesses, she is doing fine. (Female Respondent, Social Support Provider Focus Group Discussion, UMF) [Brackets my emphasis]

This rather extended account of a ‘sister-to-sister’ supportive relationship demonstrates several more general points. First, a patient’s severe health condition attracts treatment support. Second, the Treatment Supporter simply volunteers to
accord unconditional help to the patient, with such social support behaviour initiated before accessing formal HIV/AIDS treatment. Third, similar health identities generate helping behaviour; the previously infected or affected extended mutual support and health protection skills to fellow relatives living with HIV/AIDS. Fourth, entry into formal healthcare settings expands and formalises treatment support system, with the informal and formal care-givers converging to facilitate entry and utilisation of formal health services. Fifth, helping behaviour wanes as patient’s health condition improves. Six, evidence suggests that providing treatment support is a painful process, involving costs, conflict, resistance, negotiation, and the evaluation of the possibility of continuing.

However, other accounts indicate that, in spite of the volunteering spirit, not everyone’s motives for helping were altruistic. Additional evidence from social support providers suggests that the supportive behaviour is motivated by an evaluation of costs and benefits associated with the survival or death of the HIV patient being helped. According to some TSs, it is more convenient to support a relative to access and adhere to the HIV/AIDS treatment than taking on the extra burden of looking after his/her orphans (after they have died). Some wives feared the loss of their dear ones and the subsequent loss of companionship and mutual support: “I am happy if we both live. Of course two heads are better than one,” (Female, Social Support Provider FGD, UMF). On the other hand, the child Treatment Supporters feared the loss of the economic and social support that would come with the death of a parent: “Of course we love them, but also I take care of my mother so that she will live another day to pay my school tuition,” (Daughter, Social Support Provider FGD, UMF). The little ones shared the same concern of an uncertain future. Luckily, HIV positive parents taking antiretroviral medication were aware of children’s fears and concerns. The following discussion took place in a mainly female Focus Group Discussion at the RPF:

Children have special interest in our lives; all of a sudden this child can ask you, “Dad is gone, what will happen to me if you also disappear?” (Female, Social Support Recipient, FGD, UMF).

A participant interjects:

I have this little child who constantly reminds me to swallow the tablets. She sometimes wakes up in the middle of the night and asks me, “Mama, are you fast asleep, have you taken your medicine?” I assure her that I already have. Children become happy whenever our health conditions improve, and become downcast whenever our health condition deteriorates. ((Social Support Recipient, FGD, UMF).
The above quotations also confirm the desire to provide care and support to children as one of the factors driving adherence to ART.

Mother and her Daughter Treatment Supporter

**Appraisal of Treatment Support by the Recipient and Provider**

The survey included a question about patients’ perceptions of the quality of care received from the Treatment Supporters, including both Personal Treatment Supporters and Community-Based Treatment Supporters.

**Table 7.1**: Patient’s Satisfaction with Treatment Support (Both Sites Combined)

<table>
<thead>
<tr>
<th>Level of Quality</th>
<th>Personal Treatment Supporter (n=248)</th>
<th>Community-Based Treatment Supporter (n=152)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Extremely High</td>
<td>55% (137)</td>
<td>46% (70)</td>
</tr>
<tr>
<td>2. High</td>
<td>37% (91)</td>
<td>33% (50)</td>
</tr>
<tr>
<td>3. Average</td>
<td>5% (13)</td>
<td>7% (10)</td>
</tr>
<tr>
<td>4. Low</td>
<td>2% (4)</td>
<td>5% (7)</td>
</tr>
<tr>
<td>5. Negligible</td>
<td>1% (3)</td>
<td>10% (15)</td>
</tr>
</tbody>
</table>

A combination of ‘extremely high’ and ‘high’ rating shows that patients were satisfied with the quality of treatment support, with the rating being 92% (228) and 79% (120)
for both Personal and Community-Based Treatment Supporters. The rest (8% 20) and 22% 32) felt that the quality of support was equal and/or below average. The role of the community-based TS will be discussed below. Qualitative discussions with patients provided confirmatory evidence of this overall satisfaction: ‘They are not bad at all, can’t you see for yourself from our physical appearance?’

While with life-long treatment it is difficult to empirically establish the frequency and duration of social support, like social support obtainable from wider social networks, the intensity of inter-personal treatment support tends to diminish or becoming intermittent as HIV/AIDS progresses through the persistence phase.

There comes a time when we take our medications without being reminded ... But even when s/he failed to remind me (as a patient), I am not (a) child, it is my personal responsibility to take care of myself. If a child can take the responsibility of taking the medicine without being reminded by the parent, how could I fail to do so? (Social Support Recipient FGD, UMF)

Provider evaluation of the HIV patient-Treatment Supporter relationship shows a care-giver burden because of the costs, tension, and sacrifices involved in the entire process. Accounts from various TSs demonstrated that such costs and sacrifices varied from one person to another. In the course of illness, some TSs deferred their personal ambitions: “I was attending school but given the fact that I was the only person readily available at that time, I had to postpone schooling for one year” (Daughter, Social Support Provider FGD, UMF). “Even when s/he has biological children you have to take on that responsibility.” (Male, Social Support Provider FGD, UMF)

Family-based treatment relationship is characterised by stress because of the pressure and tension patients impose onto the care-givers. Some patients display a relentless demand for nice food to accompany their medication (kubayiyiiza); seek compliments and approval of the physical functioning and bodily appearance (okubesimisa), like to be showered with praise for having taken their medicine appropriately (kubasuusuuta), or demand attention like babies (kubafaako). If the treatment supporter ignores such demands the patient starts to sulk (entondo) and becomes sullen (kkekyanga). As one female supporter in the rural settings said:

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39 Here, the notion of frequency of social support refers to the occurrence of helping events within a given time period, while duration refers to the length of the period in which help is received.
40 Luganda, the local language in which the investigations were conducted, does not have masculine and feminine pronouns, hence the usage of s/he here.
We have to plead with them about their demands… But when we have some money to spare and return home with what they are looking forward to, that is when they are overwhelmed with joy.

The last form of appraisal that can be made here is the level of reciprocity of supportive behaviour between the recipient and provider. The survey assessed reciprocity between the patient and their social networks (not necessarily only Treatment Supporters). Results indicated that less than a half (46%, 116) of patients across both sites gave something in return for the assistance they had previously received from a confidant. More specifically, the assessment of treatment support itself indicated that patients tended to pay back TSs in simple ways, including with prayers, appreciation, comfort, and practical support, especially during stressful moments (e.g. bereavement) – Hence the frequent travels and attendance of burials, ultimately resulting in non-adherence to treatment. Fortunately, the TSs never expressed many of expectations of their patients.

I don’t expect anything from him/her. This is (a) person who is too weak to produce crops. S/he does not have the energy to board a lorry to go to the market to conduct business (to find money to pay back – my emphasis).

7.4.2 Health Facility Support Systems

Beyond familial or kinship support networks, patients who have been formally enrolled for HIV/AIDS treatment services in the two settings benefited from what can be called Facility-based Social Support. Two variations were identified here: peer-patient support and Healthcare Volunteers.

1. Peer-Patient Support

The second level of social support was among the HIV patients themselves, operating from the health facility and at the community level. This kind of support arose when patients met repeatedly for certain healthcare services (VCT/RCT, ART counselling, pharmacy refill) within a common healthcare setting. Repeated encounters at the general reception and in group counselling (as opposed to less common individualised sessions), brought patients closer together and stimulated peer support.

The most important benefits of such frequent focused encounters and interactions among patients themselves are motivation, a sense of belonging, and behavioural skills. First, interpersonal interaction at the waiting bench involves sharing information, compliments, and encouragement that serve as positive reinforcement:
We are encouraged by the fellow patients who make remarks that we look good. We take the compliments and tell them that our health condition used to be worse before starting medication.

Second, frequent encounters and the associated mutual experiences not only serve as a stress buffer but also reduces stigma (especially the experienced stigma⁴¹).

When I come to the clinic I become aware that I am not the only one suffering. ... You stop being haunted by that feeling of individual punishment and eventually you become strong.

Third, sharing information in a healthcare setting is associated with gaining therapeutic skills (see Chapter 6). Patients tend to share individual experiences of falling sick, management of opportunistic infections and drug side effects, coping strategies, and preventive and curative actions.

However, the benefits of such inter-patient interaction are restricted to emotional assistance as it rarely translates into practical and financial support: “One cannot get financial assistance from patients, they are completely poor.”

2. **Healthcare Volunteers**

The third category of social support system is made up of the HIV/AIDS cadres who operate at the facility and/or community level. During the implementation of community-based healthcare services in the 1980s, these were called Community Health Workers⁴² and they provided primary level care. With the appearance of HIV/AIDS, this primary healthcare approach was revived with the HIV/AIDS infected and/or affected persons transforming into care-givers. These HIV/AIDS caregivers are variously known as Homecare Facilitators (for Uganda Red Cross HIV Project in Uganda), Community ARV-TB Treatment Supporters or CATTS (for the Mission Facility-Mbuya), or simply as volunteers (in the Public Facility – Kayunga). Given the different names in use, Healthcare Volunteer is adopted here to refer to trained patients who volunteer their time and labour to provide care and support to the patients in a healthcare setting. The concept of Expert Patient is less applicable in Uganda’s context because, in the context of the developed world, it refers to patients

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⁴¹ Stigma can be ‘enacted’ (e.g. one is discriminated by the public) or ‘felt’ (e.g. one is shy about oneself).

⁴² According to WHO Study Group (WHO 1989): Community health workers should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers (in Prasad BM 2007).
with long-term illness who can effectively manage their own illnesses in partnership with health care professionals.

It should be noted, however, that while the Mission Facility uses a combination of an outreach model and a community model, the Public Facility uses a facility-based model. The outreach model consists of home-based care teams, comprised of doctors, nurses, laboratory technicians, and counsellors, taking services to communities. The community model entails community members/volunteers/community health workers providing home-based care services to people living with HIV/AIDS. On the other hand, in the case of facility-based model the volunteer perform non-technical work as well providing emotional support to fellow patients at the facility (MOH 2004). Though, in practice, the distinction between all these models is blurred.

Origin of Healthcare Volunteering in the Two Facilities

The adoption of the Healthcare Volunteers system for dealing with HIV/AIDS originates from the desire to reduce the effects of staff shortage on the quality of health services and associated potential adverse effects on adherence to ART. Hence, health facilities recruit, train, and empower volunteers to fill the human resource gap. Like the personal treatment support system already discussed above, the current Healthcare Volunteering in the two study sites consisted of spontaneous voluntary action that started as the outreach model in the Mission Facility and as the community model in the Public Facility.

At the Public Facility, healthcare volunteering began as a self-help process. Around the time I started my fieldwork at the Public Facility, I used to see a gentleman who stayed around the patients waiting for clinical consultations. At regular intervals, he rose and addressed the patients thus:

Fellow patients, kindly listen to me. I ask of you to be patient, the line is moving slowly, but the doctors will certainly attend to you. Do not walk away and return home before you see the doctor. You must realise that the number of health staff is small, but all the same, you will be served.

He would then sit down and, all of a sudden, stand up again and stroll around as if he was an officially appointed usher. He would welcome patients arriving at the HIV clinic, direct them to the relevant waiting lounge, and lead others to the consultation rooms or the pharmacy department. He would line up or ‘jump the queue’ to secure medicines on behalf of the extremely weak. As time went on, he established relationship with professional health workers and he assumed several functions, some of them including; relaying files to the relevant offices, replacing the files in the filing cabinets, and running errands at the request of the professional staff. At the end of
the day, when all his fellow patients had returned to the villages, he would thank the health staff for the day’s work, walk out of the clinic, unlock his bicycle and disappear back home. The following day, he would report to the clinic earlier than the staff to organise the office, and render a hand in pushing the medicine trolley from the main hospital pharmacy.

This gentleman was Mr Nsubuga (true name reproduced with permission). His participation in HIV/AIDS related care and support did not begin as formal healthcare but initiated at the community level. He is the founder of the herbal group mentioned in Chapter 5 that transformed into the Kayunga Hospital ART Association (KHAA) and that served as a monthly forum for talking about adherence issues in Kayunga Hospital. Mr Nsubuga also became one of the 6 Healthcare Volunteers fully integrated into the Public Facility to supplement the small number of health staff.

The Healthcare Volunteers underwent training in care and support organised by the Ministry of Health in Kampala. Facilitated by the Makerere University Walter Reed Project (MUWRP), the volunteers and the nursing staff benefited from additional training that covered several topics including; adherence, positive living, hygiene, types of ARV regimen, TB management, prevention of mother-to-child transmission (PMTCT), and nutrition. At the time this research was conducted, the MUWRP project met the extra operational costs, including the stipend for volunteers.

43 Other community based organisations (CBOs) were also emerging in the backyard of Kayunga Public Hospital. I visited one CBO in the countryside called Tulibalamu (Alive and Kicking).

44 MUWRP is a non-governmental not-for-profit HIV research organisation dedicated to finding a safe and effective HIV vaccine. Through PEPFAR funding, MUWRP donated office equipment (telephone and furniture), test kits, a CD4 machine, kidney and liver machines, and training in counselling.
The Role of Social Support in Sustaining Adherence to Antiretroviral Medication

Quite differently, at the Mission Facility, Mbuya Reach Out, the spirit of health volunteering did not originate in the villages but from the Catholic Church, during a 2001 Easter sermon presided over by an Irish priest. Speaking on the theme of salvation, the priest urged fellow Christians to reach out to the sick and needy living in nearby suburbs. The key values that inspired the work of the founding Christian members were ‘hearts and will’, guided by the principles of “Do what you have, with what you have, where you are”45. This faith-based ideology was integrated into the training of Healthcare Volunteers. The Volunteer’s Trainer Manual even inscribes a prayer of St Francis of Assisi, asking the Holy Spirit, “Lord, make me a channel of your peace. Grant that I may seek to comfort rather than to be comforted, to love rather than to be loved” (paraphrased). Even a typical HIV Clinic day in the Mission Facility opens with morning prayers and few exercises. During this session, administrative communications are made and new events or members are introduced – which I personally experienced as if being introduced and integrated into a family.

After the Easter Sermon, small Christian communities from Mbuya Catholic Church started visiting the sick and dying people in their homes, and providing emotional and spiritual support. When the workload expanded, more Christians were called out to serve as volunteers in order to staff the weekly clinic (Reach Out Project Document 2005). As time passed, the community outreach project transformed into a strong healthcare organisation, and the programme name was changed from Mbuya Outreach to Mbuya Reach Out. By 2008, the programme had five departments. The community volunteers, CATTS, are now a fully institutionalised sub-department, hosted by the Community Support Department. The first-line supervisor of The Mission Facility tracks CATTS’ performance and the Community Department

45 (http://www.reachoutmbuya.org/volunteers.html).
provides guidance and coordination. Like in the Public facility, monthly meetings serve as forum for discussing individual reports, resolving intra-group conflicts, and planning subsequent activities.

Like the Healthcare Volunteers at the Public Facility, the CATTS are well trained in home-based care activities on the basis of a simplified step-by-step training manual that covers a wide range of topics, including home-based care, the basics of HIV and tuberculosis, ART adherence, psychosocial counselling, and adherence monitoring.

