The economic consequences and coping mechanisms used by households affected by HIV/AIDS in Uganda

By

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DECLARATION

While fully acknowledging information from other sources, I do hereby declare that, this research paper is my own original work and has not been submitted in part or full to any other university.

Signature:_____ **Date:** _____

FAITH MIRIMO

This paper has been submitted for examination with my approval as the University Supervisor

Signature: _____ **Date:** _____

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EXECUTIVE SUMMARY

Objective: This study was aimed at examining the economic consequences and the coping mechanisms used by households affected by HIV/AIDS. There is concern that even with the provision of free Antiretroviral Therapy (ART); HIV/AIDS may exert negative economic consequences on People Living with HIV/AIDS (PLWHA) and their households. Households then come up with coping mechanisms in response to the economic burden of HIV/AIDS. In addition, social capital available to households may positively influence households' ability to cope with the economic burden of HIV/AIDS.

Methods: This study was mainly quantitative in nature with a qualitative component to supplement the results obtained. The study included exit interviews with the PLWHA at the health facilities where this study was carried out. In addition, Focus group discussions (FGDs) were carried out in both study sites. The study covered two sites including an urban and rural site with a total sample space of 290 participants.

Results: The direct costs of seeking care for PLWHA on ART were generally lower than the indirect costs in both the rural and urban area. However, there was a marked increase in the direct costs with particular reference to the direct medical costs in the period before the official appointment at the ART health facility. Transport costs and costs of special food contributed the highest proportion of non-medical costs for PLWHA who were on ART. On, the other hand, in response to the economic burden of HIV/AIDS, borrowing was the commonest coping mechanism used by urban and rural households. There was also a high source of social capital available to households affected by HIV/AIDS. This was shown by the high association between HIV/AIDS related service provision with community and non-governmental organisations.

Conclusion: Although free ART has significantly reduced the morbidity and mortality associated with HIV/AIDS, PLWHA are still faced with the economic burden of HIV/AIDS. Furthermore, PLWHA and their households lose income and time when they spend time away from work and other economic activities. There is also evidence that assistance from relatives and friends has reduced but there is a significant contribution by community-based organisations and NGOs in helping PLWHA and their communities.

LIST OF ACRONYMS

ART	Antiretroviral Therapy
AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral drugs
FGD	Focus Group Discussion
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
MOH	Ministry of Health
NGO	Non-Governmental Organisations
PLWHA	People living with HIV/AIDS
SES	Socio-Economic Status
TASO	The AIDS Support Organisation
U Shs	Ugandan Shillings
UBOS	Uganda Bureau of Statistics
UDHS	Uganda Demographic and Health Survey
US $	United States Dollar
WHO	World Health Organisation

TABLE OF CONTENTS

LIST OF TABLES

TABLE OF FIGURES

CHAPTER ONE – INTRODUCTION

1.1 Background

HIV/AIDS accounts for a fifth of the deaths in Africa making it the most significant cause of death in Africa and the fourth leading cause of mortality worldwide (World Health Organisation, 2003). In 2003, 42 million people were infected with HIV and 70% of these infections were recorded in Africa. In 2002, AIDS accounted for 3.1 million deaths worldwide, of which 80% were recorded in Africa. Twenty-six of the twenty-eight worst affected countries in the world were also found in Africa (WHO, 2003; Countinho, 2003). This makes Africa a crucial point for HIV/AIDS interest worldwide with indications that about 8.7% of the adult population is infected with HIV (Whiteside, 2002). There is also evidence that the HIV/AIDS scourge has left almost 30 million children orphaned, worldwide while 14, 000 new infections still continue to occur daily (Countinho, 2003).

The Human Immunodeficiency Virus (HIV) was first discovered in the late 1970s but it was not until the early 1980s that the first cases were recorded and diagnosed (Gaffeo, 2003). There are typically two variations of HIV. These include HIV-1, which is commonly encountered in the USA and all other parts of the world, and HIV-2, which is predominantly found in West Africa (Gaffeo, 2003). HIV is spread from one individual to another when there is contact with the bodily fluids of the infected person. This leads to transmission of the virus from the infected person to the other. The HIV then progresses to Acquired Immunodeficiency Syndrome (AIDS), once an infected person's immune system has been compromised. AIDS does not manifest immediately. For an individual who has been infected, there may be a long gestation period of about 5-8 years before any opportunistic infections attack their immune system (UNAIDS, 2000; Whiteside, 2002). Whiteside (2002) points out that HIV/AIDS follows an S-curve, following the period after infection and before the manifestation of AIDS. There is a significant time lag between the infection of individuals with HIV and that time when a significant number of people in a community are reported as infected (Whiteside, 2002).

Thereafter a peak is witnessed in the number of HIV/AIDS cases reported, afterwards the peak starts to come down notably at the macro-level (Whiteside, 2002). There will be varying degrees and forms of AIDS peaks even within one country. This leads to variations in morbidity and mortality associated with AIDS in various communities (Whiteside, 2002; UNAIDS, 2000). Generally, HIV/AIDS has been mostly reported as a heterosexual phenomenon. Furthermore, there are various ways through which an individual can be infected by HIV. This may be through contact with infected bodily fluids, sharing of sharp objects with infected persons and through the mother to child transmission (PMTCT). There is recognition of the fact that HIV/AIDS occurs mostly in the economically active group of 15-50 year olds, who are usually the main bread winners in their households and the main supporters of their countries' economies (Piot et al, 2007; Duraisamy et al, 2006). Unfortunately, the significant rate of morbidity and mortality associated with AIDS has negatively impacted on the productivity of the individuals, countries' economies and the society at large (UNAIDS 2000).

HIV/AIDS continues to be a major threat to the world. However there is now great hope for HIV positive individuals with the advent of Highly Active Antiretroviral Therapy (HAART). These life saving therapies have significantly reduced the rates of morbidity and mortality that previously characterised HIV/AIDS. These medicinal interventions in the form of Antiretroviral drugs (ARVs) come in various forms and combinations. These include both branded and generic forms and provide HIV positive individuals with a chance of a prolonged life and an improved quality of life as well (Gaffeo, 2003; UNAIDS, 2000). However, HAART is costly, requires life long adherence, frequent hospital check-ups, good healthy life style habits and proper dietary conditions. There is concern that HIV positive individuals may therefore require a high amount of resources for the rest of their lives so as to remain on these life saving therapies. Unfortunately that may not be a luxury that many people particularly the poor can afford, nor can most resource constrained governments afford to provide for all the people who need these therapies (UNAIDS, 2000). Although, most developed countries have managed to maintain a low HIV prevalence, many less-developed countries do not seem to have the kind of resources required to mitigate the negative consequences of HIV/AIDS on their

countries. This same phenomenon has been responsible for the increased levels of communicable diseases like HIV/AIDS and poverty in least developed countries. Subsequently, there is an inter-relationship between HIV/AIDS, other communicable diseases and poverty. There is evidence that HIV/AIDS makes households more vulnerable to poverty, even as poverty opens the gateway to a number of diseases that affect households (Whiteside, 2002).

In the context of the Millennium Development Goals (MDGs), the United Nations (UN) World Bank and other multinational organisations like the, World Health Organisation and the International Monetary Fund formulated global targets. These global targets were generally aimed at achieving reduction in poverty and improving the standard of living for people all over the world. Goal number 6 of the MDGs is aimed at combating HIV/AIDS, malaria and other diseases. However in relation to HIV/AIDS, Goal 6 of the MDG s specifically involved target 7 that was aimed at halting and reversing the spread of HIV/AIDS by 2015 (WHO, 2007c). There was further commitment from the WHO with the 3 by 5 initiative that was aimed at providing ARVs to 3 million people by 2005 (WHO, 2003). These commitments show that HIV/AIDS is a problem that requires the joint effort of all stakeholders in the world. These joint efforts are aimed at combating the negative impact of HIV/AIDS. This is because HIV/AIDS increases poverty and reduces the economic potential of a country and it also has negative effects on the household.

The first AIDS case in Uganda was reported in 1982 (Uganda AIDS Commission Secretariat, 2002; WHO, 2003). Although it was highly suspected that there could have been earlier cases of AIDS that were possibly not reported. The National Resistance Movement government openly acknowledged the HIV/AIDS situation almost as soon as they came into power in 1986 (WHO, 2003). There was therefore high government effort directly and through collaborations with the private sector and non-governmental organisations to fight HIV/AIDS. These efforts lead to a reduction in the prevalence of HIV from its highest level of 30% in the early 1990's to 7.1 % in 2005 (WHO, 2003; Kanyamurwa and Ampek, 2007). The government of Uganda considered prevention strategies in its earlier fight against HIV/AIDS in Uganda. These strategies mainly

targeted young people, with the hope that they would delay their first sexual encounter. Fortunately with discovery of ART, the Ugandan government made efforts to ensure access to ART by most of those HIV/AIDS patients who were eligible who and initially fell in the priority groups (MOH, 2003).

Anti-retroviral therapy, which was a break-through in the scientific fight against HIV/AIDS, is considered one of the main strategies to fight and manage HIV/AIDS. ART leads to a reduction in the mortality and morbidity associated with HIV/AIDS in Uganda. This has been possible through the increase in the numbers of people accessing ART (WHO, 2003). There were 1,000,000 people living with HIV/AIDS in Uganda by the end of 2005 and almost the same number of children orphaned to AIDS in Uganda. Although ART has been present in Uganda for the last 10 years, only (75,000) 34 % of those 190, 000 people in need of ART, had access to it in 2005 (WHO, 2006).

The majority of health facilities offering ART in Uganda are located in or near urban areas. This factor has restricted HIV/AIDS services to PLWHA with geographical proximity to the health facilities and those who are of higher education levels. Since 74% of the HIV/AIDS cases in Uganda are through heterosexual transmission (Uganda AIDS Commission Secretariat, 2002), more than one household member is likely to be infected in a given family. This is likely to increase the burden of HIV/AIDS on the household in terms of care and resources used to look after the affected members. This situation is further compounded by the fact that families of those infected with HIV/AIDS have to increase the number of children and people they look after, if infected caregivers pass away or are too sick to look after their households (Ntozi, 1997). This implies that the household is a very important unit of care for PLWHA and may face tremendous economic and social costs and consequences in the process. (Ntozi, 1997)

Even in situations when a PLWHA has access to ART, there are other associated services that they need, which may not be provided by the health facility. There is need for CD 4 monitoring, viral load testing, counselling, balanced diet, and transport to the health facility and other such services (MOH, 2003). However, there are currently cases where

organisations like The AIDS Support organisation (TASO) and Joint Clinical Research Centre (JCRC) offer most of the required services free of charge to their clients. Nonetheless, with reduced stigmatisation of PLWHA, more people are reporting for Voluntary Counselling and Testing (VCT). This implies that many more people who are found HIV positive and eligible will require ART. This has therefore put a strain on the amount and quality of services offered to PLWHA in Uganda (MOH, 2003). Therefore, health service providers have less capacity to cope with the number of people seeking HIV/AIDS related services. Subsequently, households may be increasingly spending their income on those services and medicines not available at health facilities. Therefore, HIV/AIDS may exert an economic burden on PLWHA who are on ART and their households. (Rosen et al, 2007; Meyer-Rath and Ritcher, 2007; Duraisamy et al, 2006).

The burden of HIV/AIDS has not spared those PLWHA who receive free HIV/AIDS related services including ARVs. There are many reasons why PLWHA on ART may still face a high economic burden due to HIV/AIDS. In many instances PLWHA and their households face high direct costs and indirect costs as a result of HIV/AIDS illness. In particular, direct non-medical costs of transport to the health facility and special food may place a high burden on households (Duraisamy et al, 2006). In seeking care, PLWHA may have to incur high costs on both health care and non-healthcare related costs in between their official appointments at the ART clinics (Rosen et al, 2007). This is because appointments to the ART clinics are usually, every after one or two months (Rosen et al, 2007; Meyer-Rath and Ritcher, 2007). Therefore although patients receive free HIV/AIDS services, they may still have to handle their own expenses, even on healthcare related expenses when they fall ill, before their official appointments.

On the other hand, households affected by HIV/AIDS are faced with the burden of high indirect costs, which may impoverish them and lead to depletion of their income. The opportunity costs associated with HIV/AIDS are not only restricted to the PLWHA but to other household members who look after them when they are ill (Sauerborn et al, 1996; Ntozi, 1997, Rosen et al, 2007). The indirect costs of seeking care for HIV/AIDS may involve loss of time for patients and caregivers away from work and therefore a loss in

income and earnings. On the other, the indirect costs of HIV/AIDS lead to exhaustion of assets and income for households to cover the costs of the illness (Ntozi et al, 1997; Ganyaza-Twalo and Seager, 2005).

Subsequently, when households are faced with the burden of HIV/AIDS, they come up with responses to mitigate the negative effects on the household (McIntyre et al, 2006). Households employ different coping mechanisms in response to direct or indirect costs (McIntyre et al, 2006). These factors may include the household size, length of the illness and the amount of resources including social capital that is available to the household. The types of coping mechanisms that households employed, included adjusting their consumption patterns, borrowing money, selling assets, diversifying their income, labour substitution and receiving gifts (Mutyambizi, 2002; Russell, 2005). The social capital available to a household is also likely to influence a household's ability to counter the burden of HIV/AIDS (Gilbert and Soskolne, 2003; Holtgrave and Crosby, 2003).

1.2 Problem Statement

HIV/AIDS has placed a high economic burden on households. Households increasingly have to incur high costs in the care and support of household members living with HIV/AIDS. These costs can be divided into direct, indirect and intangible costs. This burden is even more critical for poor and disadvantaged households. These households have to spend larger proportions of their income on health care as compared to richer households. It is of concern that households still have to incur high costs, even when ARVs are being provided free of charge to many HIV positive individuals in Uganda. The problem of high health costs is further aggravated by the epidemiological trend that HIV/AIDS takes on. That is in the case that a couple is infected with HIV/AIDS, then it is also likely that their unborn children are likely to contract the virus as well. Furthermore, as most ART centres are located in towns, they are likely to benefit only a proportion of those households who need these drugs (MOH, 2003). Those who are able to seek ART are faced with high medical costs of related services and for ARVs in some instances. Another important category of cost is the high opportunity costs (or indirect costs) of seeking care and caring for patients. These costs include days of work lost for both the patient and those looking after them. Households affected with HIV/AIDS also face prospects of substituting essential needs to pay for their health care.

Patient costs lead household to identify responses to the burden of HIV/AIDS, which are usually referred to as "coping mechanisms". These responses seek to mitigate the negative effects of the burden of disease. Households adopt a variety of coping mechanisms, some of which leave the households worse-off than they were before, both economically and psychologically. These household responses are usually adopted in the context of the community, which may be a source of social capital for households.

Social capital may be an important source of financial, social and emotional support for households affected by HIV/AIDS. The costs imposed on households by ill-health and the coping mechanisms that they use are a source of concern especially given the long-

There are few studies that have tried to analyse the costs incurred by households affected with illnesses like HIV/AIDS and the coping mechanisms developed by these households in coping with this burden. However, there is no known study that has specifically investigated the economic burden of HIV/AIDS on households in the period of provision of ART in Uganda. The era of provision of free ART in Uganda is particularly important for this research because it requires life-time adherence. This implies that households of HIV/AIDS patients have to bear the economic burden for a long period of time.

1.4 Study Aim

To analyse the economic consequences and coping mechanisms used by households affected by HIV/AIDS in Uganda.

1.5 The study objectives

The objectives of the study are:

1. To determine the direct and indirect costs of seeking healthcare for households affected by HIV/AIDS.
2. To analyse the coping mechanisms used by households of PLWHA p in relation to seeking health care.

1.6 The subsidiary objectives of the study are:

3. To describe the socio-economic and demographic characteristics of households affected by HIV/AIDS and how these influences the coping mechanisms they use.
4. To describe the role that social capital plays in the coping mechanisms that households use to respond to the economic burden of HIV/AIDS.
5. To obtain patient perspectives on the economic burden of HIV/AIDS and the coping mechanisms they employ in response.

term or chronic nature of HIV/AIDS. There is also concern that the role of the community in providing both social and financial assistance to the households is not so strong any more. There is a trend of individualism, which has led to break down in the social capital in many societies, citing a particular example of the United States of America (Putman, 1996). These facts have left households with less help from the larger community and therefore bear the burden of caring for HIV/AIDS patients. Therefore, this study seeks to examine the burden of HIV/AIDS on households with PLWHA who are receiving free ART. There is an interest to look at the coping mechanisms, if any, that these households employ in light of costs that they may when they seek care for HIV/AIDS. Indeed, there is also an interest in whether social capital plays a role in the coping mechanisms used by households affected by HIV/AIDS in Uganda.

1.3 Rationale for the Study

HIV/AIDS is a chronic condition and like many chronic conditions it requires a vast amount of resources and care for those affected. HIV/AIDS is no longer a life sentence to those infected, given the invention of ART. However, HIV/AIDS still poses a serious economic burden and possible impoverishment for affected households. The household is the most important unit of care and support for people living with HIV/AIDS (Nhongo, 2004). Thus, households have to bear the burden of disease for the time the HIV/AIDS patient is on treatment and whenever they fall sick. This, for the households affected requires a large amount of resources both financially, socially, emotionally and physically. This study seeks to analyse the burden of HIV/AIDS on the household as a unit of care. The study also seeks to examine how households respond to this burden and subsequently how they cope with HIV/AIDS. The study also seeks to describe briefly the role that social capital plays in the coping mechanisms that households respond with. This research is particularly focusing on the burden of HIV/AIDS on households in the era of provision of free ARVS. This is the first study that attempts to put into perspective the coping mechanisms that households employ in response to the economic burden of HIV/AIDS on PLWHA who are on free ART and their households.

CHAPTER 2- LITERATURE REVIEW

2.1 Introduction

This section was aimed at providing information from literature on the economic burden of HIV/AIDS, household coping mechanisms and the role of social capital in this process of coping. Therefore this section was aimed at achieving the following three objectives as listed below.

- To present and discuss the literature available on direct and indirect costs of the economic burden of HIV/AIDS for households
- To analyse the literature available on the coping mechanisms that households employ in response to the economic burden of illness that they face.
- To provide a general idea on the role that social capital may play in providing financial and social support to households faced with the burden of illness.

2.2 Theoretical Literature

2.2.1 Economic Burden, Direct and Indirect costs of Disease

When households are faced with disease or ill-health of one or more of their members, they often have to incur high costs. These costs can be differentiated into direct and indirect costs and these make ill-health very costly especially for poor households. Direct costs for the household are associated with seeking medical care and any other services related to the health condition of the patient (McCrone, 1998; Russell, 2005).

Direct costs can be differentiated into direct medical and direct non-medical costs of a disease or illness that a household faces. Direct medical costs refer to the cost of HIV/AIDS services and are not restricted to the medicinal expenditure only but also to direct costs of other associated medical services. In the case of HIV/AIDS, these services may include those things that an HIV-positive individual requires once on ART, such as CD4 count monitoring, viral-load counts, and treatment for opportunistic infections

(TOI). There are also some important direct non-medical costs including travel costs, costs of special food, caregivers' costs and costs of queuing at the health facility.

On the other hand indirect costs involve the opportunity cost of seeking health care. This implies activities (and their monetary value where possible) that have to be given up in order to seek care. Indirect costs may include the loss of days worked and wages, the cost of a caregiver who may give up an economic activity or school to look after the patient. In deriving the cost of illness, intangible costs may also be considered, however these are usually complicated to calculate or to express in monetary terms. It is therefore important to consider the appropriateness of expressing intangible costs in monetary terms. Intangible costs may include the psychological burden of disease and all other emotional aspects related to the burden of disease (McCrone, 1998; Wyss et al, 2004; Russell, 2005).

There is variation in relation to the calculation of indirect costs associated with health care but there are generally three approaches used including the "human capital approach", the "willingness to pay" approach (Drummond, 2005; Jefferson, 1998) and the "foregone earnings" approach (Glied, 1996). These measures are calculated in different ways and will lead to different approximations for indirect costs.

The human capital approach involves placing a monetary value on a human life; this approach can be used to estimate the value of an individual to his community according to the amount of income he/she earns. This approach has been used to measure the value of health interventions, by looking at how much an individual earns when in good health as a result of a health intervention (Drummond, 2005; Jefferson et al, 1996). Therefore the difference in income with and without the intervention will approximate the value of the intervention. However, this approach has its shortcomings. These may include the differences in wages due to differences in bargaining ability and attaching monetary value to human life, which the welfare economists have argued as being morally wrong (Drummond, 2005).

The willingness-to-pay approach is a type of contingent valuation method used in health economics. In this approach an individual is expected to express their highest willingness-to-pay for a service. This is then taken as the value that they place on that service. The individual is faced with a theoretical market scenario in which they try to picture themselves so as to simulate a real life situation (Drummond, 2005). In this approach an individual makes an unambiguous choice between alternatives based on the amount he would be prepared to pay for them (Drummond, 2005; Jefferson, 1996). This approach has also been criticised for one main reason that an individual's willingness to pay may be influenced by their ability to pay. This is a serious criticism that stems from the fact that this approach uses hypothetical examples to elicit an individual's preference between alternative choices.

The third approach used in health economics to measure indirect costs is the foregone earnings approach, which stems from economic concept of opportunity cost. In this case, costs are considered in terms of the alternative use for which those resources could be used for. This implies, therefore that resources are limited and yet the needs to which these resources can be allocated are endless (McCrone, 1998). Therefore an individual is faced with competing alternatives to which he should allocate resources and he will choose the best alternative based on the its urgency and the utility he experiences from it as compared to the next alternative that he gives up (Jefferson, 1998; Drummond, 2005; McCrone, 1998). Concretely, the foregone earnings are measured as the days of work missed and the value of other activities that the patient gives up to seek health care.

In summary, this study was undertaken from the household perspective and therefore all costs will be calculated from this perspective. The direct costs included both the direct medical and non-medical costs. On the other hand, indirect costs are mainly the opportunity costs of activities foregone by the PLWHA and their caregivers due to ill-health associated with HIV/AIDS (McCrone, 1998). Drummond and colleagues (2005) as well as Glied (1996) explain that both the human capital and willingness to pay estimates of the indirect costs give rise to errors, which are more difficult to eliminate. On the other

hand, foregone earnings are simpler to calculate and can give rise to suitable measures of indirect costs, if they are used with prudence (Glied, 1996).

2.2.2 Household Coping Mechanisms

A number of studies have analysed the costs associated with ill-health, the world over, however very few shed light on the coping mechanisms that households use to respond to these costs. There is even less information on the success or failure of these coping mechanisms in mitigating the negative effects of the burden of disease (Wyss et al, 2004). Coping as a theme in research has been used to refer to the different responses of individuals and households to different negative events in life. There is therefore a need to clarify the definition of coping as envisioned by this study. As explained by Pearlin and Schooler: "*...by coping we refer to things that people do to avoid being harmed by life-strains. At the very heart of this concept is the fact that people are responsive to the forces that impinge upon them...*" *(Pearlin and Schooler, 1978:2.* Yet again Pearlin and Schooler (1978) went on to define coping as to: "*...refer to any response to external life-strains that serve to prevent, avoid or control emotional distress...*"

Household coping mechanisms may be classified as short or long-term and this is in part influenced by the length of the disease and frequency of occurrence. In the case of HIV/AIDS both short term and long-term coping mechanisms may be employed. This is because the disease can be acute due to opportunistic infections and chronic in nature especially with increased life expectancy while on antiretroviral drugs. The concept of coping can be traced back to the neo-liberal economic days (Rugalema, 2000). In those days, households responded to calamity depending on how well informed they were of the situations they faced. Households usually followed similar patterns in their responses to calamity and the burden of illness. For example, they altered their basic needs' budgets to meet these changes (Rugalema, 2000). Recent studies suggested that among the most affected needs is the expenditure on food and followed closely by education budgets (WHO, 2007a). In the analysis of household coping mechanisms, various studies have taken on different perspectives and implementation of coping. Carver and colleagues

(1989) tried to analyse two aspects of individual coping in relation to stress. Individuals under stress employed problem-focussed coping and emotional-focussed coping. Pearlin and Schooler (1979) also agreed that coping is a multidimensional concept that looks at the social and psychological aspects of coping at the household level.

Households will commonly employ coping mechanisms that entail exchange of financial and non-financial assets for some monetary or non-monetary value (Mutyambizi, 2002; Russell, 2005). Households may use different coping mechanisms in response to the different aspects of cost of illness on them. For example, Russell (2004) reports that, *"....several studies have identified household coping strategies in response to illness and some have categorised these distinguishing between strategies that deal with direct costs (e.g. borrowing), and indirect costs (intra-household labour substitution), and between cost prevention strategies (ignoring illness, non-treatment, and cost management strategies (borrowing, selling assets, labour substitution)."*

Some of the approaches used to mitigate the negative effects of burden of disease are labour substitution within and among households, borrowing and reduction of their basic consumption budgets. It has also been suggested that some households respond to illness by doing nothing proactive to shield themselves from its negative consequences. (Mutyambizi, 2002; Russell, 2005). In the case of the burden of HIV/AIDS, households may 'do nothing' by not actively seeking any prophylaxis or ART depending on the patients HIV/AIDS progression. The characteristics of a household influence their ability and the type mechanisms they use to cope with illness (Sauerborn et al, 1996). The coping mechanisms that households employ frequently depend on the size of the household, constitution of the household, asset base, type and length of the disease and also on the recurrence of the disease (Sauerborn et al, 1996).

2.2.3 Social Capital

Social capital may play an important role in the choice and success of the coping mechanisms that households employ to respond to the burden of illness. Like many social science oriented concepts, social capital has been explained differently by different

authors. Putman (1996:114) explained social capital as those *"...features of social life, networks, norms and trust that enable households to act together more effectively to pursue shared objectives..."* Social capital is closely related to how members of a household, community or social networks depend on their shared trust, solidarity, support and team work (Holtgrave and Crosby,2003; Gilbert and Soskolne, 2003).

Gilbert and Soskolne (2003) carried out a study on self-assessed health on the social differentials in Soweto. Soweto is the biggest black township in South Africa. In their analysis, Gilbert and Soskolne (2003) report that the number of relatives and friends has no significant effect on the ill health of individuals however, the number of contacts with relatives and friends is what positively influences the health of family members (Gilbert and Soskolne, 2003).

