Sustaining adherence to antiretroviral therapy among HIV/AIDS patients in Uganda
Ssewaya, A.

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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 costs.21

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.

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 vulnerability²² (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

²² 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).

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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.

![Figure 4.2: Proportion of Household Spending on an Item.](image)

**N.B.:** *ND= Non-durable item; Hsh = Household; Pers = Personal*

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 Ushs</td>
<td>Number Ushs</td>
</tr>
<tr>
<td>Transport</td>
<td>39 5,005</td>
<td>107 4,002</td>
</tr>
<tr>
<td>Snack</td>
<td>77 640</td>
<td>86 1,104</td>
</tr>
<tr>
<td>Bicycle Security Charges</td>
<td>2 750</td>
<td>1 200</td>
</tr>
<tr>
<td>Total</td>
<td>118 2084.75</td>
<td>194 2697.42</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

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25 Mukene is a small protein-rich fish scientifically known as *Rastrineobola argentea*. 
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 4.2: Effect of Affordability on Adherence (n=65)**

<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\(^\text{26}\) 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,\(^\text{26}\) In transport planning, physical access encompasses ‘mobility’ of people and ‘locations’ of different services/facilities (Nejadfard, no date).

\(^{26}\) 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 conditions 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 being 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 4.3**: Proportion of Respondents who Benefited from Assistance at Any Time

<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></td>
<td></td>
<td>(site)</td>
<td>(site)</td>
<td></td>
<td>(site)</td>
</tr>
<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.