**Role of the Healthcare Volunteer System**

The role of the Healthcare Volunteer system can be evaluated by assessing the amount and quality of services performed by the volunteers themselves. There are three possible ways of estimating the amount of work performed by the healthcare volunteers namely; by counting the number of healthcare volunteers serving, by taking the working hours per day, and by looking at the functions performed.

The number of healthcare volunteers serving can be understood by using a proxy indicator of provider-patient ratio. Table 7.2 below presents the Level of Staffing and Healthcare Burden with the first three rows presenting the type of health workers at the HIV/AIDS clinic in the form of doctors, nurses, and Healthcare Volunteers in the two facilities between 2009 and 2011. The last two rows present the actual and hypothetical provider-patient ratio. The Health Worker to ART patient ratio on the second to last row reflects the reduced workload as an effect of volunteer participation. Finally, the last row shows the hypothetical increase in workload of professional staff if the Healthcare Volunteers were to be excluded from the healthcare arrangement.

**Table 7.2. Overview of Staffing and Healthcare Burden**

<table>
<thead>
<tr>
<th>Type of Health Worker</th>
<th>Mission Facility</th>
<th>Public Facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior Medical staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Healthcare Volunteers</td>
<td>250</td>
<td>232</td>
</tr>
<tr>
<td>Total No. of Health Workers</td>
<td>266</td>
<td>246</td>
</tr>
<tr>
<td>Total No. of ART Clients</td>
<td>1644</td>
<td>2099</td>
</tr>
<tr>
<td>Health Worker : ART client Ratio</td>
<td>1:6</td>
<td>1:9</td>
</tr>
<tr>
<td>Professional Staff : ART Client Ratio</td>
<td>1:102</td>
<td>1:150</td>
</tr>
</tbody>
</table>

**NB:** 1. The data for 2011 is based on a Follow-up Study.
Volunteers recruited, the more favourable the provider-patient ratio, and therefore the less the clerical and outreach workload for the professionals. The second to last row shows that the Mission Facility with a high number of Healthcare Volunteer tended to enjoy a favourable Health Worker to ART patient ratio (1:6 and 1:9 in 2009 and 2011 respectively) compared to the Public Facility that had fewer Healthcare Volunteers (1:67 and 1:120 in 2009 and 2011 respectively). The last row indicates substantial increase in the number of ART patient that professional staff would have to deal with if the Healthcare Volunteers were not participating in clerical work and outreaches. The table also shows a decrease in the number of professional staff. The reasons for this trend will be discussed later.

The technique of task shifting whereby professional health workers pass on non-technical work to the Volunteers is associated with several benefits, as it:

1. Empowers lay patients in provision of preventive, treatment, and psychosocial support services,
2. Reduces the operational costs in terms of salaries for professional staff,
3. Reduces the workload for professional staff and freeing more time for clinical and adherence activities,
4. Reduces the professional and social distance between professional and lay patients, and common modern scientific medicine,
5. Expands the scope of intervention through facility and outreach services.

The nature of work performed by the volunteers varies depending on the nature of the community-based healthcare model adopted by the facility. In the facility-based model, a model embraced by both the Mission Facility and Public Facilities, volunteers perform non-technical work that takes the form of (among other things): managing reception; retrieving, relaying, and replacing patients’ files; taking and recording clinical indicators (mainly weight); serving breakfast to the patients at the clinic; and (some) dispensing of ARVs and preventive therapies. Beyond the healthcare settings, the Healthcare Volunteers distribute basic care kits (including mosquito nets), participate in outreaches, track lost-to-follow-up patients, facilitate the transfer of patients to newly accredited treatment centres, and accompany and/or visit fellow patients to/in referral centres. The CATTS also visit homes, and administer patient assessment checklist to identify the families needing a given type of socio-economic aid.

At the Public Facility, where a facility-based approach is more pronounced, the Healthcare Volunteers system resulted in community organising. The ART
Association alluded to above organises monthly adherence support meetings within the hospital premises. During these meetings the discussion centres on perceived adherence barriers, adherence to pharmacy refill appointments, and preventive and treatment behavioural change (e.g. use of mosquito bed-nets and nutrition). In principle, a health staff representative is supposed to attend these meeting in order to handle issues of a technical nature. Given the fact that the rural-based Public Facility was not able to implement the socio-economic component of its ART programme due to limited public funding, the ART Association was increasingly exploring the possibility of implementing food and income security projects at the community level.

In addition, the Mission Facility, with a substantial amount of donor funding implements the outreach model whereby the CATT conduct home visits, check the patients’ medical forms, conduct pill-counts, identify adherence barriers including family support, counsel non-adherent patients and/or recommend referral for counselling/treatment, and remind patients about their next refill appointments. The CATTS also screen patients at the community level for treatment enrolment, screen for orphans and vulnerable children, and distribute healthcare kits for needy patients.46

As indicated in Chapter 7, the Healthcare Volunteers implemented counselling. Besides, because they are themselves either infected or affected by HIV, they are keenly aware of patients’ realities and therefore able to tailor the information given, and, using appropriate communication techniques, to address the real adherence barriers. Due to the comprehensive training in HIV/AIDS that the Healthcare Volunteers receive, they can help patients interpret technical information and pass on instructions. Often such interaction is observable at the exit point after meeting the professional. Because Healthcare Volunteers cross borders, they also bridge the professional-patient communication gap, thus receiving information and providing feedback from and to both the patients and the providers. As one volunteer in the Public Facility noted:

> Sometimes patients may come to the clinic with a personal problem but find it difficult to disclose it (to) doctors and end up confiding in us. After s/he has confided in me, I liaise with the doctor to see that such a problem is solved.

As previously indicated, a large proportion of patients were satisfied with the services provided by the community-based Treatment supporter.

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46 Patients in need include those who are bedridden, those referred by major hospitals, the unemployed, the elderly, and those abandoned by relatives. The type of assistance given is in the form of clothes, grants, water guard, starter kits, and water vessels.
The Role of Social Support in Sustaining Adherence to Antiretroviral Medication

Incentives
Lastly, while the principle of voluntarism is emphasised during recruitment, Healthcare Volunteers benefited from a wide range of incentives. These incentives sometimes take the form of an expected reward that motivates certain behaviours.\textsuperscript{47} The volunteers benefit from three types of incentives namely; intrinsic incentives, pecuniary incentives, and social incentives.

The intrinsic incentives are connected with doing work because it promotes personal interests and feelings (task enjoyment), or the direct result of the task outcome (e.g. a feeling of achievement). Both patients and staff feel happy when saving lives. The second level of intrinsic incentives is that the volunteers benefit from comprehensive and continuous training and can so expand their functional skills.

The pecuniary incentives come in the form monetary or tangible rewards. Volunteers in both facilities earned financial incentives. In the Mission Facility, the Healthcare Volunteers earn a monthly salary whereas in the Public Facility, the incentive takes the form of a transport refund per day worked provided by the Makerere University Walter Reed Project (MURP) contributing Ushs 2500 (US$ 1.6); the Joint Clinic Research Centre (JCRC) contributing Ushs 2400 (US$ 1.5); and Alliance contributing Ushs 100,000 or US$ 62 per month. However small such a financial incentive was, it helped to offset some of the financial obligations of volunteering, especially the travel costs. Unfortunately, by 2011 such financial incentives had been terminated in the Public Facility.

The social incentives stem from a particular social system, and are mainly in the form of recognition, approval, and favours from valued others or peers. The social incentives can take the form of playing the role of a model patient when dying and then being saved by the mighty antiretroviral therapy; having associational ties with professionals; participation in planning meetings, and recognition by fellow patients. The role modelling also reduces stigma. In the rural setting, these volunteers were addressed as Musawo (doctor), even though the volunteers themselves downplayed this as a flattery.

Challenges to Healthcare Volunteer Services
Overall, the figures in Table 7.2 (3\textsuperscript{rd} and 4\textsuperscript{th} row) shows a drastic increase in the number of patients in 2011 and a slight decrease in the number of health workers.

\textsuperscript{47} Adapted from Track 15: International HRM Turning Knowledge into Action: The Role of Incentives in Organisational Capabilities (p. 15).
Sustaining Adherence to Antiretroviral Therapy among HIV/AIDS Patients in Uganda

An increase in the number of HIV patients enrolling for ART services was attributed to an absolute increase in the number of patients needing HIV/AIDS, as well as the quality of care attracting more HIV patients from neighbouring facilities offering the same services.

That the number of patients enrolling into the antiretroviral programme was likely to rise dramatically is reflected in the large number of patients currently taking Cotrimoxazole Prophylaxis, with 1657 and 900 in the Mission Facility and Public Facility in February 2011 respectively. This expected increase in ART enrolment comes at a time when the number of health workers is decreasing (cf. Table 7.2). A slight increase in staff attrition rates was attributed to the effect of leaving for further studies (both sites), self-imposed retirement, forced dismissal due to inefficiency and/or malpractices (Mission Facility), and withdrawal of financial incentives for volunteers (Public Facility).

7.4.4 Healthcare Services

The last form of social support available to ART patients is the healthcare services. As already indicated in Chapter 4, owing to differences in financial resources, the Public Facility implemented a minimal healthcare package (medical and counselling), while the Mission Facility implemented a holistic package (medical, counselling, socio-economic support and community network of care). Table 4.3 is reproduced here as Table 7.3 to show the proportion of patients who ever benefited from social support.

Table 7.3: Proportion of Respondents who benefited from Assistance at Any Time

<table>
<thead>
<tr>
<th>Type of Assistance</th>
<th>Site</th>
<th>Total</th>
<th>Chi-Square value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urban Mission Facility</td>
<td>Rural Public Facility</td>
<td></td>
</tr>
<tr>
<td>Food</td>
<td>91% (128)</td>
<td>7% (9)</td>
<td>53% (137)</td>
</tr>
<tr>
<td>Micro-Credit</td>
<td>40% (56)</td>
<td>0.0% (0)</td>
<td>23% (56)</td>
</tr>
<tr>
<td>OVC Support</td>
<td>13% (18)</td>
<td>0.9% (1)</td>
<td>7% (19)</td>
</tr>
<tr>
<td>Income Generation</td>
<td>1% (2)</td>
<td>0.8% (1)</td>
<td>12% (3)</td>
</tr>
</tbody>
</table>

N.B.: Each item was analysed separately but is presented here in the same table.

In the Mission facility, 91% (128) benefited from food (WFP assistance), 40% (56) from micro-credit, 13% (18) from orphan support, and 1% (2) from income generating activities. Hardly any patient had previously benefited from such socio-

48 The districts served by Kayunga Hospital include; Kayunga itself, Mukono, Jinja, Wakiso, Kampala, Luwero, and Kamuli.
economic services in the Public Facility. While the amount of support was inadequate, temporary, and the micro-credit not necessarily invested in productive ventures (as indicated in Chapter 4), it was instrumental in sailing urban patients through the extremely demanding treatment initiation phase. Nevertheless, the most important form of assistance has been the psychosocial support accorded to patients by the health staff:

The Health Workers are our best friends. They give us treatment, handle us with dignity, give us advice, and comfort. They are not rude. There is no black spot in our relationship with them. Counselling was good, we learnt about nutrition, hygiene, dosing hour, mosquito nets, and avoiding fear and worries”, (Patient FGD, Kayunga Public Hospital).

7.5 Organisational Context
Success in implementation of participatory approaches in formal health facility settings has depended on the transformation in organisational process. In terms of interpersonal relationships, the expression of power and authority by the top management and by the technical staff is mild. Since a too overt expression of power and authority can stifle volunteering spirit the administrators in both facilities tread a delicate balance between the bureaucratic and collegial type of power and authority. At a Christmas Party at the Mission Facility in 2007, I noticed the absence of a high table for VIPs. No Guest of Honour was present, and there were no (long) speeches, and no separate dining table for the senior staff. The Executive Director was pulled over to the dance floor by the patients and the dominant pronoun was ‘we or us’. The same spirit of collegiality was echoed in the Public Facility, as a volunteer patient noted: “Whenever there is an event like a party we sit together with the doctors.”

The technical staff does not consider the volunteers as a threat but rather as partners in saving lives, which explains why the patient CBO was able to convene its meetings in the hospital premises. Embedded in all this is teamwork and despite the existence of a recognition system in the Mission Facility, CATTS seldom benefit from recognition award because, according to the senior staff, implementation of home based care services requires a group rather than an individual effort.

7.6 Conclusion
The purpose of this Chapter has been to demonstrate that beyond the biomedical interventions, there are social processes that support adherence to ART in the form of social support. The second argument has been that the expanded analysis of such
social support should be approached by assessing 1) the pre-conditions for seeking and giving social support; 2) the providers of social support (those agreeing to volunteer support); 3) the resources exchanging hands; and 4) the potential benefits accrued from social support.

The preconditions for seeking and providing social support are mainly the HIV/AIDS conditions and the associated demands along the health-seeking continuum of falling sick, treatment initiation phase, and treatment maintenance phase. Each phase is associated with different needs. The pioneer patients who endured long, multiple and severe HIV/AIDS related complications, needed substantial amounts of socio-emotional aid and instrumental support during the earlier phase of ‘falling sick’ and ‘treatment initiation phase’. With the stability of health conditions during the treatment maintenance phase, patients’ need shifted to financial and food aid required for accessing and adhering to antiretroviral therapy.

In terms of providers of social support, HIV patients survive on diversified sources of support ranging from kinship (family members and relatives), to associational ties (peer patient support, healthcare volunteers and associations), and institutional support (healthcare services). Because of the physical and social proximity, the family-based support system serves as the most durable sources of social support to the HIV-patient, proving both emotional and instrumental support. At the facility level, the associational support system is in the form of peer patient support, healthcare volunteers and associations. Unlike other forms of social support, the institutional-based social support is not exclusionary but inclusive producing society-wide benefits operating at the facility and community level. As a result, adherence to ART is sustained by multiple sources of social support at various levels.

In terms of the availability of social support measured in as amount, frequency, and timing, social support tends to be inadequate. Three major factors that determine the availability of social support are severity of illness, density of social networks, and poverty itself. Depending on the density of one’s kinship and associational ties, social support comes mainly during the critical period of falling ill and the early phase of treatment initiation, to diminish during the treatment maintenance phase. The family care-givers occasionally step in when patient fail to raise transport money for pharmacy refill, or when patients relentlessly ask for ‘luxurious’ meals.

Even at the health facility, the most important form of institutional-based social support that drives adherence is the medical and psychosocial support, as well as emotional support from fellow patients. However, it is only the philanthropic based
Mission Facility running a large externally funded budget that manages socio-economic aid. Still, only a small proportion benefited from the socio-economic aid, with food aid being subsequently terminated after this study was completed. The peer-patients provide mainly emotional support (sense of belonging), information, and practical support (directing new patients and serving porridge/snacks).

The level of prevailing poverty affects the availability of social support. Hence, commonest form of social support is not financial assistance but socio-emotional aid. Financial assistance comes third after advice and emotional support. Ultimately, in normal times, patients meet their own financial obligations and only resort to external financial support during hard times. The poverty argument might explain the generalized reciprocity, whereby social support providers do not expect the patient to pay back quickly and automatically.