The definition for social capital varies widely from study to study. Nevertheless, it is believed that social capital has a positive impact on the health of an individual (Gilbert and Soskolne, 2003; Ntozi, 1997). The authors are very clear that any meaningful study on the inequalities in health research should include analyses on the impact of social, economic and physical setting or their lack there-in on health care (Gilbert and Soskolne, 2003).

2.3 Empirical Literature

2.3.1 Introduction

This section was aimed at reviewing the literature to provide evidence on the economic burden and coping mechanisms used by households affected by HIV/AIDS and other potentially catastrophic diseases like tuberculosis and malaria. This section also aims at bringing to light, major research gaps as they relate to the burden of HIV/AIDS on households. In order to cover the issues which emerge from the literature, this section was subdivided into various themes as they pertain to the burden of illness and coping mechanisms used by households in response to illness. The identified themes include direct, indirect costs of illness and the relationship between HIV/AIDS and poverty.

There are also themes on coping mechanisms, social capital and the provision of free ART and its challenges. It is important to consider the interaction between illness and poverty, especially for poor households.

There is a correlation between ill-health and impoverishment of households especially in developing countries (Russell, 2005). There are particularly three diseases including HIV/AIDS, Malaria and tuberculosis that contribute to the highest proportion of catastrophic payments for ill-health in households (Russell, 2005). There is therefore a need to study the economic costs and consequences of diseases like malaria, HIV/AIDS and TB and to look at the coping mechanisms that low-income households employ to deal with them (Leonard, 2005, Russell, 2005). In analysing the cost of various illnesses on individuals and households, various studies considered either direct or indirect costs or both (Hutchinson et al, 2006; Duraisamy et al, 2006; Rosen et al, 2007 and Akenso-Okyere and Dzator, 1997). Similarly, coping mechanisms and social capital have been considered in various ways by different studies. The different studies on coping have approached this subject matter from different perspectives. For example, some studies have looked at coping with illnesses (Russell et al, Leive and Xu, 2007). However some other studies have looked at the emotional aspect of coping with stress (Carver et al 1989; Pearlin and Schooler, 1978). However, only a hand full of studies have attempted to study the influence that social capital has on the coping mechanisms used by households (Gilbert and Soskolne, 2003; Ntozi, 1997)

2.3.2 Direct Costs associated with illness

The direct costs of illnesses can be looked at as those costs incurred by patients that they pay for explicitly using their own money. The direct costs of illness can further be categorised as medical related costs and non medical costs (Hutchinson et al, 2006; Duraisamy et al, 2006; Rosen et al,). This indicates that due to the burden of disease a household may incur direct medical costs related to the illness or direct non-medical costs incurred as a result of other costs associated with falling ill but not necessarily the illness. The direct medical costs of illness may include the cost of medicines, laboratory tests, consultations, household healthcare related purchases and supplements. On the other

hand, direct non-medical costs include transport and special food (Akenso-Okyere and Dzator, 1997; Duraisamy et al, 2006). Households and individuals may be impoverished due to low resources with which to seek healthcare. This may be as a result of the cost of transportation to the health facilities and the cost of special food required in improving and maintaining nutrition (Piot et al, 2007). The direct non-medical costs that households incur are important to study because they can hinder households from seeking care even in cases where the healthcare for a particular illness is provided free of charge (Akenso-Okyere and Dzator, 1997). Therefore illness of any kind may negatively influence the productivity of a household by leading to losses in income and earnings. In a bid to inform public policy, Akenso-Okyere and Dzator (1997) sought to understand the direct and indirect costs of seeking healthcare for malaria in Benue state in Nigeria. The study found out that malaria affected both the physical and emotional wellbeing of the households in question (Akenso-Okyere and Dzator, 1997). Furthermore, ill-health due to malaria led to both financial and asset depletion even in instances where malaria services were offered free of charge (Akenso-Okyere and Dzator, 1997). Treatment of one bout of malaria included costs of direct medical care, transport and queuing time for patients. These costs led to a mean loss of productivity of 3.7 days for men and 4.7 days for women at a value of $ 8.67 (Akenso-Okyere and Dzator, 1997).

2.3.3 Direct costs of HIV/AIDS

There are many countries that are providing PLWHA with free ARVs and in some instances with free HIV/AIDS related services as well. Some of these countries include Uganda as a classic example, South Africa, United Sates of America and India in some instances (MOH, 2003; Rosen et al, Meyer-Rath and Ritcher, 2007; Hutchinson et al, 2006; Duraisamy et al, 2006). The provision of free ARVs has not totally deterred the fact that patients and their households still face the burden of seeking care for HIV/AIDS. There are some instances where PLWHA on ART faced higher costs in relation to their counterparts not yet initiated on ART (Duraisamy et al, 2006; Hutchinson et al, 2006). In addition patients initiated on ART may face higher costs than those HIV positive patients in their earlier stages of initiation on ART (Duraisamy et al, 2006). In a study carried out

in India in a Chennai based organisation between April in 2000 to October in 2001, there was comparison between HIV/AIDS patients on ART and those not yet initiated on ART (Duraisamy et al, 2006). HIV positive patients who were on ARVs faced a five-fold budget in comparison to other HIV positive patients were not yet on ART. The patients in this study received a number of HIV/AIDS related services at no cost from a non-profit organisation in Chennai (Duraisamy et al, 2006). In addition, the difference in the average cost of treatments to patients on ART as compared to HIV patients not on ART was found to be statistically significant.

The study of direct costs with respect to non-healthcare costs may highlight the burden of diseases such as HIV/AIDS on households in instances where ART is provided free of charge (Rosen et al, 2007; Meyer-Rath and Ritcher, 2007). The direct costs of illnesses may directly affect the individual who is ill and their household. The members of the household who are well are the ones who usually bear the burden of illness of one of their members (Sauerborn et al, 1996). Indeed, direct costs in general have negative consequences to households. However direct non-medical costs in particular may have systematically negative effects especially were health care provision is provided free of charge (Rosen et al, 2007). These costs usually deter patients from seeking care as they may be incurred before arrival to the health facility. Transportation costs may hinder the access of households and individuals in seeking free health care services for HIV/AIDS (Duraisamy et al, 2006 and Rosen et al, 2007).

In some instances patients have to walk long distances if they lack money for transport or if public transport is hard to come by. This is likely to be a disincentive for patients to come to the health facility for their ART appointments (Meyer-Rath and Ritcher, 2007; Rosen et al, 2007). A discussion on the indirect costs associated with HIV/AIDS in South Africa was commenced by the South African Clinicians society (Meyer-Rath and Ritcher, 2007). The online exchange of ideas was on the newly rolled out-free ART in South Africa that had been in place for about three years. The discussion was centred on a case-study presented on the provision of ART at tertiary, secondary and primary health care hospitals in South Africa. In spite of the free ARVs, people were hindered by transportation costs they incurred to come to the health facilities. The taxi and minibus

fares were on average R26 for 61% of all the patients who used public transport. This was a substantial proportion of the patient's income.

Furthermore, there are financial implications of other costs in addition to transport that HIV positive patients on ART incur that increase the economic burden of HIV/AIDS. The cost of special food, costs in terms of time spent travelling or waiting in queues at the health facilities may also deter patients (Rosen et al, 2007). The PLWHA and their families may have to incur caregiver costs especially when a patient is very weak. The provision of free ARVs is done on an interval basis where patients may be given appointments on a monthly basis or every two months. In between these appointments, patients may also incur direct medical costs, which may impoverish them and their households (Rosen et al, 2007). A study was carried out by Rosen and colleagues (2007) sought to calculate and approximate the non-medical costs incurred by patients on free ART in the provinces of Gauteng and Mpumalanga in South Africa. In between appointments, patients incurred costs on medicines and special foods. In the weeks before visiting the ART clinics for their appointment, 6 out of 10 patients reported that they spent between R45-R81. This was a substantial part of their incomes and therefore, even with free ART, there is still a high burden of HIV/AIDS on household.

The advent of ART has brought with it very many successful recovery stories and evidence that ARVs really work in the management of HIV/AIDS. However it is also clear that ARVs are not a cure for HIV/AIDS and this therefore implies that PLWHA have to live on ARVs for the rest of their lives. This has turned HIV/AIDS into a chronic condition where by patients get recurrent sickness episodes and require regular appointments at the HIV/AIDS health facilities. In addition, the cost of HIV/AIDS has been found to be greater than the cost of other illnesses on households (Wyss et al, 2004). This is a fact that has come to be acknowledged the world over as HIV/AIDS has caused inestimable suffering and expenses on households and individuals.

In a study carried out in four regions in Chad (Wyss et al, 2004), households affected by HIV/AIDS were compared with households not affected by HIV/AIDS. The costs

associated with HIV/AIDS were found to be four times the household income of those households of persons living with HIV/AIDS through out the life time of these households (Wyss et al, 2004). At the time the study was carried out, ART therapy was not available in Chad. Direct costs including medical expenses were about 56% of all costs closely followed by the costs of transport that were about 13% of expenses attributed to HIV/AIDS. An HIV/AIDS patient could incur up to US $ 836 due to morbidity and mortality associated with HIV/AIDS.

HIV/AIDS related mortality has drawn a lot of attention in the literature. However, it is becoming more apparent that the morbidity and disability associated with HIV/AIDS should be a more appropriate point of focus for studies today (Barnett and Whiteside, 2000). Disability and illness due to HIV/AIDS may cover a longer period of time and require more resources of the household as opposed to mortality. This is because time after time there is recurrence of opportunistic infections and AIDS can be a chronic disease whose impact can be felt over a long period of time by the household. In light of the above information, it is evident; that a number of studies have covered the impact of death on the economy. However, very little has been done to study the effect of HIV/AIDS morbidity and disability on the economy (Barnett et al, 2002).

2.3.4 Indirect Costs of HIV/AIDS

The indirect costs of illness are those costs associated with loss of productivity or foregone earnings due to the illness on individuals and their respective households (Duraisamy et al, 2006; Piot et al, 2007). Duraisamy and colleagues (2006) propose that there should differentiation between the financial and non-financial aspects of indirect costs associated with HIV/AIDS. The non-financial indirect costs are those losses that patients and other household members incur by seeking alternative jobs and doing extra work as a result of the illness. Indirect costs of illnesses are very important in study of burden of disease. The reason for this is that patients and their caregivers spend time away from their economic activities as a result of illness. This therefore implies their ability to earn income or to carry out activities that sustain them in their daily lives is

hindered (Ntozi, 1997; Russell, 2004; McIntyre et al, 2006). Subsequently, patients and caregivers incur expenses without the ability to make money. It is therefore, often common to find that the indirect cost of illness out weigh the direct costs of illnesses in many studies (Asenso-Okyere-1997; Russell, 2004).

In analysing the indirect costs of HIV/AIDS, its important to look at the profile of the individuals who are affected and therefore who bear the burden of HIV/AIDS. The indirect costs of HIV/AIDS tend to affect the more economically active age groups in society (Duraisamy et al, 2006; Piot et al, 2007). When these economically active household members fall ill and they lose time that they would have used to work. This is therefore likely to lead to reductions in household income as well as a loss in asset portfolios of the household. This may occur as a result of earnings lost due to ill health, caregiver's time away from their economic activities and assets sold to raise money to seek health care (Ganyaza-Twalo and Seager, 2005). In the Chennai based study in India, costs for HIV positive patients on ART and those not on ART were compared. The largest proportion of all participants was aged between 26 and 35 years of age (Duraisamy et al, 2006). This is the most economically active age group of people, implying a high economic and social loss not only to the economy at large but also to the respective households affected. In light of the negative impact on income of economically active household members, households also lose income and face asset depletion. As consequence, there is also a loss/reduction in the resources available to look after the household members affected by HIV/AIDS (Ganyaza-Twalo and Seager, 2005; Piot et al, 2007).

The computation of indirect costs may be difficult for any illness but even more so for HIV/AIDS were there many complexities involved in its computation (Russell, 2004). Russell (2004) argues that, what is of major importance is the study of household responses and coping mechanisms to HIV/AIDS rather than the direct and indirect costs of HIV/AIDS. In addition to the difficulty in computing indirect costs over forwards in time, there is a difference of opinion in the approaches in which indirect costs should be

calculated. This therefore leads to the difference in the results obtained in the indirect costs of illnesses like HIV/AIDS (Russell, 2004).

In terms of gender differentiation in indirect costs, women bear a higher productivity loss due to illness as compared to men (Ntozi et al, 1997; McIntyre et al, 2006; Akenso-Okyere and Dzator, 1997). For example in the calculation of indirect costs of malaria in Nigeria there was a mean loss of productivity of 3.7 days for men and 4.7 days for women at a value of $ 8.67 (Akenso-Okyere and Dzator, 1997). This fact has a lot to do with how the household activities that women take part in as compared to the men are economically valued. Women are responsible for the majority of care giving in homes and carrying out almost all unpaid activities like tending the gardens and looking after children. Therefore, although women incur less monetary losses due to illness, they incur high opportunity costs associated with HIV/AIDS (Ntozi, 1997). The household in many communities in Africa provides the labour necessary to engage in economic and other household related activities that are important to people's livelihoods. In Uganda (Ntozi, 1997), those who looked after HIV/AIDS family members noted that work related activities slowed down for both the patients and those who looked after them. Households affected by HIV/AIDS in this study lost 20.7% of their usual income due to HIV/AIDS (Ntozi, 1997). Ntozi (1997) reports that typical economic activities for people living with HIV/AIDS stalled. This was reported by 13.8% of males, 20.5% of women. On average 17.7% of all people affected by HIV/AIDS reported that their work related activities came to a stand-still.

2.3.5 HIV/AIDS and poverty

The interactions of HIV/AIDS and poverty are important in the light of the fact both phenomenon are increasing in Africa and especially in sub-Saharan Africa. Furthermore, HIV/AIDS and poverty have caused an inestimable level of suffering in this region (Ganyaza-Twalo and Seager, 2005). There are a number of studies that have looked at the impact of mortality due to HIV/AIDS on the economy but less work has been done on the impact of disability and morbidity due to HIV/AIDS on the economy (Barnett and

Whiteside, 2002). There is a relationship between HIV/AIDS and poverty and the two phenomenon negatively influence each other. It is therefore important and necessary to study the impact of HIV/AIDS on microeconomic units like households (Akenso-Okyere and Dzator, 1997; Duraisamy et al, 2006). On the other hand, many studies have focussed on the impact of HIV/AIDS on the economy and fewer studies have tried to analyse the burden of HIV/AIDS on individuals and households (Duraisamy et al, 2006). In the household, there is a combined decision making that also extends to the way in which cost of illnesses are dealt with. It is important to note, however, that household members may not contribute equally to this decision making process. The literature supports the analysis of cost of illness studies that focus on the household (Duraisamy et al, 2006; Sauerborn et al, 1996). The burden of illness studies help to determine the ability of households to access health care (Akenso-Okyere and Dzator, 1997). This therefore helps to shed light on impact that burden of illness has on households.

There seems to be no doubt as to the negative impact that HIV/AIDS and poverty have on each other (Piot et al, 2007; Ganyaza-Twalo and Seager, 2005 and Barnett and Whiteside, 2002). Poverty seems to lead to increases in the number of people infected with HIV/AIDS. On the other hand, more people infected with HIV/AIDS seem to fall into poverty or further into poverty (Ganyaza-Twalo and Seager, 2005). Ganyaza-Twalo and Seager (2005) undertook a literature review on the social and economic consequences of HIV/AIDS on households in general. This review noted that HIV/AIDS aggravates poverty by reducing the resources available to a household. While on the other hand, poverty makes households more vulnerable to HIV infection. In general, poverty is associated with a lower well being of an individual and household economically, socially and in other aspects (Ganyaza-Twalo and Seager, 2005). Subsequently, poverty opens the door to infection by HIV as HIV/AIDS reduces the social and economic capacity of the household in fighting off disease, leading to poverty or more poverty. HIV/AIDS through sickness and death makes a household more prone to impoverishment and poverty. On the other hand, poverty enhances the path way for HIV infection in the community (Ganyaza-Twalo and Seager, 2005). Economically, HIV/AIDS imposes a

systematically higher burden on poor households leading to further impoverishment and thus widening the gap of inequality in society (McIntyre et al, 2006; Piot et al, 2007).

Communicable diseases like HIV/AIDS are likely to increase the fraction of people who are living in poverty (Piot et al, 2007; Barnett and Whiteside, 2002). This has increased the need to study how HIV/AIDS and poverty interact and impact on each other. Like Hutchinson and colleagues (2007), Barnett and Whiteside (2002) analyse the two way effects of poverty on HIV/AIDS. Although, poverty may influence HIV/AIDS, HIV/AIDS may also increase the number of people living in poverty (Barnett and Whiteside, 2002). The increase in poverty due to HIV/AIDS is likely to impact on both countries with a high HIV prevalence as well as those with a low prevalence. It is expected that poverty is likely to increase by 5% more, due to HIV/AIDS in high prevalence countries and by 0.1-0.5% in low prevalence countries (Piot et al, 2007).

HIV/AIDS does not only lead households into poverty but also leads them to alter and adjust their basic consumption patterns. In the event that a household has to cut down on its basic consumption needs so as to cater for the medical and non-medical costs of the ill-health for one of its members, then that household is said to be incurring catastrophic payments (Kawakawa et al, 2002;). It has been suggested that a household's health care costs are considered catastrophic when they exceed 10% of a household's income (Ranson, 2002) or 40% of the household's capacity to pay as indicated by World Health Organisation (WHO), (Kawabata et al, 2002; Xu et al, 2003). Households are likely to fall into poverty or even deeper into poverty when faced with high health care expenses that deplete or nearly deplete their income (McIntyre et al, 2005; Gregson et al, 2006). In Chad, a study comparing both urban and rural households, reported that households that experienced an AIDS related death incurred higher costs than those that experienced a non-AIDS death (Wyss et al, 2004). A household is likely to lose income when both economically active patients and those who look after them do not carry out their usual activities. In the Ugandan study (Ntozi, 1997) HIV/AIDS translated into a 20.7% deficiency in household earnings. This is a very considerable amount of income lost by these households and is attributed to the long-term nature of HIV/AIDS. These

circumstances are likely to lead to a loss in income that may never be recovered. This is likely to further impoverish households, possibly leading to vulnerability to other diseases in future (Ntozi, 1997).

2.3.6 Coping Mechanisms for HIV/AIDS

Households will respond to the burden of HIV/AIDS using different methods so as to try and mitigate the negative effects of illness. The households' responses to the burden of illness are referred to as coping mechanisms. Coping mechanisms, in this study referred to responses that households used in the near future to counter the harmful effects of a given situation on an individual or household (Sauerborn et al, 1996). Additionally, the cost off illness to households may be compounded further for households and individuals without financial safeguards. Financial safeguards like insurance can protect poor households from potentially catastrophic health payments (Leive and Xu, 2007). The lack of insurance for households and in particular, poor households implies that individuals and their households have to incur high out of pocket payments for any illness related expenses.

The different coping mechanisms that households employ can be analysed along four major themes (Sauerborn et al, 1996). These included the kind of coping mechanisms a household employed, how the chosen coping mechanisms were influenced by social capital. The third theme was the order in which the coping mechanisms were used when multiple coping mechanisms were used. It was common for a household to use more than one coping mechanism (Sauerborn et al, 1996). Lastly, it is also important to consider the ability of the coping mechanism in mitigating the negative consequences of the cost of illness on the household.

The study carried out in India (Duraisamy et al, 2006) reported that the majority of patients (67%) reported having borrowed resources, while 16% said they had made use of their savings obtained earlier on in time. Only about 8% of PLHWA sold their assets and about 7 % used their assets as collateral to obtain money to cover costs due to ill health.

In response to the cost of illness, households take up different coping mechanisms to counter financial and time costs imposed on them (Sauerborn et al, 1996; Duraisamy et a, 2006). In response to financial costs households use cash at hand, savings, sell assets, borrow, vary income, use paid labour, free health care and receive gifts (Sauerborn et al, 1996). On the other hand, households respond to time costs by substituting labour between households and altering their capital-labour inputs in production. Households also hired labour and utilised free labour provided in the community (Sauerborn et al, 1996). Among the coping mechanisms that households employ includes labour substitution both within and amongst households. Duraisamy and colleagues (2005) report that individuals and households affected by HIV/AIDS sought alternative jobs and did extra work for other households to compensate for the work not done by the ill household members.

Households affected by HIV/AIDS in a rural area in Zimbabwe (Gregson et al, 2004) and in Chad (Wyss et al, 2004) were more likely to lose their economic productivity and fall into poverty. The negative economic impact of HIV/AIDS led to loss in assets and income associated with the direct and indirect costs of AIDS in both Chad and Zimbabwe. Mutyambizi (2002) and Russell (2005) found out that households sold assets, borrowed financial resources both informally and formally, received gifts from relatives and friends, diversified household income and sold livestock and other assets. To pay for AIDS related expenses and other related illnesses households in Chad (Wyss et al 2004) in the year 2004, spent their family savings and income, got loans from relatives and friends. These households also sold a number of assets and agricultural products. These households spent almost 50% of their budgets on health compared to control households that spent only 11% on health and 40% on food indicating that households had to sacrifice their basic needs to cater for HIV positive family members (Wyss et al, 2004).

2.3.7 Social Capital

There seems to be variance as to whether social capital plays a role in the response to the burden of illness on households (Holtrgrave and Crosby, 2003; Ntozi, 1997 and Thomas, 2006). There seems to be a decline in the role of community in supporting families and individuals affected by HIV/AIDS (Ntozi, 1996; Thomas, 2006). Furthermore, Holtgrave and Crosby (2003) confirm the perspective on the role of community and social support for households affected by disease. They suggest that the reduction in the burden of HIV/AIDS on households is closely linked to the social capital that the household had available to them.

Social capital provided affected households with both financial and human resources to counter costs of illness and loss of labour, by participating in household activities. Human resources may be used to look after the sick, orphans and also to provide the alternative labour for the household's economic activities. Gilbert and Soskolne (2003) put forward the proposition that social capital can positively influence the health of individuals in households. It is possible that not all poor or impoverished households face the same level of poor-health and this may be because of the impact of social networking (Gilbert and Soskolne, 2003). The social capital that households' can access forms a basis for some of the coping mechanisms they use. Therefore social capital is relevant in the response to economic burden of illnesses like HIV/AIDS.

The long period of illness and mortality associated with HIV/AIDS has placed serious strains on the family and other social support structures for PLWHA. Support and care is now, less widely obtained from the extended family and community (Ntozi, 1997). Consequently, in recent years the burden of caring has been restricted to the immediate family leading to further strain on these households and their resources (Ntozi, 1997). A study carried out in Namibia (Thomas, 2006) focussed on the importance of the household as a unit of care for HIV/AIDS patients. The study reported that the long periods of illness associated with HIV/AIDS, led to strains between household members.

Thomas (2006) further noted that HIV/AIDS led to a break down in family structures due to the economic and psychological strain placed on household members caring for their HIV/AIDS patients.

Ntozi (1997) suggests that extended families and communities at large in the Uganda no longer play an active role in caring for HIV/AIDS patients. The reasons put forward for this trend include the expensive nature of HIV/AIDS and the increased disintegration of households. This has resulted in lower empathy of community members for the sick. On the other hand, household members view HIV/AIDS as a disease that would most likely not get healed. Therefore, patients suffering from other illnesses tended to be provided with more care as they could later get better and participate in recovering lost income (Ntozi, 1997).

2.3.8 Free ART provision and its challenges

There is concern that even in cases of provision of free medication; households may be impoverished by the burden of HIV/AIDS (Piot et al, 2007; Rosen et al, 2007). Households may have low amounts of resources with which to advance or maintain their nutrition status (Piot et al, 2007; Rosen et al, 2007). They may also fail to get the adequate financial resources with which to cover their transportation costs, especially to health facilities.

The high donor participation in the fight against AIDS in Uganda coupled with reduced prices for ARVs has enhanced access to ART for HIV positive people. Unfortunately very many Ugandans still do not have access to these life saving drugs (Martinez-Jones et al, 2002; Diaz 2005). Families in Uganda have to give up financial and non-financial assets in order to provide their HIV positive family members with the necessary HIV/AIDS related care (Martinez-Jones and Anyama, 2002).

Although the price of ARVS was seen as the largest barrier to accessing ART, costs of related services like CD4 count and viral-load monitoring are also highly prohibitive when patients are required to pay for them. In addition to these issues, Uganda lacks adequately trained health personnel, appropriate infrastructure, has inadequate storage

and distribution facilities for ART services (Martinez-Jones and Anyama, 2002). On the other hand, voluntary counselling and testing (VCT) coverage is also not as high as it should be (Martinez-Jones et al, 2002). Once an individual has been initiated on ARVS, they require more than just medical attention to be at an optimal level of wellbeing. ART patients require special diets, time off to rest and seek health care associated with their condition. It is all these other associated needs for PLWHA, which place a strain and burden on households affected by HIV/AIDS.

2.4 The Ugandan Health System

2.4.1 Health Sector Reforms

In order to discuss the Ugandan Health System, one has to look at look at Uganda's history, first and some of the major milestones that it has faced over the years. The Ugandan health system was well distinguished as one of the best in the Eastern African region in the past. During this time, Uganda enjoyed both good health status indicators and good infrastructure. This was during the post-independence period up to the early 1970's. The health sector was however, negatively affected by the political and civil turmoil that took place during the 1970s. This later resulted in rundown, filthy structures and discontented staff. However in 1986, the then, new government of the National Resistance Movement (NRM), led by His Excellency Yoweri Kaguta Museveni took over power. The NRM government provided the impetus for change that would see the country as a whole undergoing transformation and change for the better, many years later up until this present day (MOH, 2004).

The government of Uganda put in place a national health policy and Health Sector Strategic Plan (HSSP) and a Health Policy Review Commission in 1987. The aim of these two policies was achieving redirection and reorganisation of the health sector services to attain primary health care objectives (MOH, 2000). The major programmes would be implemented through the sector wide approaches (SWAp). The HSSP has been

described as the translation of the UN MDGs into country specific targets in the context of Uganda (Ministry of Health, 2006). The HSSP, MDGs and the Poverty Eradication Action plan (PEAP) are all interlinked with the aim of achieving economic growth and poverty eradication through health sector initiatives and collaboration with other sectors. The health sector reform initiatives include the decentralization of the health care delivery system, the initiation of the Ugandan Minimum Health Care Package (UMHCP), inter-sectoral action for health, central organisation and management, public/private partnerships in health and effective community participation (MOH, 2006).

