Sustaining adherence to antiretroviral therapy among HIV/AIDS patients in Uganda
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Citation for published version (APA):

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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

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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).
Introduction

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), PLWHA, 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.
Sustaining Adherence to Antiretroviral Therapy among HIV/AIDS Patients in Uganda

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-patients 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

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.