Whatever form, amount, and timing of social support improves adherence to ART. This is because social capital is all about social organizing. Sociological and organisational behaviour show group formation and cohesiveness being associated with social control and social facilitation. According to Huczynski et al. (1991: 211), “groups invariably establish rules of conduct in order to maintain consistency of behaviour among members.” Once such role expectancy is established, patients fear being evaluated negatively by others. Moreover, adherence to ART is associated with a stream of benefits. Improved health conditions attributable to antiretroviral therapy enables patients to fend for themselves. After all, patients’ appraisal of social support received is positive, regardless of this being irregular or small.

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49 Reciprocity is “cognitive” element of social capital, refers to the provision of resources by an individual or group to another individual or group, and the repayment of resources of equivalent value by these recipients to the original provider (Baum and Ziersch 2003). H is weak.
8
Sustaining Adherence to Antiretroviral Therapy

8.1 Introduction
This study was guided by the theoretical argument that adherence to life-long antiretroviral treatment in Uganda's resource-poor settings is an outcome of a reciprocal relationship between biomedical and environmental factors. That theoretical argument was intended to tease out the relationship between the individualistic factors and the environmental factors. In classic Epidemiology, the biomedical factors are represented as the patients (host) affected by the disease (agent) in a given environment. However, in order to avoid becoming trapped in the pitfalls of the classical epidemiology, this research perceived the environmental factors to be a wider process in terms social, political, cultural, economic, and physical conditions. These environmental factors were assumed to relate to the various contexts and meanings that change between time, space, and individuals, and shape the adherence process and patterns. Second, in order to explore all possible influences of biomedical-environmental interactions, the two factors were assumed to be potentially and simultaneously both facilitating and constraining adherence to ART. Third, adherence to antiretroviral therapy was considered to be a dynamic process, entailing a set of adherence activities that precede and culminate in the pill-taking event. Such an expanded conceptual integration necessitated the adoption of innovative methodological approaches using qualitative and quantitative methods interactively. In operationalising the theoretical argument this research generated seven research questions; the empirical results have been presented in six chapters, and these are followed by the present concluding Chapter.

8.2 The Study Contribution to Knowledge
This study contributes to our understanding of adherence to ART in resource-poor settings in three ways. The first contribution is the comprehensive analysis of the adherence to chronic antiretroviral therapy. The findings presented in this study demonstrate that, adherence to antiretroviral medication is an outcome of a
complex process involving interrelated activities. However, it should be noted that the expanded analysis of the adherence activities is not intended to displace or substitute the orthodox quantitative adherence measurement using the objective and subjective adherence tools and the clinical outcome. Instead, it illuminates the fact that over-reliance on a single measurement for adherence tends to conceal the experiences and meaning surrounding the pill-taking event as well as the potential actions that may improve adherence to powerful chronic drugs.

The second contribution is the revelation of a variety of substantive issues affecting adherence to ART in resource-poor settings. The results presented in this thesis suggest a need to shift from a traditional Epidemiological approach to a Biosocial approach that situates the biomedical factors into a wider socio-cultural, economic, and political environment, while at the same time highlighting the role of actors, actions, institutions and resources at the various levels of the healthcare continuum (patient, household, facility, community and so on). Therefore, this work responds to the call for pluralism in understanding health and illness; a call that is echoed in the disciplines of anthropology and sociology.

The third contribution to the existing knowledge is the methodology. The study employed both qualitative and quantitative methods to generate understanding of adherence in two different ART accredited sites, on the expectation that location, facility ownership, and constellation of services all potentially influence the overall adherence outcomes. Combining both qualitative and quantitative data collection methods over a period of three years permitted generation of rich and insightful information. As it is in the grounded theory, the pursuance of the emergent research question/hypotheses determined the choice of data collection methods and the possible sources of information. The sequencing of research methods matters. By implementing qualitative exploratory studies before the survey it allows building the survey on the issues that matter to the respondents themselves rather than those that matter to the researcher him/herself. Specifically, clinical records, often left out in adherence studies, contain rich pill-count and clinical data which can be infused into the questionnaires and verified with patients during interview sessions. This research shows that making use of such data allows retrospective longitudinal adherence analysis, as opposed to reliance on short-term patient recall of pill-taking events. Post-survey qualitative studies are also useful in imputing meaning and context when quantitative study might have yielded inconclusive statistical results and explanations.

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50 Adherence measuring methods are: Pill-count, self-reporting, pharmacy refill, Medication Event Monitoring System (MEMS), biological markers
However, the productivity of the methodology should not be judged by the methods used but by the depth and breadth of data analysis, as well as by the policy implications that these lead to. This research undertook several analyses in terms of pill-count adherence, clinical responses, and adherence factors. By using more than one adherence measuring (adherence levels, adherence status, and adherence episodes) improves accurate reporting of adherence levels and the policy implications. In assessing adherence status, by deriving different adherence thresholds\textsuperscript{51} and the proportion of patients under each threshold, it becomes possible to pay particular attention to a given adherence group and to account for the various circumstances affecting a given adherence group. In adherence studies where majority of patients might have achieved near-optimal and optimal adherence, missed pill episodes can be useful in revealing incidences of missed pills (as opposed to number of doses) that may go undetected when 95% pill-count adherence is used as the sole measure. Cross-sectional adherence studies conceal the adherence pattern over time. Deriving a trends analysis, like the one calculated in this study, can help to design specific adherence support measures targeting non-adherence behaviour at a given time. Triangulating pill-count data with a wide range of health outcome indicators (CD4+ cell count, functional status, and weight) can provide reliable evidence on the relationship between adherence behaviour and immunological responses, even when viral load data is lacking.

8.3 General Conclusion and Discussion

8.3.1 Similarity in Adherence Levels and Patterns

The overall outcome shows that 90% of the patients achieved the 95% pill-count adherence. There was no statistically significant difference in pill-count adherence between the two health facilities ($\chi^2=109$, $df=1$, $p=.741$), even though they have very different adherence support mechanisms (Section 5.2). These findings provide confirmatory evidence that it is possible to achieve near-optimal adherence in resource-limited settings. Second, differences in the constellation of health services and location do not substantially alter the adherence outcome. In fact, in-depth analysis shows that rural folks attending the public health facility with less institutional socio-economic aid achieved twice the level of optimal adherence (i.e. 100%) than the urban-based patients (Table 5.2). These broadly similar and very positive adherence patterns can be attributed largely to the similarities in demand and supply factors. Regardless of location, patients came from poor economic backgrounds (rural poverty

\textsuperscript{51} The Four Adherence thresholds are: Optimal Adherence (100%), Near-optimal Adherence (95-99%), Sub-Optimal Adherence (80-94%), and Non-adherence (<80%).
and peri-urban poverty), were exposed to the similar pre-treatment symptomatic conditions and life goals, and also benefited from similar clinical and adherence support services.

8.3.2 Adherence as a Process and Outcome

The antiretroviral medication dose is not a discrete event but an outcome of a complex process involving interrelated activities that precede and culminate into the medication dose itself. In order to swallow the pill as intended, the HIV-infected individual must have mobilised the necessary resources and implemented a hierarchy of therapeutic activities along the adherence path. The patient should have mobilised the necessary resources to attend treatment induction appointments, and they must have returned for the pharmacy refill in a timely manner (before running out of continuity doses); they should have taken a meal/snack in order to reduce the adverse metabolic effects that are associated with empty stomach dosing; they should have remembered the dosing time; and finally, they should have swallowed the right antiretroviral dose.

This evidence becomes more compelling given the fact that a statistically significant number of patients that missed pharmacy refill also missed medication doses ($\chi^2 = 13.435, df=1, p=.000$—see section 3.2.2), and missing medication dose was attributed to failure to attend pharmacy, lack of food, and being busy (partly causing forgetfulness of the medication time) (Table 3.10). This is consistent with other studies which found that patients who collect their medication regularly are more likely to be adherent to treatment (Population Council et al. 2004).

Understanding the relationship between antecedent adherence activities and the final adherence outcomes helps to plan the medication event and to tailor counselling to the potential major adherence barriers that cut across adherence activities. In planning the medication event, we acknowledge that there are essential therapeutic resources that are needed to achieve optimal adherence. The basic assumption would then be that if the patient had access to these set of resources (inputs), then they would be likely to achieve this adherence activity, and that will enable them to take the right medication in a timely manner. The therapeutic inputs are in the form of money, food, time, concentration, effort, and the medicines themselves. Evidence presented in Chapter 4 shows that in order for a patient to report for pharmacy refill, essential inputs like transport money, among several others are required (Table 4.1 & Section 4.5). Even in days of rolling out antiretroviral therapy, some patients decided in favour of relocating to the nearest newly accredited facility in order to reduce pharmacy refill
related costs (section 4.6.3). In the same way, the antecedent adherence activities can be regarded as essential inputs into the medication dose event itself.

### 8.3.3 Complexity of Adherence Barriers

Chapters 3 and 4 have discussed the adherence barriers. Specifically, Chapter 4 has approached adherence barriers from angle of the costs involved in accessing ART services. There are two important conclusions that emerge from these two chapters. The first one is that common adherence barriers cut across the five forms of adherence activities. Second the composition of the adherence barriers reflects a combination of biomedical and structural barriers that act on and reinforce each other. These conclusions are discussed in more detail below.

### Occurrence of Barriers and Actions of Adherence Barriers

As already indicated, there are five interrelated adherence activities namely; treatment initiation appointments, pharmacy refill, meal/snack, dosing time, and medication dose. The barriers to those adherence activities are; biomedical barriers, livelihood activities, and access and adherence related costs (see Table 3.12).

However, in terms of appearances, a quick count of all the barriers under each category shows a weak appearance of biomedical barriers (Table 3.1-3.10, Table 3.12, and Chapter 4). With the exception of the interruptive effects of sickness, drug side effects, and difficulty in concentration (misplaced/lost pills, mistaken dates), suboptimal adherence was not attributed to physicians prescribing excessively complex regimens, failure to provide adequate information about antiretroviral benefits, patient characteristics, provider-patient relationship, or the general system within which care is administered (urban or rural facility). Instead, the predominant adherence barriers relate to structural constraints.

Predominance of the structural barriers can be attributed to two reasons. First, is the effective adherence support provided in the two facilities (psychosocial support, ARVs, preventive therapies) and patient’s commitment (Section 5.3.1). This implies that when biomedical factors have been controlled, livelihood-related barriers assume a centre stage position. This brings us to the second explanation.

The range of assets available to households and, therefore, the type of livelihood activities in which patients participate is likely to determine the character and degree of impact of the structural barriers. In this study, the majority of the HIV-patients had limited education (human capital), and reliable sources of income and liquidity (financial capital) and material assets (physical capital). As a result, the majority
of patients depended mainly on natural assets (land), social capital, and informal sector resources (such as casual labour) for their livelihoods (sections 2.3.1 & 4.3.1; Figure 4.1, Chapter 7). However, unlike formal employment, activities in informal sector are subject to the external environment, over which individuals may have little control. For instance, agricultural projects are subject to physico-ecological conditions (weather effects and pest/diseases). Informal sector activities are also demanding in terms of multi-spatial, scarce raw material, with insecure work, and possibility of job loss. Even the creation and maintenance of intangible resources like social capital involves a range of duties, debts, claims, and obligations claimed during bad times as social insurance. As a result, certain months have high expenditure obligation and low income (section 3.3.62). It is this unpredictability in activities, as well as a number of opportunities and problems that gives predominance to the structural barriers.

Vulnerability studies indicate that the poor are exposed to a wide range of internal and external shocks, trends, and seasonality shifts that can be environmentally-based (droughts, floods and pests), economically-based (price fluctuation, wage variability, unemployment policies), socially-based (breakdown or reduction in community support and entitlements and norms), politically-based (changes in government policies, subsidies or prices, service provision), conflict derived (instability and rivalry), and health related (exposure to disease); (Adapted from Frankenberger et al. 2000). Certainly, the current (2011) global economic crisis, in combination with unstable rainfall patterns in parts of Uganda, may be having a negative effect on adherence to ARVs in the country.

Forgetfulness is often cited as a biomedical barrier, and indeed it is because it reflects cognitive demands, or difficult concentration, or loss of focus or control. Even in this study, forgetfulness has been recorded as one of the commonest barrier to medication dose. However, co-occurrence of forgetfulness with other adherence barriers in some months suggests that forgetfulness is a misrepresentation of actual adherence barriers, (Figure 3.1). Because forgetfulness is not an act of commission but an act of omission, mentioning forgetfulness exonerates patients from the impending provider penalties, for instance, being suspended from antiretroviral treatment. This reminds us that adherence barriers should not be taken at face value because some adherence barriers are mere symptoms representing something more fundamental.

**Reciprocal Relationship between Biomedical and Structural Barriers**

There are two types of relationships between biomedical and structural barriers. The first one is when biomedical barriers cause the emergence of structural barriers that undermine adherence to therapeutic activities (negative effect). For instance,
improved health condition, as a function of antiretroviral efficacy, (biomedical factors) creates opportunity for engagement in livelihood activities which subsequently may decrease adherence to the five therapeutic activities, including the medication dose itself. Ironically, the same potent medicine that liberates the patient from severe symptoms creates a condition for forgetting to swallow it.

On the other hand, biomedical factors can create a conducive environment for improved adherence to ART (positive effect). An improved health condition, as a function of antiretroviral efficacy, creates the opportunity for accessing material and non-material resources that facilitate adherence to treatment activities. However, the prospects for achieving economic productivity can be marginal, especially when the initial household asset endowment is small, accessing and adherence costs are prohibitive, and the external environment is un-conducive. With HIV/AIDS, fatigue due to immuno suppression, bothersome drug-side effects/opportunistic infection, and perpetual pharmacy refills tend to reduce economic productivity.

**Single Barriers Matter**

Lastly, a single or a combination of adherence barriers (biomedical or structural) can decrease adherence to one or all adherence activities (Table 3.13). This confirms the earlier assumption that a given barrier can act independently or interactively to affect the final adherence outcome. A close look at the relationship between adherence barriers and non-adherence to medication dose shows that any barrier that decreases concentration, detaches the patients from the pill-bottle, and lifts the patient from the medication environment will directly decrease adherence to the medication dose. Even if a patient has access to therapeutic resources (information, food, treatment supporter) but nonetheless lacks drugs, concentration, and an appropriate medicating environment, they would be more likely to miss the medication dose. Therefore, adherence to the medication dose is complex, and achieving the high levels of adherence that are needed to ensure good treatment outcomes is very demanding.

### 8.4 Factors Sustaining Adherence to ART

Evidence presented in Chapters 5, 6, and 7 suggest that it is necessary to distinguish adherence barriers from facilitating factors. Second, even with facilitating factors in place, there is a complex interaction between biomedical and environmental factors. Third, the facilitating factors occur at the individual, facility, community level, and beyond.
8.4.1 The Effect of Individual Level Factors

In this study three interrelated patient factors facilitate adherence to ART, namely; 1) previous health condition or condition factors; 2) patient intentions, and 3) adherence competencies.