2.4.2 Health Care Providers

The delivery of health care services in Uganda is composed of three distinctive actors including the public and private sectors and the development partners. The latter, includes Non-Governmental Organisations (NGOs) all of who play a significant role in the health care services' provision in Uganda.

The public health system is characterised by a tiered system starting with the Ministry of Health (MOH) at the top of the echelon. The MOH is mandated with planning, setting policy, resource distribution and allocation functions. Health care is provided through a decentralised system with a great emphasis on health service provision at the district level. Decentralisation of the health sector took place according to the 1995 constitution and the 1997 Local Government Act, empowering the local government to participate fully in the health system at the district level and below (MOH, 2000).

The main public health facilities are 2 national referral hospitals, which are autonomous in their operations and 11 district referral hospitals. The remaining public health facilities fall under the District Health System where health centres (HC) are graded from HC 5 as the highest district referral facility to HC 1, which is the lowest district level facility (MOH, 2000).

The private Health sector in Uganda is significant and can be divided into Private Not for Profit (PNFP) and the Private for Profit (PFP). The PNFP health facilities are mostly

faith-based facilities. The faith-based facilities include hospitals and health centres, which fall under the umbrella of three faith bodies of Uganda. These are the Catholic Medical Bureau, Uganda Protestant Medical Bureau and the Uganda Muslim Medical Bureau (MOH, 2000). Uganda has a big PFP sector accounting for 70% of the total expenditure on health (MOH, 2000). The latter includes all types of health care providers who are licensed to provide health services under the auspices of private providers. The PFP health care providers include dentists, doctors and other health specialists.

There are a significant number of traditional and complementary health care providers in Uganda. These include non- biomedical health care providers like the Chinese and Indian alternative medicine providers. There are also the informal health care providers who provide health care without legal licensing from any health care providers organisation (MOH, 2000).

2.4.3 Health Care Financing

As pointed out earlier, the total health expenditure on health in Uganda in 2005 was 7.2% of GDP and the private sector contributed almost 70% of this expenditure. Health care financing in Uganda is characterised as being predominantly out-of–pocket based, as households contributed almost 51.3% to the private sector's total expenditure on health. The government of Uganda contributed 30.0% of the total expenditure on health in 2005. Although this had increased from 26.8 % in 2000, it is still very low (WHO, 2007d). The external sources of finance including NGOs contributed almost 34.9 % of the expenditure on health in 2005. Development partners including NGOs in Uganda are a major source of health financing, especially for diseases like HIV/AIDS and for areas affected by conflict and civil unrest like northern Uganda.

2.4.4 Situation Analysis of HIV/AIDS in Uganda

The first HIV/AIDS case was reported in 1982, making Uganda one of the first countries to discover and to be hit by the HIV/AIDS scourge in Africa (Uganda Aids Commission Secretariat, 2002; Coutinho, 2003). The NRM government almost immediately followed these early warning signs and adopted a transparent policy to deal with the AIDS scourge (Coutinho, 2003; MOH, 2003). The Government instituted many initiatives in the fight against AIDS. These approaches included the Multi-Sectoral AIDS control Approach (MACA) and the National Operation Plan. The various initiatives were aimed at involving various sectors, civil society and Government in the fight against AIDS (MOH, 2003). The initiatives put in place by the government were to bring about success for the country as a whole in the fight against AIDS. In spite all the initiatives put in place, success was not immediately realised as a result of the long epidemiological cycle that characterises HIV/AIDS. The HIV prevalence in Uganda declined tremendously during the 1990s from almost 22% to 6.4 % in 2006 (MOH, 2006). The prevalence varies from one area to another and presents rural-urban, regional and gender variations as well. The HIV prevalence was very low in some areas of West Nile at 2.3%. It was as high as 8.5 % in Kampala, mid-north and in some central areas of the country (MOH, 2006). The reason for this variation could be explained by the civil unrest that has characterised the mid-northern region for almost the last 20 years and has seen many people displaced into camps (Uganda AIDS Commission Secretariat, 2002).

Uganda lost about 1 million people to AIDS over the last 20 years and has almost 1.1 million people are currently living with HIV/AIDS. Of those affected, 100,000 were possibly in need of ART and 75,000 were already receiving ART in 2005 (MOH, 2003). The HIV/AIDS initiatives put in place also involved a large number of development partners who rallied behind the government and the people of Uganda both financially and also through provision of technical support. Through the intensive efforts of both the Government and development partners, ARVS were introduced in Uganda in the early 1990's (MOH, 2003). These life saving drugs, were initially only afforded by the rich and

those, whose employers contributed partly or fully to their cost. The government of Uganda has been able to bargain for lower prices for ARVS and has been also able to import cheaper generics, mostly from India. The lowered prices coupled with high development support meant that some of the people who needed these life saving drugs could have access to them (MOH, 2003). Although a lot of effort has been put into HIV/AIDS initiatives, there is still an immense need to scale-up ART provision in Uganda. Sine there is a high number of people who would be eligible but are not able to access these life saving drugs.

2.4.5 Health Facilities Providing ART in Uganda

The Ministry of Health in Uganda set up an Advisory board and Medical Access Uganda-Limited in 1998, which is a private-not-for-profit institution. This body was responsible for endorsing health facilities to provide ART. Initially, five health centres were endorsed including Joint Clinical Research Centre (JCRC), Nsambya hospital, MildMay Centre, Mengo hospital and Mulago hospital. Of all these facilities, JCRC was the first health facility to offer ARVS where 1,700 people were treated in 1998 (MOH, 2003). There are currently twenty health facilities in Uganda that have put in place a system of ART provision. These health facilities include the regional referral hospitals of Mbarara, Mbale, Soroti, Kabale, Arua, Masaka, Fort Portal, Gulu and The AIDS Support Organisation (TASO). The private health facilities include CASE medical centre, Victoria medical centre, KADIC and the surgery (MOH, 2003).

The WHO recommended that health workers follow certain standardised guidelines when initiating HIV positive individuals on ART. These guidelines state that to be eligible for ART, an HIV positive individual should have a CD4 count of <200 cells/ml and or should be in the WHO symptomatic stage 3 OR 4 (WHO, 2006). HIV positive individuals also have to undergo an adherence test, which will ensure that once they are initiated on ART, they will be able to comply with this treatment for life as it designed to be (MOH, 2003). The individual adherence may depend on a number of factors. These factors may include the socioeconomic status, the social support they receive, distance

from the health facility and their income status (Martinez-Jones and Anyama, 2002). These conditions come with high costs for many people, even though they may be lucky enough to get into free treatment regimes. They may face economic burdens, which can subsequently lead to impoverishment and poverty. This usually leads to cutting down on expenditure for other basic needs like appropriate food, so as to comply with treatment. This is also of concern as HIV positive individuals on ART require good diet due to the medication they take and they also need to take time off to attend health care facilities, which often imply that they may lose income due to days not worked as a result of illness and seeking health care.

2.5 Summary of the Literature Review

The burden of disease is generally high for households and most especially in developing countries. There are however three major diseases that contribute to the high cost of illness towards households. These include HIV/AIDS, tuberculosis and malaria; however the most outstanding disease is HIV/AIDS, which is more prominent as it affects those people in their most economically active stage in life. HIV/AIDS has placed a high burden on individuals and households through morbidity and mortality associated with HIV/AIDS. The cost of illness with particular reference to HIV/AIDS is associated with both direct costs and indirect costs due to loss in productivity of individuals and households. When an individual is infected with HIV/AIDS, they need both financial and human resources to take care of them from the time they are infected up until their death. On the other hand, in the process of seeking and providing care for HIV positive patients, households face high opportunity costs of spending time away from their economic activities. These individuals also face losses in income and earnings as they incur high expenses and yet are unable to work due to HIV/AIDS. Household members have to sell their assets and spend less time in their different productive activities so as to look after the HIV infected household members. In addition to the above facts, HIV/AIDS is also likely to affect more than one member in a particular household. This exacerbates the economic burden of HIV/AIDS on households.

Given the provision of free ARVs, patients face less medical costs associated with ARVs but may also incur medical costs for the times before their ART appointments. Patient's appointments may be up to two months apart, thereby requiring patients to cover their own medical costs in this time. Additionally, HIV/AIDS is a chronic illness that requires life long commitment to medication. In addition to this, HIV/AIDS is associated with recurrent opportunistic infections and therefore requires regular visits to health facilities to obtain ARVs and other medical supplies. In Uganda, ARVs are now being given free of charge to all HIV positive patients who qualify. However the literature suggests that even in cases of free health care, individuals and households may face hindrances in access to health care. These hindrances may come from various sources, including high non-medical costs required to seek care. These non-medical costs include the cost of transport and cost of special foods to compliment the strong drugs being taken. Foregone benefits are also deterrent for households in seeking care. The negative impact of cost of illness on households implies that households come up with responses to this burden. These responses are referred to as coping mechanisms. These coping mechanisms may also include the social capital that households have available to respond to the burden of disease. The household may employ the coping mechanisms and manage to counter the negative effects of HIV/AIDS on them or remain indifferent to coping mechanisms. However most often than not, households will be at a lower level of utility and income due to failure to cope with HIV/AIDS.

The types of coping mechanisms available to households include sale of assets, borrowing, intra-labour substitution, alteration of the basic budget and other such methods. In light of this information, a conceptual framework for analysing the data and results of this study was formulated.

2.6 Conceptual framework: Economic consequences and coping mechanisms

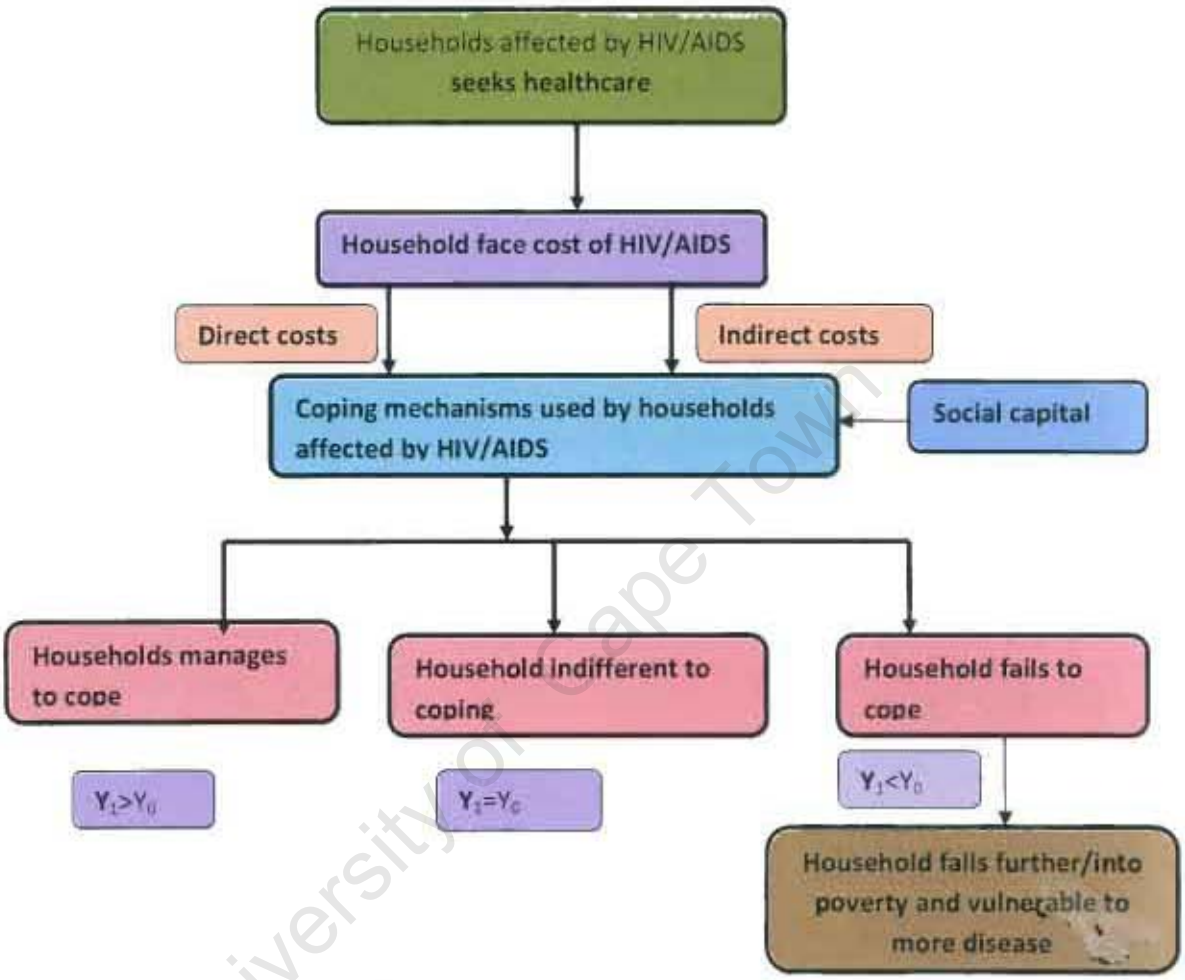
In summary of the literature, a conceptual framework has been derived that covers all the major issues that have been discussed in this chapter. Therefore this conceptual

framework is based on PLWHA who have been initiated on ART, implying that they sought healthcare for their illness. A PLWHA, who has been initiated on ART, will have to seek regular care for their status so as to maintain their health at optimal levels. PLWHA on ART are given regular appointments to the ART facilities, which are usually one to two months in between. In the event of a sickness due to an HIV/AIDS related illness, a PLWHA is faced with both direct and indirect costs. There is need to understand that the household to which the PLWHA belongs is affected as a whole and is therefore the unit of analysis for this study.

In the event of illness, the household members may have to look after the PLWHA who is ill and therefore face the indirect costs associated with HIV/AIDS. These indirect costs may include loss of time away from work or school. In addition, the PLWHA and their caregivers will also experience a loss in income due to the direct costs of HIV/AIDS and time spent away from work.

In response to the costs of HIV/AIDS, households come up with coping mechanisms, which vary given the resources they have including social capital or social networks. These coping mechanisms assist households to respond to the burden of illness through borrowing, selling their assets, altering their consumption behaviour and through other coping mechanisms. The household will therefore have to deal with the after effects of utilising coping mechanisms. The after effects of coping for a household may include the household's inability to cope with the burden of HIV/AIDS or the coping mechanisms may have no effect on mitigating the burden of HIV/AIDS on them. On the other end, coping mechanisms may also have the result into household being able to mitigate the burden of illness due to HIV/AIDS. This may be shown by a household's income increasing in the period after which they employ coping mechanisms as compared to the period before coping.

Figure 1: Conceptual framework; Economic consequences and coping mechanisms



Formulated by author

CHAPTER THREE-METHODOLOGY

3.1 Introduction

This chapter on methodology was specifically aimed at describing in detail the information that the study collects, the data collection methods and instruments and the data analysis. This chapter was divided into different sub-sections including the description of the study design, population and sampling strategy, data collection process and data analysis plan. This was specifically a cost of illness study.

There are various methods used by different studies in analysing the burden of HIV/AIDS on households. There is heterogeneity in the methods that households use to cope with illness, including HIV/AIDS. The literature also gives a variety of ways that social capital was interpreted, measured and its impact on households in terms of methods used for coping.

Given budget and time constraints, a cross-sectional study design was designed. Nevertheless, a cross-sectional study design is important in the study of coping of various variables like burden of disease and coping mechanisms used by a household at a single point in time. Cross-section study or survey is ideal in circumstances where time and finances are somewhat limited. In this study, using the cross-sectional study design, the relationship between costs incurred, coping mechanisms, social capital and the urban or rural area was examined.

3.2 Study Design

The most ideal study design that should be used to estimate the burden of disease is a longitudinal or follow-up study design. In order to understand household burden of HIV/AIDS in Uganda, this study took the form of a cross-sectional study design in which all the information of interest was collected at the same point in time. The study used a

recall period of one month. Through patient's interviews, data was obtained on both direct and indirect costs associated with various needs and services that the PLWHA received. The PLWHA who were interviewed in this study were the informants of their respective households which they represented. In this study direct costs were divided into direct medical and direct non- medical costs. Direct medical costs include the cost of medical care in general. This specifically refers to cost of drugs, laboratory tests, consultation fees and other such costs. Direct non-medical costs include the cost of transport, food and other costs associated with the HIV/AIDS condition. Indirect costs include opportunity costs of being away from work, loss of earnings due to days not worked and time of caregivers spent looking after patients.

This study was mainly quantitative in nature but included a qualitative component. Focus Group Discussions (FGDs) were carried out in each of the health facilities where patients were interviewed. These FGDs were held to obtain views and perceptions of the patients on the economic burden imposed by HIV/AIDS and the coping mechanisms that their households used to respond to this burden. The FGDs aimed at cross-checking and supplementing the information obtained from the survey questionnaire. The FGDs with the patients and interviews with other clinic staff were also aimed at highlighting themes and outstanding cases that the quantitative component may not have been able to capture.

3.3 Population and Sampling

3.3.1 Population for the questionnaires

The participants selected were HIV positive individuals on ART. They were identified from two health facilities offering ART. These health facilities were purposively selected based on the higher number of patients served The study took place in one urban and one rural area as it was suspected that the study might generate varying results in both these areas. This study therefore allows for comparability between urban and rural area patients in regards to the kinds of costs they incur, coping mechanisms and social capital they employed in response to the burden of HIV/AIDS.

The study was carried out under the umbrella of The AIDS Support Organisation in Uganda (TASO). TASO was among the first organisations to coordinate and mobilise people infected and affected by HIV/AIDS in Uganda. TASO was initially founded in a private house of a person affected by HIV/AIDS in the early 1980's when stigma and suffering for PLWHA was at its highest. TASO has over the years grown to be one of the biggest organisations dealing with HIV/AIDS in Uganda. It may have the highest geographical coverage in terms of areas and regions served with HIV/AIDS services' providers in Uganda.

Two districts served by TASO Uganda including, Entebbe and Masaka, were selected for the study. Entebbe corresponds to the urban area while Masaka district corresponds to the rural area. Entebbe district is found just about 45 minutes away from Kampala (capital city of Uganda) and is home to the only international airport in Uganda. Masaka on the other hand is about two hundred kilometres from the capital city Kampala and is located along the Trans-African high way. The location of Masaka district means that it is easily accessed by many travellers and visitors. It was also one of the earliest districts to be affected by HIV/AIDS. The criterion for the selection of the districts was mainly to keep the urban-rural divide for comparison and secondly to adjust to the researcher limited sources (time and budget).

In each of the two districts, one health facility serviced by TASO was chosen for the study. This was the main TASO operating centre in the respective area. In each district that TASO operates, it has a major centre that is the focus of its HIV/AIDS services. However, it is common to find that TASO has smaller centres that serve more far-flung communities especially in the rural settings. TASO also offers community outreach programmes and home-based care, which are facilitated by its staff from the main centre in a given district in which TASO operates.

3.3.2 Sampling of subjects

Within the two health facilities, patients to be interviewed were conveniently sampled, by selecting any first patient who was willing to take part in the study. The patients arrived very early at the facility and in large numbers on the days they had appointments for ART. There was no accurate way of randomly sampling the patients. The patients were selected as they waited to receive treatment at the different stages they had to go through in the health facility. Facility organisation arrangements imply that on the day of a patient's appointment, patients had to go through various examinations and service points to receive a comprehensive check up. The study aimed at obtaining a sample of 150 patient interviews per study location, that is, a total sample size of 300 patients' questionnaires. However, this was finally reduced to 290 due to missing questionnaires and incorrect completion of questionnaires in the field. Considering time and resources constraints, this sample size is large enough to be able to establish statistically important differences between urban and rural participants.

Table 1: Summary of respondents

	Survey Respondents	FGDs with patients	Interviews with Staff
Entebbe	**127**	**2(16 participants)**	**1(2 participants)**
Masaka	**163**	**1(14 participants)**	**1(2 participants)**
Total	**290**	**3(30 participants)**	**2(4 participants)**

3.3.3 Data collection tools

Patients' questionnaires

An administered questionnaire was developed after a series of consultations and analyses of questionnaires developed and used by other studies. The questionnaire contained four sections including: background information, socio-economic and demographic

characteristics, and patients' direct and indirect costs on healthcare, coping mechanisms and social capital.

Interviewers' Training

The study used three interviewers during the course of data collection. This included the main researcher and two assistants. The research assistants undertook some training prior to going to the field. This process facilitated the fine tuning of the questionnaire and also clarification of any issues that arose. The interviewers used in this study were university graduates who had prior, valuable training in data collection and conducting research in general. Thus, it was an advantage that they have been exposed to some level of research and fieldwork.

Piloting Questionnaire

A few days before the data collection process began; the research assistants were briefed about the study. Briefing covered issues such as the study topic, study design, prospective study participants, questionnaire content and all issues that were thought to be of relevance to the data collection process. The questionnaire was designed in English but researchers employed were well conversant in both English and Luganda, which were the languages used in the interviews with patients in both Entebbe and Masaka.

The questionnaire was then piloted to a few patients, a day before the actual survey commenced. This enabled the researchers to pick up any inconsistencies in the questionnaire and to clarify issues that arose before the actual study. This time was also used to clarify issues for the interviewers in regards to administering the questionnaire to the study participants. Thereafter, the questionnaire was adjusted in light of the corrections collected and clarifications were also made to a final questionnaire to be used for the actual data collection process.

3.4 Questionnaire design

The questionnaire used in this study was based on the four objectives as discussed in the introduction of the study. The questionnaire was further divided into six major sections for purposes of organisation and logic. These sections included;

A. Participant details
B. Socio-economic information on the household to which a study participant belonged
C. Direct costs and healthcare utilisation
D. Indirect costs of HIV/AIDS on the household
E. Coping strategies and mechanisms
F. Household expenditure patterns, social capital and support

The questionnaire was quantitative, pre-coded and close-ended in nature. It was also a structured questionnaire that followed the objectives and analytical framework of this study. The questionnaire was 24 pages long and contained about 88 questions. It took on average about 30-40 minutes to administer the questionnaire. However it was common to take longer to carry out the interview given the sensitive nature of HIV/AIDS, as patients took this opportunity to air out their feelings.

3.5 Focus Group Discussions (FGDs)

In this study, three Focus Group Discussions (FGDs) in total were conducted. These FGDs consisted of between 6-15 people per FGD at each health facility. The initial intention was to carry out four FGDs, two in each facility. However due to unforeseen circumstances the second FGD in Masaka did not take place as the participants were called on to carry out a community awareness campaign that day. Furthermore, it was difficult to re-organise another FGD given the time frame for the study and the appointment schedule for the patients.

There discussions held with staff members from each facility to obtain their views on the topic of interest to this study. The staff members included patient representatives who are also PLWHA who work at TASO as volunteers to make the process of patient handling an easier one. A discussion was carried out in each health facility with two staff members. This was to provide more information on the operations and perspectives obtained from the patients. The discussion with the staff members was also to provide an overview on how the whole process ART is handled in the respective facility and to give us more information on the operations of the particular health facilities included in the study.

The FGDs were used to obtain qualitative data that would otherwise be difficult to obtain using the questionnaires. Discussions included the provision of free ARVs and the role this plays in reducing the burden or cost of HIV/AIDS on patients. The FGDs also involved discussions on patients' perceptions on the cost of health care and suggestions on how this situation can be improved for them.

The FGD was carried out along the guidance of a schedule, which contained the guiding questions. The FGD schedule was mainly used to solicit for information on the economic burden of HIV/AIDS and social capital of PLWA. The FGD contained 17 questions, which were used to facilitate the discussions with participants.

Participants were recruited on the day that they attended the health facility. They were requested to sign a consent form prior to recruitment into the study. The study only recruited those participants aged 18 years and above. The FGDs sessions took on average between one to one and half hours and were conducted on the health facility premises. It was common for some of the FGD participants to have been part of the participants who were interviewed earlier on. The FGD sessions were tape recorded to facilitate faithful transcription for analysis. This was done after receiving informed consent given in writing by FGD participants to record the discussion. The FGD was moderated by the main researcher with the assistance of a research assistant. In addition to recording, both the researcher and assistant took down notes during the FGD. The notes, which were written out on paper, were a source of back up in case the recorder turned out to be faulty.

These hand written notes were also to be used to supplement the recorded data in case of missing data. Qualitative data obtained from the focus group discussions was transcribed from the recorded meetings into written dialogues. The data and information obtained from the FGDs was analysed manually. This enabled the analysis of the general and specific themes and messages conveyed by the participants. Full copies of the FGD schedule and consent forms are available in the appendix section as Appendix 1 and 2 respectively.

3.6 Data Analysis

3.6.1 Data Entry and cleaning of questionnaire

The closed-ended questionnaire was pre-coded prior to going to the field. The questionnaire was used to construct a template in Epi-info version 3.4.3 into which all questionnaires from the field where entered. The Epi-info software is based on the Microsoft database software. The data was then cleaned for inconsistencies and errors, while comparing with the questionnaires obtained from the field.

3.6.2 Data Analysis

The data entered into Epi-Info was exported to Microsoft office Excel 2007 and STATA statistical package Version 8.0 [stata, 2008]. The STATA package was the main software used for analysis in this study. Microsoft excel was also used mainly for organising and arranging the results and for constructing and presenting results' tables. The data collected was analysed using descriptive statistics on all variables covered in the questionnaire. In the data analysis plan, the overall form of analysis is based on the foundation of the conceptual framework. The conceptual framework was discussed earlier on in the literature review section.

The data analysis plan commences with listing the objectives and matching them with the data collected to ensure that the objectives of interest are met satisfactorily. The main variables from the quantitative data include the direct and indirect of healthcare

utilisation and expenditure in the last month. The coping mechanisms used when an episode of illness was encountered by the household is also of interest to this study. The cost of coming to the clinic on the day of the interview will be analysed.

Then variables like direct costs, indirect and coping mechanisms are presented using descriptive statistics. These include averages, ranges and relative frequencies. At this point data on socio-economic and demographic characteristics was listed and presented in quartiles, depending on whether a participant was from the urban or rural area. Qualitative data as obtained from the FGD was transcribed into a dialogue format and then sorted along similar lines of discussion. The data was then presented along the themes and variables of interest for this study. Furthermore, the qualitative data was presented using examples of the participant contributions and discussions. In addition, qualitative data obtained from the FGDs was analysed manually for major themes and common thoughts were reported by using representative cases from both the urban and rural areas.

