Sustaining adherence to antiretroviral therapy among HIV/AIDS patients in Uganda
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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\(^{50}\) 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.

\(^{50}\) 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 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

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), sub-optimal 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\(^\text{52}\) allude to the role of information as predictors of adherence to ART. Even in the Uganda’s context there is a direct relationship

\(^{52}\) 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 protection⁵³ (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

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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 \((\text{pharmacological efficacy})\). ARVs also have the quality to generate supportive behaviour at various levels \((\text{social efficacy})\). 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 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.

55 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 need. 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 commitment. 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\textsuperscript{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.