1. Conditioning Factors

Patients who are subjected to prolonged, severe, and multiple symptoms before the introduction of new medicine are more likely to achieve optimal adherence to treatment. Conversely, asymptomatic chronic conditions like hypertension are more likely to record suboptimal adherence (cf. van Wijk (2006). However, not all symptomatic conditions cause commitment to life-long treatment. Commitment to life-long treatment comes about when the pre-treatment phase involved a wide range of costs. In this case, patients incurred three types of costs namely; condition related costs in the form of physical and emotional degeneration; economic costs in the form of recurrent health expenditure (medical bills); social costs in the form of social exclusion and stigma, and perpetual dependency on care-givers (Section 5.3.2 & 7.3.1). Patients who endured a long period of multiple and severe illnesses tend to fear retrogression to the previous health condition and the associated range of costs. As a result, such patients are more likely to be committed to the drug regimens.

In addition, the pre-treatment phase can be productive especially if a patient’s symptomatic condition generates informal therapeutic skills. Subsequently, pre-treatment therapeutic skills help patients to navigate and accommodate access and adherence costs, and cope with eventual opportunistic infections and/or drug side-effects that occur during the persistent phase (Chapters 5 & 6, sections 4.6.3 & 4.5.2).

The current social support process also originates in the pre-treatment phase. As the HIV/AIDS symptoms become visibly severe, the private experience with pain transforms into collective action attracting family-based social support, and generating community organisations (herbal groups and Christian communities), that later transform into facility-based lay patient social support system (section 7.6.2).

2. Adherence Competences

Besides patient commitment, knowledge matters. Psychologically-based studies, counselling guidelines, and theories\textsuperscript{52} allude to the role of information as predictors of adherence to ART. Even in the Uganda’s context there is a direct relationship

\textsuperscript{52} For instance; the Health Compliance Model (Heiby and Carlson 1986; Heiby et al., 2005; the role of cognitive accommodation (Fogarty et al 2002)
between information and optimal adherence. From the supply point of view, the information that is provided by health workers is complete because it addresses issues of substantive nature, especially the biomedical issues (what); it counteracts a wide range of prevailing adherence barriers and provides innovative solutions on how to maximise the available scarce resources in order to achieve optimal adherence (how); and it is instructive in pointing out the appropriate behavioural change that completes the adherence duty (what to do), (Section 6.3 & 6.4.1 & Table 6.2). In addition, information success is significant if the information challenges and eliminates the previous prejudices associated with the disease and gives creative solutions that build on the pre-treatment experience to produce a coherent body of knowledge.

A combination of pre-treatment patient experiences and the formal provider counselling generated three types of therapeutic skills that drive adherence among the patients in the two facilities, namely; theoretical skills, internal skills, and social skills.

1. **Theoretical skills** are reflected in the internalisation and mastering of the technical biomedical concepts to the extent of some patients becoming counsellors themselves.
2. **Internal skills** are reflected in personal commitment to a life-long treatment plan, behavioural changes, and overcoming adherence barriers.
3. **Social skills** are reflected in the ability to seek support from one's convoy of social networks, providing peer support, and overcoming stigma including self-disclosure.

Such therapeutic skills reduce the competence gap and the attendant professional dominance. According to Jones (1991:125) a *competence gap* comes about when the patient is perceived as lacking the medical knowledge of a doctor; and the patient’s ability to negotiate is low due to low levels of knowledge. The more knowledge the patient has over his condition and the clinical environment, the less power the physician can exercise.

The overall conclusion here is that: patients who previously gained sufficient knowledge about the disease, expect to have a good treatment outcome, and who are exposed to credible information, are more likely to manifest positive adherent behaviour.

### 3. Intentionality of Adherence Behaviour

Personal commitment and knowledge makes sense if a patient has motivation to comply with health action. Taking medicines religiously is not an instinctive response
to internal pain but is also a purposive action to achieve altruistic goals. Whereas there are multiple goals that drive adherence (Section 5.3.3), providing care and support to one’s dependants seems to be paramount (Table 5.9).

However, motivation to adhere to life-long medicines in order to be able to take of ones’ dependants is also a response to the external volatile environment that causes stress to patients. The nature and effect of the exogenous forces described above also negatively affect the individual unit of the society, particularly in the form of individual well-being. Defenselessness against external shocks (vulnerability) and weak social protection\textsuperscript{53} (entitlements) increase the motivation for self-protection. However, this is not to imply that individuals who own insurance coverage (in whatever form) are more likely to engage in risky behaviour and/or be less compliant to prescribed health action. Obviously, those who have strong social security have wider freedoms compared to their counterparts who do not have this. In resource-poor settings, governments lack resources, the markets are imperfect and locally organised action or kinship-based social protection arrangements are insufficient, while private charities are few (Munro 2002). Similarly, Narayan (2002:164) indicates that when everyone is affected by an event and resources are limited, and when the network is small and homogenous, kin ties may be of little assistance. Therefore, in this case, each pill-taking event is like buying a life assurance scheme, or investing money in a social security fund. Possibly, this might also explain why pill-fatigue and long periods of missing doses (drug holidays) did not feature prominently in this study.

At the community level, imperfect social protection leads to the emergence of community-based initiatives during times of epidemic that are intended to provide care and support to the people heavily affected (also see Illiffe 2006: pp99-111). At the household level, family members will consciously maintain their HIV-infected relatives on antiretroviral treatment because for it is cheaper to provide small support for a short time than to foster the deceased’s children over a long time (section 7.5.2). When fear of having to look after somebody’s orphans is absent, other justifications emerge. For instance, the loss of a close relative may also mean the loss of benefits accrued from reciprocity during normal times.

The nature of social support received indirectly improves adherence through what Byakiika (2004) calls the synergistic cycle created by the support. ART-treated

\textsuperscript{53} Social protection may be taken to refer to a set of benefits available from the state, market, civil society, and households, either individually or in combination. Such benefits are created with intentions of protecting individual, households and indeed whole community from exogenous shocks (Munro 2002).
individuals feel a responsibility to reciprocate the assistance received, which is only possible with preserved health and excellent adherence. Therefore, in this dimension, the character of the disease and social insecurity drive adherence to antiretroviral therapy.

8.4.2 Antiretroviral efficacy or HIV Treatment Efficacy?

Beyond the patient commitment, knowledge, and intentions, the treatment objects and the meanings that they generate also facilitate adherence. Arguably, all individual and collective processes that drive adherence revolve around antiretroviral efficacy. Antiretroviral efficacy plays a central role in adherence as reflected in a stream of benefits at individual and societal level accruing to the patients and the relatives, and the emergent social organising. The antiretroviral therapy leads to the emergence of actions, actors, and practices at the household, community, facility, and national levels.

Antiretroviral efficacy is associated with a wide range of meanings. If I may apply Whyte et al.’s (2002) typology of medicine and meaning to antiretroviral therapy, antiretroviral efficacy is capable of bringing about substantial and durable viral suppression, thereby restoring and preserving the immune function (pharmacological efficacy). ARVs also have the quality to generate supportive behaviour at various levels (social efficacy). Beyond these common meanings, ARVs also have ‘economic efficacy’, as reflected in the restoration of economic productivity, thereby freeing patients from impoverishment, dependence, and social exclusion; and giving opportunity to patients to continue accessing pharmacy refills. In that sense, Sjaak et al.’s (1989:348) concept of ‘liberating substance’ becomes more relevant.

Nevertheless, the antiretroviral efficacy is overstated. Antiretroviral therapy improves immunological response but it does not cure the patient. If untreated, opportunistic infections would still undermine adherence to antiretroviral therapy itself. A total antiretroviral efficacy comes about with the help of preventive therapies and the information given to patients. For instance, the introduction of ARVs did not displace the use of preventive prophylaxes (cotrimoxazole prophylaxis, multi-vitamins); or remove the need for psychosocial support and socio-economic support. In fact, Uganda’s treatment success is attributable to three intervention pillars namely; treatment, prevention, and social support. Failure to effectively implement each of

54 The field of ‘meaning’ is linked to present understanding of culture. As Cohen (1984) noted, the discovery of meaning lies not in the lexicon but in use. “In our search for meaning, then, we are not so much concerned with matters of fact or with some objective representation of reality, but with more elusive topics of perception, cognition and expression of reality”, (Cohen, 1984).
those components results in a trade-off on adherence. Therefore, it is better to talk of HIV/AIDS treatment efficacy rather than antiretroviral efficacy.

### 8.4.3 Social Support Process

One of the research questions has been to assess the extent to which social support processes facilitate adherence to ART. Chapter 7 has been devoted to analysing the recipients of social support, providers of social support, and the resources exchanged, as well as their potential influence on adherence to ART therapy. In resource-poor settings, the form of social support that facilitates access and adherence to ART is broader than the psychologically-based social support that takes place during the provider-patient interaction. Social support also is not recent but embedded in Ugandan society, and it precedes the antiretroviral phase. The key message in that Chapter is that the availability of a wide range of social support has been instrumental in facilitating access and adherence to ART.

However, the benefits produced by social support have been exaggerated. Evidence presented here indicates that severity of the HIV/AIDS condition attracted material and non-material social support, while with improved health condition, social support, including that from the Treatment Supporter is reduced. Social support is also given for selfish motives. Hence, in matters of chronic illness, the most feasible strategy for meeting the recurrent access and adherence costs is self-reliance and self-financing (Table 4.4). Full self-sufficiency can only be achieved when an HIV-patient gains access to meaningful economic activities.

### 8.4.4 Role of Health care Institutions

Arguably, by achieving high adherence in the face of weak systemic capacity (infrastructure, human resource, finance, and laboratory facilities), health facilities must have been somewhat innovative\(^5\) in providing the minimal adherence support required by their clients. Such a healthcare process is broader than the provider-patient relationship portrayed in most background adherence studies. These innovations have been in the area of implementation strategies and the quality of adherence support.

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\(^5\) Healthcare innovation is defined as the introduction of a new concept, idea, service, process, or product aimed at improving treatment, diagnosis, education, outreach, prevention and research, and with the long term goals of improving quality, safety, outcomes, efficiency and costs, Omachonu (2010:5). For business, organisations, and external relations, there are four types of innovation namely; product innovation, process innovation, organisational innovation, marketing innovation (UNESCO in Omachonu, 2010:5):
In terms of implementation strategy, the two different facilities in this study have used an ‘open system’ strategy to mitigate the health system capacity. With an ‘open system’, the administrative health system depends on the environment for inputs in order to produce outputs for the target population, (Olsen 1998:291). However, in varying degree and by using different methods, the two ART clinics have depended largely on external support to expand their infrastructures, diagnostic capacity, human resources, and financial resources (Mission). Nonetheless, the benefits accrued from the open system largely depend on the shared goal, transformation in internal management practices to accommodate resource inflow, as well as benevolence in the external environment to inject resources into the health system needing them. In Uganda transformation in healthcare services and stakeholder inclusion is not a recent innovation. The DAI programme launched by UNAIDS and the Government of Uganda in 1997 helped in setting up capacity and systems for HIV/AIDS prevention and treatment. From that time, accreditation of ART sites using comprehensive selection criteria reduces potentially provider induced adherence barriers.

Regarding human resource constraints, the two health facilities have depended on lay health workers to overcome human resource constraints as well as promoting adherence support. Patient participation in the HIV/AIDS is associated with several advantages, namely, an improved a sense of ownership, expanded voluntary counselling and testing, community-based adherence support, decrease in HIV-related stigma and so on.

The use of community-based approaches is not an entirely new practice. Community Health Worker Schemes was a key strategy in the delivery of Primary Health Care (PHC) in early 1980s, eventually collapsing in the 1990s mainly due to attrition. The difference in the two approaches lies in the problem being addressed, the implementation strategy, and the external environment. Community-based approaches can yield desired outcomes when the lay health workers are working on felt need as opposed to perceived need56. Second, providing a set of material and non-material incentives that improves volunteers’ health condition and economic well-being also improves community participation in a health activity. Third, there must be a conducive policy and institutional environment as well as a strong political commitment57. However, the adoption of a community-based approach does solve the long standing problem of shortage and motivation of the technical staff. The few and

---

56 With the ‘perceived need’ the solutions and strategies are often determined by the external community organiser, whereas with the ‘felt need’ the affected persons feel the obligation to serve independent of external pressure because of the intrinsic concern towards problem.

57 MOH (2004) HIV Care: Home Based Care Trainers Manual for Health Workers
poorly motivated technical staff have to work harder and for long hours to maintain adherence in face of rapidly expanding enrolment for treatment services.

The last process of innovation has been in the area of choice of healthcare services. With adequate funding and a wide volunteer base, the Mission Facility was in a better position to implement a holistic service, whereas the Public Facility that depends on meagre public funding and a small healthcare volunteer force only implemented the core services. However, the choice of the adherence activity profile did not have a significant difference on the adherence levels of patients in the two facilities.

**Quality of Adherence Support**

There are a wide range of adherence support measures that drive optimal adherence in the two facilities. Satisfactory adherence support might partly explain the similarity in adherence levels between these two different ART sites.

1. *Quality of Execution and Adherence Monitoring*

The quality of execution is satisfactory given the fact that the treatment initiation phase entails 7 provider-patient encounters (Table 3.2) and, subsequently, meeting at least once a month at pharmacy refill. As the Mission Facility has a stronger Management Information capacity (MIS) than the under-resourced public facility, and therefore it is in a better position to implement evidence-based intervention, the instrumentality about provider-patient interaction is giving instant feedback to patients about the clinical and adherence status, as well as designing personalised adherence strategies.

### 8.5 Conceptual Framework for Understanding Adherence to ART in Resource-poor Settings

Having presented the discussion above, this section reverts to the emerging conceptual framework for understanding adherence to ART in resource-poor settings. No single existing health model can accommodate the concepts and variables that have been identified above. The purpose of the adherence conceptual framework is to identify a structure of ideas (concepts and relationships) for understanding the adherence factors (*conceptualisation*), for guiding the design of research studies (*inquiry*), and for providing a linchpin for guiding practical interventions (*action*) in resource poor settings. This conceptual framework captures the patient, community, and facility processes.

As noted earlier, it is necessary to distinguish between biomedical factors and environmental factors, between the facilitating factors and the adherence barriers, and
between the different analytical levels (micro-meso-macro-global interactions), and between the adherence activities. The diagram is labelled to show such distinctions: label ‘E’ represents the external environmental factors that have an indirect effect on the adherence factors (both facilitating and impeding factors). Label ‘F’, represents the facilitating factors. Label ‘A’ is for adherence Activities where the if/then assumption becomes applicable. Label ‘B’ applies to the barriers.

The arrows show the anticipated relations between concepts (domains and/or mere concepts). A one end-point arrow indicates a one-directional relationship, and the two-end arrow points to a reciprocal relationship. There are two types of arrow end-points. A solid-dashed arrow shows a strong relationship, whereas a dotted arrow shows a weak/probable influence. In each box and between boxes there other interrelationships that can be further explored.
8.6 Theoretical Concerns Arising from the Study

The research findings presented here again confirm my earlier observation that the existing health models lack the working capacity (conceptual categories and hypotheses) to accommodate the initial theoretical argument, as well as the processes that support adherence in resource-poor settings. The individual behavioural models and the structural models have strong points and limitations (see section 2.2.2). However, it is beyond the scope of this research to generate a theory. Nonetheless, there are some key issues that merit mentioning.