3.7 Direct Cost

3.7.1 Direct Costs of seeking care for the last month

The direct costs of seeking care in the last month included costs of direct medical and non-medical costs, which were incurred by the participant in the last month before they were interviewed and on the day they came for their appointment to the health facility. The direct medical costs included cost of consultations, drugs/medicine, vitamins/supplements and the cost of laboratory tests and radiology.

The non-medical direct costs of seeking healthcare in the last month included the cost of special food, transport to get to the health facility and household purchases for healthcare like bandages, disinfectant and sponges. Some equations are presented below to give more information on these costs.

Monthly direct costs= Direct medical costs + Direct non-medical costs

Direct medical costs= consultation+ drugs+ supplements+ laboratory tests

Direct non-medical costs= special food + transport + household healthcare purchases

3.7.2 Direct costs for seeking care of today's visit

The cost of seeking healthcare for PLWHA on ART was also calculated on the day of the appointment to the HIV/AIDS clinic. The costs considered on that day included the cost of all medical items, transport, fees, tests, drugs and the cost of food eaten while at the clinic.

Direct cost= medical costs + transport + fees + tests + drugs + food

The urban-rural divide and comparison were maintained in the analysis and presentation of all the variables of this study.

3.8 Indirect Costs of seeking healthcare

Indirect costs of seeking health care for PLWHA on ART included all the foregone earnings lost or the opportunity cost of seeking care or being ill due to an HIV/AIDS related illness. The indirect costs were looked in terms days lost by PLWHA when they were ill and unable to work in the last month. In addition days lost by a caregiver who looked after the PLWHA when they were ill were also considered. The indirect costs were calculated using the recall period of one month and summed up for both Entebbe and Masaka. The days lost due to illness were used to refer to the number of days a participant was seriously ill in the last month and for how many days they were looked after. The mean days lost were then derived for both PLWHA and their caregivers for

both study areas. These were then multiplied by the GDP per capita for Uganda, per day to obtain the total indirect costs of seeking care per person per year.

The indirect costs included the time lost by the PLWHA as they travelled to seek care and the time of waiting at the health facility. The indirect cost of time spent was calculated for only PLWHA as almost none reported being accompanied for their ART clinic appointment. The time costs of seeking care were presented for both study sites.

3.9 Total Direct and Indirect Costs

The total direct and indirect costs were summed up to give the total costs of seeking care for PLWHA on ART. There was comparison between the total direct costs and total indirect costs for both the urban and rural areas. This was aimed at finding out the type of cost outweighed the other and the significance of these results for future policy making.

3.10 Coping Mechanisms and Social support

The coping mechanisms used in response to the economic burden of HIV/AIDS were also recorded. These responses were divided into sections in the questionnaire, including coping strategies and coping mechanisms. The coping strategies included the responses of households to the last time they sought treatment for HIV/AIDS or when they visited the health facility. The coping mechanisms on the other hand included the coping mechanisms used when the PLWHA, fell seriously ill in the last month and how they responded to the costs they incurred.

Coping mechanisms when faced with monetary impediments in the past

The participants were required to list the various methods they had used if they had faced money constraints the last time they sought treatment in the last month. The various methods listed included; stopped or delayed treatment, sought alternative treatment,

sought cheaper providers like NGO's, reduced household expenditure, used savings, used medical aid, borrowed, sold assets, NGO support and others.

Coping mechanisms the last time you were seriously ill in the last month

The coping mechanisms also covered the time that the PLWHA fell seriously ill and what they did in response to the costs they incurred due to an HIV/AIDS related illness in the last month. The coping mechanisms listed in the questionnaire included payment of costs using medical aids, household savings and sell of valuables. The study participants were also asked whether they had used income generated from savings circles or clubs, income generating projects and home based labour. Other coping mechanisms included borrowing from various members in the household or community, sell of any assets reduced spending on various household items and financial gifts received from various people in the community

3.11 Household Income

Household expenditure, reported for the last month was used as proxy for household income. The study participants were interviewed on various household items including food, transport, energy payments, water, rent, school fees, clothing, healthcare and miscellaneous items. The individual household expenditure items were then summed up to obtain the total household income. Thereafter, four income quartiles were derived from the household expenditure. These indicated the top and poorest groups of participants and the two groups in between.

3.12 Quality Control

Quality control was a priority right from the early stages of proposal writing and questionnaire formulation. Reviews of similar studies and their questionnaires were carried out to ensure that the questionnaire was as comprehensive as possible. There was

review of all possible variables and data needed to meet the objectives of this study. The literature was used to support the selection of the variables chosen for this study. The questionnaire was thoroughly reviewed a number of times to ensure consistency and coherence. As mentioned above, interviewers were trained before the data collection took place. Similarly, a pilot study was carried out to rectify problem areas.

Quality control was also ensured for the FGD schedule before the data collection stage and also in the data analysis stage. The quality control for the FGD was similar to that of the questionnaire in this study.

While in the field, close supervision was ensured during the course of the interviews and after patients had left the clinic. There was follow-up of completed questionnaires to ensure that the interviewers were carrying out the interviews in a proper manner and that all the sections of the questionnaire had been filled properly. Beyond the piloting day, the study principal investigator was available to check that the first few questionnaires have been filled out properly. Thus, any misunderstanding regarding the interpretation of the questionnaire was rectified early on in the data collection process.

Quality of data entry and cleaning was also a priority in this study; entry of data was doubled checked against the field questionnaires for entry mistakes. To maintain quality control in data analysis stage, a data analysis plan was developed as mentioned above. This was followed as much as possible to ensure systematic and correct data analysis of the highest quality.

3.13 Potential shortcoming of the study design

The cross-sectional study design used may not give a strong suggestion of the association or relationship between variables as it lacks an element of follow-up. However, an association between variables like costs of illness and SES can still be deduced by this study design. Given financial and time constraints, the household study was not carried out in the community or at individual households. The PLHWA in this study were used as informants for the rest of the household they represented. Nevertheless, it is not possible to confirm that an individual is HIV positive without carrying out a test. These

circumstances, therefore dictate that the best way to interview PLHWA, given its sensitive nature is at a health facility dealing with PLHWA.

This study may potentially have some bias, given that participants were selected from the health facilities and not there community. There is a possibility that the PLHWA in the community may incur different costs and use different coping mechanisms from those attending the health facility. However, it is expected that the situation in the community should be worse for PLWHA who lack access to health facilities and therefore lack HIV/AIDS services like free ART.

The choice of research areas and participants may limit the extrapolation of study results to other areas and participants who vary from those used in the study. The study took place in two districts in Uganda in the central region and therefore the study results may not be easily extrapolated to other regions in Uganda, given the differences in socio-economic and demographic characteristics.

The sample used in this study may not be big enough for the results of this study to be extrapolated to all the HIV positive patients on ART. There are currently about 150,000 HIV positive patients living with HIV/AIDS, 75,000 of whom are on ART (WHO, 2005).

CHAPTER FOUR-RESULTS

4.1 Introduction

This chapter presented the results of this study in line with its objectives. The objectives were stated and described in detail in the introductory chapter of this report. The results section commenced with a description of socio-economic and demographic characteristics of participants. The study reported the monthly expenditures and health facility visits of the participants. Thereafter, the economic burden of HIV/AIDS was presented as direct and indirect costs, in relation to whether a participant was from the urban or rural area. Thereafter coping mechanisms used by households and social capital available to them was also reported. The second part of the results reports the findings of the FGDs conducted in both Entebbe and Masaka to give an overview of the findings. This study was largely a quantitative study but a qualitative component was also included to supplement the results of the later. The study presents all the results along an urban and rural differentiation, where Entebbe is the urban area and Masaka is the rural area.

4.2 Descriptive statistics of the participants

4.2.2 Socio-Economic and Demographic characteristics

Table 1 below presents the demographic characteristics of the participants of this study. There were 290 respondents for the whole study, including 127 participants from Entebbe and 169 participants from Masaka. The urban area is likely to differ from the rural area in many aspects including their socio-economic status. Therefore, this study maintained an urban and rural divide in the presentation of these results so as to study the different variables in respect to the urban and rural areas. The Average age for males and females in Entebbe was 37 and 36 respectively and 42 and 38 years for male and female participants respectively in Masaka. The majority of participants interviewed were heads of their respective households. The average household size consisted of about five

household members. Entebbe reported a higher percentage of participants who could read in any language as compared to Masaka.

Table 2: Demographic Characteristics

VARIABLES	CLINIC SITE (AREA)	
	Entebbe(Urban)	Masaka (Rural)
Number of participants	127	163
Males	26.0%	22.1%
Females	74.0%	78.0 %
Males' Age(range)	36.9 (26-67)	42.4(19-68)
Females' Age (range)	35.9(20-60)	38.1(20-69)
Mean household size	5.3	5.3
Relationship to Household head		
Household head	67.0%	71.0%
Spouse/wife	14.1%	9.8%
Daughter/son	6.3%	13.5%
Ability to read		
Very well	64.6%	53.4%
Fairly well	31.5%	43.0%
Disclosed HIV status		
	124(97.6%)	154(94.5%)

4.2.2 Socio-economic characteristics

Table 2 presents the socio-economic characteristics of the participants in this study whilst differentiating between the urban and rural areas. Almost half of the urban and rural participants reported that they had some primary education but they never completed. There were a high number of participants who had had at least some secondary school

education or obtained a higher qualification. In line with the literature, most participants from Masaka reported that they were subsistence farmers, compared with only 8.66% of the Entebbe participants. There were more unemployed participants in the urban study area of Entebbe as compared to Masaka. The majority of participants irrespective of whether they came from the urban or rural area had disclosed their status to another person.

Table 3: Socio-economic characteristics

	ENTEBBE	MASAKA
Education level		
some primary education	54(42.5%)	88(54.32%)
Secondary school +	47 (33.1%)	35(21.98%)
Never attended school	10(7.9%)	7(4.3%)
Marital status		
Single	29.13%	12.27%
Married	30.71%	20.86%
Divorced	11.81%	11.04%
Widow/widower	21.26%	44.79%
Occupation		
Unemployed	23.62%	14.11%
Subsistence farmer	8.66%	40.49%
small trader	16.55%	18.40%
self employed	19.69%	14.72%
Other	31.50%	12.27%

4.2.3 Asset profile and possessions

The findings on the asset profile and possessions of the households in this study are presented in table 4 below. There highest percentage of participants reported living in a

house or brick structure. However the study did not distinguish between participants who rented or owned the house that they reported staying in. The commonest roofing material was corrugated iron sheets, which were used by the majority of the participants in both Entebbe and Masaka. The different types of water sources reported by the participants varied greatly and not one single source was commonly used. Almost half of the participants in Entebbe reported using public taps while half of the participants in Masaka reported using public wells.

There were a low number of participants in the urban and rural area who reported using flush toilets as a sanitary facility. Conversely, the traditional pit latrine and the ventilated improved pit latrines were commonly used by participants in both sites.

Table 4: Asset profile and possessions

HOUSEHOLD TYPE	ENTEBBE	MASAKA
house or brick structure	83.46%	70.37%
Informal house made of mud	10.24%	20.37%
Roof material		
Corrugated Iron sheets	92.13%	94.48%
Water source		
public tap	40.16%	28.22%
piped water in yard/plot	22.83%	3.68%
public well	20.48%	47.85%
Other	16.54%	20.24%
Toilet type		
Traditional pit latrine	39.37%	40.49%
Ventilated improved pit latrine	51.18%	58.28%

4.2.4 HIV/AIDS services referral

The participants at the health facilities were mainly referred by health care professionals whom they had previously visited for various reasons. There were an equal number of patients referred by healthcare workers as those patients referred by relatives and friends at the urban study site. All the participants in Entebbe and the majority in Masaka reported that they had been tested and referred from another health facility before they came to TASO, where they are now registered clients.

4.3 DIRECT COSTS AND EXPENDITURE

4.4 Healthcare expenditure in the last month

This section presented the results of the direct costs and expenditure incurred as a result of seeking care for HIV/AIDS. Table 5, below, presents the results on the direct cost and expenditure incurred by PLWHA and their households in relation to access to free ART. The average expenditure on health care in the last month, before participants were interviewed was higher for Entebbe than Masaka. The expenditure incurred is in light of the fact that PLWHA have access to free HIV/AIDS care from TASO, the NGO where this study was carried out. The average cost of treatment in the last month was US $ 13 for the urban area and US $ 8.6 for the rural area participants. However, in extreme cases, some participants reported that they incurred on average, more than US $ 100 on treatment costs in seeking care for HIV/AIDS in the last month.

4.4.1 Average household monthly expenditure

The PLWHA in the urban area reported a higher average monthly household expenditure as compared to the rural area participants. The participants in the urban area reported average expenditures per household of about US $ 195 as compared to US $ 151 for the rural area participants. There was a large range between the lowest and highest reported household expenditure for both the urban and rural area participants. As shown in table 5, household expenditure on average, ranged from a few dollars per month to US $ 2339 for the urban area and US $ 1971 for the rural area.

4.4.2 Healthcare expenditure on day of appointment

There were a high proportion of participants who reported that they spent over two dollars a day on healthcare related costs on the day that they visited the health facility in

relation with their HIV/AIDS appointment. However, like most of the expenditure items in this study, some participants reported that they had not spent any money on the day they visited the HIV/AIDS facility.

Table 5: Direct costs and expenditure in U Shs and US $ in 2007

AVERAGE TREATMENT COST LAST MONTH		
Mean(min-max)	**Entebbe**	**Masaka**
U Shs	**22,705(0-240,000)**	**14,761(0-260,000)**
USD(US $)	**13.16(0-139.1)**	**8.56(0-150.7)**
Average monthly Household expenditure		
U Shs	**33,6872(8,000-4,034,000)**	**260,482(6,000-3,400,000)**
USD(US $)	**195.29(4.64-2338.55)**	**151.0(3.48-1971.01)**
Clinic visit cost for today		
U Shs	**4,618(500-31,700)**	**4,592(0-30,500)**
USD(US $)	**2.68(0.29-18.38)**	**2.66(0-17.68)**

Exchange rate: 1 USD: 1725 Uganda Shillings

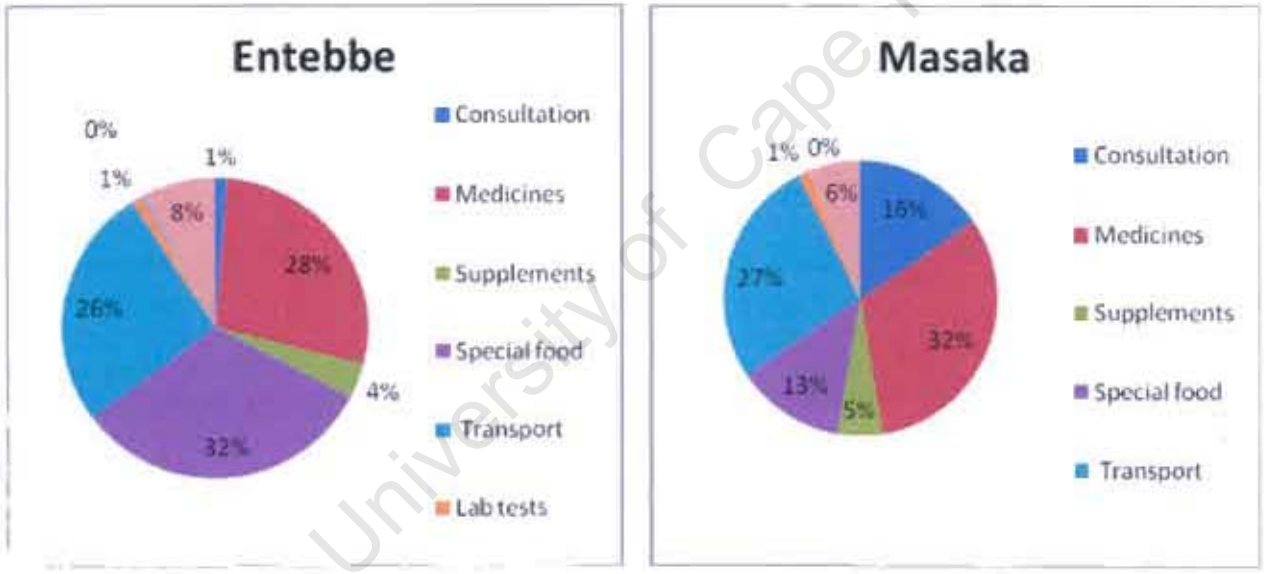
Source: (http://www.oanda.com/convert/fxhistory)

4.4.3 Breakdown of the direct costs of healthcare in the last month

The figure 2, below, presents the break down of direct costs on both medical and non-medical costs in the last month before the PLWHA's appointment at the health facility. The month prior to their appointment at the ART clinic, PLWHA incurred direct costs on various items in relation to their health care expenditure. The three major categories of expenses were on medicines, transport and special food. The trends were generally similar for participants in the urban and rural area. However, participants in the rural area incurred slightly higher proportions of their expenditure on medicines as compared to participants in the urban area. The proportion of expenditure on direct non-medical costs exceeded that on direct medical costs. The direct non-medical costs included transport

and expenditure on special foods. Transport costs were likewise high for participants in both sites. There was a significantly higher expenditure on special food by the urban participants as compared to the participants in the rural area. The expenditure on consultation costs seems was higher for the rural area participants as compared to the urban area participants who spent almost no part of their health care expenditure on consultation fees.

Figure 2: Breakdown of the last month's average healthcare related cost

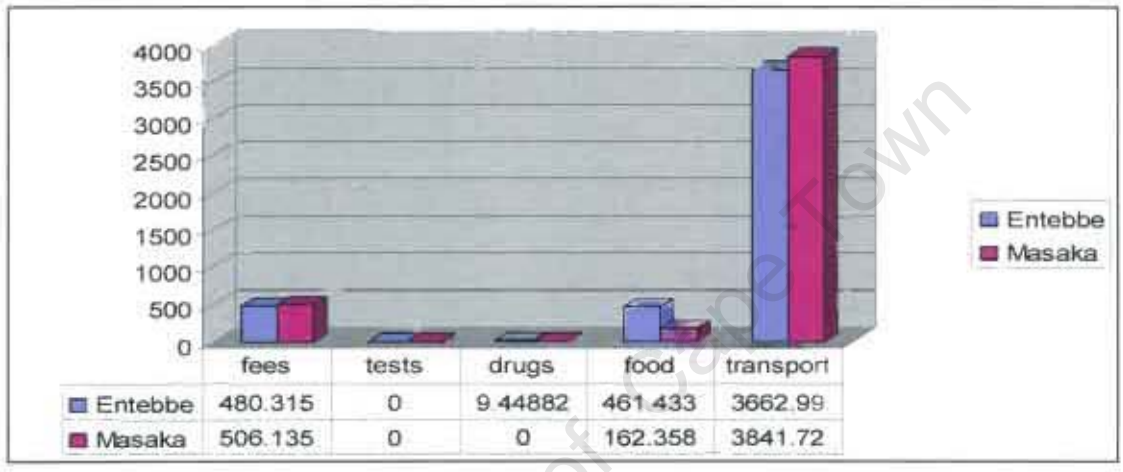


4.4.4 Direct costs on the day of appointment at health facility

In figure 3 below, are presented the results of the break down of the direct average costs associated with seeking health care for PLWHA who are on ART. Therefore as observed from the table, transport costs were the highest of all the costs incurred by patients on the day they visited the clinic. Transport costs made up about 82% of all costs incurred on the day the patients visited the clinic. The next highest cost incurred was clinic fees, paid at the health facility where patients went to seek care. The patients at this health facility

are required to pay a small fee on arrival at the clinic. Participants from the Entebbe site incurred a proportionately higher amount on food than the participants in Masaka. Therefore, transportation and cost of food were the most significant costs incurred by participants on the day they visited the health facility. Subsequently, it is shown from the figure 2, above, that direct non-medical costs were higher than direct medical costs on the day of the ART appointment for the PLWHA in this study.

Figure 3: Average Healthcare related costs on day of interview (U Shs)



	fees	tests	drugs	food	transport
Entebbe	480.315	0	9.44882	461.433	3662.99
Masaka	506.135	0	0	162.358	3841.72

4.4.5 Health Care Seeking Patterns in the last month

The table 6 below presents the results of the health facilities visited by patients in the last month before their appointment at the HIV/AIDS health facility. The most commonly visited health facility was public clinics, which were visited at least once by almost all the study participants. The second most visited health facility was the NGO facility, which was TASO in this case. TASO is a non-governmental organisation, although it is commonly located next to or at a large Government hospital. There were less than 2% of all participants in Entebbe and Masaka who visited the out patient and in-patient departments of any private hospital.

Table 6: Health facility where patients sought care

Facility	Median number visits	Entebbe	Masaka
Public clinic	2.5	127(100%)	160(98.16%)
Private clinic	2.5	19(14.96%)	31(19.02%)
Public hospital, outpatient	2.5	4(100%)	9(90.0%)
NGO facility	2.5	54(42.52%)	53(32.52%)

4.5 Household Income

Table 7 below presents the household income in four quartiles from the lowest to the highest. The household expenditure in the last month was used to approximate the household income for participants in this study. As expected the participants from the urban study site reported a much higher expenditure than those in the rural area. The poorest quarter of participants in the urban area, had an expenditure of about US $ 80 as compared to US $ 52 for the participants in the rural area. There were a considerable number of patients both in Entebbe and Masaka who reported living on more than one dollar a day, according to their reported monthly expenditure. The richest quarter of participants in the urban area reported that they lived on U S $ 200 per month as compared to US $ 179.1 in the rural area.

Table 7: Monthly expenditure in U Shs and US $ in 2007

Entebbe			
Quartiles	p25	p50	p75
U Shs	138,000	219,500	345,000
U SS	80	127.3	200
Masaka			
U Shs	90,000	166,000	310,000
U S S	52.2	96.2	179.7

Figure 4: Average Monthly expenditure in US $ in 2007

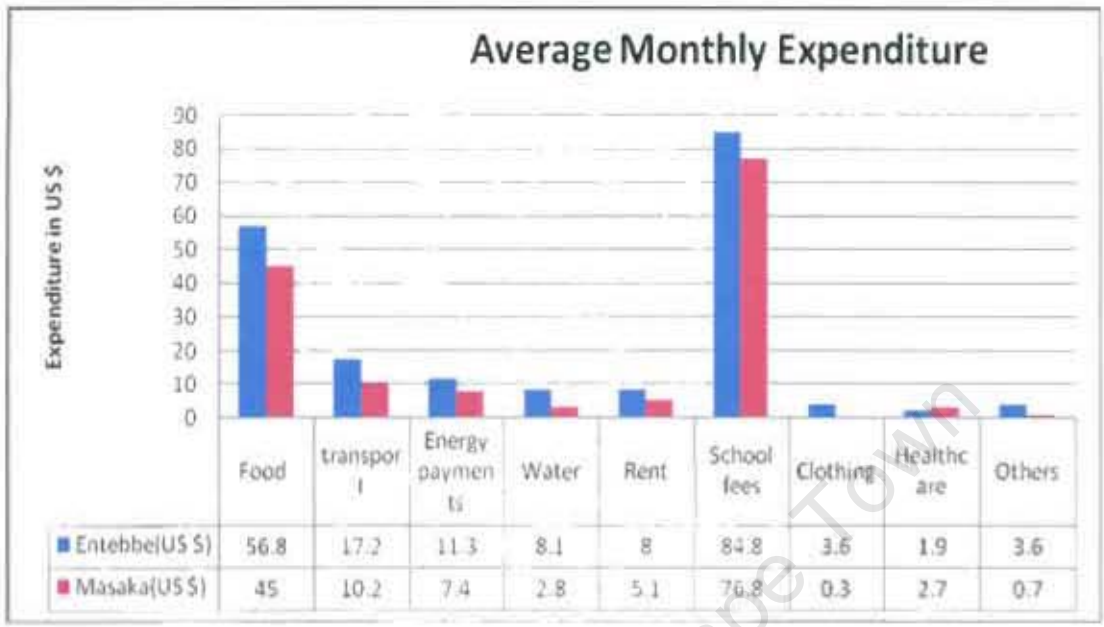


Figure 4 above, presented the breakdown of household expenditure on various household items in the last month. Households incurred the highest common costs on school fees, food, transport costs and energy costs during the month. Although the urban area had fewer participants than the rural area, it recorded higher costs on the most of the household items. Healthcare took up one of the lowest proportions of the household's monthly expenditure but participants in the rural area spent a higher amount on healthcare than participants in urban areas did. School fees took up the biggest portion of the household's monthly expenditure but the urban area participants incurred a slightly higher amount than those in the rural area.

4.6 INDIRECT COSTS OF SEEKING HEALTH CARE FOR PLWHA

4.6.1 Time lost due to HIV/AIDS

Table 8 below, presents the amount of time lost by PLWHA and their caregivers due to an HIV/AIDS related illness. There were 21 participants in Entebbe and 20 in Masaka who reported that they had fallen seriously ill in the last month. The indirect costs of seeking care for ART were calculated for both PLWHA in Entebbe and Masaka. A recall period of one month was used as mentioned in detail in the methodology section. In total, 41 participants reported that they had fallen seriously ill in the month before they were interviewed, with almost an equal number for both areas. All the participants who fell seriously ill last month reported that they had been looked after by someone else from the household or community. However, participants in the rural area lost more days due to HIV/AIDS related illness than the participants in the urban area. On average, a PLWHA lost 10.07 days in Masaka as compared to 6.34 days for Entebbe. A similar trend was maintained for the days lost by caregivers who looked after PLWHA. The caregivers in the rural area lost 19.5 days on average as compared to the 13 days for those in the urban area.

Table 8: Time lost in days in 2007

	Entebbe		Masaka	
	Total days lost	Average days lost	Total days lost	Average days lost
PLWHA	260	12.4	413	20.7
CAREGIVER	273	13	390	19.5
TOTAL	533	25.4	803	40.2

Table 9: Indirect monetary cost of seeking care for HIV/AIDS in US $ 2007

	Entebbe(US $)		Masaka (US $)	
	Total costs	Average costs	Total cost	Average cost
PLWHA	192.3	9.1	305.5	15.3
CAREGIVER	201.9	9.6	288.5	14.4
TOTAL	393.9	18.7	594	29.7

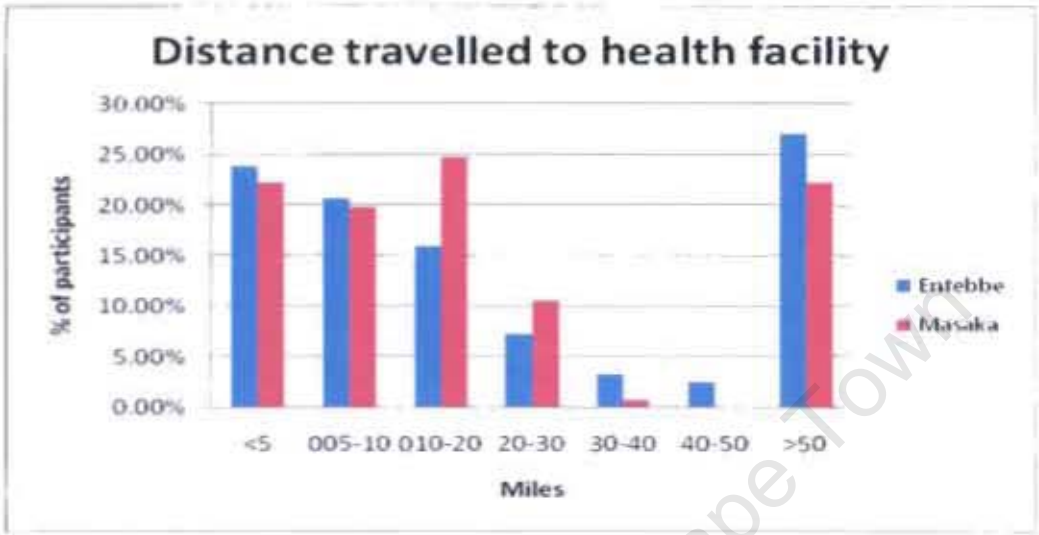
Table 9, above presented the indirect monetary costs of seeking care for HIV/AIDS. The PLWHA in the rural area incurred a higher opportunity cost due to a serious HIV/AIDS related sickness episode than those in the urban area. Given a GDP of US$ 270 per annum, a PLWHA in rural area lost almost double the amount in the last month due to HIV/AIDS as compared to a PLWHA in the urban area. The caregivers from the urban area incurred a slightly higher opportunity cost than the PLWHA who they looked after in the last month. This was however the opposite for PLWHA in the rural area whose indirect costs due to HIV/AIDS in the last month were greater than that of their caregivers. In total, both caregivers and PLWHA in the rural area incurred a higher total indirect cost than their counterparts in the urban area did.

4.6.2 Distance travelled to get to the health facility

Figure 5 below presents the distance PLWHA travelled one way, to get to the health facility on the day of their appointment. There were less than 30 % of all participants in both the urban and rural area who lived within a 5-mile radius to the health facility that offered HIV/AIDS services. Many people reported travelling more than five miles to get to the health facility. This could be an indication of the high non-medical costs that patients incur in order to get to the health facility. There are also a high number of people

who travelled more than 50 miles to get to the health facility, where they accessed free HIV/AIDS healthcare services.

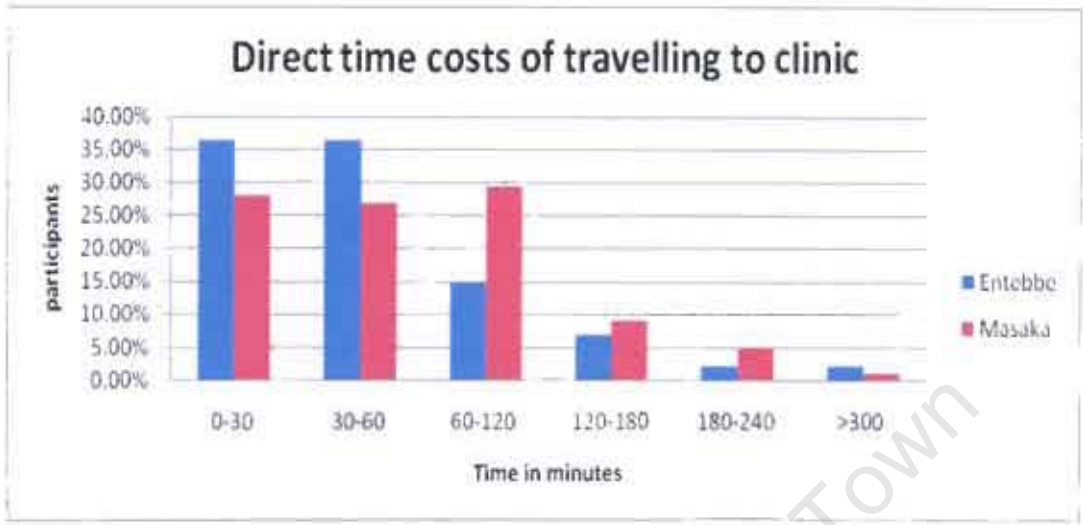
Figure 5: Distance travelled to health facility



4.6.3 Time spent travelling to health facility

Figure 6 below, presented the results of the time that PLWHA took to get to the health facility. There were almost 70% of all participants in both the urban area and rural area who travelled for more than thirty minutes to get to the health facility to seek care. Consequently, majority of participants had to travel for long periods of time to seek healthcare for HIV/AIDS. This is an indicator of the high indirect costs and time costs associated with seeking care. There were a higher percentage of participants in the rural area who travelled for more than one hour to get to the health facility as compared to the urban area. Therefore PLWHA generally and specifically for the rural area face a high opportunity cost of seeking care for HIV/AIDS as reported in this study. Consequently, PLWHA in the rural area travelled for longer times than the PLWHA in the urban areas to access the HIV/AIDS health services.

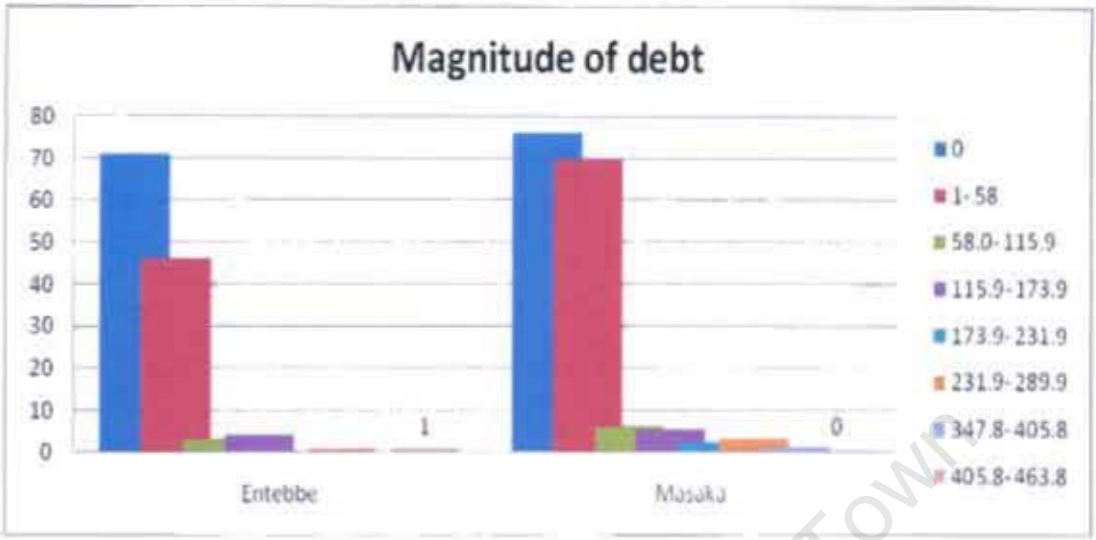
Figure 6: Time costs of travelling to clinic



4.6.4 Magnitude of accumulated debt

Figure 7 below presented the results of the magnitude of debt accumulated by PLWHA in relation to their HIV/AIDS status. There were generally a modest number of participants who did not incur any debt in relation to their healthcare. However there were a small number of participants who had incurred large amounts of debt in relation to their health status and health seeking habits. The trends were quite similar across both the urban and rural areas. The majority of participants who reported having debt fell within the US $1 to US $ 58 debt category. There were more rural participants in the rural area who had debts as compared to their counterparts in the urban area.

Figure 7: Accumulated Debt in US $ in 2007



4.6.5 Opportunity cost of HIV/AIDS

According to the study participants, an HIV positive status had an effect on the employment status of an individual after they discovered that they were HIV positive. There were more participants who reported that they were actively working before their discovered that they were HIV positive than after they discovered their status. In both Entebbe and Masaka the number of participants who reported working before they knew their status was almost equal at about 79% for each area. However, after discovering their HIV positive status, the number of those still employed dropped to less than half for the Entebbe study participants and to 60% of the Masaka participants. The number of participants who reported being unemployed increased to more than 50% for Entebbe and to about 40% for Masaka from about 23% in both areas. There was a higher increase in the unemployment rate in the urban area as compared to the rural area.

Table 10, below, presented the results of the employment status before and after their HIV status. Of these, 110 gave reasons as to what had happened to lead them to unemployment. There were more than half of the participants who reported that they had resigned from their jobs. Those who resigned did so either to seek care for their condition or because they were too sick to work any more. The rest gave numerous other reasons, which ranged from getting fired, doing less work and therefore earning less and moving places to seek care. There were a few participants who reported being in a new job and earning better and others said they had not changed their jobs. There was only one person who reported having been retrenched with benefits.

Table 10: Employment status after HIV status

	ENTEBBE	MASAKA
Employment before status		
Employed	100 (79.4%)	127(77.9%)
Not employed	26(20.6%)	36(22.1%)
Employment after status		
Still employed	53(45.7%)	87(60.0%)
Not employed	63(54.31%)	58(40.0%)

4.6.7 Ways in which HIV/AIDS has affected your Income

The participants reported that HIV/AIDS had affected their income in one way or other. Although, not every participant become unemployed after testing HIV positive many of them reported that their income had been negatively affected by HIV/AIDS. The main reasons for this included a PLWHA being too sick to work or working less time than they did before. There was a higher percentage of participants in the urban area than the rural area who reported being too sick to work. On the other hand, a higher percentage of rural

participants as compared with urban participants reported that they worked for less time due to HIV/AIDS.

Table 11: Other household members who lost their jobs

	ENTEBBE	MASAKA
Lost job	32 (25.2%)	27 (16.56%)
Not lost job	95 (74.8%)	136 (83.44%)
Total	127 (100%)	163 (100%)

Table 11 above shows the results of other household members who had lost their jobs as a result of being HIV positive. There were more interviewees in the urban area as compared to the rural area who reported that someone else in their household had lost their job due to HIV/AIDS. However, there generally a low number of PLWHA who reported that other household members had lost jobs due to HIV/AIDS.

Table 12: Children dropping out of school

	Entebbe	Masaka
Yes	26 (20.5%)	32 (19.6%)
No	101 (79.5%)	131 (80.3%)
Total	127 (100%)	163 (100%)

Table 12, above, presented the results of children who dropped out of school due to HIV/AIDS. There were a relatively high number of children who were reported to be dropped out of school or abandoned their studies since the onset of their parents or guardians' illness. The proportion of children who dropped out of school was similar for both Entebbe and Masaka at about 20% for all participants interviewed. There were more children who dropped out of school than those who were employed. There were few

PLWHA who reported that school going children in their households were working to contribute to the household income.

4.6.8 Care given during a serious period of illness

There were more than 80% of all participants reported that they had been looked after by someone the last time they fell seriously ill.

Table 13: Someone look after you were last time seriously ill

	Entebbe	Masaka
Yes	70 (87.5%)	65 (84.4%)
No	10 (12.5%)	12 (15.6%)
Total	80	77

Table 14: Caregiver's title

	Entebbe	Masaka
Working household member	8 (11.4%)	13 (18.8%)
School going child	7 (10%)	12 (17.4%)
Adult neighbour hood friend	7 (10.0%)	7 (10.1%)
Adult relative	43 (61.4%)	37 (53.6%)
Paid care taker	5(7.1%)	0(0%)
Total	70(100%)	69 (100%)

Table 14, above, presents the most common caregivers as reported by the participants the last time they were seriously ill. Adult relatives were the commonest caregivers reported by the study participants when they fell seriously ill. This was common for participants in both Entebbe and Masaka. The working household members from the same household as the PLHWA were also an important source of care in times of serious illness.

4.7 TOTAL COSTS

Figure 8 and Table 15 below presented the proportion of direct and indirect costs of seeking care for HIV/AIDS. The total direct costs outweighed the total indirect costs for both Masaka and Entebbe. It should be noted that there were more people who sought care in the last month than those who fell seriously ill in the last month. In addition, the urban area participants reported higher direct costs than the rural area participants. On the other hand, the rural area participants incurred higher indirect costs than the urban area participants.

Figure 8: Direct and indirect costs of seeking care for HIV/AIDS in US $ in 2007

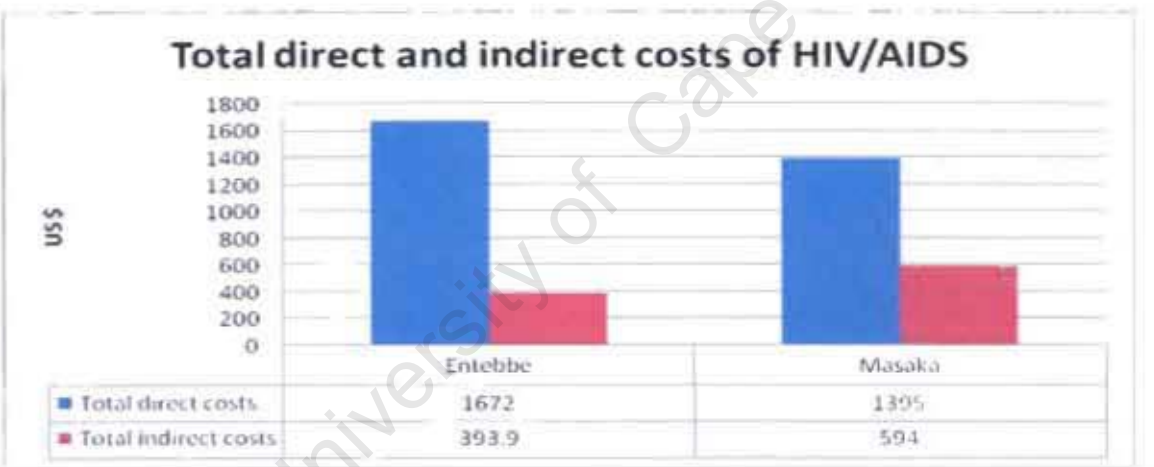


Table 15: Average costs of seeking care for HIV/AIDS

	Entebbe	Masaka
Average direct costs (US $)	13.2	8.6
Average indirect costs (US $)	18.7	29.7
Average costs (US $)	31.9	38.3

Table 15 above presented the results of the direct and indirect average costs of seeking care for HIV/AIDS. The total direct and indirect costs of seeking care associated with HIV/AIDS were weighted for the number of people in each category. Subsequently, average indirect costs on outweighed the average direct costs for both the urban and rural area. The average indirect costs for the rural area were considerably higher than the average direct costs as compared to the difference in the direct and indirect costs for the urban area. Nevertheless, the urban area participants reported higher average direct cost than the rural area participants. Furthermore, participants in the rural area incurred a higher average cost than the participants in the urban area.

4.8 COPING MECHANISMS

4.8.1 Monetary constraints

Table 16 below presented the number of participants who faced monetary constraints last month in seeking care for HIV/AIDS. Almost half of all participants both in the urban and rural area reported that they had faced money constraints. This implies that they participants had to adopt different responses to the economic burden imposed on them by HIV/AIDS. There were some respondents who did not answer the question.

Table 16: Monetary constraint to seeking in the past

Money constraint	Entebbe	Masaka
Yes	59 (47.2%)	87 (54.4%)
No	66 (52.8%)	73 (45.63%)
Total	125(100%)	160(100%)

Figure 9: Response to monetary constraints

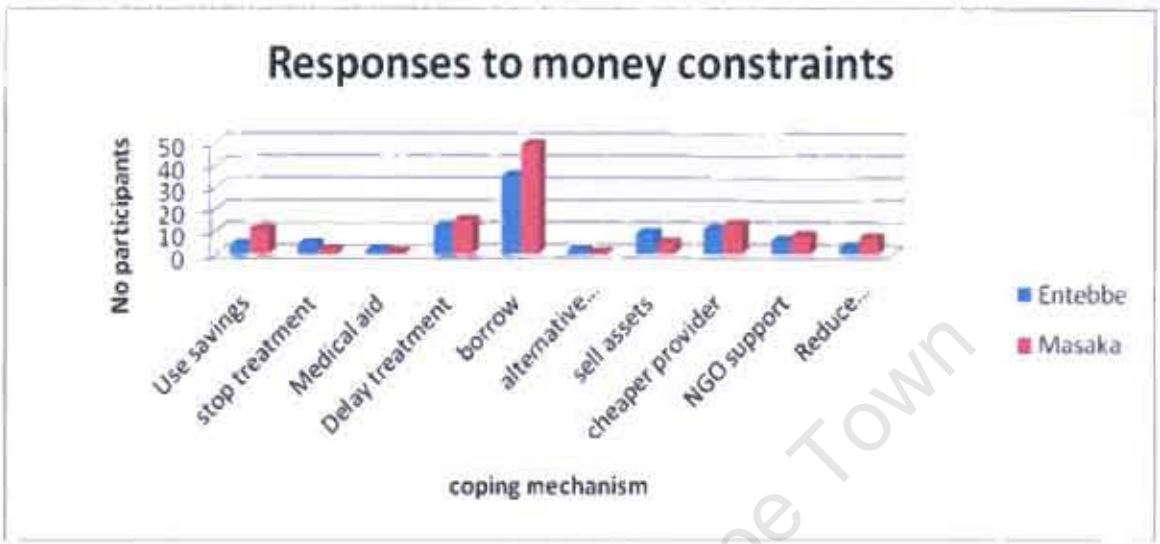


Figure 9 above, presented the responses of PLHWA when they were faced with monetary constraints to seeking care for HIV/AIDS. The participants reported various coping mechanisms in response to monetary constraints. However, a considerable number of participants reported that they had borrowed money in the last month when faced with monetary constraints to seeking HIV/AIDS healthcare. This could have been for transport, consultation fees and special foods, which are classified as direct non-medical costs.

4.8.2 Diversification of income

Table 17 below presents the results of households that diversified their income as a coping mechanism in response to seeking healthcare in the last month. There were a substantial number of participants who started up some kind of economic activity since the onset of their illness. There were more people in the rural area that had started some kind of economic activity, since the onset of their illness than those in Entebbe.

Table 17: Started Economic Activities

Economic activities	Entebbe	Masaka
Started	43 (33.86%)	81 (49.69%)
Not started	84 (66.14%)	82(50.31%)
Total	127 (100%)	163 (100%)

Coping mechanisms used the last time a PLWHA fell seriously ill

Table 18, below presents the type of method that patients used to cover their costs the last time they fell seriously ill. There are a substantial number of patients who reported that they used medical aid to pay for the treatment they used, the last time they were ill last month. This is unexpected given that at the national level, less than 1 % of the population owns a medical aid of any type. However, it is good to note that PLHWA are registered clients in HIV/AIDS organisations where they form informal medical schemes at their local village level. This money may then be used to pay for medical treatment and also to cover funeral arrangements for their group members and their families.

Table 18: Method of payment for healthcare

	Entebbe	Masaka
Medical aid payment	24 (18.9%)	36 (22.09%)
Household savings	4 (3.15%)	12 (7.36%)
sell valuables	0 (0%)	3 (1.84%)
Free treatment	7 (5.51%)	4 (2.45)

Table 19: Used income generated from various sources

	Entebbe	Masaka
Savings club	6 (4.72%)	34 (20.86%)
Income projects	3 (2.4%)	6 (3.7%)
Home based	0 (0%)	2 (1.2%)
Free health facility	3 (2.4%)	0 (0%)
Total	12(9.52%)	42(25.76%)

As discussed in table 19, above, it was mostly participants from the rural area study site who reported that they had joined some sort of savings club. Therefore for those participants who paid for the treatment they got the last time, money generated from savings clubs were the commonest source. However, it was mostly participants from the rural area who used money generated form savings clubs to cover the costs of seeking care for HIV/AIDS.

Table 20: Borrow money

	Entebbe	Masaka
Borrowed Money	22	20
Did not borrow Money	93	140
Total	115 (80.87%)	160 (98.75%)

Table 20 above shows the proportion of participants who reported that they had borrowed money. Most participants reported that they had not borrowed money the last time they had to pay for treatment, when they had faced money constraints. There were a higher percentage of participants who borrowed money when they faced monetary constraints as compared to when they fell seriously ill. Therefore it seems that money was borrowed when it was very urgent to get medical attention rather than for usual medical payments. PLHWA who are clients for TASO are given appointments after every two or one month.

which implies that patients have to try to attend these appointments. These are the times they are likely to borrow money, when faced with financial constraints.

Table 21: Source of borrowed money

Person you borrowed from money	Entebbe	Masaka
Household member	2 (1.6%)	1 (0.6%)
community leader	1 (0.8%)	0 (0%)
Friends and relatives in community	21 (16.5%)	21 (12.9%)
friends outside community	0 (0%)	1 (0.6%)
work based groups in or outside community	4 (3.2%)	0 (0%)

Table 21 above presented the results of the people from whom PLWHA borrowed money the last time they fell ill. There were a modest number of participants who borrowed money when they fell seriously ill in the last month. Among those participants who reported that they had borrowed money, the majority said they had borrowed from friends and relatives within their communities. There were a negligible number of participants who had borrowed from fellow household members.

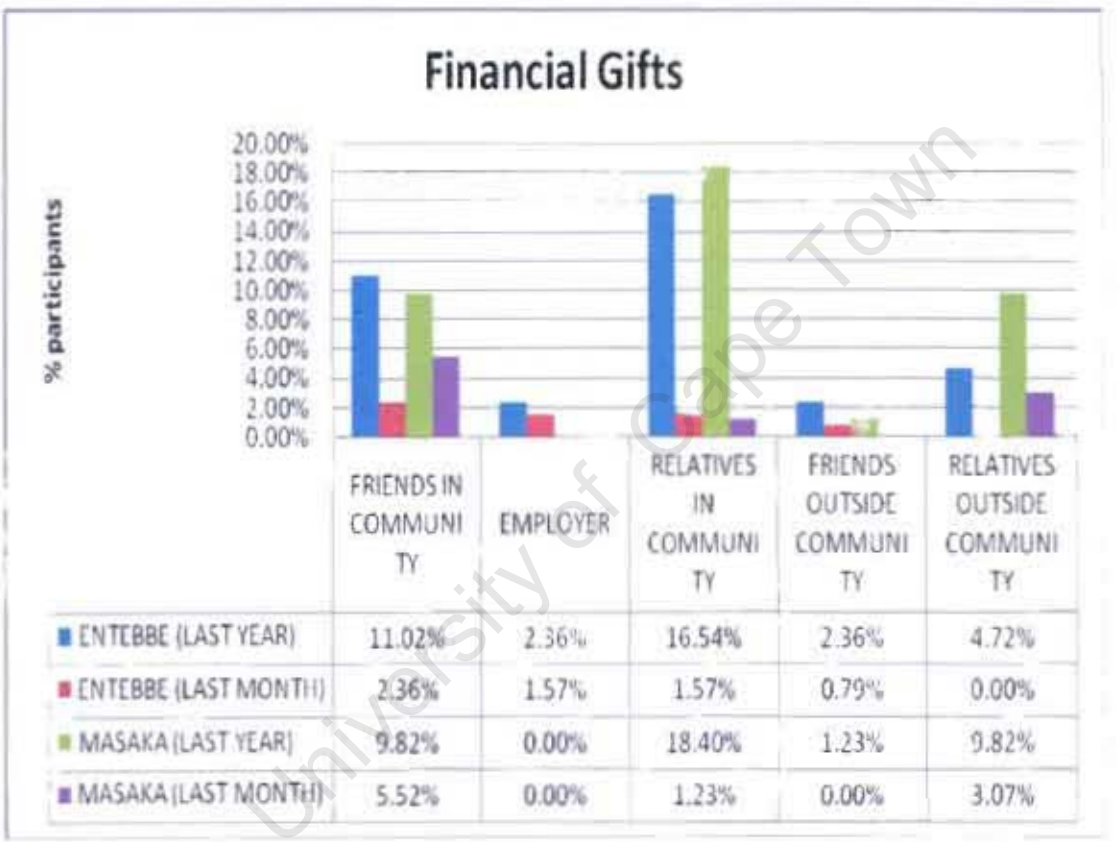
Table 22: Reduced Household Expenditure

	Entebbe	Masaka
Food	31 (24.41%)	14(8.59%)
Education	27 (21.26%)	18 (11.04%)
Healthcare	16(12.60%)	13 (7.98%)
Clothing	16 (12.60%)	3 (1.84%)

Table 22, above, represented the PLWHA who had reduced their household expenditures, the last time they fell seriously ill. Among the coping mechanisms used by PLHWA was reduction in household expenditure on items like food, education, healthcare and clothing. The most basic of necessities like food and education were the most affected for participants in the urban and rural areas. However, there were a higher proportion of

participants in the urban area as compared to the rural area who reduced their household spending on food. On the other end, more people in rural than the urban reported that they grew a substantial portion of the food they consumed. Household expenditure on education was also reduced in response to payments for treatment for PLHWA. Spending on education was more affected than spending on food for rural areas.