First, the empirical findings and the discussion presented above show that human behaviour and decisions depend on multiple factors in a given situation. The situation itself can also vary considerably, to include both patient factors and external social processes. Helman’s (2011:106) distinction of internal context and external context becomes relevant at this level. The internal context relates to prior experience, expectations, cultural assumptions, models (individual background) that each brings to the table. An external context relates to the wider social influence acting on the provider-patient encounter. But, still, in this study, the wider context that influences adherence is not social per se but also physico-ecological, economic, and political. In most studies, physico-ecological factors (climatic changes, pests/disease/vermin) are not included because they are ‘a-social’.

Second, in understanding the various levels, anthropology and sociology of development has proposed useful analytical levels as micro, meso (intermediate level), and macro (national level), (Baer et al, 1986; Booth 1996). One difficulty in applying such an analytical framework is to demarcate where each level begins and ends. Social processes migrate between time and space. In this study, patients and their Treatment Supporters operate at the household level (micro) and facility level (meso), much as the providers operate at the facility and conduct outreaches at the household level. Drugs are manufactured as pharmacological objects at the global level but they travel and create meaning for life at the micro-level.

Third, in thinking of the adherence model, it is also important to take time into account. Adherence behaviour, social support process, and environment factors change over time, hence the use of pre-treatment phase, treatment execution, and persistence phase in this study (the second and third time-point are echoed in Urguhart et al. 2005)

Fourth, in matters of chronic illness in resource-poor settings, it is misleading to restrict the discussion to the provider-patient interaction. Multiple actors participate
in the health-seeking behaviour. The most relevant concept here is the therapy management group (coined by Baer et al. 1986). Because each member of the therapy management group possesses qualities of human action and consciousness with differential responses to similar structural circumstances, the Actor-Oriented Paradigm\(^{58}\) becomes applicable (cf. to Normal Long 1996). As soon as these actors spring into action, health-seeking behaviour ceases to be individual behaviour but rather a collective process of interaction, negotiation, and conflict (see the pre-treatment and treatment initiation processes).

Fifth, in terms of content, rather than relying on a handful of predictors to understand adherence, it is necessary to think of a complex interaction of multiple factors involving material and structural factors, operating in diverse meanings and contexts. A model for understanding adherence to antiretroviral therapy should be able to give explanation to four questions:

1. Who are those participating in the antiretroviral therapy?
2. Why are they participating in it?
3. What are they using (medicine field)?
4. Under what circumstances are they participating?

### 8.7 Recommendation for Sustaining Adherence to ART

My results suggest that the level of adherence support provided at the facilities needs to be rethought. The high level of social support provided at the Mission facility did not result in higher levels of adherence. Rather, the findings suggest that people are very committed to treatment and that lapses of adherence are related to structural factors. Also, the study suggests the type and amount of adherence support needed during initiation differ from the support needed during the persistence phase of treatment, and that social support tends to wane over time.

#### 8.7.1 Specific Recommendations

**Monitoring and Evaluation of the Clinical and Adherence Data**

The first level of adherence support would be to know the patient background in its entirety. At present, all the facilities in Uganda use the Ministry of Health HIV CARE/
ART CARD to capture patient data – some of these data were used in this study. However, the way the patient data are captured may not allow systematic statistical analyses (it is not coded) and it also leaves out socio-economic data. Therefore, it is necessary for the MOH to reformat the card template, as well as to strengthen facility management information systems.

**Pharmacy Refill and Adherence Measures**

There is a strong relation between efficient (timely) pharmacy refills and adherence to medication dose. What is required is the consolidation of the existing pharmacy refill best practices with the intention of maximising adherence, while keeping access-related costs affordable. This can be achieved through dispensing short-time beginners doses and longer-time doses for expert patients; longer-time doses during festive seasons; maintaining the practice of continuity doses after next refill dates; and tailoring pharmacy regimes to patients rhythm of livelihood activities.

The most effective strategy to ensure optimal adherence is not to stop patients from livelihood engagement but by being vigilant on the part of the provider and patients themselves. If lifting patients from the therapeutic environment causes non-adherence, it is important to identify patients’ cues for action, to ask patients to carry pill-bottles, to send them phone text messages as reminders (e-reminders), and to maintain strong adherence monitoring (at the facility and/or home levels). It is also essential to maintain a strong counselling and education approach during treatment initiation and throughout the treatment persistence phase.

**Economic Empowerment**

The current adherence mechanism is based on the assumption that Treatment Supporters are often supposed to be the sole bread winner. In reality, this is wrong. A well-planned designed micro-credit and small enterprise support can facilitate patients’ own economic empowerment, thereby improving self-financing. This will reduce overdependence on communitarian social capital.

**Health System Capacity**

The accreditation of ART treatment sites using elaborate criteria (clinical expertise, laboratories, psychosocial support, drug storage, and adequate management of opportunistic infections) by the MOH should be maintained.

The anticipated increase in demand for ART services might outgrow the existing system capacity, thereby compromising the quality of adherence support and adherence outcomes. Therefore, sustainability of current ART adherence levels
will depend on the ability of the health system to respond to such an expanded demand for services. As a recommendation, the health system should maintain an open system, drawing critical resources from the immediate environment. The community-based approach is an effective approach in mitigating human resource gaps. National government should also invest in expanding human resource base as well as motivating the staff. Effective implementation of all these measures requires a transformation in national level processes in terms of regular policy updating, as well as strengthening national and district level capacity for planning, implementation, and monitoring.

8.8 Methodological Challenges

This study targeted pioneer patients who had been on medication for more than six months, and who were therefore supposedly in their early persistence phase. Because of previous prolonged illness and several therapies (herbal, spiritual, preventive prophylaxes) tried, this group of patients had experienced a wide range of medication and coping strategies, through which they managed, in many cases to achieve optimal adherence to their ARVs. Adherence outcome presented here might have been different if this study had targeted neonatal HIV-infected adolescents, elderly people, or those patients who enrol for antiretroviral treatment when the CD4 cell count is still around 200 copies. In terms of location, perhaps, the adherence results could also have been different if this study was conducted in a hard-to-reach or remote rural area, or in a war-affected zone: as war and the effects of war have been reported to have an influence on adherence to therapies, even after the war has ended (WHO, 2003). The same source reported poor adherence among adolescents because they tend to struggle with self-esteem, body image, social role definition, and peer-related issues.
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Appendix

Table A.1: Typology for Assessing Sustained Adherence to HIV Treatment

<table>
<thead>
<tr>
<th>Domain Level (Structures)</th>
<th>Factors and Sub-Factors Level (Patterns)</th>
<th>Extraneous (Contextual and Intervening Conditions)</th>
<th>Adherence Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biomedical Factors</td>
<td>- Regimen</td>
<td>- Healthcare pathways and information available</td>
<td>Non-Adherence</td>
</tr>
<tr>
<td></td>
<td>- Disease condition</td>
<td>- Access related costs</td>
<td>Sub-Optimal</td>
</tr>
<tr>
<td></td>
<td>- Patient attributes</td>
<td>- Asset</td>
<td>Near-Optimal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Livelihood strategies</td>
<td>Optimal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Meanings</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Social climate</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Seasonality of services</td>
<td></td>
</tr>
<tr>
<td>Economic Burden of Treatment</td>
<td>- Financial costs</td>
<td>- Healthcare services</td>
<td>Non-Adherence</td>
</tr>
<tr>
<td></td>
<td>- Time costs</td>
<td>- Treatment duration</td>
<td>Sub-Optimal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Intra-household resource entitlements and decision making process</td>
<td>Near-Optimal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Coping strategies</td>
<td>Optimal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Meaning</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Seasonality</td>
<td></td>
</tr>
<tr>
<td>Assets Portfolio and Coping</td>
<td>- Human capital</td>
<td>- Vulnerability</td>
<td>Non-Adherence</td>
</tr>
<tr>
<td></td>
<td>- Social capital</td>
<td>- Healthcare Services</td>
<td>Sub-Optimal</td>
</tr>
<tr>
<td></td>
<td>- Financial capital</td>
<td>- Livelihood strategies</td>
<td>Near-Optimal</td>
</tr>
<tr>
<td></td>
<td>- Natural capital</td>
<td>- Institutional processes</td>
<td>Optimal</td>
</tr>
<tr>
<td></td>
<td>- Physical capital</td>
<td>- Treatment costs incurred</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Coping strategies, outcome and impact</td>
<td>- Household structure</td>
<td></td>
</tr>
</tbody>
</table>

Stages/Persistence Levels: Acceptance → Execution → Discontinuation
Players: Patient → Supporter → Facility
Resources: Financial → Human → Social support

Table A.2: Data for Seasonal Rainfall for Central Uganda (Amount of Rainfall in millimetres)

<table>
<thead>
<tr>
<th>Months</th>
<th>J</th>
<th>F</th>
<th>M</th>
<th>A</th>
<th>M</th>
<th>J</th>
<th>J</th>
<th>A</th>
<th>S</th>
<th>O</th>
<th>N</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount in millimetres</td>
<td>131.6</td>
<td>96.2</td>
<td>55.6</td>
<td>216.5</td>
<td>24.6</td>
<td>21.7</td>
<td>15.9</td>
<td>80.3</td>
<td>173.2</td>
<td>211.1</td>
<td>198.8</td>
<td>178.8</td>
</tr>
<tr>
<td>Days</td>
<td>9</td>
<td>6.5</td>
<td>10.3</td>
<td>16</td>
<td>5</td>
<td>6</td>
<td>2</td>
<td>5</td>
<td>15</td>
<td>16</td>
<td>14</td>
<td>11</td>
</tr>
</tbody>
</table>
Table A.3a: Road Access Rating

<table>
<thead>
<tr>
<th>Road Condition</th>
<th>Site</th>
<th></th>
<th></th>
<th>Total</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urban Facility</td>
<td>Rural Facility</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Poor</td>
<td>3.4% (3)</td>
<td>9.8% (11)</td>
<td>7.0% (14)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>70.5% (62)</td>
<td>21.4% (24)</td>
<td>43.0% (86)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>21.6% (19)</td>
<td>28.6% (32)</td>
<td>25.5% (51)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>4.5% (4)</td>
<td>39.3% (44)</td>
<td>24.0% (48)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Good</td>
<td>0.0% (0)</td>
<td>0.9% (1)</td>
<td>0.5% (1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Number</td>
<td>88</td>
<td>112</td>
<td>200</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table A.3b: Means of Transport Used

<table>
<thead>
<tr>
<th>Means of Transport</th>
<th>Site</th>
<th></th>
<th></th>
<th>Total</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urban</td>
<td>Rural</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foot</td>
<td>78.0% (110)</td>
<td>13.0% (16)</td>
<td>48.3% (126)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bicycle</td>
<td>0.7% (1)</td>
<td>7.5% (9)</td>
<td>3.8% (10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vehicle</td>
<td>2.8% (4)</td>
<td>44.2% (53)</td>
<td>21.8% (57)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motorcycle (Boda-Boda)</td>
<td>18.4% (26)</td>
<td>35.0% (42)</td>
<td>26.1% (68)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Number</td>
<td>141</td>
<td>120</td>
<td>261</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table A.4: Reasons for being Highly Committed to ART (Both Sites Combined) (n=262)

<table>
<thead>
<tr>
<th>Reasons for being Highly Committed to ART</th>
<th>n</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>You want to see your children grow and succeed</td>
<td>262</td>
<td>92%</td>
<td>6%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>ARVs are miracle pill that saved your life</td>
<td>262</td>
<td>86%</td>
<td>12%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Fear the Virus might cause severe damage to your health</td>
<td>262</td>
<td>84%</td>
<td>14%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>You do not want to look sickly</td>
<td>262</td>
<td>75%</td>
<td>19%</td>
<td>6%</td>
<td>.4%</td>
</tr>
<tr>
<td>You simply want to survive longer</td>
<td>262</td>
<td>74%</td>
<td>22%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Accepted your HIV status and whatever it takes to live</td>
<td>262</td>
<td>64%</td>
<td>36%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>You have ambitions for the future</td>
<td>262</td>
<td>62%</td>
<td>32%</td>
<td>5%</td>
<td>2%</td>
</tr>
<tr>
<td>You want to prove wrong to those who laugh at you</td>
<td>262</td>
<td>49%</td>
<td>26%</td>
<td>12%</td>
<td>13%</td>
</tr>
<tr>
<td>You are pleasing relatives and/or friends</td>
<td>262</td>
<td>33%</td>
<td>25%</td>
<td>20%</td>
<td>22%</td>
</tr>
<tr>
<td>Should live longer to enjoy your wealth</td>
<td>262</td>
<td>29%</td>
<td>21%</td>
<td>33%</td>
<td>2%</td>
</tr>
<tr>
<td>Health staff threatened to punish you if non-compliant</td>
<td>262</td>
<td>23%</td>
<td>15%</td>
<td>19%</td>
<td>44%</td>
</tr>
</tbody>
</table>

* Reasons rearranged according to percentage significance
**Technical Notice:** Psychologically-based ‘attitudinal questions’ are usually criticised as not producing accurate results and soliciting subjective desirable opinions. Whereas this may be true, here the validity of such attitudinal questions should not be judged by the quantitative scores per se but also by the qualitative reasons yielded.