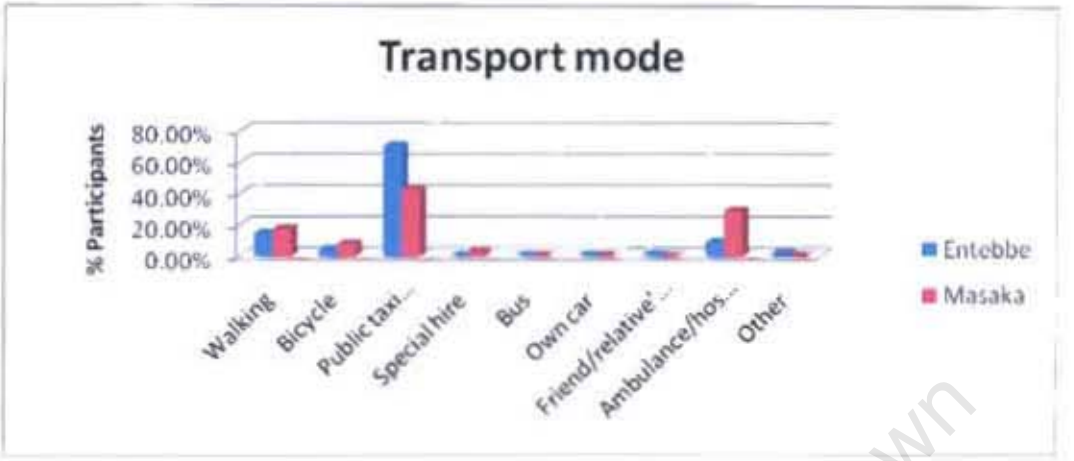
Figure 10: Received Financial Gifts



	FRIENDS IN COMMUNITY	EMPLOYER	RELATIVES IN COMMUNITY	FRIENDS OUTSIDE COMMUNITY	RELATIVES OUTSIDE COMMUNITY
ENTEBBE (LAST YEAR)	11.02%	2.36%	16.54%	2.36%	4.72%
ENTEBBE (LAST MONTH)	2.36%	1.57%	1.57%	0.79%	0.00%
MASAKA (LAST YEAR)	9.82%	0.00%	18.40%	1.23%	9.82%
MASAKA (LAST MONTH)	5.52%	0.00%	1.23%	0.00%	3.07%

There were generally few people who received financial gifts when they needed to pay for their treatment. This is consistent with the literature where PLWHA are receiving less help from their extended families and friends. In this study, PLHWA reported getting financial gifts from their relatives and friends in the community than more any other category of people. There was no participant in Masaka who reported getting help from their employer.

Figure 11: Transport mode used by PLWHA



In line with the study expectations, most participants reported that they had used public transport to get to the healthcare facility, however this more often the case in Entebbe which more urbanised and developed than Masaka. For a long period of more than 20 years in Uganda, there has been a high level of peace except for the northern part of the country. Therefore many areas in Uganda have a reliable and efficient transport network system. A high number of participants in Masaka reported that they got to the health facility by ambulance or hospital transport. This is unlike our expectations, where ambulances are more common in the urban areas. However TASO has developed an efficient system of reaching those in far reached rural areas, which may explain the use of ambulances in Masaka. There were an equivalent number of participants in both Entebbe and Masaka who walked to the health facility. The participants who reported being ill, indicated that they had lost up to 90 days due to a serious illness episode in the past.

4.9 SOCIAL CAPITAL

The concept of social capital was explained earlier in the chapter on literature review. There is indication that social capital fact that it plays a role in the coping mechanisms that households use to deal with the economic burden of HIV/AIDS. Subsequently, it seems that households with access to social capital may experience positive results in the management of HIV/AIDS. Social capital is a concept that encompasses all aspects of social set of connections amongst individuals, societies and organisations with the aim of achieving similar goals. In this study, the indicator for social capital is the percentage of participants who reported that they referred to the community for the various HIV/AIDS services that they sought. The community was used to refer to non-governmental and faith-based organisations that usually put in place activities and projects in communities. These activities will involve the participation of the community members that they serve so as to ensure their sustainability in the future. NGOs aim to help individuals and communities to become self-reliant and encourage their participation in the different services they provide.

Figure 12: Organisation/health facility associated with HIV/AIDS

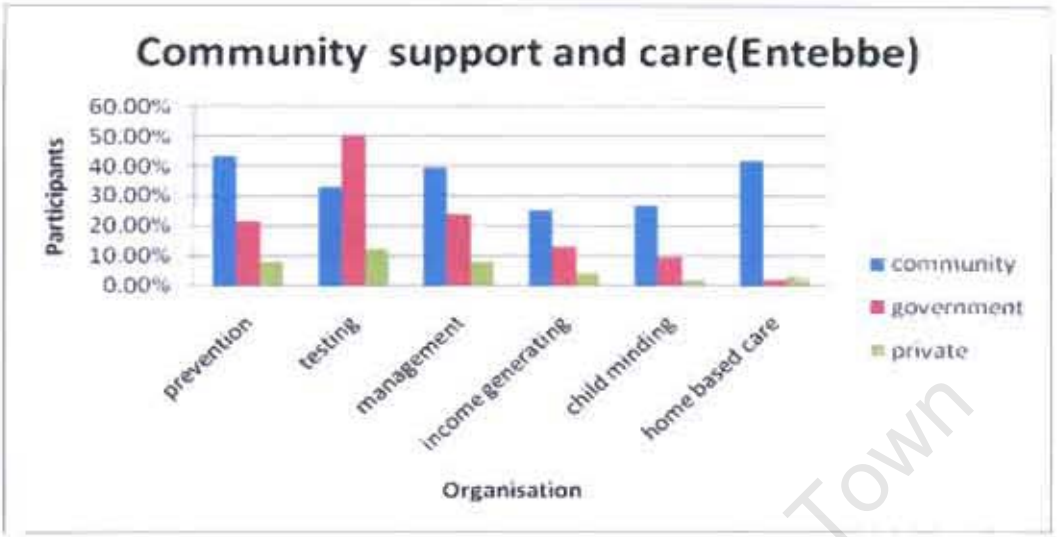
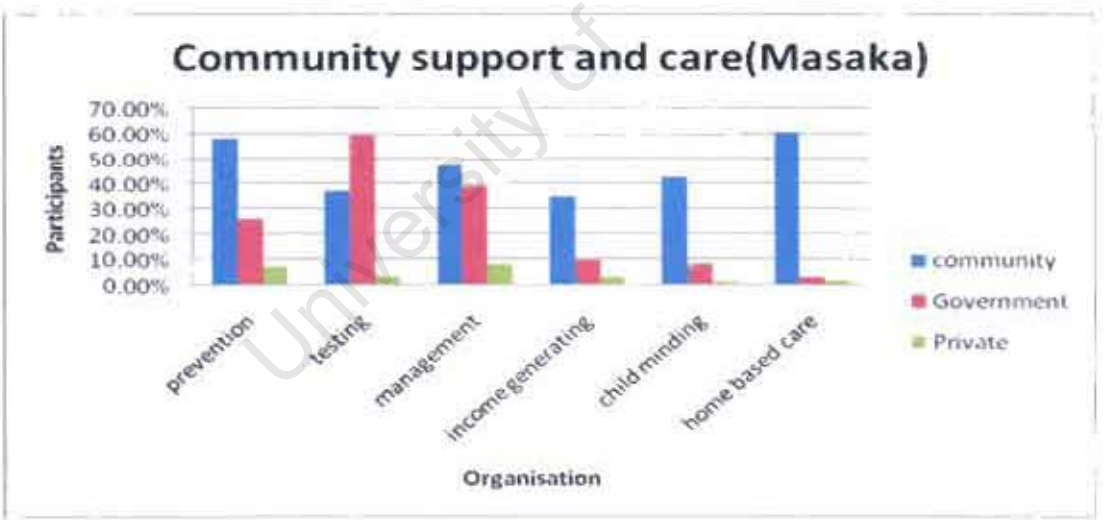


Figure 13: Organisation/health facility associated with HIV/AIDS



Figures 12 and 13 above presented the results on the availability of social capital in their respective communities. The participants reported that most HIV/AIDS activities and projects aimed at assisting PLWHA were associated with community based-organisations. This was with the exception of HIV testing which was mainly associated with government facilities. The trends were similar for Entebbe and Masaka. However, it

is worth noting that on the whole, less than 50% of all participants in Entebbe reported any associations between the different organisations and activities aimed at serving the PLWHA. This percentage of participants was lower than the percentage of participants in Masaka. Almost 60% of all participants in Masaka reported associations between activities for PLWHA and organisations responsible for their operations. The rest of the participants reported that they were no organisations in their communities that provided HIV/AIDS related services.

Figure 14: Participants who received financial gifts

Figure 14 rpresented those participants who had received financial gifts in the last month.Thc extent of social capital was also be measured from the number of participants who received financial gifts from members of their social networks. There were about 152 people who reported having received some form of financial gifts from a member within or outside their community. Relatives within the community were the main people who gave financial gifts in Entebbe and Masaka. There were more participants in Masaka than in Entebbe who reported receiving financial gifts from relatiives ouutside the community. Friends in the community were also a major source of financial gifts for both participants in Entebbe and Masaka. A very small number of participants in Entebbe

reported receiving financial gifts from their employers as compared to non of the participants in Masaka.

4.10 QUALITATIVE RESULTS FROM THE FGDs WITH PATIENTS

4.10 1 Economic burden of HIV/AIDS after provision of free ARVs

The provision of free ARVs has generally helped PLWHA to have access to healthcare services related to their HIV/AIDS status. There were positive reports from many of the patients at TASO when they compared their before and after situations of being initiated on free ART. There are many patients who were seriously ill, some at the point of death before being put on free ARVs. However, after enrolment on free ART many of he patients improved tremendously.

"Provision of free ARVs has greatly helped us, given the fact that even if I had money, I would not have enough to survive on and to buy ARVs. However, we are able to come and get free medication. If one follows the instructions on taking ARVs that the medical personnel here at (TASO) give us then one's life is returned back to normal. Before ARVs, we were at the 'doorstep to the grave' but now with ARVs we are okay. If you found me on the way, would you ever think that am sick? No!"(Woman, FGD Entebbe)

"I am a widow as I lost my husband to AIDS and people said that I would also die soon after him. They said that I was trying to keep the children's property, left by my husband, to myself. I really do not know where I would be without these free ARVs. I am now very fine and some people even fear to come near me. (Woman, FGD Entebbe)

However it was interesting to find some people who had a different opinion on the helpfulness of ARVs in accessing healthcare related to their HIV/AIDS status.

"These ARVs would have been helpful but they have side effects that are really bad. For example, I now have numbness in my feet, which was not there before the ARVs. This fact has affected me badly and taken me back". (Man, FGD Entebbe)

4.10.2 Contribution of ARVs to the monthly health expenditure

The provision of free ARVs has enhanced access to HIV/AIDS related services for PLWHA.

However, many of the participants needed more help in addition to the ARVs that they were given. This was in reference to the cost of treating other diseases and ailments, food and transport costs. The strongest emphasis was placed on treatment of other conditions like cancer and T.B at the same facility at which they received HIV/AIDS treatment. The participants seemed to hint at the fact that more money should be made available to TASO to ensure the treatment of all other ailments that they would otherwise seek care for at other health facilities.

"In relation to ARVs, we get tested for other diseases like malaria, typhoid and others for which we are also given drugs sometimes. However, to say that I will buy drugs for myself is difficult given that I do not have that kind of money. However, if a friend has some money, I ask them to give me some money so that I can buy the drugs for myself."

"There are other diseases like cancer and others that PLWHA are prone to. In my opinion, I think that the Government should provide TASO with money to treat such diseases because we need that treatment and TASO will give us the drugs. Currently it's lacking."(Woman, FGD Entebbe)

4.10.3 Other services needed to keep health in optimum health

The participants were interviewed on the various services and things they need to keep their health as PLWHA at optimal levels. However the views on what these requirements were widely varied from participant to participant. These views were split along emotional needs, monetary requirements and proper diet and the needs of the other household members. These views depended on the direct and indirect costs of HIV/AIDS that the PLWHA face in their daily fight to keep in optimal health. There are some participants who reported needing housing, school fees and the need to eat well. Other PLWHA reported the need for jobs that are not very strenuous so as to maintain their health in optimal states.

"We need money and to have a balanced diet. We need to eat greens, fresh fruits like pineapples and other fruits. However, you will find a person who is not able to purchase these things due to monetary constraints. Even if we do not buy all these things but at least one should have some money to buy and drink a cup of milk everyday. For example at my home, my children are no longer allowed to drink milk; it is only for me as am sick. I explained to them that I can not afford to buy milk for all of us but only for myself given my situation."

4.10.4 Financial consequences of seeking HIV/AIDS health care

There are financial implications for PLWHA in seeking healthcare for HIV/AIDS. This was in particular relation to the indirect costs of seeking healthcare for HIV/AIDS. This was especially true given that the direct medical costs of seeking treatment are catered for at the health facility. There were many reports of people feeling that they spend a lot of money on transportation and they lost time and money when they did not work.

"In seeking care for PLWHA, there are financial consequences that we face. For example in my case, I came here today and therefore it means that I have not worked. I also came here with my wife. We have to board taxis and therefore require money for this. This implies that today I have spent money (incurred expenditure) without earning any income."(Man, FGD Entebbe)

"We face financial constraints especially for us women. When your husband goes for HIV/AIDS healthcare and you tell him that you also need to go for treatment he may not be happy as it means spending more money on the woman's treatment. He may even decide not to support his wife and children any longer and they are left financially constrained. This is a very big problem especially for us women."(Woman, FGD Masaka)

4.10.5 Proposed measures to improve access

The main consensus by the PLWHA who were interviewed is that government should continue to provide them with ARVs even in the future given that the number of PLWHA on ART has increased. There seems to be a feeling of lack of satisfaction in the level of patient care at the health facilities by different health personnel. There are feelings that some medical personnel are not as responsive and helpful as they should be. Given the negative emotional effects of stigma and unhappiness on lowering CD4 counts, this was a major issue. The negative emotional feelings and wellbeing of PLWHA are likely to increase the indirect costs and intangible costs associated with HIV/AIDS. There was concern by mainly the upcountry participants on the distance that some of them have to travel to get treatment and medication. This increases their direct medical and non-medical costs of seeking health care.

"Sometimes we get problems with medication, where it is in short supply. If you report sick to the health centre with your child, they reduce your dosage and you have to buy the remaining from somewhere else. We need urgent help from Government to increase the drug supply."(Woman, FGD Masaka)

"Government should build smaller clinics in the villages that are specifically for PLWHA so as that access to health care for us is improved."(Man, FGD Masaka)

"I am a client representative and I will hear that a person died in the community yet no one knew that they had HIV/AIDS. This implies that there are still very many people with HIV/AIDS in the community who have not come out to test. Government should put in place educational programmes so that people know the reason why it is important to test for HIV."(Woman, FGD Entebbe)

4.10.6 Permission from work to go for ART appointments

It is not very easy to get permission from employers and bosses to go for HIV/AIDS treatment for PLWHA. It is even more difficult because most employees fear to disclose their status as they may face discrimination and stigma at work and even lose their jobs.
"I do not think that it is easy to get permission from bosses at work. I was working for one before I tested and I looked bad. He also noticed, so I told him that I was going to get an HIV test done at TASO. I then came back and told him that the results of the test were positive. He asked me to take some leave from work to rest. After two weeks, I went back and he told me that my job was no longer available. Now I cannot disclose my status to my new boss as the same thing could happen to me. Therefore, when it is time to come for ARVs, I just become creative and I think of an excuse. I can decide to stay home and not reach my work place at all."(Man, FGD Entebbe)

"It is not easy to get permission from work to go to the ART clinic for treatment. There are some bosses who insist that their employees work everyday except if there is an emergency at home. It was originally not part of the contract to take days off to get treatment. Therefore you find people missing work and giving excesses whenever their appointment to the ART clinic comes up. This is because the employer will fire the employee if they get to know the reason for not coming to work" (Man, FGD Masaka)

4.10.7 Stigma and discrimination against PLWHA

There is generally less stigmatisation and discrimination against PLWHA. However there was more stigma and discrimination reported in the rural area as compared to the urban area. There seems to be a lack of educational programmes reaching the more rural communities and therefore the lack of information and high stigma still attached to HIV/AIDS. There are still people refusing to seek care even when they are really sick due to the problem of stigmatisation in rural areas. This fact could imply that the burden of HIV/AIDS is higher than reported.

"Stigma has reduced in the towns and urban centres but it is still prevalent in the villages where many people are not well informed even at home. People are mistreated at home because of their status."(Man, FGD Masaka)

"There is a need to take educational programmes to households in the villages where stigma is still very high due to misinformation. People in the villages do not know that PLWHA are also still people. When they know that you are HIV positive and need a job, they ask you how you can look for a job in your condition. When people at work know that we are positive, they insult us and treat us with scorn. People feel that we consume food for nothing." (Woman, FGD Masaka)

4.11 Coping mechanisms and social support

4.11.1 Social and financial support

In general, there are social support groups in the different communities where the PLWHA live. These social support groups mainly provide social and emotional support and some few also provide financial support. The main source of financial support in these groups is the collection of savings from members which are made available to different members following a given schedule. This is the concept of the savings circles.

There is a feeling that these finances are too low to bring about any major changes in the financial situations of the PLWHA, as most of them are poor.

"We PLWHA have put effort to see to it that we come up with groups that connect us. Nevertheless, financially we have been disappointed by people who make promises to help us and later do not meet these promises. We try to put support groups in place but at times people get disappointed and they stop coming to attend the meetings." (Man, FGD Entebbe)

"As for us, we have come up with a group amongst the PLWHA women were we formed a savings circle. We collect money and give it to different people at different intervals. One can buy poultry with this money. This is very important as we sometimes spend the whole day here." (Woman, FGD Masaka)

4.11.2 Financial gifts or gifts-in-kind from friends and relatives

The PLWHA reported that they received gifts from the members of their communities when they were in need or when they were ill. The majority of participants reported that they received mainly food parcels but some also received money when they were ill which they used to purchase food. Indeed there were extreme cases of participants who reported that they had not received any visitors and gifts of any kind when they were ill.

"Yes we do have groups that prepare and give us food when we are in need like at funerals and other big functions. This is because one person can not clearly stand on their own in such times.' (Woman, FGD Masaka)

"Yes we do get visitors. Friends and relatives give us financial gifts. For example I have been admitted to Grade B hospital for the last two days and its friends and relatives who have given me money to purchase food. We do receive such financial gifts and food parcels even from TASO." (Woman, FGD Entebbe)

"As for me I do not have such relatives and friends. For example I am currently admitted in hospital but no one has come to visit me apart from my fellow PLWHA and yet I have children at home. They are aware of my condition but they are afraid to contract T.B."(Woman, FGD Entebbe)

4.11.3 Financial Support

The PLWHA report they are able to get financial advice from different organisations but not necessarily financial support in monetary terms. There are some participants who are able to get finances by borrowing from financial institutions and schemes. However, many of them reported that they were not willing to use their household contents and assets as collateral to get such money. There are afraid and unable to follow the very stringent rules put in place by these money-lending institutions.

"My friends no one can just give us free money, we have to come up with ideas to make money. There are organisations and people who give us advice on how to make money like teaching us how to keep goats. Even in TASO there are such groups like MUHUMUZA and NACOLA where one can invest U Shs 30, 000 and then get U Shs 300, 000, which one has to repay."(Woman, FGD Masaka)

"In our villages such groups are not very common. There are groups, however, which require one to use their property and household assets as collateral. Sometimes these people even come to view our home but what if the money you borrow goes to waste?"
"My situation as a sick person does not mean that I do not want to look after my family. However it's difficult to borrow as most institutions have stringent conditions that we can not meet."(Man, FGD Entebbe)

"Some organisations pretend to help, yet in fact they are scams. There was an organisation that asked parents to contribute to their children's fund so that they would pay for their school fees the following year. When the time came, the organisation was

nowhere to be seen. Such organisations come to rob people of their money."(Man, FGD Masaka)

4.11.4 Social Support and Emotional support

The main source of emotional and social support was NGOs and small groups that deal with PLWHA in the different communities. These NGOs included TASO as the main one as all participants interviewed were registered clients. There were other groups like World vision, Uganda cares which a Government organisation and others. However as mentioned before, PLWHA also formed small groups in which they sought to raise funds, support each other financially, socially and emotionally. There were client representatives from TASO that also visited PLWHA in the different communities.

"TASO has indeed used a multi-faceted approach to deal with HIV/AIDS by including many aspects for example medical staff, food supplies and others. We were really badly off for those of those of us who got infected long ago."(Client representative, Entebbe)

4.11.5 Most urgent needs of PLWHA

The most urgent needs of people living with HIV/AIDS were things that have to do with their non-medical welfare and that of their households. There were needs for non-cumbersome jobs, food, school fees and proper shelter for their families. This is in line with the fact that many of them need capital to set up businesses or to enhance those that are already existent. There are some people who have skills like tailoring and keeping livestock but do not have the capacity and capital to put these skills to work.

"Most of us are tenants. It would be nice if one could get a piece of land where to construct a house, so that when one dies, there is a house for their children. This could also be a place to do a small business so that at the end of the month, one is not worried about paying rent and getting kicked out of the house."(Woman, FGD Entebbe)

'I will not defer from colleagues but I will be exact. If one asks me, my answer would be capital and a job. If I have these two things, death will just get me by surprise, but I will not be waiting for it." For most of us we have learnt tailoring, the only thing we need is to take our tailoring further. We need jobs that don not require too much strength and energy."(Man, FGD Masaka)

"I really need to keep livestock, if I could be properly educated on how to keep the animals well. I wish that I could keep poultry, pigs, cattle and all such animals. This would help me to stop worrying a lot and to be much happier. However, I do not have the capital or anyone to give it to me. I really would like to keep livestock."(Woman, FGD Masaka)

CHAPTER FIVE-DISCUSSION

5.1 Introduction

This chapter was aimed at discussing the results of this study that were presented in the previous chapter.

5.2 Provision of ART to PLWHA

The participants of this study were all clients of TASO, an NGO that provides free HIV/AIDS services including ART. Therefore most of the participants in this study benefited from the free ARVS provided to them by TASO. However there were some participants who were registered clients of TASO but received their ARVs and other associated HIV/AIDS services from other facilities. Nevertheless, this was still at no cost to them. This was in line with the expectations of this study that PLWHA who were eligible have access to free ARVs. Their eligibility in the context of Uganda was determined both clinically and also in terms of their ability to adhere to ART rules and regulations (MOH, 2003). There were a number of organisations in Uganda that provided PLWHA with ART at no charge to them. However many of these organisations including TASO were commonly found in the major towns, next to or within a government hospital. This was to ensure increased access for patients who are referred and to improve access to ART for those who are already sick. This arrangement was also to facilitate the easy movement of patients if they needed to be admitted into hospital for urgent attention. Nevertheless, the location of these facilities also restricts access to HIV/AIDS services for people in the more rural areas and hinders their ability to seek care.

5.3 Healthcare at other health facilities

PLWHA in this particular study also reported that they had visited other health facilities to seek treatment. This was mostly common in the weeks before their official appointments at the ART health facility. The usual practice was that a patient on ARVs is given an appointment to report after one or two months. Therefore in between these appointments, PLWHA have to incur their own costs, in case they fall ill. The most visited health facility was the public clinic, where almost all participants reported that they had visited in the last month. This is reasonable for PLWHA, who may fall ill from time to time and therefore require regular treatment, sometimes before their scheduled appointment.

5.4 Socio-Economic Status

There were generally low levels of education among the participants in both the urban and rural area. This may be an indication of the low socio-economic status of these participants, as many of them reported that they never completed primary schooling. There were more participants in the urban area who had attained at least some secondary schooling as compared to those in the rural area. This is in line with the statistics reported by the Uganda Bureau of Statistics (UBOS, 2007). There were more participants who had been widowed in the rural area than in the urban area. The reason for this is not very clear but one could speculate that services for HIV/AIDS are more common and accessible in the urban areas than in the rural area. Subsequently, more PLWHA in the urban area were likely to have made use of these services than those in the rural areas. The levels of unemployment in the urban area as compared to the rural area were much higher than those of the whole country. The country unemployment rate was at 5.6% and 5.2% for urban ad rural areas respectively (UBOS, 2007). This may be an indication of the negative effects that HIV/AIDS has on the ability of people to carry out their normal work despite the provision of free ARVs.

There were more people in the rural area who reported being subsistence farmers as compared to those in the urban area. Additionally, there were more participants from the rural area who reported that they grew more than half of the food they consumed in their households. This may also explain why people in the rural areas in general reported lower expenditures on food than those in urban areas. The majority of participants who took part in this study were the household heads of their respective households. This information is laid out in (table 1). Therefore, the results obtained are a highly accurate representation of the participants' households. In addition to this information, it is clear that the majority of all participants reported that they were contributing to the household income at the time of the interview. There were more people contributing to the household expenditure in the rural area as compared to those in the urban area.

The average age for participants from table 1 confirms the fact that HIV/AIDS affects people in their most productive years in society. The economic consequences of HIV/AIDS are further aggravated, when the breadwinners in households get infected and fall sick. There were generally more female respondents as compared to the males and this could be attributed to the fact that more women report for HIV/AIDS services than men. This could point to the fact that women as the caregivers of homes, relatives and friends and are therefore more likely to seek care so as to live longer and look after their children and other dependants.

5.5 Expenditure as a proxy for Income

This study used expenditure of the household per month as a proxy for household income. This approach has also been used by other studies because study participants will more often reveal their expenditure rather than their income. The household expenditure per participant in the urban area was higher than that of the rural area. This is expected, as people in the urban area are likely to have higher incomes in comparison with their rural counterparts. The difference was more apparent for the first and second income quartile. However for the third quintile the difference was very small. The highest expenditures that were reported by PLWHA in their respective households were on

school fees for their children and on food in the household. This trend is also in line with the higher social economic status of people living in the urban area as compared to those in the rural area. There is also a possibility that the time the study was carried out could have affected the household expenditure, as the school fees could have been higher than in other months. The beginning of the year is the time when pupils and students are returning to school for a new academic year after a long holiday. Therefore it is expected that parents will incur higher costs in this season than any other season of the year. The transport costs and energy payments followed closely after school fees and the expenditure on food for both areas.

5.6 Direct Costs

5.6.1 Healthcare expenditure in the last month

The participants reported their expenditures in relation to their HIV/AIDS healthcare in the month before their ART appointment. Medicines constituted the largest expenditure for the rural area followed closely by transportation costs to the health facility and then the cost of special food. In the Entebbe area the highest expenditure was on special food, followed closely by expenditure on medicines and transport costs. There was a high expenditure on medicines, which may be explained by the fact that patients have to take care of their own treatment costs in weeks and months before their appointments at the health facility. The patients have to make their own purchases for medicines that they may require apart from ARVs. The proportion of expenditure on transport costs in relation to seeking healthcare was high for both Entebbe and Masaka. However, the cost of transport was on average higher for participants in the rural than the urban area. This may imply that people in the rural area did not have access to health facilities near them and therefore had to travel for long distances to a health facility. This is a reflection of the national situation were most HIV/AIDS health facilities are located in urban areas or towns as opposed to rural areas.

The higher average expenditure on special food and transport by people in the rural areas may also be an indication of the differences in the socio-economic status of these two areas. The fact that drugs were the highest contributor to the healthcare related expenditure for the last before the appointment at the health facility is in line with other studies' findings (Akenso-Okyere and Dzator, 1997; Rosen et al, 2007). Similarly in the South African study, the cost of special food and medicine bought between official appointments at the ART clinics was considerably high. Almost 6 out of 10 patients reported spending between R45-R81, in the weeks before visiting the ART clinic. The transport costs were the second highest expenditure for the rural area participants and the third highest for the urban area participants. This implies that even in the case of free ARV provision, patients still spend high amounts of money on transport and special food (Meyer-Rath and Ritcher, 2007 and Wyss et al, 2004).

5.6.2 Healthcare expenditure on the day of appointment

The average healthcare related expenditure on the day that the PLWHA visited the clinic was equally high for both Masaka and Entebbe. The participants reported having spent almost U S$ 3 on the day of their appointment. The highest expenditure on that day was on transportation costs that amounted to almost U S $ 2 per person on average. This implies that patients incur the highest costs on transportation to the health facility to seek healthcare. This is in line with other studies in the same area (Rosen et al, 2007; Meyer-Rath and Ritcher, 2007). There could be other reasons for the high transportation costs on the day of the clinic visit and these may include the high costs of transport in general (Meyer-Rath and Ritcher, 2007). There were a high number of participants who travelled more than 50 miles to come to the health facility. In the interactions with patients, reports were given of patients avoided stigma by seeking care in a facility that was not close to their homes. In addition to the cost of transport and the long distances travelled, patients incurred high time costs as 62% and 72% of participants in the urban and rural areas, respectively reported that they took more than 30 minutes to get to the health facility. It was more of the rural participants who spent more than one hour travelling to the health

facility. Meyer-Rath and Ritcher (2007) believe that long distances travelled would be a disincentive for patients to seek HIV/AIDS related healthcare.

5.7 Indirect costs

5.7.1 Time lost by PLWHA and caregiver

In the case of indirect costs, this study considered those people who reported that they had fallen seriously ill in the month before they were interviewed. There were equal numbers of people who fell ill in both Entebbe and Masaka and they all reported that they had been cared for by someone at least for a few days of their illness. The results show that patients in Masaka had fallen ill for more days in total than the people in Entebbe. This implies therefore that on average a person in the rural area fell ill for longer than a person in the urban area. This could be explained by the fact that patients in the rural areas may initially self-medicate for more days than those in the urban area before they sought care from the health facilities. This kind of self- treatment may have led to patients being ill for longer as their delayed to seek treatment early. The delay in treatment may be explained by lack of access to health facilities in the villages and the high costs of transporting patients and their caregiver to the health facility for proper treatment. This trend of events was also reported in a South African study where patients were less likely to seek care at health facilities if they had to walk or travel long distances (Meyer-Rath and Ritcher, 2007). These findings are also in line with other studies that found that patients lost income or productivity when they sought HIV/AIDS care (Duraisamy et al, 2006; Gregson et al, 2006). There is need to note that in many cases, PLWHA on ART may not fall ill for long periods of time therefore it was unlikely for many of them to have fallen seriously ill in the last month.

5.7.2 Opportunity cost of seeking care for HIV/AIDS

The caregivers in both areas reported that they had lost a substantial number of days when they had looked after a PLWHA in the past month. The caregivers in Entebbe lost more days on average than the patients they had looked after. On the other hand caregivers in Masaka reported that they had looked after patients for fewer days than they were ill. This trend of events is inline with another Ugandan study, where it was reported that PLWHA were no longer looked after as compared to people with other illness (Ntozi, 1997). The explanation for this trend is the fact that people in community perceive that PLWHA may not recover to help in the productive activities as compared to patients ill from other illnesses. Although there were more people ill in Entebbe than in Masaka, people in Masaka reported a higher productivity loss in monetary terms. On average both the patient and caregiver in Entebbe reported similar opportunity costs of seeking care for HIV/AIDS. On the other hand, patients in the rural area had a higher opportunity cost in comparison to their caregiver. In line with logic, the longer a patient was ill the more days they lost and therefore the more losses in productivity or opportunity cost they incurred. The higher productivity losses in the rural area may have been slightly exaggerated in monetary terms given that the majority of participants in the rural areas reported that they were subsistence farmers. However, many of their economic activities and household activities require that they are physically present to carry them out. This therefore, makes illness more expensive for the rural area as reflected by the loss in the productivity.

5.7.3 Debt due to HIV/AIDS

There were less than half of all the participants who reported that they had not accumulated any debt in relation to their HIV status. However, more than half of all participants had reported that they had accumulated some kind of debt due to their HIV status (table 15). Of those who reported having accumulated debt, the majority reported that their debts were at most US $ 58. The rest reported that they had debts of between

US $ 58 to US $ 463.8 that are relatively large amounts of debt. This information shows that there were a high number of people with low amounts in debt and a modest number of people with high debts. This is in line with the expectations of this study, given that patients do not have to pay for ART which would otherwise be expensive like in the earlier days of ART. However, even with free treatment, patients are still borrowing money due to HIV/AIDS. The trend of borrowing large amounts of money seemed to be more of a problem in the rural areas than in the urban areas. This trend can be explained by the distances that patients may have to travel to health facilities due to limited access to health facilities nearby in the villages. This implies that patients are likely to postpone seeking care until they are really sick and therefore requiring larger amounts of money to seek care, to travel and to cover the costs of food.

There is also a possibility that PLWHA may borrow funds so as to raise capital for their businesses and also to take care of their families. Most of the PLWHA who were interviewed in this study were of a low socio-economic status; therefore they may be faced with poverty in addition to living with HIV/AIDS.

5.7.4 Economically active age group and HIV/AIDS

There is concern that many of the PLWHA are in the economically active category of people in the community. This was the similar trend in both study areas as participants' average ages varied from early 30's to early 40's for Entebbe and Masaka respectively. This is similar to the other studies were HIV/AIDS patients were within the economically active age groups. This implies that these participants have dependants they have to look after and therefore they face a high opportunity cost when they fall ill and are unable to look after these dependants. On average each participant had four dependants to look after with some having up to 30 dependants in extreme cases. It was often common to find a widowed participant who looked after their children in addition to their spouses children after the spouse's death. This was an interesting phenomenon that shows that the effect of HIV/AIDS extends beyond the individual who is infected. From the FGDs held with participants there was information to the effect that some PLWHA had opted to look after orphans in the community. These people were clearly touched by the suffering of

these orphans, as they understood suffering more than most other community members. There were common scenarios of PLWHA who came to the health facility to seek care with their spouse and children who were also living with HIV/AIDS. This trend of events is likely to increase the cost associated with HIV/AIDS for PLWHA who had dependants living with HIV/AIDS. Subsequently, HIV/AIDS may exert a multiple economic burden on households if there is more than one member is living with HIV/AIDS.

5.7.5 Loss of jobs due to HIV/AIDS

PLWHA participant

There was a higher drop in the number of people who lost their jobs after they had been infected with HIV/AIDS in the urban area as compared to the rural area. This fact can be explained by the employment status that participants reported in this study. There were more people who were subsistence farmers and therefore working for themselves in the rural area as compared to those in the urban area. Furthermore, it was more likely to find a person in the urban area losing their paying job when they absconded from work after they fell ill and therefore leading to unemployment. There were more than half of the participants who had become unemployed in both study areas who reported that they had resigned from their jobs in order to seek care or because they were too ill to work.

Other household members

There were other household members who lost their jobs due to HIV/AIDS as reported in this study. The number of participants who reported that they knew another household member who had lost their job due to HIV/AID was higher for the Entebbe study area as compared to that of the Masaka study area. The extent of the effect of HIV/AIDS on the household emphasises the reason why the household should be the unit of study in the burden of HIV/AIDS studies (Sauerborn et al, 1996). This is given the fact that HIV is mainly spread through heterosexual relationships and from mother to child transmission. Therefore it is more likely to find more than one PLWHA in the household.

5.7.6 Employment of minors

There were a modest number of participants who reported that children in their households were employed in order to contribute to the household income. However this number was higher for the participants in the rural area than those in the urban area. This trend also indicated that ART therapy has gone along way in reducing the opportunity cost associated with HIV/AIDS. However, another argument could be that, PLWHA realised the importance of educating their children and therefore look for all possible ways to keep them in school so that they can have a better future. There were many instances in which PLWHA reported that educating their children was one of their most urgent needs. However a third possibility is that there were more children on ART and therefore they could not work or look after their sick guardians, as they are also needed care. This could be true as very few participants reported that they had been looked after by a school-going child the last time they were seriously ill. Inline with the mode through which HIV/AIDS is spread it is likely to find school-going children who became infected, especially before PMTCT was emphasised in health facilities. It was common to see a PLWHA reporting to the HIV/AIDS health facility with their children and spouse for their regular appointments.

5.7.7 Children dropping out of school

There was a similar rate in the reported school drop out of children in both Entebbe and Masaka. These rates seem to be high given the current provision of ART for PLWHA were it is expected that HIV positive patients will be able to take care of their children's schooling and welfare. However this may bring to light the fact that the majority of PLWHA in this study are of poor economic status and like the rest of the country were also struggling to make ends meet. Therefore HIV/AIDS and poverty have to be dealt with hand in hand as reducing one may directly and indirectly lead to reductions in the other. Therefore empowering people as well as providing them with ART may reduce poverty levels as well as the school drop out rates of children. This discussion is in line

with other studies that have discussed the impact of poverty on HIV/AIDS and HIV/AIDS on poverty (Ganyaza-Twalo and Seager, 2005; Piot et al, 2007).

5.7.8 Caregiver the last time you were ill

More than 80% of all participants reported that they had been looked after by someone the last time they were ill. The main caregivers that participants reported were adult relatives. This illuminates the indirect costs of seeking care for HIV/AIDS as it extends beyond the PLWHA to other household members. Subsequently, when PLWHA fell ill, it was the healthy members of their household or community who looked after them. This therefore implies that both the PLWHA and their caregiver lost earnings and time when they sought care. Furthermore, participants and their caregivers lost time that they could have spent carrying out economic activities and other activities that brought them utility.

5.7.9 Total Costs

The total direct costs outweighed the total indirect costs of seeking care for HIV/AIDS. However, the total direct and indirect costs were weighted by the number of participants who incurred each of them. Subsequently, the average indirect cost outweighed the average direct cost per person. This also brings to light the fact that although PLWHA are receiving free HIV/AIDS services, they are still facing high indirect costs of seeking care for HIV/AIDS. This is consistent with other studies which looked at the cost of illness. In summary, it is clear that the urban area participants incurred higher average direct costs than their counterparts in the rural area. However the rural area participants incurred a higher average indirect cost than those in the urban area.

5.8 Coping mechanisms

5.8.1 Started Economic activities/Diversification of income

There were more participants in Masaka than in Entebbe who reported that they had started some economic activity to bring in income or supplement it. This is was a type of coping mechanism to safeguard households against the burden of HIV/AIDS by ensuring that they had some kind income to sustain their households. This was confirmed by the FGDs were many people in the urban areas complained that they lacked land were they could carry out economic activities as many of them lived on rental property which was usually small in size. The participants in the urban area also complained that they were not allowed to carry out any economic activities on their owners' property. The major economic activities that participants in the rural area reportedly carried out were rearing livestock, tailoring and frying and selling local pastries. The other reason for this trend was that many participants did not have enough capital to start up their own small businesses even after they had been trained to keep livestock and in tailoring by various NGOs. There was a fear to borrow money as the rules were stringent and the pay back periods are usually long and therefore PLWHA do not find them conducive. There is also concern by the PLWHA that they may be forced to worry about paying back these loans and in the process may affect their health as their CD4 counts may be reduced. There were very few participants who reported that they had received any kind of financial gifts from relatives. Subsequently, although PLWHA may live longer with the help of ARVs, they find it difficult to sustain themselves due to the lack of resources, proper credit that suits them and high levels of poverty that plague them. There is a possibility that lack of trust and social capital in the communities may further aggravate the economic burden of HIV/AIDS on households. There are participants who reported that some organisations that are apparently supposed to help them turn out to be scams that dupe people out of their money which PLWHA and other community members had invested with them.

5.8.2 Money constraints to seeking healthcare

There were almost equal numbers of people who reported that they had faced money constraints in the past when they the needed to seek healthcare for HIV/AIDS. This indicates that even before PLWHA get to the health facility there are certain costs they incur which may hinder their access to free ART. These costs may include the cost of transport which patients have to pay for out of pocket to get to the health facility. There is therefore need to pay attention to such costs that PLWHA are faced with prior to coming to the health facility.

The patients in both study areas reported that they mainly borrowed money when they were faced with monetary constraints, closely followed by delaying treatment and using a cheaper provider. These responses highlight the fact that PLWHA are still facing monetary issues, which may not be necessarily solved by providing free ARVs alone. The types of responses used when patients were faced with monetary constraints indicate that borrowing was the easiest way to get out of their predicament. However, many participants report that they usually avoid borrowing money as it leads them to worry which puts their health in danger.

5.9 COPING MECHANISMS

There were generally a modest number of patients who said they had fallen seriously ill in the last month. The participants who fell ill in the last month reported various coping mechanisms that they had used to deal with the costs and expenditure they incurred related to an HIV/AIDS illness in the last month. There were a high number of reports by participants on the use of medical aids. This surprising given the fact that for Uganda less than 1% of the population has health insurance. However this can be explained by the fact that PLWHA usually form small informal groups in which they undertake saving and contributions that they use when people fall ill or for covering the costs of funerals. It is such groups that may provide patients with some form of informal medical scheme in which they are able to cover their expenses when they fall ill. This was mainly common

in the rural area as compared to the urban area, which may indicate that trust and solidarity were stronger in the rural area as compared to the urban area.

There were more people in the rural area as compared to the urban that used money generated from a savings club to cover their costs the last time they fell ill. This is not surprising and could be explained by the capacity of people in rural areas to carryout economic activities as communities due to the high solidarity and trust levels in the villages. However this is also an indication of the social capital in the rural area as compared to the urban area since more people can come together and participate in community-based activities. The other coping mechanisms like using household savings and sell of valuables were not frequently used but also registered a higher percentage of participants in the urban areas who made use of them as compared to those in the rural area.

5.9.1 Borrowed money

The reality is that borrowing money seems to be a popular coping mechanism for the last time that participant's fell seriously ill. There was however a higher percentage of participants in the urban area than in the rural area who reported that they had borrowed money to pay for their expenditures the last time that they fell ill. This can be explained by the reports given by participants that they lacked capital and land resources to carry out economic activities to generate income. There is even less social cohesion and social capital in the urban areas, which implies that there less informal groups that can support participants in the urban area when they fell ill.

The participants reported that they mainly borrowed money from relatives and friends in their communities. Again, it was more common for participants in the rural area as opposed to those in the urban area to borrow money from relatives and friends. Friends and relatives outside the community, work based groups and household members were not very popular sources of loans in both Entebbe and Masaka.

5.9.2 Reduced household spending

There was a marked reduction in the household expenditure on various household items for both the urban and rural areas. However there were a higher percentage of participants in Entebbe than Masaka who reduced their household expenditure the last time they fell seriously ill. The most affected household item was food, followed by children's education, healthcare and clothing for the Entebbe area. The Masaka area participants reported that they had reduced expenditure on education mostly, followed by food, healthcare and clothing. This trend of events shows that food and education are the most important and basic items in households. A likely explanation for this trend of affairs is that people in Masaka were mainly subsistence farmers and many of them grew their own food which implies that even in times of sickness they may not reduce their food expenditure as much as those participants in the urban area. The other reason for the difference in reduction in expenditure for these two areas is that people in urban areas generally have higher out of pocket expenditures as compared to rural participants who may be more self sufficient and have less money to spend. Households are likely to resort to reduction of household expenditure on the basic household items when faced with health related expenses (Leive and Xu, 2007). Among the first items to be affected include food and children's education.

5.9.3 Financial Gifts

The fact there were very few numbers of participants who reported that they had received financial gifts the last time they were ill is not surprising. In another Ugandan study, it was reported that PLWHA were getting less assistance from their relatives and friends (Ntozi, 1997). However it is important to note that participants of the FGDs reported that some of them had received non-financial assistance in the form of food parcels and emotional support the last time they fell ill. This may be explained by the fact that most PLWHA are part of groups, which seek to help each other in times of need. However these groups may be too poor to give money but may give help in-kind. This is possible

as there were higher numbers of participants in the rural area than in the urban area who reported receiving financial gifts last month when they fell ill.

5.10 Social Capital

The majority of participants associated community based organisations like NGOs with the provision of most HIV/AIDS related services with the exception of testing (Figure 36). In line with the study's expectations the results show an over whelming presence of community based organisations that provided HIV/AIDS related services in the rural area as compared to the urban area. The association of community-based organisations and provision of HIV/AIDS services was used as a proxy of social capital in an area. This is based on the principle that for communities with a higher social cohesion and trust are more involved in community activities and promotion of the welfare of other participants. The social capital has the ability to improve the health of individuals in cases where it is made available in communities (Gilbert and Soskolne, 2003). In the FGDs, some participants reported that they did not they did not want to be visited by client representatives. However this could be due to stigma, which is also promoted in communities where there is a lack of social cohesion as thereby discouraging people from revealing their status.

There were more participants in Masaka than Entebbe who related home based care with community based organisations. It is also worth noting that most people in rural communities in Uganda are related and have a sense of solidarity with each other. This sense of unity is what encourages community participation in activities that benefit the greater community.

5.10.1 Financial gifts

There were generally a low number of participants who received financial gifts the last time they fell ill. There were even less participants in the Entebbe as compared to Masaka who received financial gifts the last month. The main source of financial gifts was

relatives and friends in the community, followed by a small number of friends and relatives outside the community. This is also an indication of the high level of solidarity in the communities in the Masaka as compared to Entebbe. This is even more surprising given that people in the urban areas are of a higher social economic status as compared to those in the rural area where more participants reported that they had received more financial gifts than in the Entebbe area.

5.11 Summary of discussion

There is need to recap on the major issues that this discussion has brought to light. The major point to note is that ARVs have gone a long way to reduce the morbidity associated with HIV/AIDS. However this implies that people have to live with HIV/AIDS for a long time. The chronic nature of this disease implies that PLWHA are likely to fall ill from time to time and thereby require regular healthcare. This has affected the non-medical direct costs, which were highest for transport, and special food costs. ART has however led to reduction in the direct medical costs. There are still some costs being incurred on medical items by patients before their appointments at the ART clinics.

In response to the burden of HIV/AIDS, patients have used the commonly presented coping mechanisms that have been reported in the literature. It was common to find that most patients borrowed money, reduced their expenditure on household basic items and started up economic activities to bring in some money. The other coping mechanisms were scarcely used. This study also discovered that poverty may hinder the positive impact that ART has on PLWHA. This means that although PLWHA's health may improve greatly once on ART, they need financial resources so as to improve their socio-economic status.

5.12 Generalisability of study results

The results obtained from this study should be interpreted and applied with prudence. This is because as many internal and external factors under which this study was carried

out may influence the generalisability of its results to another setting. The relatively small sample space of this study is the main factor that may affect the extrapolation of these s results to other study settings. Therefore, it may be safe to say that the results of this study may be uniquely applicable only for the participants of this study.

There is also concern that that the demographic, cultural and unique country settings in which this study was carried out may have influenced the results obtained. This is a factor that should be considered in extrapolating these results to another group of PLWHA or study setting that varies from the one above.

There may have been an exaggeration in the results obtained using the household expenditure as a proxy for household income. This is in line with other studies, which have reported that study participants have a tendency to overstate their expenditures.

In addition to all the above points, Uganda has recorded one of the best successes in management of HIV/AIDS in the world. This fact may therefore influence the kind of results that any study on HIV/AIDS that is carried out in Uganda may obtain.

CHAPTER SIX- POLICY IMPLICATIONS AND CONCLUSIONS

6.1 Introduction

This chapter aimed at describing the policy implications and conclusions deduced from the results of this study. The policy implications stated here are only recommendations in light of the data obtained.

6.2 Major findings from the study

There is very little data and information on the burden of HIV/AIDS on households in light of the provision of free ART and other free HIV/AIDS related services in many countries. The few studies that were found were mainly from a few countries including South Africa and India. In addition, there were even fewer countries where all HIV/AIDS related services like ART were provided to PLWHA completely free of charge. According to our knowledge, this is the first study of its kind in Uganda, which has attempted to consider the economic burden of HIV/AIDS in the era of provision of free ART. There is evidence from other countries that even when ART and other HIV/AIDS related services are provided free of charge, PLWHA may still face an economic burden. The study results indicate that not only were most participants of economically active age but they were also the household heads and therefore the main breadwinners in their homes. The burden of HIV/AIDS in terms of its direct and indirect cost was still high even though PLWHA on ART were not charged for any of the medical items they needed. The direct costs associated with seeking care for PLWHA on ART were generally greater for the urban area participants than the rural participants. The direct non-medical costs outweighed the direct medical costs in this study. This is expected as the free ART has ensured that PLWHA on ART do not have to pay for these or any other associated HIV/AIDS services. However PLWHA still incurred substantial direct medical costs in the time before their scheduled appointments. Generally PLWHA incurred the highest expenditure on transportation and special foods. The average indirect medical

costs in this study outweighed the average direct medical costs of HIV/AIDS for PLWHA who were on ART. This finding is inline with other studies that looked at examining the economic burden of disease and particularly of HIV/AIDS. However this study also discovered that on average, the indirect costs outweighed the direct costs of seeking care for HIV/AIDS.

There is still a burden of HIV/AIDS on PLWHA as many of them reported that they had faced money constraints the last time they sought healthcare. Although there were relatively few participants who had fallen seriously ill in the last month, the number was still substantial given that they are provided with free HIV/AIDS related services. These participants reported that they had mainly borrowed money and received financial gifts from friends and relatives within their communities when they needed money in the last month. This was however more common for the rural area participants than those in the urban area. On the other hand it was participants in the urban area who substantially reduced their household spending when a PLWHA fell seriously ill in the last month. In the rural area, participants mainly reduced their household expenditure on education and used income generated from savings clubs. The other coping mechanisms were not commonly reported by participants.

There was a clear indication that social capital in the form of social networks and HIV/AIDS community based organisations was highly recognised in the urban and rural communities. There is evidence that social capital plays a major role in helping PLWHA and their communities to cope with the economic burden of HIV/AIDS. This is clearly seen as the majority of HIV/AIDS related services were commonly associated with community-based organisations like NGOS and support groups, which encourage high community participation to ensure the sustainability of these projects in the future.

6.3 Policy implications

6.3.1 Burden of HIV/AIDS

The burden of HIV/AIDS on households in this study was considerably high given that the population of interest was a generally poor one. Although the PLWHA in this study had access to free ART, they continued to incur expenditures related to their health status. The participants incurred high non-medial costs on transport and special food. Participants also reported that they incurred high expenditures in the month before their appointments. There is a need to look at subsidising or providing free care for PLWHA, even during the weeks and months between their official appointments. It is important to note that although PLWHA are receiving ARVs, they may face other illnesses in the time between their official appointments.

There is therefore need for government to address the issue of transport costs, as they were the highest costs incurred by participants in both study areas. There could be some sort of subsidisation for transport fees for patients on the day they need to seek care. Alternatively, government could put into place transportation support for people living in hard to reach areas like in the rural areas when they need to get to the health facilities. A similar strategy was reported by a South African study (Meyer-Rath and Ritcher, 2007).This transport subsidisation could also be used to encourage people to go for voluntary counselling and testing especially in Uganda where ART has had a positive effect on people' health in general.

The government should put in place HIV/AIDS clinics in villages and rural areas, as this is where most complaints concerning transport and drug stock outs were reported. There were many participants who believe that government has the capacity to put in place clinics that target PLWHA specifically so that they can travel less and have regular access to drugs to treat opportunistic diseases without having to travel far. This is realistic given that ARVs do not cure HIV/AIDS and therefore PLWHA are prone to fall ill from various illnesses from time to time. There is therefore need for participants to have access

to a health facility in between their appointments at the official ART facility. There were a high number of participants who visited public health facilities the month before their appointment at the clinic to show the importance of supplementary health facilities for those days before the official appointments of the PLWHA.

6.4 Indirect costs

The average indirect costs in this study outweighed the average direct costs associated with seeking care for PLWHA on ART. This is inline with other studies that have been carried out comparing direct and indirect costs of illnesses. The indirect costs were also high for caregivers of PLWHA; this was particularly evident for Entebbe where the indirect costs for caregivers were greater than that of the participants they looked after. This is where the government has to come in to put in place support for the household as a whole rather than focusing on an individual in the management of AIDS (Sauerborn et al, 1996). The household is a very vital unit of analysis when it comes to the study of the burden of illness in general. In particular HIV/AIDS will have a clinical and financial impact on the household as a unit. There is also need to focus more on children in these households as the government, in addition to what the government is already doing. There are still a high percentage of children who dropped out of school as reported by the PLWHA participants in this study. There is a need to look at the education needs of children in households affected by HIV/AIDS. Although there are organisations that are currently providing help for the education needs of these children, there still very many who are not covered. There is need to give PLWHA hope by ensuring that their children's future is secured by educating them. This will reduce on the stress and the level of worrying for parents and guardians whose health and CD4 count may be affected and thereby hindering the positive effects of ARVs.

There is also need to recognise that most people who are affected by HIV/AIDS are the poorest and least well off in society. This implies that there is need to put in place more initiatives that target the poor living with HIV/AIDS especially in the urban areas so as to alleviate some of the economic stress that PLWHA are faced with.

The results indicate that many people in the rural area and urban area pointed out the need for more educational studies and programmes to encourage more people in the community to test for HIV. This was particularly brought up in the FGD in Masaka were participants reported that many people are still dying from HIV/AIDS related illnesses without seeking care at all. There are also other people in the communities who decide to seek care and to go for voluntary counselling when they are already too sick. This is also clear in the current government reports in which the HIV infection rate has in the last few years risen. This is therefore in line with the recommendations given here, that government should reinforce the fight against HIV/AIDS. The government should encourage prevention and voluntary testing for everybody in the country but particularly for the young people.