**Table A.5:** Treatment Support Provider-Recipient Relationship

<table>
<thead>
<tr>
<th>Provider-Recipient Relationship</th>
<th>Facility</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mission</td>
<td>Public</td>
</tr>
<tr>
<td>Father to Son</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Mother to Son</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Son to Mother</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Daughter to Mother</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Son to Father</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Daughter to Father</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sister to Sister</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Brother to Sister</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Wife to Husband</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Husband to Wife</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>7</td>
<td>8</td>
</tr>
</tbody>
</table>

**Source:** Focus Group Discussion

**Table A.6:** Number of Staff by Department in Kayunga Hospital (Public Facility)

<table>
<thead>
<tr>
<th>Category of Staff</th>
<th>Number</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administrative Staff</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Doctor</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Allied Staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Dental</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>• Anaesthetic Officer</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>• Radiographer</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>• Laboratory Technologist and Assistants</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>• Dispenser</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>• Clinical Officer/Medical Assistants</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>• Orthopaedic Officer</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>• Psychiatric Officer</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>• Ophthalmologist</td>
<td>1</td>
<td>21</td>
</tr>
<tr>
<td>Nurses (Nurses, Midwives, Nursing Assistants)</td>
<td>80</td>
<td>80</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>109</td>
</tr>
</tbody>
</table>

**NB:** For Confidentiality No equivalent data from the Mission Facility was availed
# Sustaining Adherence to Antiretroviral Therapy among HIV/AIDS Patients in Uganda

## Table A.7: Comprehensive Healthcare Services in the Mission Facility

<table>
<thead>
<tr>
<th>Department</th>
<th>Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical Department</strong></td>
<td><strong>1. Counseling</strong> – Pre and post-test counselling, paediatric VCT, Discordant couple intervention, On-going counselling, peer-alcohol counselling, Grandmothers counselling <strong>2. Clinical Section</strong> – Client consultation, home visits for terminally ill and advanced age; referral for further investigation, admission, specialised services <strong>3. Adherence support unit</strong> – adherence to treatment, (ART, PMTCT&amp;TB), CD4 &amp; Viral load, PCTC <strong>4. Laboratory</strong> (CD4 count, biochemistry, hemoglobin concentration, hepatitis antigen are carried out at Mildmay, viral load testing is conducted in CDC lab at Entebbe <strong>5. Pharmacy</strong></td>
</tr>
<tr>
<td><strong>Community Support</strong></td>
<td><strong>1. Friends for Life</strong> which include; Good Samaritan for bed-ridden, Together for Life (young generation), Operation Gideon (adults), Adult Literacy program, Youth out of School (targeted messages), Post-test club <strong>2. Community Network of Care</strong> (CATTS), who hold monthly meeting to discuss with clients’ access and adherence challenges, Mother-to-Mother Community Supporters female CATTS making a follow up antenatal and postnatal clients, &amp; Teenager Community Supporter. <strong>3. Food for Health</strong></td>
</tr>
<tr>
<td><strong>Social Support</strong></td>
<td><strong>1. Bread for Life</strong> 2. Operations School Fees 3. Roses of Mbuya (Widow IGA)**</td>
</tr>
</tbody>
</table>

## Table A.8: Household Asset Ownership and Technical Notes

<table>
<thead>
<tr>
<th>Asset</th>
<th>Site</th>
<th>Total</th>
<th>Chi-Square Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urban</td>
<td>Rural</td>
<td>Total</td>
</tr>
<tr>
<td><strong>Information &amp; Communication</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radio</td>
<td>64% (91)</td>
<td>76% (91)</td>
<td>70% (182)</td>
</tr>
<tr>
<td>Clock</td>
<td>43% (61)</td>
<td>43% (52)</td>
<td>43 (113)</td>
</tr>
<tr>
<td>Watch</td>
<td>36% (51)</td>
<td>38% (45)</td>
<td>37% (96)</td>
</tr>
<tr>
<td>Cell phone</td>
<td>39% (56)</td>
<td>20% (24)</td>
<td>31% (80)</td>
</tr>
<tr>
<td>TV</td>
<td>23% (31)</td>
<td>14% (17)</td>
<td>18% (48)</td>
</tr>
<tr>
<td>Newspaper (once a week)</td>
<td>18% (26)</td>
<td>12% (14)</td>
<td>15% (40)</td>
</tr>
<tr>
<td>Telephone</td>
<td>7% (10)</td>
<td>9% (11)</td>
<td>8% (21)</td>
</tr>
</tbody>
</table>
Appendix

<table>
<thead>
<tr>
<th>Productive Assets</th>
<th>32% (45)</th>
<th>50% (59)</th>
<th>40% (104)</th>
<th>$\chi^2=8.298, df=1, p=.004$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plot of land</td>
<td>18% (26)</td>
<td>43% (51)</td>
<td>29% (77)</td>
<td>$\chi^2=18.339, df=1, p=.000$</td>
</tr>
<tr>
<td>Kiosk/shop</td>
<td>13% (18)</td>
<td>14% (17)</td>
<td>13% (35)</td>
<td>$\chi^2=.125, df=1, p=.724$</td>
</tr>
<tr>
<td>Rental Houses</td>
<td>11% (15)</td>
<td>15% (18)</td>
<td>13% (33)</td>
<td>$\chi^2=1.163, df=1, p=.181$</td>
</tr>
<tr>
<td>Sewing machine</td>
<td>11% (15)</td>
<td>3% (3)</td>
<td>7% (18)</td>
<td>$\chi^2=6.609, df=1, p=.010$</td>
</tr>
<tr>
<td>Commercial water</td>
<td>6% (8)</td>
<td>.8% (1)</td>
<td>3.4% (9)</td>
<td>$\chi^2=4.51, df=1, p=.034$</td>
</tr>
<tr>
<td>Wheel cart</td>
<td>3% (4)</td>
<td>.8% (1)</td>
<td>2% (5)</td>
<td>$\chi^2=1.367, df=1, p=.379$</td>
</tr>
<tr>
<td>Draught (plough &amp; ox)</td>
<td>1% (2)</td>
<td>.8% (1)</td>
<td>1% (3)</td>
<td>$\chi^2=190, df=1, p=.663$</td>
</tr>
<tr>
<td>Rickshaw</td>
<td>.7% (1)</td>
<td>.0% (1)</td>
<td>.4% (1)</td>
<td>$\chi^2=848, df=1, p=.357$</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quality of Life</th>
<th>79% (112)</th>
<th>79% (95)</th>
<th>79% (207)</th>
<th>$\chi^2=003, df=1, p=.954$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reliable water supply</td>
<td>69% (98)</td>
<td>68% (82)</td>
<td>68% (180)</td>
<td>$\chi^2=.14, df=1, p=.906$</td>
</tr>
<tr>
<td>Staying in a descent House</td>
<td>11% (16)</td>
<td>46% (55)</td>
<td>27% (71)</td>
<td>$\chi^2=39.334, df=1, p=.000$</td>
</tr>
<tr>
<td>Bicycle</td>
<td>33% (47)</td>
<td>16%</td>
<td>25% (19)</td>
<td>$\chi^2=10.288, df=1, p=.001$</td>
</tr>
<tr>
<td>Electricity Supply</td>
<td>3% (4)</td>
<td>9% (11)</td>
<td>6% (15)</td>
<td>$\chi^2=4.858, df=1, p=.028$</td>
</tr>
<tr>
<td>Motorcycle</td>
<td>.7% (1)</td>
<td>.8% (1)</td>
<td>.8% (2)</td>
<td>$\chi^2=014, df=1, p=.905$</td>
</tr>
<tr>
<td>Vehicle</td>
<td>8% (11)</td>
<td>2% (2)</td>
<td>5% (1)</td>
<td>$\chi^2=5.098, df=1, p=.024$</td>
</tr>
</tbody>
</table>

N.B: Descent House refers to cement, brick, Iron roof

In terms of information and communication, a large (70%, 182) proportion of households had access to a radio set, with almost equal access at both sites (urban 64%, 91 and rural 76%, 91). In terms of quality of life indicators, quantitative results indicated that, in both study sites, a large proportion (79%, 207) of HIV-patients belonged to households with reliable sources of water (urban 79%, 112 and rural 79%, 95); and a large proportion (68%, 180) stayed in semi-permanent housing [iron roof and plastered] (urban 69%, 98 and rural 68% 82). Though, by means of a separate question, results also revealed that half (56%, 78) of the respondents in the urban setting came from a one-roomed house. Only a small proportion of households had access to a bicycle, electricity supply, a vehicle, and a fridge, with the level of access and/or ownership under 27%. In terms of transport utilities, a statistically significant number of rural patients came from households with a bicycle (45.8% N55 vs 11.33% N26; $\chi^2=39.334 df=1, p=.000$).

In terms of productive assets, less than 40% (both combined) had access to productive land, a plot of land (≤0.25 acres), On the other hand, rural-based households were more likely to have access to land (49% N59 vs. 32% N45 $\chi^2=8.298, df=1, p=.004$), or a plot of land (43% 51 vs. 18.3% 26; $\chi^2=18.339, df =1, p=.000$). However, the economic return from such land was likely to be marginal since, as revealed by a separate question, three-quarters (urban 69%, 11 and rural 76%, 55) of respondents indicated that the majority of economic activity on their land consisted of subsistence.
farming. With both urban and rural respondents having access to land the earlier findings (Chapter 3) that the intensity of seasonal agricultural activities tend to disrupt adherence to antiretroviral treatment activities is confirmed.

**Technical Notes A.9**

The independent variables tested included: Type of study site ($p=.741$), gender ($p=.296$), marriage (married and unmarried; $p=.115$), place of residence (rural and urban; $p=.920$), ever suffered from risk/shocks ($p=.340$), household having access to regular sources of income ($p=.776$), (having) number of confidants [1-3 & 4-5+] ($p=.546$), receiving access to care and support ($p=.243$), type of regimen (single pill and multiple pills; $p=.340$), changes in health conditions after being on treatment for some time ($p=.595$), having orphans in a home ($p=.352$), ever used herbal medicine ($p=.771$), pre-antiretroviral being the highest health expenditure ($p=.430$), self-disclosure of HIV/AIDS condition ($p=.114$), number of people disclosed ($p=.943$), whether duration of taking septrin/herbal medicine influenced drugs ($p=.136$), satisfied with amount of information received ($p=.726$), quality of care received ($p=.585$), satisfaction with quality of Treatment supporter ($p=.348$), satisfaction with quality of community-based Treatment Supporter ($p=.885$), number of people in a home who are HIV positive ($p=.009$), having members contributing to health expenditure ($p=.574$), incurrence of health expenditure whenever coming to the facility ($p=.547$), travel time to reach the health facility ($p=.808$), distance covered to the facility ($p=.337$), mode of transport used ($p=.939$), whether ever benefited from food aid ($p=.730$), whether ever benefited from income aid ($p=.206$) etc.

**Figure A.1: Changes in WHO Clinical Stages by Quarter. (Both Sites Combined)**

![Figure A.1](image)

**NB:** 6th Qtr+ includes marginal figures for subsequent quarters
Figure A.2: HIV Diagnosis by Age Group in Public Facility

![Figure A.2: HIV Diagnosis by Age Group in Public Facility](image1)

Figure A.3: Eligibility for ART by Gender and Age in Kayunga Public Hospital

![Figure A.3: Eligibility for ART by Gender and Age in Kayunga Public Hospital](image2)

Source: Health Unit Annual Report 2007 and 2008 reproduced with permission from the hospital authority. NB: No equivalent data from the Mission Facility was obtained.
SM.1: HIV/AIDS Treatment Pathways in the Public Facility

STAGE I
1. Ascertain the HIV status; Open the file and take patient's bio data and disease history (WHO clinical stage of disease, weightings, and ascertain).
2. Based on patients complaints provide appropriate treatment or refer to Doctor or Clinical Officer.
3. Give Septrin Prophylaxis for stage 2 and above.
4. Refer for CD4 Check on Friday and other Chemistry.

STAGE II
1. Check BP, and Weight.
2. Record patient complaints, and provide the relevant treatment, if needed.
3. Study the CD4 count, if the CD4 cell count is below 2000, refer the patient to adherence counselling.
4. Take PRR or VDR test for syphilis – refer to the clinical officer, prescribe, or exempt. Take liver function test, refer to the doctor for treatment or exempt.

STAGE III
1. Adherence Counselling.
2. Collect all necessary information especially about side-effects.
3. Discuss the importance of adherence (using adherence information).
4. Start treatment depending on weight (and height for children)
5. Prescribe more Septrin prophylaxis (Treatment of the anticipated).
6. Take note of TB status.

STAGE IV
1. Patient on ART
   - Take weight, BP etc (Height for children)
   - Refer to the Clinical Officer/doctor/nurse for refill
   - Do pill count and ascertain adherence level. If discrepancy is noted send the patient for more counselling.
2. Set another appointment for refills, ensure that proper documentation of appointment is made, bearing in mind that the remaining pills and the...
re-supply take the patient till that date. But avoid follow-up dates with a big pill load.

**SM.2: Exploratory Qualitative Interviews**

**SUSTAINING ADHERENCE TO ANTIRETROVIRAL THERAPY UNDER ROUTINE CONDITIONS IN UGANDA**

**Exploratory Qualitative Studies: Patient Interview Guide**

1. Tell me about your life history from infant to adulthood
2. Tell me how you came to know that you had the virus and coping with it
3. How about the decision and process of seeking health services
4. Tell me about the costs involved in seeking HIV/AIDS treatment, and how you coped with such costs
5. Tell me about your daily activity (daily calendar)
6. Can you tell me about your sources of support?
7. What do you think of the future?

**SM.3: Health Staff Interviews**

**SUSTAINING ADHERENCE TO ANTIRETROVIRAL THERAPY UNDER ROUTINE CONDITIONS IN UGANDA**

**Assessment of Quality of Healthcare: Interview Guide**

**Aim:** To identify the contextual factors that are likely to influence adherence and sustainability of treatment between private and public providers.

**Key Informants:** Doctors, Clinical Officers, Nurses, Counsellors/Community Healthcare Volunteers, Pharmacists, and Administrative staff.

**Source of Information:** Records and health staff.

**Procedure:** Introduce the overall objective of the PhD program and the interview.

**Record:** The Name of the respondents and his/her position and responsibility.

1. **Historic Context of the Program**
   - Program objectives (NGO), or mandate (Public Facility), of the HIV/AIDS project.
   - Factors that inspired the intervention.
2. Biomedical Factors

- Composition of the clientele – age, gender, residence, marital status, number of years on treatment, treatment support-aided, lost to follow-up.
- Clientele biomedical characteristics – number of patients by various line of treatment, number of persons by single and multiple doses, HIV/AIDS, opportunistic infections and side effects profile.
- Regimen characteristics – type of ARVs dispensed and respective medical considerations, regimen side effects and remedial actions.
- Type of tests done – when, where, how often and the charges.

3. Adherence Factors

- Professional definition of adherence – dosage, multiple dose, scheduling and dosing interval, dietary instructions, appointments.
- Tools for measuring adherence and their perceived limitations.
- Adherence trends and current rating – significant, sub-optimal, and non-adherence (obtain adherence statistics if available).
- Factors influencing adherence – socio-demographic characteristics, personality traits, nature of regimen, treatment support, stigma, clinical conditions, information, costs, longevity of treatment, seasonality factors, other contextual factors.
- Strategies intended to elicit or enforce significant adherence, and the potential or actual challenges.

4. Role of Quality of Healthcare

- Technical competence – level of staffing, knowledge and skills, training and refresher courses attended.
- Pathways and sequencing of counselling and the expected outcome of each phase – pre-test, post-test, ARV initiation, refill, and follow-up.
- Amount of information provided and the counselling techniques – physical contact, drama, spiritual health, simplification of technical terms.
- The level of health infrastructure and its effect on delivery of services and adherence inducement.
The appropriateness and constellation of services and its potential effects on patients’ livelihood outcome and adherence – medical care and nursing, socio-economic support, psychosocial support, human rights.

Follow-up and continuity mechanism – drug refill management, monitoring and evaluation through clinic-based and community-based approaches of adherent patients, non-adherent patients, failed reporting cases, referral options.

Organisational culture – organisational values, management style, teamwork, communication style, coordination, networking, patient-patient interaction, patient empowerment to act and react.

5. **Health Staff Perception of Treatment Burden**

- Charges for blood tests and services – blood tests, CD4 count, viral load, lymphocytes.
- Perceived income and production loss on part of patients and treatment supporters – treatment and refill waiting time and costs.
- Effects of improved health conditions on consumption tendencies – improved appetite.
- Effects of improved health conditions on person’s productivity (positive effects).
- Health facility-based treatment burden mitigation measures – appropriateness and constellation of services and subsidy through home-based follow-ups.
- Patients’ coping mechanisms.