There is need to address the issue of distance travelled by patients to access the health facilities that provide ARVs to PLWHA. In line with the distance travelled, patients are also spending a lot of time travelling to the health facility, which also increases the indirect costs of seeking care for HIV/AIDS. There is need to study and understand some of the reasons that lead people to travel these long distances even when there are some facilities near them. However, it seems that there is a new type of stigmatisation and discrimination aimed at PLWHA. There is a new phenomenon where PLWHA no longer get physical symptoms due to illnesses with HIV/AIDS, therefore many of them opt to travel long distances to get to health facilities far from their home areas so as to avoid stigma and being known as an HIV positive patient. In some instances there is need increase access to health facilities especially in the rural areas but in some instances its necessary to increase knowledge and educational programmes in communities to reduce stigma and increase the number of people coming for voluntary counselling.

6.5 Economically active group

There is need to target the economically active group that has been mainly affected by HIV/AIDS. This is also in relation to those people who look after PLWHA when they fall serious ill. In this study care for PLWHA was mainly given by adult relatives both from the household and outside the household. This implies that there is even more need to

target the general household members in households affected by HIV/AIDS. There is growing need to address the needs of other household members who are usually are the ones who bear the burden of looking after those who fall ill due to HIV/AIDS related illness. The impact of HIV/AIDS on the economically actively age group will definitely be felt by other household, community and child members. This brings in place the need to address all parties affected by HIV/AIDS in a holistic manner so that all the aspects of this disease are dealt with.

6.6 Coping mechanisms

In response to money constraints to seeking care, participants chose the option to borrow or delay treatment more than any other option. These responses show that the participants made a choice before the reached the health facility that provides free ARVs. This clearly indicates that even before the provision of free HIV/AIDS services, there is need for government to look into those costs incurred by patients before arrival to the health facility. Indeed, if patients lack money to cater for their expenses incurred before they arrive at the clinic, they may more likely miss their treatment, which may affect their adherence and their health in the end. The government needs to tackle the problem of transport since it is the highest expense that participants incurred on the day hey visited the clinic. For example in a South African study, Meyer-Rath and Ritcher (2007) suggest that government should provide ART patients with travel vouchers. The same strategy could be adopted or enforced in the Ugandan case so that patients are protected from high transport costs of seeking free health care.

The main method of payment for health care for participants who fell seriously ill in the last month was use of medical aid. This is higher than the national statistics were about 1% of the population is covered by some sort of medical aid (WHO, 2007d).This is an indicator that introduction of a proper health insurance may be timely in Uganda. The majority of PLWHA have formed small groups in which they contribute small amounts of money that can be used to support individuals in case of sickness, death and support for other functions. These groups may be a foundation for the introduction of community

health insurance with particular reference to the rural areas where community support for PLWHA seems to be strong.

There were very few participants who used money generated from various sources to cover their expenses for those who fell seriously ill in the last month. However, there were a high number of rural participants who used income generated from savings clubs. In light of this fact, there is need to encourage the formation of savings clubs in the urban areas where formation of groups is almost non-existent. This also points to the level of solidarity and trust among community members. The government needs to encourage other forms of saving in urban areas like personal savings since it may not be easy to build trust and solidarity among urban community members. The government could encourage some financial institutions to put in place savings accounts for health ailments like HIV/AIDS. This may be appropriate for PLWHA as they would have peace of mind if their future and that of their children is secured. There is still a need to encourage community health insurance especially in rural communities where there are already structures in place like savings clubs, which may facilitate this process.

In addition to the above coping mechanisms, participants also chose to borrow to settle their expenses when they fell ill in the last month. They mostly borrowed from relatives and friends in the community especially for those participants in the rural area. This clearly shows that there is a high level of social cohesion in these communities. This could be an area that government could look make use of to encourage formation of insurance schemes where both those PLWHA and the rest of the community contribute to so as to subsidise the financial and risk profile of these schemes once they are put in place. Again the government could look at empowering the households of those PLWHA as a whole as they bear the burden of HIV/AIDS with the individuals who are affected.

6.6.1 Altering the basic household items expenditure

The basic household expenditure was reduced when PLWHA fell seriously ill even in this era of provision of free ARVs. This indicates that the burden of HIV/AIDS may be considered disastrous for these households. The expenditure on food and education were the most affected implying that government needs to look into putting in place financial

safe guards for the PLWHA especially the poor. Indeed from the socio-economic status and education levels of most of the participants in this study it is clear that most are poor and therefore any small change in their expenses affects their expenditure on basic household items. Such safeguards could include provision of food parcels, totally free education for children from such affected households. Although there is free universal primary education, parents have to contribute some money to buy scholastic materials, uniforms and food. This still imposes burdens for poor households affected by HIV/AIDS. In fact, many FGD participants reported that their main concern is for their children's education and well being in the future. Therefore, government has to approach provision of free ARVs in a manner that it encompasses even other aspects of the lives of PLWHA like their children's education, food needs and shelter. On the other hand, although there are NGOs, which try to look into to the education of children infected, affected by HIV/AIDS, there is still more that can be done on the side of government. Coping is an important aspect of dealing with the economic burden of HIV/AIDS even where ART is provided free of charge. The study has shown that ARVs have reduced the direct healthcare costs, PLWHA are still faced with indirect costs of seeking health care.

6.7 Social Capital and Support

There is a strong indication of social capital in both the rural and urban area in relation to the provision of HIV/AIDS associated services. This is a clear indication of the community involvement in the fight against AIDS and its management. Indeed if the community projects have the support and contribution of the community then there is likely to be greater success in the fight against AIDS. The provision of HIV/AIDS related services is almost exclusively restricted to NGOs in both the urban and rural areas. The relatives and friends in the community contributed the most in providing financial gifts the last time that the PLWHA were seriously ill. This also shows that the level of social cohesion is still present in communities and it extends to PLWHA. The level of social cohesion may not be at its optimal but it can still be exploited to improve on the outcomes of managing HIV/AIDS in communities. Indeed effort should be put in place by government to invest in the promotion of social connections and networks among

communities so as to improve the management of HIV/AIDS. Although this may be an advantage for the promotion of community solidarity in the fight against AIDS, there is also a need for government to take these services closer to the people in the communities where these NGOs do not usually reach.

6.8 Summary

Although the morbidity and mortality associated with HIV/AIDS has reduced tremendously over the past years, there is still a lot to be done in the fight against HIV/AIDS. Even in the era of provision of free ART in Uganda, PLWHA and their households are still faced with the economic burden of HIV/AIDS. There is need to address and put in place measures to deal with the burden of HIV/AIDS on households. In many instances, PLWHA may fail to reach the health facility to receive free ART as they are hindered by certain costs way before they get to the health facility. In other cases, PLWHA have to pay for treatment in the weeks before their appointments at the health facilities. In order to mitigate the negative effects of the burden of HIV/AIDS, patients come up with coping mechanisms. This is an important area for government to look at and to also help households to manage the economic burden of HIV/AIDS.

Although the study was carried out on PLWHA who sought care, there is a need to study those people in the community who are ill and do not seek care. Their situations are expected to be worse than those of PLWHA who have sought care. Therefore the burden of HIV/AIDS may be even higher than this study has shown if HIV positive people in the community were also included in the study.

CHAPTER SEVEN-REFERENCES

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APPENDICES

APPENDIX 1

FOCUS GROUP DISCUSSION GUIDE

Respondents:

HIV/AIDS Patient participants

Name of facility.....

Date.....

Number of participants.....

Introduction to the study (from the information sheet/consent form)

The participants will be invited to give a brief introduction of themselves with whatever name they would like to be known by. The participants will be encouraged to share their experiences in regards to the assistance associated with the HIV status of patients. The participants will also be encouraged to give their experiences of other people they know including relatives and friends. The focus group discussions (FGDs) will be divided into two sections.

Economic Burden of HIV/AIDS

1. Do you feel that provision of free ARVs has helped you in accessing health care services related to your HIV status?
2. Do you think that free ARVs are enough, in relation to the amount of money you spend on health care every month?
3. What other services or things do you need regularly to keep your health and treatment in an optimal status?
4. Are there people who do not benefit from these free ARVS? Why do you think this happens? (E.g. because they have to pay for them or do not qualify)?
5. What do you think about the adherence guidelines for HIV, are they easy or too difficult to follow?

6. Is there any financial consequence for patients and their households related to seeking cake for HIV/AIDS?
7. What do you think can be done by government to improve your access to health care? (e.g. Government could provide you with other sources of income to sustain you and your family, or provide free health services for your family)
8. Is it easy to get permission from work to attend treatment for ARV?
9. Do you feel that people living with HIV/AIDS still face stigma and discrimination from other people in the community?
10. Do you feel that the information relating to your HIV/AIDS status is kept confidential by the health workers you visit?

Social Capital

11. Are there support groups in place that you can relate with to provide you with the social and financial support that you need?
12. How do you feel, when a member of your social support group or community visits you especially when you are ill?
13. Do these support group members and community members (e.g. relatives, friends) give you any financial gifts and gifts-in-kind like food parcels when you need them?
14. What is the best place/organisation that you go to when you need emotional support?
15. What is the best place/organisation that you go to when you need financial support?
16. What is the best place/organisation that provides you with social support?
17. What do you think are the most urgent needs for people living with HIV/AIDS in relation to the economic situation of these people and their families?

APPENDIX 2

CONSENT FORM FOR PARTICIPATION IN FOCUS GROUP DISCUSSION

Dear Participant,

My name is Faith Mirimo and I am pursuing a Masters degree in Public Health (health economics) at the University of Cape Town. I am conducting a study that includes talking with a group of patients that come for treatment to this clinic for HIV treatment. We call this a focus group discussion of which participation is voluntary and you will be free to withdraw from participation at any time. In the discussion session you are encouraged to give your views on specific issues for about 1.5-2 hours.

This study is aimed at understanding the economic consequences of HIV/AIDS on the household and the ways in which they respond to this burden. The decision you take on whether to participate or not will not influence the type of health care that you will receive at this health facility.

All information provided in the discussion will be kept confidential and you can introduce yourself with any name you want to use. I would like to inform you, that I do not work at this health facility and therefore I will not discuss the opinions of specific patients with the staff of this clinic. The study findings will inform policy decisions to improve the access to health care services for patients living with HIV/AIDS in Uganda.

A discussion group will take place on the [_____] in [_____]. If you accept to participate we will reimburse your travel costs for total of [_____]

Do you have any question so far?

In order to make the analysis of the conversation easier, and to avoid missing any important information discussed we will record the conversation. But once again the tapes will be kept under the domain of the primary investigator only and they will be deleted as soon as the information is transcribed.

Do you agree to participate? .....YES ..... NO

This study has been explained to me in detail and in the language that I understand. My questions about the study have been responded to in full. I am aware that my identity will not be revealed and that I may leave the study without providing a reason at any time and that this will not have any negative impact on me in any way.

Participant's Name.....

Participant's Signature.....

Date.....

FOCUS GROUP DISCUSSION INFORMATION

Venue.....

Date.....

Time.....

APPENDIX 3

CONSENT FORM FOR EXIT INTERVIEWS

Dear Participant,

My name is Mirimo Faith and I am pursuing a Masters degree in Public Health (Health Economics) at the University of Cape Town. I am conducting a survey to patients that receive care in this facility. The participation is voluntary and the participant can withdraw at any time without any condition. You will be asked to answer a questionnaire which takes between half and one hour of your time. This study is aimed at understanding the economic consequences of HIV/AIDS on the household and the ways in which they respond to this burden. The decision you take on whether to participate or not will not influence the type of health care that you will receive at this health facility. Any information provided here will be strictly confidential and name(s) will remain anonymous in any report drawn from the study. I would like to inform you, that I do not work at this health facility and therefore I will not share specific patients' information with the staff of this clinic. You are also free not to answer any specific question and this will not have any negative consequences on you. The study findings however, will inform decision makers on how to improve access to health care services for patients living with HIV/AIDS in Uganda.

Do you have any question?

Do you agree to participate? .....YES ..... NO

This study has been explained tome in detail and in the language that I understand. My questions about the study have been responded to in full. I am aware that my identity will not be revealed and that I may leave the study without providing a reason at any time and that this will not have any negative impact on me in any way.

Participant's Name.....

Participant's Signature……...

Date……..

APPENDIX 4

ECONOMIC BURDEN OF HIV/AIDS COPING MECHANISMS PATIENT EXIT INTERVIEW QUESTIONNAIRE PART A: PARTICIPANT DETAILS			
A.1	Patient's study number	[.....]	
A.2	Date of interview (dd/mm/yy)	_____/_____/_____	
A.3	Interview start time (hh:mm)	_____:_____	
A.4	Questionnaire number	[.....]	
A.5	Site (name of clinic)	Health facility, Kampala..... = 01 Health facility, Mbarara..... = 02	
A.6	How many people live in your household		
A.7	In what language is the respondent answering the questions?	English....=01 Luganda.....=02 Runyakore..... =03 Other=04 (specify)	
A.8	Signed informed consent form obtained?	Yes.....=01 No.....=02	
A.9	Date informed consent form signed (dd/mm/yyyy)	____/_____/_____	
A.10	Interviewer code	[.....]	
In the following sections we will be referring to the household in almost every question and when we mention a household, we mean those people who live in the same household for 2 or more weeks a month, and share a common source of food.			

PART B: SOCIOECONOMIC INFORMATION
SECTION ONE: INFORMATION ABOUT PARTICIPANT

B.1 How many people live in your household (family members)?_____ CODE
(N.B: Interviewer: Please encourage the participant to provide all the information below, in relation to him/her self)

B.2 Identifier code for the patient participant	B.3 Age (in years) Enter age at last birthday	B.4 Gender 1=M 2=F	B.5 Relationship of member to household head 1= Head 2= Spouse/Wife 3=Daughter/son 4=Grandchild 5=Parent 6=Grandparent 7=Brother 8= Other relatives 9=Other 98= Do not know	B.6 How well can you read in any language 1= Very well 2= Fairly well 3= Not at all	B.7 What is the highest educational level of the patient? 1=Never attended school 2= Some primary schooling 3=Completed primary schooling 4=Some secondary schooling 5=Completed ordinary level (S.4) 6=Completed Advanced Level (S.6) 7= Tertiary Training 8=University training 9=Other(Specify below)	B.8 Patient's marital status 1= Single 2= Married 3= Divorced 4=In relationship but not living together 5=In relationship and living together 6=Widow 7= Other (Specify below next to household member)	B.9 What is the patient's occupation? 1=Unemployed 2=Subsistence farmer 3=Agricultural labourer 4=Non-Agricultural labourer 5=Skilled labourer/tradesman 6=Small trader 7=Civil servant 8=Soldier/Security 9=Student 10= Housewife 11=Self employed 12= Other 13=Pensioner 14=Fisherman 60=Not applicable
Respondent							

PART B: SOCIO-ECONOMIC PROFILE & POSSESSIONS SECTION 2:			
B.10	What is the name of the area in which you are currently living? Which suburb, slum, village, community e.g. Katanga, Kawempe, Rwebitoma	[.....]	CODE
B.11	For how long have you lived in this area?	1=Less than 1 year 2=1-5 years 3=More than 5 years	
B.12	About how much of the consumed food, does your household grow at home?	1 =Very little/None 2 =About half 3=Almost all 4=Do not know	
B.13	What type of house do you live in?	1=House or brick structure 2=Traditional dwelling made with traditional material 3=Informal house made with mud 4=Informal house made with iron sheets 5=Flat in a block of flats 6=Other (Specify).....	

B.14	What type of material is the roof of your house made from?	1=Thatch 2=Tile 3=Corrugated Iron Sheets 4=Canvas 5=Wood 6=Other, (specify)	
B.15	What is your household's main source of drinking water?	1=Piped water in dwelling 2=Piped water in yard/plot 3=Public tap 4=Open well in yard/plot 5=Open public well 6=Protected public well 7=Borehole in yard 8=Public borehole 9=Spring 10=River, stream 11=Pond, Lake 12=Dam 13=Rainwater	

		14=Tanker, truck 15=Bottled water 16=Gravity flow scheme 17=Other	
B.16	What type of sanitary/toilet facility is available for this household? (Please circle the relevant choice)	1=Flush toilet 2=Traditional pit toilet 3=Ventilated improved pit latrine 4=No facility, bush, field 5=Other, (Specify)	

PART C: PAST HEALTH CARE UTILISATION AND COSTS Utilisation, expenditure(Direct Costs)				
In this section we are asking you some questions about the use of health care providers during the last month as well as expenditure on health care during the last month. That is from the [date] to the [date]				
C.1	In the last month how much and what type of health services have you used? **Indicate the number of visits (if ambulatory care) or nights in hospital(if inpatient care) in the last month** **If no inpatient care skip to C.5**	Type of facility	Visits/days of stay	
		a) Public clinic visit		visits
		b) Private clinic visit		visits
		c) General Practitioner/Doctor		visits
		d) Traditional healer visit		
		e) Public hospital emergency department visit		
		f) Public hospital outpatient department visit		
		g) Public hospital inpatient stay		nights
		h) Private hospital emergency department visit		
		i) Private hospital outpatient department visit		
		j) Private hospital inpatient stay		nights
		k) Church/Faith based		
		l) NGO-based		
C.2	Did you pay for the inpatient care?	1=YES 2=NO		
C.3	If NO, were you given an exemption?	1=YES		

		2=NO			
C.4	If YES, how did you sort out your payment?	1=Paid in cash at discharge 2=Account issued (already paid) 3=Account issued (payment pending) 4=Other, (Specify)			
C.5	How much in total did you spend on treatment in the last month? (e.g. GP/Doctor visits, pharmacies, traditional medicines, special foods)	[.....] Ugandan Shillings			
C.6	Could you give me an estimate of the break down of your expenditure on the following items?	**Cost item**	**Uganda shillings**		
		Consultations			
		Drugs/medicines			
		Vitamins/food supplements			
		Special food			
		Transport to get to the health facility			
		Lab tests and radiology			
		Household purchases for your health care(bandages, disinfectant, sponge)			
		Other, specify			

		_____			
C.7	How satisfied were you with the service received in the facilities you visited in the last month? Very satisfied.....=1 Satisfied.....=2 Not satisfied.....=3 Completely unsatisfied.....=4	a) Public clinic visit			
		b) Private clinic visit			
		c) General Practitioner/Doctor			
		d) Traditional healer visit			
		e) Public hospital emergency department visit			
		f) Public hospital outpatient department visit			
		g) Public hospital inpatient stay			
		h) Private hospital emergency department visit			
		i) Private hospital outpatient department visit			
		j) Private hospital inpatient stay			
		k) Church/Faith based			

PART D: INDIRECT COSTS OF HIV/AIDS ON THE HOUSEHOLD			
The following questions are about the circumstances when you got sick and the impact of the disease has had on your ability to participate in paid activities			
D.1	Are you looking after anyone else in your household, including any children, elderly or disabled people?	1=Yes 2=No	
D.2	How many people are you looking after, including children?		
D.3	When did you first find out that you were infected?	MONTH_____YEAR_____	
D.4	Have you disclosed your HIV status to anybody?	1=YES 2=NO	
D.5	Were you tested for HIV/AIDS at another health facility before coming here?	1=YES 2=NO	
D.6	How did you get to learn about the HIIV/AIDS related services offered here?	1=Heard from a friend or relative 2= My doctor or nurse referred me 3=My employer told me 4= Saw an advertisement or announcement 5= I just knew 6=Other_____(Specify)	
D.7	Were you working at the time you discovered your HIV status?	1=YES 2=NO	
D.8	If YES, are you still working in the same job, with the same or	1=YES	

	better salary?	2=NO	
D.9	If NO, what happened?	**Do not read options aloud** 1=I was fired 2=I resigned to seek care 3=I resigned because I was sick 4=I do less work and earn less now 5=I moved places to seek care 6=I am in another job but still earn the same amount 7=I was retrenched with benefits pay 8=Other, (Specify) ……..	
D.10	In what ways has the disease affected your income?	**Do not read options aloud** 1=I was too sick to work 2=I work less time now 3=I lose income when I seek treatment 4=I spend more money on drugs and special food 5=I was fired 6=It has not affected my income 7=Other, (Specify) ……	
D.11	How many times have you been seriously ill since your diagnosis?		

	(Being seriously ill means when you were so sick that you could not carry out your regular physical activities)	_____ (number of times)	
D.12	Were you working at the time you discovered your status?	1=Yes 2=No	
D.13	Were you the main bread winner at that time that you fell sick with HIV?	1=Yes 2=No	
D.14	Are you still contributing to your household income?	1=YES 2=NO	
D.15	Are you still the main bread winner from your household?	1=YES 2=NO	
D.16	Since the onset of your illness, have you started any activities in the home to raise income, since the onset of your illness? (Can be as simple as frying pan cakes for sale)	1=YES 2=NO	
D.17	Please list the types of activities you do at home that bring you income.(List them in space provided)	_____ _____	
D.18	Have other working members of your household (e.g. your wife) lost their jobs due to the same illness?	1=YES 2=NO	
D.19	Have any household members started to increase the number of jobs	1=YES	

	they do, since the onset of your illness?	2=NO	
D.20	If Yes, how many people? (specify)	_____	
D.21	Where do they work? (e.g. with an N.GO project or on other people's farms.(specify)	_____	
D.22	Has any household member of less than eighteen years old currently working to contribute to the household income?	1=YES 2=NO	
D.23	Has anybody dropped or abandoned school/studies in your household since the onset of your illness?	1=YES 2=NO	
D.24	When was the last time that you were seriously ill?	[_____] month [_____] year	
D.25	Did somebody else have to take care of you the last time you were seriously ill?	1=YES 2=NO (If No, go to D.32)	
D.36	If yes, for how many days did they have to look after you?	[_____] (days)	
D.27	If YES, Who took care of you the last time you were seriously ill?	1=Working household member 2=School going child 3=Adult Neighbourhood friend 4=Adult Relative 5=Paid care taker 6=Other, (Specify)	

D.28	When was the last time you were very ill that you had to be hospitalised?	Month _____ Year_____ [_____] Not applicable	
D.29	How many days did you spend in hospital?	[.....] Days	
D.30	Did you have to pay?	1=YES 2=NO	

PART E:

SUB-SECTION 1: COPING STRATEGIES

The following questions relate to what you do when you do not have enough money to pay for/seek treatment.

E.1	In the past, has money been an impediment/constraint to continue treatment /or to seek care when you needed it?	1=YES 2=NO	
E.2	If YES, what have you done in relation to your treatment when this has happened? (Tick the appropriate choice.)	If NO, what would you have done with your treatment, if it happened to you?	
	Method (can select more than one) Please tick the appropriate choice	**E.3 If YES in previous E.1**	**E.4 If NO, in previous E.2**
	1=Stop the treatment		

	2=Delay the treatment		
	3=Seek alternative treatment-traditional healers		
	4=Seek cheaper provider-government, NGOS		
	5=Reduce expenditure on other goods (education, food, clothing, health care of other household members)		
	6=Use savings		
	7=Use Medical aid/insurance		
	8=Borrow		
	9=Sell assets		
	10=NGO support		
	11=Other(Specify e.g. pension)		

	PART E: Sub-section 2: Coping Mechanisms		
E.5	How did you pay for the treatment that you received the last time? Tick where appropriate.		
		Refer to the last time you were seriously ill (if happened within one year ago)	**Refer to the last month**
E.6	**Method of payment**		
	1=Paid for by medical aid		
	2=Use of household savings		
	3=Sell valuables		
E.7	**Use income generated from**		
	1=Savings club/circles		
	2=Income generating projects		
	3=Home based labour		
	4= Other, (Specify)		
E.8	**Did you have to borrow money?**	**1=YES** **2=NO**	**1=YES** **2=NO**

	If YES, whom did you borrow from?		
	1=A household member		
	2=A community leader		
	3=Relatives in the community		
	4=Friends within the community		
	5=Friends outside the community (work mates)		
	6=Work based group inside the community(Community projects)		
	7=Work based group outside the community		
	8=Money lender inside in the community		
	9=Money lender outside the community		
	10=Past employer/ current		
	11=A commercial bank		
	12=Other (specify)		
E.9	**Did you have to sell any Assets (please state asset type)**		
	_____ .....=1		
	_____ .....=2		

E.10	**Did you reduce spending on**		
	1=Food		
	2=Children's education e.g. change of school or drop out		
	3=Health care treatment for other family members e.g. to use a cheaper facility		
	4=Clothing e.g. Christmas clothes?		
	5=Other (Specify)		
E.11	**Did you receive any financial gifts from**		
	1=Relatives within the community		
	2=Relatives outside the community		
	3=Friends/neighbours within the community		
	4=Friends outside the community		
	5=Money lender inside in the community		
	6=Current/past employer		
	7=Other (specify).....		

		If YES, please specify	
E.21	How much did you incur on the following items today?	Cost in Ugandan shillings	
	Cost of all medical items(e.g. consultations)		
	Transport		
	Fees		
	Tests		
	Drugs		
	Food while waiting		

PART E: Sub-section 4: Debt as a result of your illness.			
E.22	Have you accumulated any debt as a result of your illness?	1=YES 2=NO	
E.23	How bad is your debt situation?	1=Very bad 2=Bad 3=Not so bad 4=Manageable	
E.24	How big is your debt?	[_____] Ugandan Shillings	

PART F: HOUSEHOLD EXPENDITURE PATTERNS	
F.1 Could you give me an estimate of your monthly household expenditure on the following items?	**Expenditure(UG SHS)** **(Per Month)**
Food	
Transport	
Electricity and paraffin	
Water	
Rent	
School fees, books, uniform	
Clothing	
Health Care	
Other major expenses (specify)	

PART F: COMMUNITY SUPPORT AND CARE

F.2 Using the experience of your community, with which organisation or health facilities do you associate the following activities that seek to support people living with HIV/AIDS.

Organisation / Activity	Community(NGO, Church)	Government Facilities	Private doctors; traditional healers
Where in your community have you seen adverts/campaigns on: Prevention of HIV/AIDS?			
Where in your community can you be tested for HIV/AIDS?			
Where in your community can you get advice on management of HIV/AIDS? (e. g on medication, diet, exercise)			
Where in your community can you get advice on Income generating projects(projects that can bring you income)			
Where in your community can you get information on child minding?			
Where in your community can you get information on home based care			
Other (Specify)			

THANK YOU SO MUCH FOR YOUR TIME AND PARTICIPATION!