6. **Structural Problems**

- Have you ever experienced stock-outs in the past three months?
- If yes, what drugs were out of stock? What caused such a problem? What did you do about it?

7. **Activity: Tour and Observation of the Facility**

- Departments/desk attending to the ARV users and those coming for refill.
- Staff-patient ratio.
- Average number of hours worked.
- How can the delivery of services be improved?
SM.4: Survey Questionnaire

SUSTAINING ANTI-RETROVIRAL TREATMENT IN RESOURCE-POOR SETTINGS UGANDA

Questionnaire for Patients Taking ART

SECTION ONE: SOCIO-DEMOGRAPHIC CHARACTERISTICS

ARV Site

1.1 Name of the Head of the Household __________________

1.2 Age ___________________

1.3 Gender
   1. Female
   2. Male

1.4 Marital Status
   1. Never Married
   2. Married Monogamous
   3. Married Polygamous
   4. Separated/Divorced
   5. Widow/Widower
   6. Other

1.4b) If polygamous, how many wives/co-wives? _________________

1.5 What is the household structure and characteristics?

<table>
<thead>
<tr>
<th>a) Initials of the members of Hsh including self</th>
<th>b) Age in complete years</th>
<th>c) Gender 1. Male 2. Female</th>
<th>d) Relationship to the head of Hsh (Insert codes below)</th>
<th>e) Education (Insert codes below)</th>
<th>f) Hsh member attending school? 1. Yes 2. No</th>
<th>g) Employment status Employed Unemployed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Transfer these codes into the table cells

**Education Codes**


**Status Codes**

1.6 Place of residence (CR6)
   1. Rural
   2. Urban
   3. Landing site

SECTION TWO: HOUSEHOLD ECONOMY

Vulnerability
2.1 Have you suffered any risk, shock, or misfortune in your household/community over recent years? (probe natural/man-made)
   1. Yes
   2. No
2.2 If yes, which one
   a) Type of risk and shock
   b) What strategies were adopted

<table>
<thead>
<tr>
<th>a) Type of risk and shock</th>
<th>b) What strategies were adopted</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Physical and Natural Assets
2.3 Do you have any of the following items in your home that are functional? (Multiple responses)

<table>
<thead>
<tr>
<th>a) Info &amp; communication</th>
<th>b) Productive Assets</th>
<th>c) Quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. TV</td>
<td>2. Ox and Plough</td>
<td>2. Motorcycle</td>
</tr>
<tr>
<td>5. Clock</td>
<td>5. Kiosk/shop</td>
<td>5. Electricity supply</td>
</tr>
<tr>
<td>7. Phone</td>
<td>7. Land</td>
<td>7. Staying in a descent house</td>
</tr>
<tr>
<td></td>
<td>8. Plot of land (less than an acre)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9. Rental house</td>
<td></td>
</tr>
</tbody>
</table>

2.4 If own land, what productive activity is on that land? ________________________
2.5 How many rooms is the household occupying? ________________________

Financial Assets
2.6 What are the usual household expenditures?
### a) Household Expenditure?

<table>
<thead>
<tr>
<th>Probe</th>
<th>b) Amount</th>
<th>c) Frequency</th>
<th>d) Source of Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food, beverages and tobacco</td>
<td>(Free of charge Use Code 99)</td>
<td>1. Daily</td>
<td>1. Salary</td>
</tr>
<tr>
<td>Non-durable goods frequently purchased</td>
<td></td>
<td>2. Weekly</td>
<td>2. Wages</td>
</tr>
<tr>
<td>Semi-durable and durable goods and services</td>
<td></td>
<td>3. Monthly</td>
<td>3. Organisation</td>
</tr>
<tr>
<td>Non-consumption expenditure</td>
<td></td>
<td>4. Half yearly</td>
<td>4. Assistance</td>
</tr>
<tr>
<td>Household and enterprise asset</td>
<td></td>
<td></td>
<td>5. Borrowed</td>
</tr>
</tbody>
</table>

### b) Amount (Free of charge Use Code 99)

#### c) Frequency
- 1. Daily
- 2. Weekly
- 3. Monthly
- 4. Half yearly

#### d) Source of Income
- 1. Salary
- 2. Wages
- 3. Organisation
- 4. Assistance
- 5. Borrowed
- 6. Other (specify)

### 2.7 Do you members of the household have access to regular sources of income?

1. Yes  
2. No

### 2.7b What are the various sources of income for the household?

<table>
<thead>
<tr>
<th>a) What is the Hsh sources of Income</th>
<th>b) Who participates in that activity (Transfer the code)</th>
<th>c) Income?</th>
<th>d) Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be guided by probing 2.6(d) above</td>
<td>Head</td>
<td>1. Daily</td>
<td>1. Daily</td>
</tr>
<tr>
<td>Expenditure = income</td>
<td>2 Spouse</td>
<td>2. Weekly</td>
<td>2. Weekly</td>
</tr>
</tbody>
</table>

1. Agriculture  
2. Self-employment  
3. Salary employment  
4. Wage employment  
5. Assistance/begging  
6. Loan  
7. Transfer (pension, social security, remittances)  
8. Profits (dividends, interest, rental)  
9. Other (specify)

### Social Capital and Social Support

2.8 Do some household members leave and return home after 3 months?

1. Yes  
2. No

---

203
2.9 If yes, reason for migration

2.10 Do you have close friends and/or relatives you feel at ease with and talk to about personal life, including health problems?
1. Yes 2. No

2.11 If yes, how many? ________________

2.12 Can we talk more about your confidants, please tell me? *(Transfer the code)*

<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
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</tr>
</tbody>
</table>


2.13 Do you usually receive care/assistance/support from those confidants?
1. Yes 2. No

2.14 If yes, what it?

<table>
<thead>
<tr>
<th>a) Form of Assistance or Support (Specify 2, 3)</th>
<th>b) Relationship (Insert Codes, use 2.12 Codes)</th>
<th>c) How regular? 1. Always 2. Occasional 3. Rarely</th>
<th>d) Are you happy with that kind of assistance? 1. Yes 2. No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Financial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Material</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Practical support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Advice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Spiritual support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Emotional</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Compliments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Social network</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Food</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2.15 Do you give anything in return?
1. Yes 2. No
2.16 If yes, what assistance? ____________________________________________

2.17 Do you belong to any association?
   1. Yes  2. No

2.18 What form of assistance do you get? ________________________________

SECTION THREE: ADHERENCE FACTORS [Most info will be extracted Clinical Records]

Adherence Characteristics

3.1 When did the patient start ART treatment? ____________________________

3.2 What has been the patient adherence to VCT dates (see CR)

<table>
<thead>
<tr>
<th>a) Types of Compliances</th>
<th>b) Expected</th>
<th>c) Reported</th>
<th>d) Reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date for seeking VCT/diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date returned for CD4 test</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date picked CD4+ results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date returned for 1(^{st}) counselling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date returned for 2(^{nd}) counselling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date returned for 3(^{rd}) counselling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date started ARVs</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.3 Type of regimen (see CR26)
   1. Triomune  2. Multiple (PEPFAR)

3.4 What is the client’s treatment history? (see RCR 11)
   1. Interrupted  2. Continuous

3.5 If interrupted, why? ________________________________________________

3.6 Client ever been switched from one ARVs to another? (see CR27)
   1. Yes  2. No

3.7 If yes, why? ________________________________________________________

3.8 Client ever been discontinued? (see CR30)
   1. Yes  2. No

3.9 If yes what were the reasons? (Probe) ________________________________
Table: Reasons for discontinuation

3.10 Has the client ever missed a refill appointment? (CR 32)
1. Yes  
2. No

3.11 If yes, indicate (see CR32)

<table>
<thead>
<tr>
<th>a) Date Expected</th>
<th>b) Actual Date of reporting</th>
<th>c) Actual Days Missed</th>
<th>d) Reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.12 Have you ever forgotten taking pills on time? (can be before time or lately)
1. Yes  
2. No

3.13 If Yes

<table>
<thead>
<tr>
<th>a) Expected pill taking time</th>
<th>b) Actual time s/he took the pills</th>
<th>c) Time difference in hours</th>
<th>d) Reasons for missing the scheduled time</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.14 According the respondent has s/he ever skipped taking ARV dose on any given day?
1. Yes  
2. No

3.15 According to records, has the patient ever skipped taking ARVs dose? (CR 33)
1. Yes  
2. No

3.16 If yes, reasons

<table>
<thead>
<tr>
<th>a) Date</th>
<th>b) Type of ARVs</th>
<th>c) Total Pills prescribed</th>
<th>d) Actual Number Taken</th>
<th>e) Reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Multiple 2. Max/Triomune</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Codes

1. I was too sick  
2. Was feeling better  
3. Side effects  
4. I was too busy  
5. Disgusted with the pill  
6. Attending a social event  
7. Vomited  
8. Attending a burial  
9. Forgot  
10. Misplaced medicine  
11. Was sharing medicine  
12. Can’t tell  
13. Ran out medication  
14. Lacked accompanying food  
15. Run out money/transport  
16. Facility out of stock  
17. Lost the pills  
18. Went to the village
3.17 Has the patient ever taken an extra dose (CR 33)?
1. Yes  2. No

3.18 If yes, reasons for taking extra pills

<table>
<thead>
<tr>
<th>a) Type of regimen</th>
<th>b) Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.19 How committed are you in taking ARVs for life?
1. Highly committed  2. Fairly committed

3.20 Why that level of commitment?

3.21 Have you ever taken your ARVs before taking food (if not recommended)?
1. Yes  2. No

3.22 If yes, what were the causes? _______________________________

3.23 How many times do you take the following types of food in a fortnight?

<table>
<thead>
<tr>
<th>a) Food item (Read out and circle the code)</th>
<th>b) Number of times</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Yes, number of times</td>
</tr>
<tr>
<td></td>
<td>2. Rarely</td>
</tr>
<tr>
<td></td>
<td>3. Never</td>
</tr>
<tr>
<td>1. Meat</td>
<td></td>
</tr>
<tr>
<td>2. Eggs</td>
<td></td>
</tr>
<tr>
<td>3. Milk</td>
<td></td>
</tr>
<tr>
<td>4. Fish (Mukene)</td>
<td></td>
</tr>
<tr>
<td>5. Beans</td>
<td></td>
</tr>
<tr>
<td>3. Fruits</td>
<td></td>
</tr>
<tr>
<td>5. Vegetables</td>
<td></td>
</tr>
</tbody>
</table>

Disease Conditions

3.24 What have been changes in weight since he started treatment? (CR13, use the last page)

3.25 What have been changes in patient function? (CR 14, last page)

3.26 What have been changes in WHO clinical stage? (CR15, last page)

3.27 What have been the changes in CD4 count? (CR 25)?

<table>
<thead>
<tr>
<th>a) Dates</th>
<th>b) CD4 count</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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3.28 What opportunistic infections have you ever suffered from since you started treatment? (CR Q24)

<table>
<thead>
<tr>
<th>a) Opportunistic infection</th>
<th>b) Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Zoster</td>
<td></td>
</tr>
<tr>
<td>2. Pneumonia</td>
<td></td>
</tr>
<tr>
<td>3. Demential/Encephalitis</td>
<td></td>
</tr>
<tr>
<td>4. Thrush (Oral/vagina)</td>
<td></td>
</tr>
<tr>
<td>5. Ulcers (Mouth/genital)</td>
<td></td>
</tr>
<tr>
<td>6. Fever</td>
<td></td>
</tr>
<tr>
<td>7. Cough</td>
<td></td>
</tr>
<tr>
<td>8. Difficult Breathing</td>
<td></td>
</tr>
<tr>
<td>9. IRIS</td>
<td></td>
</tr>
<tr>
<td>10. Weigh Loss</td>
<td></td>
</tr>
<tr>
<td>11. Other (specify)</td>
<td></td>
</tr>
</tbody>
</table>

3.29 Do you get discouraged in taking ARVs because of the OI?

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
</tbody>
</table>

3.30 Why

______________________________

3.31 Have you ever suffered from side effects since you started ART treatment? (CR 31)

1. Yes  
2. No (Skip to Q 3.34)

3.32 If yes, which ones?

<table>
<thead>
<tr>
<th>a) Side effects</th>
<th>b) Dates</th>
<th>c) How bad were the side effects?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1. Severe</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Moderate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Mild</td>
</tr>
<tr>
<td>1. Rash</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Diarrhoea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Headache</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Abdominal pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Nausea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Burning/numb/tingling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Fatigue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Anaemia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Jaundice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Fat changes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Anxiety/ depression/confusion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Other (Specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.33  Do you get discouraged in taking ARVS because of those side effects?

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
</table>

3.34  Why? ____________________________________________

3.35  How do you evaluate your health conditions after being on treatment for some time? (confirmatory question)

1. Excellent  
2. Very Good  
3. Good  
4. Bad  
5. Worse  
6. Worst

**Individual Circumstantial Factors**

3.36  Do you have orphans in your household?

1. Yes  
2. No (Skip to Q3.38)

3.37  If yes, what is their survival status?

<table>
<thead>
<tr>
<th>No. of orphans</th>
<th>a) Both parents dead</th>
<th>b) Only mother alive</th>
<th>c) Only father alive</th>
<th>d) Don’t know survival status</th>
</tr>
</thead>
</table>

3.38  Have you ever used herbal medicine prior to ART treatment?

1. Yes  
2. No (Skip to Q 3.40)

3.39  If yes, for how long? __________ (years)

3.40  What was the most compelling reason for taking HIV test?

1. Curiosity  
2. To get married  
3. Lost a partner  
4. Lost a child/parent  
5. Recurrent illness  
6. Spouse post-test results  
7. Other

3.41  What illness bothered you most before taking up ARVs (include TB CR 16)?

<table>
<thead>
<tr>
<th>a) Illnesses</th>
<th>b) Duration in months</th>
<th>c) Severity of condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td>1. Active</td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td>2. Ambulatory</td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td>3. Bedridden</td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.42 If you can recall, what was the highest health expenditure you incurred prior to ART treatment? ___________________ Shs

3.43 How do you rate your daily activity schedule before and after being on ART for some time? (Insert the codes)

<table>
<thead>
<tr>
<th>a) Before ART</th>
<th>b) After ART</th>
<th>c) Reason to account for that trend</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Light work</td>
<td>5. None</td>
<td></td>
</tr>
</tbody>
</table>

3.44 On the dosing hour, what reminds you to take your ARVs? ___________________

3.45 Have you ever disclosed to anyone about your HIV/AIDS status?
1. Yes  
2. No (Skip to Q 3.47)

3.46 If yes, to how many people? ____________

3.47 If No why? ___________________________________________

3.48 For how long did you take Septrin before being initiated on ARVs? (CR 12 & 19)

<table>
<thead>
<tr>
<th>a) Commencement date (d/m/y)</th>
<th>b) ART date (d/m/y)</th>
<th>c) No. of days</th>
</tr>
</thead>
</table>

3.49 Do you think that that period of taking Septrin and/or herbal medicine must have influenced you in taking ARVs?
1. Yes  
2. No

3.50 Either y/n, why? ___________________________________________

3.51 State whether you agree or disagree on the following statements? (Read out the statements but not the responses)

<table>
<thead>
<tr>
<th>You are committed to ART treatment because:</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Health staff threatened to punish you if do not take ARVs as recommended</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Fear the virus might cause severe damage to your health</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. ARVs are miracle pill that saved your life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. You accepted your HIV status and whatever it takes to live</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. You have ambitions for the future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
6. You simply want to survive longer
7. You are pleasing relatives and/or friends
8. You want to see your children grow and succeed
9. Should live longer to enjoy your wealth
10. You do not want to look sickly
11. You want to prove wrong those who laugh at you

Programmatic Factors

3.52 Were you satisfied with the amount of information you received on ART counselling?
   1. Extremely satisfied
   2. Satisfied
   3. Somewhat satisfied
   4. Dissatisfied

3.53 What is your comment on the quality of care and support you receive whenever you come for the HIV clinic?
   1. Extremely High
   2. High
   3. Average
   4. Low
   5. Negligible

3.54 How do you evaluate the support given to you by the treatment supporters?

<table>
<thead>
<tr>
<th>a) Personal Treatment Supporter</th>
<th>b) Community-based Treatment Supporter (CATTS for Mbuya Reach Out)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Extremely High</td>
<td>1. Extremely High</td>
</tr>
<tr>
<td>2. High</td>
<td>2. High</td>
</tr>
<tr>
<td>3. Average</td>
<td>3. Average</td>
</tr>
<tr>
<td>4. Low</td>
<td>4. Low</td>
</tr>
<tr>
<td>5. Negligible</td>
<td>5. Negligible</td>
</tr>
</tbody>
</table>

SECTION FOUR: ECONOMIC BURDEN OF ART TREATMENT

Direct Cost

4.1 How many people in your household are HIV positive? (CR 8)________

4.2 Do household members contribute to your healthcare expenditure?
   1. Yes
   2. No

4.3 Why?________________________

4.4 Do you incur health expenditure whenever you come to this facility?
   1. Yes
   2. No (Skip to 4.6)

4.5 If yes

<table>
<thead>
<tr>
<th>a) Type of item you spent? (Probe: medical and non-medical including transport and food requirement)</th>
<th>b) Amount in Ushs</th>
<th>c) Source of funding?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.6 If no, how do you avoid incurring health expenditure? __________________________

4.7 How much do you spend on that food on a weekly basis (relate it with 4.5 above)?

<table>
<thead>
<tr>
<th>a) Type of food? (Probe: food, fluid, milk, greens, fruits)</th>
<th>b) Number of days buys that food in a week</th>
<th>c) Average cost per food item</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Indirect Burden**

4.8 What is the condition of the road that you normally use when coming to this [ART] health facility?


4.9 For a return journey, tell me about the distance, transport cost, and travel time to this health facility.

<table>
<thead>
<tr>
<th>a) Travel time taken</th>
<th>b) Distance covered</th>
<th>c) Mode of transport used</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1. Foot</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Bicycle</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Vehicle</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Boda</td>
</tr>
</tbody>
</table>

4.10 How many hours do you spend here in picking your ART pills? __________________________

4.11 Do you forego income whenever you come to the clinic?

1. Yes  2. No (Skip to 4.13)

4.12 If yes, how much? __________________________

4.13 If no, why? ___________________________________________
**Coping Strategies**

<table>
<thead>
<tr>
<th>a) Q4.14 Since you started ART, have you ever</th>
<th>b) Yes</th>
<th>c) No</th>
<th>d) Reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Foregone <strong>minimum</strong> basic necessities in order to allocate resource to ART treatment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Forced to sale household property in order to raise money for accessing and utilising ART services?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Borrowed money in order to meet the ART expenses?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Postponed implementation of plans due to ART recurrent expenses?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Cancelled attending social obligations due to fear of skipping a dose?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Lived elsewhere and returned in order to have easy access to ARVs?</td>
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<tr>
<td>7. Sometimes take medicines on an empty stomach due to scarcity of food?</td>
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</table>

**Quality of Healthcare**

4.15 Have you ever benefited from the following services?

<table>
<thead>
<tr>
<th>a) Services</th>
<th>b) Yes</th>
<th>c) No</th>
<th>d) How many times?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Food</td>
<td></td>
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<tr>
<td>2. Loan Scheme</td>
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<td>3. Orphan support</td>
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<tr>
<td>4. Income generating activity</td>
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4.16 If ever acquired a loan, how did you utilise that loan?

______________________________

4.17 With or without such assistance would you still be committed to your ART treatment?

1. Yes  2. No

4.8 Why? ___________________________________________________________

______________________________

THANK YOU
### Q 3.25 WEIGHT

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**Reasons**

### Q 3.26 FUNCTION


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**Reasons**

### Q 3.27 WHO CLINICAL STAGE

1, 2, 3, 4,

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<tr>
<th>Date</th>
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Summary

This thesis is the product of a PhD project, entitled ‘AIDS Medicines in Resource-Poor Settings: Learning from District Level Transformations in Health Cultures and Arrangements in Uganda and South Africa’ (2004), funded by the Dutch Foreign Ministry. The generic proposal consisted of national, district, and community clusters. In particular, this PhD is located in and contributes to the cluster of ‘community level transformations and effects’. The objective of this cluster was to formulate best practices for introducing antiretrovirals (ARVs) in resource-poor settings, and to develop a generic model for implementing pragmatic ARV regimes for People Living with HIV/AIDS (PLWHA) in resource-poor settings.

At the operational level, the theoretical argument that guided this particular PhD was that adherence to life-long ARV treatment in Uganda’s resource-poor settings was an outcome of a reciprocal relationship between biomedical and environmental factors. That argument was intended to establish the relationships between biomedical factors in the form of the host (patient), the agent (health damaging organism), and the healthcare settings, on the one hand, and the environmental factors in the form of social, cultural, and economic factors, on the other hand. The actual fieldwork was implemented at two comparative ART accredited sites in Uganda, namely: Mbuya Reach Out, known as the urban-based Mission Facility (UMF), and Kayunga Hospital, known as the rural-based Public Facility (RPF). The Mission Facility was implementing comprehensive HIV/AIDS services in the form of medical, psychosocial, and socio-economic support; while the Public Facility was providing basic HIV/AIDS services in the form of medical and psychosocial support. The rationale for selecting two different sites was that these sites were likely to manifest different patterns in adherence to antiretroviral therapy (ART). The actual methodology entailed iterative qualitative and quantitative methods implemented over a time period of more than two years (January 2006 and May 2008). The actual fieldwork lasted longer than expected because of the desire to collect data against emergent research questions and hypotheses as writing progressed through advanced stages. The measurement of adherence was based on pill-count data for a period of three years preceding the study. The adherence results were validated by health indicators, namely: CD4 count, weight, and functional status at 6 month intervals.

Results indicated high adherence rates. Out of the 262 patients, 90% (236) achieved a pooled 95% adherence for the 3 years preceding the study. Surprisingly, there was
no significant difference between the two different health facilities: 89% of patients in UMF (providing comprehensive healthcare services) and 92% in RPF (providing basic healthcare services) achieved the 95% adherence. In fact, analysis of optimal adherence (100%) shows that 74% (89) of patients in the RPF compared to only 23% (32) of patients in the UMF achieved the 100% adherence. Retrospective longitudinal analysis of adherence reflected consistently high adherence levels, as well as positive evolution in health indicators throughout the entire treatment period.

In a complex relationship, biomedical and environmental factors facilitated and constrained adherence to ART. At the patient level, the factors associated with high adherence rates were mainly biomedical in nature, namely: 1) previous health condition; 2) desire to achieve personal goals in life; 3) therapeutic skills; 4) effective HIV/AIDS treatment; and 5) individual characteristics. Beyond the patient level, the quality of healthcare services and the availability of social support from kinship and associational have facilitated access and adherence to HIV/AIDS treatment.

Even in terms of adherence barriers, sub-optimal adherence was attributed to: 1) biomedical factors (sickness, side effects, feeling better or worse, and forgetfulness); 2) livelihood activities (domestic work, production work and social engagements), and; 3) access related barriers (mainly the inability to raise money for transport, difficult journey, access to food).

Both the facilitating factors and adherence barriers are mediated by external barriers. In this study, the physical-ecological conditions (weather conditions) was found to be the major external environment influencing factor.

The findings in this study confirmed the initial theoretical argument that adherence to life-long antiretroviral treatment in Uganda’s resource-poor settings was an outcome of a reciprocal relationship between biomedical and environmental factors. However, the composition of adherence barriers reveals that, contrary to background studies in the developed world, biomedical barriers did not feature prominently.

As part of fulfilling one of the research questions, this thesis proposes recommendations for sustaining adherence to ART in Uganda’s resource-poor settings.
Samenvatting

Deze thesis is het resultaat van een PhD-project, getiteld ‘AIDS Medicines in Resource-Poor Settings: Learning from District Level Transformations in Health Cultures and Arrangements in Uganda and South Africa’ (2004), gefinancierd door het Nederlandse Ministerie van Buitenlandse Zaken. Het algemene voorstel bestond uit nationale -, district -, en gemeenschapsclusters. Dit doctoraat is in het bijzonder gelegen in, en draagt bij aan het cluster van ‘transformaties en effecten op gemeenschapsniveau’. Het doel van dit cluster was het formuleren van beste praktijken voor de invoering van antiretroviralen (ARV) in omgevingen met weinig voorzieningen, en om een generiek model voor de implementatie van pragmatische ARV regimes voor mensen die leven met HIV/AIDS (PLWHA – People Living with HIV/AIDS ) in omgevingen met weinig voorzieningen te ontwikkelen.

Het leidende theoretische argument van deze dissertatie was dat naleving van levenslange ARV behandeling in Uganda's gebieden met weinig voorzieningen het resultaat is van een wederkerige relatie tussen biomedische en omgevingsfactoren. Dit argument was bedoeld om de relaties tussen biomedische factoren in de vorm van de gastheer (patiënt), agens (organisme schadelijk voor de gezondheid) en gezondheidszorginstellingen enerzijds en omgevingsfactoren in de vorm van sociale, culturele en economische factoren anderzijds vast te stellen. Het daadwerkelijke veldwerk werd uitgevoerd op twee verschillende ART geaccrediteerde locaties in Uganda, namelijk: Mbuya Reach Out, bekend als de stedelijke missie faciliteit (UMF – Urban Mission Facility), en Kayunga ziekenhuis, bekend als de landelijk gelegen publieke faciliteit (RPF – Rural Public Facility). De missie faciliteit bood uitgebreide HIV/AIDS diensten aan in de vorm van medische, psychosociale en sociaal-economische steun terwijl de publieke faciliteit basale HIV/AIDS diensten in de vorm van medische en psychosociale ondersteuning leverde. De reden voor het selecteren van twee verschillende locaties was de veronderstelling dat deze verschillende locaties verschillende patronen in naleving van antiretrovirale therapie (ART) zouden vertonen. De gebruikte methodologie bestond uit iteratieve kwalitatieve en kwantitatieve methodes toegepast over een periode van meer dan twee jaar (van januari 2006 tot mei 2008). Het veldwerk duurde uiteindelijk langer dan verwacht vanwege de wens om gegevens naar aanleiding van ontstane onderzoeksvragen en hypotheses te verzamelen naarmate het schrijven vorderde. De mate van naleving was gebaseerd op data gebaseerd op pillen tellen gedurende een periode van drie
jaar voorafgaand aan de studie. De resultaten van de naleving zijn gevalideerd door middel van gezondheidsindicatoren, namelijk: hoeveelheid CD4 cellen, gewicht en functionele status gemeten met intervallen van steeds zes maanden.

De resultaten gaven hoge nalevingcijfers aan. Van de 262 patiënten, bereikte 90% (236) een gezamenlijke naleving van 95% voor de drie jaar voorafgaand aan de studie. Verrassend genoeg was er geen significant verschil tussen de twee verschillende gezondheidszorgfaciliteiten: 89% van de patiënten in de UMF (welke uitgebreide gezondheidszorg verleende) en 92% in de RPF (welke basisgezondheidszorg verleende) behaalde een naleving van 95%. Analyse van de optimale naleving (100%) laat zien dat 74% (89) van de patiënten in de RPF in vergelijking met slechts 23% (32) van patiënten in de UMF een naleving van 100% bereikt. Terugkijkende analyse over een langere periode van naleving wees op naleving van constant hoge niveaus, alsmede op een positieve ontwikkeling van de gezondheidsindicatoren gedurende de volledige behandeling.

In een complex samenspel maakten biomedische en omgevingsfactoren de naleving van ART zowel makkelijker als moeilijker. De factoren die geassocieerd worden met een hoog nalevingniveau waren voornamelijk biomedisch van aard, namelijk: 1) de eerdere gezondheidsstoestand; 2) het verlangen om persoonlijke doelen in het leven te bereiken; 3) therapeutische vaardigheden; 4) effectieve behandeling van HIV/AIDS; en 5) individuele eigenschappen. Daarnaast faciliteren de kwaliteit van de gezondheidszorg en de beschikbaarheid van sociale steun van familie en verenigingsleven de toegang tot en naleving van de HIV/AIDS-behandeling.

Wat betreft belemmerende factoren voor naleving werd suboptimale naleving toegeschreven aan: 1) biomedische factoren (ziekte, bijwerkingen, betere of slechtere gemoedstoestand en vergeetachtigheid); 2) activiteiten om in levensonderhoud te voorzien (huishoudelijk werk, productiewerk en sociale verplichtingen) en; 3) toegang gerelateerde belemmeringen (voornamelijk het onvermogen om geld te verzamelen voor vervoer, moeilijke reis, toegang tot voedsel).

Zowel de faciliterende als de belemmerende factoren voor naleving worden beïnvloed door externe barrières. In deze studie bleken de fysieke-ecologische omstandigheden (weersomstandigheden) de voornaamste externe omgevingsbeïnvloedende factor te zijn.

De bevindingen in deze studie bevestigen het initiële theoretische argument dat naleving van levenslange antiretrovirale behandelingen in Uganda’s omgevingen met weinig voorzieningen het resultaat is van een wederkerige relatie tussen biomedische
en omgevingsfactoren. Echter, de aard van de barrières tot naleving laat zien dat, in tegenstelling tot achtergrondstudies in de ontwikkelde wereld, biomedische belemmeringen niet prominent aanwezig waren.

Als onderdeel van het beantwoorden van een van de onderzoeksvragen doet deze thesis ten slotte aanbevelingen voor de instandhouding van naleving van ART in Uganda’s omgevingen met weinig voorzieningen.

**Footnotes in Tables**

1 The professional staff at Kayunga took the form of 12 clinical officers, 80 nurses, and non-medical workers operating in a hospital setting.

2 Outpatient departments included: general, diabetic clinic, hypertensive clinic, eye clinic, mental health clinic, ENT, orthopaedic, and HIV/AIDS clinic.

3 The number of patients varied from one appointment to another.

4 In the Mission Facility this includes the Doctor (1), Senior Medical Officer (1), Medical and Medical Officer (2).